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Intermediate Care and Its Impact on The Functional Health and Quality of Life of Older Adult Stroke Survivors in Southwest Nigeria

Temitope Hannah Farombi

A thesis submitted to the University of West London in partial fulfilment of the requirements for
the degree of Doctor of Philosophy in Global Health

Public Health Group
College of Nursing, Midwifery and Healthcare

22nd June 2024.

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Signature

Date: 22nd June 2024

Dedication

This thesis is dedicated to God Almighty, the author and the finisher of my faith.

My husband Olatunde Farombi and my two beautiful daughters Victoria Farombi and Sophia Farombi through their sacrifices made learning and rediscovery possible.

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The completion of this thesis represents a significant milestone in my academic journey, and it would not have been possible without the support and guidance of many individuals. I would like to take this opportunity to express my deepest gratitude to all those who have contributed to the success of this study.

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Abstract

Background: Stroke is the leading cause of functional disabilities and the second cause of disease morbidity and mortality globally. With the increasing population ageing, there is a rise in the prevalence of stroke across the world.

Objectives: This study aimed to investigate the impact of the intermediate care model on the functional health and quality of life of older adult stroke survivors in southwest Nigeria

Methods: A systematic review and mixed method (qualitative and quantitative) were to answer research questions. The systematic review followed (Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline. Eighteen (18) Informal caregivers of stroke survivors participated in focus group discussions, 8 formal care providers and 8 community gatekeepers participated in key informant interviews. Data was analyzed thematically using NVivo version 12 pro. Older adult stroke survivors and family caregivers (n=58) were recruited at the study's final phase. The intervention included caregiver training provided at discharge and telephone follow-up for eight weeks. Pre- and post-tests were carried out before the intervention and at the eighth week respectively. Data was obtained on stroke survivors' functional health and quality of life.

Findings: Systematic review revealed that home-based care options include physical therapy, occupational therapy, speech therapy, and meaningful task-specific for training patients. Findings from this qualitative study identified four major themes; experiences in stroke management; community gatekeepers' perceived social and welfare support needed for older adult stroke patients; strategies that promote interpersonal relationships between formal and informal care providers on home-based care treatment; identification of home-based care needs of older adult stroke patients. There were significant

improvements in the Stroke Specific Quality of Life ($p<0.001$) and functional outcome ($p<0.001$) across all domains in the post-intervention phase.

Conclusion: This study highlights the need for effective intervention for improving the functional health and quality of life of older adult stroke survivors. Overall, study findings reflect that the delivery of home-based intermediate care model through combining caregivers' training and telephone follow-up could be effective for continuous stroke care in Nigeria.

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LIST OF ABBREVIATIONS

ADL- Activities of Daily Living

AOU- Amount of Use

ARAT- Action Research Arm Test

ARIC- Atherosclerosis Risk In Communities

BI- Barthel Index

BHIN- Brain Health Initiative Nigeria

BP- Blood Pressure

CHW- Community Health Workers

CI- Confidence Interval

COPE- Care of Person with dementia in their Environment

CVA- Cerebro-Vascular Accident

CVD- Cardiovascular diseases

DALY- Disability-adjusted Life Years

DG- Domiciliary Group

FGD- Focus Group Discussions

FMA- Fugl-Meyer Assessment

FMA-UE- Fugl-Meyer Assessment of upper extremity

GSES- General Self-Efficacy Scale

GWMFT- Graded Wolf Motor Function Test

HBIC- Home-Based Intermediate Care

HCBC- Home and Community-Based Care

HCISM- Hospital Community-Integrated Services Model

HRQOL – Health-Related Quality of Life

JBH - Johanna Briggs Institute

KII- Key Informant Interview

LMIC- Low- and Middle- Income Countries

LTC- Long Term Care

MAL- Motor Activity Log

MAL-AOU- Motor Activity Log-Amount of Use

MBI- Modified Barthel Index

MMAS- Modified Motor Assessment Scale

MoCA- Montreal Cognitive Assessment

MRS- Modified Ranking Scale

MRT- Modified Reminiscence Therapy

MTST- Meaningful Task-Specific Training

NHIS- National Health Insurance scheme

PAC- Post-acute Care

PHCG- Primary Health Center Group

PHQ-9- Patient Health Questionnaire

PICO- Participants, Interventions, Comparators and Outcomes

PRISMA- Preferred Reporting Items for Systematic Review and Meta-Analysis

QoL- Quality of Life

QOM- Quality of Movement

SAS- Self-Rating Anxiety Scale

SDS- Self-Rating Depression Scale

SF-PASS- Short Form-Postural Assessment for Stroke

SS-QOL- Stroke Specific Quality of Life

SSA- Sub-Saharan Africa

SWLS- Satisfaction with Life Scale

TIA- Transient Ischemic Attack

UCH- University College Hospital

UI- University of Ibadan

WHO- World Health Organization

CHAPTER 1

Introduction

1.1 Background to the study

Stroke predominantly affects older adults and plays a significant role in determining its impact. Approximately 75 percent of all strokes are a condition that primarily affects older adult persons (Anatskaia, 2011). Transient ischemic attack (ITIA), hemorrhagic stroke, and Ischemic stroke are a few types of strokes that can affect older adults. Stroke remains the second leading cause of death globally, and its prevalence is expected to increase due to the aging population globally (Katan and Luft, 2018). Age is primarily a non-modifiable risk factor for stroke, and as life expectancy increases, a majority of stroke patients are projected to be older adults and very older adults (Gur et al., 2012). Efforts to raise stroke awareness, prevention, early treatment and rehabilitation in the last three decades have yielded significant improvement and reduced disability-adjusted life year (DALY) of older adult stroke patients in developed countries (Katan and Luft, 2018).

Stroke is the leading cause of functional disabilities and the second cause of disease morbidity and mortality globally (Feigin et al., 2020). Low- and middle-income countries (LMIC) bear a significant burden of stroke-related deaths, with over 85% of recorded mortalities and more than half of survivors experiencing permanent functional disabilities (Katan and Luft, 2018). The epidemiological transition in the aging population and emergence of non-communicable diseases led by cardiovascular disease (CVD) in sub-Saharan Africa (SSA) and Nigeria further worsened the burden of disease in this region that is still being ravaged by the scourge of infectious diseases such as HIV/AIDS, Malaria

and Tuberculosis (Mudie et al., 2019). Advanced age is a significant risk factor for stroke, leading to higher mortality rates, worse functional outcomes, and reduced ability-adjusted life years (Katan and Luft, 2018).

Intermediate care is defined as a healthcare approach aimed at facilitating the transition from illness to recovery, preventing chronic impairment from escalating into dependence on institutional care, and providing comfort to terminally ill patients toward the end of their lives (Young et al., 2015). The services link the hospital and the social care system where patients typically live. Intermediate care is frequently used to enhance stroke rehabilitation in discharged patients (Prvu Bettger et al., 2012). It plays a crucial role in minimizing frailty and functional decline, particularly in older adults, by providing comprehensive geriatric assessment, enablement, and targeted rehabilitation to maximize independence and recovery. Intermediate care is crucial in minimizing the beginning and progression of frailty and functional decline in individuals, particularly older persons, as they provide full geriatric assessment, enablement, and rehabilitation targeted at maximizing independence and recovery (Loeffler, 2016; Lowthian, 2016; Peel et al., 2013). Prior intermediate care approaches provided stroke patients with health education, emotional support, physical therapy, and medication reconciliation through telephone follow-ups and home visits. However, there is limited knowledge about the impact of intermediate care on the functional outcome, especially in older adult stroke patients (Sezgin et al., 2020).

Projections indicate that by 2023, the global percentage of people aged 60 years and older will rise approximately to 16.67%, by 2030, with this figure expected to double by 2050 (Rudnicka *et al.*, 2020). Between 2015 and 2050 the proportion of people in the aged group will increase from 12% to 22%. (Rudnicka *et al.*, 2020; Tan, 2022). Signaling a significant change. While population ageing is a global phenomenon, it is particularly pronounced in low- and middle-income countries (LMICs), experiencing both rapid population growth and significant changes in age structure. By 2050, it is projected that two-thirds of persons aged 60 years and above will reside in LMICs (Phillips and Gyasi, 2020). This demographic transition presents profound implications for health systems and social services, particularly in LMICs, where resources are often limited. Ageing populations are more susceptible to chronic diseases, including neurological disorders like dementia, stroke and Parkinson's disease, placing significant strain on healthcare infrastructure (Gu, Andreev and Dupre, 2021). As a result of the growing older adult population, long-term care services for frail older adults are becoming increasingly necessary. Costs and consumer preferences have caused an age-related movement away from long-term institutional care toward home and community-based care (Ruggiano and Edvardsson, 2013) and this trend is expected to continue. Home and community care services, also known as domiciliary, non-medical home care, or social care, are designed to assist seniors in maintaining or enhancing their quality of life while still living independently in their homes for as long as possible. Several services, including home care, housekeeping, home maintenance, shopping, transportation, daycare, outings with friends, home visits, and allied health, could contribute to the achievement of this objective.

The implementation and utilization of intermediate care models in the current healthcare policy environment have gained support from many stakeholders. However, the broad acceptance of this concept lacks full substantiation from available data. Therefore, it is necessary to evaluate intermediate care due to the unclear understanding of its advantages and drawbacks (Black, 2002; Hamerman, 1999).

1.2 Statement of the Problem

With increasing population ageing comes a rise in the prevalence of stroke (Sharrief and Grotta, 2019). The Global Burden of the Disease Study 2021 forecasted an improvement in life expectancy and age-standardised disease between 2022 and 2050 with the majority of the burden continuing to shift from communicable, maternal, neonatal and nutritional diseases (CMNN) to non-communicable diseases (NCDs) from 60.1% (56.6-63.1) due to CMNNs in 2022 to 35.8% (31.0-45.0) in 2050 as a result of the ageing population (GBD 2019 Stroke Collaborators, 2021a). This shift is forecasted to be pronounced in Sub-Saharan Africa and by extension Nigeria. The implication for this is increased mortality and Disability-Adjusted Life year (DALY) due to ischaemic heart diseases, stroke, diabetes and chronic obstructive pulmonary disease. Stroke remains the second leading cause of death and the third leading cause of death and disability combined globally (GBD 2019 Stroke Collaborators, 2021a). However, stroke-related mortality and DALY are 3.6 and 7.7 times higher in low-income countries compared to high-income countries. Stroke and stroke-related disability accounted for 70% and 80% of all mortality in low-income and middle-income countries (LMICs) between 1970 and

2020 (Akinyemi *et al.*, 2021). This current increase in DALY is attributable to high BMI (88.2%(53.4-117.7)), high ambient temperature (72.4%(51.1 to 179.5)), high fasting plasma glucose (32.1%(26.7-38-1)), a diet high in sugar-sweetened beverages(23.4%(12.7-35.7)), low physical activity(11.3% (1.8-34.9)), high systolic blood pressure (6.7%(2.5-11.6)), lead exposure(6.5%(4.5-11.2)), and diet low in omega-6 polyunsaturated fatty acids (5.3%(0.5-10.5)) (Feigin *et al.*, 2024) shift from what was previously reported in the GBD study 2019 of unhealthy behaviours and metabolic hazards to the increasing role of environmental factors on the heightened burden of stroke. The economic impact of stroke and stroke care is far-reaching. In 2019, the estimated value of lost welfare from stroke was \$2059.67 billion (1.66% of global GDP) (Gerstl *et al.*, 2023)

In stroke patients, age is frequently significantly connected with decreased functional gains and poor rehabilitation results (Lui and Nguyen, 2018a). When recovering from a stroke after leaving the hospital, stroke survivors must deal with a long-term medical condition with permanent functional deficits, multiple new medications, rehabilitation goals, and different diets. Two critical problems with hospital-to-home care for stroke patients are fragmented care and insufficient patient-healthcare professional communication (Geng *et al.*, 2019).

According to Murray and Lopez (1997), stroke is the main reason for adult impairment (Murray and Lopez, 1997). Up to 50% of stroke victims never regain their independence and need ongoing medical attention (Sturm *et al.*, 2004). In a study examining eight

wealthy countries, stroke care costs 0.27 per cent of the gross domestic product or approximately 3% of all healthcare spending (Evers et al., 2004).

Stroke can strike anyone at any age, but as people age, it happens more frequently and is more prevalent (Goldstein et al., 2006). The most critical and unalterable risk factor for all types of strokes, including ischemic stroke, is age (Rothwell et al., 2005). The stroke rate doubles for both men and women after the age of 55 for each subsequent decade (Rojas et al., 2007). According to reports, people over 65 years old account for 75-89% of stroke cases (Feigin et al., 2003; Writing Group Members et al., 2008). Of these strokes, 50% happen in adults under the age of 70, while over 25% happen in people beyond the age of 85.

There are still significant gaps in post-acute care, which makes it difficult to get older adult stroke patients and their carers ready for recovery and secondary risk factor management (Adeoye et al., 2019; Broderick and Abir, 2015). Care and knowledge gaps are a factor in unsuccessful outcomes. After being discharged from the hospital, 25% of stroke patients return within 90 days (Prvu Bettger et al., 2015) over 25% stop taking their medication (Bushnell et al., 2009), over 50% do not have control over their blood pressure (BP), patients are sedentary for more than 78% of the time (Fini et al., 2017), and 73% fall asleep during the day (Forster and Young, 1995). Therefore, the prevalence of stroke-related impairment is rising and worsening over the post-acute healing period, and the incidence of recurrent stroke stays high (Benjamin et al., 2018; Dhamoon et al., 2017; Ovbiagele et al., 2013). After a brief hospital stay, more than 50% of stroke patients are

sent home without fully understanding the lingering deficiencies that may affect their capacity to manage subsequent prevention or recovery (Adeoye et al., 2019; Prvu Bettger et al., 2015). In Nigeria, post-stroke case fatality at 30 days ranges between 28 to 40% and more than 60% at 12 months (Wahab, 2008a). Also, 60% of post-stroke patients were functionally dependent at discharge (Oyewole et al., 2016). These rates are believed to be higher among older adults in Nigeria due to underlying clinical multimorbidity, frailty, low immunity, and poor care management. Nigeria is experiencing a rising incidence of stroke (Owolabi et al., 2015), and older adults are expected to be worst hit due to background multimorbidity, poorer functional outcomes, and overwhelming emotional and financial burdens on the family and society. The existing rehabilitation services are medical rehabilitation and are grossly underdeveloped, limited to acute care, and not comprehensive. The availability of trained professionals is also grossly insufficient.

1.3 Justification for the study

The primary function of intermediate care is to bridge acute, primary, and social care, particularly for older adult patients with chronic conditions, such as stroke (Plochg et al., 2005). These transitional care programmes are designed to reduce hospital stays and improve continuity of care. Even while many models assume positive results, it is frequently unclear what the benefits are or whether they can be used in other situations. This is because different collaborating partners created different intermediate care models, which are heterogeneous (Plochg et al., 2005).

It is questionable whether stroke survivors can receive the most excellent care in an outpatient setting. They frequently have weak health and require enough time to

recuperate (Hammerman, 1999). Early hospital release can put them in danger, which can have an impact on patients with complex care requirements, such as older adults and chronically ill.

Numerous care models have been created with these challenges in mind to replace hospital inpatient care and to enhance transitional care (Mulley, 2001). The phrase "intermediate care" can be used to describe one model. This idea refers to services that connect acute, primary, and social care. It is believed to contribute to achieving goals like reducing hospital stays, stopping hospital admissions and readmissions, improving transitions from the hospital to post-acute care settings, and maintaining patients' independence for as long as is practical (Steiner, 2001). However, the advantages and mobility of intermediate care could be clearer (Carpenter, 2002; Melis et al., 2004; Pencheon, 2002; Steiner, 2001b). This can be attributable to the concept's ambiguous definition and the extensive range of services that are designated as such. Focus, setting, case mix, staffing, experts participating, commissioning, and context are all different between models.

Consequently, defining the notion, establishing best practices, and comparing various contexts takes time and effort. In light of this, it is stated that the "black box" of intermediate care, or the caregiving procedures, should be unlocked. Evaluations of the process are consequently necessary and encouraged (Clendon, 2003; Pearson, 2003). Increasing life expectancy, changing demographics, cardiovascular risks, and events inform the need to consider care for older people, especially those with functional

disabilities. However, in Nigeria, there is a lack of data that supports the management and outcome of stroke among older adults (Wahab, 2008a). A significant number of studies have reported that the mean age of stroke patients in Nigeria is at least 10 years younger than that of those in developed countries (Adeloye et al., 2019; Akinyemi et al., 2021a). This age disparity may be largely attributable to demographic differences between regions. Like many other low- and middle-income countries, Nigeria has a predominantly young population, whereas developed nations typically have a higher proportion of older adults (Osareme et al., 2024). This younger demographic in Nigeria means that stroke, which is generally associated with ageing populations, is affecting younger individuals in this context. The higher incidence of stroke at a younger age could be influenced by various factors such as lifestyle, socioeconomic conditions, and healthcare access, alongside the demographic structure itself (Adeloye et al., 2019). Thus, issues associated with disabilities and functional independence in older people are not at the forefront of health policies, planning, and implementation (Bello et al., 2021; Katan and Luft, 2018). Nigeria's health service delivery organisational structure is divided into three tiers: primary, secondary, and tertiary care, which align with the country's federal structure. Each level of government is responsible for different aspects of healthcare delivery (Kuye and Akinwale, 2021). This tiered structure does not adhere to a specific international healthcare model but reflects the decentralisation of healthcare responsibilities. However, gaps in service integration between these levels create a demand for intermediate care models. Intermediate care, positioned between acute care and home/community care, could address some of the challenges in transitioning stroke patients from hospitals to home-based rehabilitation. This model could particularly benefit

stroke survivors by filling the care gap between discharge from tertiary care and re-entry into everyday life, thereby improving long-term outcomes.

In summary, Nigeria's health service delivery structure presents an opportunity for integrating intermediate care models, which could bridge the current disconnect between secondary/tertiary care and community-based support. These models are critical for improving functional health and quality of life, particularly for vulnerable populations like stroke survivors. It is, therefore, imperative to explore relevant literature to identify knowledge gaps that will inform the formulation of research questions and relevant interventions with appropriate methodological approaches to develop a culturally adaptable care model for older adult stroke survivors, keeping in view the limitations that abound in Nigeria.

1.4 Research Questions

The overall research question of the thesis is as

'What is the impact of the intermediate care model on the functional health and quality of life of older adult (60 years and above) stroke survivors in southwest Nigeria?

The following specific research questions will be answered through this study.

1. What are the key findings in the existing literature regarding the effectiveness of the intermediate care model in promoting functional health outcomes for older adults with stroke?

2. What are the perspectives of healthcare providers, caregivers, patients, and community leaders regarding the need for intermediate care for older adults recovering from stroke?
3. What culturally tailored interventions are currently available in Nigeria to support the recovery of older adults affected by stroke?
4. Can the home-based intermediate care model effectively enhance functional health and improve the quality of life among older stroke survivors?

1.5 Specific Objectives

1. Conduct a comprehensive review of the existing literature on the intermediate care model and its impact on the functional health of older adult individual with stroke.
2. Investigate the perspectives of various stakeholders (including healthcare providers, family caregivers, patients, and community leaders) regarding the implementation of intermediate care model for older adult individuals recovering from stroke.
3. Develop an intermediate care model tailored to support the recovery of older adult individual affected by stroke in the community, based on insight obtained from stakeholders.
4. Assess the effectiveness of the intermediate care support provided in improving the functional outcomes of older adult individuals recovering from stroke.

1.6 Outline of the thesis

Chapter one of this thesis will discuss the background, statement of the problem, justification, research questions and objectives. Chapter two will be used to explore the

conceptual, empirical, and theoretical review of the study. In chapter three, the detailed methodology which includes study area, sampling technique, methods of data collection, instruments and data analysis will be discussed. Chapter four will present the results of the study based on the secondary analysis of data collected in literature while chapter five will present the results of qualitative analysis and thematic narration of perceptions of stakeholders in stroke care at the hospital in the community. Other chapters present the quantitative phase of the study and discussion of findings by triangulating the study findings with previous studies. Chapter eight reads the conclusion and recommendation.

CHAPTER 2

LITERATURE REVIEW

This chapter aims to detail the concept and ideas related to the intermediate care model and stroke care, establish the theoretical basis for the research and identify research gaps. The chapter presents information on recent evidence of stroke epidemiology and burden, functional health and quality of life, complications that arise after stroke, intermediate care models, and the role of a multi-disciplinary team and informal caregivers in providing intermediate care. The conceptual framework of this study is also outlined in this chapter.

2.1 CONCEPTUAL REVIEW

2.1.1 Stroke Epidemiology

The annual estimated rise in stroke prevalence in low-income nations is 14.3%. Lower-middle-income countries saw the least increase, at 6% yearly. There is a 62% (95% CI 6% to 147%), increase in the prevalence of stroke survivors for every ten years increase in the mean age of the participants (Ezejimofor et al., 2016). The stroke burden increased significantly from 1990 to 2019. Globally, there is a 70.0% increase in incident strokes, 43.0% stroke mortality, 102% prevalence, and 143.0% DALYs, with LMICs estimates amounting to 86.0% of deaths and 89.0% of DALYs of the global burden (Feigin et al., 2022). The lifetime risk of stroke has also increased over the last 20 years by 50% and is now one in four people (Feigin et al., 2022). Despite the infectious disease scourge, LMICs account for at least seven times the DALYs lost due to stroke in high-income

countries (Feigin et al., 2014). Many studies have demonstrated racial disparities in the incidence of stroke; however, these differences change by racial group and by age (Mozaffarian et al., 2016). Although the incidence rate ratio between the two groups decreases as people get older, the risk of stroke is higher for African Americans than for Whites (Howard et al., 2011). Atherosclerosis Risk in Communities (ARIC) data show that the incidence rates of stroke and transient ischemic attack (TIA) were 2.4 for white men aged 45 to 54, 6.1 for white men aged 55 to 64, and 12.2 for white men aged 65 to 74 (1987–2001). The rates for white women in the same age groups were 2, 4, and 9, respectively. The rates for African American men in the same age categories were 9.7, 13.1, and 16.2, while for African American women, they were 7.2, 10.0, and 15.0 (Writing Group Members et al., 2012). There is no question that older people have higher overall incidence rates, but little is known about the racial and sexual demographics of older groups. According to the Bradford Stroke study in the UK, age adjusted-standardized rate to the World Health Organization world population of first-ever-stroke among the Pakistani and Whites is 155 and 101 per 100,000 person-years respectively (Ramadan et al., 2018). Stroke is the primary cause of impairment and is ranked as the second most prevalent cause of death worldwide, after ischaemic heart disease (Feigin et al., 2022).

In Nigeria, the burden of stroke is increasing, as with many other LMIC, where stroke incidence is estimated to increase to 80% of the global stroke burden by 2030 (Katan and Luft, 2018). The crude incidence of Stroke in Nigeria is 27.4 per 100,000 in a year, and that of stroke survivors is 7.5 /1000 (95%CI; 5.8-9.1). The pooled crude prevalence of stroke survivors in Nigeria was 6.7 (5.8–7.7) /1000 population. Males have a higher

prevalence of 6.4/1000 compared to females with 4.4/1000 (Adeloye et al., 2019), which is predicted to worsen as the population ages. Two previous studies conducted in southern Nigeria reported age-adjusted prevalence rates of 1,230 per 100,000 and 1,460 per 100,000 (Ezejimofor et al., 2016; Onwuchekwa et al., 2014). Another study conducted in Northwestern Nigeria reported that 30-day mortality was 37%, with the majority being hemorrhagic stroke patients (69.6%). Additionally, a high proportion (74.5%) of the mortalities occurred within one week from the stroke onset (Femi and Mansur, 2013). Older people are at higher risk of stroke, and they are more likely to die from stroke complications, have poorer functional outcomes, stay longer in the hospital, and end up in long-term care facilities (Lui and Nguyen, 2018b). Of note, research shows that there has been a consistent decline in mortality and disabilities associated with stroke incidences in developed countries despite the ageing populations (Mira Katan and Luft, 2018).

2.1.2 Stroke burden in the older adult

The global burden of stroke continues to be extremely large (Thayabaranathan et al., 2022). Seventy per cent of strokes, along with 87% of stroke-related fatalities and disability-adjusted life years, occur in LMICs, despite statistics showing that age-standardized stroke incidence and mortality are significantly reducing in high-income nations. Individuals in these areas typically encounter stroke-related mortality at a younger age, and a larger percentage of strokes are hemorrhagic (Johnson et al., 2016). The decline experienced in developed countries is due to improved risk factor management and stroke prevention strategies. Their acute stroke care and rehabilitation services have improved the functional outcomes for stroke patients. Although ischemic

strokes are the most common, the global burden of stroke, measured by mortality and DALYs, is predominantly due to hemorrhagic strokes who suffered a stroke (Feigin et al., 2017). Socioeconomic status significantly impacts stroke burden, with higher disability rates observed in patients with lower education and income levels (Bettger et al., 2014). In Nigeria, the average time from stroke onset to presentation at the hospital ranges between 1 to 90 days (Ekeh, 2014; Ogbole et al., 2016), resulting in difficulty in carrying out vascular thrombolysis that will invariably reduce functional dependency. Stroke survivors may experience disabilities that necessitate temporary or lifelong assistance, imposing substantial human and economic burdens (Avan et al., 2019). Lack of access to standardized healthcare delivery, poor healthcare infrastructure, lack of expertise in stroke care and rehabilitation, and poor funding are among many other factors responsible for poorer health outcomes for older patients with Stroke (Wahab, 2008b). The limited availability of hospital beds, the lack of integrated acute and post-acute care settings, and out-of-pocket expenditures imply that patients must be discharged from hospitals and sent to their homes to fend for themselves. As high as 90% of patients are discharged home with varying functional disabilities and no intermediate care plan (Wasserman et al., 2009), leading to an increase in morbidity and mortality among older adults. There is a lack of stroke epidemiological data and integrated rehabilitation care research in the community. Most studies are hospital-based and are self-funded by individual researchers. Knowledge of stroke prevalence, incidence, and risk factors is essential to achieve adequate resource distribution for stroke care LMICs (Lanas & Seron, 2021). However, the lack of accurate data on stroke burden at the community level

has made adequate intervention for efficient and effective stroke care, rehabilitation, and reintegration difficult

2.1.3 Functional Health and Quality of life after stroke

Functional health is defined as the ability to perform daily activities necessary to meet basic needs, fulfil typical roles, and maintain overall health and well-being (Skube et al., 2018), and this is inversely proportional to health outcomes and Quality of life. Approximately 90% of stroke survivors have compromised functions (Arene and Hidler, 2009). Improving patients' ability to perform activities of daily living (ADL) and aiding older adult stroke patients in returning home are significant issues facing rehabilitation medicine practitioners (Mutai et al., 2018). A study conducted by Kong and Lee suggested that most recovery of activities of daily living occurs three months after stroke onset (Kong & Lee, 2014). Advancing age is a major risk factor for stroke incidence, as more than fifty per cent of all stroke incidences occur at ages 75 years and above, and it is the primary cause of disability, functional dependence, and poor Quality of life in older adults (Engstad et al., 2012). These factors significantly affect the functional health and quality of life of stroke survivors and their caregivers. Several studies have reported that older adult stroke patients have significant impairment of function, poor Quality of life and functional dependence than younger patients (Duangjit et al., 2014; Kuptniratsaikul et al., 2016). A 1- year follow-up study in older adult stroke survivors reported dependence on basic activities daily, more use of assistive devices, and lower health-related quality of life in patients with moderate to severe stroke severity. Gender differences were significant as more females were affected than their male counterparts (Gosman-Hedström et al.,

2008). However, more men were reported to die within 12 months of stroke compared to women.

Similarly, it has been reported that the female gender is an independent predictor of functional dependency post-stroke in Nigeria (Ojagbemi and Owolabi, 2013). In a Nigerian study, stroke survivors experienced significant improvements in functional outcomes from the acute stroke phase up to six months and beyond six months (Hamza et al., 2014). Quality of life assessment is frequently included in the comprehensive evaluation of stroke's impact (Opara and Jaracz, 2010). QoL comprised an internal dimension revealing how patients' feel good about her/himself and an external dimension revealing patients' feel good about others (Post, 2014). Identifying factors that decrease quality after stroke can help manage risk factors in this domain, and it is essential to reduce the burden of stroke (Kwakkel and Kollen, 2013). Family, community, and social reintegration, and maintaining recovery are paramount for achieving good QoL (Haley et al., 2011). Badaru and colleagues also reported that stroke severity, disability and depression are the critical predictors of Quality of life among Nigerian stroke survivors (Badaru et al., 2015).

2.1.4 Complications that Arise After a Stroke

Following a stroke, several problems arise that lower the Quality of life for stroke victims. Although people frequently experience anxiety, pain, sexual dysfunction, and other problems, depression and cognitive impairment are the most common stroke-related concerns (Flaster et al., 2013; Hackett et al., 2014; Rosenbaum et al., 2014). Many of these illnesses are incorrectly identified and treated after a stroke (Moran et al., 2014).

Increased detection and treatment of these disorders may lead to better outcomes and Quality of life for stroke victims. Thirty percent of stroke survivors report suffering depression three months following a stroke (Hackett et al., 2014; Hackett & Pickles, 2014). Depression is associated with a greater mortality rate from stroke, a stroke recovery time that is insufficient, and cognitive damage (Naess et al., 2010; Ayerbe et al., 2013). Treatment for depression following a stroke may produce better outcomes (Chollet et al., 2011; Mead et al., 2012). Age above 75, the presence of vascular risk factors, cognitive decline, and decreased ability to conduct everyday activities all serve as predictors of depression (Allan et al., 2013).

Depression should be checked for in every stroke patient, and therapy should be initiated as needed. The patient health questionnaire (PHQ-9) is a rapid screening tool for stroke patients that can be used in inpatient or outpatient settings (Turner et al., 2012). Drug interactions, adverse effects, and pharmaceutical pharmacokinetics should all be considered when beginning antidepressant therapy in older patients, with a focus on minimizing medications with anticholinergic properties (Alamo et al., 2014). A worse quality of life, a loss of independence, an increased chance of disability, depression, and mortality are all associated with poststroke cognitive impairment (Crichton et al., 2016; Lo Coco et al., 2016). Despite the severe implications that cognitive impairment can have on stroke survivors, there are no guidelines for routinely screening for it. There are various screening methods. However, a recent systematic evaluation of psychometric instruments revealed that the Montreal Cognitive Assessment (MoCA) is the most

valuable and trustworthy screening test for poststroke cognitive impairment (Burton and Tyson, 2015).

Due to the inadequate resources available to the health system in Nigeria, it is expected that older adult stroke survivors are likely to have worse functional health outcomes and a lower quality of life. Stroke severity, depression, motor impairment, educational attainment, and social status are the variables that affect stroke survivors' quality of life in Nigeria (Ojagbemi and Owolabi, 2013). There are enough reasons to expect a higher burden in Nigeria because of health literacy, linked to quality of life (Cevik and Kayabek, 2022) and a higher rate of cardiovascular events (Yusuf et al., 2014). The state of health services and lower utilization of those services, which is lower in old age, also add to the functional health burden among older adults (Prince et al, 2015). In Nigeria specifically, no integrated care model addresses post-acute stroke management in the community. Patients are often discharged to go home for continuous care by family carers who have little or no knowledge of post-acute care management, risk assessment, care needs, and support the patients require, hence the recorded high incidence of post-stroke mortality. The ability to sustain skills to live independently requires both physical and cognitive function. Studies have clearly shown the link between cognition and functional dependence (Egüez-Guevara and Andrade, 2015; Galanth et al., 2014). A combination of both worsens the risk of functional disabilities and increases both patient's and caregivers' burden and health-related Quality of life. Ischemic stroke is most typical among older adults, and 25 -30% of survivors develop cognitive impairment (Lo Coco et al., 2016). Kuo et al. (2019), in a study of cognitive impairment and post-stroke health-

related Quality of life (HRQOL), reported worsening functional outcomes in older adults with cognitive impairment following stroke. They are 5.6 times more likely to have mobility problems and 12.20 times more likely to have self-care problems than stroke survivors without cognitive impairment.

Similarly, a study in Ghana reported increasing age for successive 10-year rise (odds ratio (OR)1.44, 95% CI:1.01-27.52) and lack of education. It worsened functional disability on a modified Rankin scale (OR 2.46,95% CI:1.61-3.75) as a significant risk of developing vascular cognitive impairment and poor HRQL (Sarfo et al., 2018). This implies that strategies and prompt intervention are needed in stroke care to address the Quality of life of older adult stroke survivors.

2.1.5 Intermediate care models

Sharieff and Grotta (2019) define intermediate care as an approach to health care that helps patients transition from illness to recovery, prevents them from moving from home-managed chronic impairment to institution-based dependence, or makes terminally ill patients as comfortable as possible at the end of their lives. A set of interventions designed to facilitate the transition from the hospital to home and from medical dependence to functional independence may also be referred to as intermediate care if the patient's discharge location is anticipated and a clinical outcome of recovery (or restoration of health) is desired. It has regularly been used to improve stroke rehabilitation in patients released from the hospital (Puhr & Thompson, 2015; Pruv Bettger et al., 2012). Intermediate care is crucial in minimizing the beginning and progression of frailty and functional decline in individuals, particularly older persons, as it provides full geriatric

assessment, enablement, and rehabilitation to maximize independence and recovery (Peel et al., 2013; Loeffler, 2016).

Previous intermediate care approaches provided stroke patients with health education, emotional support, physical therapy, and medication reconciliation through telephone follow-ups and home visits (Geng et al., 2019; Fortster et al., 2013). Despite the recent increase in the use of intermediate care as a transitional period between types of care, little is known about how it affects function-related outcomes, especially in older stroke patients (Sezgin et al., 2020). Following a stroke, there are numerous options for rehabilitation therapies and discharge disposition. Patients who require or can endure at least three hours of rigorous therapy five days a week and are projected to experience significant short-term functional improvements may get treatment in inpatient rehabilitation units or facilities (Miller et al., 2010). Inpatient rehabilitation services are offered by skilled care facilities for patients who are unable to commit to three hours of therapy every day. With or without physical, occupational, or speech therapy at home or in an outpatient facility, patients with a reduced disability may be discharged from the acute care setting.

The type of rehabilitation care patients receive after leaving the hospital and how they are discharged are both influenced by their age (Everink et al., 2016). Determining the optimum discharge strategy for older adult stroke patients requires a multidisciplinary approach to facilitate the optimal recovery from Stroke (Miller et al., 2010). Older people are more likely to be transferred from their homes to post-acute care facilities after having

a stroke (Prvu Bettger et al., 2015). Additionally, older patients are more likely to be discharged to a skilled nursing facility rather than a center that offers intensive acute rehabilitation (Stein et al., 2015). Intermediate care units serve a less defined patient group, generally older, excluded from Intensive Rehabilitation Programs and unable to return home directly from the acute hospital for various reasons (Oliver et al., 2014). The role of intermediate care in dependent older adult patients following an acute illness is not new. Studies have shown that elderlies require a longer time to recover from acute illnesses and lose 25 to 35% of their premorbid functional capability. 25% have cognitive decline, 20 to 25% develop emotional instability, and 20 to 40% lose nutritional status (Chumney et al., 2010). Many are discharged home with no laid down plan for optimal functional recovery.

The success of a rehabilitation program depends on factors outside the rehabilitation intervention itself. Barnes et al., using 449 adults aged 70 years and above, reported that age, gender, number of instrumental activities of daily living dependencies before admission and at discharge, the presence of dementia, creatinine levels, and the presence of comorbidities were all determinants of success after rehabilitation (Barnes et al., 2013). Similarly, it has been reported that female gender, presence of diabetes, coma on admittance, previous stroke, atrial fibrillation, and intra-cerebral haemorrhage predict ADL dependency deterioration (Ullberg et al., 2015). Schnitzler et al. postulated that the functional outcome of stroke patients has a link to the rehabilitation setting (Schnitzler et al., 2014). They noted results from a study involving 83 505 stroke survivors in France where rehabilitation in a neurological rehabilitation centre led to a greater probability of

functional improvement (OR: 1.75) and home discharge (OR: 1.61) when compared to those who went to general rehabilitation centres. Cho et al. (2013) reported that among 8 750 older adults in home health care agencies, those with informal caregivers had less functional dependence after 60 days than those with a paid caregiver.

There is evidence of the feasibility and effectiveness of a home-based rehabilitation programme for functionally independent older adult patients. The Care of Persons with Dementia in their Environments [COPE] randomized trial in 2010 showed a positive effect on functional dependence among other outcome measures – engagement, caregivers' wellbeing, and confidence. The programme aimed to reduce environmental stressors and enhance caregiver skills with education and training in patient-specific intervention modalities. Basic clinical parameters were carried out by trained personnel instead of the control group where research staff was used (Gitlin et al., 2010). Hauer et al. (2017) reported improved functional performance in patients with cognitive impairment from a pilot study after a session of home-based training. Gitlin et al., using veterans with dementia, reported a reduction in functional dependence levels and caregiver burden after an individually customized activities-based home-based activity programme using occupational therapists. Though the intervention was primarily aimed at reducing behavioural symptoms by design, improvement in functional health was noted (Gitlin et al., 2018).

