Experiences of Family/Informal Caregivers of Disabled Stroke Patients in Lusaka, Zambia

By

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Declaration

I, Evelyn Muleba Kunda Ng’andu declare that this work has not previously been done or submitted for a Degree, Diploma or any other qualification at this or another University.

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Certificate of approval

This dissertation for Evelyn Muleba Kunda has been approved as fulfilling the requirements for the award of the Master's Degree in Public Health-Health Promotion by the University of Zambia.

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Abstract

Background: Stroke is one of the leading causes of death and disability in the world. It is the leading cause of adult-onset disability, and causes nearly 80% of all global stroke mortalities. After suffering from a stroke, patients, suffer from varying degrees of disability that require management and extended care at home. Caregivers' responsibilities in caring for the patient result in stress, particularly when their own needs are inadequately addressed during the patient's recovery.

Aims: This study aimed to document the experiences of family/informal caregivers of disabled stroke patients in Lusaka, Zambia.

Settings and Design: A phenomenological qualitative study was conducted at the University Teaching Hospital and in three communities of Lusaka district.

Methods and Materials: Participants for in-depth interviews were purposively selected for their experience in caring for their family members who survived a stroke**.** 12 participants in total were interviewed. With participant's permission, the interviews were audio-recorded to accurately capture the narratives. Field notes complemented the audio recorded data to account for non-verbal communication and in case of technological failure. Data was collected using an interview guide for the family caregivers and for the key informant interview a separate guide for the key informants was used.

Analysis used: Phenomenological hermeneutic interpretation was used to analyse the data. Themes were generated and explained from the comprehensive understanding. Data were managed on Nvivo.

Results: Caregiving absorbed the caregivers' strength and robes them of the freedom to be their own person as they had to adjust to the role of caregiving. Experiences of tiredness, giving up, sadness, hope, fulfilment and distress were intensely expressed present in the narratives. It was also found that more of the family caregivers were female compared to males.

Conclusion: Family caregivers of disabled stroke patients experience physical, social, financial, and emotional challenges in their execution of care. Despite the stress that they go through in their care giving role, they receive very little support from society as a whole. It is important therefore, that caregivers are supported in their caregiving role in order to facilitate the rehabilitation of disabled stroke patients. Caring for the careers will also improve their mental health and overall wellbeing, and negate the development of non-communicable diseases which they are prone to as a result of their care giving role. It is recommended that the Ministry of Health looks into providing social support for the caregivers.

Key words: *stroke, family, caregivers, experiences*

Dedication

I dedicate this work to my husband Clive Ng'andu, for his support and unfailing encouragement. To my children, Malaika, Choolwe and Clive, for you to know that there is no limit in who you can become in life. I love you. To my parents, for being my champions. My brothers and sisters, I know that together we can conquer. To my friend, Kekelwa Inyambo Yeta, you are the best.

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List of Abbreviations and acronyms

ADL	Activity of Daily Living
IC	Informal Caregiver
CR	Care Recipient
TIR	Timing It Right
QOL	Quality of Life
WHOQOL	World Health Organization Quality of Life domains
REC	Research Ethics Committee
SSA	Sub-Saharan Africa
UTH	University Teaching Hospital

Definition of terms

Stroke / cerebrovascular accident: A stroke occurs when a blood clot blocks an artery (a blood vessel that carries blood from the heart to the body) or a blood vessel (a tube through which the blood moves through the body) breaks, interrupting blood flow to an area of the brain. When either of these things happens, brain cells begin to die or brain damage occurs (NAS, 2014).

Family caregivers: The term Caregiver refers to anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help: a husband who has suffered a stroke; a wife with Parkinson's disease; a mother-in-law with cancer; a grandfather with Alzheimer's disease; a son with traumatic brain injury from a car accident; a child with muscular dystrophy; a friend with AIDS. Informal caregiver and family caregiver are terms that refer to unpaid individuals such as family members, friends and neighbors who provide care. These individuals can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately. Formal caregivers are volunteers or paid care providers associated with a service system (Hunt and Watson, 2010).

A stroke family caregiver refers to an unpaid or a not professionally trained caregiver who provides care to a partner, spouse, relative, or friend who suffers from a stroke in the acute, rehabilitation or chronic phase (Zhang and Lee, 2017).

Anxiety: Anxiety is the anticipation of a future threat that can be described as a feeling of worry, nervousness, or unease (Barlow, 2002; APA 2013). Symptoms of anxiety can include physical sensations such as rapid heartbeat, dizziness, and sweating; cognitive symptoms like unwanted, recurrent thoughts; and behavioral symptoms like avoidance of anxiety-provoking circumstances (Lang, 1968).

Distress: According to the global stress organization (2019) McEwen and Mendelson (1993) defined "stress" as a term for certain types of experiences, as well as the body's responses to such experiences. The term generally refers to challenges, real or implied, to the homeostatic regulatory process of the organism". Humphrey (1992) found that "stress can be considered as any factor, acting internally or externally that makes it difficult to adapt and that induces increased effort on the part of the person to maintain a state of equilibrium both internally and with the external environment''.

Operational definitions

A disabled stroke patient: Someone who has in the past suffered from a stroke and has been left impaired and not able to perform daily living activities.

Training: a form of skills and information passing on in order to teach the caregiver about stroke, including what they expect, how to deal with what might be encountered including what to do and not do to avoid re-occurrence of stroke in the patient or occurrence to them.

Formal training: a well-documented and guided training provided for the caregivers

Informal training: skills passing on done in the ward as students are being taught

Family caregiver experience: an encounter that affects the day to day activities of an individual who is providing care to a stroke patient/survivor

Untrained/informal caregiver: an individual who provides care to a stroke survivor without any professional training provided

CHAPTER ONE: INTRODUCTION

1.1. Background

Stroke is one of the leading causes of death and disability in the world and exerts a significant effect on patients and family caregivers (Gbiri *et al*., 2015). As the leading cause of adult-onset disability, stroke is a major public health concern particularly pertinent in Sub-Saharan Africa (SSA), where nearly 80% of all global stroke mortalities occur, and stroke burden is projected to increase in the coming decades (Akapalu *et al*., 2015). Stroke is a neurological deficit of sudden occurrence mainly in those of the adult age group (Heart & Stroke Foundation of Ontario, 2003). Additionally, Nkusi *et al.*, (2017) argues that cerebrovascular accidents or stroke constitute the second leading cause of mortality worldwide. Various authors have argued that countries of low and middle income have the largest burden of stroke, accounting for more than 85% of stroke mortality worldwide (O'Donnell and Yusuf (2009); Connor *et al*., 2007; Nkusi *et al.*, 2017). The overall stroke incidence rate in low to middle income countries exceeds the level of stroke incidences seen in high-income countries, by 20% (Connor *et al.*, 2007; Warlow 1998; Johnston *et al*., 2009).

Stroke is one of the growing concerns in Zambia in addition to other non-communicable disease burdens (Mukanu et al., 2017). In Zambia, stroke is attributable to various factors including blood pressure, HIV-related and stress, at the University Teaching Hospital, it was found that hospital mortality was high which stood at 40% (Atadzhanov *et al.*, 2012). According to the latest WHO data published in 2017 Stroke deaths in Zambia reached 33, 939 or 3.4% of total deaths (WHO: 2017).

Patients, suffer from varying degrees of disabilities after stroke, (Pinter and Brainin2012). These disabilities require management and extended care at home (McCullagh *et al.*, 2005). Caregivers' responsibility in caring for the patient results in stress, particularly when their own needs are inadequately addressed during the patient's recovery (Lopez-Espuela *et al*., 2018). In many cases if not all, family members who are usually spouses take the responsibility of family or home care giving. These are what are termed as family caregivers.

A family caregiver is defined as someone who is responsible for attending to the daily needs of another person (in this study this is qualified by that person being part of that family) (Toyama and Honda, 2016). Family caregivers are responsible for the physical, emotional and often financial support of another person who is unable to care for him/herself due to illness, injury or disability (Friedemann and Buckwalter, 2014). Family caregivers are sometimes described as "informal," a term professionals use to describe those who care for family members or friends in the home, typically without pay. "Formal" caregivers, including home health care providers and other professionals, are trained and paid for their services (Hunt and Watson, 2010).

Additionally, stroke survivors returning to the community often have difficulties performing activities of daily living like dressing, eating, and mobility that can last well into the first year post-stroke (Mayo *et al*., 2002). Care giving brings about various psychological, social, physical, and financial burdens for the caregiver (Asiret and Kapucu, 2012; Atagun *et al*., 2011; King *et al*., 2010). For instance, in a study conducted in the USA, it was established that stroke patients aged 65 years or more bring an economic burden of 14.2 billion dollars upon informal caregivers (Joo *et al*., 2014).

Furthermore, some studies done submit that caregivers can, often, develop some problems such as pain, fatigue, loneliness, depression and poor health outcomes (Bridges *et al*., 2010). This may affect their well-being, life satisfaction, quality of life and mood (Quinn *et al*., 2013; Larson *et al*., 2008). It is also argued that family caregiving can also bring positive experiences, such as a more purposeful life, greater inner strength, learning new skills (medical/nursing tasks) or a greater closeness with the patient (Levine *et al*., 2010; Gillespie and Campbell, 2011; Home Alone: Family Caregivers Providing Complex Care, 2016).

The majority of family caregivers are women (66%), although men also serve as caregivers (Caregiving in the US 2009 and Family Care Alliance 2001). Caregiving remains largely a woman's responsibility, for instance, a considerable number of

American women find themselves employed full-time in addition to caregiving 20 hours a week, the equivalent of a second part-time job (Navaie-Waliser *et al.*, 2002; caregiving in the US 2009 and Family Care Alliance 2001).

Each year 800,000 people experience a new or recurrent stroke event (Jones *et al.*, 2010), with approximately 4.8 million stroke survivors living in the community with some form of disability requiring assistance from Family Caregivers (Lutz *et al*., 2011). Of the 4.8 million, 50 percent, that is, 2.4 million need assistance with Activities of daily living (ADLs (American Heart Association 2006).

Furthermore, in 2009 more than 65.7 million unpaid caregivers in United States provided an average of 20 hrs. per week of care, with an estimated market value of $375 billion (Lutz *et al*., 2011). This stresses that caregiving is a very costly role on both the family caregiver and the economy. The cost is high due to the length of stay in the hospital for stroke rehabilitation (Dobrez *et al*., 2010; O'Brian 2010).

As a result of the high cost implication it has on the family, patients are discharged from the hospital "earlier and more sick" resulting in increased stress for Family Caregivers who are unprepared to meet accommodation and needs for assistance with Activities of Daily *Living* (ADLs) required; Needs such as establishing wheelchair access, assisting with toilets, dispensing medications and driving to doctors' appointments (Lutz *et al*., 2011). Financial constraints include out of pocket expenses, having to juggle work and caregiving. Furthermore, some exit the labor force; forego income and benefits to provide care. Employers also have a cost to bear which include employment-related costs for those who replace workers who leave the labor force or have to work reduced hours because of caregiving (Keating *et al*., 2014). Additionally, the cost of hospital bills may be one of the reasons why stroke patients receive care from home.

1.2. Statement of the problem

Family caregivers' role of patient care is unarguably important for stroke rehabilitation. This is because family caregivers play a key role in facilitating recovery (Andrew *et al*., 2015; McCullagh *et al*., 2005); however, care giving is a complex concept (McCullagh *et al*., 2005). Clinical observation and early empirical research indicates that assuming a caregiving role can be stressful and burdensome (Haley et al., 1987). Caregiving creates physical and psychological strain over extended periods of time and is accompanied by high levels of unpredictability and uncontrollability (Schulz and Sherwood, 2008) with the ability to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance (Vitaliano et al., 2003).

