PREVALENCE AND DETERMINANTS OF STRAIN AMONG CAREGIVERS OF STROKE SURVIVORS IN OYO STATE, NIGERIA

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CERTIFICATION

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Dedication

This dissertation is dedicated to the supreme sovereign of the universe Jehovah, for making this dream come true.

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ABSTRACT

Stroke, a cerebrovascular accident, is one of the leading causes of death and disability in the world. It exerts a significant effect not only on patients but also on family caregivers. Caregivers play a vital role in the functional recovery of stroke survivors, their role however, puts them in an extremely stressful and dauntingly overwhelming position which leaves them feeling quite strained, hence the concept of caregiver strain. Hence, this study aims to find the prevalence of caregiver strain, to determine the factors associated with caregiver strain and to assess the quality of life of Caregivers of Stroke survivors in Oyo State, Nigeria.

This was a multicenter study conducted in the following clinics; University College Hospital, Ibadan (UCH), Ring-Road State Hospital Adeoyo, Ibadan, Adeoyo Maternity Hospital, Yemetu, Jericho Nursing Home, Ibadan, Family Medicine Clinic, Ibadan and General Hospital, Oyo town. This study focused on caregivers of stroke patients who accompany the patients to clinic visits. It employed a cross-sectional study design. Two hundred and forty-one caregivers of stroke patients were selected using systematic sampling were studied. A four-part questionnaire was used to collect data on socio-demographic characteristics of caregivers, caregiver strain index (CSI), disability status (Barthel Index) of stroke survivors and quality of life (using WHO-BREF 26) short form tool. Data was summarized using percentages, frequencies for categorical data and mean ± SD for continuous variables. Chi-square tests was used to check for association between categorical variables, correlation was used to check for association between continuous variables, and logistic regressions were employed to measure extent of association between variables. All test for associations were conducted at 95% Confidence Level. Data analysis was done with Statistical Package for Social Sciences (SPSS) version 20.

The mean age of respondents was 39.5 ± 15.6 years. Females numbered 134 (55.6%) and 108 (44%) had secondary education. Respondents were caregivers to their parents (42.7%), spouses (21.6%) and siblings (6%). The prevalence of caregiver strain was 71.8%. Factors associated with caregiver strain include; availability of support and finances ($\chi2 = 22.561$, $p < 0.05$), length of caregiving time ($r = 0.143$, $p = 0.02$), disability status ($r = -0.326$, $p = 0.04$), physical health of caregiver ($r = -0.129$, $p = 0.00$). Mean Quality of life scores by their domains include; Physical (72.44 ± 11.321), Emotional / Psychological (62.19 ± 9.04), Social relationships (72.44 ± 16.20) and Environmental (62.77 ± 10.49).

Findings of this study shows high prevalence of strain among caregivers of stroke survivors. Caregivers should be well integrated into the program for rehabilitating stroke survivors so as to lessen their strain. Strain or burden interviews should be performed on each clinic visit. Caregivers should be assessed when they present at the Clinic each time they visit with patients as a beneficial intervention.

Key words: Caregiver, Strain, Quality of life, stroke survivors, stroke

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CHAPTER ONE

1.1 BACKGROUND OF STUDY

Stroke is a cerebrovascular accident (CVA) (Paciaroni and Bogouslavssky, 2009). The World Stroke Organization (2019) also comments that 2 out of every 3 people who suffer from a stroke live in low- and middle-income countries (World Stroke Organization, 2019). In a systematic review by Owolabi, *et.al.* (2015) it was found that the incidence of stroke in Africa showed a significant mean increase. In age-standardized ischemic stroke, incidence of 14.8% was recorded between 1990 and 2010. They conclude that the incidence of stroke in Africa is not only among the highest in the world, the incidence velocity is also very high. (Owolabi *et.al.*, 2015). In Nigeria, Wahab (2008) reports prevalence of stroke to be about 1.14 per 1000 in a study conducted in Lagos (Wahab, 2008). Another study by Sanya, *et.al.* (2015) in Kwara reveals a crude prevalence rate of 131/100,000 (Sanya, *et.al.* 2015).

According to Jansen *et.al.*, (2020) an informal caregiver is defined as one that provides any brief or long term care to an individual in his social network in need of care, complementary to institutional care (Janssen *et.al.*., 2020). Zhang and Lee (2016) report that interest in caregiving issues is growing along with the increased attention on the aging population and chronic illnesses like stroke. A sizable number of family members become caregivers who provide support to their loved ones who are older, sick or disabled. As one of the leading causes of death and disability in the world, stroke exerts a significant effect not only on patients but also on family caregivers (Zhang and Lee, 2016).

The Oncology Nursing Society (ONS) defines caregiving strain or burden as encompassing all the difficulties assuming and functioning in the caregiver role as well as associated deviations in the caregiver's emotional and physical health that can occur when care demands exceed available resources which can significantly impact their functioning and quality of life. Caregiving could be quite exhausting and strenuous. Gbiri, Olawale and Isaac (2014) in a cross-sectional study on informal caregivers' burdens and strains of caring for stroke survivors report that caregiving is a complex phenomenon having both physical and emotional components. The experience of burden or strain by the informal caregivers may be related to the ever constant need to meet the requirements for optimum performance in the stroke survivors. Caring for stroke survivors put great social, emotional, health and financial challenges on the informal caregivers. These burdens and strains increase with length of stroke time, intimacy, smaller number of caregivers and length of daily caregiving. So, informal caregivers should be involved in the rehabilitation plan for stroke patients and their welfare should also be given proper attention (Gbiri, Olawale and Isaac, 2014). A longitudinal study on stroke caregiving trajectory in relation to caregiver depressive symptoms, burden and intervention outcomes conducted by Graf, *et.al.* (2017) shows that depressive symptoms and burden were both negatively associated with duration of caregiving experience. They concluded that although outcomes of caregivers may improve over time, long duration stroke caregivers may still face unmet requirements long after the initial stroke (Graf, *et.al.* 2017). In another longitudinal study by Schulz and Beach (1999) mortality risk was shown to be sixty-three percent (63%) higher in participants who were providing care and experiencing strain than non-caregiving controls (Schulz & Beach, 1999).

The World Health Organization defines Quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards and concerns (WHO, 2017). Jafari and Colleagues (2018) have also observed that caregiver strain affects quality of life and may result in reduced provision of care and deteriorating condition for patient with chronic illness patients, which in turn increases care burden and creates a vicious cycle that may result in a gradual exhaustion of the caregiver (Jafari, Ebrahimi, Aghaei, & Khatony, 2018)

1.2 PROBLEM STATEMENT

Johnson, *et.al.* (2016) relates that on average, stroke occurs 15 years earlier in – and causes more deaths of – people living in low- and middle-income countries (LMICs), when compared to those in high-income countries. Strokes mainly affect individuals at the peak of their productive life. Despite its enormous impact on countries' socio-economic development, this growing crisis has received very little attention to date (Johnson, *et.al.*, 2016). An estimated 43.5 million Americans are caring for a loved one, with 11 million

Americans providing intergenerational care for multiple loved ones (National Alliance for Caregiving, 2019). Graf *et.al.*, (2017) observes that unlike other chronic diseases, strokes occur suddenly and caregivers have little time to prepare and adjust to their new roles. The sudden life change can be physically and psychologically draining for caregivers, resulting in caregiver depression and burden. The majority of stroke survivors are cared for by family members or friends who must learn to cope within a short period of time with the survivors' physical and cognitive deficits (Graf *et.al.*, 2017). Another study conducted by Lui, Ross and Thompson (2005) reported that many caregivers encounter a variety of problems including financial difficulties, social isolation, lack of information, and poor physical and mental health (Lui, Ross and Thompson, 2005). Morley, *et.al.* (2012) reported that 77% of caregivers report deterioration in health as a result of the role they play providing care. It was even predicted that by 2017, caregivers will be completely overwhelmed and outweighed by demands (Morley *et.al.*., 2012). Chung, *et.al.* (2020) reports that one in every five caregivers' experiences persistent depressive symptoms during their first year of caregiving for stroke survivors. Caregivers who reported depressive symptoms at discharge were at a higher risk of having persistent depressive symptoms during the first year of caregiving. Caregivers with persistent depressive symptoms were at a higher risk of worsening health status at one year of caregiving. Caregivers with persistent depressive symptoms reported the highest levels of burden or strain, the lowest levels of perceived availability of social support, and the unhealthiest family function compared with other caregivers and that one in every 10 caregivers reported newly developed depressive symptoms during the first year of caregiving (Chung, Lee, Son, Miller, & King, 2020). Still on this trail, Hurh, *et.al.* (2021) reports that continued caregiving especially with disabled patients was more associated with the risk of depression compared to non-caregivers (Hurh, Youn, Park, & Park, 2021). Due to the demands associated with caregiving, compound and non-compound caregivers (those caring for multiple patients or relatives) have experienced adverse effects on their quality of life (Marsack-topolewski, 2020). So, this study set out to study prevalence of strain among caregivers of stroke patients and quality of life among them. The quality of life includes components of physical, environmental, social and emotional health of the caregivers that were explored. Factors affecting caregiver strain was also fully explored among respondents.

1.3 JUSTIFICATION

Vincent, Ali & Hamzat (2013) observed that informal care of stroke survivors after hospital discharge in many African communities is often the responsibility of caregivers in the home setting due to the shortage or nonexistence of institutional care facilities such as nursing homes. The cultural structure in many African countries usually encourage community and family care rather than institutional and nursing home care (Vincent-Onabajo, Ali, & Hamzat, 2013).

Quality of life is another aspect of caregivers that should be taken into consideration. A study on quality of life and burden of informal caregivers of stroke survivors by Ogunlana, Dada, Oyewo, Odole and Ogunsan (2014) shows that caregiver strain was found to increase as QOL reduces (Ogunlana, *et.al.* 2014). Relatively few studies have been conducted in Africa measuring caregiver strain, its determinants and quality of life among caregivers of stroke survivors. Furthermore, the interplay between caregiver strain and quality of life is often ignored in these studies. Currently, we are in the chronic disease phase of epidemiologic transition. Stroke is a chronic disease and usually leaves its survivors with mild or moderate disability. So, survivors need the assistance of caregivers to live. Moreover, this study compared to other studies uses a higher sample size powered to detect significant associations. In Oyo State, Nigeria, there are not so many published studies yet on caregiver strain among stroke survivors and its determinants including their quality of life. Hence, this study aimed to investigate the relationship between caregiver strain and quality of life of caregivers of stroke survivors and also explore other possible factors responsible for caregiver strain which if appropriate interventions are instituted would improve caregiving and speed up recovery of stroke patients.

1.4 RESEARCH QUESTIONS

1. What is the prevalence of strain among caregivers of stroke survivors in Oyo State?
2. What is the quality of life caregivers of stroke survivors experience in Oyo state?
3. What are the factors associated with strain among caregivers of stroke survivors in Oyo state?