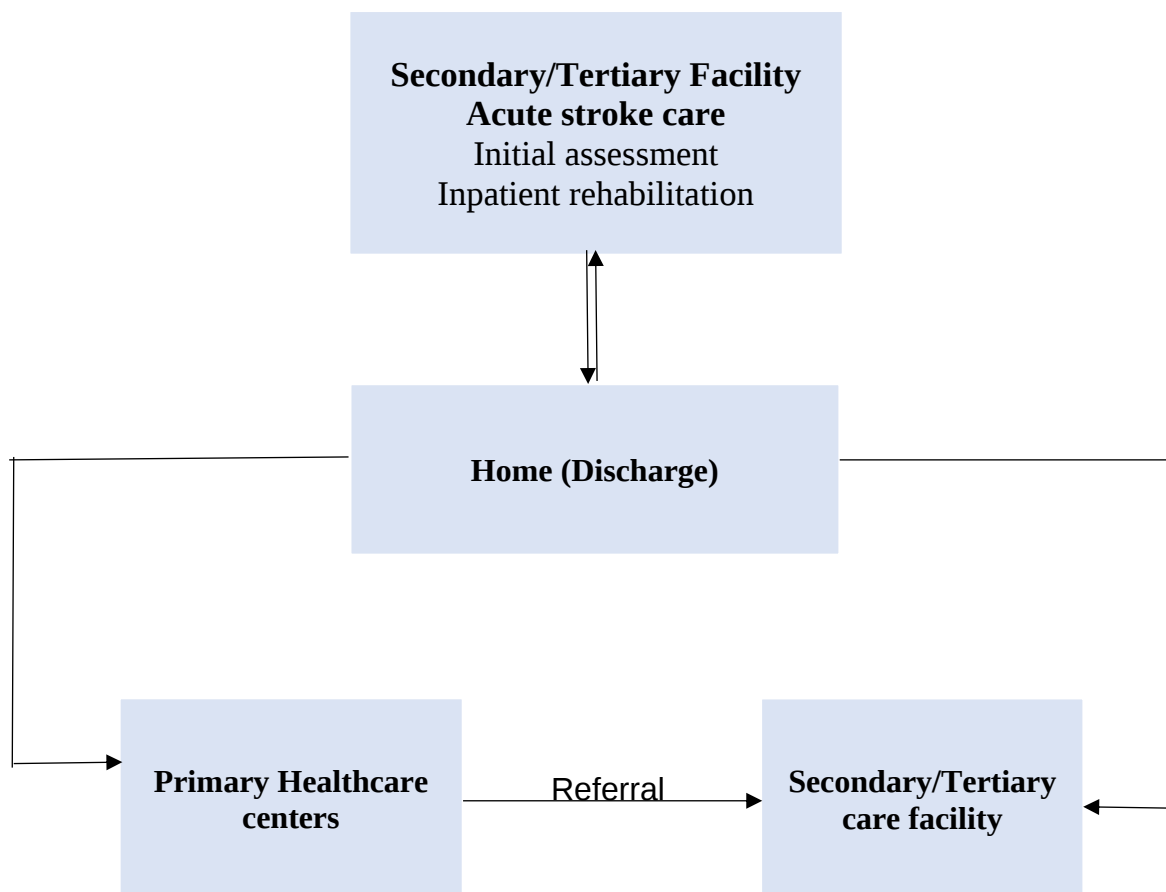


Fig 2.1: Care Pathway for Post Stroke Patients in Nigeria.

2.1.5.1 Home-Based Intermediate Care

Numerous research demonstrating comparable effectiveness between home-based and institution-based rehabilitation provide evidence that it is advantageous for Nigeria. For patients in need of more acute nursing care or medical attention, home health services are offered (Landers et al., 2016). It's important to recognize the home environment's capacity to provide people with a sense of purpose, organization, and belonging in their

life as well as to foster meaningful social contact (Graham et al., 2015). In order to adequately serve the needs of older adult stroke patients, effective home-based intermediate care services (HBIC) are a key component of a complex puzzle. Home environment familiarity has been found to help the restoration of functional abilities and 'meaning' in the lives of service users. (Pearson et al., 2015). A meta-analysis revealed that while home-based support did not enhance physical function, it could help stroke survivors with their depressive symptoms (Huang et al., 2017). In their 2018 study, Hsieh et al. examined the benefits of home-based versus clinic-based rehabilitation for stroke survivors, finding similar results in terms of disability level. On the other hand, the home-based group showed higher motor activity, while the clinic-based group showed a higher health index (Hsieh et al., 2018), which is unsurprising. The best course of therapy, frequency, and cost estimation for the home-based intervention were not considered in this study. According to Allen et al., a community stroke rehabilitation team's home-based stroke rehabilitation program is more cost-benefit than standard treatment, with a net benefit of \$43,655 and superior in 100% of iterations (Allen et al., 2018). Studies have found comparable efficacy in telerehabilitation (Chen et al., 2015) and an infrared capturing system-based virtual reality system (Standen et al., 2017).

The absence of easily accessible physiotherapists (Agho & John, 2017) and occupational therapists (Béguin, 2013) suggests that employing specialists in this setting and constructing home-based therapy based on specifically stated programs that call for ongoing follow-up is impractical. Furthermore, considering social and environmental stresses are so common, it is necessary to replicate the interventions that were employed in the COPE study. However, it is less practical in developing nations due to the intense

requirement for human, financial, and social resources without state involvement. Meanwhile, an efficient, cheap, and cost-benefit intervention is needed to help people who are functionally dependent recover from acute illnesses while managing environmental stressors in the setting of a typical African society.

2.1.5.2 Institution-based intermediate care

Programmes for community-based rehabilitation enhance, support, encourage, and aid patients with medical conditions, including stroke survivors and family caregivers. These services are delivered by paid volunteers and qualified rehabilitation staff in a community-based rehabilitation facility (Ru et al., 2017). After being introduced in France in 1961 under the name Hospitalization à Domicile, the idea of a "hospital at home" has since spread to the US, the Netherlands, Australia, and other nations (Bosna., 1993). At its inception, Hospitalization à Domicile aspired to provide comprehensive treatment, including specialized services, to a particular patient population demographic that was used to obtaining medical attention in hospitals but who, with family support, preferred to receive care at home (Clarke et al., 1984). For conditions that generally require hospital admission, the hospital at home/hospital in the house offers acute or subacute care in the patient's home (Shepperd et al., 2009). Hospital-at-home programs vary in philosophy and care focus and can be run by the community or with resources from the hospital. While hospital-based plans build on the existing community resources, such as home health agencies, hospital-resourced plans provide an outreach service through hospital workers doing domiciliary visits (Sheppard et al., 2009).

Bed-based intermediate care was one strategy that was found to be effective in enabling early release to other PAC institutions, such as community hospitals and care homes for patients who have not fully recovered from acute illness (McGettigan et al., 2021). Such PAC strategies aim to reduce avoidable readmissions to the hospital, prevent the placement of elderly patients in long-term care (LTC), and encourage independence in these fragile patients (McGettigan et al., 2021). Intermediate-care hospitals eased the burden on hospital inpatient services, avoided extended hospital stays, and allowed early hospital discharge for patients in need of additional institutional care (Dahl et al., 2015). A prior study found that receiving intermediate care at a community hospital resulted in a significantly higher rate of independence after 26 weeks of follow-up and a significantly lower number of readmissions for the same disease to a general hospital when compared to ordinary prolonged care at a general hospital (Garåsen et al., 2007). In addition, patients showed increased independence six months following the intervention in a randomized controlled trial examining post-acute care for older individuals in community hospitals (Young et al., 2007). There are several ways to provide care at a level between acute care hospital and home, however, for certain individuals and situations, a community bed-based institution is the best place to receive transitional or chronic care (Mac Arthur and Hendry, 2017). In residential rehabilitation, patients receive treatment while temporarily housed in a care facility to improve their cognitive and physical capacities to the point where they can live independently. These care facilities include long-term care facilities, nursing homes, rehabilitation centres, and community hospitals (Wang et al., 2019).

2.1.6 The role of a multi-disciplinary team in intermediate care

A multidisciplinary team may be composed of a range of healthcare professionals functioning under one organizational umbrella or professionals from a range of organizations, including private practice, who function as a virtual team to meet each patient's unique needs. The care approach is central to providing older people with a patient-centred care approach to improve the management of multiple chronic conditions (Hickman et al., 2015). This team includes doctors, nurses, medical social workers, nurses, occupational therapists, and physiotherapists with varying levels of experience and length of service (Blendell and Ojo, 2020). Multidisciplinary teamwork has a compelling justification as disease management becomes increasingly intricate. Bringing together a group of experts, all of whom can independently contribute to a diagnosis and suggested treatment strategy, is important for the intermediate care of patients (Whiteman et al., 2016).

Research has shown that after a stroke, cognitive abnormalities are prevalent and can have a significant impact on functional status. These dysfunctional domains are not always assessed consistently in clinical practice (Cramer et al., 2023). However, patients who have experienced a stroke should initially receive 45 minutes of therapy at least five days per week from each of the relevant therapy teams, such as physiotherapy, occupational therapy, and speech and language therapy, to work on areas such as mobilization, cognition, speech and communication, and swallowing (Clare, 2018). Additionally, therapeutic nurses seek to assist stroke survivors in regaining a meaningful life by providing the stroke survivor and family with education on the scope and intensity of post-acute care services and associated outcomes and, thus, can effectively advocate

to support effective patient and family decision-making (Camicia et al., 2021). Studies have indicated that visual impairments negatively impact the course of rehabilitation (Herron, 2016). Although visual impairments are not as evident as motor or speech impairments, without thorough screening, subtle visual complications may go undiagnosed (Sand et al., 2013). Therefore, the role of optometrists is to ensure that people with visual field deficiencies have prisms included in their spectacles and that compensating eye movements are taught as part of the treatment. These deductions highlight the necessity of incorporating multidisciplinary teams into intermediate care for older adult stroke survivors.

It has been concluded that specialized treatment, including multidisciplinary care, leads to better outcomes (Adeoye et al., 2019).

2.1.7 The role of informal caregivers in intermediate stroke care

Stroke rehabilitation has focused on patient-directed therapies to lower the rate of institutionalization and severe disability. As a result, more patients with disabilities are being cared for at home (Smith-Carrier et al., 2017). An informal caregiver is often defined as someone who gives unpaid, continuing support with activities of daily living or instrumental activities of daily living to a person suffering from a chronic disease or handicap (Roth et al., 2015). Family members often serve as informal carers during stroke recovery. Informal caregivers may be paid or unpaid. Unpaid informal caregivers include family members, friends, and relatives, whereas paid informal carers are domestic workers or skilled professionals (Pucciarelli et al., 2019). In Nigeria, informal caregiving is often a culturally accepted practice, where family members or close relatives are responsible for caring for older adults with stroke (Vincent-Onabajo, Ali and Hamzat,

2013). This stems from the deep-rooted traditions of family cohesion and communal responsibility. However, the burden of care on informal caregivers, who are often untrained, can negatively affect both the caregiver and the patients. In many cases, informal caregivers may lack the proper skills and resources to provide effective care, leading to poorer outcomes (Akosile *et al.*, 2013). Though informal caregiving may seem to have cost benefits, there are hidden costs, such as loss of income for caregivers who may have to reduce their working hours or quit their jobs to care for the patients, cost of medications and transportation to medical appointments. On the other hand, formal caregiving through healthcare professionals tends to be more expensive and out of reach for many families due to lack of health insurance (Saini *et al.*, 2017).

Informal caretakers play a rising role in early release, treatment, and rehabilitation at home. This aligns with a political focus on maximizing limited resources in modern healthcare (Quinn *et al.*, 2014). Informal caregivers are critical to survivors' ability to heal and adjust to life after stroke (Sennfält, 2020). They play a central role in post-stroke patients' care. To improve their functional status, stroke survivors require extensive care, particularly when doing daily activities. As a result, carers are encouraged to become involved in post-stroke patient care to improve patient management quality (Lloyd *et al.*, 2018). In the research study conducted by Muhrodji *et al.* (2022), some of the themes related to caregivers' roles were connecting patients with medical personnel and other family members, preserving patients' health by meeting basic needs and supporting rehabilitation, and maintaining patients' psychological well-being by promoting recreational activities and communication.

The informal caregivers are intermediaries for communication between the patient, family and medical personnel, including doctors, psychologists, nurses, and therapists, or the patient and their family (Muhrodji et al., 2022). This position is crucial to patient care and can be used as a guideline for adult stroke rehabilitation and recovery (Winstein et al., 2016).

The role of carers in supporting patients' psychological health is critical in preventing depression in post-acute stroke patients. Depression is one of the most common side effects of stroke (Caplan, 2016). Informal caregivers contribute to maintaining stroke survivors' psychological conditions by spending a significant amount of time engaging with them. Research has shown that caregivers promote patients' psychological well-being by sharing entertaining stories, joking, and engaging in leisure activities (Muhrodji et al., 2022). They have a great influence on the development of the patients' psychological condition and prognosis (Zhao et al., 2018).

Informal caregivers assist stroke survivors with their daily tasks and are responsible for their health care. Caregivers assist patients with impairments in meeting basic needs such as feeding, bathing or showering, toileting, clothing, grooming, walking, and transporting. They also monitor their patients' sleep patterns and aid them in getting enough sleep (Schulz et al., 2016). During rehabilitation, caregivers assist by providing additional physiotherapy services at home (Winstein et al., 2016). Furthermore, caregivers play an important role in avoiding and managing complications that may occur.

This involvement is consistent with prior research, which revealed that carers can assist lower the occurrence of post-stroke challenges (Pitthayapong et al., 2017).

2.1.8 Challenges and barriers in intermediate care

Specifically, in Nigeria, there is an absence of a defined intermediate care model for elderly stroke patients at home. However, discussing the challenges and barriers experienced in other regions with established intermediate care is imperative. The main challenges to developing intermediate care include workforce and financial constraints, inadequate collaboration between health and social care agencies, and a lack of support from the medical community (Regen et al., 2008). Intermediate care faces several significant challenges, as highlighted in recent research. One key issue is the complexity and variability of patient needs, which require flexible and fast transitions between care settings. Delays in admission and discharge processes can hinder the effectiveness of intermediate care. Engaging general practitioners is particularly challenging and changing staff skills and attitudes has also proven difficult (Young, 2009).

In a hospital-based setting, the financial and organizational pressure on healthcare providers involves conflicting incentives, such as the need to maintain high bed occupancy rates for economic reasons, which can lead to the admission of patients with more severe health issues than originally intended. This mismatch between patient needs and available care resources can strain the system and reduce the quality of care provided (Cowie et al., 2020).

Many intermediate care services struggle to recruit and retain skilled professionals, crucial for delivering high-quality care (Regen et al., 2008). This shortage is particularly acute in areas with high demand for intermediate care services, leading to increased workloads and burnout among existing staff.

Another key issue research has shown in intermediate care is caregiver burdens. The degree to which carers believe that providing care has negatively impacted their mental, social, economic, physical, and spiritual well-being is known as the carer burden (Perlick et al., 2016). The long-term detrimental effects of caregiving on carers' physical and mental well-being occur over many years (Sallim et al., 2015). Compared to non-caregivers, informal carers "live to provide care" for their patients; as a result, they cease taking care of themselves, suffer from carer stress, and have worse physical, mental, and emotional health (Yeh and Bull., 2012). Caregiver burden arises from the belief that the demands of providing care are beyond the physical and mental capabilities of informal carers, or that these capabilities are compromised (Mosquera et al., 2016).

These challenges and barriers highlight the need for improved staffing, better discharge planning, increased financial investment, and interventions to ease caregiver burden and develop robust frameworks for sustainable implementation to effectively address the challenges in intermediate care.

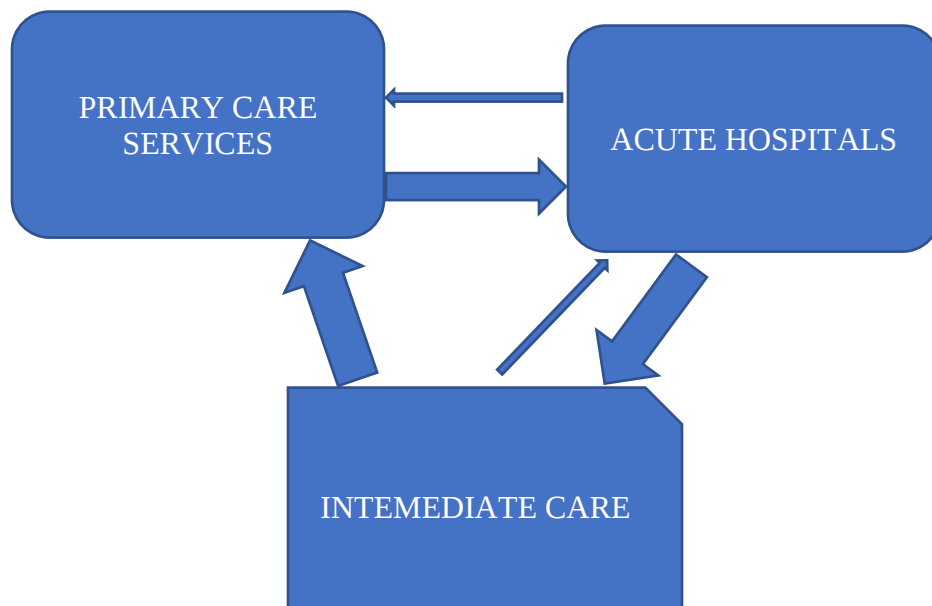


Fig 2.2: Continuum of healthcare pathway. Adapted from: Mabunda et al., 2018.

Very few studies have investigated out-of-hospital rehabilitation in a typical African setting. A narrative review of physiotherapy stroke rehabilitation research performed in South Africa revealed that stroke survivors have poor functional ability at discharge and have poor access to transport, work, and education. Due to limited rehabilitation services, survivors are discharged to the family care resulting to stress and a poor quality of life for caregivers (Ntsiea, 2019).

To the best of our knowledge, no study has been carried out in Nigeria to explore the implementation of an intermediate care model for stroke patients in the community. It is

anticipated that adapted home-based intermediate care for older adult people with stroke will improve the functional outcome and quality of life of older people.

2.2 CONCEPTUAL FRAMEWORK

The conceptual framework is designed to link the research questions, proposed interventions, and expectations that form my research study. This displays the flow of the research to achieve the study objectives. The framework is aimed at understanding the mechanism by which the home-based intermediate intervention produces changes using context-mechanism-outcome pattern configuration.

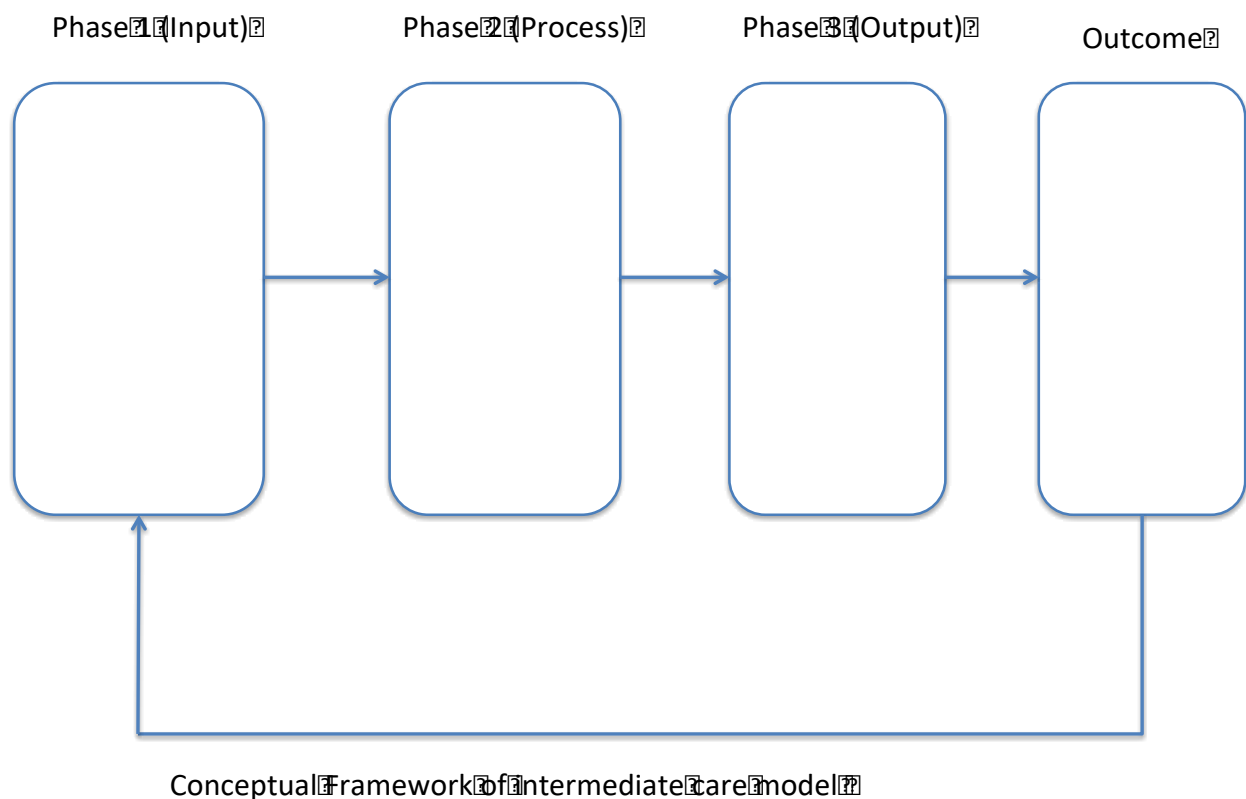


Figure 2.3: Conceptual framework of intermediate care model

2.3 Summary of Chapter

This chapter was used to discuss the conceptual, theoretical, and empirical review for the study. It was reviewed that lack of access to standardized healthcare delivery, poor healthcare infrastructure, lack of expertise in stroke care and rehabilitation, and poor funding are among many other factors responsible for poorer health outcomes for older patients with stroke (Wahab, 2008b). Limited availability of hospital beds, lack of integrated acute and post-acute care settings, and out-of-pocket expenditure imply that patients must be discharged from hospitals to their homes and fend for themselves. As high as 90% of patients are discharged home with varying functional disabilities and no intermediate care plan (Wasserman et al., 2009) leading to increases in morbidity and mortality in the older adult. Research shows that there has been a consistent decline in mortality and disabilities associated with stroke incidences in developed countries despite the ageing populations (Katan and Luft, 2018). This may be due to improved functional outcomes resulting from a pragmatic approach to risk management and continuous care models following acute stroke management. However, little is known about post-stroke care management at family and community levels in Africa generally. In Nigeria specifically, no integrated care model addresses post-acute stroke management in the community. Patients are often discharged to go home for continuous care by family caregivers who have little or no knowledge of post-acute care management, risk assessment, care needs, and support the patients require, hence the recorded high incidence of post-stroke mortality.

CHAPTER 3

METHODOLOGY

3.1 Introduction

This methodology chapter explains in detail the stepwise approach employed to answer the research questions and achieve the study objectives. It addresses the general overview of how the research design, data collection methods, the data analysis techniques combine in line with best practices to gather and analyze the research data. The methodological framework of this study is outlined in this chapter to enhance the reliability and validity of our research findings. The National Stroke Association reported that 40% of all stroke patients acquire moderate to severe impairments and need special care, while 10% require constant care in long-term care facilities (Stroke.org., 2018). This study aimed to develop an adaptable intermediate care model for older adult stroke patients in southwest Nigeria.

3.2 Philosophical Approach

The main aim of this doctoral study is to explore the possibilities of development and adaptation of an intermediate care model for older adults with stroke in the community through relevant literature and exploration of stakeholder's perceptions of the need for continuous stroke care. Though, similar studies have proven cause /effect linkage in post-acute care in stroke and functional outcomes (Lai et al., 2017; Garåsen et al., 2007;Heikinheimo & Chimbayo, 2015). This is probably the first study of the intermediate care model in stroke care in the Community in Nigeria. To accomplish this objective, It is imperative to adopt a combination of research design and methodology that captures the

existing knowledge gaps, stakeholders' perceptions and development of a culturally accepted intermediate model for continuous stroke care in the community. Hence, the philosophical approach was pragmatism. Pragmatism philosophy is based on the epistemology of the use of multiple research methods to understand multiple realities (Kaushik & Walsh, 2019). This approach aligns with the research questions and objectives as it captures different experiences and perceptions through combined research methods to enhance the richness and validity of research findings. The selected research design for this study is a mixed-methods approach, combining both quantitative and qualitative techniques to provide a comprehensive and holistic understanding of the research phenomenon.

3.3. Research Design and Planning

An exploratory method was used for the study to gain insight into the subject using a mixed-method approach. The goal is to arrive at a description of lived experiences among older people with stroke and their functional outcomes. A three-phase design was used. The first phase was a systemic review of the research literature on the intermediate/post-stroke care model and functional outcomes among older adults. The review explored post-stroke interventions in older adults, identified knowledge gaps, and generated research questions and relevant interventions with appropriate methodological approaches for data collection and analysis that drew culturally adaptable care models in Nigeria. The second phase sought to understand the perception of stakeholders in stroke care on an intermediate care model that is culturally adaptable to the community by conducting focus group discussions among family caregivers of persons living with stroke

and in-depth interviews of other stakeholders to gain deeper insights into their experiences and needs. Finally, an intervention framework will then be developed, and a small pilot test of its efficacy conducted.

3.4. Systematic Review

3.4.1 Introduction

The systematic review aimed to explore existing knowledge of intermediate care models in stroke care and describe the evidence on improvement of the functional health of older adults recovering from stroke. A protocol was developed that explained the objectives and method of this review and synthesis of results. Prevalence or incidence of outcomes quantitative studies were pooled together where there is significant heterogeneity. A summary of key findings of similar studies was explained in a narrative synthesis. Through secondary data, the review was conducted following the preferred reporting items for systematic Review and Meta-Analysis (PRISMA) guidelines for systematic review.

3.4.2 Study Design

A systematic review was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Page et al., 2021).

3.4.3 Eligibility Criteria

Table 3.1: Studies that met the following criteria using the PICO (Participants, Interventions, Comparators, and Outcomes) were included.

Population	Included: Older adult patients with stroke $\geq$ 60 years (United nation definition of older older adult)
Intervention	Intermediate home-based/ Community stroke care
Control	Hospital or community or post-acute care rehabilitation setting
Outcome	Function or quality of life, measured by psychometrically appropriate measures

3.4.4 Search Strategy

Multiple databases were systematically searched for relevant resources. Medically inclined databases were selected which include EMBASE(Ovid) PubMed, CINAHL, MEDLINE and Scopus databases. Additionally, search engines such as Google Scholar, ResearchGate and published reviews and the reference lists of retrieved publications were searched manually to broaden the scope and ensure the inclusion of all relevant articles. The search terms comprised “Stroke,” “Functional Health,” “Older adult,” “Intermediate Care,” “Home Based,” Quality of Life,” and “Post-Acute Care Stroke rehabilitation.” These terms were combined using AND, and OR and some were expanded, especially those with multiple synonyms, to encompass all pertinent articles.

Adjustments to the search were made as necessary, following the specific requirements of the search engines and databases utilized. Cross-referencing was conducted, and the search spanned 10 years from January 2012 to December 2022. The full search strategy used for the database search is presented in Table 3.2 below.

Table 3.2: Database full search strategy

Database	PubMed
Date	29/07/2022
#1	"Aged"[Mesh]OR "Elderly" [tw] OR "older adults*" [tw] OR "frail elderly*" [tw]
#2	"Intermediate Care Facilities"[Mesh]OR "post-acute care *" [tw] OR "sub- acute care*" [tw] OR rehabilitation OR "stroke rehabilitation*" [tw] OR "Community care *" [tw]
#3	"Stroke"[Mesh]OR "Cerebrovascular accident*" [tw] OR "cerebrovascularaccidents" [tw]
#4	"Health Status Indicators"[Mesh]OR "functional health status*" [tw] OR "Motor skills" [tw]OR "cognitive skills " [tw] OR "activities of daily living*" [tw] OR " quality of life*" [tw]
Strategy	#1 AND #2 AND #3 AND #4
Database	CINAHL
Date	29/07/2022
#1	"Aged" OR "Elderly" OR "Older" OR "Elder" OR "Geriatric" OR "Elderlypeople" OR "Old people" OR "Senior"
#2	"Intermediate care"OR Subacute care OR Post-acute care transition OR home-base OR Community care OR Stroke Rehabilitation ORRehabilitation
#3	Stroke OR Cerebrovascular accident Or Cerebrovascular accidents OR cvaOr Stroke survivors OR Ischemic stroke

#4	"Functional outcome" OR "Functional Health" OR "Functional Mobility" OR "Stroke Rehabilitations" OR "Rehabilitation" OR "Quality of life" OR "Activities of daily living"
Strategy	#1 AND #2 AND #3 AND #4
Database	MEDLINE
Date	29/07/2022
#1	"Aged" OR "Elderly" OR "Older" OR "Elder" OR "Geriatric" OR "Elderly people" OR "Old people" OR "Senior"
#2	"Intermediate care" OR Subacute care OR Post-acute care transition OR home-base OR Community care OR Stroke Rehabilitation OR Rehabilitation
#3	Stroke OR Cerebrovascular accident Or Cerebrovascular accidents OR cva Or Stroke survivors OR Ischemic stroke
#4	"Functional outcome" OR "Functional Health" OR "Functional Mobility" OR "Stroke Rehabilitations" OR "Rehabilitation" OR "Quality of life" OR "Activities of daily living"
Strategy	#1 AND #2 AND #3 AND #4
Database	EMBASE (OVID)
Date	20/07/2022
#1	"Aged" OR "Elderly" OR "Older" OR "Elder" OR "Geriatric" OR "Elderly people" OR "Old people" OR "Senior"
#2	"Intermediate care" OR Subacute care OR Post-acute care transition OR home-base OR Community care OR Stroke Rehabilitation OR Rehabilitation
#3	Stroke OR Cerebrovascular accident Or Cerebrovascular accidents OR cva Or Stroke survivors OR Ischemic stroke

#4	"Functional outcome" OR "Functional Health" OR "Functional Mobility" OR "Stroke Rehabilitations" OR "Rehabilitation" OR "Quality of life" OR "Activities of daily living"
Strategy	#1 AND #2 AND #3 AND #4
Database	Scopus
Date	20/07/2022
#1	"Aged" OR "Elderly" OR "Older" OR "Elder" OR "Geriatric" OR "Elderly people" OR "Old people" OR "Senior"
#2	"Intermediate care" OR Subacute care OR Post-acute care transition OR home-base OR Community care OR Stroke Rehabilitation OR Rehabilitation
#3	Stroke OR Cerebrovascular accident OR Cerebrovascular accidents OR cva OR Stroke survivors OR Ischemic stroke
#4	"Functional outcome" OR "Functional Health" OR "Functional Mobility" OR "Stroke Rehabilitations" OR "Rehabilitation" OR "Quality of life" OR "Activities of daily living"
Strategy	#1 AND #2 AND #3 AND #4

3.4.5 Study Selection and Data Extraction

All identified citations were downloaded in the RefWorks referencing software manager (<https://refworks.proquest.com/library/>). Duplicates were excluded, and the screening process was carried out manually. TF initially conducted the title/abstract and full-text

screening. A second reviewer, HK independently tested a random 10% of all references. TF, HK and ML independently screened the full text, and any area of variance was resolved through consensus among the reviewers. RA also provided input in developing the study methodology. The PICO framework was employed for the search as outlined in

Table 3.3: inclusion and exclusion criteria for studies

Inclusion criteria	Intervention studies using the intermediate care model to enhance the functional outcomes in older adult stroke patients, limited to English-language research articles. The study setting was either community-based or home-based. Quantitative studies.
Exclusion criteria	Cross-sectional research, animal studies editorials, short commentaries, papers published before 2010, non-peer-reviewed studies and inaccessible full texts.

3.4.6 Study Outcomes

Main Outcome: This systematic review aims to assess the effectiveness and pattern of outcomes associated with the implementation of the intermediate care model among older adult individuals with strokes.

Secondary outcome: To investigate the effects of intermediate care on the functional health of older adult individuals with stroke in the community.

3.4.7 Quality assessment

TF conducted the quality assessment using the Cochrane Collaboration's technique for risk bias in randomized trials (Higgins et al., 2011) and the Johanna Briggs Institute (JBI) checklist for quasi-experimental and longitudinal studies (Porritt et al., 2014). HK and ML served as references, checking 40% of the papers and providing alternative perspective clarification where needed on articles.

3.4.8 Critical Appraisal

Quantitative studies were evaluated using the Critical Appraisal Skills Program (CASP) instrument (Zeng et al., 2015). JBI checklist was used to assess quasi-experimental and longitudinal studies (Porritt et al., 2014).

3.4.9 Data analysis

The results table was cleaned before analysis, and a quantitative data analysis technique was employed. Descriptive and narrative analysis methods were used for the quantitative data.

Heterogeneity Test

A qualitative assessment of the differences between the results of individual studies in terms of study design, participants, interventions, and outcome measures was done using the PICO framework and study methodologies were carefully compared to identify potential clinical heterogeneity

3.4.10 Patients and Public Involvement: None

3.5. Qualitative Study

3.5.1. Introduction

The aim here is to understand how different stakeholders in stroke care perceive the adoption of an intermediate care model for older adult people recovering from stroke and to describe suggestions on how to modify the intermediate care model to be culturally acceptable in Nigeria.

3.5.2. Study setting: This study was conducted in Ibadan, the capital city of Oyo State. Ibadan is located on seven hills with an average elevation of 200 metres and approximately 100 miles (160 km) from the Atlantic coast. It is the largest city by geographical area and the third most populous city in Nigeria. The city has a total population of three million, six hundred and forty-nine thousand (3,649,000) as of 2021. The University College Hospital (UCH) was strategically located in Ibadan, the largest city in West Africa. Currently, the hospital has over 30 wards, 1,000 bed spaces and 200 examination couches with occupancy rates ranging from 65 to 70%. The University College Hospital, Ibadan has an established Cerebro-Vascular Accident (CVA) clinic for the treatment of stroke and stroke-related diseases with approximately 40 doctors and 60 physiotherapists. This clinic is also operated in the Accident and Emergency Unit of the hospital.



Fig 3.1: Study showing the study location, Ibadan. Adopted from *Encyclopedia Britannica, Inc.*

3.5.3. Participant Selection: Stakeholders in stroke care i.e., formal caregivers (Doctors, Nurses, Medical Social Workers and Physiotherapists) and Informal caregivers (Family caregivers and patients, stroke-specific community advisory board leaders).

3.5.3.1. Inclusion Criteria:

- Older people aged 60 years and above with stroke,
- A dedicated in-dwelling caregiver(s),
- Signed informed consent from Next of Kin or legal caregiver,
- Healthcare providers in stroke care
- Community advisory board

3.5.3.2. Exclusion Criteria:

- Denial to provide informed consent

3.5.4. Sampling and recruitment: The sampling method used was purposive to provide information-rich cases for in-depth study (Rai & Thapa, 2015). Participants were recruited using the pre-selected criteria. Before recruitment, permission was obtained from administrators and appropriate departmental heads in charge of the study hospitals and communities (Feine et al., 2009). Initial contact with prospective participants was made through face-to-face conversation and telephone calls were initially made by one of the researchers to identify the convenient date, time and venue for the interviews. The group selection was homogenous as these were divided into healthcare providers of stroke patients, stroke family caregivers and members of the community advisory board. A focus group discussion was conducted among the family caregivers of a person living with stroke to gain insight into resilience to the burden of care, and their needs and explore understanding of the intermediate care model in the community. The informal caregivers were recruited through patients' case notes at Chief Tony Anineh Geriatric Centre and Medical Outpatient Clinic, University College Hospital (UCH), Ibadan after permission was taken from necessary authorities. They were stratified by age and

gender. An in-depth interview was conducted among the formal caregivers (who are involved in stroke care in the hospital which include doctors, nurses, physiotherapists, and occupational therapists) and key informant in the community included both orthodox (religious setting) and the non- orthodox community leaders who have had experience of someone with stroke in the community.

3.5.5. Data Collection

3.5.5.1. Focus Group Discussion: Focus group discussion was used due to its ability to generate new ideas within a social context (Breen, 2006). A total number of 3 focus groups discussions comprising two female groups and a male group were conducted. Participants were purposively sampled. Each group contained a sample size of 6 family caregivers. The sample size according to Creswell (2007) was chosen to provide rich data for a phenomenological study. A direct data was collected using a semi structured interview with open ended questions and appropriate probes (Appendix) to address the following roles: nursing care, mobility skills, medical complications, basic communication, and other extract from the systematic review. The interview was carried out in a hall at Geriatric centre for older adult patients in UCH at a convenient time for the participants. Audio tape recorder, consent forms, participant information sheet were provided at each process. The interview was conducted among homogenous groups until saturation is achieved. The interviews lasted between one to two hours. Research assistants transcribed and arranged the empirical data.

3.5.5.2. Key Informant Interview

Key informant interviews probes individual experiences, thereby encouraging self-reflection on issues that could be distorted if social pressure were placed on the individual (Breen, 2006). Sixteen (16) Key Informant Interviews (KIIs) were conducted. 8 community stakeholders and 8 formal caregivers were recruited to participate in the KII. The community stakeholders who have had contact with stroke patients in their community were interviewed. They include two Christian leaders, two Islamic leaders, two traditional healers and two community heads. The formal caregivers include two doctors, two nurses, two medical social workers and two physiotherapists, all who are involved of stroke care. The interview guide contained open ended questions and appropriate probes (Appendix) to obtain in-depth information on the topic of interest. The interview was audio-recorded and done at a convenient time and location chosen by each interviewee.