In Zambia, there have been no national representative population-based studies to determine the burden of NCDs (Mukanu et al., 2017), which includes Stroke. According to the latest WHO data published in 2017 Stroke Deaths in Zambia reached 3,939 or 3.40% of total deaths. The age adjusted Death Rate is 64.18 per 100,000 of population ranks Zambia #120 in the world (WHO 2017).

Furthermore, much of the findings are as a result of research done at Global and regional levels and not much of such research has been done in Zambia as stated except some studies on the outcomes of stroke, for instance on the income status of the families involved after a member of the family suffers a stroke and are left in a state where they are unable to continue working to support the family. Given the deficiency of information on the subject, it was imperative to undertake this study.

1.3. Rationale

The study was conducted to explore and document the experiences of family caregivers of disabled stroke patients. It was vital for this study to be conducted because, just as the health of the patient is of concern, the health of the caregivers is also imperative for them to provide quality care to the patients. This is because these patients in most cases need full time attention and they need to be in a complete state of wellbeing to be fully available. The other vital reason for this study to have been conducted as Hayashi *et al* (2013) argues in a study done in Vietnam is that such information can be used to enhance the caregiver’s support system.

In Zambia, there are no well-established caregiver support systems, thus understanding the experiences of the caregivers may be instrumental in setting it up. The other reason why it was imperative to explore and document the experiences of family caregivers of stroke patients was that, it is through the experiences of the caregivers that the various needs, challenges and gaps in the health care system are understood in the Zambian context. In addition, exploring experiences made clearer and known, gaps and challenges with regard to those who are family caregivers of disabled stroke patients.

The study also brought out areas for further research and added to body of knowledge. The study was also very useful for Health Promotion practice because it provided evidence of what the issues and gaps are with regard to family caregivers of disabled stroke patients. These in turn may be used by health promoter as bench marks for promoting better ways to deal with family caregivers. Further, findings of this study may aid the provision and establishment of community based services for stroke rehabilitation and support of family caregivers.

1.4. Research questions

1. What are the experiences of family caregivers to disabled stroke patients?
2. What challenges do family caregivers face and how do they cope?
3. What support mechanisms exist for home based care of stroke patients?

1.5. Objectives

1.5.1. Main objective

To explore and document the experiences of family caregivers of disabled stroke patients in Lusaka district

1.5.2. Specific objectives

1. To document the day to day circumstances that family caregivers of stroke patients go through in their care giving role.

2. To explore the support systems family caregivers receive in offering home-based care to stroke patients

3. To document the challenges faced by caregivers and their coping strategies

CHAPTER TWO: LITERATURE REVIEW

2.0. Introduction

Numerous studies have been done on family caregivers to stroke patients in general, and some of these studies have been on the experiences of family caregivers, outcomes of caregiving such as the Quality of Life, Economic impact on affected families and training of the caregivers. The literature reviewed focused on studies that looked at stroke family caregivers' outcomes and other related issues pertaining to patients with stroke and the caregivers. The Literature reviewed has been categorized and will be outlined under four subheadings namely: 1. Experiences of Caregivers 2. Caregiver Burden, Impact of the Burden and Health related quality of Life 3. Burden of stroke caregiving versus resources and hospitalization 4. Training of caregivers to stroke patients and the approach for rehabilitation.

2.1. Experiences of caregivers

Different people experience life situations differently; this is the same with family caregivers of stroke patients. Given different settings, age, financial capacities to mention but a few situations, caregiving is most likely to be very different from one person to the other.

In a study by Backstrom and Sundin (2009) aimed to illuminate the experience of being a middle-aged close relative of a person who has suffered a stroke, one year after the stroke sufferer's discharge from a rehabilitation clinic. This study used narrative interviews which were audio-taped. The study highlights the middle-aged relatives' realization that they live an inevitability altered future. Furthermore, it was found that individually, the stroke sufferer's relatives need support in their relationships within the family for emotional confirmation and to help them recognize and verbalize their needs without feeling guilty. The study also found that gaining these supportive factors may help the relatives to recover their sense of well-being and give strength for a future, properly functioning family life.

Bully *et al.* (2010) in a study whose aim and objective was to explore carers' experiences of caring for a stroke survivor including reactions and changes in their lives, using a phenomenological approach to collect and analyze the data, had an overarching theme emerge, entitled: ‘lives turned upside-down’. It took time for participants to understand the long-term impacts of stroke. Carers experienced increased caring and domestic workloads alongside reduced participation and altered expectations of life. They found emotional and cognitive changes in their partners particularly distressing, and would have valued more information and help with adjusting to the increased emotional, physical and cognitive workload of caring. The authors concluded that it is important to support carers of people who have survived a stroke in adjusting to their changed lifestyles. This may affect their quality of life as well as sustainability of caring, and requires further research.

Lopez- Espuela *et al.* (2018) in a study where they explored and documented the experiences and values of spouse caregivers of stroke survivors using phenomenological qualitative design found that spouse caregivers of stroke survivors undergo a process of disruption in their private lives and relationships, marked by their caregiving duties. They condensed experiences of spouses caring for stroke survivors into topics and subtopics: “*Caregiving and that´s all”*, summarizing the sense of having no life horizons and also caregiver impossibility of moving away from caring role. Further, “*Breaking the couple´s life together”* enlightens the further consequences of stroke in couple’s shared live biography, which needs to be understood and rebuilt the authors argued. The other theme was, “*Going through the (non) loss alone”* alluding to how spouses reinterpret meaning of loss, which is not appreciated by others and that refers to the balance between stroke survival and any acquired global disability.

In this study it was concluded that a comprehensive approach to the family, from a psycho-socio-emotional and relational perspective, is essential for ensuring adequate quality of life for people who suffered a stroke as well as their caregivers. Also that, spouses-caregivers must be considered as individuals living a transition process due to their unexpected disrupting change, which nurses should address through a comprehensive and integrated approach focused on transition care. The authors further argued that care resources must be adapted to the interpretation that the spouses have of their caregiving role and their relationship with the different components of the caregiving process.

Gosman-Hedström and Dahlin-Ivanoff (2012) in a study that explored and learnt from older women how they experience their life situation and formal support as carers' of their partners after stroke concluded that the carers' lives had changed radically. The results according to the authors draw attention to the carers' need for time to themselves, a greater knowledge of stroke and continuous support from formal care.

2.2. Caregiver burden, Impact of the burden and Health related quality of life

Various studies have been conducted on the burden of caregiving, the impact of the burden on care provided and the health related quality of life thereof. As maybe the fact that there is an interlink of one's environment and their health, it is vital to note that what surrounds the caregiver including what kind of assistance, challenges and experiences they have while providing care to a patient has a bearing on their health as well as that of the patient they are taking care of.

Halley (2017) in his review and analysis of literature with regard to family caregiving for patients with stroke discusses very thought-provoking points. To start with he asserted the importance of studies to systematically examine both negative and positive aspects of caregiving. He further notes that early interventions are vital in dealing with complications that may arise with regard to caregivers of stroke patients such as risk of depression and subsequent psychological morbidity. Also that this may lead to unsuccessful social rehabilitation of the stroke patients, he noted.

Research on family caregivers has over the years demonstrated that with an increase in care burden there is a subsequent decrease in mental and physical health. And among the stroke caregivers, what is severely compromised is the mental health and social functioning as health related quality of life domains (Morimoto T *et al.*, 2017). Furthermore, in a study by Yu Y *et al.,* (2013) on social support, coping strategies and health related quality of life among caregivers of stroke survivors in China, it was found that higher education levels, planning and active coping were positively associated with health- related quality of life. Also that the chronic conditions, hours of care per day and functional dependence of the survivor was negatively related to quality of life. The authors argued that caring for stroke survivors is highly stressful which can negatively affect a caregivers' physical and psychological wellbeing and stroke caregivers report much more of somatic symptoms, depressive symptoms, disorders related to sleep and isolation of the social kind. They generally have poorer quality of life than the general population.

Fatoye F *et al* (2006) did a cross sectional study to investigate the emotional symptoms and domain quality of life (QOL) among primary caregivers of stroke survivors and to determine survivor related and care related predictors of these variables. In their study, it was found that caregiving imposes high burden on stroke carers' and recommended that attention should be paid to the stroke carers' needs and services need to be designed for them to ameliorate the burden. Twenty three (22.3%) and twenty five (24.3%) stroke caregivers were observed with clinically significant anxiety and depressive symptoms respectively compared with twelve (11.7%) and fourteen (13.6%) subjects in the control group. Stroke caregivers were observed with significantly higher mean anxiety and depressions scores, and also, with significantly lower mean scores on the four QOL domains (physical health, psychological health, social relationships and environment). By multiple linear regression analysis, anxiety symptoms in stroke caregivers were predicted by high socioeconomic status of survivors and paresis in them. Depressive symptoms were predicted by high caregivers' age and depression in the patients.

Furthermore, the study found that higher QOL on one or more WHOQOL-Bref domains was predicted by intimate relationship with survivor, female gender of caregiver, longer duration of caring, higher education of survivor and higher age of survivor. Low QOL on one or more domain(s) was predicted by higher caregivers' age, carers' perception of survivor as cooperative, female gender of survivor, depression in survivor, paresis and cognitive impairment in survivor (Fatoye F *et al*., 2006).

An important aspect of stroke rehabilitation is to bridge the gap between patients' or care givers' expectations of recovery and residual disability to promote overall wellbeing of patients and their families. One method of capturing wellbeing is to assess quality of life and several different measures have been used, despite various limitations. Although the practical importance of the effects of any intervention on quality of life can be difficult to interpret, moderate differences in average scores can mask large biological effects. The significant improvements in quality of life scores associated with caregiver training are likely to indicate an important effect that has implications for clinical practice (Kalra *et al*., 2004).

2.3. Burden of stroke, resources and hospitalization

Already a major cause of death and disability in high-income countries, the burden of stroke in Sub-Saharan Africa is also expected to be high. However, specific stroke data are scarce from resource-poor countries argued Damasceno *et al* (2010). This was in a study done in Maputo of Mozambique were they studied the incidence, characteristics, and short-term consequences of hospitalizations for stroke in Maputo, Mozambique. From the results, it was indicated that from almost no preadmission disability, 64.4% of 370 survivors at 28 days had moderate-to-severe disability. The results of this study showed that the burden of disease associated with stroke was high in Maputo, emphasizing the importance of primary prevention and improvement of the standards of care in a developing country under epidemiological transition.

Kamalakannan *et al* (2016) in a study on rehabilitation needs of stroke survivors after discharge from the hospital in India, they found that about 82% of the needs expressed by stroke survivors and 92% of the needs expressed by caregivers indicated that they had a substantial need for information. The qualitative data revealed major gaps in access to stroke rehabilitation services. Service providers identified availability and affordability of services as key problems. Stroke survivors and their caregivers identified lack of information about stroke as major barriers to accessibility of stroke rehabilitation services and caregivers expressed a tremendous need for support to manage family dynamics. The authors concluded that there is a considerable unmet need for post stroke rehabilitation services. And given the lack of rehabilitation resources in India, developing an accessible, innovative, patient-centered, culturally sensitive rehabilitation intervention was of public health importance. It was crucial for low- and middle-income countries like India to develop technology-driven stroke rehabilitation strategies to meet the growing rehabilitation needs of stroke survivors, the study concluded.

Krieger *et al* (2016) in a review of studies done, argued that in Germany, there was no stroke caregiver support programme that operated throughout the course of rehabilitation. The aim was to develop a complex intervention programme for stroke caregivers in North-Rhine Westphalia, Germany. In this study under the methods a naturalistic enquiry approach, using a mixed-methods design, was applied. After the review it was found that there was a need to a personalized, holistic and multicomponent caregiver support programme. As strategies for rehabilitation, the study found that caregivers should be approached directly after stroke using outreach counseling. Support should be provided by a specially trained focal person across the entire patient's rehabilitation trajectory.