1.5 GENERAL OBJECTIVE

To determine prevalence and determinants of strain among caregivers of stroke survivors in Oyo State.

1.6 SPECIFIC OBJECTIVES

1. To find out the prevalence of caregiver strain among caregivers of stroke survivors in Oyo State.

2. To determine factors associated with caregiver strain among caregivers of stroke survivors in Oyo State.

3. To assess the quality of life of stroke patients' caregivers in Oyo State.

CHAPTER TWO

LITERATURE REVIEW

2.1 HISTORY OF STROKE

According to Coupland, Thapar, Qureshi, Jenkins and Davies (2017), Stroke's first recorded use appeared in the year 1599, and it was used to describe being struck with a deadly blow and strongly relates to the Greek word apoplexy. It was an umbrella term used in explaining a situation where the sufferer had a "sudden abolition of all activities of the mind with the preservation of pulse and respiration." Hippocrates suggested that the pathogenesis of apoplexy was connected to the humoral theory (Coupland, Thapar, Qureshi, Jenkins, & Davies, 2017). Paciaroni and Bogouslavssky (2009) writing on the history of stroke and cerebrovascular disease report that the history of these has spanned many centuries. Stoke etymologically means struck down by violence, and appears first in Hippocrates writings as 'apoplexy'. The word must have been formed due to the sudden paralysis and change in well-being. Galen however integrated some anatomy into his description of stroke. As time passed, William Harvey was able to explain blood circulation, and understanding of cerebrovascular anatomy was enhanced. Johann Wepfer theorized that a blockage in one of the brain's vessels could cause apoplexy. Thomas Willis (father of modern neurovascular anatomy) provided the best description of the brain's neurovascular structure. Virchow coined the term ischemia to describe a physiological abnormality (lack of oxygen) that could lead to stroke. The last part of the twentieth century could be described as an era of therapeutic revolution with the advent of novel imaging techniques and the likes. Rapid expansion of knowledge has been observed and would continue so (Paciaroni, Bogousslavsky, & Willis, 2009). Kelly (2011) in an article 'Stoke a modern history' observes that enormous progress has been made over the last five decades. In the future, we can expect improvements in neuro-imaging, better risk stratification allowing more precise regimens for anti-thrombotic therapies amongst others (Kelly, 2011). With the discoveries of the 21st century, the subject of stroke has been demystified.

2.2 PREVALENCE AND BURDEN OF CAREGIVER STRAIN

A systematic review undertaken by Lui *et.al.* (2005) on Supporting Family Caregivers in Stroke Care, A Review of the Evidence for Problem Solving reveals that many family caregivers experience uncertainty and difficulty in addressing the problems encountered when caring for a stroke patient (Lui, Ross, & Thompson, 2005). According to Skolarus *et.al.* (2017), few caregivers of stroke survivors used a service to enable them to take some time away from caregiving. This may account for the large burden usually felt by caregivers (Skolarus *et.al.*, 2017). Caregiving could be quite exhausting and strenuous. Gbiri, Olawale and Isaac (2014) in a cross-sectional study on Informal caregivers' burdens and strains of caring for stroke survivors report that caregiving is a complex phenomenon having both physical and emotional components. The experience of burden by the informal caregivers maybe related to the ever constant need to meet the requirements for optimum performance in the stroke survivors. Caring for stroke survivors put great social, emotional, health and financial challenges on the informal caregivers. These burdens and strains increase with length of stroke time, intimacy, smaller number of caregivers and length of daily caregiving. So, informal caregivers should be involved in the rehabilitation plan for stroke patients and their welfare should also be given proper attention (Gbiri, Olawale, & Isaac, 2015).

Lu *et.al.* (2019) in a qualitative study on family caregivers' experiences of caring for post-stroke survivors in China relates that these felt like they were living on the edge, in other words, their lives were being pulled in multiple directions creating an unstable situation, and reducing their well-being and health. The participants believed they had total responsibility and felt that this was expected from both themselves and society. Little external understanding and insufficient support was emphasized, resulting in the caregivers feeling all alone, drained by caring, and like prisoners in their own lives. The family caregivers had to face all of the family events and make all of the decisions by themselves. They expressed love for their family members with stroke, but this was often overshadowed by feelings of sadness, depression, sensitivity, and anger. This resulted in an inability to see how things could improve and in the family caregivers being uncertain about the future.one of the study's serious limitations however is its sample size of 11 (Lu, Mårtensson, Zhao, & Johansson, 2019). Another longitudinal study conducted in India on factors affecting burden on caregivers of stroke survivors measured stress as strain conducted by Bhattacharjee, *et.al.* (2012), reveals that at the moment, nearly one-third of stroke survivors in India stay at home and take domiciliary care, which in reality is a burden on the caregiver. For all study participants in the study, this was their first experience. It highlights the financial, emotional, physical and mental anxiety faced by stroke caregivers and the influence of family bonding and social customs. The caregivers also had to adjust their work schedule while many had to give up their jobs. Younger caregivers and daughters-in-law faced major stress, whereas spouse caregivers had relatively mild stress or strain (Bhattacharjee, Vairale, Gawali, & Dalal, 2012). Another study (cross-sectional) on burden, predictors and quality of life in caregivers of stroke survivors conducted in India by Kumar, Kaur and Reddemma (2016) measured strain with the Zarit burden interview revealing that caregivers felt frustrated in making relationship with other family and friends (40.96%) followed by feeling of loss of control in life (40.44%), personally strained (36.44%), and disturbed in emotional well-being (32.14%). However, financial problem was least (11.5%) reported constrained in management of patient by caregivers (Kumar, Kaur, & K, 2016). Further purporting these views is a literature review by Camak (2015) who reported that caregiving stress can result in negative psychological impact anxiousness and poor physical health in the caregiver. Furthermore, burden could be compounded by isolation from prior social networks and the huge toll of providing care for the stroke survivor ant it is correlated with risk of deleterious health outcomes among the aged caregivers. It also asserted that due to lack of proper education concerning specifics of care, caregivers usually feel ill-prepared and overwhelmed and abandoned to take on this daunting role after being discharged. The study further highlights the lack of practical interventions to squarely address caregiver burden (Camak, 2015). A cross-sectional study by Carod-artal, *et.al.* (2009) on burden and perceived health status among caregivers of stroke patients conducted in Brazil on two hundred caregivers (200) showed that about a quarter (26.4%) felt exhausted and overwhelmed (extreme/high burden) by the caregiving process (Carod-Artal, Ferreira Coral, Trizotto, & Menezes Moreira, 2009). Gbiri, Olawale and Isaac (2015) in a cross-sectional study on stroke management: Informal caregivers' burdens and strains of caring for stroke survivors conducted in Lagos Nigeria measured both objective and subjective burden using caregiver strain index and a self-reported appraisal report. In the objective axis, 47, 96 and 14 reported mild, moderate and severe burdens respectively while in the subjective axis, 1, 125, 29 and 2 reported little, mild, moderate and severed burdens in that order. The total perceived burden showed that 80, 75 and 2 were mildly, moderately and severely burdened respectively (Gbiri, *et.al.* 2015).

A descriptive cross-sectional study carried out by Akosile, *et.al..*, 2013 on burden, health and quality of life of Nigerian stroke caregivers revealed that 83.5% of the population was considerably strained due to the enormous task of caregiving (Akosile, *et.al..*, 2013). Ilse, *et.al.* (2008) in a study on stroke caregivers' strain: prevalence and determinants in the first six months after stroke done longitudinally with assessments at 2, 4, and 6 months post stroke reveal that 28%, 31% and 29% of the caregivers were under strain at 2, 4 and 6 months, respectively (Ilse, Feys, de Wit, Putman, & de Weerdt, 2008). Another longitudinal study by Jaracz, *et.al.* (2015), measured prevalence of strain at 6 months and 5 years post stroke revealed a prevalence of 44% and 30% at the two time periods respectively (Jaracz *et.al..*, 2015). Another study on burden of stroke survivors on caregiver and quality of life conducted in India by Rawat, *et.al.* (2017), shows that about 56.7% of the caregivers were strained (Rawat, *et.al..*, 2017). A cross-sectional study by Tosun and Temel, (2017) on burden of caregiving for stroke patients showed that most caregivers perceived caregiving as an advanced burden (Tosun and Temel, 2017). Kaur *et.al.* (2018), in a study conducted in India among family caregivers of patients with stroke discovered that majority of caregivers, about 73.5% were undergoing caregiver strain (Kaur, *et.al..*, 2018).

Bugge, Alexander and Hagen (1999) in a cross-sectional study in a longitudinal study with data collected at one, three and six months showed that on average, caregivers scored 4.5 (95% CI, 3.8 to 5.3; n=592) on the CSI 1 month after stroke, 4.3 (95% CI, 3.6 to 5.1; n=585) at 3 months, and 4.5 (95% CI, 3.7 to 5.3; n= 581) at 6 months. At all measured time points after stroke, a small but considerable number of caregivers indicated that they were not under any strain (14% at 1 month, 17% at 3 months, and 19% at 6 months). In contrast, an increasing proportion of caregivers reported that they were under considerable strain from 1 to 6 months (25% at 1 month, 28% at 3 months, and 37% at 6 months) (Bugge, Alexander and Hagen, 1999). Blake, Lincoln and Clarke (2003) in a prospective longitudinal study conducted in England of caregiver strain in spouses of stroke patients shows that levels of strain were relatively high with 39% under strain during the first contact and increased to 40% in the course of 6 months (Blake, Lincoln, & Clarke, 2003). A prospective longitudinal study on factors associated with strain in informal caregivers of stroke patients by

Hung, *et.al.* (2012) in Southern Taiwan with a sample size of eighty-nine (89) shows that considerable strain was reported in 46% and 43% of the caregivers at the 3rd and 6th month, respectively. A little issue with this study however is that the sample size may reduce the power and hence reduce its generalizability (Hung *et.al.*., 2012). Katan and Luft (2018) in a review article on global burden of stroke report that in the last decades, stroke remains an important cause of disability and death worldwide. Globally, the burden of stroke has increased substantially over the past few decades due to expanding population numbers and aging as well as the increased prevalence of modifiable stroke risk factors, especially in low and middle-income countries. The number of patients who will need care by clinicians with expertise in neurological conditions will continue to grow in the coming decades and so will the number of caregivers (Katan & Luft, 2018).