3.5.6. Data Management and Analysis

Several procedures were followed as part of the data management and analysis process. To avoid loss or omission of key details, the transcription of tape recordings of the focus groups and key informant interviews was performed on the same day they were collected as part of the data management and analysis process. All the interviews that were conducted with local languages were translated into English Language. Further validation was performed on the transcribed notes. The validation involved correction of some structural, grammatical, and typographical errors. The validation also helped to ensure that fragmented issues were meaningfully combined. Similar issues in each discussion or interviewee transcription that were disjointed were gleaned together. After the notes had been transcribed, NVIVO (version 12 Pro) was used to enter them into the computer.

Using NVivo, researchers may produce rich data with greater authenticity. Additionally, it makes it possible to manage a vast amount of data centrally. Researchers can use NVivo to explore qualitative data using a variety of methods, including the case study technique, constant comparative method, and grounded theory approach (Ozkan, 2004). A literature review and qualitative analysis can both be done using NVivo (Di Gregorio, 2000). It makes it easier for researchers to access available resources and handle enormous amounts of data with greater accuracy. The approach is even more rigorous when handling data with NVivo (Ozkan, 2004). The three primary phases of the research process: data analysis, theoretical development, and findings presentation are covered by Nvivo (Hutchison et al., 2010).

Using transcriptions from KIIs and FGDs, an image for data analysis was created. The methods used for data analysis included creating resources, using nodes to code, and running queries to provide findings that allowed theories to be verified and developed. This was done on three different levels: within-case analysis, cross-industry analysis, and study of all instances. To obtain accuracy, generalizability to diverse contexts, and complexity, researchers are increasingly turning to NVivo as a data analysis tool (O'Neill, 2012).

A variety of methods were employed to acquire the data for this investigation. For instance, in-depth interviews with community leaders and professionals in the field of health, while FGD were conducted among informal caregivers. The interviews were captured with a Sony voice recorder and then transferred to Nvivo after being verbatim

transcribed. During the transcription process, some of the interviews that were conducted in the native tongue (Yoruba) were translated into English. An iterative approach was made possible by the analysis of the pilot survey, in which initial data collection and analysis guided sampling and analysis techniques later. This procedure allowed for a back-and-forth method and required simultaneous participation in data collection and analysis (Hutchison et al., 2010). The iterative process approach was used to modify the interview guide questions in response to the pilot study findings.

3.5.7. Data analysis stages

To enable the reader to follow the analytical process, it is crucial that the methodologies are given logically (Hutchison et al., 2010). Several methods have been suggested for NVivo-based data analysis. O'Neill's (2012) toolset was found to be helpful for this research; hence, a similar data analysis process is used throughout the chapter. Table 3.1 displays the steps taken in the data analysis using the NVivo tools (O'Neill, 2012).

3.4: Phases of data analysis for this study

NVivo stages	Procedures used in each stage
Stage 1: Descriptive	Project specifics and research methodology
	Sources
	Attributes
	Values
	Classifications
Stage 2: Topic	Choosing obvious topics
	Establishing first nodes
Stage 3: Analytic	Combining nodes to create hierarchies
	Data sets
	Models and connections
	Utilizing queries

	Running queries
	Matrix coding query
	Cross-case query analysis

Stage 1: Descriptive

The creation and construction of a database for the research study serves as the initial stage of this study's data analysis with NVivo. Internals, memos, and externals all have their subsections in NVivo's sources (O'Neill, 2013).

Sources

This section in NVivo consists of internals, memos and externals (O'Neill, 2013).

Internals

Internals are primary research details that are imported or created in NVivo, such as documents, PDFs, audio, video, pictures and data sets (O'Neill, 2013). The internals for this research were transcriptions of sixteen (16) KIIs and eighteen (18) FGDs.

Memos

Memos are an important tool for the analysis of qualitative data. According to Gibbs (2002), memos are documents containing commentary on primary data or nodes of a project. They are used to keep records of activities, decisions and thoughts on ongoing analysis, changes in the project and links between items. In this research study, memos were also used to record comparisons and conclusions extracted from data analysis. These memos were linked with nodes or sources to create a summary of these nodes and sources. They were also used to record observations. Various types of memos are commonly used by researchers, such as research diaries, reflective notes, and conceptual, emergent questions-related, explanatory, literature-related, technical or

model-describing memos (Hutchison et al., 2010). NVivo memos in the sources section of the program allow researchers to record any ideas developed during the analysis process, replacing footnotes and annotations. Memos were created for all the thirty-four (34) interviewees. Memos related to the findings from the data analysis were created for all cases.

Stage 2: Topic

Stage two involved the development of themes from the transcripts. It also included coding interview material and grouping related concepts under a single heading called a 'node' to be used for later data analysis. After coding the material, NVivo helps the user in highlighting selected text and giving a particular colour to coding stripes. Coding stripes are used to provide a visual overview of how nodes might relate to each another and to display emergent concepts (Hutchison et al., 2010). For this research study, initial themes were developed from the interviews. Coding stripes were used for theme modification.

Creation of initial coding.

Coding is the 'process of identifying and recording one or more discrete passages of text or other data items, that, in some sense, exemplify the same theoretical or descriptive idea' (Gibbs, 2002). In NVivo, coding is carried out by connecting each passage or item to a node. Miles and Huberman (1994) make no distinction between the terms 'variable' and 'code', using the terms interchangeably. During the coding process, meaning labels are usually attached to segments of data (Charmaz, 2006). NVivo allows users to create nodes and store relevant text in these nodes (Bazeley, 2007). Therefore, every time a new concept is found, a new node is developed. With every new node, a memo is created

to add notes and record findings from this node. When using NVivo for data analysis, it is important to associate data with each source to enable queries to be generated: a node classification sheet is created in the relevant section of the programme (O'Neill, 2013). In this study, a source and reference were created with the position of the participants. According to O'Neill (2013), this enables the generation of queries. Inductive-dominant coding approach (Assarroudi et al., 2018) was used to facilitate the coding process. The generated codes and specimens were checked carefully by the researcher and a team of three experienced qualitative researchers for review and critique. Themes were generated based on the following: (a) objectives of the study; (b) sample quotes from transcripts; (c) patterns of comments and agreements, reflections, suggestive innuendos and underlying meanings based on non-verbal transcripts; and (d) group reflections (contributions from members of the research team) including sex and age. Each of the FGDs and KIs transcripts was carefully read and examined based on the contents and theme by theme to identify relevant texts, repeating words, and phrases similar and divergent opinions. For each theme, common and peculiar trends as well as similar and divergent opinions were noted. Summary of findings were written, and sample of appropriate verbatim quotes were provided.

The emerging themes and sub-themes were identified and written out in the results. Quotes from respondents were used to support the emerging patterns of concepts from the data. A conceptual framework of an intermediate care model was developed, and a pilot study will be carried out among family caregivers of older persons with stroke in Phase 3.

3.5.8. Methodological limitation

The focus group discussion for male caregivers was conducted among only one group of males as several eligible participants didn't give consent to participate in the study due to busy schedules and lack of interest to participate in the study.

3.6. Quantitative study

This was the final stage of data collection. The model tested with a small group of family caregivers, to provide evidence of proof of concept and to demonstrate feasibility using pre and post-test design.

3.6.1. Study design

A prospective longitudinal study design was used to answer the objectives of the study.

3.6.2. Study location

The study was conducted in Ibadan. Ibadan is the capital city of Oyo state, Nigeria located on seven hills (average elevation 200 meters) about 160 kilometers from the Atlantic coast. It is one of the most populous cities in the country.

3.6.3. Study participants

Participants included in this study were stroke patients and their family caregivers. Stroke patients within 1-30 days post-discharge from acute care were recruited from stroke wards at the point of discharge and from neurology clinic at University College Hospital, Ibadan.

3.6.4. Participants selection

- Inclusion criteria for stroke patients

Older adults ≥ 60 years with recent stroke of within 30-day post hospital discharge from acute care.

Suffering from physical disabilities.

Needing help with their daily activities.

- Inclusion criteria for carers.

Have dominant caring role in assisting the patients at home.

Aged ≥ 18 years

3.6.5. Sampling technique

Patients were recruited using a non-random sampling technique.

3.6.6. Sample size

Sample size is calculated using G-Power software to assess the family carers experience towards health improvement of stroke patients. The required sample size for phase 3 is 54 carers.

3.6.7. Recruitment and retention

A total number of 58 older adult stroke survivors and their family caregivers were initially recruited. Of the 58, 7 were lost to follow-up. In the post-intervention phase, 51 stroke survivors and their respective family caregivers were assessed.

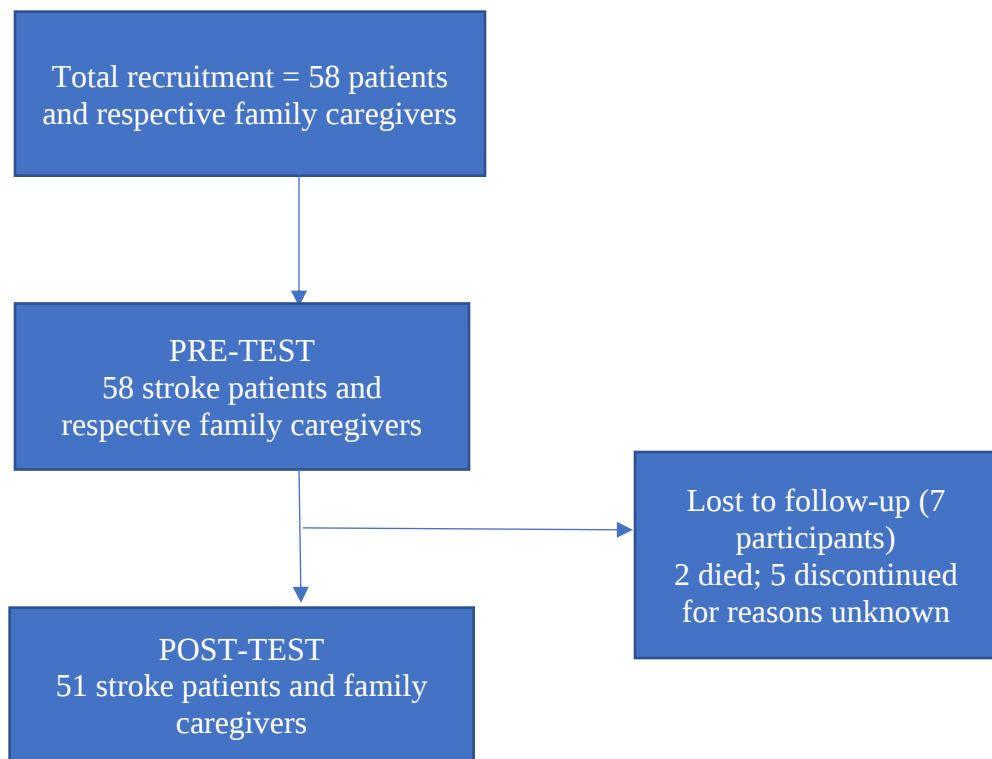


Fig 3.2: recruitment and retention flow chart

3.6.8. Intervention procedure

The intervention protocol was designed into training curriculum which was casted into audio-visual (Appendix 10). Different domains included in the audio-visual are knowledge about stroke and stroke prevention, seizure management, medication management, mobility and fall prevention, vital signs, service referral, reminiscence therapy, nutrition, and financial education. The training was provided the family caregivers of eligible participants for a duration of one hour (1hr). After which the audio-visual content was made available on the smartphones of participants for home support. The participants were encouraged to follow all instructions given to the caregiver. Subsequently, each family caregiver received a once weekly telephone follow-up with the researcher to

support their capability and coping mechanism in providing care for the patients at home and to identify early signs of potential problems over eight-week period.

3.6.9. Data collection instrument and procedure

Patients and family caregivers who met the inclusion criteria were selected consecutively. At recruitment, a pre-test was carried out. The pre-test investigated the patient's functional capacity and quality of life using Barthel's index (Zhang et al., 2022) and stroke-specific quality of life (SSQoL) scale (Williams et al., 1999) respectively (Appendix 5). Additionally, family caregivers' knowledge on stroke care, intermediate care model, and training needs were evaluated (Appendix 6). Following the pre-test, the family caregivers were trained with the developed model. Data on patient recovery trajectory on quality of life and functional health domains were obtained during the follow-up sessions (Appendix 9). At eight weeks, a post-test was performed to re-assess the functional health of the older adult with stroke following the use of the intervention (Appendix 7). The functional capacity was assessed using Barthel's index and the SSQoL 12-item-scale short version was used to measure the quality of life after stroke. Similarly, the family caregivers were assessed for the effect of the model using a post-test questionnaire (Appendix 8).

3.6.10 Outcome measures

3.6.10.1 Quality of life

Quality of life (QoL) was measured using the 11-item SSQoL scale (Williams et al., 1999) for stroke survivors. The domains in the SSQoL were scored using a 5-point Likert scale. The rating used 'strongly agree' to 'strongly disagree', 'total help' to 'no help needed' and 'couldn't do it all' to 'no trouble at all' where applicable. The domains rated were energy, language, mobility, mood, personality, self-care, social roles, thinking, upper extremity function, vision, work, and productivity. Higher scores in overall SSQoL indicate a higher quality of life.

Functional outcome

For functional ability, Barthel index (Zhang et al., 2022) was used to assess the ADL performance on an individual level. The 10-item scale included domains such as feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers (bed to chair and back), mobility (on level surfaces) and stairs. The maximum score attainable is 100. Higher scores indicated a high level of independence and vice versa.

3.6.11 Data quality control

3.6.11.1 Delphi procedure for developed model:

Delphi technique was used to validate protocol contents (Thangaratinam, and Redman, 2005). A multidisciplinary team was recruited from a tertiary hospital to review the contents under each domain of the designed intervention for the accuracy and ease of use for end users. The team comprised a consultant neurologist, a geriatric doctor, a geriatric nurse, a medical social worker, and a physiotherapist. Corrections were made to the contents and placed under a final review. A 10-item questionnaire (Appendix 11) was developed to obtain experts' opinions on the adequacy of each domain. The questionnaire was designed using a Likert scale to quantify the level of agreement or disagreement with intervention contents. Additionally, the questionnaire was made open-ended to allow for the addition of suggested corrections from experts. More than 80% of participants agree or strongly agree with the intervention contents. Suggestions from experts were included after a consensus was reached.

3.6.11.2 Validity and reliability of the Research Instrument: The opinions of the supervisor of this research and other experts were sought to ascertain the face and content validity of the developed questionnaire. A pilot test among 5 stroke patients and their family caregiver was carried out before the commencement of the study. This action was necessary to determine the effectiveness of the developed data collection instrument. Reliability analysis for the instrument was achieved using the Cronbach-Alpha statistical test with a reliability coefficient of 0.8.

3.6.12 Data analysis and management

Data obtained was transferred into excel for cleaning and exported into STATA (version 16) for analysis. Background description such as socio-demographic and clinical variables were presented in tables using mean, median, standard deviation, frequencies, and percentages. Independent and paired sample t-test were used to determine mean difference between each domain in the SSQoL and the overall SSQoL at the pre and post assessment phase. For Barthel's Index score, the mean difference between the pre and post assessment phase was assessed using paired sample t-test. The follow-up data was analyzed using repeated measures analysis of variance to assess significant differences in variables between time periods. Line graphs were used to show changes in variables over a period.

Table 3.5: Summary of table of how research questions were addressed.

Research Questions	Data Collection	Data Analysis	Intermediate care model generation
1. What is the impact of intermediate care model on functional outcome of older adults with stroke	Systematic review	Narrative analysis	Synthesis of evidence from the literature
2. How will intermediate care improve stroke outcome among older adult stroke survivors in Nigeria	Focus Group discussion	Thematic analysis	Cultural adaptation and model formation by stakeholders in stroke care
3. How Effective home-based intermediate care is adapted in the community	Questionnaire administered	Descriptive analysis Graphical analysis Exploratory analysis Logistic regression analysis	Training and implementation

3.6.13 Research Ethical Considerations:

Ethical approval was obtained from the University of West London as well as from the University of Ibadan (UI)/UCH Institutional Review Board (Appendix 1). The UI/UCH Ethics Committee's assigned number is UI/EC/22/0410. Participants and caregivers recruited to participate in the study were informed that their participation was strictly voluntary and can decide to withdraw at any time. The study process and purpose were explained, and informed consent was obtained from each participant and/or caregiver before the administration of the interview guide/questionnaires.

Confidentiality was maintained by ensuring that all data obtained from participants and consent forms were kept in a locked file cabinet and computer access was password protected with access only to principal investigators. All identifiers were removed from transcripts. Handheld devices and laptops with connection to the Internet was not used in this study to prevent hacking. If there were any need for future use for educational purposes, special permission would be requested from patients and/or caregivers. The result of the study would be published in reputable journals and presented at clinical conferences

3.6.14 Expected Impact

The project is expected to have a far-reaching impact in the following

- Providing research output to inform others in the field of stroke care and neurorehabilitation and contribute to the body of knowledge

- Provide research output that will inform policymakers to implement a care continuum for dependent and vulnerable older adults with stroke in the community in Nigeria and (Potentially other underdeveloped countries)

3.6.15 Dissemination of Findings

Doctoral conferences, workshops, seminars, Publications etc.

CHAPTER 4

Impact of intermediate home-based care on functional health of older people with stroke in low- income and middle-income countries: a systematic review

4.1 INTRODUCTION

Stroke is a burgeoning public health concern and continues to be a leading cause of death globally (Wan et al., 2014). It remains the second leading cause of death worldwide, with its prevalence projected to rise globally (Mira Katan and Luft 2018; Feigin et al., 2016). The primary driver behind this surge in stroke prevalence is the ageing of the population (Sharrief and Grotta, 2019). While the overall number have increase, age-standardized rates have been decreasing. Nevertheless, these rates persistently remain highest in low-income groups (GBD 2019 Stroke Collaborators, 2021b). The Global, regional and national Burden of Stroke 2019 report identified high systolic blood pressure, high body mass index, high fasting plasma glucose, air pollution and smoking as major contributors to stroke incidence (GBD 2019 Stroke Collaborators, 2021c). Age is significantly correlated with reduced functional gains and poor rehabilitation outcomes in stroke patients (Lui and Nguyen, 2018). Recovery from stroke following hospital discharge presents a significant challenge for survivors. The must contend with long- term medical conditions characterized by lasting functional impairments, the introduction of multiple new medications, rehabilitation goals, and altered diets from their hospital experience, which represent a major challenge for survivors. Prominent issues associated with hospital-to-home care for adults with stroke include fragmented care and poor communication between patients and healthcare providers (Geng et al., 2019) Substantial gaps persist in post-acute care, hindering the preparation of older adult stroke patients

and their caregivers for secondary risk factor management and recovery (Broderick and Abir 2015; Adeoye et al., 2019)). These gaps in care and knowledge contribute to poor outcomes. After hospitalization, 25% of stroke patients are readmitted within 90 days (Prvu Bettger et al., 2015), over 25% are not medication compliant (Bushnell et al., 2010), more than 50% do not have their blood pressure (BP) under control (White et al., 2013) and patients are sedentary for over 78% of the time (Fini et al., 2017) with a 73% incidence of falls (Forster and Young 1995). Consequently, the recurrence of stroke remains high, and the prevalence of stroke-related disability increases, and escalates during the post-acute recovery (Benjamin et al., 2018, Ovbiagele et al. 2013). More than 50% of patients are discharged directly home after a brief hospital; stay without full understanding of their residual deficits, which can impact their ability to manage secondary prevention or recovery (Adeoye et al., 2019; Prvu Bettger et al., 2015).

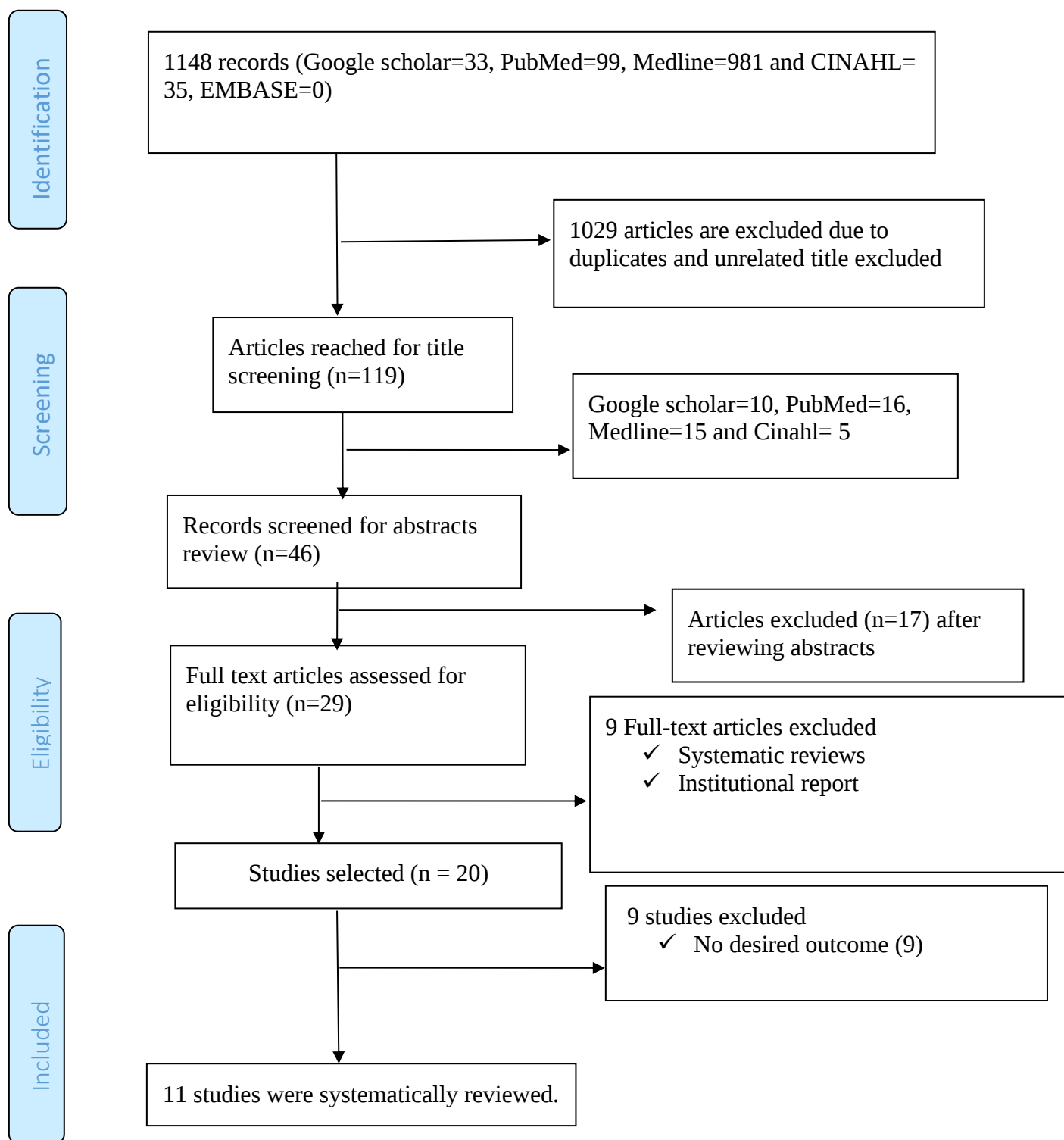
Intermediate care is considered a range of services designed to facilitate the transition from hospital to home and from medical dependence to functional independence. The primary objectives of care are not solely medical, as the anticipated discharge destination of patients is considered, with the desired clinical outcome being recovery or restoration of health. Intermediate care has been widely used to enhance stroke rehabilitation in discharged patients (Puhr and Thompson 2015; Prvu Bettger et al. 2012). Previous intermediate care interventions provided stroke patients with health education, emotional support, physical therapy, and medication reconciliation via telephone follow-ups and/or home visits. Despite the recent growth in their use as a bridge to care transitions, there is limited data on the impact of intermediate care on function-related outcomes in the

LMIC (Sezgin et al. 2020), especially among the older adult affected by stroke This study, therefore, aimed to systematically review the impact of intermediate care on functional health of older adult with stroke in LMIC.

4.2 Results

4.2.1 Study overview

The search results are shown in Figure 1, along with a synopsis of the papers consulted (the PRISMA flow chart). Although the databases contained 249 research articles, only 11 of them met the inclusion criteria for this systematic review (Figure 4.1). All articles reviewed were published between 2012 and 2022, with 25% published in 2018. Majority (85 %) of the studies were randomized control trial, and 25% were carried out in China. Summary description of eligible papers are in Table 4.4 and Table 4.5 shows commonalities and disparities among selected studies.



**Desired outcome: functional outcome and quality of life*

Figure 4.1: PRISMA Flow chart of the study selected.

4.2.2 Methodological Quality Assessment

All studies generally meet the criteria of the CASP assessment checklist (for randomized controlled trials) and JBI checklist (for quasi-experimental and longitudinal studies). However, there are variations in the consideration of the relationship between researchers and participants, ethical issues, and the clarity of findings across different studies. The assessment suggests that most studies are of good quality, but researchers should be aware of potential limitations in certain areas (Table 4.1 and 4.2).

TABLE 4.1: CASP checklist for assessing the quality of randomized controlled trial studies.

Author/ Year	Q1. Did the study address a clearly focused research question?	Q2. Was the assignment of participants to the intervention randomized?	Q3. Were all participants who entered the study accounted for at its conclusion?	Q4. Were the Participants/ investigator or or assessor/ analyst 'blind' to the intervention given?	Q5. Were the study groups similar at the start of the randomized controlled trial?	Q6. Apart from the experimental intervention, did each study group receive the same level of care?	Q7. Were the effects of the intervention reported comprehensively?	Q8. Was the precision of the estimate of the intervention or treatment effect reported?	Q9. Do the benefits of the experimental intervention outweigh the harms and costs?	Q10. Can the results be applied to your local population/ in your context?	Q11. Would the experimental intervention provide greater value to the people in your care than any of the existing interventions?
Chaiyawat and kulkantrakorn , 2012.	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Day <i>et al.</i> , 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Feng <i>et al.</i> , 2021.	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes
Olaleye <i>et al.</i> , 2013.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Nordin <i>et al.</i> , 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hsieh <i>et al.</i> , 2018.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Narayan <i>et al.</i> , 2012.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mei <i>et al.</i> , 2017.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

TABLE 4.2: JBI critical appraisal checklist for quasi-experimental and longitudinal studies

Author/year	Q1. Is it clear in the study what is the cause and what is the effect?	Q2. Were the participants included in any comparisons similar?	Q3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest	Q4. Was there a control group?	Q5. Were there multiple measurements of the outcome both pre-post the intervention/exposure?
Chen et al., 2016	Yes	Yes	Yes	Yes	Yes
Choi and Paik, 2018	Yes	Yes	Yes	Yes	Yes
Scheffler and Mash, 2019	Yes	Yes	Yes	Yes	Yes
Author/year	Q6. Was follow-up complete and if not, were differences between groups in terms of their follow-up adequately described and analysed?	Q7. Were the outcomes of participants included in any comparison measured in the same way	Q8. Were outcomes measured in a reliable way?	Q9. Was appropriate statistical analysis used?	
Chen et al., 2016	Yes	Yes	Yes	Yes	
Choi and Paik, 2018	Yes	Yes	Yes	Yes	
Scheffler and Mash, 2019	Yes	Yes	Yes	Yes	

4.2.3 Risk of Bias Assessment

The overall risk of bias varies across the studies. Eight studies have a low risk of bias across all domains (Chaiyawat et al, Chen et al, Choi et al, Nordin et al, Narayan et al, Feng et al, Scheffler & Mash et al, and Mei et al) while three studies (Day et al, Olaleye et al, Hsieh et al) have some concerns. It is essential to consider the risk of bias when interpreting the results of this study. Additionally, three studies are not randomized controlled trials (Scheffler & Mash et al, Choi & Paik et al, Chen et al) (Table 4.2 and 4.3).

Table 4.3: Evaluation of the risk of bias in the included studies by the Cochrane

Risk of Bias Assessment for RCT studies

Studies	RCT	Assignment of intervention	Adherent to intervention	Missing outcome	Measurement of outcome	Selection of reported result	Overall risk of bias
Chaiyawat and Kulkantrakorn (2012)	L	L	L	Some concerns	L	L	L
Day et al (2019)	L	L	L	L	L	Some concerns	L
Nordin et al, (2019)	L	L	Some concerns	L	L	L	L
Olaleye et al (2014)	H	Some concerns	Some concerns	Some concerns	L	L	Some concern
Narayan Arya et al (2012)	L	L	L	L	L	L	L
Mei et al (2018)	L	L	L	L	L	L	L
Hsieh et al. (2018)	L	L	L	L	Some concerns	Some concern	L
Feng et al (2021)	L	L	L	L	L	L	L

Table 4.4: Summary description of eligible papers for the systematic review

Author (year)	Study size	Study design	Country of study	Objectives/Research question	Outcome	Key Findings
Scheffler and Mash (2019)	160	Prospective, longitudinal survey design	South Africa	To describe and analyze the outcomes of patients with stroke from a rural PHC setting in the Western Cape, South Africa.	1.Functioning and independence 2.Caregiver strain 3. Patient and caregiver satisfaction	Outcomes of HCBC for stroke patients and their family caregivers in the Cape Winelands were poor. High dependence levels persisted and were exacerbated by environmental factors and poor assistive-product provision. Caregiver strain remained unchanged and patient and caregiver satisfaction with services were low. Referral guidelines to HCBC were absent and referral rates low. HCBC failed to provide seamless continuity of care following discharge from acute hospital care. Service provision was fragmented, of low intensity and short duration, and did not meet family and caregiver expectations regarding intervention and information needed.
Chaiyaw at and Kulkantra korn (2012)	60	A randomized controlled trial	Thailand	To develop and examine the effectiveness of individual 6-month home rehabilitation program in ischemic stroke patients upon	1.The Barthel Index (BI) 2.Modified Rankin Scale provides (mRS)	Early home rehabilitation program in the first 6 months period after ischemic stroke leads to more rapid improvement in function, reducing disability and increase quality of life than usual care

				disability and quality of life at 2 years.		
Narayan Arya et al., (2012)	103	A Randomized Controlled Trial	India	To evaluate the effectiveness of the meaningful task-specific training (MTST) on the upper extremity motor recovery during the subacute phase after a stroke.	Primary outcome measures 1.Fugl-Meyer assessment 2.Action Research Arm Test Secondary outcome measures 1.Wolf Motor Function Test 2.Motor Activity Log 3.Amount of use (AOU) 4.Quality of movement (QOM)	The MTST produced statistically significant and clinically relevant improvements in the upper extremity motor recovery of the patients who had a subacute stroke.
Olaleye et al., (2014)	52	Single-blind randomized clinical trial	Nigeria	To compare the outcomes of physiotherapy intervention on selected indices of recovery for stroke survivors treated at a primary health centre group (PHCG) with those treated in their respective places of	1. Modified Motor Assessment Scale (MMAS). 2. Short Form-Postural Assessment Scale for Stroke (SF-PASS	Physiotherapy intervention at the primary health care center and respective home of stroke survivors similarly improved clinical outcomes. Treatment at any locations may enhance access to physiotherapy after stroke in a low-income community like Nigeria

				domicile group (DG).		
Choi & Paik (2018)	24	A quasi-randomized, double-blind, controlled trial	Korea	This paper describes the development of a mobile game-based VR program and its use for patients who have experienced a stroke and suffer from upper limb dysfunction	1.To improve strength, endurance, range of movement, control, speed, and accuracy of movement in the upper extremities	The findings from the study show that the mobile game-based VR program effectively promotes upper extremity recovery in patients with stroke. In addition, patients completed two weeks of treatment using the program without adverse effects and were generally satisfied with the program.
Hsieh et al., 2018	24	A Randomized Crossover Trial	Taiwan	To investigate the treatment effects of a home-based rehabilitation program compared with clinic-based rehabilitation in patients with stroke.	1. Fugl-Meyer Assessment 2.Motor Activity Log (MAL)	Home-based rehabilitation resulted in significantly greater Improvements on the Motor Activity Log amount of use subscale (PZ.01) and the sit-to-stand test (PZ.03) than clinic-based rehabilitation. The clinic-based rehabilitation group had better benefits on the health index measured by the EuroQoL-5D Questionnaire (PZ.02) than the home-based rehabilitation group. Differences between the 2 groups on the other outcomes were not statistically significant.
Day et al., 2019	48	A randomized	Brazil	To evaluate the effect of home-care nursing intervention	Caregiver's Burden Scale	The Caregiver Burden Scale was applied to assess the burden outcome 1 week, 60 days and 1 year after hospital discharge. The caregivers of the intervention and CGs had no difference

		controlled trial		on the burden of family caregivers for older adults surviving a stroke.		regarding baseline data. There was an interaction effect between the CG and the IG in the isolation domain ($p = 0.037$) and in the emotional involvement domain ($p = 0.003$) over time.
Feng et al., 2021	120	a randomized trial	China	The purpose of this study is to explore the effect of HCISM in home rehabilitation of stroke disabled older adult	Self-care ability Compliance behavior General Self Efficacy Scale	The modified Barthel Index (MBI) score of the observation group after 3 months of intervention was higher than that of the control group ($P < 0.05$). In the observation group, the changes in the proportion of medication, reasonable diet, moderate exercise, and regular return visits after 3 months were higher than those in the control group ($P < 0.05$). The General Self-Efficacy Scale (GSES) score of the observation group was higher than that of the control group after 3 months of intervention ($P < 0.05$). Zung's Self-rating Anxiety Scale (SAS) and Self-rating Depression Scale (SDS) scores in the observation group were low after 3 months of intervention than those in the control group ($P < 0.05$)
Mei et al., 2018	75 couples	A randomized controlled trial	China	To evaluate the effectiveness of a modified 8-week reminiscence therapy on the burden, positive experience, and life	1.Barthel Index 2.Caregiver's Burden Scale 3.Positive Aspects of Caregiver (PAC) questionnaire 4.5-item Chinese version of the Satisfaction with Life Scale (SWLS)	The use of a modified 8-week reminiscence therapy in this study sample improved the life satisfaction of stroke survivors and their spouse caregivers, improved the positive experience of caregivers, and decreased the burden of caregivers.

				satisfaction of older spouse caregivers and the life satisfaction of stroke survivors.		
Nordin et al., 2019	90	A randomized controlled trial	Malaysia	To assess the effectiveness of a home-based carer-assisted in comparison to hospital-based therapist-delivered therapy for community-dwelling stroke survivors.	Mobility level, balance, lower limb strength and gait speed. Secondary outcome EQ5D-Health utility and EQ-Visual analogue Scale.	The home-based carer-assisted therapy is as effective as the hospital-based therapist-delivered training in improving post-stroke functions and quality of life.
Chen et al., 2016	341	Quasi experimental study	China	To evaluate the effectiveness of a modified home care model in China.	The following outcomes were measured and compared between the two groups: average length of hospital stay, satisfaction with acute hospitalization, ability to perform ADL; and rates of stroke recurrence, self-reported medication compliance, aspiration pneumonia, and stroke-related readmission.	Modified home care was associated with shorter acute hospitalization, higher compliance and ability to perform daily activities and a lower rate of re-hospitalization.

Table 4.5: Showing commonalities and disparities among selected studies of intermediate home-based care

Randomized controlled trial				
S/N	Author/year	Intervention	Provider	Effect/Impact
1	Mei et al., 2017	Home-based care modified reminiscence therapy (MRT)	Psychologist	- The 8-week MRT intervention at stroke couples produced a better outcome in caregivers' positive experience, life satisfaction, and life satisfaction of stroke survivors. - There was a significant reduction in burden in those caregivers who received the MRT than those who did not.
2	Choi and Paik, 2018	Game-based therapy	Occupational therapist	- Upper limb function recovery improved significantly in the intervention group compared to conventional therapy. - Gained improvements were fully maintained at one-month follow-up. - Improvement in the Fugl-Meyer Assessment of the upper extremity (FMAUE), B-stage, and manual muscle testing were greater with game-based therapy treatment than with conventional therapy
3	Olaleye et al., 2013	Domiciliary Group (DG) (Home-based care) received physiotherapy twice weekly for 10 consecutive weeks using a physiotherapy protocol	Physiotherapist	- DG showed a statistically significant increase in the postural balance scores. - DG and Control group demonstrated a significant increase in walking speed level of community reintegration from baseline to week 10 - However, there was no significant difference between the two groups at any point in time throughout assessment.
4	Nordin et al., 2019	home-based therapy	Home caregiver	Intervention and control groups demonstrated small but significant gains in all outcomes such as functional mobility, balance ability, functional lower limb strength and walking speed, and health-related quality of life on completing 12-week interventions.