In all, during the rehabilitation process, it is vital to consider the caregiver who is core to the whole process and thus strategies for rehabilitation should include strategies that will improve and take care of the needs of the caregivers.

2.4. Training of caregivers and the approach for rehabilitation

Training of the family caregivers of stroke patients is very vital as they are in close contact and the rehabilitation process and outcome depend much more on how they handle the patient. Nevertheless, their sanity and wellbeing are also very important.

Several studies have been done on the need for education for the caregivers of stroke patients for various reasons. A study done by Hayashi *et al* in 2011 in Vietnam indicated that comprehensive stroke care is that which includes caregiver education. It specified the kind of education which includes caregiver education about healthful diets and prevention of stroke recurrence needed at state owned acute care hospitals.

Pesantes *et al* (2013) argued that in the absence of structured institutional responses, family members endure with the provision of care for stroke survivors, a task escorted by major emotional, financial, and social strains. This burden could be prevented or curtailed if caregivers were to be targeted by interventions providing psychological and financial support, together with basic training on post-stroke care. Kalra *et al* (2004) also validated the need for training of caregivers in his study were he asserted that the training reduces the costs and the burden on the caregiver at the same time improving psychosocial outcomes in caregivers and patients at one year after the stroke event. They further argued that training care givers in basic skills of moving and handling, facilitation of activities of daily living, and simple nursing tasks reduces burden of care and improves quality of life in patients and care givers. Were improvements in care givers' emotional health and quality of life have been described to improve with education and family support.

Given that patients of stoke are totally dependent upon the assistance due to the severe disability in most cases. The caregivers become very key persons in caring for them to enhance recovery and avoid further complications. Studies have shown that post stroke care is complicated and different from caring for patients with other chronic illnesses, therefore, family care givers need to become well-informed and have the necessary skills about prevention of complications, activities of daily living, rehabilitation, emotional and stress management (Pitthayapong *et al*., 2017).

In this study, it was found that apart from the family caregivers needing knowledge on how to manage and prevent complications after stroke, supporting a patient’s activity daily living and in accessing rehabilitation services, they also required training. And this training should be in providing nursing care appropriate to patients’ problems and needs which include feeding technique, pressure ulcer prevention and wound care to mention but a few (Pitthayapong *et al*., 2017).

It is very imperative for an individual in any position to be conversant if they are to perform a task well. To do so, there should be some of form of training that should be provided for one to have the confidence in provision of the service, equally with family caregivers, there is need for training to be provided for them to be able to have self-reliance and to avoid any kind of panic in taking care of the patient (Pitthayapong *et al*., 2017).

Furthermore, given that patients of stroke have different problems at different phases of the condition, the caregiver must be made fully mindful of these problems as it is an important part of the caring process for the patients. It is with this process that the patients and caregivers are made aware of the illness by providing them the information and this may be of assistance in making various decisions with regard to the condition (Hafsteinsdottir *et al*., 2010).

It is estimated that 25-74% of stroke survivors require help with activities for daily living from informal care givers, often family members. Although the physical, psychological, emotional, and social consequences of caregiving and its economic benefit to society are well recognized, the caregivers' needs are often given low priority in the management of stroke. Advances in stroke rehabilitation have successfully reduced severe disability and institutionalization, which has increased the number of disabled patients living at home and being supported by care givers, who feel inadequately trained, poorly informed, and dissatisfied with the extent of support available after discharge (Kalra, L *et al*., 2004).

The assertion by Kalra *et al* (2004) study, that advances in stroke have successfully reduced severe disability requires further investigation to ascertain for sure if these results could be applied in Zambia. This is in the view to find out if at all there are any advances in Stroke rehabilitation and whether or not it reduces severe disability and institutionalization.

2.5. Caregiving in the Zambian context

In a study done on caring for the aged in old people's homes in Zambia and implications for adult education programmes, “it was found that the challenges faced by caregivers included inadequate and erratic funding, low staffing levels, lack of training opportunities, absence of a national policy on ageing, lack of transport, lack of information communication technology facilities and high demand for admission of the aged to old people's homes. The paper concluded that the combination of the above challenges made caregivers in old people's homes in Zambia operate under difficult and demotivating conditions. It recommended that the challenges needed to be mitigated by the government and other stakeholders so that caregivers could operate better and, ultimately, provide improved services and care to the aged residing in these homes" (Changala et al., 2016).

Another study that explored changes in home-based care (HBC) in the light of widespread ART rollout in the Lusaka and Kabwe districts of Zambia found that since the roll-out of ART, home-based caregivers spend less time on hands-on physical care and support in the household, and are increasingly involved in specialized tasks supporting their clients' access and adherence to ART. Despite their pride in gaining technical care skills, caregivers lament their lack of formal recognition through training, remuneration or mobility within the health system. Care relations within homes have also been altered as caregivers' newly acquired functions of monitoring their clients while on ART are met with some ambivalence. The study concluded that as their responsibilities and working environments are rapidly evolving, caregivers' motivations are changing. The study further concluded that, it is essential to identify and address the growing tensions between an idealized rhetoric of altruistic volunteerism in home-based care, and the realities of lay worker deployment in HIV care interventions that not only shift tasks, but transform social and professional relations in ways that may profoundly influence caregivers' motivation and quality of care (Cataldo et al., 2015).

Furthermore, a mixed method study done to look at caring for a cerebral palsy child form the caregivers' perspective concluded that the burden inflicted on those caring for children with cerebral palsy should be addressed if the quality of care for those with cerebral palsy is to be improved (Chiluba and Moyo, 2017).

2.6. Conclusion

It is clear from the literature that communication is suggested as a method that works for any caregiving situation. In that provision of adequate communication training to enhance the levels of communication between the patient and the caregiver as well as the whole family, the caregiver and the patient improves how one provides care. Improving communication skills for the caregiver, empowers them to advocate for the patient (Wittenberg et al., 2017).

The literature reviewed did not include adult caregivers who provided care from the home setting as the caregivers for the stroke patients in this study did. Thus it comes as an addition to literature and the body of knowledge.

CHAPTER THREE: METHODOLOGY

3.1. Study design

A hermeutic phenomenological qualitative study was done. This type of data is common whenever people are the focus of the study, particularly in social groups or as individuals”. Hermeutic Phenomenological study design was used given that the study was focusing on documenting lived experiences of the family caregivers of disabled stroke patients. “Lived experiences involve the immediate consciousness of life’s events prior to reflection and without interpretation, and are influenced by those things internal and external to them. Furthermore, a phenomenological analysis does not aim to explain or discover causes. Instead, its goal is to clarify the meanings of phenomena from lived experiences. And practiced within a human science perspective can thus result in valuable knowledge about individuals’ experiences”(Penner and McClement, 2008). This is why the study design was selected, so that the phenomenon of caring for a disabled stroke patient is explained and understood from the point of view of the caregivers themselves.

3.2. Study site and population

The study was conducted in Lusaka District and participants were purposively sampled from the University Teaching Hospital, specifically the Adult hospital using maximum variation technique and expert sampling technique for the Physiotherapist. The participants included those individuals who were providing care to a stroke patient who was not able to perform daily living activities like dressing, eating and bathing etc. Informal caregivers such as spouses, blood relatives and relatives in-law regardless of age, as long as they provided care at home for their stroke survivors most of the week were identified. Permission to use the adult hospital was sought from the hospital management prior to the study. The department of physiotherapy was used as a reference point for the selection of most of the participants. Some of the participants were identified from three communities in Lusaka which included Chaisa, Kaunda Square stage one, National Resource Development Centre (NRDC). This was done by going to the communities through a contact person who was provided by former home-based care volunteer this was to carter for those who unable to go for physiotherapy sessions at the hospital.

3.3. Selection of participants, sample size and sampling methods

A total of 12 participants were interviewed, comprising of 11 caregivers and one Physiotherapist. The number of interviewed participants was considered enough to describe the experiences of family caregivers as initially intended given that no additional themes were emerging from reviewing of successive data. The sample was chosen using purposive sampling considering those that are providing care for stroke survivors and are part the patients' family.

Only those who have been caregiving for at least six months and more were picked and those people must be a family relation. Those who were visiting the physiotherapy department for the first time were excluded from the study.

3.4. Data collection

Data was collected by conducting one to one in-depth audio taped interviews with the participants using a narrative interview method. Participants were asked to narrate step by step what their experiences were, starting from when the patient had the stroke to that time of the interview. The purpose of narrative interviews was to create a condition for understanding the meanings and experiences that emerged in the dialogue (Mishler, 1986). This was to provide a platform for the participants to speak as precisely as possible about their experiences to get full spell out of what they meant. The data was collected over a period of two months after familiarizing with the hospital and the staff. The interviews were recorded so that the information is well backed up for a true representation of what the participants actually said. The interviews lasted from 20 to 40 minutes per individual. Additionally, notes were also taken to compliment the audio recorded data.

3.5. Data collection tools

Data was collected using an interview guide for the family caregivers and for the key informant interview a separate guide was used. The data was collected by the principle investigator and an assistant who was employed. An audio recorder was used to record the interviews and notes were taken to supplement the recorded interviews as stated above.

3.6. Data management and storage

The information collected was stored on a password secured laptop where no unauthorized persons were able to access it.

3.7. Data analysis

The data was reviewed at the end of each day so as to appraise the processes and check for any missing questions that came up after the interviews with the interviewee of the day. Narrative analysis was done by transcribing the narrative interviews. The interviews that were done in Bemba and Nyanja were translated to English by the principal investigator who is fluent in both languages.

Phenomenological hermeneutic interpretation according to Anders Lindseth and Astrid Norber (2004) was used in analyzing the data after the transcription. This method implies a process of interpretation involving three phases characterized by a constantly progressing dialectic movement between the whole and the parts of the texts, between understanding and explanation, and a progression from explanation to a new comprehension (Öhman, Söderberg and Lundman, 2003).

This included three main steps which are 1. Naïve understanding; to get a sense of the whole; that is, the picture of the whole situation; 2. Structural analysis which is aimed at explaining the text and; 3. Interpretation of the text as the whole, the first and second steps including the pre-understanding of the phenomena combined into a new comprehensive understanding. Themes were generated and explained from the structural analysis and comprehensive understanding discussed. Nvivo was used as an aid for data management. The data was imputed into Nvivo software and information categorized to aid with theme generation. The data was manipulated to group similar thoughts and quotes for final presentation of themes and quotes.

3.8. Rigor

To enhance study rigor the researcher considered reflexivity as a strategy. A record of the researchers' thoughts, approaches, ideas and challenges were maintained throughout the study. The reflexive notes were then used during the discussion of the study findings. Apart from being reflexive, the researcher considered peer interrogation and support. This strategy was used because it ensures that ideas and advice from other researchers increases the validity of one's study. The principle investigator (PI) worked closely with the supervisors to also validate the methods and process of the study. There was close monitoring and availing of all documentation used and collected in the filed which ensured auditability. The PI also kept records of written field notes, verbatim transcriptions and recordings for review by others. Finally, the process of replicability can be reached as the methodology that was used has been cleared stated so that in an event anyone wants to undertake a similar approach, they are able to follow through with ease.

3.8. Ethical considerations

Details of the study were provided to the participants and the purpose clearly explained. The study ensured that participation in the study was on a voluntary basis and those that declined to take part of the study despite making them understand the importance of the study were not forced. Consent forms were signed as proof of ones' willingness to be part of the study and a copy was provided to the participant and the other kept. There was no need for the participants to provide their names so as to assure their privacy instead codes were assigned for the sake of tracking the information.