2.3 FACTORS AFFECTING CAREGIVER STRAIN IN POST-STROKE SURVIVORS

2.3.1 GENDER OF CAREGIVER

Bugge, Alexander and Hagen (1999) found that male gender was associated with decreased strain (Bugge, Alexander and Hagen, 1999). A cross-sectional study on factors affecting the burden on caregivers of stroke survivors in South Korea by Choi-Kwon, *et.al.* (2005) revealed that the caregiver being female was related to caregivers' higher burden scores (Choi-Kwon, Kim, Kwon, & Kim, 2005). Corroborating this assertion is the evidence provided by a cross-sectional study conducted by Kumar, *et.al.* (2016) wherein they used the Zarit burden scale to measure strain in a rural community in India and found that female gender was significantly associated with strain (Kumar, *et.al.* 2016). Similarly, Bhattacharjee, *et.al.* (2012) in a longitudinal study, on factors affecting burden on caregivers of stroke survivors in India, measured burden as strain using the Caregiver strain index tool found that female gender was significantly associated with increased strain (Bhatttacharjee, *et.al.* 2012). Contrasting this trend is a noteworthy report presented by Blake, Lincoln and Clarke (2003) in a longitudinal study where data was collected at three months after stroke and at six months on caregiver strain in spouses of stroke patients. They found levels of strain not being significantly different among male and female spouses (Blake, *et.al.* 2003).

Another study by Gbiri, *et.al.* (2015), which was a cross-sectional study observes that there was no significant relationship between gender of the participants and strain of caregiving (Gbiri, *et.al.* 2015). So, two sides of the argument exist from findings of research- gender may or may not significantly be associated with caregiver strain.

2.3.2 RELATIONSHIP OF CAREGIVER TO STROKE SURVIVOR

A cross-sectional study on factors affecting the burden on caregivers of stroke survivors in South Korea by Choi-Kwon, *et.al.* (2005) revealed that the caregiver being the patient's daughter-in-law was related to caregivers' higher burden scores (Choi-Kwon *et.al.*., 2005). Bhattacharjee, *et.al.* (2012) in a longitudinal study on factors affecting burden on caregivers of stroke survivors in India, Caregiver characteristics such as caregivers being daughter-in-laws was significantly related to strain (Bhattacharjee, *et.al.* 2012). Blake, Lincoln and Clarke (2003) in a longitudinal study on caregiver strain have also observed that being a female spouse is significantly associated with strain (Blake, Lincoln and Clarke 2003). Gbiri, *et.al.* (2015), found out a negative correlation between the type of relationship with the patient and the burden of caregiving or strain and further asserts that the closer the relationship with a patient the greater the burden on a caregiver (Gbiri *et.al.*, 2015).

2.3.3 AGE OF CAREGIVER

Ilse, *et.al.* (2008) using a longitudinal study design revealed that age of caregiver was significantly associated with caregiver strain (Ilse *et.al.*, 2008). However, a report by Gbiri *et.al.* (2015), which was a cross-sectional study observed that there was no significant relationship however between age of the participants and burden or strain of caregiving (Gbiri, *et.al.* 2019). Still lending support to this observation is a cross-sectional research carried out in Thailand by Boonsin, *et.al.* 2021 where they found caregiver's age having no direct effect on caregiver burden or strain (Boonsin *et.al.*., 2021).

2.3.4 LENGTH OF STROKE CAREGIVING

A longitudinal study on stroke caregiving trajectory in relation to caregiver depressive symptoms, burden and intervention outcomes conducted by Graf, *et.al.* (2017) shows that depressive symptoms and burden were both negatively associated with duration of caregiving experience. They concluded that although outcomes of caregivers may improve over time, long duration stroke caregivers may still face unmet requirements long after the initial stroke (Graf, *et.al.* 2017). Morimoto, Schreiner and Asano (2003) in a cross-sectional study on caregiver burden and health-related quality of life among Japanese stroke caregivers revealed that duration of caregiving didn't have any significant association with the degree of caregiver burden or strain. Increased caregiving hours was significantly related to increased burden. Zarit Burden interview however, was used to get strain or burden scores. (Morimoto, Schreiner, & Asano, 2003). Another report by Gbiri, *et.al.* (2015), which was a cross-sectional study observes that there was significant relationship between, hours of caregiving, duration of stroke (which could by extension apply to duration of caregiving) and perceived burden or strain expressed by the participants (Gbiri, *et.al.* 2015). Also nested in duration is the mean amount of time caregivers spend attending to stroke victims. Hung, *et.al.* (2012) in a longitudinal study on factors associated with strain in informal caregivers of stroke patients in Taiwan. Participants were recruited in their 3rd to 6th month after an occurrence of a stroke. Caregiver characteristics associated with increased strain included spending more than 3 hours a day caring for patients (Hung, *et.al.* 2012). In a cross-sectional study on factors affecting the burden of family caregiving for survivors of Stroke, Boonsin *et.al.*, (2021), found that duration of caregiving and number of hours of care had a direct effect on caregiving burden (Boonsin *et.al.*., 2021) Bhatacharjee, *et.al.* (2012) also found out that caregiver characteristics such as long caregiving hours (mean of 8.4 hours a day) was significantly associated with caregiver strain (Bhattacharjee *et.al.*, 2012). A cross-sectional study on Factors Affecting the Burden on Caregivers of Stroke Survivors in South Korea by Choi-Kwon, *et.al.* (2005) revealed that the caregiver being the patient's spending more than 15 hours of caregiving a day was related to caregivers' higher burden scores (Choi-Kwon *et.al.*., 2005).

2.3.5 DISABILITY STATUS (BARTHEL INDEX) OF STROKE SURVIVOR

Bhattacharjee, *et.al.* (2012) in a longitudinal study on factors affecting burden on caregivers of stroke survivors in India, found out that poor recovery at 28 days with barthel index (<50) was significantly associated with caregiver strain (Bhattacharjee *et.al.*, 2012). Also noteworthy is the report presented by Blake, Lincoln and Clarke (2003) in a longitudinal study where data was collected at three months after stroke and at six months on caregiver strain in spouses of stroke patients. Another version of barthel index- extended activities for daily living was used to compute dependence and it was a significant predictor of strain (Blake, *et.al.* 2003). Bugge, Alexander and Hagen (1999) found that increased time spent on caring for patients was significantly associated with strain at all the three-time intervals. Predictors of strain were; neurological impairments, disability and reduced motor coordination was also associated with increased strain (Bugge, Alexander and Hagen, 1999). Predictors of strain as seen in a study titled stroke caregivers strain: prevalence and determinants in the first six months after stroke" conducted by Ilse *et.al.* (2008) using a longitudinal study design revealed that motor functioning was significantly correlated with strain. Barthel index and motor functioning were significantly associated with caregiver strain (Ilse, *et.al.* 2008). Hung, *et.al.* (2012) in a longitudinal study on factors associated with strain in informal caregivers of stroke patients in Taiwan. Patient factors associated with increased strain were; neurological deficit, severe disability, cognitive impairment (Hung, *et.al.* 2012). Jaracz and colleagues (2015) in a longitudinal study on burden in caregivers of long-term stroke survivors at 6 months and 5 years post stroke conducted in Poland revealed about 7 caregiver and patient characteristics were significantly related to substantial burden at both times of assessment. Amongst which disability status was included. In this study, burden and strain are used interchangeably (Jaracz, *et.al.* 2015). Boonsin, *et.al.* (2021) in a study on family caregiving burden using a cross-sectional study design found functional status as having the strongest effect on caregiver burden (Boonsin *et.al..*, 2021).

2.3.6 POOR HEALTH OF CAREGIVERS

In a longitudinal study on factors associated with strain in informal caregivers of stroke patients in Taiwan conducted by Hung, *et.al.* (2012), certain caregiver characteristics associated with increased strain were explored and it was found that poor health of caregivers was among these (Hung, *et.al.* 2012). Also noteworthy is the fact that a cross sectional study on Morimoto, Schreiner and Asano (2003) in a cross-sectional study on caregiver burden and health-related quality of life among Japanese stroke caregivers revealed that certain factors such as degree of patient functional recovery and even caregiver chronic illness - none of these related to the degree of caregiver burden or strain (Morimoto, Schreiner and Asano 2003). Also noteworthy is the report presented by Blake, Lincoln and Clarke (2003) in a longitudinal study where data was collected at three months after stroke and at six months on caregiver strain in spouses of stroke patients. General health of caregivers was found to be significantly associated with caregiver strain (Blake *et.al.*, 2003). A cross-sectional study on Factors Affecting the Burden on Caregivers of Stroke Survivors in South Korea by Choi-Kwon, *et.al.* (2005) revealed that caregiver changes in health status was related to caregivers' higher burden scores (Choi-Kwon *et.al.*., 2005). Findings by Gbiri, *et.al.* (2015), which was a cross-sectional study observes that caring for the stroke survivor had a significant influence on the health and the social life of the informal caregivers (Gbiri, *et.al.* 2015). Further supporting this view is a study titled "stroke caregivers strain: prevalence and determinants in the first six months after stroke" conducted by Ilse, *et.al.* (2008) using a longitudinal study design and he found that sickness or poor health of caregivers was significantly associated with strain (Ilse, *et.al.* 2008).

2.3.7 AVAILABILITY OF SUPPORT AND FINANCES

A cross-sectional study by Kumar, *et.al.* (2016) used the Zarit burden scale to measure strain in a rural community in India and found that presence or availability of support were significantly associated with strain (Kumar, *et.al.* 2016). Morimoto, Schreiner and Asano (2003) in a cross-sectional study on caregiver burden and health-related quality of life among Japanese stroke caregivers revealed that presence of a respite caregiver did not significantly relate to the degree of caregiver burden or strain. Statistical test employed here was analysis of variance (ANOVA) and Zarit Burden interview was used to get burden scores. (Morimoto, Schreiner and Asano, 2003). Still using the Zarit scale, Boonsin and colleagues (2021) also found no direct effect between social support and caregiver burden scores (Boonsin *et.al.*., 2021). Bhattacharjee, *et.al.* (2012) in a longitudinal study on factors affecting burden on caregivers of stroke survivors in India, measured burden as strain using the Caregiver strain index tool. Caregiver characteristics like financial stress, were significantly related to strain. On the other hand, factors such as presence of an additional caregiver didn't significantly relate to strain. Data was collected three times; 28 days, 6 months and 1 year. (Bhatttacharjee, *et.al*. 2012).

2.3.8 EDUCATIONAL STATUS OF CAREGIVERS

Bhattacharjee, *et.al.* (2012) in a longitudinal study on factors affecting burden on caregivers of stroke survivors in India, measured burden as strain using the Caregiver strain index tool found that certain factors such as educational status didn't significantly relate to strain. (Bhatttacharjee, *et.al.* 2012). A cross-sectional study on Factors Affecting the Burden on Caregivers of Stroke Survivors in South Korea by Choi-Kwon, *et.al.* (2005) revealed that patients' level of education, was not related to caregivers' burden scores (Choi-Kwon *et.al.*., 2005).