				However, no significant difference was found between the groups.
5	Narayan Arya et al., 2012	Meaning Task-Specific Training (MTST)	Physiotherapist	- The beneficial effect of MTST on motor recovery began in the post-treatment phase and continued during the 8-week follow-up evaluation. - There was improvement in the sensorimotor recovery, functional use of the paretic upper extremity, and independence level of participants.
6	Hseih et al., 2018	Home-based rehabilitation Treatment: Mirror therapy and task-specific training	Physiotherapist	- Patients in the home-based group indicated higher improvements in the AOU of their paretic upper extremity in daily tasks measured by the Motor Activity Log-Amount of Use (MAL-AOU) and lower extremity force measured by the sit-to-stand test than the facility-based group. - The facility-based group demonstrated increased gains in the health status measured by the EQ Index than the home-based group. - No statistically significant difference in the outcome of both groups.
7	Chaiyawat and Kulkantrakorn, 2012	Home-based individual exercise program	Physiotherapist	After 2 years, a 6-month home rehabilitation intervention yielded increased gains and higher levels of functional independence and ability than did the conventional care
8	Feng et al., 2021	Home-based care: Hospital Community-Integrated Service Model	Multidisciplinary: Team approach which involved neurologists, rehabilitation therapists, head nurses, specialist nurses, community	- MBI and GSES score of the observation group after 3 months of intervention was higher than that of the control group ($P<0.05$) - In the intervention group, the changes in the proportion of medication, reasonable diet, moderate exercise, and regular return visits after 3 months were higher than those in the control group ($P<0.05$).

			doctors, and nursing staff	
9	Day et al., 2019	Home-based care for guidance on disease and care activities for older adult stroke patients	Nurse	- There was no difference between the intervention and control groups in the follow-up period regarding total burden, which increased in both groups, with control group having higher burden. - An interaction effect was found between the intervention group and control group in the isolation domain ($p = 0.037$) and in the emotional involvement domain ($p = 0.003$) over time
Non-experimental longitudinal study				
10	Scheffler and Mash et al., 2019	Home and Community-Based Care (HCBC) service	Community Health Workers	Results from the study revealed improved function but overall, poor patient and caregiver outcome and low satisfaction rates.
Quasi-Experimental study				
11	Chen et al., 2016	Intervention group received home based care based on healthcare services model and translational care model	Multidisciplinary team: chief physician, clinical pharmacist, psychologist, specialist dietician, rehabilitation therapist, specialist nurse and community nurse	- Outcomes were significantly better in the intervention group than in the control group. - Hom-based care was associated with shorter acute hospitalisation, higher compliance, and ability to perform daily activities and a lower rate of admission.

4.2.4 Existing Intermediate Home-Based Care

Of the eleven studies highlighted, nine employed randomized controlled trial designs, two other studies used longitudinal and quasi-experimental study designs. The interventions targeted older adult stroke patients and were administered either in a home-based or community-based setting. Various interventions were utilized, encompassing meaningful task-specific training, modified reminiscence therapy, game-based therapy, physiotherapy, mirror therapy, Hospital-Community Integrated Service Model, and Home-based guidance and care activities. The majority of the interventions were delivered by healthcare professionals, including psychologists, nurses, physiotherapists, occupational therapists, community health workers, or multidisciplinary teams. However, Nordin et al (Nordin et al., 2019) utilized carer-assisted therapy for intervention delivery. Regular follow-up carried out at different intervals was a common practice across intervention studies to ensure intervention adherence and enhance outcomes.

Narayan Arya et al. (Narayan et al., 2012) and Hsieh et al. (Hsieh et al., 2018) employed task-specific training administered by physiotherapists. Narayan and colleagues observed significant improvements in the sensorimotor and upper extremity recovery within the intervention group compared to the control group. The intervention group demonstrated superior improvement across all outcomes compared to the control group, including Fugl-Meyer assessment (FMA), $F(1, 100) = 16.34$, $P < 0.001$) at post and follow-up assessments, Motor Activity Log-Amount Of Use and Quality Of Movement ($F(1,100) = 56.79$, $P < 0.001$; $F(1,100) = 57.09$, $P < 0.001$, respectively) at post and follow-up

assessments. The FMA was designed by Fugl-Meyer to provide a numeric score of motor status post stroke based on the sequential stages of motor recovery using measures such as limb synergy and range of motion (Fugl Meyer et al., 1975; Twitchell et al., 1951). The Graded Wolf Motor Function Test (GWMFT) time significantly decreased ($F(1,100) = 21.72, P < 0.001$) at post and follow-up assessments, Action Research Arm Test (ARAT) scores, including its subitems (grasp, grip, pinch, and gross movements) significantly changed ($F(1, 100) = 24.47, P < 0.001$ from pre-test to post-test. Hsieh and colleagues (Hsieh et al., 2018) combined mirror therapy with task-specific training. The intervention included a crossover period for the home-based and facility-based rehabilitation groups. Consistent with the Narayan et al (Narayan et al., 2012) report, participants in the initial home-based group showed better improvements in the Motor Activity Log ($P=0.01$) and sit-to-stand test ($P=0.03$). However, the initial facility-based participants reported superior improvements in health status measured by EQ-Index compared to the home-based group ($P=0.02$). there was no statistically significant difference between the groups on other outcomes ($p=0.21 - 0.86$). Furthermore, physiotherapist-led home-based care conducted by Chaiyawat and Kulkantrakorn (Chaiyawat and Kulkantrakorn, 2012) observed greater gains in functional outcomes such as Barthel Index (BI), Modified Rankin Scale (mRS), and utility index in participants recruited to home-based rehabilitation group with statistical significance of $p < 0.001$, $p=0.02$ and $p=0.03$ respectively. Additionally, Choi and Paik (Choi and Paik, 2018) employed a mobile game VR upper extremity rehabilitation programme (MoU Rehab) to achieve functional recovery in older adult stroke patients. The MOU Rehab utilized improved FMA-UE and manual

muscle testing in the intervention arm. However, there was no statistical significance between the groups regarding FMA-UE ($p=0.735$).

Other studies have yielded divergent findings. Olaleye et al. (Olaleye et al., 2014) and Nordin et al. (Nordin et al., 2019) employed physical therapy for the functional recovery of participants, utilizing trained physiotherapists and home caregivers, respectively for intervention delivery. The intervention group received home-based rehabilitation while the comparators group underwent facility-based therapy. Results from Nordin et al. (Nordin et al., 2019) revealed significant improvement in all functional measures for both therapy groups: mobility ($p < 0.01$), balance ($p < 0.01$), lower limb strength ($p < 0.01$), and gait speed ($p < 0.05$). Olaleye et al also reported statistical significance in outcomes within the two therapy groups: motor function score ($p=0.01$), postural balance score ($p=0.01$), and walking speed ($p=0.01$). However, the two studies found no significant difference in outcomes between the intervention and control groups, suggesting the likelihood of similar outcomes for home-based and facility-based rehabilitation.

In a randomized controlled trial, Feng et al. (Feng et al., 2021), specifically employed a multidisciplinary approach in delivering Hospital Community-Integrated Services Model (HCISM) to older adult stroke patients recruited in the intervention group for home-based care. Implementation of the model began from patient admission to discharge to community health facility and to eventual home discharge. The uniqueness of this model lay in the incorporation of personalized care for older adult stroke patients, with intervention plans tailored to specific patient needs. The control group received routine

home rehabilitation knowledge, training guidance, and encouragement to ensure medication compliance. Outcome measures were assessed after 3 months of intervention. Results revealed improved Modified Barthel Index (MBI) score ($p<0.05$) and General Self Efficacy Scale (GSES) score ($p<0.05$) in the intervention group than in the control group. Zung's Self-rating Anxiety Scale (SAS) and Self-rating Depression Scale (SDS) scores in the intervention group showed significant reduction than those in the control group ($p<0.05$).

Mei et al. (Mei et al., 2018) conducted a randomized controlled trial using a psychologist-led MRT intervention for 8 weeks. The participants were categorized into three groups. Group 1 consisted of couples who all received MRT. Group 2 included only spouses who received MRT, and Group 3 (control) received routine health education. Overall, participants in Group 1 experienced a significant improvement in caregivers' positive experience, life satisfaction, burden, and life satisfaction of stroke survivors ($p<0.001$). In Day et al. study (Day et al., 2021), the intervention group received three home visits within a month post-discharge by nurses to provide guidance on the disease and care activities for older adult individuals. The control group relied on the service network for access. The study reported no significant difference between the intervention and control groups concerning the total burden at the one-year follow-up period ($p=0.708$). However, there was an interaction effect between the control group and the intervention in the isolation ($p=0.037$) and emotional involvement domain ($p=0.003$).

A longitudinal study conducted by Scheffler and Mash et al. (Scheffler and Mash, 2019), applied HCBC provided by community health workers (CHWs). Despite improving functional outcomes ($p = .019$) from 40.0 (IQR 15.0–70.0) to 62.5 (IQR 30.0–81.25), a high level of dependence persisted, and low satisfaction rates were recorded for both patients and caregivers in all aspects. Poor patient outcomes were linked to inactive engagement of CHWs in assisting stroke patients to achieve functional goals.

Chen et al (Chen et al., 2016) conducted a quasi-experimental study design using a multidisciplinary approach to deliver home-based care. The intervention group significantly outperformed the control group. Study outcomes indicated that the intervention group showed a shorter average length of hospitalization (11.29 ± 2.18 vs. 12.36 ± 4.33 d, $p = 0.03$), increased ability to perform activities of daily living (38.25 ± 10.22 vs. 32.08 ± 10.32 , $p = 0.03$), lower rates of readmission [2 (1.19%) vs. 11 (6.36%), $p = 0.02$], increased medication compliance [161 (95.83%) vs. 92 (53.18%), $p = 0.004$] and a higher rate of satisfaction with acute hospitalization [168 (100.00%) vs. 142 (82.08%), $p = 0.01$]. Chen et al. (Chen et al., 2016) and Feng et al. (Feng et al., 2021) employed different study designs. However, similarity in their results suggests that considering a multidisciplinary approach has great potential in achieving significant improvements in patient functional outcomes and quality of life.

Among the studies, Nordin et al (Nordin et al., 2019) and Chaipayat and Kulkantrakorn (Chaipayat and Kulkantrakorn, 2012) specifically stated improved health-related quality of life in stroke survivors of their study. Using the utility index, Chaipayat and Kulkantrakorn (Chaipayat and Kulkantrakorn, 2012) reported a significant increase in

quality of life scores in the two study groups with significantly higher improvement in the intervention group (intervention group 0.9 ± 0.02 and control group 0.7 ± 0.04 , $p = 0.03$). Nordin et al measured quality of life using EQ5D Health utility score. Although both groups had significant improvement in the quality-of-life score ($p < 0.05$), there was no statistical difference.

4.2.5 Existing Gaps in the Intermediate Home-Based Care

Gaps identified in the selected studies could be linked to various factors. However, the majority of the gaps highlighted were due to methodological limitations. In one of the studies, Scheffler and Mash (Scheffler and Mash, 2019) reported the possibility of recall bias if proper measures were not taken in the data collection procedure. The same study recognized probable variation in data quality due to a high number of research assistants used. The inclusion of only ischemic stroke with middle cerebral artery infarction in the Chaiyawat and Kulkantrakorn (Chaiyawat and Kulkantrakorn, 2012) study limited the applicability of the findings to populations with other types of stroke. Conducting research that includes other types of stroke will establish the possible benefits for such a population. In two of the studies reviewed, Mei et al. (Mei et al., 2018), and Choi and Paik et al. (Choi and Paik 2018), reported the use of a small sample size. This undermines the internal and external validity of the studies and limits their generalizability. In the Hsieh et al. (Hsieh et al., 2018) study, treatment and duration frequency for home-based stroke rehabilitation were designed based on the authors' discretion. The justification stated was the non-existence of an established treatment and duration frequency for home-based stroke rehabilitation. Another limitation highlighted was the inability to provide an

estimated cost of home-based care. This should be put into consideration for future studies to ascertain a standard for home-based therapy in this context. Aside from methodological limitations, the presence of confounders may affect the presented outcomes if not adjusted. Day et al (Day et al., 2021) documented that caregivers received assistance from the facility, and this might influence the eventual patient and caregiver outcome. Similarly, Olaleye et al. (Olaleye et al. 2014), reported that study participants could receive other forms of treatment together with the intervention which could have an impact on the recorded outcomes. Additionally, implementing individualized care was unachievable owing to the inability to obtain necessary baseline data that could inform the design of such therapy. For instance, Choi and Paik et al. (Choi and Paik, 2018) acknowledged missing kinematic data which could assist in optimizing individualized rehabilitation therapies. These identified gaps and limitations underscore the necessity for further research to address these issues and enhance our understanding of the effectiveness of intermediate home-based care for stroke patients.

4.3 Discussion of results

This study underscores the effectiveness of home-based care options which include physical therapy, occupational therapy, speech therapy, and meaningful task-specific for training patients (Chaiyawat and Kulkantrakorn, 2012; Narayan et al., 2012). Notably, task-specific training exhibited superiority over impairment-focused training, leading to improved motor recovery and functional use of the affected upper extremity when conducted over an extended period (Narayan et al., 2012). Consistent with these findings, other studies have robustly supported the efficacy of task-related motor training in enhancing gait and gait-related activities post-stroke (Verma et al., 2011; Johansson

et al., 2012). Bilateral training procedures, such as meaningful task-specific training (MTST), have shown particular benefit for tasks involving the activation of proximal muscles, highlighting the role of bilateral descending pathways in proximal musculature (Rose and Winstein, 2004). In patients with subacute stroke, the MTST has been associated with enhanced motor recovery, reduced activity limitation, improved time and quality of movement, and increased use of the paretic arm and hand during ADL.

Furthermore, a systematic review comparing home-based and centre-based rehabilitation for stroke patients in communities emphasized the functional advantage of home-based care, suggesting that individuals adapt better to residual impairments when receiving home therapy (Hillier and Inglis-Jassiem 2010; Anderson et al., 2000). Stroke-related impairments are more apparent in patients' homes or everyday circumstances, making it easier to tailor rehabilitation programs to individual needs. noticeable in patients' homes or everyday circumstances, making it simpler to customize rehabilitation programs to patients' indicated requirements. It could also be that patients are better able to develop adaptation strategies to compensate for the apparent impairments when at home than in other environments. Olaleye *et al.*, (Olaleye et al 2014) reported a statistically significant improvement in postural balance over 10 weeks, highlighting the effectiveness of balance training when related to a specific task (Bayouk et al., 2006). Stroke survivors training their balance using Ber Balance Scales's domains have been associated with improved community reintegration (Au-Yeung et al., 2003; Hamzat and Fashoyin, 2007) emphasizing the importance of balance function in social integration post-stroke. The study emphasizes the critical connection between improved motor function and

community reintegration, as functional status significantly influences social integration post-stroke (Baseman et al., 2010).

4.4 Strengths and Limitations

While our study exhibited thoroughness in study selection, screening processes, search strategy, and quality assessment, there are noteworthy limitations. The primary limitation lies in the single-reviewer approach for title, abstract, and full-text screening.

Despite these limitations, our review successfully identifies gaps in the existing home-based model, highlighting the crucial role of intervention and rehabilitation programs in improving the functional health of individuals living with stroke. However, diverse methods used in the reviewed articles posed challenges in evaluating the impact and effectiveness of interventions.

4.5 Conclusion

In conclusion, the study provides significant data supporting the effectiveness of the existing intermediate home-based care model, emphasizing positive impacts on motor recovery, quality of movement, motor acquisition, walking speed and postural balance. Identified home-based intermediate care options for older adult stroke patients include Physical therapy, occupational therapy, speech therapy, and meaningful task-specific training. The study not only highlights the positive functional outcomes of these interventions but also underscores existing gaps in the current home-based care model due to varying methodologies. The findings emphasize the importance of continued research to refine and optimize interventions for individuals living with stroke, thereby enhancing overall functional health.

Chapter 5

Perspectives of Stakeholders (Family Caregivers, Formal care providers and Community gatekeepers) in the implementation of Intermediate Care Model for Older Adult Stroke Survivors in Southwestern Nigeria: A Qualitative Study.

5.1 Introduction

Stroke survivors have the likelihood of experiencing a decrease in functional ability and increased stroke risk factors (Dhamoon et al., 2017). Often, they are discharged home with multiple preexisting comorbidities and without a plan for rehabilitation and recovery (Duncan et al., 2021). Caregivers need proper guidance to provide adequate and appropriate aged care to reduce hospital readmissions (Martins et al., 2011). Comparable to acute stroke intervention, intermediate care could improve longevity and quality of life (Duncan et al., 2021). Evidence showed that initiative programs for family caregivers such as training intervention after hospital discharge could produce beneficial effects on stroke survivor's recovery (Kalra et al., 2004; Alim et al., 2016). Given the benefits of intermediate care, Nigerian older adult stroke survivors are often discharged home for continuous care by informal caregivers who have little or no knowledge of intermediate care, hence the recorded high incidence of post-stroke mortality. It is therefore imperative to explore the perspectives of various stakeholders (including healthcare providers, family caregivers, patients, and community leaders) regarding the implementation of an intermediate care model for older adults recovering from a stroke. The study findings could inform the design of a culturally acceptable intermediate care model for better patient outcomes among the Nigerian population.

5.2 METHODS

5.2.1 Data collection procedure

After potential participants consented to participate in the study, interviews were subsequently scheduled at the participants' convenient time. FGD and KII methods were to answer the objectives of the study. Open-ended questions which included main and follow-up questions for clarification were developed by researchers to facilitate interviews. Sociodemographic characteristics of participants and stroke-related questions (e.g. caregivers' experience of stroke management, rehabilitation services in the post-stroke phase etc.) were captured in the interview guide (Appendix 2, 3, and 4). All informal caregivers participated in FGD which took place at the Geriatric Centre, University of Ibadan. Participants were informed that their responses would be audio-recorded and given ground rules before the commencement of the interview. Each FGD, moderated and audio-recorded by respective research assistants, lasted for about 60–90 minutes. KIIs were conducted and audio-recorded at the respective offices of formal caregivers and a pre-selected community hall for community stakeholders. The average duration of KIIs was 30 minutes. FGDs and community stakeholders KII were conducted in Yoruba language while formal caregivers KII was conducted in English Language. Interviews were conducted between January 2023 to March 2023.

5.2.2 Data Management and Analysis

Audiotapes were translated, transcribed verbatim, and checked by the researchers for data quality and accuracy. All identifiers were removed from interviews after transcription. Nvivo 12 software for qualitative data analysis was used. An inductive-dominant approach was used to facilitate data analysis. The data analysis process included coding,

sub-coding, categorization, categories, and identification of themes/subthemes. Throughout the analysis, the transcribed data was repeatedly returned to, to ensure to ensure authenticity and accuracy. Quotes that best illustrate each theme/subtheme were provided within the result section for reader scrutiny.

5.3 Results

5.3.1 Section A: Socio-Demographic Characteristics

Table 5.1 shows the socio-demographic characteristics of the study participants. Thirty-four respondents/participants participated in this study with a mean age of 47.53 ± 14.0 years. Most participants were between 35 and 59 years old, with more than half (55.9%) females, 76.5% were married, married (84.7%), and 94.1% were Yoruba.

Table 5.1: Socio-demographic characteristics (N=34)

Socio-demographic (N=34)	No	%
Age*		
22-34	7	20.6
35-59	20	58.8
60 and above	7	20.6
Gender		
Male	15	44.1
Female	19	55.9
Marital Status		
Single	6	17.6
Married	26	76.5

Educational Qualification (n=26)		
No formal	2	7.7
Primary	3	11.5
Secondary	8	30.8
Tertiary	13	50.0
Religion	20	56.9
Christianity	12	43.1
Islam	2	5.9
Traditional		
Relationship with Patients		
Son	7	38.9
Daughter	6	33.3
Wife	5	27.3
Ethnicity		
Yoruba	32	94.1
Igbo	1	2.9
South-South	1	2.9
Duration of care given (months) (n=18) **		
1-23	13	72.2
24-48	4	22.2
49 and above	1	5.6
Patients age (Years) (n=18)***		
60-70	32	94.1

**Participants mean age 47.53±14.0; **Mean duration of care 16.11±17.8;*

****Patients mean age 69.7±7.8;*

5.3.2 Section B: [Experiences in stroke management](#)

5.3.2.1 Experiences about stroke management of a family member/significant other: Most

of the female FGD participants reported that their experience was a difficult one because they had to help the hospitalized family member/significant other with their daily routines, either eating, bathing or using the toilet as they could not do them on their own. Some reported that they also experienced financial difficulties as they were asked to get different drugs and do various tests daily. It was also added that few participants experienced stress from running around to get medicines and tests apart from the financial challenges. One of the participants specifically;

"The experience I have, one of the experiences is the issue of money and the issue of you running around to get drugs. The experience is we couldn't get enough money to buy some of those drugs. Another experience is that different doctors attend to them when hospitalized. One doctor will come today, we will buy the drug, and another will come tomorrow and give you another test. I sometimes stand up to challenge them when they ask me to buy drugs; I ask many questions. At times, I have to look at which other. I tell them that I can't afford it."

However, few participants said their experience was that their family member/significant other had been suffering from ailments like severe headaches and low potassium. They were treated, not knowing it was a stroke attack. A participant said;

"We didn't even know that it was a stroke because he was managing some things; they said the potassium is low, something is low, that is what we came to the hospital for and was discharged, and we got home we even

had some visitors, we did a meeting. On the third day, we noticed that as he was watching the ball, his voice changed; we asked him to get up, but he couldn't, and then immediately we had to call a family who was working here, who is a professor here, he said we should bring him to the hospital. Then, we noticed that they said we should go and do all these things, MRI. He was there for seven days, and the hand returned, and it was only the leg."

Most of the male participants also reported financial difficulties and stress they experienced when their family member/significant was hospitalized for a stroke. Furtherly, some participants added that they experience behavioral changes/ mood swings from the family member/significant other hospitalized for a stroke, like laziness/inability to do what they were doing before hospitalization, getting easily angry, and angry being aggressive. One of the participants specifically said;

"The experience I have is that it is difficult, the kind of stress we pass through in hospital; another thing is that doctors are trying, but it was difficult to get water from east 3; I will have to come to the ground floor. That's my experience in UCH, water."

However, few participants mentioned that their family members/significant others suffering from a stroke were not initially hospitalized. They were given home treatment by a doctor and procured a massage machine. Other experiences mentioned by the

participants were good food management by providing a balanced diet, regular exercise, and regular usage of drugs.

5.3.2.2 Information and or support received at the facility: Most of the female FGD participants mentioned that they were given information on the type of food that should not be eaten by the patients, like sugary food, fresh fish, or liquid milk, and that the patient should have some minutes of walking with assistance. Half of the participants also reported that the only information given at the hospital was that they should go for tests and get drugs. One of them specifically said;

"When we called the doctor, he told us to do a CT scan which we did that night. We were initially given film before we got the report. Later we were told to do several other tests, such as ECHO. The doctor gave us an appointment for two weeks. When we went for the appointment with the results, he told us that mama had a stroke and would direct us to the neuro-clinic, so he told us to see an appointment for yesterday to see a neuro-doctor. The general doctor also prescribed some drugs for her: Vitamin E, Vitamin C 500mg."

However, two of the participants mentioned that no information was given at all. One of them added that the support he expected they would provide is the aspect of NHIS (National Health Insurance Scheme), but they didn't have any. Another participant reported that she was supported by reducing the admission fee and given free drugs and

massage. She also added enough information was provided because she always asks questions. The participant said specifically;

"That was in Lagos; they tried; I have some matron and nurses that said if it is something 7'0 clock, they will tell me not to worry. They supported this by reducing the admission fee. Because she's an older woman, we were given drugs for free, and they supported us by helping us sometimes with the massaging and all that stuff. I was given information because I asked a question like what, why, what is the cause because, you know, my mother is a very agile person they now said thinking, high blood pressure caused and we didn't know she has that, she has it. After all, we don't use to do tests for her. So, they said that caused it because too much of, I mean too high of that blood pressure. So that was the information we learned. Because of that time, she couldn't talk or do anything. I asked if she could walk, and they said yes if we could follow her up and all those stuffs, so we were given some instructions about doing much exercise, making her happy, talking with her, and letting her carry weight."

More than half of the male participants said they received different types of information at the hospital, like following the doctor's drug prescriptions, the type of food to be given, using drugs with monitoring, not stressing the patient with arguments, and doing exercise by the patient, among others. A participant specifically said;

"It helped us because before, we thought it was a spiritual problem. We thought maybe we would see a traditional medicine that would

cure it, but when we heard from a doctor that it was a stroke and could be treated with exercise, we started doing it. And we've been doing it about three times a week, once in a general hospital and twice in Wesley."

When asked how it was provided, most female participants reported that the doctor provided the information during consultations while explaining what caused the problem, while few noted that it was delivered during ward rounds.

5.3.2.3. The usefulness of the information: Most participants reported that the information was helpful because they could see some improvement after following the information. One of the participants specifically said;

"It was useful because when the doctor told me that the vein was getting blocked, I was surprised and had to say God is great; the doctor said old age does cause it. The information was useful because we also learned from it and got exposed to more experiences. What we don't know before, we got to know about it."

More than half of the male participants reported the information to be very useful because there had been changes in their knowledge of stroke and their family member's health. One of the participants said;

"It helped us because before, we thought it was a spiritual problem. We were thinking maybe we would see a traditional medicine that would cure it,

but when we heard from a doctor that it was a stroke and could be treated with exercise, we started doing it. And we've been doing it about three times a week, once in a general hospital and twice in Wesley."

5.3.2.4 Unmet needs for information and social support training: Some of the female participants mentioned training and information on "seizure," were not given, information on the test result, and not be able to treat insomnia affecting her family member that was hospitalized. One of the participants specifically said;

"What I can say I expect them to tell us here is that it was eye treatment we brought here, he has glaucoma, and we were directed to general outpatient that he needs to see a doctor for his health. After seeing the doctor, we were directed to the Geriatric. At the Geriatric here, they prescribed some tests for us, and we did it. So, I expected the doctor to explain the test result and tell us what happened to Daddy, but he just collected the test, prescribed drugs, and gave us the next appointment. On getting here for the appointment, he prescribed another test worth #100,000, and for the initial one, we did; the doctor didn't explain to us."

A few of the male participants mentioned that their unmet need is the inability of the physiotherapist in the hospital to spend more time with the patient and that there are machines that could help with the patient's recovery that the physiotherapist in the hospital failed to use or give information on. Furtherly, some participants reported details

on how long a drug should be used, expected side effects of some medicines, and patients' recovery period as unmet needs. One of the participants specifically said;

"I can say that the doctors are trying and cannot express what they read in the book about the illness. Those outside with the experience of the illness know what the patient will use for them to recover. Like in the hospital now, we have physiotherapy, but there are some things they are meant to tell us and didn't. Outside the hospital, those with experience will tell us the kind of machines and things we should buy, and it is helping the patient. Another thing is doctors prescribe drugs for us; I don't understand how the patient will be using it for life or if it has a stopover for some time, and maybe some drugs will be added or removed. That's one of the things that I don't understand. That's one of the things that made me come today to know if the drugs will be continued for life."

5.3.2.5 How would you have loved to receive this information and training: The majority of the female participants said they were ready to receive any information on training regarding stroke and its maintenance. A participant specifically said;

"I would receive it. Stroke experts can lecture us to know more about the disease because what is baffling me is that she doesn't have high blood pressure. After all, I've heard that someone with high blood pressure can easily develop a stroke. The one she did yesterday was 100; on Friday, it was 110. She has never nursed high blood pressure; she does not have diabetes; she doesn't have any sickness."

More than half of the participants said they would take training or information to help their family member's recovery. A participant added that she wanted to be given details on the type of ailment and how to prevent future occurrences. A few male participants said they would be glad to receive the training if informed a few days before the move. Two other participants noted that in as much they are being given necessary information as when needed, there won't be any problem or need for training. One suggested providing more doctors to allow enough time for consultation. A participant specifically said;

"Why won't we receive it; we would receive it. When they wanted to give the first one, it was that morning we were called to report to Ibadan at 10:00 am. That's why I said it's not possible to come. I prefer to be informed about three to four days before the training day."

5.3.3 Section C: Community gatekeepers perceived social and welfare support needed by older adult stroke patients.

5.3.3.1 Opinion on support for stroke patients after being discharged from the hospital:

When asked whether a stroke patient needs help after being discharged from the hospital, all the community gatekeepers agreed a stroke patient needs help after being discharged. Half of the respondents reported a lack of strength. Others said they needed to monitor their condition, such as using prescribed drugs and doing particular tests, which is why stroke patients need support after discharge. One of the respondents specifically said;

"I thought they could assist the patient because of everything he wants to take or do. If he wants to cook and he doesn't have the strength to cook the

food he wants to eat at that particular time, the person will assist him. Getting water for bathing, he wants to be jovial; they want to share stories when the patient is happy, he won't have negative thoughts on if he can be able to associate with his contemporaries. Stories, tales, and songs will relieve the person; it won't make the person have a heavy heart, which may lead to hypertension and worsen the condition."

5.3.3.2 Help offered to a stroke patient that is recovering before All the community gatekeepers said they have been of help to at least one recovering stroke patient before, including their family members. It was reported that their service was essential to support (such as helping them to sit, stand, eat, use a toilet, and change their bedding), money, foodstuff, and herbal medicine. One of the respondents stated that:

"My mother died of a stroke and was with us for two years. She lost mobility, and we must carry her with that, put her in bed, support her to sit down to eat, and regularly monitor her toileting and other things. I usually do that with my wife and children taking the necessary care."

Another respondent reported that:

".....aha... its many. I've been in this ministry full-time for the past 23 years, so I can't count the number of people I've helped. I render the help I can afford, like assisting them and giving them money every month. Sometimes give them money according to the number of people that needs it."

5.3.3.3 How an older adult stroke patient can be supported in the community: Majority of the community gatekeepers said an older adult stroke patient in the community can be supported financially, morally, materially, and also by caring for and educating them. One of the community members specifically stated:

".....we should educate him/ her on the importance of adequate food and heavy foods should be avoided and if they want to eat it because I've been to the training....if they want to eat dinner, they should do so around 6 pm so it can digest on time and we will educate them on using their drugs as expected. The drugs they use sometimes don't affect modern medicine's usage. They can use their drug in the morning and eat the local soup in the afternoon. But if it's a concoction, I can tell them to drink it in the morning and use the drug in the afternoon. One drug does not affect the other because the drug is a daily thing."

5.3.3.4 What can be improved in the community to help older adult stroke patients: Many community gatekeepers said home visitation to check on their well-being and assist their caregivers. The respondents also mention giving them moral support, practicing an excellent hygienic environment, awareness creation, and support from the Government.

5.3.4 Section D: Strategies that promote interpersonal relationships between formal and informal care providers on home-based care treatment.

5.3.4.1 Role in the management of stroke in the older adult: When asked about the roles played in the management of stroke in the older adult, the majority of the formal caregivers stated that they help rehabilitate the patients. A respondent specifically said;

"...we take history we physically examine from there; of course, you will know if it's a stroke, and of course, there are other things that can present like a stroke, so before you can make a definitive diagnosis of a stroke, you will need a brain CT scan that would make that diagnosis and exclude other things that can mimic stroke symptoms, and after the diagnosis is made, we go ahead and try and reduce the effect of the stroke on the body."

One-quarter of the respondents also said they offer assistance and support to the older adult affected by stroke. A respondent stated that:

"...I am involved in the care of the older adult to get social support for them. Especially in the area of daily living, areas where assistance is required to get social support for the patients, especially for them to be able to cope well so that patient will not suffer, so I take part or am involved in social activities."

Additionally, it was stated by a few respondents that their roles in managing stroke in older people are educating people, living active lifestyles through drug compliance, and exercising compliance to prevent them from having a stroke.

Most of the female FGD participants mentioned that roles they performed at home to help their older adult that are recovering from a stroke were helping them with their daily routine; bathing, feeding, use of the toilet, a routine checkup of blood pressure and glucose, and assisting and monitoring them with drug intake, among others. One of the participants specifically said;

"In the morning, I wake up at four, and I will pray, waiting for him to wake up; immediately he wakes, I'll do his routine checks, BP and sugar, then I'll give him a glass of water to drink; after that, I will ask him to get down from bed, will assist. I have a career will assist in taking him down then brushing his teeth, then we give him a banana, he takes his drugs, BP drugs; after that, he will eat, then take his sugar drugs and other drugs, then we walk him to the sitting room so that he doesn't sleep there, but after sometime after taking lunch, I walk him back to the room to have some rest. We bathe him at times when we say we want to bathe him; he says he doesn't want to, but it is in the evening. At times, in the morning today, he bathed. So those are the things that we do."

Provision of presentable food, cleaning of their wear and keeping their surrounding clean, assisting/advising them to do to try things the way they did before, and exercising, among others, are mentioned by most of the male participants as roles they performed at home to help their older adult that are recovering from a stroke. One of the participants specifically said;

"Some of the roles are the provision of food that are presentable. They shouldn't eat what they are not meant to eat. Secondly, their house should be cleaned, their clothes should be neat and monitored, and the plates, bathroom, and toilet should be monitored and prevented from bad odor so they won't relapse in recovering from the illness. If the person can do ten

things before, once the illness begins, hardly will the person be able to achieve one thing."

5.3.4.2 Specific services rendered while on admission: Majority of the formal caregivers stated that assessing the patients to identify what they require, like optimizing their breathing if unconscious, was one of the specific services proffered. One-fourth of the respondents also said that encouragement and counseling to patients and relatives was one of the services provided while rendered on admission. It was claimed that this was being done to prevent the illness from affecting their health. A respondent stated that;

"...Number one is to counsel the patients about the medical condition and how to cope. We counsel the relations because we have to carry them along. If we don't carry them along, if they are not carried alone, it will not work well for that patient because they might be reacting or overreacting, and they will not understand the patient. But when they understand the medical conditions, they can emphasize with the patient."

Additionally, some respondents stated that they proffered rehabilitation services to patients during admission. One of the respondents specifically said;

"We monitor their vital signs; if their blood pressure is higher than a certain value, we go ahead and try and reduce it; otherwise, the first 48 hours, there is a certain blood pressure you would need to, you try and increase perfusion to those part of the brain that has been affected, and so we go

ahead. If it's an ischemic stroke, you want to anticoagulant, so we give antiplatelet and aspirin. As a guideline, we give anti-lipids and anti-oxidants to help the brain recover. Of course, after identifying the risk factor for the index stroke, you go ahead and manage accordingly...."

Prevention was also stated as a specific service offered to the patients while on admission. A respondent specifically said;

"...Our target is to prevent any recurrent stroke, so identifying what cause the stroke is important in which different things can cause it, modifiable factor, non-modifiable factor, the fact that we are blacks, commoner in men then hypertensive patients, diabetic, dyslipidemia, these last three are the commonest modifiable factors...."

5.3.4.3 Specific services rendered after discharge: Some of the formal caregivers mentioned that follow-up is one of the particular services rendered after discharge; however, a respondent said no services are rendered after discharge. A respondent specifically said;

"...follow-up, hypertension, you have to follow-up and make sure that the blood pressure is well-monitored and controlled; if there is any heart condition, atrial fibrillation, you ensure they take their medication to ensure any clot formation. Follow-up is essential..."

Continuity of care was stated as one of the specific services rendered after discharge because most patients do not stay up to the end of treatment, resulting in zero

achievements. Additionally, educating patients on stroke was one of the specific services to be rendered after discharge. The importance of preventing reoccurrence and taking prescribed medications was also taught to the patients upon discharge. A respondent said;

"We explain to them what caused the stroke and the importance of preventing the reoccurrence; when we are discharging the patient home, our pharmacist will do a lot of job in explaining the importance of drugs; we also educate them about their condition and how important it is to abide and adhere to their medications...."

Provision for carers to stay with the patients was one of the specific services rendered after discharge. The environment where the patients will be visiting will be checked to see if conducive enough. A respondent stated that;

"...Maybe the patient cannot mobilize or use the upper or lower part of the limb, so when they are about to be discharged, we have carers who stay with the patient. We need to know about the environment. Is it conducive? If the patient is going to be in a wheelchair, what about the place? Is it going to be modified?"

Spiritual support: Almost all the female FGD participants said they provided spiritual help by praying, worshiping, and singing praise. A participant said;

"As we are praying, which is even the most important at times when the situation goes beyond control, like when she spoke about convulsion, that

convulsion comes regularly, we pray, so when it happens, it is the only prayer that remains, we pray."

Only half of the male participants said they provide spiritual support in prayers, medicine, and drinks. One of the participants said;

"Yes, I do. I have been praying for my dad, though, and with the help of prayers and some spiritual medicine, he regained his consciousness, believing that the stroke will become history in his lifetime."

Domestic chores: More than half of the female FGD participants reported domestic assistance in household chores as one of the roles they performed for their older adult recovering from a stroke. One of the participants said;

"I do everything, apart from the fact that she has a stroke; she is old, so I am the one doing the chores."

Half of the male participants also responded that they provide domestic support for their older adult recovering from a stroke. A participant said;

"That's another thing, in all house chores, we are the one that helps her...in the washing of clothes, bathing because they are supposed to be very neat...cleaning her room, her environment shouldn't be dirty such that they won't be thinking that if their hands are functioning well, they would have done the chores themselves."

Exercise: Most female FGD participants reported that they do help their older adult recovering from stroke with exercises like massaging their hands, legs, and every other affected area. A participant specifically said;

“We help her in...there is this thing they gave her in Lagos to be using to stretch her hands, so we use that on all the time...it’s like an elastic thing like this, I don’t know the name the thing, but it’s like an elastic thing like this so she uses it to stretch her hands and her legs.”

Half of the male participants said they support their older adult recovering from stroke with exercise by getting machines that could make exercise easier, general body massage, and learning physiotherapy skills through media. A participant specifically said;

“Like my mother now, we order some machines from the United States, her hands that couldn’t stretch well, she puts her hand into that machine to exercise the hand...there is another one called rider machine that she uses...she will stay on it and ride it.”

Medication: Most female FGD participants said they help serve medicines at home for their older adult recovering from a stroke. A participant said;

“We make sure we give him his drugs, then we give him food and fruits; that’s what we do.”

However, another participant reported no need to help serve the drug because the patient knew the dosage. Almost all of the male participants said they do help their older adult

recovering from stroke by administering their medications, and that had been their daily routine. A participant specifically said;

“Yes, that stuff; I took it as a routine; before I go out in the morning, I rub her body after her bath. I will ensure she uses her drugs before I leave in the morning. That is the secret of her, you know, getting well, recovering quickly.”