Furthermore, the participants were not required to provide their names to ensure confidentiality and to give them a sense of privacy for accurate provision of facts and truths. No remuneration was provided to the participants for their participation which was solely on voluntary basis and their appreciation of the why the research was being done and knowing that it was for their benefit and others that the information be obtained.

Written permission was obtained from the various authorities for the research to be undertaken such as the University of Zambia biomedical research ethics committee (UNZABREC) – ref no. 037-08-18 and National Health Research Authority (NHRA). A letter from the University Teaching Hospital was gotten from the adult hospital and the physiotherapy department for permission to undertake the research from the hospital.

The participants were given time to break off from the narration so as to recollect themselves in an event they could not go on. A trained psychosocial counselor was employed as an assistant to deal with issues that arose as the study was being conducted.

All sources of information and literature are acknowledged.

3.9. Study Limitations

1. Time and place of the interview was of the essence, given that most interviews were done at the hospital grounds as the caregivers waited for the patient to be done with physiotherapy, the participant seemed to be in a rush to go home with the patient. this does not in any way have an implication on the quality of experiences shared but is to be of help to those doing research in the future, to be more weary.
2. This study did not diagnose clinical depression which would have made the argument of participants being depressed more concrete.

CHAPTER FOUR: RESULTS

4.1. Introduction

This chapter is an outline of the findings. The findings are presented following the outline of the analysis method which was used, the first being a naïve understanding of the findings; the second is the structural analysis which is the findings presented including the themes derived and the last is the comprehensive understanding which is the discussion of the findings. Quotes will be presented in italics to separate them from the main text.

Table 1: Attributes of participants

Code	Relationship to patient	Sex	Participant Age	Patient age	Marital status	Employment status
PF01	Daughter	Female	35	62	Widow	Unemployed
PF02	Daughter	Female	55	73	Married	Unemployed
PM03	Brother-in-law	Male	48	60	Married	Unemployed
PF04	Mother	Female	58	29	Widow	Business
PF05	Daughter	Female	36	65	Married	Unemployed
PF06	Son	Male	43	70	Married	Employed
PF07	Daughter	Female	36	70	Single	Unemployed
PM08	Nephew	Male	21	50	Single	Unemployed
PF09	Wife	Female	67	73	Married	Business

PF10	Wife	Female	70	73	Married	Unemployed
PM11	Grandchild	Male	21	66	Single	School going
P12-KI	Physiotherapist	Female	44	N/A	Married	Employed

Key: P is for participant, **F** for female and **M** for male and the number of the participant follows. For instance, **PM11** is a participant who is male and was the eleventh to be interviewed.

The table presented, **(Table1)** illustrates the number of interviewed participants and the relation to the care recipient or the patient. The total number interviewed was 12 which included 11 family caregivers and one key informant. One key informant was interviewed to get an understanding of what training they provide to the family caregiver so as to reinforce what the participants had said.

Generally, being a family caregiver to a disabled stroke patient comes with many feelings of anguish which may not be acted upon by the caregiver as they fear letting their patient and those who surround them down. It absorbs their strength and takes away the freedom they have to be their own person as they have to do what they do as a responsibility only they can take care of. To some, it is a moment that they have to prove their purpose of being and at the same time, be there for their family member or relation with a realization that they too are prone to be in the same situation and someone who is cognizant to their contribution to the patient’s life may as well be more open to the idea of taking care of them should they suffer the same fate. For others it is a reality that is before them and they have no choice on how it turns out but just have to live each day with the hope of things getting better. Experiences of tiredness, giving up, sadness, hope, fulfillment and distress were intensely expressed present in the narratives.

Table 2: Overview of the themes derived from the structural analyses of the interview with participants

Main theme	Sub-theme
Lifestyle changes	Orientation of caregivers to provision of care
Emotional experiences of the caregivers	Healing taking too long
Social support for caregivers	Taboo vs. responsibility A sense of responsibility
Challenges faced by caregivers and their coping strategies	Challenges Coping strategies

4.2. Lifestyle changes

This theme encompassed the various experiences that were part of the abrupt changes that came with caring for a loved one and what it means to live a life different from the usual old life. It was about living a whole different life full of different emotional times which included sadness, joy, anxiety, fear and despair. It was experiencing the different responsibilities that came with having to take care of one who in their past life could for instance, wake up in the morning, take a bath and go for work without them needing any aid but were now unable to do so.

4.2.1. Orientation of caregivers to caregiving

This theme entailed the processes that the caregivers had undergone in order to gain confidence as they provided care to the patient.

When it came to training for the caregivers, participants said that they were in a way shown how to take care of the patients with regard to the rehabilitation process. All participants confirmed that they had been shown how to do the exercises and how to provide general care to the patient. The key informant referred to it as skills transfer and not training per se because there was no formal method of passing on the information.

For instance one of the female participants *(PF10)* had this to say*: exercises, they showed us how to do it...hands and legs…we were told to pull him here and there. We were also advised to be giving him some fried maize so that he exercises his mouth.*

The key informant had this to say*: …when they are in the ward, there are some simple things that we teach them. It is some kind of informal training, of course it is a one on one, and it will depend on the severity of the stroke. I can safely say that there is some form of training given, some form of skills passing on to the caregiver on how they can handle the patient to avoid complications from happening…*

Participants seemed to appreciate the information that was provided to them despite them not receiving formal training. This could be because they have not experienced being formally trained. It would be important to train them and do a follow up to note the difference in experiences given both situations.

Some participants also found at least a positive experience that they shared mostly about what they learnt through the process of providing care to their loved one.

For instance a male participant aged 48 caring for his brother in law revealed:

(PM03) I think I have learnt a lot in the process of taking care of him...firstly I have learnt what causes stroke…then also I have an idea of type of medication…he is on medications which he is not supposed to stop that it is very important to do regular checks because I check his blood pressure everyday…

On a contradictory note one echoed that their life was much more on the negative end and drawing anything positive was so difficulty.

For instance this male 21 year old participant who was nursing the grandmother had this to say:

PM11: really I have to dig deeper for me to get any positive from an unfortunate situation like this one, mostly there are just sad times, eehh but perhaps I must say that the only positive thing is that I have learnt to be responsible at an early stage in life, eehh caring for the old, it helps with maturity, that is one positive thing I can draw from this. Basically you just mature and learn to appreciate that really on earth there are also diseases that I might find myself in when I grow old.

What one might see as positive may vary from one participant to the other, in that one participant may not see anything positive in caring for a patient because of the pressure it comes with. Despite the challenges, this participant does admit that positive experiences can be drawn, despite it being difficulty given the situation. Most of these participants regarded learning as a positive experience despite the learning taking place through the sickness of a loved one.

For example, one mother taking care of her daughter said she had acquired a new skill which even professional nurses do not know, she said:

*PF04: even that 'tracker' (*a device to protect the patient from head injury), *the ENT* (Ear, Nose and Throat specialist) *showed me how to change it and even some nurses do not know these things…they don't know...so they would ask me to teach them how to do it..*

It is very encouraging that participants are able to at least pick one thing that is positive about them taking care of their loved one. For instance, this woman knowing that she is the only one who is able to insert an important device on the child would reinforce the need to care for the child. In that, it becomes apparent to her that without her, then the work may not be done at all, which in turn may have an implication on the child's life.

4.3. Emotional experiences of caregivers

This theme was a reflection of the participants' narrations of how they felt this new life that they were leading was very tough and full of emotional moments. It described how even from the beginning of the sickness, participants were made to lead a life were they were uncertain of what will become of the patient, everyday wondering if it's their last moment of life not knowing what will happen next.

For example, a woman aged 70 (PF10) narrated; how she thought the husband was going to die when he just got sick, she did not have the hope that he would survive the attack, in her narration she said:

PF10: while at the hospital, they checked him and we sat there waiting for them to tell us what was wrong…as we were waiting he asked that he wanted to go to the toilet...So my son and I took him to the toilet, I remained outside because it was a men's toilet…but as I was standing outside, my son called for help...he said please hurry up dad has fallen...I run inside the toilet and I found him down helpless…I told myself that this is the end of my husband…he is dying.. So the doctor came and looked at him and said that this is stroke…and at the same time his blood pressure dropped.

This could be the most unbearable feeling and thought for any individual, not knowing whether the patient will pull through a sickness event or not. What's more is the fear of what is to come, and psychologically a caregiver convinces themselves that they may not be able to do anything about it.

Furthermore, some participants expressed how unbearable it was to see a loved one who was able to go about life without any help in a state of helplessness. For instance, one male participant taking care of his mother talks about how one may try to be strong and not show the patient the weak side of them despite one being hurt and wanting to express themselves. One would rather appear to be strong all the time so as to encourage the patient. This is what he expressed:

PM07: There are emotional experiences…you know….seeing someone who used to work but has now been reduced to a chair and failing to do something…sometimes you are just so emotional…you go on the side…you cry and cry and dry your tears and go back trying to be strong and yet you are not strong…uhhaaa…its hard…its…aaa… is hard to tell you the truth...

Similarly, a woman aged 58 and taking care of the daughter had this to say:

(PF04) "*Seeing a loved one on a wheelchair when they were able to do things on their own is heartbreaking. Mwaliishiba umwana aleenda, elyo asaangwa pa*

wheelchair...chilikalipa" (You know, your child was walking then suddenly they are in a wheelchair, it hurts).

There is an emphasis of the hardships of being in the shoes of a family caregiver caring for a once well abled person who is unable to care for themselves anymore.

Emotional moments for the family caregivers were not only experienced because they were going through a difficult time, but at times it was as a result of the general mood of the patient. From the interview with the key informant, it was established that patients needed to be understood, in that sometimes they tend to be very temperamental and difficult to deal with. It was therefore the work of the family caregiver on one hand to understand that it is not the fault of the patient but the nature of the condition.

On the other hand, it was the work of professionals to make the family caregivers understand the condition in order for them to care for the patient with ease. In this vain, the key informant reported:

KF1: The bottom line is that I have to advise this person that is refusing, because the psychological aspect is affected? The cognitive component is defective that is why this person may be appearing to be refusing to the relatives because they don't understand or it's just because in terms of the psychological aspect, *everything is not okay, he may be depressed and you may need to deal with depression or the relatives do not understand that actually this person, the ability to understand instruction is not there. So I need to weigh and see what the problem is...I assess the patient to be sure were this is coming from? Is it is to do with ability to understand instruction, and so the psychological components, then it means that I have to start explaining to the caregivers that he is not just refusing; just to help them manage the patient, because this patient, the cognitive functions are defective.*

Given that stroke tempers with an individual in many aspects as illustrated in the above quote, some participants seemed to understand that this was as a result of the condition of the patient. For example a female participant aged 70 and nursing her husband narrated how temperamental the husband was:

PF10: Sometimes he is temperamental and moody...you find that you greet him and he will not answer you….he will just look at me…and that time he will be very upset the whole day. But then am used to that, I know that even if he is upset now, it will eventually pass and he will be okay…I have gotten used to him…I know that even if he is upset, he won't chase me…because he knows that am the one that takes of him...he knows that and so I know he know that no one will take care of him if I chase her.

This quote implies that, in a sense, the participant understands that this comes with the patient being in this condition. Knowing him before getting sick could be one reason why she understands that this is as a result of him being in his condition. To the lady, being all the husband has at the moment in is life, gives her the sense of security, because if the husband was well and was able to do things on his own he would not see the need of her and he would even chase her away from the house.

For example, at one moment this is what she said: "*if it was those days in the past, he would have been slapping me and even chase me away from his house".*

From this narration, it is clear that the husband to this woman was a violent one and is only no longer in a position to treat her that way because he is sick. All this, including the changes that come with being sick, in a sense contribute to the emotional moments for these family caregivers.