2.4 QUALITY OF LIFE (QOL) OF STROKE CAREGIVERS

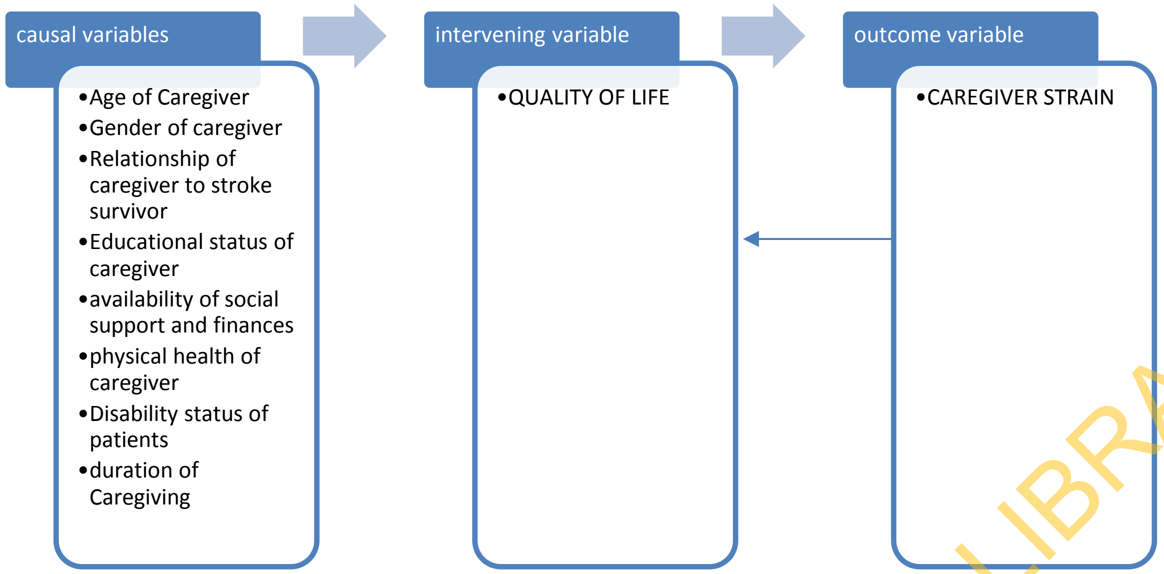
Mc Cullagh, Brigstocke, Donaldson and Kalra (2005) conducted a randomized trial of caregiving training on stroke survivor caregivers and found out that Caregiver QOL had a significant inverse relationship with caregiver burden and correlated with the same patient and caregiver variables as caregiver burden. And also, caregiver QOL was adversely affected by patient disability and caregivers' age, male gender, and physical health. Social services actions had little influence on caregiver burden or QOL but reduced the need for institutional care. Training caregivers in the management of patients reduced caregiver burden and increased their QOL but had no effect on institutionalization (Mc Cullagh, Brigstocke, Donaldson and Kalra, 2005). A study conducted in Ghana by Boakye, *et.al.* (2020) on quality of life among caregivers of stroke survivors in Ghana showed that caregivers had lesser quality of life scores compared to non-caregivers (Boakye, Kwakye, African, & Academy, 2020). Another study on quality of life and burden of informal caregivers of stroke survivors by Ogunlana, Dada, Oyewo, Odole and Ogunsan (2014) shows that since rehabilitation focuses on patient-centered interventions, the number of stroke survivors being managed by caregivers at home has increased, placing an increased amount of strain on their caregivers. Burden was found to increase as QOL reduces. The study also revealed that female and unmarried caregivers had significantly higher QOL scores than their male and married contemporaries. Being a single female caregiver however had no marked influence on the strain index. Caregivers increased ages had markedly reduced QOL scores (Ogunlana, Dada, Oyewo, Odole and Ogunsan, 2014).

In a cross-sectional study by Jeong, Myong and Koo (2015) on the modifying role of caregiver burden on predictors of quality of life of caregivers of hospitalized chronic stroke patients, caregivers with high burden taking care of patients who were unemployed, having poor health status and lower income, and being the patient's spouse were negative predictors of quality of life. However, those with lower burden having patients hospitalized for a longer duration and experiencing poor health were negative predictors of quality of life. Caregiver strain or burden was also observed to have quite a substantial effect on caregivers' quality of life (Jeong, Myong, & Koo, 2015). Onabanjo, Ali and Hamzat (2013) in a similar study on Quality of life of Nigerian informal caregivers of community dwelling stroke survivors found out that quality of life of stroke caregivers in this study, although above average in all domains, was observed to be lowest in the physical domain. Significant association was also observed between the physical domain of quality of life and educational background of caregivers. Employment status was significantly associated with the physical and environment quality of life domains, quality of life of caregivers in this study was found not to be significantly influenced by being either family or acquaintance of stroke survivors. Time after onset of stroke was found to significantly influence the environmental domain of caregivers' quality of life (Vincent-Onabajo *et.al.*., 2013).

A study carried out in India on burden, its predictors and quality of life in caregivers of stroke survivors at a rural community, Punjab, India by Kumar, *et.al.* (2016) shows that the highest quality of life score was observed in the social domain (69.91 ± 14.87) and lowest scores were seen in the physical category (57.64 ±

8.36) (Kumar *et.al*.., 2016). Another cross-sectional study on quality of life and psychological distress of care-givers of stoke patients by Efi, *et.al.* (2017) conducted in Greece revealed that burden, anxiety and depression all predicted psychological stress among care-givers. Severity of disability was found to be inversely proportional to quality of life. They conclude that psychotherapy should be helpful for the care-givers to manage their burden and cope with anxiety and depression (Efi et. al, 2017). A longitudinal study conducted by Bierhals, Low, Lisane, and Paskulin (2019) shows that non-spouse family care givers had the lowest perceptions of quality of life at both times one and two. They also recorded the lowest quality of life perceptions with respect to satisfaction derived in personal relationships (Bierhals, Low, Lisane, and Paskulin, 2019). Another study on informal caregivers' wellbeing and care recipients' quality of life and community reintegration – findings from a stroke survivor sample by Okoye *et.al.*, (2019) showed that a good proportion (95.1%) had high QOL scores with physical domain being where highest scores were observed and lowest scores found in the emotional domain. There was also a negative association between caregivers' burden and QOL scores (Okoye *et.al.*, 2019). Senfἂlt and Ullberg (2019) in a longitudinal study of Swedish stroke informal caregivers' life, impact, support and psychological wellbeing reveal that about fifty-one percent (51.4%) in the dependent group reported poor psychological wellbeing as opposed to the nineteen percent (19.3%) seen in the independent group of stroke survivors. Psychological wellbeing was assessed using an adapted version of the 36-item short form health survey (BREF-36). It was also noted that female caregivers and those who expressed an unmet need of support were more likely to present with poor psychological wellbeing and children on caregiving roles were the least likely to report poor psychological wellbeing. From all indications as observed, support to caregivers would significantly ease or prevent strain and increase survivor care (Senfἂlt and Ullberg, 2019).

2.5 CONCEPTUAL FRAMEWORK (FIGURE 1)



All the causal variables above have been shown to play some part in the development of caregiver strain with quality of life mediating some effects.

CHAPTER THREE

METHODS

3.1 STUDY SETTING

The study was conducted in the University College Hospital (UCH) Ibadan, Ring Road State Hospital, Ibadan, General hospital, Oyo, Adeoyo hospital, Yemetu, Jericho Nursing Home and Family Medicine Clinic, Dugbe.

The University College Hospital, (UCH) Ibadan was established by August 1952. The Hospital runs about 96 consultative out-patient clinics a week in numerous specialty and sub-specialty disciplines. Other relevant departments in the hospital are physiotherapy, Geriatric clinic, medical out-patient (MOP), internal medicine and neurology clinic. The physiotherapy clinic which provides rehabilitative services to patients with activity limitations and restrictions such as stroke patients, sees about $\geq$ 20 stroke patients weekly.

Ring Road State Hospital Adeoyo, on the other hand was established in 1927 and is a general hospital that provides curative services to the populace. It is located in Oluyole Local Government Area inside Ibadan metropolis. It offers a host of specialized services including physiotherapy to rehabilitate a number of patients including stroke survivors. On average about $\geq$ 15 stroke patients come for their sessions each week. Caregivers could also be found at medical outpatient and neurology clinics.

Adeoyo Maternity hospital founded in 1928 provides mainly maternal and child health services to residents of Ibadan and beyond. Its services were later extended to include other specialist clinics including medicine, surgery and others. The Medicine Department runs a neurology clinic and has a functional physiotherapy unit which rehabilitates stroke patients amongst others. An average of $\geq$ 5 stroke patients could be seen there in a week.

Jericho Nursing Home is mainly a geriatric center that provides clinical care to older ones. It was established in 1905. It has a physiotherapy unit that provides services to stroke patients. About less than 5 stroke patients visit each week.

General hospital, Oyo is a secondary health facility located in Oyo town, Oyo state. It provides pediatric, maternal and child health care, an out-patient clinic and in-patient medical and surgical services. It is also equipped with a functional physiotherapy unit that provides rehabilitative services to stroke survivors. On an average about 10 stroke patients can be seen visiting this clinic each week.

3.2 STUDY POPULATION

This study focused on caregivers of stroke patients who accompany the patients to clinic visits.

3.3 INCLUSION CRITERIA

1. Stroke caregivers who are present to assist stroke patients at the time interviews are being conducted.

2. Willingness to participate in the study.

3.4 EXCLUSION CRITERIA

1) Stroke caregivers who are in a haste and who refuse to give consent to the study.

2) Minors where permission wasn’t granted.

3.5 STUDY DESIGN

This was a cross-sectional study geared towards finding prevalence and determinants of strain among caregivers of stroke patients.

3.6 SAMPLE SIZE DETERMINATION

Using formula for sample size estimation in cross-sectional studies, $n = \frac{Z^2pq}{d^2}$

Where n is the minimum sample size required,

Z_α is the Standard Normal Deviate at 95% confidence level,

p is the prevalence of occurrence of the condition in question (caregiving strain among stroke survivors),

q = 1 - p and,

d = is the margin of error or precision chosen.

Substituting parameters into the formula,

Z = 1.96 at 95% confidence level

p = 0.83 prevalence of strain among caregivers of stroke survivors in Lagos, Nigeria (Akosile *et.al.*, 2013)

q = 1 – 0.83 = 0.17

d = 5% or 0.05

$$n = \frac{1.96^2 \times 0.83 \times 0.17}{0.05^2}$$

n= 216,

adjusting for a non-response rate of 10%,

$\frac{n}{(1-f)}$, where n = sample size, f = 10% that is 0.1,

substituting parameters into formula, $\frac{216}{(1-0.1)}$ = 240 respondents.

3.7 SAMPLING TECHNIQUE

Caregivers of stroke patients seen at the Physiotherapy clinic were randomly recruited into the study by a systematic random sampling technique. A sampling frame of all patients booked for physiotherapy clinic on that date was used to select respondents. To find the sampling interval term used in selecting respondents, this formula was used; k = Total Sample size ÷ sample needed. Thereafter the first number was selected at random and the sampling interval was applied to select respondents.