5.3.4.4 Interpersonal relationship with the caregivers of stroke survivors: Most of the formal caregivers stated that there is an establishment of a cordial interpersonal relationship with the caregivers of stroke survivors, in which some respondents stated they advised the caregivers to get carers. One of the respondents said;

“yes, we have a relationship with them; we advise them to get carers or helpers. Some even call me, asking me to get them carers for their aged parents. Maybe they have a stroke or other medical conditions. We advise them. Unlike getting someone from the street, they come to us to help them get carers. So they come to us for advice.”

Few of the respondents mentioned that they educate and enlighten the caregivers of stroke survivors on the prevention and proper handling of these survivors. One of the respondents stated that forming interpersonal relationships with the caregivers of stroke survivors was the social worker's role. The respondent specifically said;

“Most of the time, the social worker does that; they try to do a follow-up. When they come for a follow-up here, we often try to see if there is any improvement.”

Almost all the female FGD participants said they have a cordial relationship with the health workers providing care for their patients. One of the participants said;

“The relationship is that we take them like one, and they also take us as family. They don’t behave cranky; they joke with us. They don’t treat us like an outsider.”

However, a few participants said they have no interpersonal relationship with the health workers providing care for their patients. A participant said;

“Well, I don’t have any interpersonal relationship with them. I go to the hospital for a checkup; I don’t have any interpersonal relationship.”

Also, half of the male FGD participants reported a healthy relationship with the health workers caring for their patients. A participant said;

“Ehnn... you see on the relationship of we the caregivers and the health care providers in the hospital, there are some of them among the nurses or doctors that are friendly. The way some of them will approach you will make you open to explaining the challenges you experience with patients. Still, there are some whose countenance and manner of speech to others around you will not make you free to say the challenges you face with the patient. Personally, my relationship

because I am not the only one that brings my mother to treat stroke. My relationship with the healthcare provider is smooth to some extent”.

However, another half of the male participants reported no relationship with the health workers caring for their patients. A participant said;

“I don’t have any relationship with them except I come here, and they give us the necessary treatment.”

Home-based care support: One-fourth of the formal caregivers said they visited patients and caregivers in their homes. One of the respondents specifically said;

“I usually go to care homes and see how the carers operate, even when I go to their homes. I relate with clients, and I also relate with carers. I also have an old age, I’ve been to these centres. I regularly see clients in a nursing home, so I see a lot of that in a week...going to see the older adult, not less than 20 in the homes, nursing homes. I usually see their carers; I spend hours there.”

Some respondents stated that they offered support by educating caregivers on how to care for the patients. A respondent noted that;

“We support them by educating them before they leave on how to prevent bed sores at home; they also know about what is happening and how to go about it and prevent further complications before leaving the hospital and ensure that they maintain follow-up.”

Evaluation of the home settings to see if it is conducive enough for the patients' requirement was also stated for home-based support.

Almost all the female FGD participants said that the home-based treatment support they receive from the providers includes providing information, follow-up, encouragement, good interpersonal relationship, and motivational support. One of the participants said;

“At times when we get there, they encourage us because it’s not an easy task, especially the doctors greet us for taking care of them, so when we get home, it gingers us to do more for the patient.”

However, some participants said they did not receive any support from the providers. Also, male FGD participants noted that the healthcare providers gave them dietary information that was useful for them. However, one of the participants indicated no support from the providers.

5.3.4.5 Gaps in the interpersonal relationship: Majority of the formal caregivers stated that there were no gaps in the interpersonal relationship established with the caregivers of the stroke survivors. However, few noted that language barriers, accessibility to their homes, poor social support, and inability to communicate were the gaps faced. A respondent said;

“For some people, I feel the language barrier is a factor. If they don't speak English or your native language, that can lead to getting an interpreter who understands what you are trying to go for. Another barrier is the accessibility

of their homes if you have patients who live far away. Some patients come to UCH now, and when they are discharged, they go to a distant place with no nearby physiotherapists, so assessing their homes and training them can be tricky as well. People also have poor social support. In cases where patients have been on admission for like two weeks, not once will a physiotherapist meet a relative, we will leave messages with the nurses, and they say they don't see the relatives as well. So, those are some of the factors that affect the interactions with the relatives.”

Almost all the female FGD participants said there is no gap in the interpersonal relationship. A participant said;

“I don't think they can do more than that because there are more patients, few doctors, and they can spend more than 1 hour, 30 minutes on one patient. So, they are trying their best; they can't kill themselves”.

However, one of the participants mentioned inadequate information about the illness as the gap in interpersonal relationships.

“I told you earlier that they should tell us what caused the illness so that another person will not experience it. Like maybe the patient overthinks or has stressed himself too much in the past. I want to know what can make someone experience such an illness when one is about his age. At least I've seen people who have clocked 80, or 90 years and can still go out. So, all of a sudden, he hadn't fallen sick before, so it just happened suddenly to the extent that it weighed him down, and the illness has persisted since

then. I want them to enlighten us on what happened to Daddy in cases; this is what you can do that can cause it and also the man it has happened to; if you want him to recover well, these are the things you can be doing for him. Apart from prescribing tests and drugs, they won't tell us anything".

Most of the male FGD participants mentioned that they don't get to express themselves freely because of the poor attitude/reaction from the doctors. A participant said;

"The gaps there is what my brother has mentioned that some of them, once you are with them, the way they will address you will make you keep whatever you want to say, but another person, the way he will joke with you will make you feel free to say your mind. Most of the time, one does not get to speak his/her mind because of how the doctor/nurse addresses us so that they won't see us as a local or broadcasting person".

However, few of the participants reported no gap in interpersonal relationships.

"I don't see any lapses; I don't see any... they are doing their job the way they supposed to do it; they are doing fine to my view".

5.3.4.6 Process of providing follow-up advice/precaution for stroke patients: When asked how follow-up advice /precaution is provided for stroke patients, some of the formal caregivers stated that stroke education was a method in which follow-up advice is offered.

Some respondents stated that they encourage patients through counselling to prevent a recurrence. A respondent specifically said;

“Yes, we counsel them, as I told you earlier, to prevent falls and the implication of a repeat stroke. Not to allow the patient to fall or be exposed to any injury. For example, if they live upstairs and want to move the patient downstairs, three or four people will carry the patient.”

When asked if they do this in the presence of their caregivers, the majority of the formal caregivers stated that the follow-up advice/precaution is given, in fact, by caregivers.

5.3.4.7 Opinion on caregiver support or care for stroke recovery in patients at home: Half of the formal caregivers said that caregiver support is critical and vital since patients recovering from a stroke cannot perform activities on their own and require all the help and support they can receive. One of the respondents stated;

“Caregiver support is critical because stroke patients cannot care for themselves. They need the assistance of family members, loved ones, and people around them. Caregivers are expected to give adequate support because they cannot do that alone if a stroke patient needs a drug or food. Hence, people around, family members, need to assist the patient to get better and get adequate care.”

5.3.4.8 How to promote the interpersonal relationships between formal and informal care providers on home-based treatment: One-fourth of the formal caregivers stated that

health education and training of caregivers foster the interpersonal relationships between formal and informal care providers. One of the respondents said;

“A lot of people are into training, training caregivers, and I believe it’s going a long way in helping manage stroke patients at home, especially when they get paid carers; there is a lot of training I know BHIN do training, UCH, even geriatrics too does some caregiver training.”

Financial support was reported to promote interpersonal relationships between formal and informal care providers on home-based treatment. Communication was also written to encourage interpersonal relationships between formal and informal care providers. Teamwork was said to be the reason for communication. A respondent said;

“Communication because it is teamwork; it is not what one person can do. If the trained caregivers do their work, the other carers do their work. Everybody has a role to play in this teamwork.”

Some of the female FGD participants mentioned that the home care provider should be a professional healthcare provider, and they should be educated. A participant said;

“Well, what I think is that healthcare providers should be educated on how to attend to patients and their caregivers because this is very important so that caregivers will have a free mind to ask questions on what they don’t understand.”

In addition, other participants said they need training, more care, and access to contact doctors and home-based caregivers. Also, some male FGD participants noted that staff should be advised from time to time concerning patients and caregivers. A participant said;

“One of the ways to promote interpersonal relationships between formal and informal carers is that staff should be advised from time to time concerning patients and caregivers. So, they should be advised on how to talk to caregivers and act toward people coming to the hospital”.

5.3.4.9 Things necessary for consideration: Some female FGD participants mentioned rendering free physiotherapy services as part of the considerations. A participant said;

“Then, concerning the physiotherapy aspect, if there is the assistance they can render when we come to the clinic say, ‘this is a stroke patient, let’s render free physiotherapy service to him before going home.’ If they can help us with that, not all the time, but whenever we come to the clinic, and we don’t come to the clinic all the time”.

A few of the participants also mentioned that healthcare providers in hospitals should ensure good relationships, there should be follow-up through phone calls, and social media platforms should be used for communication.

Some male FGD participants mentioned employment of doctors, good attitude, and communication between the caregiver and the healthcare provider as necessary for consideration. A participant said;

“When we get there at times, and we say we want to see the doctor, at times they will say there is no doctor on the ground. So if they can employ doctors that know about stroke care and put them in each primary health care centre, that’s that. Secondly, if we have any information that something like this is happening to the patient, we should be able to communicate with them”.

Likely challenges: One-fourth of the formal caregivers reported that stroke patients' unfriendly attitude toward caregivers is the most credible challenge. A respondent stated;

“Sometimes one of the challenges is that it depends on the attitude of the patient towards the relations because you find out that some of these patients don’t want to obey their relations when they tell them that “mama don’t go out if you want to go out come and call me, this mama they may still do their own, going toilet without caking for assistant which they can fall and have another stroke again or head injury so most of the time that’s what we tell the relations that these persons they are older adult person, you treat them as a baby, most of the instruction, you try to play with them, have a good cordial relationship with them though most of them they are tough to treat when you have a good relationship with them you can at least to some extent cope with them.”

A few respondents also stated that there is a lack of proper communication between informal and formal carers and financial problems as the caregivers might be unable to afford the necessary items for stroke patients. Other likely challenges few respondents mentioned to disrupt interpersonal relationships between formal and informal care providers on home-based treatment include time, workforce, workload, accessibility of the patients, and workforce. However, another one-fourth reported no likely challenges would be faced to disrupt interpersonal relationships.

Some female FGD participants reported finances and accessing formal caregivers as the challenges to promoting interpersonal relationships. One of the participants said;

“There is a challenge of meeting up with the formal carers when you want to see them; it’s not easy; we don’t easily see them like that. There should be a cordial relationship between the formal and informal carer; the challenge is that what will, I say, capital, money (Interjection by I: how?) of them some people might not be able to a get a paid caregiver... hmmm, I don’t know”.

Few of the male FGD participants said the carefree attitude of the staff late arrival of the head of staff to the office as the challenges to promoting interpersonal relationships.

5.3.4.10 Key needs of informal carers that are currently not being met: Some of the informal caregivers mentioned that the financial needs of informal carers are not being met. One of the respondents stated that;

“Most of the time, it’s this issue of money because you found out that, let’s assume, you have a carer and you negotiated that you are going to pay a certain amount, and you are not paying it, even the way that care will be taking care of it patient, you will not be happy about it, he will be nagging, shouting on the patient but when they can reach an agreement on the amount to be paid and the money is being paid on time, you know, the person will be happy, he will do the right thing at the right time for the patient.”

Inadequate training on proper management, enlightenment, and education was reported as critical needs of informal carers that are not currently being met. Another urgent need identified was overburdening informal caregivers with obstacles, for which equipment could be beneficial to ease their work. A respondent said;

“You don’t overburden them of the challenge that comes with the duty. If there is equipment that can ease their work, I think that equipment should be provided. For example, the thin sheet can aid in carrying stroke patients instead of the carer carrying on their neck, back, or something. I think all these should be taken into consideration. If the carer is sick today, he won’t be able to do the work well.”

5.3.4.11 Suggestions for improvements: Most of the formal caregivers suggested training on effective communication for healthcare providers. Also, stroke education for informal caregivers on stroke and its management. A respondent said;

“Formal caregivers can go through training on effective communication skills. Finding better ways of educating patients and informal caregivers without using physiotherapist jargon. Things or analogies they will understand. Sometimes it is easier said than done. Physiotherapists can take courses in patient education to reach this level and look for better ways to understand.”

Collaboration with the relations and the carers to also be involved in the care of the stroke patients was also suggested as an improvement. A respondent stated that;

“The children should work hand in hand with the carer because most of the time, these children are not around, and those old women are in the hands of the carer, so they should at least work with them. They should not just neglect the care of their parents to the hands of the carers alone; they should at least visit once in a while to see the parents.”

Some female FGD participants mentioned phone calls, checkups, finances, availability of home caregivers, free drugs, and training as ways they can be assisted to function better as family carers. Half of the male participants reported the availability of expert doctors for them to perform better as family caregivers. A participant said;

“The help that can be done is to those who are expert doctors because the illness needs an expert doctor. Maybe there should be a program that will be done generally once a week or once a month. Maybe a TV program or radio program such that if one person didn’t listen to it, another person would be able to... such

that those that listened to will be able to tell others that a doctor was brought to the program who spoke about stroke. The Government can help us with that kind of program”.

Few male participants mentioned the availability of a nearby health facility for therapy sessions. A participant said;

When the participants were probed on training expectations, few female FGD participants expected the training to focus on food and exercise. Many participants expect the training to focus on stroke prevention, effects, and treatment. A participant mentioned that the training should include appropriately using a manual blood pressure machine. She said;

“Like myself now, the manual blood pressure this thing I don't know how to do it very well. It's my sister that used to do and when my brother comes around so most of the time I use the automatic one and my mum doesn't like the automatic one because there is one thing there that used to pain her so she doesn't...when you are bringing the automatic one she will raise her hand like this (describing action) that she doesn't want. She prefers the manual one, so only my sister knows how to do it, and my sister comes around maybe every other day”.

Two-thirds of the male participants wanted the training to focus on physiotherapy and feeding patterns. One-third of the participants enjoy the training to focus on treating stroke.

5.3.5 Section E: Identification of home-based care Needs of older adult stroke patients

5.3.5.1 Home-based care needs of older adult stroke patients: Half of the formal caregivers indicated that proper care of older adult stroke patients is a home-based need of older adult stroke patients. One-fourths reported conducive housing to be modified according to the requirement of older adult stroke patients. A respondent specifically said;

“Home setting modifications that accommodate wheelchairs, walking aids, probably electricity or to make sure there is brightness or lightening that enable them to navigate. Ultimately, I feel they need carers that care. I feel like for the stroke of the older adult, there is this thing that “won ti dagba”; they are old, people don’t want to give in their best as opposed to a younger person suffering a stroke, people tend to go all out.”

Some respondents stated that social care is a home-based care need for older adult stroke patients.

Most of the community gatekeepers clearly stated that the home-based care need of older adult stroke patients includes home cleaning and surrounding, feeding of the patients, drug usage, and caregiving. One of the respondents said that:

“..... need is that we should monitor them in their medication or concoction use, it should be regular. We should help them wash their clothes; if we have the grace of helping them cook, like a caregiver job, we can do it. We should commit. They can even have food items at home and won’t be able to prepare them, so that we can help them with that. For instance, I got to a

stroke patient's place; she wanted to prepare vegetables and was waiting for someone to help her; I helped her destalk it, grind pepper and onion, and prepare the soup."

Some of the female FGD participants mentioned that the importance of home-based care for older adult stroke people is to help them get better and not to think about their condition because thinking about their situation at times adds to their problem and it may also cause their blood pressure to rise, one of the participants says;

"The kind of home-based care needs I can identify shouldn't be lonely. They should have people around. Their favorite songs can be collated on their mobile phones; they will forget their condition as they listen. We can also play games with them, such as ayo and ludo if they can play it, and even if they can't, we can motivate them."

Few male participants mention that leaving an older adult stroke patient alone is not a good thing; they need people to talk to and look after them to get better. One of the participants said;

"The older adult we take care of at home needs optimum and regular care, so one should not leave them anytime, be with them to assist them in anything'.

However, one of the participants specifically talked about the medical instrument useful for stroke patients in checking their blood pressure and another instrument that aids their quick recovery.

5.3.5.2 Reasons for care need: Few formal caregivers reported that care is required for follow-up purposes. It was said that patients do not return for follow-up after being discharged from the hospital. A respondent said;

“For so many patients, when you discharge them, they won’t want to go for follow-up; they will say ‘I’m ok, I’m already well, I’m not going to the hospital, but when the relation/caregiver are there, they will be able to tell them they have to go for follow-up so with this it will help in their coming to the hospital.”

Additionally, lack of strength and power was also stated as a reason for the care needed by the respondents. A respondent specifically said;

“The reason for the need is that they don’t have enough strength and power to carry out those activities. Like a 75-year-old older adult with no wife, you won’t expect him to be the one cleaning the house, going to the market.”

The majority of the community gatekeepers also said the reason for the care need is to recover quickly and relieve their caregiver. One of the community gatekeepers stated:

“There could be many reasons like the one that readily comes to mind now. One, you have access to ambulate on your own, and nobody wants to

become a liability. He wants to be able to do some things on their own without becoming a permanent liability to someone else. That's the reason why some of these things might be provided so that the person will be able to move freely. Another reason is that it will give the carer time for other things without necessarily being afraid of anything happening to the person she is taking care of. She can have some time to relax. Those things readily come to mind, but there should be no reason."

Almost all the female FGD participants stated that the care needed is to make them feel better, not to worsen their condition. However, one of the participants explained further that the care required is to help them know that their condition is not permanent, just for a short period. Few male participants mention that having an assistant or someone to care for them positively impacts their lives. One of the participants said:

"Reasons for the home care is that there are some things they cannot do without having assistance. So, they will need someone to assist them on one thing or the other before they can do what they want to do".

5.3.5.3 Things being done at home to meet the care need: None of the formal caregivers reported anything currently being done to meet the care need. However, providing home carers who can meet these needs was suggested. A respondent stated that;

"A home carer to meet all these needs is needed. Please help them to cook, wash their clothes, take medication; maybe they need company, things like that. Just help them to carry out the activity."

Some female FGD participants mentioned that to meet their carer needs at home; they helped them take good care of themselves and improve their condition by administering their drugs to them as prescribed by the physician. One of the participants said:

“The care we do at home is that once he wakes up in the morning, we will ensure he has his bath, we will take care of the environment and lay his bed. We will help him do everything and take care of the house. So, after taking care of the house, he will bathe, after which his food will be ready. He will eat, and if he needs to use drugs, he will use them after then; if there is nobody that wants to stay with him at the moment, we can put a small radio beside him to listen to because he doesn’t like to stay alone and my little children are also at home that plays with him when they are back from school. We don’t allow him to be lonely”.

Few of the male participants mentioned that to meet their care needs at home, they assist them and help them improve their condition. One of the participants said;

“if they carry something before, and we know that they want to relax due to their perception of the illness, we will encourage them to forge ahead and try so that their recovery can improve. And after we’ve patiently spoken to them because anyone taking care of them must be patient, after speaking to them patiently, they will try it and succeed, and they will be happy that they have improved on it”.

5.3.5.4 Challenges in implementing home care need: Half of the formal caregivers mentioned financial challenges. A respondent said that;

“Financial challenges, some of them don’t have money to take care of themselves, home physiotherapy is a lot of money you need to have so if you don’t have that kind of money, the patient might not be getting the best, getting medications for them, their drugs are not so cheap, and they have to be on them for a very long time so those can be challenges they can face at home.”

Some respondents stated sociocultural beliefs are one of the challenges faced in implementing home care needs. A respondent said;

“I’ve seen an 85-year-old man struggling to walk; I told him to be using a walking stick; he was like a walking stick. I can’t use a walking stick to walk; I am a retired colonel. He said please, I will do everything you want me to do to walk but not walking stick. I’ve also seen a 64-year-old man who was limping. I told him it would help if he had support, and he said he was too young to use a walking stick. I had to tell them the walking stick is made for humans. Some will even say that their mother at 85 didn’t use a walking stick, so why will they use it at 70...so cultural belief.”

The lack of trained carers was a challenge in implementing home-based needs. One respondent specifically stated;

“They don’t have a trained career; that’s the challenge. They pick someone from the street to care for a stroke patient. Suppose the relations are not giving adequate social support. Maybe the patient needs to come to the

hospital or get this or that that will make the patient comfortable. If all those things are not in place, there will be a problem.”

Additionally, the distance between houses and house settings is one of the challenges stated to have affected the implementation of home care needs. A respondent said;

“Most of the challenges are if you have the mind of visiting those people, their house may be far; then some people don’t want you to come maybe because of their home setting. Even most social workers, before they go to the house, have to get their consent; most of them say their house is far. You cannot just go to their house.”

Majority of the community gatekeepers said that finance is a major challenge. In addition to the failure of service providers like NEPA, water corporations, etc., some stroke patients are impatient and aggressive toward their caregivers. One of the respondents reported:

“...the person with a stroke doesn’t want it, but since they have the sickness already. They should not insult or mock them. But the challenge is that if the person is stubborn and insults people because they didn’t take care of him on time or attend to his needs, such people can be insulting. People will say he has a bad mouth and is sick, but he has an evil character. People won’t get closer to such a person. He might not get someone to take care of them. It can be challenging to send people away from them, but if someone with good character and behavior believes this sickness is from God and he is

nice to people, he will have people closer to them and be well taken care of.”

Majority of the female FGD participants said the challenges they faced in implementing home care included finance, workload, inadequate sleep and rest, and emotional stress. Also, some participants said the challenge they faced in implementing home care was insufficient knowledge. Two-thirds of the male participants said they lacked support from their families in caring for their older adult with stroke. A participant said;

“One of the challenges is that if more support is absent, one person can’t do it alone, and if that’s the case, it will eventually return to the body. So if one can get a younger brother/sister or someone else who is a family member to assist, it will be easy to care for them”.

5.3.5.5 How best to develop intermediate care for the older adult recovering from a stroke after discharge from the hospital: Some of the formal caregivers stated that relatives and informal caregivers of the older adult should receive proper education to reduce or prevent stroke reoccurrence. Few respondents said that adequate training of carers and intermediate care facilities would be best for developing intermediate care for the older adult recovering from a stroke after discharge from the hospital. Furthermore, the education of community members was also said to be best for developing immediate care for the older adult recovering from a stroke after discharge from the hospital. A respondent said;

“At the same time, more education. More community educating people of the importance of intermediate care needs.”

When asked about the reasons, it was stated that a carer alone could not provide patient care; family members needed to be involved. A respondent said;

“The carer alone cannot do it; the children have to be involved because these patients get better when they see their own close immediate family; they will be happy and verbalize what is in their mind but with the carers, they may not talk,, even most of them when they see their carer, they will not eat. There was a time we had a patient on the bed; it was the carer that was with the mama; they begged mama to eat, but mama would not eat; but there was a time mama’s son came from Abeokuta, immediately mama heard the voice of her son, she ate very well that day.”

The majority of the community gatekeepers said they can be supported financially in kind and cash. Some said giving moral support, visiting them, and NGOs supporting caregivers. One of the respondents clearly stated that:

“... what we can do, as I've said earlier, is through finance to encourage them, especially in giving them money and food items. The caregiver is the one that will also take care of the environment. We can go there to encourage them regularly that the illness is not a rare case and some people have recovered from the stroke once they believe it's possible. All

problems start from the mind. If one has a positive mind and hope, he will recover quickly. That's what we can do."

Another respondent stated that:

"... we won't let such a person get weary with words. We would let the person know that someone that is not yet dead does not know the ailment that will kill him, so If such a person needs help health-wise, if they let us know, we have to help the person. Some caring for the sick won't have the chance to go to work, and he would be eating and drinking; he might even have other needs to meet in his house. So, for the person not to be depressed from overthinking, that can result in future problems."

Many female FGD participants said they would like to be supported in finance and the provision of free physiotherapy services. A participant said;

"In the aspect of physiotherapy, if they can, some groups do things like rotary that do free services. It can be once in a while if they can come to render physiotherapy service for free or at a reduced cost; it won't be that we need to come to the hospital to access the service".

Most male participants said they would like to be supported in finance, subsidizing drugs, reducing physiotherapy service charges, and providing wheelchairs for carriage.

5.3.5.6 Types of services that should be incorporated as “intermediate care” for the older adult recovering from a stroke:

All the formal caregivers stated physiotherapy service; the majority mentioned speech therapy, and a half mentioned nutritional and minor medical services. Additionally, one-fourth of the formal caregivers reported mood disorder management; few stated nursing care. In contrast, two respondents stated that all services should be combined and incorporated into the intermediate care of the older adult recovering from a stroke. A respondent said;

“Yes, using drugs. Then social service because I could remember one of our discharged patients. One of the major issues is who will take care of him at home, so having a caregiver that would take care of him at home so social service can intervene in such a situation.”

Another respondent said;

“The care has to be all-encompassing, involving all health professionals and not the doctors alone. Nurses, physiotherapists, social workers, and carers we are talking about must join hands to ensure this person is properly trained. You cannot depend on doctors alone because this is a long-term sickness that's capital intensive and requires a lot of funding, so it should involve all the health workers. The medication cannot depend on doctors and nurses alone to dispense medication. If nurses and health professionals are unavailable, the carer should be trained to dispense medication for patients using a chart, medication but 8 am then food. Evening or afternoon, and so on, it's the duty of that carer or anyone who has volunteered to care

for that patient. So it has to be a sort of collaboration that's all-encompassing”

Almost all the community gatekeepers mentioned physiotherapy (majorly exercising) and speech therapy, which will encourage them to speak better. Most respondents said nutritional service because food and water are important to stroke patients. Some respondents stated minor medical treatment and few mentioned mood disorder management. Half of the respondents mentioned that medication assistance should be incorporated. Among the respondents, one said:

“.. depending on the financial status, there could be a private physiotherapist checking on him/her with a reduced charge so that the charges will not be too much for them to pay, and there could be online education on what they can do. If professional physiotherapists are not coming, what the members of the home can do in their way, what they can do, education from online, what they can provide for them to be able to do some physiotherapy.”

Almost all the FGD participants agreed that minor medical treatment, speech therapy, medication assistance, and nutrition services should be incorporated as home-based care for the older adult recovering from a stroke. Most FGD participants also mentioned physiotherapy services, management of mood disorders, and speech therapy. A participant said;

“That is it; speech therapy is necessary because we have not done anything about speech, and I want the speech to improve; I don’t know how to get that.”

All the male participants agreed that minor medical treatment, speech therapy, medication assistance, and nutrition services should be part of the necessary services; some said exercise, advice and encouragement, mood disorders management regular checkup should be done for the older adult recovering from a stroke. A male participant said;

“Nutritional service shouldn’t be overlooked. It has taught me what my dad’s intake should look like. The information about which food is healthy for my dad and which foods are meant to be avoided has aided his quick recovery”.

5.3.5.7 Who should be primarily involved in the intermediate level of care for the older adult recovering from a stroke: One-fourth of the formal caregivers mentioned that doctors, nurses, and physiotherapists should be primarily involved for older adult people who are recuperating from a stroke. Family members were also noted to be primarily involved in the intermediate level of care for older adult people recovering from a stroke. A respondent said;

“It should be a close relationship because most of the patients’ children are not around, so when getting a caregiver, they should get someone who can care for mama very well. When the patient comes to follow-up, they will have access to doctors and nurses; the only thing is that when the social

worker goes for visitation, and there is any need for medical treatment or intervention, they will call“.

Additionally, carers and social workers were also said to be primarily involved in the intermediate care of older adult people who are recuperating from stroke. Furthermore, neurologists and dermatologists were also said to be involved in the intermediate care of older adult people recovering from a stroke.

Majority of the community gatekeepers said those that should be primarily involved in the intermediate level of care for the older adult that are recovering from a stroke are their closest family members (the wife or the children). Some said the siblings of the patients, medical teams (doctors and nurses), paid caregivers, and herbalists should be primarily involved. One of the community gatekeepers reported that:

“... relatives. Probably the patient's younger brother or younger sister, or elder one that doesn't have the condition or children. Doctors, nurses, and herbalists should be primarily involved in intermediate care because we have seen native medicine that cured stroke such that our people, whenever they first experience it, don't come to the hospital. They will say it won't get healed once they receive an injection, but it's not. We make them understand that if someone has malaria, it has specific injections, modern medicine, and herbs that can be used to treat it. Doctors, nurses, and caregivers are important because they are the ones that will educate the family members on home care.”

Many female FGD participants think the family member should be primarily involved in the home-based care for the older adult recovering from a stroke. A participant said;

“It is the family who is very important in home-based care treatment, you know, if we mention doctor or nurse, it’s for a while, but the family members are those who are staying in the house and know what the patient need. The patient understands the family members, and even if the patient cannot talk, they already understand if he makes a sign to any family member. Still, an outsider will not easily understand unless the family members interpret”.

Also, some participants think family members and doctors should be involved in home-based care for the older adult recovering from a stroke. All the male participants agreed that family members should be primarily engaged in home-based care for the older adult recovering from a stroke. A participant said;

5.3.5.8 Benefits of instituting an intermediate level of care for the older adult that are recovering from a stroke: Half of the formal caregivers stated that instituting an intermediate level of care for the older adult that are recovering from stroke will help them recover well to avoid the risk of reoccurrence. Families coping better, happiness, and good emotional health were stated as the benefits of instituting intermediate care for the older adult recuperating from a stroke. A respondent said;

“Even the families must have gone over the shock to know what is expected. They will be able to cope more than when you just discharge the patient

from the hospital and take them home. It's enormous; it is tasking even on the part of the caregivers or the relations. Still, when the patient is allowed to pass through the intermediate care, it helps everybody, both the patient and the relations or even the carer or whatever. “

Most of the community gatekeepers, when asked about the benefits of instituting an intermediate level of care for the older adult that are recovering from a stroke, said it would bring a lot of benefits to the community, such as reduced transportation fare to the hospital, access to care information, reduce stress and relieve on caregivers.

Many female FGD participants mentioned it is a benefit that will lead to a better and faster healing process. A few other participants noted that it would go a long way because it would be focused on them. A participant said;

“it will go a long way because it will focus on them. When we get to the clinic now, they will have their own specification, just their area. It's not as if, oh, wait for the consultant to come and attend to you. The consultant will now start asking what happened to you, what is your ailment this, and that you know when there is a segment that has been made available for them, they will go straight that this patient that wants to attend to you is a stroke patient though have been discharged but at least needs some medical attention to be checked up. If such a thing is instituted, it will help them a lot. It will go a long way, and your special attention will be given to them, which will greatly help”.

Many male participants said it will give them access to care, hasten their healing and reduce the hours spent on the road to get to the hospital. A participant said;

“If it can help him, he will go there to access the care. Err. It’s a great benefit; if such a program is in his community, he can listen to educative talks they have for them there”.

5.3.5.9 Problems that may be associated with establishing an intermediate level of care for older adult people that are recovering from a stroke: When asked about the problems related to establishing an intermediate level of care for older adult people recovering from a stroke, some of the formal caregivers mentioned financial challenges in which there will be insufficient funding in establishing immediate care for these people. Some respondents also stated that lack of expertise and inadequate personnel were problems associated with establishing an intermediate level of care for older adult people recovering from a stroke. A respondent said;

“There is huge unemployment which is why people are taking the job to do it, but will they do it well? They won’t do it well because a lack of jobs makes them take up that job. Who among the family members will now leave his or her job to do that except if something is attached to it? Maybe they will have to be paid?”

House modification was listed as a challenge for establishing immediate care because it cost a lot of money. A respondent specifically said;

“For instance, where a sitting down is tiled, an older adult environment does not need tiles because if they fall, they can easily fall...fracture and when you are going to do that means you would probably need to spend more money or change some modifications because when you are talking about older adult, you have to make specific modifications, the bathroom, you shouldn’t use tiles, don’t use the bathtub. But setting up these institutions and employing qualified people cost a lot of money and requires finance and a perfect idea.....”

Few community gatekeepers said finance could be a significant barrier, especially if the patient can’t afford it. One of the respondents said that:

“...If payment for care is expensive, it may be a barrier, but if it is cheap, just like if the care will cost about #50,000 in UCH but may be in the community it will only cost #5000, patients will be eager to adopt it. It won’t burden their family carer because the place is not far, and they won’t need transport fare.”

Some female FGD participants mentioned stress, lack of money, and food as the likely barriers to adopting the intermediate care model. A participant said;

“Lack of money and if the stress is too much on the caregiver, it can result in the patient not having enough quality care. The patient may be denied access to the type of food the person they are meant to eat when there is

no money. Also, there won't be quality care if there is no money to buy drugs”.

Few participants mentioned inadequate equipment as the likely barrier to adopting the intermediate care model. A participant said;

“What I can say could be a barrier is if the department lacks the necessary equipment. Suppose they lack the necessary equipment. In this Nigeria, some patients may not even be able to afford the drug; one of the drugs she is talking about is up to #10,000 per month. Just the drug is up to #10,000 per month. If such a patient cannot afford that kind of a drug, you know there is a high tendency that the stroke can revert. So, if they have a special thing instituted for them, the Government can even assist in providing such drugs so that those who are less privileged and could not afford it would be given them at the clinic. So, if this department is not instituted, getting the drug could be a barrier and could even bring back the patient's ailment. If there are no proper facilities to care for them, it's a big barrier”.

Also, a few other participants mentioned the phobia of the clinic and the cost of service as the likely barriers to adopting the intermediate care model. Some male participants cited a lack of finance and poor perception of people as the likely barriers to adopting the intermediate care model.

5.3.5.10 Ways you think caregivers and patients can be motivated to adopt the intermediate care model: Half of the formal caregivers reported that counseling, encouragement, and educating the caregivers and patients is a method by which this model can be done. The availability of intermediate care to people and the provision of necessary facilities were also stated as ways to motivate caregivers and patients to adopt the intermediate care model. One respondent specifically said;

“I think first of all is availability. If it is available, I think many more people will utilize it. Once it becomes available, educating them on its importance, comparing it to institutional care, and they own it, I think they will see the benefits of it. Like, oh, they are coming to our home to see us as opposed to us spending thousands of naira to transport and carry this person and transfer and require multiple help. Now we can train transfer to help them to turn to either... ability to turn from to their side so that they are not lying on their back and buttocks. They will end up getting pressure sores, so the ability to turn from one side to the other, transfer from lying on your back to side lying, transfer from that side lying to sitting at the edge of the bed, transfer from sitting to standing. That's what I mean by transfer.”

Most community gatekeepers also mentioned that caregivers and patients could be motivated to adopt the intermediate care model through awareness creation so that everyone in the community can be aware. Also, counselling aside from drug distribution and the model should be eco-friendly were also stated by the respondents.

Some female FGD participants said caregivers should be appreciated by giving incentives. Also, caregivers should be encouraged and motivated by subsidizing the cost of tests, removing consultation fees, and providing financial help. A participant said;

“The patient's relations should appreciate the family carer by giving them things. An adage says, ‘If the way we gather during burial were the way people gather to care for the individual while ill, the individual would have survived.’ If an individual dies, relations go as far as borrowing money to do necessary things; such energy can be diverted into appreciating the caregiver”.

In addition, some of the participants mentioned public awareness as one of the ways by which caregivers and patients can be motivated to adopt intermediate care models. A few of the participants also mentioned enticement through the provision of free testing for community members. Many male participants said that the availability of qualified doctors and nurses, reduced long waiting periods in the hospital, and awareness creation will motivate people to use the program. A participant said;

“Number one, awareness, you make them aware that this thing is here, and you advertise it for them, you educate them. If they can be educated and have enough awareness about what is within their domain, I think that will help”.

5.4 Discussion of Results

This study presented the perceptions of different stakeholders on the intermediate care model for older adults with stroke in Nigeria. Findings from this qualitative study identified four major themes; experiences in stroke management; community gatekeepers' perceived social and welfare support needed by older adult stroke patients; strategies that promote interpersonal relationships between formal and informal care providers on home-based care treatment; identification of home-based care needs of older adult stroke patients.

One of the key findings, "experiences in stroke management", focused on subjective reports of informal carers' experiences when their family member had a stroke. Few reported positive experiences such as good food management by providing a balanced diet, regular exercise, and regular usage of drugs. Many participants reported they had difficulties with care, financial challenges, stress, behavioural/mood swings and increased daily routine in helping the patients with activities of daily living. This is consistent with findings in the literature which suggests that caregivers of stroke patients face overwhelming burdens due to the demanding and complicated nature of caregiving (Lutz et al., 2011; Zhang & Lee, 2016). Existing literature highlights the demands and stress placed upon informal family caregivers in stroke scenarios as a considerable proportion (25 -75%) require assistance for daily activities from family caregivers (Bhattacharjee et al., 2012; Costa et al., 2015; Danzl et al., 2013). This emphasizes the pivotal role these caregivers play (Kalra et al., 2004). Our study resonates with prior research, exemplified by Jika et al., (Jika et al., 2021), which illuminated the physical, financial, and psychological strains endured by family caregivers in a similar context. Several studies

carried out in different geographical regions in Nigeria highlighted high levels of caregiver strain as a result of a lack of social support and strain on family income (Akosile et al., 2018; Vincent-Onabajo et al., 2018). Additionally, studies conducted in different countries including Denmark and Italy gave an exposition on the caregivers' emotional tolls emanating from difficult communication and memory deficits with stroke survivors (Bakas et al., 2006; Kitzmüller et al., 2012; Pallesen, 2014; Simeone et al., 2015). Similarly, a study conducted in Brazil revealed detrimental changes in different domains such as overall quality of life, physical, emotional, social, and environmental of family caregivers of stroke survivors (Caro et al., 2018). This indicates that family caregivers of stroke survivors across various parts of the world undergo similar burdens and experiences. Research suggested that interventions that help carers to develop coping strategies should be focused on (White et al., 2006). Hence personalized interventions focusing on improved overall quality of life are needed to reduce the associated stress of caring for stroke survivors who are older adults.

