



**A community – based study of stroke survivors in a semiurban population in
the Southeast (SE) regions of Nigeria using a mixed methodology**

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ABSTRACT

Background: Stroke is the leading cause of death and the root of long-term disability worldwide; this has become an international concern. Studies have identified a 42% decrease in stroke incidences in high-income countries (HICs) but 100% increase in LMICs –such as in Nigeria.

Objectives: The purpose of this study was to investigate the impact of stroke on the quality of life (QOL) of stroke survivors in the SE communities of Nigeria by utilising the health-related quality of life in stroke patients' questionnaires. The secondary objective was to investigate the perceptions, attitudes, and cultural approaches of stroke survivors to provide evidence of the variables and determinants that predict the impact of stroke on QOL from the perspective of the survivors.

Methods: The research employed an explanatory sequential mixed methodological strategy involving two phases. Quantitative phase 1 utilised a cross-sectional design with convenience sampling, administering a robust HRQOLISP questionnaire to 101 people, 53 male and 48 female (who were spread over 4 medical institutions) over over two years. Qualitative phase 2 combined a phenomenological approach with purposive sampling. This entailed conducting ten semi-structured interviews (6 male and 4 participants) over a two-year period and analysing them using an interpretative phenomenological methodology.

Results: The results had a twofold effect on the QOL of the stroke survivors: positive and negative.

In quantitative phase 1, HRQOLISP descriptive statistics indicated that the category with the lowest score, showing a negative impact on QOL, was the physical domain (mean = 2.52, SD = 0.76). In contrast, the spiritual domain had the greatest positive influence on QOL (mean = 3.70, SD = 0.50).

The results also revealed the significance of the relationships between the HRQOLISP which demonstrated a significant positive relationship between the emotional dimension and the intellectual and soul dimensions.

Qualitative phase 2 indicated that the physical dimension – portrayed by an unknown self, which includes (physical and psychological)– was the most negatively affected, while the spiritual dimension – reflecting reconstruction of the embodied self, was positively affected mainly by the spiritual interaction of one's faith.

Conclusion: The most affected HRQOL domains in this study were physical and spiritual. The findings emphasise the importance of rehabilitation, which should involve a holistic multidimensional approach within the community that will address not only the physical aspect of rehab but equally the psychological circumstances and existential issues. A simple form of partnership between rehabilitation clinics or hospital-based stroke rehabilitation centres and faith-based organisations and traditional healers is recommended.

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In loving memory of my father, who passed away on December 16, 2023.

I dedicate this thesis to Mr Clement Adigwe, my dear dad, may you rest in perfect peace.

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Thank you, and God bless.

LIST OF ABBREVIATIONS AND ACRONYMS

ADL	Activity of Daily Living
CAM	Complementary and Alternative Medicine
CVA	Cerebral Vascular Accident
CHC	Comprehensive Health Care
CT	Computerized Tomography
DALY	Daily Adjusted Life Years
EDAL	Extended Activities of Daily Living
EPR	Electronic Patients Record
FAST	Fast, Arms, Speech, Time
GP	General Practitioner
HBP	High Blood Pressure
HIC	High Income Countries
HC	Health Clinics
HRQOL	Health Related Quality of Life
HRQOLISP	Health Related Quality of Life in Stroke Patients
ICF	International Classification of Function
IPA	Interpretative Phenomenological Analysis
IT	Information Technology
LMIC	Low Middle Class Income Countries
MAS	Motor Assistance Scale
MRI	Magnetic Resonance Imaging
MM	Mixed Method Approach
PHC	Primary Health Centres
PTSD	Post Traumatic Stress Disorder
QOL	Quality of Life
SAN	Stroke Action Nigeria
SSA	Sub – Saharan Africa
SIS	Stroke Impact Scale

TIA Transient Ischaemic Attack
WHO World Health Organisation

LIST OF PAPERS

1. Adigwe G. Quality of life of stroke survivors in Nigeria (Low-income country). Can outcome be predicted? *J Clin Hypertens (Greenwich)*. 2021 Aug;23(8):1459-1462. doi: 10.1111/jch.14258. Epub 2021 Jun 30. PMID: 34196105; PMCID: PMC8678786.
2. Adigwe G, Tribe R, Alloh F, Smith P (2022) The impact of stroke on the quality of life (QOL) of stroke survivors in the Southeast (SE) communities of Nigeria: A qualitative study. *MDPI Disabilities*, Volume 2. Issue 3. Pg 501-515.

DECLARATION

I hereby declare that this thesis and the work presented is original and represents my own work. It has not been submitted for any other degree.

CHAPTER ONE

Introduction to the Thesis

This chapter introduces the thesis, highlights the author's position, and provides an overview of the study's background and context. This is a community-based study of the impact of stroke on the quality of life (QOL) of stroke survivors in Nigeria's Southeast region. The chapter begins with an overview of the stroke burden, followed by a problem statement, research aims and objectives, and a rationale for the study. Next, it identifies literature gaps and provides an overview of the methodology and the contribution to knowledge. The author then expresses her position and reflections before concluding the chapter with an overview of the structure that 'scaffolds' this study before delving into each issue in greater depth.