4.3.1. Healing taking too long

This sub-theme was about how participants expressed the agony of waiting for a long time for a time when the patient would actually get better, every day's action being considered as a part of the contribution to the awaited progress and healing. Some of them narrated how hard it was as they had been providing care for the patient for many years and hoping that one day the patient may actually get better. However, they expressed happiness when a patient responded to care and was doing better than before. For instance, a woman aged 67 who was nursing her husband, when asked which day was most memorable in her experience, said:

PF09: I remember very well the time he stated to walk on his own, it was a very great moment and it made me very happy.

At the same time, it saddened them to see their loved one in a state of helplessness for many years without healing and just hoping for a better day. They described it as a very challenging way to live. A 43 year old man caring for the mother said:

PM07…you know, you want something good for someone but it is taking long...to actualize what you want…it is very difficult.

Healing in stroke survivors takes long naturally and caregivers need to be made to understand that it is a gradual process. In a way that may make their experience easier as they will be patient from the very beginning because they know that it is a normal situation.

4.4. Social support for caregivers

This theme summarized the experiences that are part of a family caregiver life of being the only support that a patient has; and how one as a caregiver needs to balance living their life and at the same time, always be there for the patient. It also describes the importance for social capital and how it would be imperative to have family members provide social support to caregivers. This is because, some children had to nurse their parents which included bathing them, which they regarded as a taboo as may be in most African settings. This would be avoided if aunties or uncles were present in the patients' life and thus provide support to their nieces or nephews who were the primary caregivers. Sub-themes derived from this theme were *Taboo vs. Responsibility* and *A sense of owing and having no other choice.*

4.4.1. Taboo vs. Responsibility

This theme is about what it means in the Zambian setting to be one's child and at the same time have a responsibility to take care of the patient as a caregiver when they survive a stroke. There was a case where two children were taking care of their mother, a daughter and a son. They were considered as two different participants despite them caring for one patient because they both had unique experiences as persons in their own right.

They were limited in how much they had to do as caregivers for their mother by the fact that they were children to this woman. Therefore certain tasks proved to be more difficult than others, for instance bathing the mother.

For instance, a 36 year old lady describes how they feel about having to take care of their mother as a girl child and this is what she had to say:

PF06 "*Bathing her is the most challenging thing…given that this is my mother that I am taking care of. You know what I mean; being a girl child and seeing your mothers' nakedness…that is hard".*

Similarly a 43 year old male participant who was nursing the mother had a similar experience to the previous participant and had this to say:

PM07 "*…you know, me I am a man I cannot attend to her because she is my mother and my young sister here, she has no choice because we don't have money to hire a nurse or put her in a nursing home…but we do it on our own…ahhh…ideally...coming from an African setup, it's like a taboo for us to be bathing mum but there is nothing we can do".*

A man aged 43 who was nursing his brother in law echoed the experience he has in line with it being a taboo for a daughter to nurse the father. He had this to say as he narrated his challenges*:*

PM03: *I can't leave him because the daughter cannot do what I am doing because she is the daughter. That is the agony am undergoing.*

It is evident from these narrations that culture and beliefs do play a role in how a family caregiver behaves and perceives their experience. For instance in the Zambian tradition, it is mostly normal for a grandchild to take care of their grandparents and not the children. It regarded as a kind of respect to a parent if a child does not see them naked if they birthed them. This could be the reason why these participants regard it as a taboo, as it may be in our setting.

4.4.2. A sense of responsibility as a family member

This theme is about the expressions of the participants who narrated that they had to provide care to the patients regardless of the challenges they faced because the care recipient was their relation and loved one. Participants also spoke about how important the role they played in the lives of their loved ones was and how they needed not to leave them alone as it would not be a good way to show support and additionally narrated how the patient is helpless without the help of them as caregivers. They further described the need for a patient never at any point to be left alone in the house or left in someone else's care as it was their responsibility to be present.

To some it was a responsibility they had accepted to undertake and to some even when they felt like they had other pressing situations, they could not leave the patient because they had no option. They had an obligation, and thus owed it to the patient as a relative, either as a mother, a daughter, a son, a nephew or brother in law to take care of the patient because he or she was their relation, who of course they loved and by all means needed to support even at the expense of the other responsibilities they had. Some participants said that it is normal and right thing for one to do as a relative to the patient to be there and take care of the other if they are sick and not able to do things on their own. This is because if it happened that they too were to get sick; they would expect their family relation to take care of them as well.

For instance, a 21 year old male participants taking care of the uncle had this to say:

PM08: *What makes me go on is that he is my uncle so I must do it... tomorrow it could be me and he too can take care of me…*

The Christian value system could have a role to play in the way participants viewed this responsibility and how they reacted to it. In that as Christians, the belief is to do unto others what one hopes to be done unto them. For instance the above quote, the participants says he does it because even he would want that the same to be done for him if he were to get sick.

4.5. Challenges faced by caregivers and their coping strategies

This theme portrays the challenges that the participants faced and how they cope. The sub-themes generated from the narrations were; the challenges (getting tired and not giving up; restricted movements) and coping strategies. At the beginning of the interview, patients seemed mixed up on expressing the challenges that they faced.

Instead, they seemed more defensive when asked whether they managed on their own; they did not want to be seen to be failing in their duties.

While at the end of the interview as they got comfortable they expressed many challenges among which included, exhaustion, difficulties in bathing the patient, diet for the patient, not being able to move to attend other responsibilities, resources and pain of seeing a loved one sick among others.

Given that most participants had expressed that bathing was the most challenging task, one woman who was taking care of her 29 year old daughter said otherwise. She said that she had no challenges at all with bathing her daughter because she had a mould, (which is an object made like a bathing tub or chair), which made it very easy to bath the care recipient. The subthemes are described below.

4.5.1. Challenges

Getting tired and not giving up

This theme is derived from the synthesis of expressions of feelings of being tired and wanting to give up the task of caregiving by the participants. Some participants said they were so tired and that age also played a part in their experience, in that those who were old got tired easily because of their frail nature.

On the contrary, to some, it never even crossed their mind to ever give up on the patient that they cared for, regardless of the challenges or being tired. For instance, a woman aged 58 providing care to her 29 year old daughter had this to say:

PM04: Not even one day…you know what is yours is yours…you know she is my daughter...and being my first born child…I can't ever give up... I have even told her that ...my child I will never give up until the Lord himself makes you well...I will be here…look your husband died...your father also died a long time ago, so now it is you and I taking care of each other…when I tell her that...she even cries.

In connection to not giving up, a male aged 43 providing care to his 70 year old mother had this to say:

PM07: I have never...I have never…never…everything that I am and everything I will ever become on this earth...I owe it to her…she raised us as a single parent...aaaah…you know…we had a dad but he had his own means but she is a strong woman...and aaa me and my siblings we have vowed that we will do anything we can for her...we show her love and we encourage her here and there..

In a way it is a natural phenomenon for a child to love the mother, but further to this attachment and love are values and beliefs. In the Zambian or African culture, children tend to take care of their parents when they are of age or whenever care and attention may be needed. Furthermore, in the scenario above, the mother to the participant was a single mother who provided for the participant and this could be the reason why he expresses that he would never give up on her as she never gave up on him and his siblings.

Contrary to the participants who said they would never give up and that they never get tired, one female participant taking care of her husband narrated and emphasized how much she sometimes gets tired and fed up but she has to do it because she believes that God has suctioned the responsibility. This is what she had to say:

PF10: I do feel tired, so much, I can tell you that this job is very tiring, but then I must tell myself that there is nothing I can do, this is the task that God himself has sanctioned upon me...I do get tired especially when bathing him, my back aches a lot and my hand also ache...I just stop once in a while to rest. Time comes when I also complain in my heart, to say am done, because looking at my age also, it is hard. It is different from the time I was young.

This participants’ belief played a role in her caregiving and why she continues to do it. It could be because she believes that she has to do whatever it is that God has sanctioned in her life regardless of how she feels.

Not only did the thought of giving up come as a result of direct experiences with the patient but also the encounters participants had when trying to get help for their patients. Some participants found it challenging with the way health care providers treated them and how they hesitated in the provision of care. This woman who used to take her husband for physiotherapy at the hospital but received less attention had this to say:

PF10: we continued going for physiotherapy at chainama clinic at ward A...behind Levy… we used to go to Levy at first for about a month but they were not serious…you would find that all they did was tell stories...by the time they attended to you time would have gone and little is done to help the patient…time was not enough…we would go early but they started late and that was not helpful,…it was frustrating… so we stopped.

This poses as a time when one may refrain from getting help if they perceive formal caregivers as not being helpful. This has an impact on the process of rehabilitation, given that if a patient is not given full attention then the progress in recovery will be slow if not absent. In that there is little that is done with providing the best and necessary care because formal caregivers are not doing their part. In a way, this also proves that a family caregiver may be the only hope because they are attached to the patient and thus they are obliged to provide the best of care.

Restricted movements

Furthermore, participants shared that they had been restricted with movements and that they were not able to move and go anywhere they wanted due to need for them to be present at all times at the patients' side. This meant that participants who were working stop to work, while those that could be doing some personal businesses may not be in a position to do so. They lose out on financial income and this has implications on the economy as caregivers may not be contributing to its growth.

One female participant aged 70 nursing her 75 year old husband said that it interfered with her practice of faith, in that they were no longer able to go to church and worship or do Gods' works like attending church meetings. In her narration she said:

PF10: It was a year later that I decided to start going to church…because I thought it was pointless for me to be staying home without going to church, I asked myself what value was in living such kind of life were I did not have time to worship my God.

The above scenario could be because the participant believes that one's life is empty and nothing if they are not able to work and worship their God. They attaché value in life if and only if what they do is in tandem with worshiping their God. This shows that there is power in values and beliefs in one's life which play a role in whatever task they may be required to undertake. In as much as caregiving required them to be present all the time, it must have no impact on their moments of worship.

One participant when asked how she managed to maneuver in everyday life given her current situation; she said that there was nothing really happening, in that she was limited with what she could do and when. She is a 36 year old woman who was taking care of her mother and this is what she had to say:

PF05: You know, just as I said, they are many…like you can't go anywhere you want to go at any time...you are restricted in movement because you have to be with the patient. You can't go...you just can't.

Participants live a life that is centered on the patients' needs and wants. They in many cases as described, had no time for themselves and gave themselves completely to caring for their loved one. And for some, they believed that it is their purpose for living to be the ones to care for the patient in question.

There were different varying responses when it came to most challenging task and experiences. Despite this being the case, most of them had mentioned bathing the patient as one of the most challenging as it involved carrying the patient and for children seeing the parents' nakedness. There were a number of participants who had left their home and moved into with the patient, this proved to be challenging for some, for instance, a woman aged 55 who was nursing her mother had this to say:

PF02: Like for me, it is very difficult because I have left my own home and you know when you are living in another person's house (hesitation), just staying there waiting…I am sure you understand that it is very difficult plus being a woman old enough…being taken care of in someone else's house, it is different from your own.

This is in the context of what is perceived in the Zambian norm that women are most comfortable in their home because they are able to live freely and do anything they deem fit. In that they make decisions and run things as they wish, but this is not the case if they are being taken care of by someone else in a place other than their home.

For instance, in a case were a 35 year old woman taking care of the mother aged 62 years, said to her the most challenging task was carrying the mother who is unable to take care of herself anymore. This is what she had to say:

PF01: Carrying her…I would say is most challenging...and then when a parent is sick...there is a feeling that I cannot really describe in words…it does not just feel right, you know. Another thing is that, there is just a difference between a person who is able to take care of him or herself and someone who does not and from nowhere, things just change.

While a male grandchild aged 21 taking care of his female grandmother had this to say:

PM11: okay, the most challenging thing really is moving this patient from point a to point b…because you find that the patient wants to fall...so you need to put in some stamina…ya, you find that the patient wants to move when you are doing something, that way...it becomes challenging.