3.8 DATA COLLECTION INSTRUMENT

A four-section questionnaire was employed for this study (please see appendix 2). It was pretested at Ring Road State Hospital, Adeoyo on 30 caregivers and was found to be quite understandable by respondents. These questionnaires have already been validated by previous studies and records a high level of internal consistency. It was translated to Yoruba from English by a native Yoruba speaker and then it was back translated to English which mirrored the original copy so well and ensured accuracy of this tool.

Section A of the questionnaire contains the socio-demographic variables of the respondents. Section B collects data on strain the caregiver experiences while attending to the patient using the caregivers strain index tool. This is a 12-item scale with yes and no responses scored as 1 and zero respectively and quantifies strain as a summed composite score of 7 and above after administration.

Section C assessed the stroke patient's functionality (Barthel index) with questions about movement and restrictions. It is a 10-item questionnaire that is used for measuring level of disability with higher scores indicating reduced dependency and lower scores showing high dependency. Its maximum obtainable score is 100 and its minimum score is 0.

Quality of life questions would follow using WHO quality of life short form tool. This is a 5-point likert scale with 26 questions. It measures quality of life under four domains which include physical, emotional, social and environmental aspects. Each section's scores are computed and higher scores represent higher quality of life in these domains.

3.9 DATA COLLECTION PROCEDURE

After being given sufficient information and their consenting to participate, caregivers who met the inclusion criteria were given questionnaires (interviewer-administered) to assess variables of interest. These were interviewed at the various clinics waiting room and wards where stroke patients are found.

Three (3) research assistants were properly trained in a one-day pre-data collection workshop for research assistants on good interview techniques, how to get informed consent from study participants and a host of other important issues that could arise during data collection. Research assistants recruited were able to speak Yoruba fluently so as to correctly collect data from those who do not understand English.

Respondents were approached and intimated of the purpose of this research and its benefits to Caregivers. Thereafter, upon receiving enough information to make a decision, the Caregiver signs the informed consent form and is recruited into the study. A study identification (ID) is recorded on the questionnaire and the interview takes place there at the waiting room of the clinic in the Caregiver's preferred language (English or Yoruba).

3.10 DATA ANALYSIS AND MANAGEMENT

Data analysis was done using Statistical Package for Social Sciences (SPSS) version 20. Categorical data summaries were presented using, percentages and frequencies. Continuous variable summaries were presented using mean and standard deviations. Bivariate analytic techniques such as correlations have been employed to explore the relationship between caregiver strain, functional index (Barthel scores) and quality of life scores in their domains, duration of caregiving, age of caregiver, average income. Caregiver strain scores greater than or equal to 7 and above were categorized as strain and all scores less than 7 were termed as not strained (Robinson.,1983). Quality of life scores were categorized into good (mean score + 1 standard deviation) and poor (all scores less than mean score + 1 standard deviation) (Okekunle *et.al.*., 2015). All statistical associations for numerical outcomes were tested using correlation. Categorical outcomes were assessed using chi-square tests and binary logistic regression technique. Associations were considered significant at $p < 0.05$. However, any factors significant at lower levels of significance were noted and reported

3.11 ETHICAL CONSIDERATIONS

Ethical approval was sought and gotten from two different Ethical Review Boards { UI/UCH Ethics Committee (UI/EC/19/0467) and Oyo State Ethical Review Board } for this multi-center study before data collection took place (Appendix 4). All respondents were given code numbers and no names were recorded to ensure anonymity. Data generated during this research was only accessible by the researcher. Questionnaires were securely kept in sealed envelopes and locked in secure cabinets away from unauthorized access. The computer system which was used for data entry was secured with a password by the researcher to ensure that respondent's information is kept confidential. Information generated during data collection was kept away from any third parties. The ethical principles of autonomy, non-maleficence, beneficence and justice were applied during the conduct of this research.

The research was beneficial to the Caregivers in that, counselling was provided to respondents who indicated a high level of strain (strain scores ≥ 7) on how to deal with the strain of caregiving without becoming overwhelmed. In the future, the recommendations of this research would help to greatly reduce the strain Caregivers face when discharging their responsibilities.

The research wasn't harmful to participants in any way. The only little cost of the research was the time implication (which is estimated to be about 20 minutes or less) on the respondent.

The autonomy of each respondent was well respected. Respondents weren't coerced into the study for any reason and if for any reason at any time, respondents wish to withdraw from the study, their autonomy was respected and didn't influence the quality of care they received at the facility.

CHAPTER FOUR

RESULTS

4.1 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS

The mean age of respondents observed was 39.5 ± 15.6 years. The proportion of females was fifty-five percent (55.6%) 134 while males formed the remainder. Among the various relationships of respondents to the stroke survivors, the highest proportions observed were children, spouse and siblings with about forty-three percent (n, 42.7%), twenty-two percent (21.6%) and six percent (6%) respectively. Categories of occupations most observed are sales or business (37.8%), students (19.5%), and household & domestic workers (10.7%). The mean income of respondents observed was ₦43,483 ± 84359. Highest educational status category observed were those who completed secondary education, about forty five percent (44.8%). Other characteristics of this population observed include; mean duration of stroke (1.74 years ± 2.92), mean number of caregivers per stroke patient (3 ± 2), health insurance status of stroke patients revealed that 6.2% insured and 83.8% were not insured, and mean duration of caregiving recorded was 1.52 years ± 2.67. (Table 1).

Table 1- Socio-demographic characteristics of respondents (N=241)

Variable	Frequency (n)	Percentage (%)
Gender		
Male	107	44.4
Female	134	55.6
Educational status		
Completed primary	34	14.1
Completed secondary	108	44.8
Completed tertiary	77	32.0
Completed post-graduate	22	9.1
Occupation		
Sales	91	37.8
Students	47	19.5
Household & Domestic Workers	26	10.7
Professional/Managerial	21	8.7
Skilled manual workers	20	8.3
Civil servants	15	6.2
Retired	10	4.1
Agricultural Workers	4	1.6
Unemployed	3	1.2
Clerical	2	0.8
Armed forces	2	0.8
Relationship to stroke survivor		
Child	103	42.7
Spouse	52	21.6
Sibling	16	6.6
Nephew/Niece	14	5.8
Paid caregiver	12	5.0
Grand child	11	4.6
Friend	10	4.1
Parent	7	2.9
In-law	5	2.1
Driver	4	1.7
Employee	2	0.8
Fiancée	1	0.4
Neighbor	1	0.4
Mentee	1	0.4
Second cousin	1	0.4
Insurance status		
Yes	39	16.2
No	202	83.8

Table 2 - Other characteristics of respondents (N=241)

Variable	Mean ± SD
Average monthly income (₦)	43,483 ± 84,359
Duration of stroke (years)	1.738 ± 2.92
Length of caregiving (years)	1.52 ± 2.67
Number of caregivers	3 ± 2

4.2 PREVALENCE OF STRAIN AMONG CAREGIVERS OF STROKE SURVIVORS

The prevalence of caregiver strain among respondents is seventy two percent (72%) (Table 3b). Of those strained, about forty-two percent (42%) were males and fifty-eight percent (58%) were females. The mean Caregiver Strain Index (CSI) score observed is 7.11 ± 2.03. (Table 3a)

TABLE 3a- CAREGIVER STRAIN INDEX (CSI) AMONG STROKE SURVIVORS (N=241)

Variables	**Yes [n (%)]**
Sleep is disturbed	171 (71.0)
Caregiving is inconvenient	160 (66.4)
Caregiving is a physical strain	144 (59.8)
Caregiving is confining	171 (71.0)
There have been family adjustments due to caregiving	152 (63.1)
There has been changes in personal plans due to caregiving	175 (72.6)
There have been emotional adjustments due to caregiving	40 (16.6)
Some behavior of patient is upsetting	89 (36.9)
It is upsetting to find that the patient has changed so much from his/her former self	123 (51.0)
There have been work adjustments due to caregiving	187 (77.6)
Caregiving is a financial strain	179 (74.3)
Caregiving makes me feel completely overwhelmed	123 (51.0)

TABLE 3b - PREVALENCE OF STRAIN AMONG CAREGIVERS OF STROKE SURVIVORS

categories of strain score	Frequency (n)	Percentage (%)
not strained	68	28.2
Strained	173	71.8
Total	241	100.0

Table 4- Major themes on Caregivers perception of what can be done to reduce their strain (N = 241)

Themes	n (%)
Build more facilities with physiotherapy units that are accessible	4 (1.6)
Health education	10 (4.1)
Improved Patient outcomes	43 (17.7)
Increased number of caregivers	4 (2.8)
Health Insurance	11 (4.5)

4.3 DISABILITY STATUS OF STROKE SURVIVORS

Disability status as measured by Barthel Index assesses the functional status of patients by scoring activities for daily living and computation of these gives us an insight into the disability status of patients. Scores range from 0 to 100, lower scores imply greater disability and higher scores imply lesser disability. Mean Barthel Index score ± SD = 60.44 ± 29.12.

Table 5- DISABILITY STATUS OF STROKE SURVIVORS (BARTHEL INDEX)

Variable (N = 241)	n (%)
Feeding	
Unable	17 (7.1)
Needs help	22 (9.1)
Independent	202 (83.8)
Bathing	
Dependent	137 (56.8)
Independent	104 (43.2)
Grooming	
Needs help	170 (70.5)
Independent	71 (29.5)
Dressing	
Dependent	107 (44.4)
Needs help	70 (29.0)
Independent	64 (26.6)
Bowels	
Incontinent	63 (26.1)
Occasional accident	40 (16.6)
Continent	138 (57.3)
Bladder	
Incontinent	55 (22.8)
Occasional accident	36 (14.9)
Continent	150 (62.2)
Toilet use	
Dependent	64 (26.6)
Needs some help	48 (19.9)
Independent	129 (53.5)
Transfers (bed to chair and back)	
Unable	35 (14.5)
Major help	53 (22.0)
Minor help	64 (26.6)
Independent	89 (36.9)

Mobility	
Immobile	36 (14.9)
Wheel chair independent	12 (5.0)
Walks with help of one person	79 (32.8)
Independent	114 (47.3)
Stairs	
Unable	102 (42.3)
Needs some help	82 (34.0)
Independent	57 (23.7)

4.4 FACTORS AFFECTING CAREGIVER STRAIN AMONG STROKE SURVIVORS

The following factors were found to be associated with strain ($p<0.05$); availability of support and finances, health status of caregiver and disability status of stroke survivors. There was a direct proportional relationship between caregiver strain and duration of caregiving time spent on a stroke survivor. Whereas, disability status (as scores reduced), caregiver strain increased. Those who had more financial support reported lesser caregiver strain compared with those who didn’t and the association was significant at 95% Confidence level (Table 6 and 7).