Financial concerns emerge as a salient issue, with participants expressing varying perspectives, ranging from support such as subsidised admission fees and free medication to unmet expectations, such as the absence of the NHIS provision. Out-of-pocket payment is a major challenge in Nigeria as health insurance is limited to only 5% of which the majority are government employees. This has made individuals and families incur catastrophic expenses further impoverishing them because of their health challenges (Aregbeshola, 2016). This aligns with findings by Gott *et al.*, (Gott et al., 2015) underscoring the financial strain endured by family caregivers due to the direct and

indirect costs of care, significantly impacting both the quality of care received by patients and the well-being of caregivers. Providing a comprehensive support system, including financial assistance and health counselling, becomes imperative for mitigating these challenges (Denham et al., 2019). The healthcare system in Nigeria is still largely underdeveloped with poor facilities and inadequate staffing of skilled personnel especially in the rural area (Onyeme et al., 2019). Our study was carried out in the urban centre of Ibadan, Oyo State in one of the leading teaching Hospitals in Nigeria, University College Hospital. The care received by the patients and their family caregivers while on admission and after admission is suboptimal as expressed by our participants. However, the scope of our study is limited to the experiences of stroke survivors and their respective family caregivers. It is imperative to explore the institutional or health system capacity in stroke management.

Informal carers in this study viewed information on stroke care as essential for better health outcomes. Notably, most of the participants reported that the information provided on diet, tests, drug prescriptions, and exercise in the facility was helpful because there was an increase in knowledge and improvement in their family members' health. When combined with the right support, information tailored to individual impairment enhances better care and reduces healthcare costs (Forster et al., 2012). However, unmet needs for information and social support training on seizure management and type of physiotherapy machines for the patient were identified as a major challenge by some caregivers, particularly the females. This is by Hafsteinsdottir et al., (2011) and McKeivitt et al., (2011) reports that revealed the existing knowledge gap of caregivers and stroke

survivors on stroke prevention and management. Many of the participants reported that they would love to receive adequate information on the type, prevention, and treatment of stroke.

The interpreted theme of “community gatekeepers perceived social and welfare support needed by older adult stroke patients” emphasized that older adult stroke patients need help after discharge. In the community, older adult stroke patients can be supported morally, financially, and materially. Most of the community gatekeepers clearly stated that the home-based care need of older adult stroke patients includes home cleaning and surroundings, feeding of the patients, drug usage, and caregiving. However, the challenges faced in implementing home care need to include financing, socio-cultural beliefs, lack of trained carers, inadequate sleep, emotional stress etc. Community gatekeepers felt that helping stroke caregivers should be considered by community members and other relatives. Oftentimes, caregiving is done solely and could lead to caregivers having physical and emotional trauma (Lutz et al., 2011). It is known that receiving support from others can help stroke family caregivers attain fulfilment and identify meaning in caregiving (Greenwood and Mackenzie, 2010).

In the third theme “Strategies that promote interpersonal relationships between formal and informal care providers on home-based care treatment”, the findings revealed the role and specific services rendered by formal and informal caregivers to older adult stroke patients. During admission and after admission, formal carers respectively provide rehabilitation and continuity of care. Informal carers reported their support to the patients on activities of daily living. The majority of the formal caregivers stated that there were no

gaps in the interpersonal relationship established with the caregivers of the stroke survivors. However, few noted that language barriers, accessibility to their homes, poor social support, and inability to communicate among others were the gaps. More than half of the informal stroke carers in this study, predominantly males, expressed their displeasure with poor reactions and attitudes from the medical practitioners which limits their access to the right information. Access to adequate and timely information is a crucial component of poststroke management (White et al., 2014). Poor communication in the health and social care system has been identified as a major factor that contributes to a gap in the continuum of care (Greenwood et al., 2016). Stakeholders in the current study indicated that training and telephone follow-up calls could improve interpersonal relationships. The formal caregivers in this study described home-based care support delivered in terms of educating the informal caregivers on patient care post-discharge. This resonates with informal caregivers' views who noted the receipt of information including dietary education motivational support and follow-up. Delivery of adequate support including information, education, or patient-family care provision will help informal caregivers handle their caregiving role effectively with reduced burden (Tyagi et al., 2021). Notably, some claimed that they received no support which may be linked to gaps in the interpersonal relationship. Language barriers, inaccessibility to patient homes, poor attitudes towards patients, and the inability of the informal caregiver to express themselves are issues that disrupt interpersonal relationships. A female informal caregiver in this study expressed her frustration with the inability to receive information on the causal factors of stroke, its management, and the interpretation of the patient's condition from the formal care provider (Luker et al., 2017) reported the readiness of

patients and their caregivers to receive information from the formal care provider. Previous research has identified gaps and suggested ways for improvement including creating effective connections between primary and secondary care and ensuring the delivery of appropriate and adequate information along the care continuum (Tang et al., 2017). Regardless of the awareness that healthcare providers such as nurses should play various roles in providing care and health counselling for stroke patients (Kirkevold et al., 2010), clinicians in this study attested to the essentiality of informal caregiving in stroke recovery. Ideally, informal caregivers should be an integral part of a multilateral partnership together with formal care providers and stroke patients (Luker et al., 2017). Acknowledging this fact provides a promising way for formal care providers to view informal caregivers as partners and be willing to initiate interpersonal relationships to achieve better home-based treatment outcomes.

A further theme that emerged “identification of home-based care needs of older adult stroke patients” revolved around stakeholders’ expectation of essential care for older adult stroke patients after discharge home. Diverse perceived needs described included house modification, hygiene, assistance in feeding and medication use, and ensuring patients are not lonely. Participants consistently expressed that intermediate care should encompass physiotherapy service, minor medical treatment, nutritional service, speech therapy, mood disorder management and medication assistance. Several literatures have documented the impact of intermediate care services on the functional outcome of older adult patients post-stroke (Moore *et al.*, 2020; Choi and Paik. 2018; Hsieh et al., 2018). Another unique finding from this theme revealed that informal carers perceived family

members as the most important in a patient's intermediate care. Although, family support is essential for dependent persons (Rose-Murphy et al., 2014), a report from Greenwood et al., (2016) suggested that the belief that families are in the best position to provide support often fails to engage with needed services. When asked about the problems related to establishing an intermediate level of care for older adult people recovering from a stroke, some of the formal caregivers mentioned financial challenges, lack of expertise, inadequate personnel, and house modification among others. Furthermore, half of the formal caregivers recommended counselling, encouragement, and educating the caregivers and patients as ways they think caregivers and patients can be motivated to adopt the intermediate care model.

5.5 Summary of the chapter

This study provided insight into the experiences and perceptions of stakeholders on stroke management in southwestern Nigeria. It has also made a significant contribution that could assist the policy that there are gaps between formal and informal carers on the continuum of care for older adult stroke patients. Furthermore, this study is an eye-opener to the detail that older adults recovering from stroke need an intermediate level of care services tailored to individuals' impairment at the post-stroke phase. This can inform the design of an effective intermediate care model and policies that make the program easily accessible.

CHAPTER 6

Development of a Culturally appropriate Intermediate Care Model for Older Adult Stroke Survivors

6.1 Introduction

Many healthcare systems worldwide are facing challenges due to an increasingly ageing population (Beard and Bloom). In Nigeria, quite several stroke patients are discharged home with no laid down plan for optimal functional recovery (Soeker and Olaoye, 2017). In response to these healthcare challenges relating to the needs of older adults, interventions and intermediate care models to improve the coordination of services and safety during hospital discharge have been introduced (Storm et al., 2014; Dahl et al., 2015). Programs have been designed and delivered to post-discharge stroke survivors, aiming to improve QOL and functional and psychological outcomes (Chen et al., 2016; Zhou et al., 2019). There is evidence suggesting that a coordinated early discharge program with home visits had a better chance of reducing mortality and producing ADL benefits for stroke survivors (Wang et al., 2017). The development of intermediate care is intended to promote safe and early discharge out of acute care, foster independence and enhance reintegration in community settings (Department of Health, 2009). However, in Nigeria, there is little or no data on the implementation of an intermediate care model for elderly stroke survivors. This chapter aimed to develop an intermediate care model tailored to support the recovery of older adult individuals affected by stroke in the community, based on insight obtained from stakeholders.

6.2 Methods

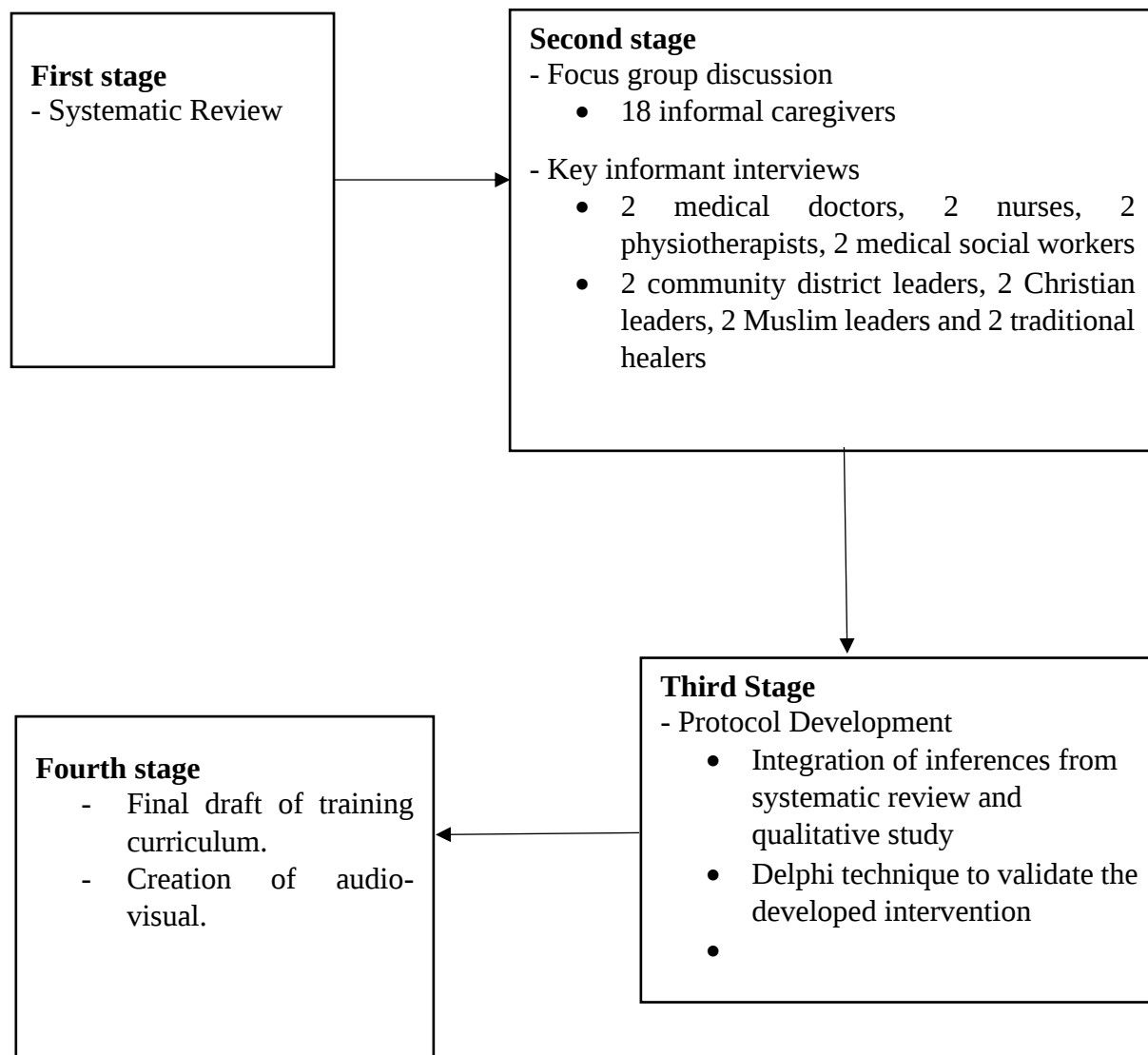


Fig 6.1: Process of intermediate care model development.

6.3 Results

The systematic review identified existing home-based intermediate care for older adults with stroke including physical therapy, occupational therapy, speech therapy, meaningful task specific training and reminiscence therapy. They demonstrate positive impact on the functional outcome and significant improvements in activity of daily livings and quality of life.

The second phase (qualitative study) revealed diverse perceived needs, including house modification, hygiene, assistance in feeding and medication use, and ensuring patients are not lonely. All stakeholders consistently expressed that intermediate care should encompass physiotherapy, minor medical treatment, nutritional service, speech therapy, mood disorder management and medication assistance. This phase identified their cogent need of informal caregivers for information on general knowledge on stroke, seizure management and type of physiotherapy machines for stroke recovery.

The systematic review and the qualitative study findings were integrated during the third stage to develop the intervention protocol. Subsequently, the Delphi technique was used to reach a consensus on the integrated results for intervention. The intervention was titled Information Support. It consisted of 10 domains as presented in Fig 6.2. These include stroke knowledge, seizure management, medication management, mobility and fall prevention, vital signs, service referral, reminiscence therapy, nutrition, and financial education. The content under each domain was prepared using scientific texts and

literature (Appendix 10). This was done to ensure the inclusion of evidence-based practices for home-based level of care.

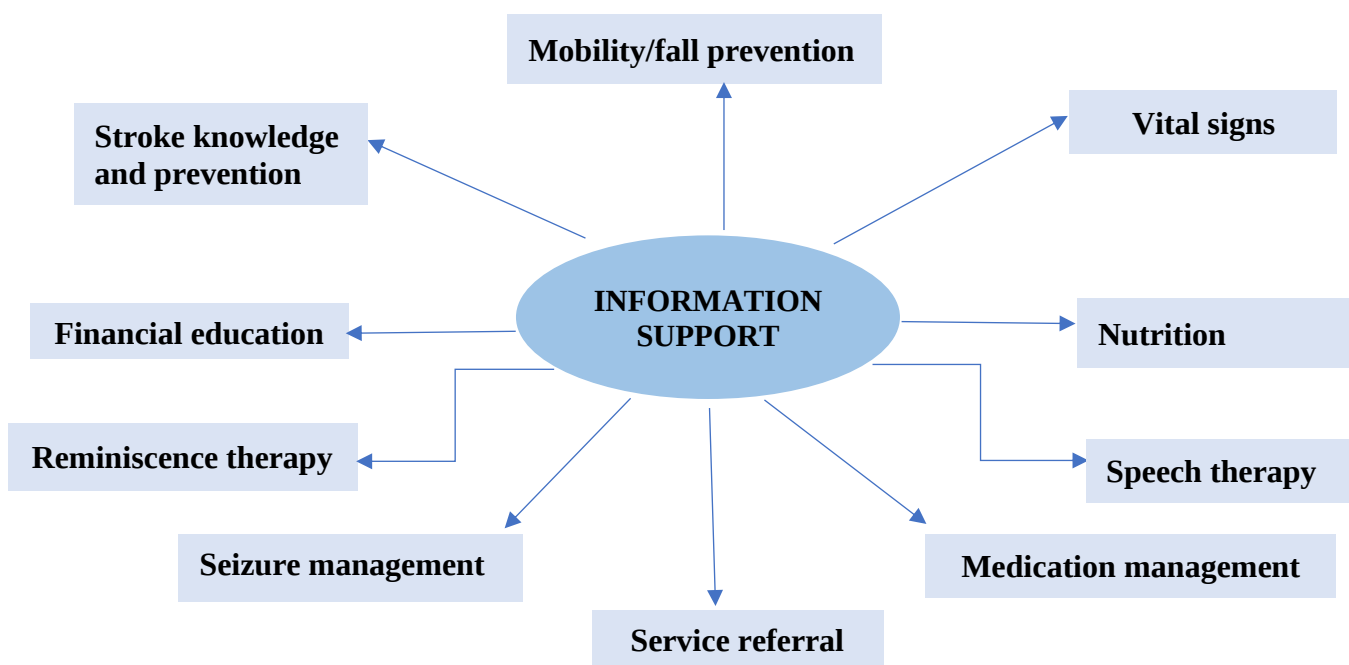


Figure 6.2: Diagrammatic representation of information support

Intervention Protocol developed for informal caregivers of older adult stroke patients	
Domain	Content
Stroke knowledge	- Causes of stroke - Symptoms of stroke - Stroke prevention and management (ASA, 2002).
Mobility and fall prevention	- Physiotherapy techniques (Narayan Arya et al., 2012).
Vital signs	- Blood pressure measurement - Pulse rate - Body temperature - Respiration rate (Kaur et al., 2018)
Speech therapy	- Visual and verbal cueing - Picture matching - Sentence completion task (Dobkin 1991).
Reminiscence therapy	- General guidelines (Mei et al., 2018)
Nutritional service	- Healthy foods for stroke patients - Unhealthy foods to avoid

	- Feeding techniques (Dobkin, 1991; Spence and Tangney, 2020; Kernan et al, 2014).
Medication management	- General guidelines - Timely medication use - Medication discrepancy tool (Smith et al., 2004)
Seizure management	- Guidelines and first aid measures (CDC, 2022)
Financial management	- Use of Health Insurance Scheme
Service referral	

Table 6.1: Domains and content of Intermediate care model developed

6.4 Discussion of results

The development and validation of the education protocol resulted in 10 domains of caregiving. These include stroke knowledge, seizure management, medication management, mobility and fall prevention, vital signs, service referral, reminiscence therapy, speech therapy, nutrition, and financial education. These findings are pertinent because stroke survivors deal with deficits in different functional and quality-of-life domains which may lead to feelings of inadequacy on the part of caregivers in their newly assumed roles (Lin et al., 2022). Therefore, providing adequate educational intervention is essential to stroke recovery and the well-being of their caregivers.

The Delphi technique has been widely used in the content validation of interventions for stroke survivors (Santos et al., 2020; Andrades-González and Molina-Mula, 2022). Consensus was reached by different medical experts in stroke care using the Delphi technique on the developed protocol before implementation. The experts included a geriatric doctor, a geriatric nurse, a medical social worker, and a physiotherapist. This mix of professionals was included based on their vast experience in stroke care for the elderly which would inform their judgment and addition on the adequacy of the developed intervention protocol. The developed protocol in this study has its basis on evidence-based practices in literature and stakeholders' insight on intermediate stroke care.

The stroke knowledge domain highlighted information on stroke risk factors, symptoms, and primary and secondary prevention. The fear associated with stroke incidence prompts the quest to have information on the causes of stroke and lifestyle modifications needed for stroke conditions (Parappilly et al., 2020). It has been shown that caregivers who lack the knowledge and skills for post-stroke care may endanger the stroke survivors and themselves (Kariasa, and Waluyo, 2021). Thus, the guidelines in this domain could assist caregivers in preventing a recurrent stroke while providing care at home.

The medication management domain emphasizes the timely and safe use of medications. Information on this domain is crucial as stroke survivors and informal carers sometimes lack the knowledge and support to properly manage medication after discharge (Gibson, et al., 2021).

Service referral in stroke care involves treatment from different experts which is not limited to physiotherapy, nutritionist and dietician, speech therapist, and psychologist. Prompt referral of stroke survivors to the right medical specialists guarantees the continuation of rehabilitation following discharge (Whitehead and Baalbergen, 2019). The referral domain stressed the importance of early treatment-seeking behavior by the stroke survivors and their family caregivers to specialist care at the onset of complications that could not be handled with the knowledge from the training.

Although experts suggested more explanations, all protocol domains reached a consensus. This suggests that the included domains are all important for improved

outcomes of stroke survivors. The protocol provides information for training family caregivers of older adult stroke survivors.

6.5 Summary of the chapter

Older adults affected by stroke should be provided with needed support that enhances their recovery and community reintegration. Developing a home-based intermediate care model is vital for improved functional outcomes. Insights from the literature and stroke survivor caregivers are imperative to establish the practical needs of stroke survivors at home. The designed model could be a cost-benefit option and could also assist family caregivers and healthcare systems solve the burden of survivors' complex care needs in home care provision considering the limitations in infrastructure and unavailability of skilled personnel in stroke care in Nigeria. Findings from this study could inform policymakers and stakeholders in health care on stroke care guidelines for stroke survivors and their families at discharge.

CHAPTER 7

Assessing the Effectiveness of home-based Intermediate Care Model among Older Adult Stroke Survivors in Southwest Nigeria

7.1 Introduction

Following discharge from acute care, stroke survivors deal with chronic medical conditions, functional impairment, increased medications, and rehabilitation goals (Geng et al., 2019). Delayed discharge is associated with acute illness episodes and death, and older adult patients discharged from hospitals with unmet functional needs have an increased risk of readmission (Depalma et al., 2013). Researchers found that early assisted discharge could improve functional outcomes, and quality of life, and reduce the risk of hospitalization, referral to a nursing home, or mortality (Chaiyawat and Kulkantrakorn, 2012; Puhr and Thompson, 2015). However, older adult stroke survivors in Nigeria are discharged home without any laid down plan for recovery at home or in the community. This study aimed to assess the effectiveness of the developed intermediate care model in improving the functional outcomes of older adult individuals recovering from stroke.

7.2 Methods

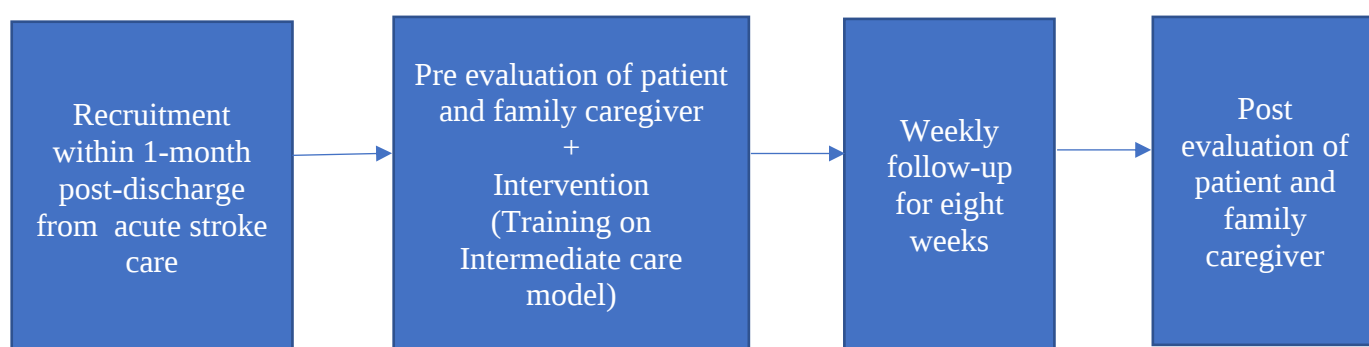


Fig 7.1: Framework for intervention procedure

7.3 Results

7.3.1: Socio-demographic and Clinical Characteristics of Study Participants (N=58)

A total of 58 participants were recruited into the study with their socio-demographic characteristics summarized in Table 7.1. The average age of the study participants was 69.10 ± 8.47 , with majority of them 34(58.6%) being female. Meanwhile, regarding the participant's religion, the vast majority of them 47(81.0%) were Christians. In addition, a very high proportion (94.8%) of the study participants were from the Yoruba ethnic group. This could have been to the fact that the study was conducted in the region of the country where the Yoruba ethnic group is predominant. Meanwhile, only a few 8(13.8%) of the study participants had no formal level of education. Notably, most 25(43.1%) of the study stroke survivors had attained tertiary level of education while 15(25.9%) had attained secondary education.

Furthermore, majority 43(74.1%) presented as having stroke for the first time, while the remaining 15(25.9%) were recurrent stroke survivors. Notably, nearly all the study participants 56(96.5%) reported to visit the hospital during their first stroke. The length

of days of hospital stay among the stroke survivors varied with a reported average – Median (Q1, Q3) of 7(6, 10). This implies that an average of the stroke survivors reported to the hospital 7 days after the ictus. Among these stroke survivors, the Ischemic stroke 35(60.3%) was the predominant type of stroke, while a considerable number 16(27.6%) of the participants had haemorrhagic stroke type. These results are summarised in Table 7.1

Table 7.1: Socio-demographic and Clinical Characteristics of Study Participants
(N=58)

	Frequency (n)	Percent (%)
Age (Mean±SD)	69.10±8.47	
Gender		
Female	24	41.4
Male	34	58.6
Age group (years)		
<65	20	34.5
>=65	38	65.5
Religion		
Christianity	47	81.0
Islam	11	19.0
Ethnicity		
Non-Yoruba	3	5.2
Yoruba	55	94.8
Level of education		
None	8	13.8
Primary	10	17.2
Secondary	15	25.9
Tertiary	25	43.1
First stroke		
No	15	25.9

Yes	43	74.1
Visited hospital during first stroke		
No	2	3.5
Yes	56	96.5
Average time (days) to presentation at the hospital: Median(Q1,Q3)	1(0, 2)	
Stroke type		
Haemorrhagic	16	27.6
Hemispheric	2	3.5
Ischemic	35	60.3
Others	5	8.6
Average length of hospital stay: Median(Q1, Q2)	7(6, 10)	

7.3.2 Comparison of Participants Lost to Follow-Up Baseline Characteristics

Between the baseline and follow-up period of the study intervention, six (7) patients were lost to follow-up which implies an attrition rate of 10.3%. Of the seven participants that were lost to follow-up, 2 had died while 5 chose to discontinue with participating in the study. The lost to follow-up necessitated the sensitivity analysis that compared data of those who completed the study 51(89.7%) and those who were lost to follow-up 7(10.3%).

According to the result, the average age (Mean $\pm$ SD) of participants who completed the study was 65.8 $\pm$ 9.0 years compared to 69.4 $\pm$ 8.4 years of those who were lost to follow-up. The result found no significant difference ($p=0.623$) in the age of those who completed the study and those who were lost to follow-up. Meanwhile 87.5% of the females compared to 92.1% of males in the study were completed the study. The proportion of those in the different gender categories was not found to have a significant association ($p=0.157$) with their staying to the end of the study. Meanwhile, none (0) of the non-Yoruba stroke survivors was lost to follow-up, except for 4(7.3%) of the survivors who were Yoruba by ethnic categorization that were lost to follow-up. Overall, while the study participants had slightly reduced at post-intervention, the result revealed that those who were lost to follow-up were not significantly different from those who completed the study in terms of their age ($p=0.623$), location (0.591), religion (0.898), level of education ($p=0.174$), ethnicity ($p=0.804$), experience of first stroke ($p=0.299$), visiting the hospital during their first stroke ($p=0.866$), and stroke type ($p=0.078$). Thus, this implies that though the sample size had reduced due to the participants that were lost to follow-up, the missing data would not significantly impact on the findings from this study. It therefore suggests that the results of this study could

not have been significantly different if the seven participants were present till the end of the study. These results are presented in Table 7.2.

Table 7.2: Comparison of Participants Lost to Follow-Up Baseline Characteristics

	Lost-to Follow up		
	Yes (7)	No (51)	p-value
Mean Age (Mean $\pm$ SD)	65.8 $\pm$ 9.0	69.4 $\pm$ 8.4	0.366
Gender			
Female	3(12.5)	21(87.5)	0.157
Male	1(2.9)	33(97.1)	
Age group			
<65	1(5.0)	19(95.0)	0.679
>65	3(7.9)	35(92.1)	
Religion			
Christianity	3(6.7)	42(93.3)	0.898
Islam	1(7.7)	12(92.3)	
Ethnicity			
Non-Yoruba	0	3(100.0)	0.804^a
Yoruba	4(7.3)	51(92.7)	
Level of education			
None	2(25.0)	6(75.0)	0.174^b
Primary	0	9(100.0)	
Secondary	1(6.7)	14(93.3)	
Tertiary	1(3.8)	25(96.2)	
First stroke			

No	2(12.5)	14(67.5)	0.299
Yes	2(4.8)	40(95.2)	
Visited hospital during first stroke			
No	0	2(100.0)	0.866^a
Yes	4(7.1)	52(92.9)	
Stroke type			
Haemorrhagic	0	15(100.0)	0.078^a
Hemispheric	1(50.0)	1(50.0)	
Ischemic	2(5.6)	34(94.4)	
Others	1(20.0)	4(80.0)	

^a = Fisher's exact

7.3.3 Mean Difference in SS-QoL Using the Independent Samples Approach (N=58)

Before and after providing the study intervention, the Stroke Specific Quality of Life (SS-QoL) was used to evaluate the quality of life of the stroke participants. However, considering that not all the participants were followed up till the end of the study, an independent sample approach was first utilized to evaluate if there was any significant difference in the different domains of the SS-QoL and the overall quality of life. By this method, the average QoL for all the stroke survivors at baseline (N=58) was compared to the average of all those that were followed up till the end of the study (N=52).

According to the result, the average (Mean $\pm$ SD) energy quality of life of the stroke survivors at baseline was 6.79 ± 3.2 (95% CI = 5.93-7.65). However, there was an improvement in this domain of quality of life at post-intervention with an average of 12.42 ± 3.07 (95% CI = 11.54-13.29). The mean difference in quality of life of the stroke survivors after the study was found to be statistically significant ($p<0.001$). This implies that the quality of life of the stroke survivors at the energy domain significantly increased at post-intervention.

In addition, the average quality of life of the stroke survivors increased from 16.12 ± 7.27 (95% CI = 14.20-18.03) before the study intervention to 21.06 ± 5.23 (95% CI = 19.57-22.54) after the study intervention and statistically significant ($p\text{-value}<0.001$).

Regarding the mobility domain of the quality of life of the stroke survivors, there was an improvement in the average score ranging from 11.65 ± 7.20 (95% CI = 9.76-13.54) at pre-intervention to 21.94 ± 7.48 (95% CI = 19.81-24.06).

Meanwhile, a significant improvement was also found in the mood domain of the SS-QoL among stroke survivors after the study intervention was provided. According to the result, the average SS-QoL (mood) was 17.91 ± 4.98 (95% CI = 16.60-19.22). This significantly improved among the participants to an average of 22.12 ± 4.63 (95% CI = 20.80-23.43) after they had received the study intervention. The mean difference in SS-QoL (mood) performance of the study participants was statistically significant ($p < 0.001$), which is indicative of an improvement in mood aspect of the quality of life of the stroke survivors.

Furthermore, the average SS-QoL (personality) performance of the stroke survivors was 11.65 ± 3.35 (95% CI: 10.77, 12.53) at pre-intervention, which increased minimally to 13.14 ± 2.75 (95% CI: 12.35, 13.92). However, the result also indicated that this difference was significant ($p = 0.014$) and was not merely due to chance.

A significant improvement was also found in all other domains of the Stroke Specific Quality of Life – self-care ($p < 0.001$), social role ($p < 0.001$), thinking ($p < 0.001$), upper extremity function ($p < 0.001$), vision ($p < 0.001$), and work/productivity ($p < 0.001$).

The overall SS-QOL of the patients was 106.65 ± 34.33 (95% CI = 97.62-115.68) before the study intervention was provided. However, after the intervention had been given, the overall quality of life of the study participants increased significantly to an

average of 146.44 ± 37.49 (95% CI = 136.58-156.30). These results are presented in Table 7.3.

Table 7.3: Mean Difference in SS-QoL Using the Independent Samples Approach
(N=58)

SS-QoL	Mean$\pm$SD	95% CI	p-value
Energy			
Pre-intervention	6.79 $\pm$ 3.2	5.93-7.65	<0.001
Post-intervention	12.42 $\pm$ 3.07	11.54-13.29	
Language			
Pre-intervention	16.12 $\pm$ 7.27	14.20-18.03	<0.001
Post-intervention	21.06 $\pm$ 5.23	19.57-22.54	
Mobility			
Pre-intervention	11.65 $\pm$ 7.20	9.76-13.54	<0.001
Post-intervention	21.94 $\pm$ 7.48	19.81-24.06	
Mood			
Pre-intervention	17.91 $\pm$ 4.98	16.60-19.22	<0.001
Post-intervention	22.12 $\pm$ 4.63	20.80-23.43	
Personality			
Pre-intervention	11.65 $\pm$ 3.35	10.77-12.53	0.014
Post-intervention	13.14 $\pm$ 2.75	12.35-13.92	
Self-care			
Pre-intervention	9.55 $\pm$ 5.81	8.02-11.08	<0.001
Post-intervention	17.00 $\pm$ 6.34	15.19-18.80	
Social role			
Pre-intervention	7.43 $\pm$ 3.96	6.38-8.47	<0.001
Post-intervention	11.74 $\pm$ 4.43	10.47-13.00	

Thinking			
Pre-intervention	10.32±3.81	9.32-11.33	<0.001
Post-intervention	13.04±2.79	12.24-13.83	
Upper Extremity Function			
Pre-intervention	10.15±6.80	8.36-11.94	<0.001
Post-intervention	17.62±6.30	15.82-19.41	
Vision			
Pre-intervention	11.81±3.49	10.89-12.72	<0.001
Post-intervention	13.86±2.52	13.14-14.57	
Work/Productivity			
Pre-intervention	5.05±2.95	4.27-5.82	<0.001
Post-intervention	8.62±3.92	7.50-9.73	
Overall QOL			
Pre-intervention	106.65±34.33	97.62-115.68	<0.001
Post-intervention	146.44±37.49	136.58-156.30	

7.3.4 Mean Difference in QoL Using the Paired Sample Approach (N=51)

This study further examined if there was a significant difference in the different domains of the Stroke Specific Quality of Life by using the paired sample approach. This way, though the number of participants who had sufficient information to be used for the analysis was reduced to fifty-two (52), the method ensured that the performance of each participant before the intervention was given was compared with the performance post-intervention.

Notably, the pattern of results was similar to when the independent sample approach was utilized. For instance, the average SS-QoL (energy) of the participants at pre-intervention was 7.21 ± 3.20 (95% CI = 6.27-8.15), it improved to an average of 12.53 ± 3.02 (95% CI = 11.64-13.41) at post-intervention. In addition, the average SS-QoL (mobility) at post-intervention - 22.17 ± 7.48 (95% CI = 19.97-24.36) nearly doubled the performance pre-intervention - 11.65 ± 7.36 (95% CI = 11.65 $\pm$ 7.36). Meanwhile, though the average SS-QoL (personality) at pre-intervention - 11.95 ± 3.12 (95% CI = 11.04-12.87) marginally increased to 13.14 ± 2.82 (95% CI = 12.32-13.97) at post-intervention, the mean difference was found to be statistically significant ($p=0.009$).

Additionally, a significant improvement was found in the SS-QoL (thinking) of the stroke survivors from an average of 10.48 ± 3.78 (95% CI = 9.37-11.60) at pre-intervention to an average of 13.08 ± 2.78 (95% CI = post-intervention) and statistically significant ($p\text{-value} < 0.001$). Similarly, there was a significant improvement in the average SS-QoL (upper extreme function) and SS-QoL (vision) of stroke survivors post-intervention.

The overall average Stroke Specific Quality of Life of the study participants at pre-intervention was 109.57 ± 35.45 (95% CI = 99.38-119.75). At post-intervention, the average SS-QoL of the participants significantly improved to an average of 148.06 ± 36.53 (95% CI = 137.56-158.55). (Table 7.4).

Table 7.4: Mean Difference in QoL Using the Paired Sample Approach (N=51)

SS-QoL	Mean$\pm$SD	95% CI	p-value
Energy			
Pre-intervention	7.21 $\pm$ 3.20	6.27-8.15	<0.001
Post-intervention	12.53 $\pm$ 3.02	11.64-13.41	
Language			
Pre-intervention	15.68 $\pm$ 7.16	13.57-17.78	<0.001
Post-intervention	21.06 $\pm$ 5.20	19.53-22.59	
Mobility			
Pre-intervention	11.65 $\pm$ 7.36	9.49-13.82	<0.001
Post-intervention	22.17 $\pm$ 7.48	19.97-24.36	
Mood			
Pre-intervention	18.14 $\pm$ 4.76	16.74-19.54	<0.001
Post-intervention	22.02 $\pm$ 4.76	20.62-23.41	
Personality			
Pre-intervention	11.95 $\pm$ 3.12	11.04-12.87	0.009
Post-intervention	13.14 $\pm$ 2.82	12.32-13.97	
Self-care			
Pre-intervention	9.36 $\pm$ 6.01	7.59-11.12	<0.001
Post-intervention	17.06 $\pm$ 6.18	15.24-18.88	
Social role			
Pre-intervention	7.55 $\pm$ 3.67	6.47-8.63	<0.001
Post-intervention	11.76 $\pm$ 4.29	10.50-13.02	
Thinking			

Pre-intervention	10.48±3.78	9.37-11.60	<0.001
Post-intervention	13.08±2.78	12.26-13.90	
Upper Extremity Function			
Pre-intervention	10.55±6.97	8.50-12.60	<0.001
Post-intervention	17.70±6.24	15.86-19.53	
Vision			
Pre-intervention	11.76±3.35	10.78-12.75	<0.001
Post-intervention	13.91±2.56	13.16-14.66	
Work/Productivity			
Pre-intervention	5.27±2.97	4.40-6.15	<0.001
Post-intervention	8.63±3.84	7.50-9.76	
Overall QOL			
Pre-intervention	109.57±35.45	99.38-119.75	<0.001
Post-intervention	148.06±36.53	137.56-158.55	

7.3.5 Mean Difference in Barthel Index Using the Paired Sample Approach (N=52)

Disability after stroke is a significant outcome that leads to personal suffering and burden on the families of stroke survivors. The Barthel Scale/Index (BI) is an ordinal scale that is used to assess performance in daily activities (ADL). Ten variables describing ADL and mobility are scored, a higher number being a reflection of greater ability to function independently following hospital discharge. Results on the functional dependency of study participants before and after the intervention are presented in Table 7.5.