This was common in the narrations of most participants and this could be because of the stature of the patients. In that if one is not able to move their body; it means the weight is concentrated on the person who is taking care of him or her.

A man who was taking care of his brother in law, said there were a number of most challenging tasks according to him in caring for the patient. Among them, is him having left his family to take care of his brother in law, as well as the diet of the patient which was selective in a sense. In that they had to buy him food separate from other people in the house given his condition. The other thing he expressed as most challenging was bathing and feeding his brother in law. This is what he had to say:

PM03: ...it is a tough going...you know I leave in Itezhi Tezi...and since I came I have no one to swap with or to leave the responsibility for...and now I have left my family for a long time, schools will be opening but am here to have to take care of him…and I can't leave because the daughter cannot do what am doing because she is the daughter. I think the most challenging is taking him to the toilet...and also bathing him and also *feeding him...because his diet is selective. He has certain foods that he has to eat but sometimes you do not have the money to buy it for him…it's another challenge...if he was allowed to eat anything that family members are allowed to eat…it would be okay...but now…you need resources to manage his diet.*

One of the youngest participants aged 21 taking care of his 50 years old uncle, narrated that the most challenging task was his uncle's cough, which made him wake up every night to turn his uncle on the sides. The uncle was in a position where he was not able to move any part of his body, fed on a tube and could not talk.

PM09: the challenge is the cough, I hear the sound of his cough, and then I turn him this side... (Gestures) pointing in the sideward direction…if he is sleeping like this… (Gestures) on his left side…I turn him the other side. Because it is his left side which is mostly affected, I have to move him...and turn him at 25 past 12, at 25 past 3 and at 25 past 5 so when his sleeping this side... (Showing the right side) he coughs. Waking up three times every night? It's a hard time ...you know. It's tough.

This was a very unique case of all the participants because the uncle was totally unable to move or speak. Thus it can be argued that, given the state of the uncle and him as a caregiver being young should in a way contributed to the challenges that he was facing. From the narratives, it gives the impression that this participant was in a way very willing and found joy in caring for his uncle.

4.5.2. Coping strategies

When asked about how the participants cope in taking care of their loved ones, most of them said that they only have to live and take each day as it comes. They related family and God as coping mechanisms. Some did not mention specifically ways they cope as strategies while some said that it is only by the grace of God and that God is their anchor. For some, they said that the love they had for their patients was what kept them going and having other family members' and friends support was another way some of them said they managed their situation.

PM07: Love… for our mother is what drives us…you know she looked after us and now it is our time to look after her…I have friends who do not have parents and they encourage me...when they come…so we are all being driven by love for our mother.

Very vital in our culture is that, we believe that it is a duty of a child to care for the parents as they grow. We believe that a parent plays their role in bringing up a child and therefore, when they grow old, they become the children’s responsibility. Children therefore, have to ensure that the parents do not luck in any way for as long as they have children. That is why, a long time, people used to have a lot of children because according to them, children were wealth, in that the more one had the higher the chances of them not suffering when they become of age. It is a way of showing love and appreciation for their love to the children.

Similarly, a wife taking care of the husband said that there were two most important things that helped her cope:

PF10: Gods’ grace and power is the first thing, the second thing is that I vowed to be with this man in sickness and in health even amidst problems, I vowed before God and therefore I have to be strong and fulfill my vows.

When the grandchild who was taking care of the grandmother was asked to share how he manages, he narrated:

PM11: I am able to manage because I love this woman, I do it knowing that this person that am caring for is my family, is my blood, so this thought helps me endure, so really, it is different from work, like when you are helping relatives, you are doing it with all your heart, you also always thinking that this person will get better, they will be fine someday, that keeps you going, and start doing things on their own.

In the Zambian setting, mostly people live in extended family system setting. In that one does not just live with his or her children but takes care of many other members of the extended family. For instance, a man may be married and has children of his own but takes care of his brothers’ children and his mother or father. Additionally, grandchildren usually are brought or spend much time at the grand parents’ home and get to grow fond of them. Therefore, caring for the family members does not come as work but part of a way one was brought up.

CHAPTER FIVE: DISCUSSION

As the last step in the analysis, the entire text as a whole was viewed. The naïve understanding, the structural analyses, and the researchers' pre-understanding were merged in a comprehensive understanding that was reflected upon and discussed from the various points of views and compared with findings of other similar studies.

Family caregivers' experiences would be said to be a mixture of some positive and many negative feelings. This is consistent with the findings of other authors who argue that caregiving brings also positive experiences such as a more purposeful life, greater inner strength and learning new things (Levine *et al*., 2010, Gillespie and Campbell 2011).

To some being a caregiver was a task they did, giving it their all. Some provided care because according to them, they too are prone to getting sick and may need someone who is close to them to take care of them. This may be looked at as a way in which meaning is derived from the perspective and experience of a family caregiver. For instance, this is similar to findings in a study by Zhang and Lee (2017) that argues that there are several ways in which family caregivers attach meaning to their experience.

Farran and others (1991) argued that the absence of meaning in family caregivers may result in despair and hopelessness. It is further argued that those that fail to find meaning in caregiving may endure anxiety and depression and by contrast those able to find positive meaning in caregiving and derive something positive out of it could reinforce their desire to provide care (Bäckström, Asplund and Sundin, 2010).

Furthermore, findings of other studies are consistent with the findings of this study which looked at experiences of family caregivers of disabled stroke patients. They found that family caregivers were living a completely different life which comes abruptly without any form of preparation. They found an overarching theme emerging, entitled: 'lives turned upside-down' (Bully *et al.*, 2010; Saban, 2012, Bäckström and Sundin, 2007, Bäckström, Asplund and Sundin, 2010, Wallengren, Friberg and Segesten, 2008). In this study the theme that represents this is "living with disruption", in that lives of the participants were not the same as they had to adjust to the new form of doing things, which changed abruptly.

Furthermore, Backstrom and Sundin (2009) highlighted family caregivers' realization that they live an inevitably altered future. It took time for participants to understand the long-term impacts of stroke. Like has been noted in this study, participants did not fully understand what was going on in the lives of the patient and only lived and took everything as it came.

Bully's study (2010) also found that carers experienced increased caring and domestic workloads alongside reduced participation and altered expectations of life. This is evident in the findings of this study that participants did not have time to themselves as they had to take care of the patients at all time. This in a way altered their expectation of what life looked like and how it should be, for instance, instead of one practicing their faith and being part of a larger Christian community they had to be home at all times. One participant said that life was not worth living if one cannot work for God. Participants also described how providing care for the person who had a stroke impacted on other relationships, reduced their social networks and often resulted in isolation following the stroke event (Denham *et al.*, 2019).

Similar to what was found in a study by Bully *et al* (2010) is that family caregivers found emotional and cognitive changes in their partners particularly distressing, and it would be valuable to provide more information and help with adjusting to the increased emotional, physical and cognitive workload of caring. It is imperative to support carers of people who have survived a stroke in adjusting to their changed lifestyles as it affects their quality of life as well as sustainability of caring. While Backstrom and Sundin (2009) argued that gaining these supportive factors may help the relatives to recover their sense of well-being and give strength for a future properly functioning family life.

Furthermore, they argued that individually, the stroke sufferer's relatives need support in their relationships within the family for emotional confirmation and to help them recognize and verbalize their needs without feeling guilty (Backstrom and Sundin, 2009). In the same vain, it is very vital for relatives to have time and give support to family caregivers because that is what they lean on and it helps them cope with the challenges of caregiving as evident in the findings of this study. Family caregivers need assurance of speaking out without being judged or looked at as not caring and being able to ask for help without them being looked at as having failed in their duty.

Most participants as described in the narratives expressed having no other option but to continue taking care of the patient due to different reasons, which included not stopping what they started, i.e. care provision and others said they are all the patient had and thus could not abandon them. This is similar to a study by Lopez-Espuela *et al* (2018) which concluded that family caregivers could not do much with regard other spheres of life but dedicated much of their time caring for the patient. Similarly, Leng *et al* (2019) found that since caregivers spend much of their time caring for a family member, they lack time for personal entertainment and social engagement.

This in a sense may be compared to even other life experiences such as one when one is sick, having someone to support you and be with you makes the situation better. Thus the argument that social support enhanced quality of life is not only true with the family caregivers' experiences but can be compared to other life experiences.

Additionally, from the literature reviewed, it has been seen that experiences of family caregivers produced very similar results such as caregivers suffering from poor caregiving health outcomes such as depression, distress, anxiety, fear, tiredness and giving up (Sukmak and Sangsuk, 2018, Leng *et al*., 2019). Nonetheless, despite the many negative outcomes, some family caregivers were satisfied with their current life, and had positive feelings about caregivers' roles. This is very similar to what this study also found. For instance, the tradition in Zambia, of living as an extended family and social support system could in a way be tied to the positive outcomes in caregiving expressed in this study.

Other authors argued that, in the development of the caregiving experience, both negative and positive feelings co-exist such that family caregivers experiencing burden and depressive symptoms also simultaneously experience positive feeling (Malhotra *et al*., 2018, Levine *et al*., 2010, Gillespie and Campbell 2011). Not every experience would be said to be all positive or negative, in that depending on situation and circumstances, things which include feelings, experiences may be perceived differently.

This could also be because of how one is brought up; persons from persons may see and experience life in very different ways. Just as it was found in this study, that both positive and negative experiences were expressed meaning that they do actually co-exist.

From the different experiences that had been shared by family caregivers of disabled stroke patients, participants seemed more willing to talk about how their experience was impacting positively on the well-being of the patient. They were willing to talk about how the patient improved and responded to rehabilitation through physiotherapy. They seemed very happy, satisfied, and honored, they showed a sense of fulfillment in being a part of the patients journey and loved to take care of the patient as it was their duty to do so as a relative to the patient. This was noted from the interface with the participants and from their narrations during the interviews. Furthermore, a similar study (Quinn, Murray and Malone, 2013) indicated experiences of caregiver strain and relationship difficulties following a stroke while on the contrary, this study found that spouses did not seem to have any relationship issues but were more inclined to being sad about having to see their loved one in the position of a ‘disabled patient’.

Findings of this study were also consistent with those of other studies that looked at family caregivers for various conditions, that challenges mostly faced were financial and resource (Tseng *et al*., 2015). For instance, two participants had indicated in their narrations that the financial challenges were as a result of the ‘special’ diet that these patients are expected to have. In that they were told at the hospital what type of food the patient had to eat and not to eat. On its own diet comes as a challenge in its own right, in that it was difficult for the caregivers to manage the demand that came with buying and preparing different foods for the patient.

Finally, no study discussed how participants seem to believe that it is a taboo for them as children to be family caregivers who have to bath and see their mothers’ nakedness. Even though they had to do it because it was their responsibility and they felt that it was time for them to pay back and take care of the mother who brought them up. They saw it as a way of appreciating her sacrifices and love she has for them as well as them showing her love. This is as reflected in the taboo vs. responsibility theme.

From the gender perspective, several factors may be looked at to explain the experiences of family caregivers and also the finding that more women play the caregiving role. These include biological, socially constructed and differences in the issues of gender and illness.

Furthermore, it is argued that women are nurturing by nature, in that given the biological state of them giving birth and caring for their young, they by nature tend to be more responsive to such duties. For instance, Lovell, 2007 argues that the interaction between biological and social determinants is also important when considering gender differences in health. The biological differences can be amplified or suppressed by socialization and how society responds to sex-specific behavior. This is to say, society in a way, responds to what already exists or is innate in the men and women alike. Meaning that, mostly in our society here in Zambia, women are the ones that play the role of caring or nurturing and this may be the reason many of them are family caregivers.