TABLE 6 - FACTORS ASSOCIATED WITH OCCURRENCE OF CAREGIVER STRAIN AMONG CAREGIVERS OF STROKE SURVIVORS

Variable (N=241)	Strained n(%)	Not strained (%)	χ2	p-value
Gender			0.655	0.418
Male	73 (30.2)	34 (14.1)		
Female	100 (41.5)	34 (14.1)		
Relationship to stroke survivor				
Spouse	39 (16.2)	13 (5.4)	3.921	0.417
Child	77 (31.9)	26 (10.7)		
In-law	3 (1.2)	3 (1.2)		
Nephew/Niece	9 (3.7)	5 (2.1)		
Others	46 (19.1)	21 (8.7)		
Availability of support and finances				
Yes	143 (59.3)	36 (14.9)	22.561	0.000*
No	30 (12.4)	32 (13.2)		
Educational status				
Completed primary	26 (10.7)	8 (3.3)	5.003	0.172
Completed secondary	82 (34.0)	26 (10.7)		
Completed tertiary	48 (19.9)	29 (12.03)		
Completed post-graduate	17 (7.1)	5 (2.1)		
Insurance status				
Yes	28 (11.6)	11 (4.6)	0.00	0.999
No	145 (60.2)	57 (23.7)		

Table 7 – OTHER FACTORS ASSOCIATED WITH STRAIN AMONG CAREGIVERS OF STROKE SURVIVORS

Variable (N = 241)	Correlation value	p-value
Length of caregiving time daily	0.136	0.034*
Disability status (Barthel Index)	-0.316	0.000*
Health of caregiver (Physical health domain of QOL)	-0.129	0.001*
Environmental domain of QOL	-0.168	0.023*
Number of caregivers	0.030	0.958
Age of caregiver	0.001	0.992
Duration of stroke	-0.109	0.090
Emotional / Psychological domain of QOL	-0.122	0.735
Social relationships	-0.102	0.116

*significant @ 95% Confidence level

4.5 DETERMINANTS OF STRAIN AMONG CAREGIVERS OF STROKE SURVIVORS

Of the factors entered into the logistic regression model, only financial strain was found to be significantly associated with the development of caregiver strain, those who experienced financial support were 78.1 times less likely to develop caregiver strain, as shown in Table 8 below.

TABLE 8- DETERMINANTS OF STRAIN AMONG CAREGIVERS OF STROKE SURVIVORS

Variables (N=241)	β	Standard Error (SE)	Odds Ratio (OR)	Lower	Upper	p. value
Relationship to patient						
Spouse (reference)			1			
Child	0.240	0.449	1.271	0.527	3.066	0.594
In-law	0.305	0.386	1.357	0.637	2.892	0.429
Nephew/Niece	-1.382	0.995	0.251	0.036	1.767	0.165
Others	-0.199	0.660	0.820	0.225	2.991	0.763
Gender						
Female (reference)			1			
Male	0.328	0.320	1.389	0.742	2.601	0.305
Insurance Status						
Yes (reference)			1			
No	0.295	0.445	1.343	0.561	3.215	0.508
Educational status						
Completed primary (reference)			1			
Completed secondary	-0.502	0.719	0.605	0.148	2.479	0.485
Completed tertiary	-0.582	0.623	0.559	0.165	1.897	0.351
Completed post-graduate	-1.116	0.619	0.327	0.097	1.101	0.071
Availability of finance and support						
Yes	-1.520	0.341	0.219	0.112	0.427	0.00*
No (reference)			1			

*Significant @ 95% confidence level

4.6 QUALITY OF LIFE OF CAREGIVERS OF STROKE SURVIVORS

The highest mean scores were recorded in the physical and social relationships domain. While the lowest mean scores were recorded in the psychological / emotional domain. (Table 9).

TABLE 9- QUALITY OF LIFE OF CAREGIVERS OF STROKE SURVIVORS

Domains	Mean ± SD	Poor (%)	Good (%)
Physical	72.44 ± 11.321	23 (9.5)	218 (90.5)
Emotional/Psychological	62.19 ± 9.04	30 (12.4)	211(87.6)
Social relationships	72.44 ± 16.20	33 (13.7)	208 (86.3)
Environmental	62.77 ± 10.49	18 (7.5)	223 (92.5)

CHAPTER FIVE

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 PREVALENCE OF STRAIN AMONG CAREGIVERS OF STROKE SURVIVORS

Prevalence of caregiver strain ranges from very high values to quite lower values in different studies. Lots of study designs have been employed to study the concept of caregiver strain ranging from cross-sectional to longitudinal designs. This study used a cross-sectional design to measure prevalence of strain among caregivers of stroke survivors. This study observed prevalence of strain to be 71%. A similar study conducted by Kaur, *et.al.* (2018) among family caregivers in India showed that strain was almost as high, recording a prevalence of 73.5% (Kaur *et.al.*., 2018). Still in India, Rawat, *et.al.* (2017) in a study on caregiver strain recorded a relatively high prevalence of 56.7% (Rawat *et.al.*, 2017). Still on this trend of prevalence is a study conducted by Akosile, *et.al.* (2013) in Nigeria who measured caregiver strain to be 83.5% among caregivers of stroke survivors (Akosile *et.al.*., 2013).

Deviating a bit from this trend of strain observed above however is Carod-Artal *et.al.*, (2009) study conducted in Brazil on 200 caregivers where about 26.4% felt caregiver strain (Carod-Artal *et.al.*., 2009). Caregiver strain tends to lower as longitudinal study designs are employed. Blake, *et.al.* (2003) reported caregiver strain as 39% and 40% at times 1 and 2 respectively (Blake *et.al.*., 2003). Hung, *et.al.* (2012) in a study conducted in Southern Taiwan showed a prevalence of 46% and 43% at times 1 and 2 (T1 and T2) respectively (Hung *et.al.*., 2012). Jaracz, *et.al.* (2015) also measured strain at two time periods; 6 months and 5 years thereafter (Jaracz *et.al.*., 2015). Ilse, *et.al.* (2008) at times 1, 2 and 3 measured strain to be 28%, 31% and 29% respectively among caregivers (Ilse *et.al.*., 2008).

5.2 FACTORS AFFECTING STRAIN AMONG CAREGIVERS OF STROKE SURVIVORS

5.2.1 GENDER OF CAREGIVER

In this study, gender was not a significant determinant of caregiver strain. This finding goes in line with other observations in other studies where no significant relationship was found between gender and caregiver strain (Bhattacharjee *et.al.*., 2012; Gbiri *et.al.*., 2015). However, there are other studies that have observed associations or significant relationships between caregiver strain and gender. Choi-Kwon, *et.al.* (2015) in a study on factors associated with caregiver strain found that females were more likely to present with strain when rendering care to stroke survivors (Choi-Kwon *et.al.*., 2005). Another study by Kumar, *et.al.* (2016) observed that the female gender was associated significantly with caregiver strain (Kumar *et.al.*., 2016). So, it could be said that gender may or may not be associated with caregiver strain.

5.2.2 RELATIONSHIP OF CAREGIVER TO STROKE SURVIVOR

This study found no significant association between caregiver strain and relationship to stroke survivors. This results differs from what other studies that observed that daughters-in-law were most likely to feel strained from caregiving (Bhattacharjee *et.al.*., 2012; Choi-Kwon *et.al.*., 2005). A possible reason for variations observed may be due to the little proportion of in-laws seen in this study. The highest proportion of caregivers seen in this study were child caregivers (43%).

5.2.3 AGE OF CAREGIVER

This study results show no significant relationship between age and caregiver strain. This rhymes with results presented in another cross-sectional study carried out by Gbiri *et.al.* (2015) who also observed no significant relationships between strain scores and caregiver age (Gbiri *et.al.*., 2015). Similarly, Boonsin, *et.al.* (2021) didn’t find age to be a significant factor influencing burden (Boonsin *et.al.*., 2021). Still following this line of evidence is a longitudinal study by Ilse, *et.al.* (2008) who observed increasing age not to be significantly associated with caregiver strain (Ilse *et.al*.., 2008).

5.2.4 LENGTH OF CAREGIVING TIME

The results of this study show that there was an association between length or duration of caregiving time. This results do not agree with Morimoto, *et.al.* (2003) who observed that there was no association between caregiver strain and duration of caregiving (Morimoto *et.al*.., 2003). However most other studies actually observed a significant relationship between length of caregiving time and strain. Gbiri, *et.al.* (2015) in their study on caregiver burden or strain observed a significant relationship between caregiver strain and increased hours of caregiving (Gbiri *et.al*.., 2015). Other research works like Hung and colleagues (2012) and Bhattarcharjee, *et.al.* (2012) also observed that increased caregiving hours each day caring for stroke survivors was associated with increased strain (Bhattacharjee *et.al*.., 2012; Hung *et.al*.., 2012). This is to be expected as more hours would imply more exertion and lead to increased levels of caregiver strain.

5.2.5 DISABILITY STATUS OF STROKE SURVIVORS

Many scales could be used to measure the extent of disability a patient face. The Barthel index is one of the tools developed to asses a patient's ability to perform activities for daily living. Higher scores usually indicate lesser disability of respondents. The extent of disability of stroke survivors has been found to be a significant predictor or determinant of caregiver strain. This is to be expected as greater disability would imply more assistance to be rendered which will leave the caregiver feeling quite strained. In this study, disability status was measured and assessed against strain scores and was found to be significantly associated with strain. This findings have been found to agree with results from similar studies on caregiver strain who observed patient factors associated with caregiver strain include amongst others disability status (Bhattacharjee *et.al*.., 2012; Ilse *et.al*.., 2008; Jaracz *et.al*.., 2015; Boonsin *et.al*.., 2021)

5.2.6 POOR HEALTH OF CAREGIVERS

Physical health of the caregivers was found to be significantly associated with strain. These results go in line with those by Hung, *et.al.* (2012) where he found that poor health of caregivers was a predictor of strain (Hung *et.al.*., 2012). Similar studies also observed similar results. Ilse, *et.al.* (2008) in a cross-sectional study found that sickness of caregivers was significantly associated with strain. Blake, *et.al.* (2003) observed that general health of caregivers was a significant determinant of caregiver strain (Blake *et.al.*., 2003; Ilse *et.al.*., 2008). This is to be expected as ill health of caregivers would make assistance quite strenuous.

5.2.7 AVAILABILITY OF SUPPORT AND FINANCES

Availability of funds/finances or financial support was found to be significantly related to caregiver strain in this study. This is in harmony with what Bhattarcharjee, *et.al.* (2012) found in their study when they observed significant association between strain and availability of finances (Bhattacharjee *et.al.*., 2012). Kumar, *et.al.* (2016) also observed that the presence or availability of social and financial support was significantly linked to reduced levels of strain (Kumar *et.al.*., 2016). Deviating from this trend, Boonsin *et.al.* (2021) reported that no direct association was observed between caregiver burden and social support (Boonsin *et.al.*., 2021).