Based on the result, the average BI (feeding) of the stroke survivors at pre-intervention -5.81 ± 2.57 (95% CI = 5.07-6.55) showed that though the stroke survivors were not overly dependent, their performance in this domain significantly improved to an average of 8.16 ± 2.64 (95% CI = 7.40-8.92) with a mean difference of 2.34 (95% CI = 1.37-3.32; $p < 0.001$).

In addition, most of the study participants were functionally dependent on relatives or caregivers in bathing at pre-intervention with an average BI (bathing) of 0.91 ± 1.95 (95% CI = 0.35-1.48). This could understandably be due to impairment they may have had in some motor functions after the stroke incidence. However, the participants significantly improved in their BI (bathing) at post-intervention with an average of 2.55 ± 2.52 (95% CI = 1.82-3.27), thus a significant mean difference of 1.63 (95% CI = 0.83-2.42; $p < 0.001$).

In terms of grooming, the average stroke survivor in the study had an improvement from an average of 2.04 ± 2.48 (95% CI = 1.32-2.75) at pre-intervention to an average

of 3.57 ± 2.28 (95% CI = 2.91-4.22) post-intervention. Similarly, the ability of the stroke survivors to be functionally independent in terms of dressing nearly improved significantly by three folds at post-intervention from an average of 2.95 ± 3.52 (95% CI = 8.96-10.01) to an average of 6.93 ± 3.19 (95% CI = 6.02-7.85) and a mean difference of 1.53 (95% CI = 0.74 – 2.31; p-value<0.001).

However, regarding BI (bowels), though the average performance of the participants improved from an average of 8.67 ± 3.02 (95% CI = 8.96-10.01) before the intervention to an average of 9.48 ± 1.83 (95% CI = 7.80-9.54) after the intervention, this improvement was not statistically significant considering its mean difference of 0.81 (95% CI = -0.17, 1.80; p-value=0.103). Thus, this suggests that the study intervention, though improved the bowel domain of the stroke survivors, may not be a suitable intervention for such.

On the other hand, the average BI (bladder) of the stroke survivors got better after the intervention considering that the average performance of the participants at baseline was 7.04 ± 4.19 (95% CI = 5.83-8.24) but improved to an average of 8.46 ± 2.73 (95% CI = 7.68-9.25) at post-intervention. Though the improvement could be considered minimal, it was significant (p=0.021).

Furthermore, all other domains of the ADL of the study participants benefited significantly from the intervention with at least a double improvement at post-intervention. These domains include toilet use, with a mean difference and 95% confidence interval of 3.87 and 2.77-4.98 respectively, transfers to bed or chairs (mean difference = 5.51; 95% CI = 4.25-6.76; p<0.001), mobility (mean difference= 5.51; 95%

CI = 3.68-6.52; $p < 0.001$), and stairs (mean difference = 3.06; 95% CI = 2.09-4.02; $p < 0.001$).

The average overall functional independence of the stroke survivors was 44.08 ± 25.20 (95% CI = 36.84-51.32) at baseline. However, this significantly improved to an average of 73.36 ± 25.82 (95% CI = 65.94-80.78) at post-intervention. Considering its significant mean difference of 29.28 (95% CI = 22.23-36.33), this suggests that the study intervention provided an improvement in the activities of daily living of stroke survivors.

**Table 7.5: Mean Difference in Barthel Index Using the Paired Sample Approach
(N=52)**

	Mean$\pm$SD	95% CI	Mean difference (95% CI)	p-value
Feeding				
Pre-intervention	5.81 $\pm$ 2.57	5.07-6.55	2.34(1.37-3.32)	<0.001
Post-intervention	8.16 $\pm$ 2.64	7.40-8.92		
Bathing				
Pre-intervention	0.91 $\pm$ 1.95	0.35-1.48	1.63(0.83-2.42)	<0.001
Post-intervention	2.55 $\pm$ 2.52	1.82-3.27		
Grooming				
Pre-intervention	2.04 $\pm$ 2.48	1.32-2.75	1.53(0.74 – 2.31)	<0.001
Post-intervention	3.57 $\pm$ 2.28	2.91-4.22		
Dressing				
Pre-intervention	2.95 $\pm$ 3.52	1.94-3.97	3.97(2.92-5.03)	<0.001
Post-intervention	6.93 $\pm$ 3.19	6.02-7.85		
Bowels				
Pre-intervention	8.67 $\pm$ 3.02	8.96-10.01	0.81(-0.17, 1.80)	0.103
Post-intervention	9.48 $\pm$ 1.83	7.80-9.54		

Bladder				
Pre-intervention	7.04±4.19	5.83-8.24	1.42(0.21-2.63)	0.021
Post-intervention	8.46±2.73	7.68-9.25		
Toilet use				
Pre-intervention	3.06±3.79	1.97-4.15	3.87(2.77-4.98)	<0.001
Post-intervention	6.93±3.65	5.88-7.98		
Transfers				
Pre-intervention	5.61±4.16	4.41-6.80	5.51(4.25-6.76)	<0.001
Post-intervention	11.12±3.98	9.97-12.26		
Mobility				
Pre-intervention	5.81±5.03	4.36-7.26	5.10(3.68-6.52)	<0.001
Post-intervention	10.91±4.64	9.58-12.25		
Stairs				
Pre-intervention	2.14±3.53	1.12-3.15	3.06(2.09-4.02)	<0.001
Post-intervention	5.20±4.07	4.03-6.37		
Overall Barthel Index				
Pre-intervention	44.08±25.20	36.84-51.32	29.28(22.23-36.33)	<0.001

Post- intervention	73.36±25.8 2	65.94- 80.78		
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7.3.6 Relationship Between Functional Independence (Barthel Index) and SS-QoL

To examine the strength of the linear relationship that exists between functional dependence and stroke-specific quality of life, a test of normality was first conducted for both variables – BI and SS-QoL using the Shapiro-Wilk test. Both variables were found not to be normally distributed ($p=0.004$, and 0.001 respectively), which necessitated the use of a non-parametric test (Spearman Rank correlation) instead of the parametric test (Pearson Product Moment correlation).

Findings from this study (Table 7.6) revealed a significant strong positive correlation between function independence and stroke-specific quality of life ($\rho=0.895$; $p<0.001$). This result implies that the higher the functional independence in stroke survivors, the better their quality of life and otherwise.

Table 7.6: Relationship Between Functional Independence (Barthel Index) and SS-QoL

	Functional Independence (BI)	SS-QoL
Functional Independence (BI)	1.00	
SS-QoL	0.895(<0.001)	1.00

7.3.7 Trajectory of Recovery in Different Domains During the 8-Week Follow-Up

Health conditions and challenges of the stroke survivors were also examined through feedback from their respective caregivers and the results are presented in Table 7.7. The results show a progressive improvement in various aspects of stroke survivors' recovery over eight weeks, as reported by their caregivers.

Initially, 81.1% of stroke survivors experienced energy-related problems in the first week, which reduced to 76.5% in the second week, and further consistently decreased up to 61.2% by the eighth week. This trend indicates a steady improvement in energy levels among patients,

Similar improvements were observed in speech-related problems. In the first week, 64.1% of survivors had trouble with speech, which decreased to 54.9% in the second week, slightly increased to 55.8%, and then reduced consistently to 51.0% by the eighth week.

In contrast, mobility improvements were inconsistent over the eight weeks. While 66.0% of survivors showed mobility improvements in the first week, this increased to 83.7% in the second week, fluctuated to 74.4% in the third week, rose to 82.1% in the fourth week, and peaked at 85.7% by the eighth week.

Mood improvements were not apparent in the first three weeks. Initially, 66.7% of patients reported improved mood in the first week, but this proportion declined to 62.5% and 58.3% in the second and third weeks, respectively. However, from the fourth week onwards, over 80% of patients reported improved mood, which remained

high until the end of the study. Self-care difficulties showed a continuous reduction, from 90.2% in the first week to 66.7% by the end of the study period.

Memory improvements were consistently observed throughout the study. The proportion of patients with improved memory increased from 63.2% at baseline to 76.2% in the second week, 83.3% in the third week, 88.2% in the fourth week, and remained over 90% from the fifth week until the end of the study.

Table 7.7: Trajectory of Recovery in Different Domains During the 8-Week Follow-Up

	Wk 1	Wk 2	Wk 3	Wk 4	Wk 5	Wk 6	Wk 7	Wk 8
Patient has any problem with energy	43(81.1)	39(76.5)	37(71.2)	35(70.0)	36(70.6)	33(64.7)	31(62.0)	30(61.2)
Energy level of patient improved	36(83.7)	36(92.3)	34(91.9)	33(94.3)	36(100.0)	32(97.0)	30(96.8)	29(96.7)
Patient has any trouble with speech	34(64.1)	28(54.9)	29(55.8)	27(54.0)	27(52.9)	26(51.0)	27(54.0)	25(51.0)
Improvement in patient's speech	26(76.5)	23(82.1)	26(89.7)	26(96.3)	27(100.0)	25(96.2)	25(92.6)	24(96.0)
Patient has any trouble with mobility	47(90.4)	43(84.3)	43(82.7)	39(78.0)	39(76.5)	39(76.5)	38(76.0)	35(71.4)
Patient's mobility has improved	31(66.0)	36(83.7)	32(74.4)	32(82.1)	33(84.6)	34(87.2)	33(86.8)	30(85.7)
Patient has any trouble with mood	15(28.8)	16(31.4)	12(23.1)	12(24.0)	12(23.5)	12(23.5)	12(24.0)	10(20.4)
Patient's mood has improved	10(66.7)	10(62.5)	7(58.3)	10(83.3)	10(83.3)	10(83.3)	10(83.3)	8(80.0)
Patient has personality issue	8(15.4)	7(13.7)	6(11.5)	5(10.0)	5(9.8)	5(9.8)	5(10.0)	5(10.2)
Patient's personality has improved	4(50.0)	2(28.6)	2(33.3)	2(40.0)	2(40.0)	3(60.0)	3(60.0)	2(40.0)

Patient has trouble with self-care	46(90.2)	42(84.0)	40(78.4)	38(76.0)	37(72.5)	37(72.5)	38(76.0)	32(66.7)
Patient's ability to provide self-care has improved	33(71.7)	33(78.6)	32(80.0)	30(78.9)	31(83.8)	33(89.2)	31(81.6)	26(81.2)
Patient has problem interacting with people	17(32.7)	17(33.3)	16(30.8)	15(30.0)	16(31.4)	16(31.4)	18(36.0)	14(28.6)
Patient's social interaction has improved	12(70.6)	12(70.6)	13(81.2)	13(86.7)	15(93.7)	14(87.5)	16(88.9)	12(85.7)
Patient has trouble with memory	19(36.5)	21(41.2)	18(34.6)	17(34.0)	16(31.4)	14(27.5)	16(32.0)	16(32.6)
Patient's memory has improved	12(63.2)	16(76.2)	15(83.3)	15(88.2)	15(93.7)	13(92.9)	15(93.7)	15(93.7)
Patient has problem performing upper extremity functions	45(86.5)	41(80.4)	44(84.6)	40(80.0)	41(80.4)	40(78.4)	36(72.0)	34(69.4)
Patient has improved in upper extremity function	34(75.6)	34(82.9)	34(77.3)	36(90.0)	37(90.2)	37(92.5)	33(91.7)	32(94.1)
Patient has vision problem	4(7.7)	5(9.8)	4(7.7)	5(10.0)	4(7.8)	5(9.8)	5(10.0)	4(8.2)
Patient's vision has improved	1(25.0)	2(40.0)	1(25.0)	2(40.0)	1(25.0)	2(40.0)	2(40.0)	1(25.0)

7.3.8 Average Rating of Improvement in Different Domains at Follow-Up

Table 7.8 showed different domains of quality of life and functional outcome of stroke survivors monitored across the period of 8 weeks. The average energy level rating of the stroke survivors in this study had an improvement from 4.69 ± 1.90 in week 1 to 7.75 ± 1.97 in week 8. Similarly, their average speech rating had an improvement from 5.00 ± 1.67 in week 1 to 7.00 ± 1.88 in week 8. Meanwhile, the average mobility rating of the stroke survivors' results showed a gradual improvement from 4.54 ± 1.92 in week 1 to 6.56 ± 1.90 in week 8. However, the results showed a faltering in the average mood rating with an average of 5.90 ± 1.96 in week 1 to a progressive decrease of 4.40 ± 2.01 in week 4 then a gradual increase to 5.12 ± 1.88 in week 8. Similarly, the average personality rating presented with fluctuating with 6.00 ± 2.70 in week 1, 4.50 ± 3.53 in week 2, 3.00 ± 2.82 in week 5 then back up to 5.66 ± 2.30 in week 7 and a final decrease to 5.00 ± 2.82 in week 8. Meanwhile, the average self-care rating had an improvement of 4.15 ± 1.82 in week 1 to 6.03 ± 2.39 in week 8 while the average social interaction rating showed a slight floundering with an average of 5.33 ± 2.46 in week 2 to 5.00 ± 2.58 in week 3 then a steady increase to 6.91 ± 2.93 in week 8. The average memory rating results revealed an average of 4.91 ± 1.72 in week 1 to 5.66 ± 1.91 in week 3, 5.53 ± 2.32 in week 4 then a progressive increase to 7.06 ± 2.21 in week 8. Simultaneously, the average upper extremity function rating improved from 4.44 ± 1.72 in week 1 to 6.34 ± 2.37 in week 8. The average rating for how well patient can perform work improve from 5.78 ± 1.43 at week one to 7.42 ± 1.87 at week 8.

Table 7.8: Average Rating of Improvement in Different Domains at Follow-Up

	Wk 1	Wk 2	Wk 3	Wk 4	Wk 5	Wk 6	Wk 7	Wk 8
Average energy level rating	4.69±1.90	5.36±1.79	5.85±1.82	6.12±2.07	6.58±1.93	7.34±1.73	7.56±1.63	7.75±1.97
Average speech rating	5.00±1.67	5.00±1.73	5.19±1.67	5.61±1.79	5.92±1.59	6.64±1.41	6.96±1.71	7.00±1.88
Average mobility rating	4.54±1.92	4.85±1.83	5.31±1.73	5.62±1.64	6.06±2.01	6.35±2.02	6.48±1.87	6.56±1.90
Average mood rating	5.90±1.96	5.70±1.49	5.42±1.27	4.40±2.01	4.60±2.63	5.00±1.94	5.60±1.83	5.12±1.88
Average personality rating	6.00±2.70	4.50±3.53	5.00±0	4.50±0.70	3.00±2.82	5.33±2.88	5.66±2.30	5.00±2.82
Average self-care's rating	4.15±1.82	4.42±1.83	4.87±2.04	5.26±1.99	5.38±2.17	5.78±2.21	5.90±2.27	6.03±2.39
Average social interaction rating	4.75±2.63	5.33±2.46	5.00±2.58	5.30±2.56	5.73±2.40	6.57±2.50	7.25±2.14	6.91±2.93
Average memory rating	4.91±1.72	5.06±2.08	5.66±1.91	5.53±2.32	5.80±2.21	6.53±2.14	7.20±1.85	7.06±2.21
Average upper extremity function rating	4.44±1.72	4.88±1.96	5.41±1.84	5.69±1.96	5.94±2.05	5.91±2.30	6.24±2.26	6.34±2.37
Average rating of how well the patient can start and complete a work	5.78±1.43	6.16±1.42	6.04±1.80	5.61±1.81	6.50±1.87	6.67±1.90	7.23±1.88	7.42±1.87

7.3.9 Sociodemographic Characteristics of Family Caregivers of Older Adult Stroke Survivors

For this study, a total of 58 caregivers were recruited with their sociodemographic characteristics summarized in Table 7.9. The average age of the study participants was 41.9 ± 13.5 with the majority of them 40 (69.0%) being female. The study participants were predominantly Christians with 48 (82.8%) of them following and engaging in the beliefs of the Christian faith while 10 (17.2%) practiced Islam. Meanwhile, a vast majority of them 55 (94.8%) were from the Yoruba ethnic group. Regarding levels of education, only a few 4 (6.9%) participants stopped at the primary level of education. However, a greater number of them 40 (69.0%) attained tertiary level of education while 14 (24.1%) secured secondary education

Table 7.9: Sociodemographic Characteristics of Family Caregivers of Older Adult Stroke Survivors

	Frequency	Percent
Gender		
Female	40	69.0
Male	18	31.0
Average age (Mean$\pm$SD)	41.9 $\pm$ 13.5	
Religion		
Christianity	48	82.8
Islam	10	17.2
Ethnicity		
Igbo	1	1.7
Yoruba	55	94.8
Others	2	3.5
Level of education		
Primary	4	6.9
Secondary	14	24.1
Tertiary	40	69.0

7.3.10 Mean Difference in Family Caregivers' Knowledge and Support at the Pre- and Post-Intervention Phase

At the pre-intervention phase, 58 caregivers participated in the baseline assessment. However, 51 caregivers participated in the post-intervention assessment. The reduction in sample size was due to loss of follow-up of 7 participants. In terms of stroke knowledge, the average family caregiver in the study had an improvement from an average of 1.891.83 (95% CI=1.41-2.37) at pre-intervention to an average of 5.470.94 (95% CI=5.20-5.73) post-intervention. Similarly, caregivers' knowledge on what to do to prevent stroke recurrence had an improvement from an average of 1.791.88 (95% CI=1.29-2.28) at pre-intervention to an average of 5.171.16 (95% CI= 4.84-5.50) post-intervention. Additionally, the average caregivers' knowledge on adaptation exercises for stroke patients improved from an average of 1.671.95 (95% CI=1.15-2.18) at pre-intervention to an average of 5.330.99 (95% CI=5.05-5.61) post-intervention.

The average overall stroke knowledge of family caregivers was an average of 8.085.67 (95% CI=6.59-9.57) at the baseline. However, there was a significant improvement to an average of 14.055.82 (95% CI=12.51-15.58) post-intervention.

Concerning patients' support, the average caregivers' support for better medication use for patients had an improvement from an average of 4.941.60 (95% CI=4.52-5.37) at pre-intervention to an average of 6.131.05 (95% CI=5.83-6.43) post-intervention. Regarding caregivers' support of patients' feeding needs, the results showed improvement from an average of 4.821.67 (95% CI=4.38-5.26) at pre-intervention to an average of 6.210.96

(95% CI=5.94-6.48) post-intervention. Similarly, the average caregivers' knowledge on what to do in the case of patients developing complications improved from an average of 2.202.36 (95% CI=1.58-2.82) at pre-intervention to an average of 5.001.38 (95% CI=4.61-5.38) post-intervention.

The average overall patient support of family caregivers was an average of 11.983.85 (95% CI=10.97-12.99) at the baseline. However, this significantly improved to an average of 15.256.25 (95% CI=13.61-16.90) post-intervention. (Table 7.10).

Table 7.10: Mean Difference in Family Caregivers' Knowledge and Support at the Pre- and Post-Intervention Phases

	Mean $\pm$ SD	95% CI	Mean difference (95% CI)	p-value
Stroke knowledge				
Have knowledge on stroke care				
Post-intervention	5.47 $\pm$ 0.94	5.20-5.73	3.57(3.01-4.13)	<0.001
Pre-intervention	1.89 $\pm$ 1.83	1.41-2.37		
Know what to do to prevent recurrence of stroke				
Post-intervention	5.17 $\pm$ 1.16	4.84-5.50	3.38(2.77-3.98)	<0.001
Pre-intervention	1.79 $\pm$ 1.88	1.29-2.28		
Know about the adaptation exercise for stroke patients				
Post-intervention	5.33 $\pm$ 0.99	5.05-5.61	3.66(3.06-4.26)	<0.001
Pre-intervention	1.67 $\pm$ 1.95	1.15-2.18		
Overall stroke knowledge				
Post-intervention	14.05 $\pm$ 5.82	12.51-15.58	5.96(3.84-8.08)	<0.001

Pre-intervention	8.08±5.67	6.59-9.57		
Patients' support				
Better support medication use for patient				
Post-intervention	6.13±1.05	5.83-6.43	1.18(0.66-1.71)	<0.001
Pre-intervention	4.94±1.60	4.52-5.37		
Better support patients' feeding needs				
Post-intervention	6.21±0.96	5.94-6.48	1.38(0.85-1.91)	<0.001
Pre-intervention	4.82±1.67	4.38-5.26		
Know what to do when patient develops complications				
Post-intervention	5.00±1.38	4.61-5.38	2.79(2.04-3.54)	<0.001
Pre-intervention	2.20±2.36	1.58-2.82		
Overall patients' support				
Post-intervention	15.25±6.25	13.61-16.90	3.27(1.36-5.18)	<0.001
Pre-intervention	11.98±3.85	10.97-12.99		

7.4 DISCUSSION of results

This longitudinal study assessed the effectiveness of the intermediate care model on the functional health and quality of life of older adult stroke survivors. The mean age of the older adult stroke survivors and their family caregivers were 69.10 ± 8.47 and 41 ± 13.5 respectively. Our findings revealed the preponderance of male stroke survivors (58.6%) and female family caregivers (69%). Forty three percent, 43.1% (25) of stroke survivors and 69% (40) of family caregivers had attained tertiary level of education. Before initiating the intervention, baseline measurements were obtained on SSQOL and Barthel Index scores. Although 7 out of 58 participants recruited at baseline were lost to follow-up, the reduction in sample size did not significantly impact the study findings. Overall, there was significant improvement in the SSQoL of the older adult stroke survivors across all domains at the post- intervention phase. The domains assessed were, energy ($p < 0.001$), mobility ($p < 0.001$), language ($p < 0.001$), self-care ($p < 0.001$), mood ($p < 0.001$), personality ($p < 0.009$), upper extremity function ($p < 0.001$), social role ($p < 0.001$), thinking ($p < 0.001$), vision ($p < 0.001$), work/productivity ($p < 0.001$). Similarly, significant improvements were reported in Barthel index scores across all domains such as feeding ($p < 0.001$), bathing ($p < 0.001$), toilet use ($p < 0.001$), grooming ($p < 0.001$), dressing ($p < 0.001$), bladder ($p = 0.021$), transfers from bed to chair ($p < 0.001$), mobility ($p < 0.001$), stairs ($p < 0.001$), except bowel continence ($p = 0.103$). A strong positive correlation was observed between functional independence and quality of life. Findings of the 8-week follow-up period indicated a progressive increment in the average rating of improvement across the domains. Notably, except for mood and personality, all domains (energy, speech,

mobility, self-care, social interaction, memory, and upper extremity) assessed during the follow-up period indicated that a progressive improvement over time. This suggests that continuous intermediate care service to older adult stroke survivors could be beneficial for optimal recovery. Our findings supported the hypothesis that the intermediate care model improves the functional outcome and quality of life of older adult stroke survivors. Overall caregivers' stroke knowledge and patient support had significantly improved at post-intervention.

Consistent with our findings, several studies reported participants' mean age to be 69 ± 14.1 (Sit et al., 2016), 69 ± 14 (Urrea et al., 2013). However, other studies conducted among older adults reported divergent findings concerning participant mean age (Balaban et al., 2011; Walcott et al., 2014; Mas et al., 2017). As seen in this study, other studies also described the preponderance of male stroke survivors (Alawneh et al., 2022; Rupasinghe et al., 2022). This may be attributed to the lesser withdrawal bias in males as compared to females (Ospel et al., 2023). The significant improvements observed on patients' functional health and quality of life in this study could be attributed to the predominance of stroke survivors and family caregivers with high educational level (tertiary education). Having low educational level has been proposed as one of the factors that could limit access to health information and the understanding of drug prescription, treatments, and adequate care required by patients living with chronic diseases such as stroke. This feature impacts patient's attitude and practice of self-care and adherence to treatment plan (Carvalho-Pinto and Faria, 2016).

Similar to our findings, numerous studies have documented the mean age of caregivers falling within the middle-age range (Shyu et al., 2010; Torabi Chafjiri et al., 2017; Kazemi et al., 2021). This could have an unfavorable implication on the individual and nation's economy considering that the middle-aged are still in their active and productive years. The prevalence of female caregivers in this study supports previous findings (Oni et al., 2019; Menon 2017; Tseng et al., 2015). This may be explained with the sociocultural norms that places caregiving demands women (Sharma et al., 2016; Akpınar, 2011). Moreover, female caregivers may likely combine caregiving with their job demands thereby resulting in increased burden (Menon et al., 2017).

7.4.2 Functional Health Outcome of Older Adult Stroke Survivors

This study's findings present the evidence that home-based intermediate care model could yield functional gains in older adult stroke survivors. Previous studies have demonstrated that stroke survivors can achieve functional improvement and reduced physical and economic burdens on their family caregivers through outpatient or home-based rehabilitation after acute phase (Wang et al., 2015; Wang et al., 2019; Miller et., 2010). The Barthel index scores of participants in this study significantly increased from 44.08 ± 25.20 to 73.36 ± 25.82 at the post-intervention phase which suggest significant improvements in their physical functioning. Several studies reported a similar finding (Sit et al., 2016; Radajewska et al., 2016). A study conducted by Wang et al. (2015) indicated that post-acute care program resulted in improvements in the Barthel index scores of stroke survivors with moderate disability and moderately severe disability (Wang et al., 2019). Adding further, in a Taiwan study, participants who received intervention attained significant functional improvement in all domains (Peng et al., 2017). Another study

stratified for type of strokes and observed no significant difference in the functional ability of the two subgroups after a 6-week post-acute care program. However, among those who participated in 6-12weeks program, hemorrhagic stroke survivors indicated greater functional ability than ischemic stroke survivors (Chu et al., 2020). This highlights a limitation in this study as stratification for stroke subtypes, which could provide more clarification on the effect of the intermediate care model in this context, was not applied. In a study that investigated the effect of stroke on long-term functional recovery of stroke survivors, functional improvement was observed in participants aged <70 years until 6 months after stroke onset; this was maintained from 6 to 30 months after stroke onset. However, further reports from the study indicated a functional decline in older adults ≥ 70 years between 6 to 30 months (Yoo et al., 2020). This suggests that age significantly predicts functional improvement. Similarly, the findings of this study indicated significant functional gains among the older adults until 2 months after stroke. However, further investigations on a long-term follow-up would provide information on how long the gains are sustained.

Contrasting reports have been documented in the literature. The results of the post-intervention phase of a study indicated an insignificant effect of caregiver-mediated exercise on the activity of daily living of stroke survivors which is suggestive of no functional improvement (Vloothuis et al., 2016). Araujo et al. (2020) conducted a study on the effect of InCARE intervention on functional outcome of older adults. Although the program supported informal caregivers' practical skills stroke survivors, there was no evidence of it's positive effect on post-stroke functional recovery. The suggested reasons

for this insignificance were advanced age and possibility of 3-months follow-up not being enough for monitoring recovery trajectory. In contrast, despite having an aged population and a shorter follow-up period, stroke survivors in this study experienced significant improvement. The differences in results of the two studies could be linked to disparities in developed intervention program for each study and level of stroke severity in the participants of each study. Stroke survivors who do not receive appropriate rehabilitation or care support generally exhibit a considerable decline in physical functioning (Dhamoon et al., 2012). Therefore, establishing an effective treatment pathway for stroke survivors with disabilities is crucial and could foster recovery to a premorbid state and enhance community reintegration

7.4.3 Quality of Life of Older Adult Stroke Survivors

Several studies have identified the beneficial effect of intermediate care services on stroke survivors' quality of life. Our findings revealed statistically significant improvement for each domain and the overall quality of life ($p < 0.001$). This finding is consistent with Bavarsad et al.'s (2022) study, which reported significant improvements across all quality of life domains for participants in the intervention group (Bavarsad et al., 2022). Although the intervention provided in the study spanned 10 weeks post-discharge, it was initiated during patients' admission. The initiation of intervention at the acute phase could interact with the eventual patient outcome and highlight the need for a cautious comparison. At the post intervention phase of an intermediate care program conducted for approximately 6 weeks, significant improvement was observed in some aspects of quality of life such as balance, mobility, self-care, usual activity, depression, intake condition, and mental ability.

However, there were no significant improvements in other aspects of quality of life associated with pain/discomfort and Speech function (Lai et al., 2017).

Peng and colleagues also observed a beneficial effect of post-acute care services on quality of life (EQ-5D utility) after stroke. However, the much older participants who had experienced stroke within 2 years before the study displayed minimal gains (Peng et al., 2019). According to authors, intermediate care services for older stroke survivors are expected to emphasize personalized treatment goals and integrate specific services required according to individual impairment (Wang et al., 2019). Putting this into place may assist in achieving recovery in different domains for diverse populations.

Previous studies highlighted the inconsistent result in the effect of intermediate care type employed on the quality of life of older adult stroke survivors. Chen et al. (2023) deduced that home-based rehabilitation achieved a significant improvement in the quality of life of participants, however, greater positive results were obtained with hospital-based rehabilitation (Chen et al., 2023). Contradictory reports indicated no significant difference in the improvement for quality of life of home-based and in-patient rehabilitation patients (Tung et al., 2021). Despite these inconsistencies, the literature has emphasized the potential benefit of early home-based rehabilitation in reducing disability and increasing quality of life of stroke survivors (Rasmussen et al., 2016; Jafari et al., 2020; Chaiyawat and Kulkantrakorn et al., 2012).

7.4.4 Relationship between functional outcome and quality of life of older adult stroke survivors

Several studies have observed a positive relationship between functional health and quality of life (Mandić et al., 2017; Mahran et al., 2015). For instance, a study involving geriatric patients indicated that high functional independence, together with other factors such as minimal depressive complaints and neuropsychiatric symptoms, is associated with good quality of life (Buijck et al., 2014). Lee and colleagues concluded that a significant correlation exist between physical therapy and functional recovery, along with positive improvement in pain depression symptoms (Lee et al., 2012). Consistently, strong positive linear correlation was observed in this study between stroke survivors' functional outcome and their quality of life. Study participants simultaneously experienced a significant improvement in their functional recovery and quality of life. These evidence supports authors' deductions that lower the dependence, the higher the quality of life of older adults (Loredo-Figueroa et al., 2016; Samadarshi et al., 2021).

7.4.5 Family caregivers' knowledge and support in intermediate stroke care.

According to Prvu Bettger et al. (2015), 44% of stroke survivors are sent home right away without receiving any hospital or outpatient rehabilitation care (Prvu Bettger et al., 2015). For patients and the family caregivers, the transition home frequently signifies a new challenge regardless of the hospital recovery trajectory (Lutz et al., 2011). One of the most crucial pre-discharge requirements for family caregivers of stroke survivors is the knowledge and training necessary to provide the proper care (Cameron et al., 2015; İnan and Polat, 2023). Early studies emphasized on the reinforcement of older adult stroke survivors' caregivers training through combination of verbal techniques with written educational materials (Hinojosa and Rittmann 2009; Gustafsson et al., 2010). This study involved the use of video demonstrations along with verbal training to enhance caregivers

understanding and easy practice at home. This method aligns with inferences from literature that explained that effective and efficient stroke care education of family caregivers occurs when practical skills and demonstration are included in the training process (Gustafsson et al., 2010).

Study caregivers demonstrated improved knowledge of stroke care, secondary prevention and adaptation exercise. These improvements could be attributed to the training received during the intervention phase. Additionally, the training translated into significant improvements in caregivers' ability to provide support on domains such as feeding, assistance in medication use and complications management. Other studies also showed that training intervention for family caregivers yielded better outcomes on adherence and compliance levels to different care domains including rehabilitation, medication and dietary routines (Dehghan Nayeri et al., 2014; Galvin et al., 2011). Research have demonstrated that increased caregiver awareness may boost favourable results including patients' functional improvements and caregiver satisfaction (Kalra et al., 2004; Hong et al., 2017). This implies that prioritizing adequate information, training and skill development for family caregivers before or at the point of home discharge stands to yield better results.

7.4.6 Application of Mhealth for follow-up of Older adult stroke patient

Adequate follow-up and support for patient functional health is required to prevent further disability and improve health outcomes (Arene and Hidler et al., 2009). Follow-ups offers the potential to foster communication, education support, and compliance for better health outcomes (Wan et al., 2016). Comprehensive telehealth system has proven to improve

the quality of life, functional, social, psychological, and self-care domains of stroke survivors (Bartoli et al., 2024). This has led to the use of several Mhealth methods for the delivery of follow-up in home-based interventions for older stroke survivors and their family caregivers which include telephone calls, mails, and mobile applications (Ostwald et al., 2014; Bartoli et al., 2024).

A telephone follow-up intervention has been demonstrated to enhance health habits in many people with chronic illnesses and is quite easy to use and inexpensive (Cicolin et al., 2014).

Telephone follow-up used in this study assisted in the monitoring of functional health and quality of life domains and providing support for family caregivers. Study result revealed a progressive improvement within the follow-up period for all domains except mood and personality which indicated inconsistent patterns. The observed similar fluctuating wave in mood and personality may be suggestive of a direct correlation between the two domains. This may be further explained by the deduction that psychological factors such as personality are significant predictors of mood problems (Van Mierlo et al., 2015).

A study conducted among ischemic stroke patients using telephone follow-up intervention patients indicated no improvement in dietary pattern, substance use, physical activity level, or blood pressure frequency. However, it was observed that adherence to the medication regimen improved significantly. Another study used web-based caregiver intervention comprising one telephone orientation session and subsequent eight virtual

messaging centre sessions. Improvements in functional outcomes were observed by 11 weeks, but the improvements were not maintained after 19 weeks (Quinn et al., 2023). A stroke telerehabilitation program used an in-home messaging device, 3 home visits, and 5 telephone calls for exercise instructions and adaptive strategies. The intervention improved functional health up to 3 months after the intervention. The authors concluded that telerehabilitation could be an additional strategy for home-based stroke care, particularly in low-resource settings (Chumbler et al., 2012).

There is growing evidence that the combination of caregivers' education and telephone follow-up produces a beneficial effect on stroke survivors' outcomes (Markle-Reid et al., 2023; Cha et al., 2022). Other studies have shown that family caregivers stand the chance to benefit from such intervention. A report showed a significant reduction in the care burden of family caregivers after a 12-week education and telephone follow-up (Bani Ardalan et al., 2022). Similarly, another study that utilized discharge training and telephone counselling observed a significantly lower caregiver burden at three months post-discharge (Bitek and Erol, 2023). Owing to the evidence from the literature, it may be concluded that the inclusion of mhealth in the provision of intermediate care could enhance better outcomes for both the patient and their caregivers.

7.5 Summary of the chapter

The findings of this study revealed that home-based intermediate care could be effective for achieving significant improvement in the functional recovery and quality of life of older adult stroke survivors. Significant improvements were obtained during the 8-week follow-up period after hospital discharge. This implied that older adult stroke survivors could benefit from the intermediate care model when applied early enough after acute care. In summary, the result of this study indicated that the inclusion of home-based intermediate care in the stroke continuum of care in Nigeria would yield better health outcomes in stroke survivors.

CHAPTER 8

Conclusion

This chapter summarized the main findings obtained of this study. According to the conceptual framework, a systematic review, qualitative and quantitative studies were used to provide answers to the research questions.

8.1 Main results of the thesis

Overall, this study aimed to investigate the impact of the intermediate care model on the functional health and quality of life of older adult stroke survivors in southwest Nigeria. The study used a systematic review followed by mixed methods (qualitative and quantitative) to answer the four research objectives.

Stroke is a leading cause of disability and mortality and if not properly managed, could result in severe conditions such as dementia. In Nigeria, several stroke survivors are discharged home to their family caregivers who have poor or no knowledge of stroke management. Consequently, this may result in poorer quality of life, increased caregiver burden due to functional dependence of stroke survivors, high risk of recurrent stroke, and increased risk of mortality. Incorporating intermediate care could assist these caregivers in the provision of adequate and appropriate care and reduction of negative outcomes for stroke survivors.

Literature revealed the existence of various intermediate care such as home-based and institution-based intermediate care. Findings from the systematic review in this study indicated that home-based intermediate care could be an effective tool in achieving functional recovery through improved motor recovery, quality of movement, motor acquisition, walking speed and postural balance. Identified home-based intermediate care options for older adult stroke survivors include physical therapy, occupational therapy, speech therapy, and meaningful task-specific training.

The home-based intermediate care services identified in the review underscored similarity with the narratives of the study's family caregivers on home-based care needs of older adult stroke survivors. Most of the family caregivers expressed the presence of a caregiving burden, notable gaps in communication between them and formal care providers, and unmet needs for information and training on stroke management. Consistently, literature provides evidence that family caregivers across different regions of the world experience similar challenges, particularly in terms of caregiving burdens and unmet needs.

The intermediate care model developed in this study, through the integration of inferences from literature and family caregivers' perceptions, yielded significant improvements in the functional health and quality of life of older adults. Participants experience significant improvement in all domains of functional health. All domains except bowel continence in the Barthel index increased significantly. Participants weekly scores over the follow-up period also revealed a significant increase in quality of life and performance of activities

of daily living. However, personality and mood revealed inconsistent increases during the follow-up period. A statistically significant positive correlation was observed between functional independence and quality of life. Caregivers' knowledge and patient support scores improved significantly in the post-test. These findings revealed that the introduction of intervention at discharge generates a positive effect on stroke survivors and their family caregivers. Consequently, the implementation of the intervention model in Nigeria could assist in reducing poor health outcomes in stroke survivors and caregivers' burden through empowerment with adequate knowledge needed for stroke care and proper follow-up.