He further argues that, social norms endorsing particular kinds of behavior may exacerbate negative tendencies, such as violence, or reinforce positive propensities, such as nurturing. By contrast, socialization can suppress innate negative or positive tendencies (Lovell, 2007). This would explain why there are at least a few of men who do actually take up the role, the nature of not caring or nurturing may be said to have been suppressed by socialization. For example, it could be because of how the few men who are taking up the role were brought up in families were there was no gap between a man and a woman in terms of roles.

Family caregivers expressed some of form of suffering, termed as challenges and endured, here in termed as coping. Given this, we would connect this to Morse's argument, where she has identified two broad and divergent behavioral conditions of suffering. She terms these conditions as emotional suppression or enduring and emotional suffering. She argues that emotional suppression or enduring of feelings is central to the condition of enduring. The person does 'what must be done' to maintain control and not break down (Morse, 2001). This is how some family caregivers of disabled stroke patients who were interviewed described how they managed each day and those emotional moments. To them it was a normal way of behaving so as to protect the feelings of the care recipient. Morse argues it as a "*natural and necessary type of behavior that enables the person to function from day to day"* (Morse, 2001).

Furthermore, according to Morse (2001) the condition of 'enduring' occurs as a response to a threat to the integrity of the self. Such a threat can be experienced as dependency and loss of dignity (Dewar and Morse, 2006), for instance in this study, participants endured and did not ask for help because they said it was the right thing to do. They believed that the patient depended on them for support and their part was to provide the care without thinking twice. Not knowing that there are consequences of living a life of suffering alone. For example, Morse emphasizes 'enduring' as a "condition that requires extraordinary reserves of energy" (2001), this could be the reason that these family caregivers are so exhausted and tired at times without thinking about what the cause could actually be.

The suppression of feelings can also be related to Eriksson's ideas (1995) about suffering as a 'death' in the suffering that kills, the human being as a person and complete being is erased, dissolved by hopelessness, grief, guilt and loneliness. This would mean that family caregivers are not themselves as they act because of the suffering that they endure. Therefore, it is imperative to have services such as counseling sessions that would enlighten them of their being and who they are or were. This is so that their 'self' is illuminated and kept intact.

Morse defines emotional suffering as being 'ready for it' or strong enough to acknowledge what has been endured and that it involves the person yielding to suffering. Suffering is therefore an emotional response to phenomena that have previously been endured and suppressed (Morse and Carter, 1996; Morse 1997). The emotional release that takes place in this state finds expression in such people in crying and being weighed down by grief and self-pity (Morse, 2002). Some family caregivers can be said to have accepted or given into the suffering and have come to acknowledge the state they are in. This is why they were able to accept and say that this condition they are in is here to stay and they have no option but to live each day as it comes.

More so, the emotional experience is overwhelming (Morse and Penrod 1999; Morse 2001) thus human beings who have gone through a condition of enduring do not submit to emotional suffering before they are emotionally capable of accepting their loss. It would then be right to argue that most family caregivers in this study have accepted the loss of their physically fit loved ones and have to live and care for the loved one in a disabled state.

Furthermore, suffering according to Morse implies that the human being is transformed, formed or disintegrated. Thus the state of confusion illustrated in the diagram of family caregivers' experiences as a whole, in that they are 'different individuals' at different stages of the care giving. They are transformed to conform to their current state of affairs, transformed by fear, anxiety, stress, being fade up, exhaustion and further disintegrated by the challenges they face.

From this perspective, being a family caregiver of a disabled stroke patient can be said to be suffering that is viewed and comes out in different ways such as distress, anxiety, fear and pain among other terms. But in all, it is a continuum of suffering and enduring given the levels of acceptance of ones' situation, in that if one accepts the changed life they have to lead, then they can endure with fewer challenges.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1. Conclusion

The findings of this study suggest that being a family caregiver of a disabled stroke patient in Zambia is not an easy task because it abruptly changes how they live daily life without any form of preparation and very little help. The study also demonstrated that caregivers experience different feelings such as hopelessness, fear, distress, and anxiety about the health of the patient. Some felt responsible due to family ties and indebted to previous financial/social support. Thus, they felt they had no option but to embrace the reality before them.

The study further revealed that caregivers experienced practical, financial and emotional difficulties with a loved one being in a state of helplessness. Unique to this study, participants struggled to provide a special diet for the patient due to cost. Also preparing food that could be easily ingested by the patient was difficult. The other challenge unique to this study was the taboo around caring for a parent such as seeing them naked.

Furthermore, this study found that participants coped with these challenges through personal beliefs and social expectations of being the sole caregiver. The study demonstrated the presence of social rather than formally established support mechanisms for community and home based care in Zambia. The study however established that the counseling given to caregivers at the hospital did impart knowledge on continuing the rehabilitation process for the patient at home. Finally, family caregivers to disabled stroke patients are vital in the fight and management of NCDs in Zambia and must be considered a population at risk of NCDs due to the nature of caregiving.

6.2. Recommendations

The recommendations provided in this section are for policy makers, program support institutions and the scientific community showing the gaps and what research may be done in this area.

1. Post stroke rehabilitation and service provision

Kamalakannan *et al* (2016) concluded that there is a considerable unmet need for post stroke rehabilitation services. Also that it is crucial for low- and middle-income countries to develop technology-driven stroke rehabilitation strategies to meet the growing rehabilitation needs of stroke survivors.

From the direct observation of the stroke rehabilitation services provided, it would be prudent to establish technological strategies as this is not present in the Zambian system. There is a gap on the stroke rehabilitation services provided at present with what would be ideal. Further research is required to ascertain why only a few, or starters attend stroke rehabilitation given that the study found that the same number of people attended the sessions within the two month period the research was done.

2. Sessions to share experiences with fellow caregivers

It would be imperative to set up a time for family caregivers to interact with their fellow caregivers to share experiences and how to cope. This could be done as they wait to pick their patients at the physiotherapy department. In a study by Denham *et al*., 2019, participants often expressed the importance of connecting with other people who care for a stroke survivor. They described appreciating interactions with other carers; sometimes more so than interactions with family and friends. Some in particular described the importance of seeking other carers of stroke survivors to share their experiences with. Support services such as counseling support, financial assistance and general health advice may improve the family caregivers' health and wellbeing outcome.

3. Home based care stroke rehabilitation services

Furthermore, there is a need for improvement of skills training for home based stroke care to prevent reoccurrence of the stroke which will in turn reduce the burden of caregiving. Coming up with a formal system for training the family caregivers would prepare them for the anticipated tasks and challenges.

With regard to community-based rehabilitation, given that such services are not existent, it would be imperative to come up with centers in various communities for provision of rehabilitation services for stroke patients. This would reduce the stress of moving to and from hospitals to access the service. Other burdens such as resources and financial burdens may further be reduced.

4. Training

Formal systems for training of family caregivers are required given that they are non-existent in Zambia. This way, many family caregivers will have the necessary skills required in the provision of care for both their sake and that of the care recipient.

Recognition of family caregivers as an important driver in the process of rehabilitation for the stroke patients is vital for future rehabilitation service provision planning and for the public health planning with regard to management of Non-Communicable diseases.

5. Future research

This study did not for certain diagnose clinical depression but worked on assumptions from symptoms and a trained participant' views who feared that there are very high possibilities of depression in one with such an experience. Therefore, a study to ascertain depression in family caregivers of disabled stroke patients would be necessary which would recommend workable solutions in Zambia. A study to also consider looking into the extent of the burden of depression in the country and see to what extent it would be considered of public health importance.

The other gap that needs to be filled is that of having to determine the numbers of stroke patients, those who are disabled and thus quantifying the numbers of family caregivers of disabled stroke patients; which we currently do not have or may have not yet been published in Zambia. Prevalence of stroke as well is not well documented in Zambia, such data may be vital to show how much of a burden stroke is.

Some family caregivers were different from those that were present at the time that the patient was sick and so some of the skills learnt while admitted in the hospital were not passed on: Need for research on how exactly the transition of care is managed to avoid complications that arise due to neglect of care.

During this research, it was observed that only the same people attended stroke rehabilitation sessions, a study to find out the reasons why and if this is actually the case would be imperative so as recommend possible solutions and document what could possibly be working for others.

A study to also look at the gender differences in health and how these may explain what was found of having more female caregivers than males in the Zambian perspective would be very remarkable. As well as further considering culture and beliefs and family caregiving.

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Appendices

1.0. Work plan

TASK	May 2018	June 2018	Jul 2018	Aug 2018	Sep 2018	Oct 2018	Dec 2018	Jan 2019	Feb 2019
Proposal submission	🟦								
Graduate Forum		🟦							
Submission to REC			🟧						
Data collection/analysis					🟩	🟩	🟩	🟩	🟩 ⇨
Exams			🟨	🟨					
Ethical approval				🟫					

2.0. Budget

ITEM	**QUANTITY**	**COST (kwacha)**	**TOTAL COST**
Interpreter	1	2000	2000
Transcribing	1	1000	1000
Fuel costs	20	200	4000
Allowance (FA)	20	150	3000
Total			**10000**
Research Materials			
Cell phone	1	500	500
Internet modem	1	700	700
Portable hard drive	1	500	500
Laptop computer	1	2000	2000
Recorders	2	1500	3000
Note books	3	35	105
Pens/pencils	10	2	20
Batteries for recorder	10	15	150
Internet cost Monthly bundle	12	200	2400
Photocopying	4	1	4
Printing-proposals	2	100	200
Ream of paper	1	60	60
Total			**9639**
Final Report			0
Printing and biding of thesis	3	200	600
Journal application fee	1	2000	2000
Ethical clearance	1	1000	1000
Total			**3600**
Overall total			**23239**

3.0. Consent form for participation in a research study

University of Zambia

Title of Study: Experiences of Family Caregivers to Disabled Stroke Patients: Lusaka District

Description of the research and your participation

My name is Evelyn Kunda who is a student at the University of Zambia, pursuing a Masters in Public Health. You are invited to participate in my research whose purpose is to understand the experiences and needs of family care givers of stroke patients.

Your participation will involve having a discussion or you narrating your experiences as the person who is taking care of the patient.

Risks and discomforts

There are certain risks or discomforts associated with this study. They include you being overtaken by emotions as a result of certain experiences. To minimize this you will be given time to break from the narration so as to recollect yourself.

Potential benefits

There are no direct benefits to you that would result from your participation in this study. There is an indirect benefit to you participating which is that the findings of the study will contribute positively to the body of knowledge and these findings may be published as a paper in a recognized journal.

Description of the Study Procedures

If you agree to be in this study, you will be asked to narrate your experiences freely and openly without any fear. This may take approximately an hour but this will depend much on how much you are ready to share. Given that you are not able to go on with the proceedings or interview, please be free to let me know and stop me at any point.

Protection of confidentiality

You as a participant will be protected by keeping your participation confidential. Your identity will not be revealed to anyone or revealed in any publication or at any point of the study, nor will the recordings done during the interview be shared. This information will be used specifically for academic purposes. I will do everything we can to protect your privacy. Furthermore, I will not include any information in any report I may publish that would make it possible to identify you.

Voluntary participation

Your participation in this study is voluntary. You may decide on participating or not and you may decide to withdraw your consent to participate at any point in the study. You will not be penalized in any way should you decide not to participate or to withdraw from this study.

Contact information

If you have any concerns or queries about this study or if any problems arise, please contact Ms. Evelyn Kunda at The University of Zambia on cell no. 0977453346. If you have any questions or concerns about your rights as a research participant, please contact The University of Zambia Ethics Review Board at 0211 256067.

CONSENT

I declare that I have read this consent form and that I have been provided with enough information with regard to the study. I have been given the opportunity to ask questions and they were answered to my satisfaction. I therefore give my consent to participate in this study

Participant's signature/thumb print___________________________________

Date: _________________

Note: A copy of this consent form will be given to you.