5.2.8 EDUCATIONAL STATUS OF CAREGIVERS

Educational status wasn't a significant factor affecting caregiver strain. This findings agree with that carried out in South-Korea by Choi-kwon, *et.al.* (2005) whose results show that level of education wasn't related to caregiver strain (Choi-Kwon *et.al.*., 2005). Bhattacharjee, *et.al.* (2012) also observed similar results, that level of education wasn't significantly associated with caregiver strain (Bhattacharjee *et.al.*., 2012). Obviously, the caregiver's level of education should play little or no part to how much strain they feel.

5.3 QUALITY OF LIFE AMONG CAREGIVERS OF STROKE SURVIVORS

This study measured quality of life and found out that highest scores were recorded in the physical health and social relationships domain. Domains 1 and 4 physical health and environment domains respectively show an inverse significant relationship with caregiver strain. About 48.5% of caregivers recorded bad scores in the physical health domain and 51.5% recorded good scores here. The emotional domain had 93.8% of caregivers recording poor scores while 6.2% were in the good category. Social relationships domain had 87% of respondents recording bad scores whereas 12.4% recorded good scores. The last domain (Environmental) had about 88% of caregivers recording bad scores while 11.2% were in the good category.

Mc Cullagh, *et.al.* (2005) also arrived at similar findings when he observed an inverse relationship between caregiver strain and quality of life (Mc Cullagh *et.al.*., 2005). Ogunlana, *et.al.* (2014) also reported an inverse relationship between burden or strain and quality of life scores. Jeong and colleagues (2015) also reported strain having a substantial effect on quality of life of caregiver (Jeong *et.al.*., 2015).

Other studies in the community tend to deviate from the trend observed above. Onabanjo, *et.al.* (2013) observed physical health domain having lowest scores (Onabanjo *et.al.*., 2013). Still on this trend a community based cross-sectional study carried out by Kumar, *et.al.* (2016) also revealed lowest scores recorded in the physical health domain (Kumar *et.al.*., 2016). Okoye, *et.al.* (2019) however records a deviation from this trend when he observed physical health domain recording highest scores and an inverse relationship of strain to quality of life scores (Okoye *et.al.*., 2019).

5.4 CONCLUSION

Caregivers play a vital role in functional recovery of stroke survivors. However, their role puts them in an extremely stressful and dauntingly overwhelming position which leaves them feeling quite strained, hence the concept of caregiver strain. From the findings of this study, it can be deduced that the prevalence of strain among caregivers of stroke survivors is really high and needs urgent action. The determinants of caregiver strain found were; disability status of stroke survivors, physical health of caregivers and availability of support and finances. Caregivers quality of life was also explored and it was found that highest scores were recorded in 1st and 3rd domains, that is physical and social relationships domains respectively. Physical health and environmental domains showed an inverse relationship with strain upon being subjected to correlations. In general, quality of life scores was fair for caregivers.

5.4 RECOMMENDATIONS

Based on the results of this research, the following recommendations have been proposed:

1) Caregivers should be well integrated into the program for rehabilitating stroke survivors. This should be implemented by the health care providers taking care of stroke patients.
2) Strain or burden interviews should be performed on each clinic visit. This could also be implemented by attending physicians, nurses and physiotherapists directly involved in providing care to stroke patients.
3) Caregivers should be physically assessed, examined and treated of any morbidities being experienced on each clinic visit. The doctor managing the stroke survivor should implement this.
4) Health insurance schemes should be made readily available and easily accessible to caregivers. The Government could create more inclusive health-care insurance schemes for all its citizens.
5) Social support groups and networks could be created, where caregivers interact and benefit from each other's experiences, creating a social support mechanism. Physiotherapists could create a network of stroke survivor caregivers as their exercise sessions even make this very attainable.

6) Caregivers suggested that functional nursing homes, proper health education on how to manage strain, more stroke rehabilitation centers closer to their homes and improved patient outcomes would go a long way in reducing the strain they experience.

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APPENDIX 1

INFORMED CONSENT FORM

Research Title: Prevalence and determinants of strain among caregivers of stroke survivors in Oyo State

This study is being conducted by Otu, David Samuel, a student of the Faculty of Public Health, University of Ibadan. The research aims at finding out the factors associated with caregiver strain among stroke survivors. You would be interviewed using the tools for this study. The interview sessions last at most 20 minutes. Strain scores would be computed and recorded on the instrument. Participants with high scores would be given adequate counsel.

Risk

The only possible risk in this study could be attributed to time costs. This would be dealt with by ensuring that interview sessions do not last more than 20 minutes.

Benefit

Counselling services would be administered to participants with high strain scores ($\geq$ 7 on Caregiver Strain Index) to enable these not to be overwhelmed by the rigors of caregiving.

Confidentiality

All respondents would be given code numbers and no names would be recorded to ensure anonymity. Data generated from the study would be secured from any unauthorized access. Information disclosed by respondents would not be disclosed to any third parties.

Voluntariness

In accordance with the principles of ethical research, autonomy of each respondent will be well respected. Respondents wouldn't be coerced into the study for any reason and if for any reason at any time, respondents wish to withdraw from the study, their autonomy will be respected.

Alternatives to participation

If you chose not to engage in the study, this will in no way affect the way they are treated.

Inducements:

After interview sessions a free pen would be given to each respondent. However, fees will not be paid for participating in the study. Caregivers would get to know their strain levels and counseled accordingly

What happens to research participants when research is over?

Findings of the research would be disseminated through scientific journals and posters would be pasted at the clinics used.

Conflict of interest:

None

Statement of person obtaining informed consent:

I have fully explained this research to ______________________________ and have given sufficient information, including about risks and benefits, to make an informed decision.

Date: ______________________ Signature: _________________________

Name:____________________________________

Statement of person giving consent:

I have read the description of the research and have had it translated into a language I understand. I have also discussed with the doctor to my satisfaction. I understand that my participation is voluntary. I know enough about the purpose, methods, risks and benefits of the research study to judge that I want to be part of this study. I understand that I may freely stop being part of this study at any time. I have received a copy of this consent form and additional information to keep for myself.

Signature of participant:_______________________ DATE:___________

Appendix 2

QUESTIONNAIRE

Title of the study: Prevalence and determinants of caregiver strain among stroke survivors in Ibadan, Oyo State

I am a student of the Department of Epidemiology and Medical Statistics, University of Ibadan. I am conducting a survey on factors associated with caregiver strain in post stroke survivors. This exercise will not take much of your time. Your honest answers to these questions would be highly appreciated. Be sure to read and sign the informed consent form to engage in this study.

Study No/code. ------------ Date: Interviewer:

Section 1 (Socio-demographics)

1) Age (years):
2) Sex: Male ☐ Female ☐
3) Relationship to stroke survivor: ☐ Spouse ☐ Child ☐ in-law ☐ nephew/niece ☐ Cousin ☐ others(please specify)_______________________
4) Duration of caregiving (months):
5) Occupation:
6) Educational status: completed primary ☐ completed secondary ☐ completed tertiary ☐ completed post graduate ☐
7) Average monthly income (salary or earnings per day):_N___________________________
8) Is the stroke survivor on any insurance scheme? Yes ☐ No ☐

If yes, please specify_________________________________

9) How long has the patient suffered the condition? ______________________(Months)

10) How much time does caregiving take from you each day? _______________(Hours)

11) Number of caregivers ____________

Section 2

Caregiver Strain Index (CSI) Score

I am going to read a list of things that other people have found to be difficult. Would you tell me whether any of these apply to you? (GIVE EXAMPLES)

	Yes = 1	No = 0
Sleep is disturbed (e.g., because . . . is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		

There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; . . . has trouble remembering things; or . . . accuses people of taking things)		
It is upsetting to find . . . has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about . . . ; concerns about how you will manage)		
Total Score (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

What do you think can be done to reduce the level of strain you face? ___________________________

Section 3

THE
BARTHEL
INDEX

Activity Score

FEEDING

0 = unable

5 = needs help cutting, spreading butter, etc., or requires modified diet

10 = independent ______

BATHING
0 = dependent

5 = independent (or in shower) ______

GROOMING
0 = needs to help with personal care

5 = independent face/hair/teeth/shaving (implements provided)

______

DRESSING
0 = dependent

5 = needs help but can do about half unaided

10 = independent (including buttons, zips, laces, etc.)

______

BOWELS
0 = incontinent (or needs to be given enemas)

5 = occasional accident

10 = continent ______

BLADDER
0 = incontinent, or catheterized and unable to manage alone

5 = occasional accident

10 = continent ______

TOILET USE
0 = dependent

5 = needs some help, but can do something alone

10 = independent (on and off, dressing, wiping) ______

TRANSFERS (BED TO CHAIR AND BACK)
0 = unable, no sitting balance

5 = major help (one or two people, physical), can sit

10 = minor help (verbal or physical)

15 = independent ______

MOBILITY (ON LEVEL SURFACES)
0 = immobile or < 50 yards

5 = wheelchair independent, including corners, > 50 yards

10 = walks with help of one person (verbal or physical) > 50 yards

15 = independent (but may use any aid; for example, stick) > 50 yards ______

STAIRS
0 = unable

5 = needs help (verbal, physical, carrying aid)

10 = independent ______

TOTAL (0–100): ______

SECTION 4
QUALITY OF LIFE

Are you currently ill?

Yes No

If something is wrong with your health what do you think it is?______________________________

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the option that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, a question might ask:

		Not at all	Not much	Moderately	A great deal	Completely
	Do you get the kind of support from others that you need?	1	2	3	4	5

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

		Not at all	Not much	Moderately	A great deal	Completely
	Do you get the kind of support from others that you need?	1	2	3	4	5

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5
		Very Dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
		Very poor	Poor	Neither poor nor good	Good	Very good
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