. Frequently, high rates of hospitalization are reported, especially, within the first year after hospital discharge. This highlight the need for optimizing stroke survivors' transitions from hospital to home and into the community. The optimization of the transition process is aimed at achieving three major goals of poststroke rehabilitation which include enhancing the quality of care received, enhancing the stroke survivors' and caregivers' health, and promoting cost-effectiveness. Additionally, successful transitioning from acute care to home or community rehabilitation demands communication between multidisciplinary teams across various locations. However, there are notable challenges and gaps that inhibit the successful transition of stroke survivors. Such include the dilapidated healthcare system due to challenges such as financial barriers, reduced healthcare provider staffing due to the search for greener pastures, accessibility problems, absence of a robust communication pathway, and poor service integration. Owing to the highlighted factors, there is urgency in the need to establish metrics for the structure and

processes of intermediate care services received by stroke survivors. In addition, technology-based solutions such as mobile-based telephony should be considered for intermediate care intervention to improve secondary prevention and promote compliance among survivors. Overall, study findings reflect that the mechanism combining caregivers' education on stroke care and technology could be integrated into the stroke system of care for better health outcomes.

8.2 Strength and limitations

To the best of my knowledge, this is the first study to investigate the effect of the intermediate care model on the functional outcome and quality of life of older adult stroke survivors. This study provides first-hand information on the effectiveness of the model. The weekly telephone follow-up call reduced the occurrence of recall bias and served as a source of support for caregivers. This study provides robust information on the existing intermediate care models, stakeholders' perception of the implementation of the intermediate care model, and the effectiveness of the home-based intermediate care model developed in this study for stroke survivors' functional health and quality of life in Southwest Nigeria. The use of qualitative data collection techniques provided in-depth knowledge of the researchers' aim in the study context. Focus group segregation according to gender enhanced the generation of responses from participants without any gender-related restriction. It is also worthy of note that this is the first study of its kind nationwide that detailed the perception of stakeholders on intermediate level of care model for older adult post-stroke patients

Despite these, the study is limited by geographical context due to the use of a single geopolitical zone in the study. The follow-up period of the study was eight weeks and might not be sufficient to predict the impact of the model on the functional outcome and quality of life. The study did not assess the impact of the model's implementation on caregivers' burden and satisfaction.

Also, the study did not use a control group which could have provided more illumination on the impact of the intervention.

8.3 Implications for clinical practice and policy.

There should be a focus on bridging the gap among carers of older adult stroke patients to eliminate barriers to care. Interventions that focus on helping stroke caregivers in burden relief and gaining mastery in caregiving should be put in place. Services tailored to individual needs should be provided for patients discharged into the community for proper management, improved functional ability and reduced mortality.

Consequent to the findings of this study, the following are recommended:

1. Collaboration between formal care providers and informal caregivers of stroke survivors through acute care to the post-acute phase is imperative.
2. A similar study should be conducted in other regions of the nation to establish similarities or differences in the experiences and perceptions of stakeholders on the topic of interest.
3. Policymakers should consider the integration of a home-based intermediate care model into the existing stroke care system for improved functional health outcomes and quality of life in older adult stroke survivors.
4. Allocation of sufficient funds for the implementation and sustainability of a home-based intermediate care model should be given consideration.

8.4 Recommendations for future research

1. There is a need to understand the association between socio-demographic variables and stroke survivor's health outcome.
2. Further research should investigate the effect and long-term impact of the home-based intermediate care model on the functional outcome and quality of life of older adult stroke survivors using a larger sample size to confirm the validity of study results.
3. Further investigation should be conducted on the effect of the home-based intermediate care model on the caregiver's burden, satisfaction, and quality of life.

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APPENDICES

APPENDIX 1

Ethical Approval



College of Nursing, Midwifery and
Healthcare

Research Ethics Panel

Paragon House

Boston Manor Road

Brentford TW8 9GA

Name: Temitope Farombi

Student No: 21443677

Date: 23rd June 2022

Re: Application for Ethical Approval No. 1325

Intermediate care and its impact on the functional health of the elderly with stroke in Southwest Nigeria

Dear Temitope

Thank you for sending in your application for approval. The Panel has considered this and approved the research without major amendment.

If the research does not progress, or if you make any changes to your research proposal or methodology can you please inform the Panel in writing as this may entail the need for additional review. It is your responsibility, as the principal investigator, to submit a report on the progress/completion of the research twelve months from the date of this letter. Please find attached a blank report form to be completed by

June 23rd 2023.

The Panel wish you well with your research and look forward to your report.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Rowan Myron'.

Rowan Myron

Associate Professor

College Research Ethics Panel

Ethical Approval



INSTITUTE FOR ADVANCED MEDICAL RESEARCH AND TRAINING (IAMRAT)
College of Medicine, University of Ibadan

Director: **Prof. Ike Oluwapo O. Ajayi**,
MBBS (Ib), M. Cl.Sc., Ph.D, MD, FMCGP, FWACP
Tel: 08023268431
E-mail: ikeajayi2003@yahoo.com



UI/UCH EC Registration Number: **NIIREC/US/01/2008a**

NOTICE OF FULL APPROVAL AFTER FULL COMMITTEE REVIEW
Re: **Intermediate care and its impact on the functional health of the elderly with stroke in Southwest Nigeria**

UI/UCH Ethics Committee assigned number: **UI/EC/22/0410**

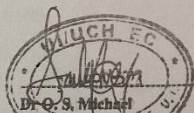
Name of Principal Investigator: **Dr Temilope H. Farombi**
Address of Principal Investigator: **College of Nursing, Midwifery & Healthcare
University of West London**

Date of receipt of valid application: **21/11/2022**

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 **20/12/2022 to 19/12/2023**. 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.



Dr. O. S. Michael
For: Chairperson, UI/UCH Research Ethics Committee
E-mail: uiuchec@gmail.com

Research Units * Genetic & Bioethics * Malaria * Environmental Sciences * Epidemiology Research & Service * HIV/AIDS
* Behavioural & Social Sciences * Pharmaceutical Sciences * Cancer Research & Service * Neurosciences & Ageing Research

APPENDIX 2

INTERVIEW GUIDE FOR INFORMAL CAREGIVERS OF STROKE SURVIVORS

WELCOME NOTE

Welcome and thank you for coming to the interview. My name is _____

and I will facilitate today's interview. We want to learn from your view of home-based care needs for an older adult patient recovering from stroke and your perception of intermediate care model as an intervention for the identified needs. This will help us to gain understanding of how to implement the intermediate care model.

May I have your permission to record our conversation, so I don't miss any of your suggestions and thoughts?

GROUND RULES

Before we begin, I will like to review some ground rules for the discussion.

- i. I am going to ask you several questions and I'd like to give you a chance to give your input.
- ii. There are no wrong or right answers. I'd like you to tell me your opinion the way you feel.
- iii. If there is a particular question you don't want to answer, you don't have to.
- iv. Your responses will be treated as confidential and used solely for research purposes
- v. We will not include your name or any other information that could identify you.
- vi. I am audio recording the discussion so as not to miss any of your suggestions.

Inclusion criteria: In-dwelling caregivers of older adult stroke patients.

Sample size: 18 caregivers

Data collection method: Focus group discussion comprising of three (3) groups of six (6) caregivers segregated by gender.

Research Question: What is the perception of stakeholders (healthcare providers, carer and community leaders) on the intermediate care need for older adult persons recovering from stroke?

Specific objectives:

- i. To explore the experiences of informal caregivers on stroke management.
- ii. To identify home-based care, need of older adult stroke patients.
- iii. To identify strategies that promote interpersonal relationship between formal and informal care provider on home-based care treatment.

Socio-Demographic Characteristics

- i. Age (in years) as at last birthday: _____
- ii. Gender: Male [] Female []
- iii. Relationship status: Single [] Married [] Widowed []
- iv. Relationship with patient _____
- v. Duration of caregiving to stroke patient (months) _____
- vi. Residence location: _____
- vii. Religion: Christianity [] Muslim [] Traditional []
- viii. Ethnicity: Yoruba [] Igbo [] Hausa [] Others _____ (Specify)
- ix. Level of education: None [] Primary [] Secondary [] Tertiary []
- x. Patient's age:

Section A: Strategies that promote interpersonal relationship between formal and informal care provider on home-based care treatment.

S/N	Main Questions	Follow-up questions
1	When your family member/significant other was hospitalized for a stroke, can you describe your experiences about stroke management of a family member/significant other?	What information and or support did you receive t the facility? How was it provided? How useful was the information Can you tell me about your unmet needs for information, social support training? How would you have loved to receive this information and training?
2	What roles do you perform at home to help the older adult that are recovering from stroke?	Probe for spiritual support Probe for domestic chores Probe for exercise Probe for helping to serve medication
3	What is your interpersonal relationship with the health workers providing care for your patient?	Probe for home-based treatment support receiving from the providers What are the gaps in the interpersonal relationship you observed?

4	How do you think we can promote interpersonal relationship between formal and informal care provider on home-based treatment?	Probe for: Things necessary for consideration, likely challenges
5	How do you think you can be assisted to function better as a family carer?	Probe for training and training expectation
Section B: Identification of home-based care need of older adult stroke patients		
6	What is the home-based care need of older adult stroke patients?	Probe for: Reasons for the care need What is being currently done at home to meet the care need What are the challenges facing in implementing home care need?
7	How best do you think we can support you with home-based care need?	Probe for their reasons
8	What are the types of services that should be incorporated as home-based care for the older adult that are recovering from stroke?	Probe for physiotherapy service Probe for minor medical treatment
		Probe for nutritional service Probe for medication assistance Probe for mood disorders management Probe for speech therapy service
9	Who do you think should be primarily involved in the home-based care for the older adult that are recovering from stroke?	Describe the service providers – MD, Nurses, physiotherapy, family member etc.

10	What are the benefits of instituting intermediate level of care for the older adult that are recovering from stroke?	What can be the likely barriers to the adoption of intermediate care model if provided for older adult recovering from stroke?
11	Please provide ways by which caregivers and patients can be motivated to adopt intermediate care model?	

APPENDIX 3

INTERVIEW GUIDE FOR FORMAL CARE PROVIDERS OF STROKE SURVIVORS

Inclusion Criteria: Health professionals who currently work with stroke and post-stroke units.

Sample size: 8 healthcare providers.

Data Collection Method: Key Informant Interview.

Research Question: What is the perception of stakeholders (healthcare providers, carer and community leaders) on the intermediate care need for older adult persons recovering from stroke?

Specific objectives:

- i. To identify home-based care needs of older adult stroke patients.

- ii. To identify strategies that promote interpersonal relationships between formal and informal care providers on home-based care treatment.

Socio-Demographic Characteristics

1. Age (in years) as of last birthday: _____
2. Gender: Male ☐ Female ☐
3. Relationship status: Single ☐ Married ☐ Widowed ☐
4. Specialty _____
5. Years of service in stroke care _____
6. Religion: Christianity ☐ Muslim ☐ Traditional ☐
7. Ethnicity: Yoruba ☐ Igbo ☐ Hausa ☐ Others _____ (Specify)

Section A: Identification of strategies that promote interpersonal relationship between formal and informal care provider on home-based care treatment.

S/N	Main questions	Follow-up questions
1	What is your role in the management of stroke in the older adult?	Probe for specific services rendered while on admission Probe for specific services rendered after discharge
2	What is your interpersonal relationship with the caregivers of your stroke survivors?	Probe for home-based care support Gaps in the interpersonal relationship
3	What is your interpersonal relationship with the caregivers of your stroke survivors?	Probe for Presence of caregivers Opinion on caregiver support or care for stroke recovery in patients at home

4	How do you think we can promote interpersonal relationship between formal and informal care provider on home-based treatment?	Probe for: Things necessary for consideration Likely challenges
5	What do you think are the key needs of informal carers that are currently not being met?	What will you suggest for improvement?
Section B: To identify home-based care need of older adult stroke patients.		
6	What is/are the home-based care need of older adult stroke patients?	Probe for: Reasons for the care need What is being currently done at home to meet the care need What are the challenges facing in implementing home care need?
7	How best can we develop intermediate care for the older adult that are recovering from stroke after discharge from the hospital?	Probe for their reasons.
8	What are the types of services that should be incorporated as "intermediate care" for the older adult that are recovering from stroke?	Probe for physiotherapy service Probe for minor medical treatment Probe for nutritional service Probe for medication assistance Probe for mood disorders management Probe for speech therapy service
9	Who do you think should be primarily involved in the intermediate level of care for the older adult that are recovering from stroke?	Describe the service providers – MD, Nurses, physiotherapy, family member etc.
10	In your opinion, what are the benefits of instituting intermediate level of care for the older adult that are recovering from stroke?	What are the problems that you think may be associated with establishing an intermediate level of care for older adult people that are recovering from stroke?

11	Please provide ways you think caregivers and patients can be motivated to adopt intermediate care model?	
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APPENDIX 4

INTERVIEW GUIDE FOR COMMUNITY GATEKEEPERS

Inclusion criteria: Community stakeholders including orthodox and non-orthodox leaders who have experienced someone with stroke.

Sample size: 8 community stakeholders.

Data collection method: Key Informant Interview.

Research Question:

- i. What is the perception of stakeholders (healthcare providers, carer and community leaders) on the intermediate care need for older adult persons recovering from stroke?
- ii. What are the culturally acceptable interventions for older adult persons recovering from stroke?

Specific objectives:

- i. To identify home-based care need of older adult stroke patients.
- ii. To ascertain the community gatekeepers perceived social and welfare support needed by older adult stroke patients.

Socio-Demographic Characteristics

- iii. Age (in years) as at last birthday: _____
- iv. Gender: Male [] Female []
- v. Relationship status: Single [] Married [] Divorced [] Widowed []

- vi. Residence location: _____
- vii. Position in the community _____
- viii. Religion: Christianity [] Muslim [] Traditional []
- ix. Ethnicity: Yoruba [] Igbo [] Hausa [] Others _____ (Specify)
- x. Level of education: None [] Primary [] Secondary [] Tertiary []

Section A: Community gatekeepers perceived social and welfare support needed by older adult stroke patients.		
	Main questions	Follow-up questions
1	Do you think a stroke patient needs support after being discharged from the hospital?	If yes, why? If no, why?
3	How much help have you offered to a stroke patient that is recovering before?	
4	How do you think an older adult stroke patient can be supported in the community?	Probe for social and welfare support
5	What do you think can be improved in the community to help older adult stroke patients?	
Section B: Identify home-based care need of older adult stroke patients.		
6	What is/are the home-based care need of older adult stroke patients?	Probe for: Reasons for the care need What is being currently done at home to meet the care need What are the challenges facing in implementing home care need?
7	How best do you think we can support caregivers of older adult stroke patients with home-based care need?	Probe for their reasons.

8	What are the types of services that should be incorporated as “intermediate care” for the older adult that are recovering from stroke?	Probe for physiotherapy service Probe for minor medical treatment Probe for nutritional service Probe for medication assistance Probe for mood disorders management Probe for speech therapy service
9	Who do you think should be primarily involved in the intermediate level of care for the older adult that are recovering from stroke?	Describe the service providers – MD, Nurses, physiotherapy, family member etc.
10	In your opinion, what are the benefits of instituting intermediate level of care for the older adult that are recovering from stroke?	What can be the likely barriers to the adoption of intermediate care model if provided for older adult recovering from stroke?
11	Please provide ways you think caregivers and patients can be motivated to adopt intermediate care model?	

APPENDIX 5

QUESTIONNAIRE FOR STROKE SURVIVORS (PRE-TEST)

PATIENT ID: _____

DATE: _____

Stroke Specific Quality of Life Scale (SS-QOL)

Respondents: Careers of Stroke patients. Data will be collected from carers in two stages: baseline and timeline

Carers opination on patients' functional conditions at baseline:

Carers opinion on patients' functional conditions at timeline (follow-up stage):

Carers experience in stage 2 data collection:

Scoring: each item shall be scored with the following key

Total help - Couldn't do it at all - Strongly agree 1

A lot of help - A lot of trouble - Moderately agree 2

Some help - Some trouble - Neither agree nor disagree 3

A little help - A little trouble - Moderately disagree 4

No help needed - No trouble at all - Strongly disagree 5

Energy

1. I felt tired most of the time. _____

2. I had to stop and rest during the day. _____

3. I was too tired to do what I wanted to do. _____

Family Roles

1. I did not join in activities just for fun with my family. _____

2. I was a burden to my family. _____

3. My physical condition interfered with my personal life. _____

Language

1. Did you have trouble speaking? For example, get stuck, stutter, stammer, or slur your words? _____
2. Did you have trouble speaking clearly enough to use the telephone? _____
3. Did other people have trouble understanding what you said? _____
4. Did you have trouble finding the word you wanted to say? _____
5. Did you have to repeat yourself so others could understand you? _____

Mobility

1. Did you have trouble walking? (If a patient cannot walk, go to question 4 and score questions 2-3 as
1.) _____
2. Did you lose your balance when bending over to or reaching for something? _____
3. Did you have trouble climbing stairs? _____
4. Did you have to stop and rest more than you would like when walking or using a wheelchair? _____
5. Did you have trouble with standing? _____
6. Did you have trouble getting out of a chair? _____

Mood

1. I was discouraged about my future. _____
2. I was not interested in other people or activities. _____
3. I felt withdrawn from other people. _____
4. I had little confidence in myself. _____
5. I was not interested in food. _____

Personality

1. I was irritable. _____

2. I was impatient with others. _____

3. My personality has changed. _____

Self-Care

1. Did you need help preparing food? _____

2. Did you need help eating? For example, cutting food or preparing food? _____

3. Did you need help getting dressed? For example, putting on socks or shoes, buttoning buttons, or zipping? _____

4. Did you need help taking a bath or a shower? _____

5. Did you need help using the toilet? _____

Social Roles

1. I did not go out as often as I would like. _____

2. I did my hobbies and recreation for shorter periods of time than I would like. _____

3. I did not see as many of my friends as I would have liked. _____

4. I had sex less often than I would like. _____

5. My physical condition interfered with my social life. _____

Thinking

1. It was hard for me to concentrate. _____

2. I had trouble remembering things. _____

3. I had to write things down to remember them. _____

Upper Extremity Function

1. Did you have trouble writing or typing? _____

2. Did you have trouble putting on socks? _____

3. Did you have trouble buttoning buttons? _____

4. Did you have trouble zipping a zipper? _____
5. Did you have trouble opening a jar? _____

Vision

1. Did you have trouble watching the television well enough to enjoy a show? _____
2. Did you have trouble reaching things because of poor eyesight? _____
3. Did you have trouble seeing things off to one side? _____

Work/Productivity

1. Did you have trouble doing daily work around the house? _____
2. Did you have trouble finishing jobs that you started? _____
3. Did you have trouble doing the work you used to do? _____

TOTAL SCORE _____

PATIENT ID: _____

DATE: _____

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

Patient Name: _____ Rater Name: _____
Date: _____

TOTAL (0–100): _____

APPENDIX 6

QUESTIONNAIRE FOR CAREGIVERS (PRE-TEST)

PARTICIPANT ID : _____ DATE : _____

Caregivers' experience

1) Stroke Knowledge

a) Do you have knowledge on stroke care? Yes [] No []

1 2 3 4 5 6 7

Not knowledgeable Extremely

knowledgeable

b) Do you know what to do to prevent recurrence of stroke? [Yes] [No]

1 2 3 4 5 6 7

Not knowledgeable Extremely

knowledgeable

c) Do you know about adaptation exercise for stroke patients? Yes [] No []

1 2 3 4 5 6 7

Not knowledgeable

Extremely

knowledgeable

d) Can you better support during body movement of patients?

Yes []

No

[]

1

2

3

4

5

6

7

e) Which of the following are stroke complications? Tick all that apply

Seizure []

Fall []

Repeat stroke []

Cognitive impairment []

Urinary tract infection []

Bladder problems []

2) Patients' support

a) Can you better support medication use for patients? Yes [] No []

1

2

3

4

5

6

7

Not at all supportive

Extremely

supportive

b) Can you better support patients' feeding needs? Yes [] No []

1

2

3

4

5

6

7

Not at all supportive

Extremely

supportive

c) Can you better support patients grooming? E.g., Bathing, combing of hair, wearing clothes etc. Yes [] No []

1

2

3

4

5

6

7

Not at all supportive
supportive

Extremely

d) Do you know what to do when patient develop complications e.g seizure, falls e.t.c.

Yes [] No []

1 2 3 4 5 6 7

3) Caregiver's Training

a) Do you think you need training to better support? **Yes []** **No []**

1 2 3 4 5 6 7

b) Do you think the training will improve your feeling of stroke care? Yes [] No []

1 2 3 4 5 6 7

No Improvement Minimal Improvement Great Improvement

c) Will the training adequate? **Yes []** **No []**

d) Will you recommend such training for caregivers of stroke patients? **Yes []** **No [.]**

e) Will the training improve your overall health and well-being? **Yes []** **No [.]**

1 2 3 4 5 6 7

No Improvement Minimal Improvement Great Improvement

g) Will the training improve your social interaction with the patients? **Yes []** **No [.]**

1 2 3 4 5 6 7

No Improvement	Minimal Improvement	Great
Improvement		

h) Will the training help to reduce your physical workload? **Yes []** **No []**

4) Intermediate care model

a) Do you know about intermediate care model? Yes []
No []

Will you recommend the model for stroke care in the community? **Yes []** **No []**

b) Do you think the model will improve patient functional health? Yes []
No []

1	2	3	4	5	6	7
No Improvement		Minimal Improvement			Great	
Improvement						

c) Do you think the model will improve patients' quality of life? Yes [] No []

1	2	3	4	5	6	7
No Improvement		Minimal Improvement			Great	
Improvement						

d) Do you know who to talk to or where to get help? **Yes []** **No [.]**
mention them

APPENDIX 7

QUESTIONNAIRE FOR STROKE SURVIVORS (POST TEST)

PATIENT ID: _____

DATE: _____

Stroke Specific Quality of Life Scale (SS-QOL)

Respondents: Caregivers of Stroke patients. Data will be collected from caregivers in two stages: baseline and endline

Carers opinion on patients' functional conditions at baseline.

Carers opinion on patients' functional conditions at timeline (follow-up stage).

Carers experience in stage 2 data collection.

Scoring: each item shall be scored with the following key

Total help - Couldn't do it at all - Strongly agree 1

A lot of help - A lot of trouble - Moderately agree 2

Some help - Some trouble - Neither agree nor disagree 3

A little help - A little trouble - Moderately disagree 4

No help needed - No trouble at all - Strongly disagree 5

Energy

1. I felt tired most of the time. _____

2. I had to stop and rest during the day. _____

3. I was too tired to do what I wanted to do. _____

Family Roles

1. I did not join in activities just for fun with my family. _____

2. I was a burden to my family. _____

3. My physical condition interfered with my personal life. _____

Language

1. Did you have trouble speaking? For example, get stuck, stutter, stammer, or slur your words? _____
2. Did you have trouble speaking clearly enough to use the telephone? _____
3. Did other people have trouble understanding what you said? _____
4. Did you have trouble finding the word you wanted to say? _____
5. Did you have to repeat yourself so others could understand you? _____

Mobility

1. Did you have trouble walking? (If a patient cannot walk, go to question 4 and score questions 2-3 as
1.) _____
2. Did you lose your balance when bending over to or reaching for something? _____
3. Did you have trouble climbing stairs? _____
4. Did you have to stop and rest more than you would like when walking or using a wheelchair? _____
5. Did you have trouble with standing? _____
6. Did you have trouble getting out of a chair? _____

Mood

1. I was discouraged about my future. _____
2. I was not interested in other people or activities. _____
3. I felt withdrawn from other people. _____
4. I had little confidence in myself. _____
5. I was not interested in food. _____

Personality

1. I was irritable. _____
2. I was impatient with others. _____
3. My personality has changed. _____

Self-Care

1. Did you need help preparing food? _____
2. Did you need help eating? For example, cutting food or preparing food? _____
3. Did you need help getting dressed? For example, putting on socks or shoes, buttoning buttons, or zipping? _____
4. Did you need help taking a bath or a shower? _____
5. Did you need help using the toilet? _____

Social Roles

1. I did not go out as often as I would like. _____
2. I did my hobbies and recreation for shorter periods of time than I would like. _____
3. I did not see as many of my friends as I would have liked. _____
4. I had sex less often than I would like. _____
5. My physical condition interfered with my social life. _____

Thinking

1. It was hard for me to concentrate. _____
2. I had trouble remembering things. _____
3. I had to write things down to remember them. _____

Upper Extremity Function

1. Did you have trouble writing or typing? _____
2. Did you have trouble putting on socks? _____
3. Did you have trouble buttoning buttons? _____

4. Did you have trouble zipping a zipper? _____
5. Did you have trouble opening a jar? _____

Vision

1. Did you have trouble watching the television well enough to enjoy a show? _____
2. Did you have trouble reaching things because of poor eyesight? _____
3. Did you have trouble seeing things off to one side? _____

Work/Productivity

1. Did you have trouble doing daily work around the house? _____
2. Did you have trouble finishing jobs that you started? _____
3. Did you have trouble doing the work you used to do? _____

TOTAL SCORE _____

THE BARTHEL INDEX

PATIENT ID: _____

DATE: _____

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

Patient Name: _____ Rater Name: _____

_____ Date: _____

TOTAL (0–100): _____

QUESTIONNAIRE FOR CAREGIVERS (POST-TEST)

DATE : _____

1) Stroke Knowledge

knowledgeable

knowledgeable

knowledgeable

Cognitive impairment []

Urinary tract infection []

Bladder problems []

2) Patients' support

a) Can you better support medication use for patients? Yes [] No []

1	2	3	4	5	6	7
Not at all supportive					Extremely supportive	

b) Can you better support patients' feeding needs? Yes [] No []

1	2	3	4	5	6	7
Not at all supportive					Extremely supportive	

c) Can you better support patients grooming? E.g., Bathing, combing of hair, wearing clothes etc. Yes [] No []

1	2	3	4	5	6	7
Not at all supportive					Extremely supportive	

d) Do you know what to do when patient develop complications e.g seizure, falls e.t.c.
Yes [] No []

1	2	3	4	5	6	7
---	---	---	---	---	---	---

3) Caregiver's Training

a) Did the training help to better support? Yes [] No []

1	2	3	4	5	6	7
---	---	---	---	---	---	---

b) Did the training improve your feeling of stroke care? Yes [] No []

1	2	3	4	5	6	7
---	---	---	---	---	---	---

No Improvement	Minimal Improvement	Great
Improvement		

c) Was the training adequate? **Yes []** **No**
[]

d) Will you recommend such training for caregivers of stroke patients? **Yes []** **No**
[.]

e) Did the training improve your overall health and well-being? **Yes []** **No**
[.]

1	2	3	4	5	6	7
No Improvement		Minimal Improvement			Great	
Improvement						

g) Did the training improve your social interaction with the patients? **Yes []** **No**
[.]

1	2	3	4	5	6	7
No Improvement		Minimal Improvement			Great	
Improvement						

h) Did the training help to reduce your physical workload? **Yes []** **No**
[]

4) Intermediate care model

a) Do you know about intermediate care model? **Yes []**
No []

Will you recommend the model for stroke care in the community? **Yes []** **No**
[.]

b) Do you think the model improved patient functional health? **Yes []**
No []

1	2	3	4	5	6	7
No Improvement			Minimal Improvement		Great Improvement	

c) Do you think the model improved patients' quality of life? Yes [] No []

1	2	3	4	5	6	7
No Improvement			Minimal Improvement		Great Improvement	

d) Do you know who to talk to or where to get help? **Yes** [] **No** [.]

mention them

APPENDIX 9

QUESTIONNAIRE FOR FOLLOW-UP

Week No: _____ Date: _____ CAREGIVER ID NUMBER: _____

1a. Does the patient have any problem with energy? Yes [] No []

1b. Has the energy level of the patient improved? Yes [] No []

1c. How is the patient's energy level on a scale of 1-10? _____

2a. Does the patient have any trouble with speech? Yes [] No []

2b. Is there improvement in the patient speech? Yes [] No [] 1-10? _____

3a. Do you have any trouble with mobility? Yes [] No []

3b. Has the patient's mobility improved? Yes [] No [] 1-10? _____

4a. Does the patient have any trouble with mood? Yes [] No []

4b. Has the patient's mood improved? Yes [] No [] 1-10 _____

5a. Does the patient have any personality issues (i.e. being irritable or impatient)? Yes [] No []

5b. How well has patient personality improved on a scale of 1-10? _____

6a. Does the patient have any trouble with self-care such as eating, bathing, dressing, using toilet etc? Yes [] No []

6b. Are there improvements in the patient's ability to provide self-care? Yes [] No []

6c. 1-10 _____

7a. Does the patient have problems interacting with people? Yes [] No []

7c. Has the patient social interaction improved? Yes [] No [] 1-10? _____

8a. Does the patient have any trouble with memory? Yes [] No []

8b. Has the memory improved? Yes [] No [] 1-10 _____

9a. Does the patient have any problem performing upper extremity functions such as buttoning, zipping, opening a jar or bottle? Yes [] No []

9b. Are there improvement in upper extremity function? Yes [☐] No [☐] 1-10_____

10a. Does the patient have any vision problem? Yes [☐] No [☐]

10b. Has the patient vision improved? Yes [☐] No [☐] 1-10? _____

11a. Can the patient perform any task/work? Yes [☐] No [☐]

11b. How well can the patient start and complete a work? 1-10_____

12. Was there cause for re-admission during the past one week? Yes [☐] No [☐]

13. What were the complications experienced during the week?

14. Were there challenges in providing proper care for the patient?

15. Additional comment from caregiver

APPENDIX 10

Intervention protocol

Audio-visual

link:

<https://drive.google.com/file/d/1uowNtbR2knzIYE7kX8wl9zxmfu4HGERH/view?usp=sharing>

Curriculum for intervention

1. Stroke knowledge and prevention

Stroke warning signs

- Sudden facial, arm, or leg numbness or weakness, especially on one side of the body
- Sudden disorientation, difficulty speaking and understanding
- Sudden vision problems in one or both eyes
- Sudden difficulty walking, light-headedness, unsteadiness, or lack of coordination
- Sudden, intense headaches without apparent cause (ASA, 2006).

Stroke prevention

- Hypertension, smoking, diabetes mellitus, physical activity, nutrition, psychological variables, alcohol, abdominal obesity, cardiac causes, and apolipoproteins are among the modifiable risk factors for preventing stroke. (O'Donnell et al., 2016).

2. Physiotherapy/Mobility

Meaningful task	Repetition	Duration	Target movements	Specific method to perform
Reaching B/L for a glass	20		Scapular mobility – protraction/retraction Shoulder flexion/ extension	Guide Assist Encourage for more effort

			Elbow extension Hand mass grasp	Progressively increase either distance / speed / repetition Randomly order the tasks in every session Give auditory
Stabilizing a glass with the affected hand and pouring water from a bottle by the sound side 10			Hand cylindrical grasp Wrist dorsiflexion Finger abduction & mild flexion	
Stabilizing a glass with the sound hand and pouring water from a bottle by the affected side 10			Shoulder abduction, flexion & media rotation Elbow flexion Forearm pronation Wrist extension & radial deviation Hand cylindrical grasp	
Lock and key manipulation		4min	Lateral prehension Forearm – pronation supination	

Narayan Arya et al., 2012

- Range of motion in the leg, as well as in the arm, is maintained with positioning, splints, and slow rhythmic rotation and stretch of all joints several times a day on the paretic side, along with minimal weight bearing as soon as possible.
- At the onset of therapy, the physical therapist might stimulate this pattern just enough to allow weight bearing on the leg. At the same time, flexion at the hip, knee, and ankle would be encouraged by such mat exercises as rolling onto the side and bringing the knee to the chest with whatever sensory stimulation and physical assistance is needed. (Dobkin, 1991).
- use of a combination of body-weight support with an overhead harness and rhythmic oscillation of the lower extremities made possible by simultaneous treadmill training (Dobkin et al., 1991; Finch L, Barbeau, 1986).

- Use of assistive devices such as grab bars, rails, ramps, and environmental controls at home; architectural changes such as widening a doorway to allow wheelchair access (Dodkin, 1991).
- Forced to use the paretic hand, for example by tying down the normal limb as they practice self-care skills, some improve the function of the paretic upper extremity (Wolf et al., 1989).

3. Vital signs

They are the body's most basic functions such as body temperature, blood pressure, pulse rate and respiration rate.

Body temperature is measured using a thermometer and can be taken orally, rectally, axillary, by ear or by skin. The normal body temperature is 36.5 degrees Celsius.

The number of times the heart beats each minute is known as the pulse rate. An adult's typical pulse should be between 60 and 80 beats per minute. Pulse can be measured with a pulse rate machine. Manually, press the arteries at the wrist firmly until you find a pulse. Count for one minute concentrating on the pulse.

Blood pressure can also be measured with a BP machine. Normal blood pressure for an adult is 120/80mmHG

Respiration rate is the number of breaths per minute. An adult's normal respiratory rate is between 12-20 breaths each cycle (Kaur et al., 2018).

4. Speech therapy

- Visual and verbal cueing techniques that include picture matching, sentence-completion tasks, frequent repetition, and positive reinforcement as the patient

approaches the desired responses are among the most common interventions (Dobkin 1991).

5. Reminiscence therapy

The caregiver assists the patient in re-visiting the past by asking the patient to talk about:

- The wonderful experiences spend together on special moments, eg, acquaintances, getting married, and raising children.
- Dreams of our youth
- Experience in taking care of children
- Efforts and performance while working
- The most rewarding things in work or family
- Positive change during care
- Caring experience
- Funny or happy things during care (Mei et al., 2018)

Patients should not be rushed or forced to answer all questions during reminiscence therapy sessions.

Guides and Materials

Precious old photos, collections, old songs or movies, diaries, letters, notes and pads etc.

6. Financial management education

- Registering the patient under a health insurance scheme such as the National Health Insurance Authority (NHIA).
- Inform social workers and Non-Governmental Organizations about financial needs.
- Power of attorney (accessibility to patient's account).

- Handling bank issues for patients such as signatures.

7. Nutritional service

Caregivers will be given information on knowledge and skills about attending to a poststroke patient's food and medicine, proper types and amounts of food, food preparation, and feeding methods.

- Patients with swallowing difficulty could undergo therapies such as compensatory head repositioning such as flexing or turning to one side, icing the pharynx, tongue and sucking exercises, double swallowing, supraglottic cough, and dry coughing. Dysphagic patients should be fed with patience to allow them to get enough food and adequate nutrition (Dobkin, 1991).
- Consumption of vegetarian (Spence and Tangney, 2020) and Mediterranean-type diet (instead of a low-fat diet), with a reduction of sodium intake to less than 2.4 g per day and eventually to refer them for individualized nutritional counselling (Kernan et al, 2014).

8. Medication management

Caregivers will be taught how to reconcile all of the patient's medication regimens and the use of medication discrepancy tool (Smith et al., 2004)

Sample of Medication Discrepancy Tool

Patient level Causes and Contributing Factors

- [] 1. Adverse drug reactions or side effects
- [] 2. Intolerance
- [] 3. Didn't fill the prescription
- [] 4. Didn't need prescription medication."

[] 5. Money/financial barriers

[] 6. Intentional nonadherence "I was told to take this but I choose not to."

[] 7. Nonintentional nonadherence (ie, knowledge deficit) "I don't just understand how to take this

[] 8. Performance deficit "Maybe someone showed me, but I can't demonstrate to you that I can."

9. Seizure management

- Place the person gently on one side to assist him/her in breathing
- Clear all hard objects close to the person.
- Never hold, try to restrain, or halt the person's movements.
- To prevent damage to the person's teeth or jaw, avoid putting anything in their mouth.
- Check if the person has any emergency information.
- Tuck a soft cloth beneath his or her head, for instance, a folded jacket.
- Remain at the person's side until the seizure stops and they are completely awake. After it ends, help the person sit up gently.
- Comfort the person and speak calmly.
- Until the person is fully alert, do not give any food or liquid. (CDC, 2022)

10. Service referral

- See a psychologist for mood disorders
- Make referrals to primary care for minor medical treatment,
- In cases of emergencies, visit speciality care or community rehabilitation services.

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APPENDIX 11

Delphi Technique Questionnaire for Stroke Intervention Curriculum

Title: Impact of Intermediate Care Model on the Functional Outcome and Quality of Life of Older Adults in Southwest Nigeria.

Objective

To develop a home-based intermediate care model for improved functional outcomes in elderly with stroke

Instruction: Kindly provide your candid opinion on the adequacy of the domain and its content using the Likert scale below each domain. Suggestions for improvement should be written in the spaces provided.

1. Stroke knowledge and prevention

**I strongly disagree [] I disagree [] I neither disagree nor agree [] I agree [] I strongly agree []

Free text Comments

2. Vital signs

**I strongly disagree [] I disagree [] I neither disagree nor agree [] I agree [] I strongly agree []

Free text Comments

3. Physiotherapy/Mobility

**I strongly disagree [] I disagree [] I neither disagree nor agree [] I agree [] I strongly agree []

Free text Comments

4. Speech therapy

**I strongly disagree [] I disagree [] I neither disagree nor agree [] I agree [] I strongly agree []

Free text Comments

5. Reminiscence therapy

**I strongly disagree [] I disagree [] I neither disagree nor agree [] I agree [] I strongly agree []

Free text Comments

6. Financial management education

**I strongly disagree [] I disagree [] I neither disagree nor agree [] I agree [] I strongly agree []

Free text Comments

7. Nutritional service

**I strongly disagree [] I disagree [] I neither disagree nor agree [] I agree [] I strongly agree []

Free text Comments

8. Medication management

**I strongly disagree [] I disagree [] I neither disagree nor agree [] I agree [] I strongly agree []

Free text Comments

9. Seizure management

**I strongly disagree [] I disagree [] I neither disagree nor agree [] I agree [] I strongly agree []

Free text Comments

10. Service referral

**I strongly disagree [] I disagree [] I neither disagree nor agree [] I agree [] I strongly agree []

Free text Comments