4.0. Interview guide

Background information

Age:

Marital status:

Sex:

Code for participant:

Opening statement

Interviewer: .....as you know, I'm interested in what it's like for people who are taking care of loved ones who suffered a stroke and have been left in a position where they can do nothing for themselves. And what it means to be a woman or man in that situation is the focus of this study. And so I just wanted you to think generally, to begin with, about what comes up for you when you think about what it's like to be the main help and all that this patient has right now. Is there a situation that stands out for you that you might want to talk about?

- Tell me about what happened, how did it all start?
- What has changed from before?
- Tell me about your experience at the hospital/time of discharge
- How would you describe the experience of aiding a bath?
- How do you actually go about a day?
- Have you had any help given to you in terms of resources?
- What is your experience with the most challenging tasks or events?

To probe more

- Can you explain a little more what you mean
- Can you give me an example
- And when you don't do anything, what do you do?

5.0. Interview guide for the key informant

Background information

Age:

Marital status:

Sex:

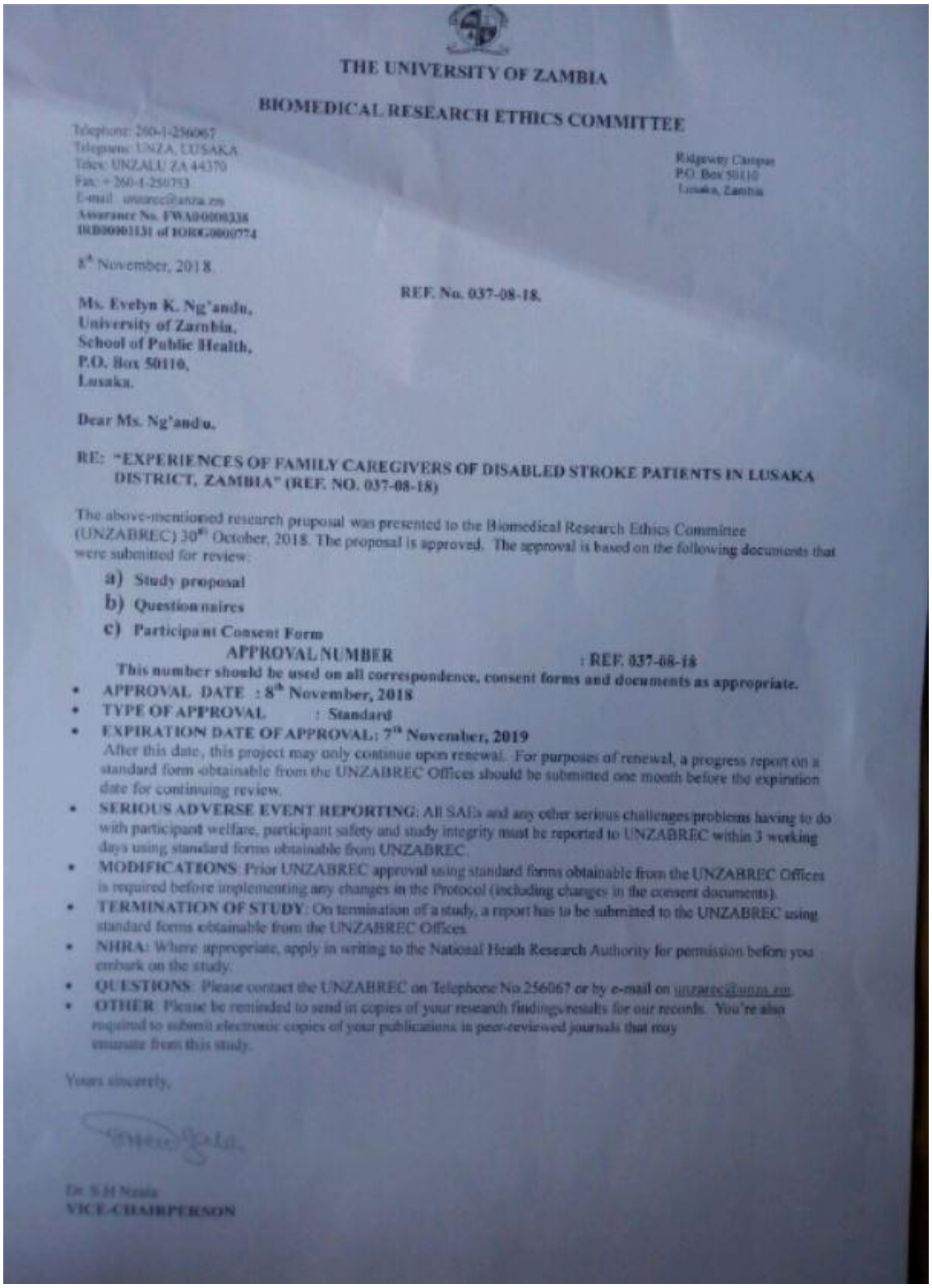
Code for participant:

Opening statement

Interviewer: .....as you know, I'm interested in what it's like for people who are taking care of loved ones who suffered a stroke and have been left in a position where they can do nothing for themselves. And what it means to be a woman or man in that situation is the focus of this study. And so I just wanted you to think generally, to begin with, about what comes up for you when you think about what it's like to be the main aid when the patient is in hospital? Is there any situation or things that stand out for you that you might want to talk about?

- Tell me about what happens when a patient is brought in with a stroke?
- Tell me about your experience with how you deal with such cases?
- What happens when you are discharging the patient? Tell me about that

6.0. Letters of permission



THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

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IRB00001131 of IORG0000774

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

8th November, 2018.

REF. No. 037-08-18.

Ms. Evelyn K. Ng'andu,
University of Zambia,
School of Public Health,
P.O. Box 50110,
Lusaka.

Dear Ms. Ng'andu,

RE: "EXPERIENCES OF FAMILY CAREGIVERS OF DISABLED STROKE PATIENTS IN LUSAKA DISTRICT, ZAMBIA" (REF. NO. 037-08-18)

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee (UNZABREC) 30th October, 2018. The proposal is approved. The approval is based on the following documents that were submitted for review:

a) **Study proposal**
b) **Questionnaires**
c) **Participant Consent Form**

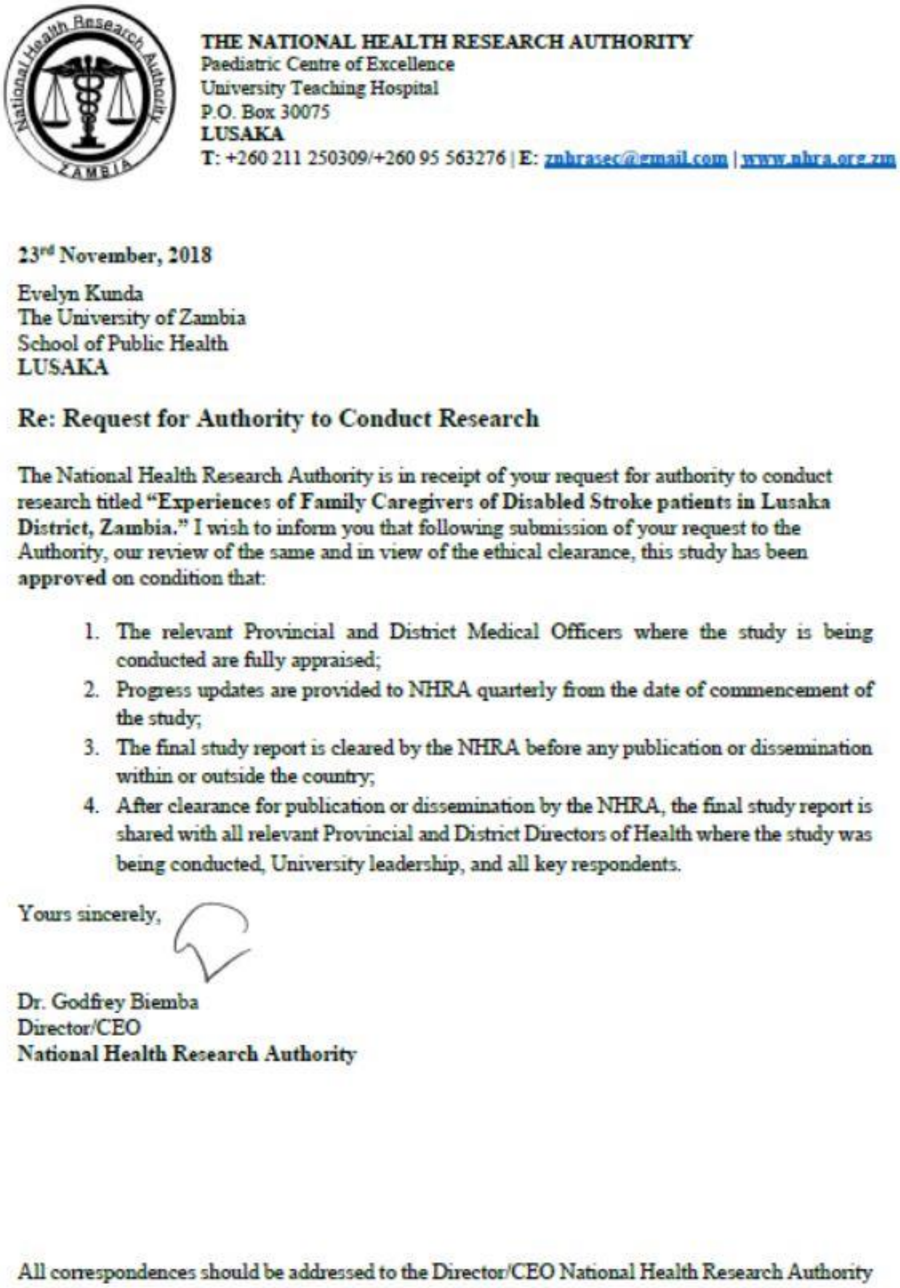
APPROVAL NUMBER : REF. 037-08-18

This number should be used on all correspondence, consent forms and documents as appropriate.

- **APPROVAL DATE : 8th November, 2018**
- **TYPE OF APPROVAL : Standard**
- **EXPIRATION DATE OF APPROVAL: 7th November, 2019**
  After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the UNZABREC Offices should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING**: All SAEs and any other serious challenges/problems having to do with participant welfare, participant safety and study integrity must be reported to UNZABREC within 3 working days using standard forms obtainable from UNZABREC.
- **MODIFICATIONS**: Prior UNZABREC approval using standard forms obtainable from the UNZABREC Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the UNZABREC using standard forms obtainable from the UNZABREC Offices.
- **NHRA**: Where appropriate, apply in writing to the National Heath Research Authority for permission before you embark on the study.
- **QUESTIONS**: Please contact the UNZABREC on Telephone No.256067 or by e-mail on unzarec@unza.zm.
- **OTHER**: Please be reminded to send in copies of your research findings/results for our records. You're also required to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours sincerely,

Dr. S.H Nzala
VICE-CHAIRPERSON



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23rd November, 2018

Evelyn Kunda
The University of Zambia
School of Public Health
LUSAKA

Re: Request for Authority to Conduct Research

The National Health Research Authority is in receipt of your request for authority to conduct research titled **"Experiences of Family Caregivers of Disabled Stroke patients in Lusaka District, Zambia."** I wish to inform you that following submission of your request to the Authority, our review of the same and in view of the ethical clearance, this study has been **approved** on condition that:

1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to NHRA quarterly from the date of commencement of the study;
3. The final study report is cleared by the NHRA before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the NHRA, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, University leadership, and all key respondents.

Yours sincerely,

Dr. Godfrey Biemba
Director/CEO
National Health Research Authority

All correspondences should be addressed to the Director/CEO National Health Research Authority