		Very Dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

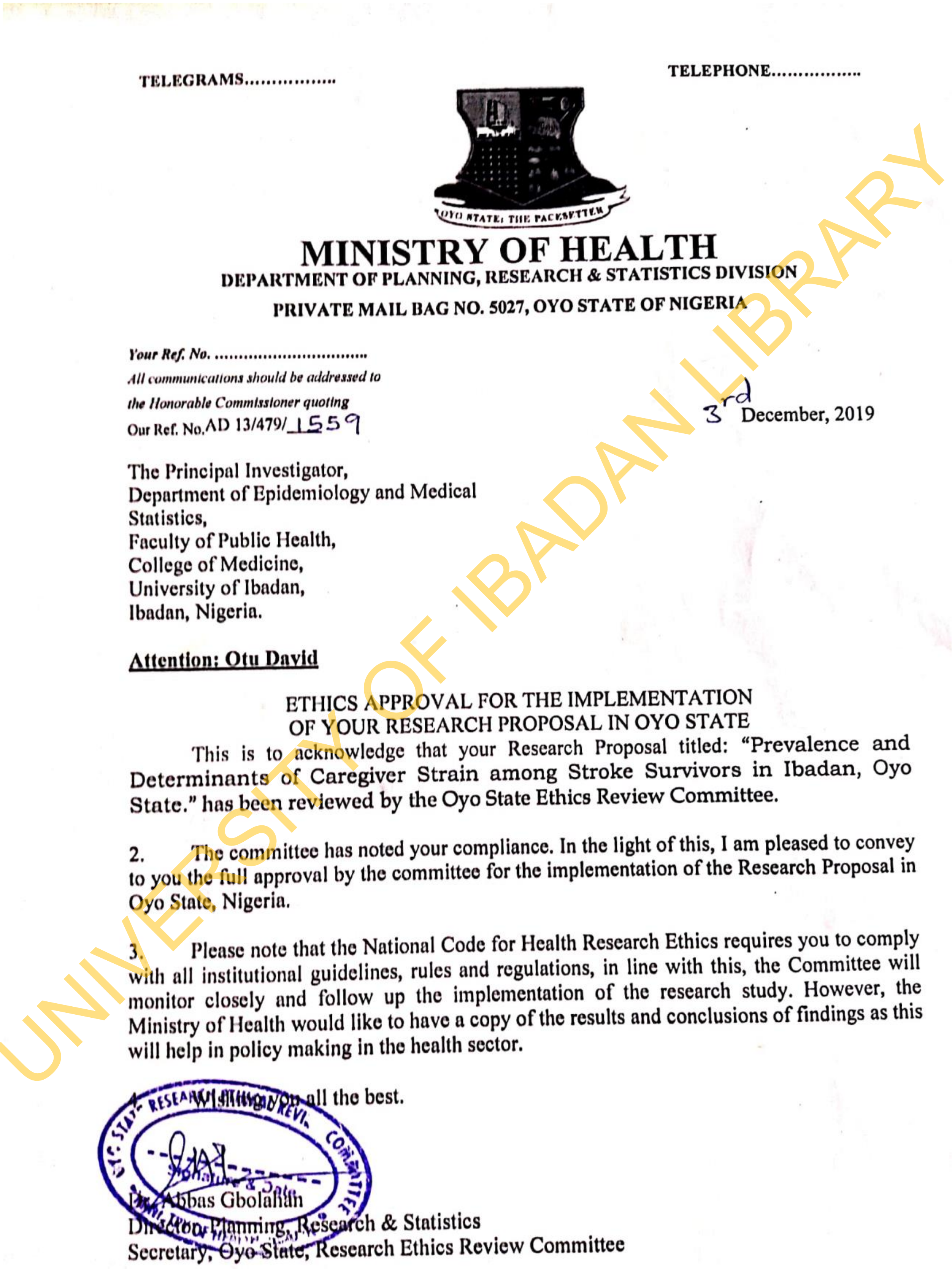
Appendix 3

Data Analysis Matrix

S/N	Specific objective	Dependent variable	Independent variable	Tool for Data analysis
1	Prevalence of caregiver strain among stroke survivors	Caregiver Strain		Proportion
2	Quality of life of caregivers of stroke survivors		Quality of life	Proportion
3	To determine factors associated with caregiver strain	Caregiver strain	Factors associated with caregiver strain	Correlation, linear regression, multivariate linear regression, binary logistic regression, and chi square

Appendix 4

OYO STATE ETHICAL APPROVAL



TELEGRAMS................ TELEPHONE................

OYO STATE: THE PACESETTER

MINISTRY OF HEALTH
DEPARTMENT OF PLANNING, RESEARCH & STATISTICS DIVISION
PRIVATE MAIL BAG NO. 5027, OYO STATE OF NIGERIA

Your Ref. No. ....
All communications should be addressed to
the Honorable Commissioner quoting
Our Ref. No. AD 13/479/1559

3rd December, 2019

The Principal Investigator,
Department of Epidemiology and Medical
Statistics,
Faculty of Public Health,
College of Medicine,
University of Ibadan,
Ibadan, Nigeria.

Attention: Otu David

ETHICS APPROVAL FOR THE IMPLEMENTATION
OF YOUR RESEARCH PROPOSAL IN OYO STATE

This is to acknowledge that your Research Proposal titled: "Prevalence and Determinants of Caregiver Strain among Stroke Survivors in Ibadan, Oyo State." has been reviewed by the Oyo State Ethics Review Committee.

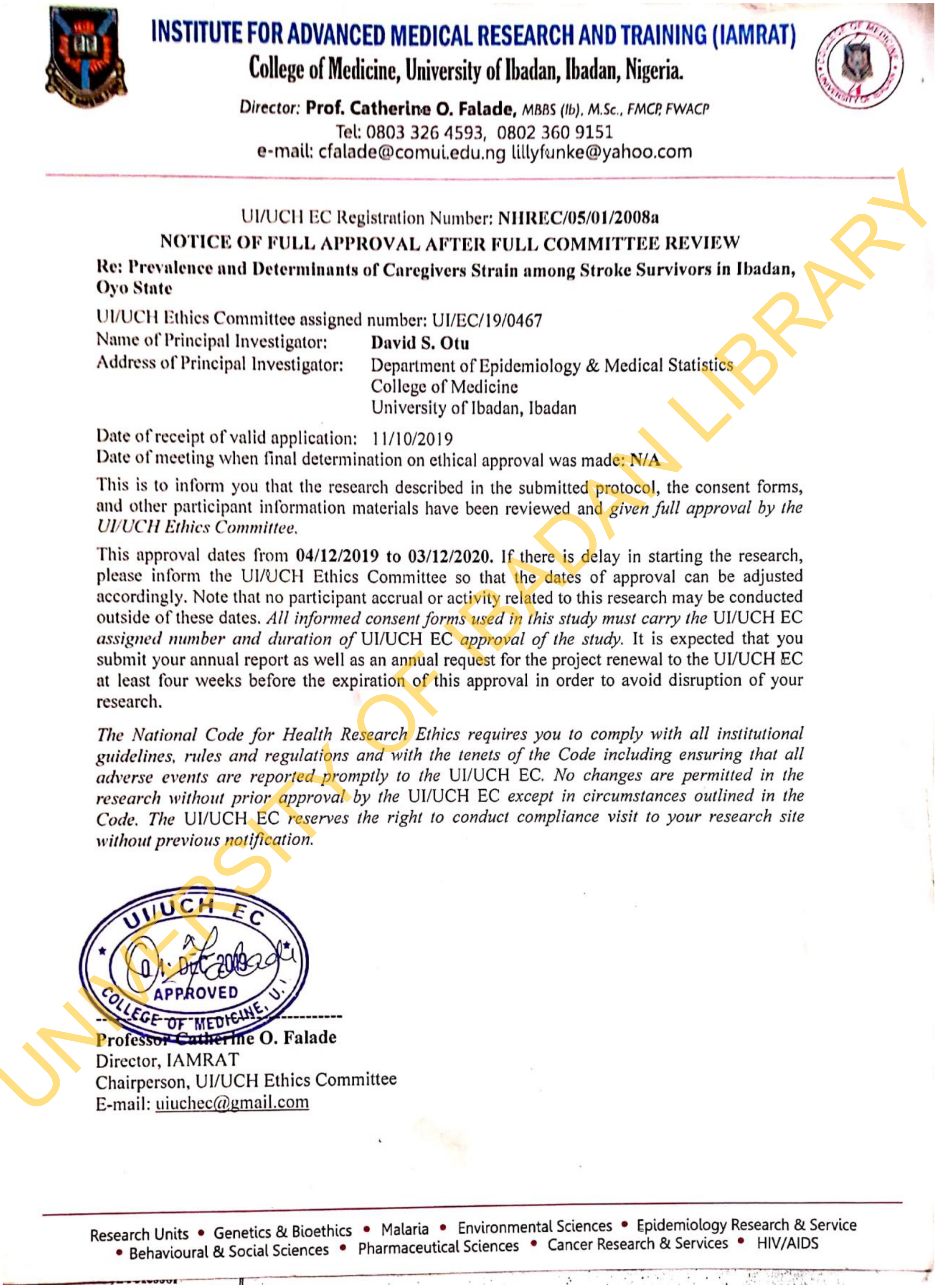
2. The committee has noted your compliance. In the light of this, I am pleased to convey to you the full approval by the committee for the implementation of the Research Proposal in Oyo State, Nigeria.

3. Please note that the National Code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations, in line with this, the Committee will monitor closely and follow up the implementation of the research study. However, the Ministry of Health would like to have a copy of the results and conclusions of findings as this will help in policy making in the health sector.

4. Wishing you all the best.

Dr. Abbas Gbolahan
Director, Planning, Research & Statistics
Secretary, Oyo State, Research Ethics Review Committee

UI / UCH ETHICAL APPROVAL



INSTITUTE FOR ADVANCED MEDICAL RESEARCH AND TRAINING (IAMRAT)
College of Medicine, University of Ibadan, Ibadan, Nigeria.
Director: **Prof. Catherine O. Falade,** *MBBS (Ib), M.Sc., FMCP, FWACP*
Tel: 0803 326 4593, 0802 360 9151
e-mail: cfalade@comui.edu.ng lillyfunke@yahoo.com

UI/UCH EC Registration Number: **NHREC/05/01/2008a**

NOTICE OF FULL APPROVAL AFTER FULL COMMITTEE REVIEW

Re: Prevalence and Determinants of Caregivers Strain among Stroke Survivors in Ibadan, Oyo State

UI/UCH Ethics Committee assigned number: UI/EC/19/0467
Name of Principal Investigator: **David S. Otu**
Address of Principal Investigator: Department of Epidemiology & Medical Statistics
College of Medicine
University of Ibadan, Ibadan

Date of receipt of valid application: 11/10/2019
Date of meeting when final determination on ethical approval was made: N/A

This is to inform you that the research described in the submitted protocol, the consent forms, and other participant information materials have been reviewed and *given full approval by the UI/UCH Ethics Committee.*

This approval dates from **04/12/2019 to 03/12/2020.** If there is delay in starting the research, please inform the UI/UCH Ethics Committee so that the dates of approval can be adjusted accordingly. Note that no participant accrual or activity related to this research may be conducted outside of these dates. *All informed consent forms used in this study must carry the* UI/UCH EC *assigned number and duration of* UI/UCH EC *approval of the study.* It is expected that you submit your annual report as well as an annual request for the project renewal to the UI/UCH EC at least four weeks before the expiration of this approval in order to avoid disruption of your research.

The National Code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations and with the tenets of the Code including ensuring that all adverse events are reported promptly to the UI/UCH EC. *No changes are permitted in the research without prior approval by the* UI/UCH EC *except in circumstances outlined in the Code. The* UI/UCH EC *reserves the right to conduct compliance visit to your research site without previous notification.*

UI/UCH EC
01 DEC 2019
APPROVED
COLLEGE OF MEDICINE, U.I.

Professor Catherine O. Falade
Director, IAMRAT
Chairperson, UI/UCH Ethics Committee
E-mail: uiuchec@gmail.com

Research Units • Genetics & Bioethics • Malaria • Environmental Sciences • Epidemiology Research & Service • Behavioural & Social Sciences • Pharmaceutical Sciences • Cancer Research & Services • HIV/AIDS