1.1 Background

Stroke is the second-leading cause of death and the third most common cause of long-term disability worldwide (Feigin et al., 2016). There are over 5.5 million deaths due to stroke and 44 million people who become disabled annually, making it an international concern (Hamza et al., 2014; Owolabi et al., 2013; Ezejimofor et al., 2016; Feigin et al., 2016). A stroke, also known as a cerebrovascular accident (CVA), in the medical term is a clinical syndrome rather than a homogeneous condition. It was first mentioned in the medical literature by Hippocrates (460 to 370 BC) as 'apoplexy' (a Greek word that means 'struck with violence') to describe the phenomenon of sudden paralysis. The word 'stroke', a literal translation of the original Greek term, is the currently used medical term. A stroke can also be defined as 'the sudden loss of blood supply to a brain region, leading to permanent tissue damage' (Robinson, 1998). The most popular and widely used definition of stroke is that offered by the WHO in 1978, pg 11, which states that 'stroke is a syndrome of rapidly developing clinical signs of focal or global disturbance of cerebral function, with symptoms lasting 24 hours or longer, or leading to death, with no apparent cause other than of vascular origin'. The incidence of stroke is expected to increase significantly as the global population of those above 65 years continues to grow by approximately nine million per year (WHO, 2015). By 2025, the global population of this age group will be more than 800 million people, of whom it is expected that two-thirds will be living in low-income, middle-class countries (LIMC) (United Nations, 1997; WHO, 2014). Sub-Saharan Africa, specifically Nigeria (as this has one of the largest populations in Africa), will be one area that falls into this category.

1.2 The Burden of Stroke

In this study on the impact of stroke on the quality of life of stroke survivor in the SE communities of Nigeira, the word prevalence will be limited to the study population. The prevalence of a disease is the proportion of a population living with a particular disease at a point in time (Badaru et al., 2015; Vincent-Onabajo et al., 2018). The living experience of the disease focuses on how an individual living with a condition life and responds to the situation daily. The lived experience of stroke will focus on the impact of stroke on the quality of life of the individuals. Stroke is a disease of immense public health importance because it has economic and social consequences (Feigin et al., 2016), particularly in low-middle-class income countries (LMIC) and is a critical health research area (Sampane-Donkor, 2014; Ezejimofor et al., 2016; Feigin et al., 2016). The burden of stroke not only lies in the high mortality figures but rather in the increased morbidity; up to 50% of stroke survivors are chronically disabled (Vincent-Onabajo et al., 2018; Ezejimofor et al., 2017). Geographically, the burden of stroke varies widely, with the highest burden falling on Europe, North Asia, Central Africa, and the South Pacific (Vincent-Onabajo et al., 2018). Until recently, stroke was a disease of High-Income Countries (HIC), but, through the application of evidence-based control measures and the implementation of various validated public health tools, the burden of stroke has been reduced drastically in many (HIC) (Lopez et al., 2006; Feigin et al., 2016). However, In LMIC these tools have not been easily accessible, this therefore may have contributed to the increase cases of stroke within the regions. As these tools are used as essential monitoring of stroke outcome and early detection of the illness (Ezejimofor et al., 2016; Mahesh et al., 2020)

Now, two-thirds of deaths due to stroke occur in Africa (Lopez et al., 2006; Owolabi et al., 2018), where poverty, malnutrition, and non - communicable diseases are also prevalent. Data on sub-Saharan Africa show an annual stroke incidence rate of up to 316 cases per 100,000 people, a prevalence rate of 315 cases per 100,000 people, and a fatality rate of approximately 84% (Feigin et al., 2016). In sub-Saharan Africa, the estimated number of disability-adjusted life years (DALYs) lost to stroke is around seven times that in HICs (Feigin et al., 2014). Studies have suggested that in the next few decades, the burden due to stroke in sub-Saharan Africa is likely to increase substantially due to the epidemiological transition in the region from infectious to non-communicable diseases (Ezejimofor et al., 2016; Vincent-Onabajo et al., 2018).

1.3 Problem Statement

The literature indicates that there has been a decrease of 42% in incidences of stroke worldwide in high-income countries (HIC). Still, in Low to Middle-Income (LMIC) countries, such as Africa, there has been a 100% increase in incidences of stroke (Feigin et al., 2014; Ezejimofor et al., 2016; Virginia et al., 2016). Every minute, approximately six Africans experience stroke, mainly young and middle-aged adults, aged on average 57 years (Owolabi et al., 2008; Waheb et al., 2010; Oviagele et al., 2013). However, little is known about the burden of stroke in sub-Saharan Africa (O'Donnell, 2010; Norrving & Kissela, 2013).

The financial burden of stroke is colossal in most countries. In the UK, the cost to the NHS alone was estimated at £2.3 billion for 1995-1996. In America, approximately 500,000 strokes occur each year, the direct cost estimated at roughly \$17 billion with an additional \$13 billion in indirect costs (Norrving et al., 2013). This also has substantial financial implications in LMIC, such as Nigeria, with a population of over 200 million people, and a prevalence rate of 1.14 strokes per 1000; indirect costs of strokes, excluding nursing care, are estimated at an average of \$1.1 billion (N173.8 billion) each year in Nigeria (Owolabi et al., 2017). With that said, research into stroke survivors' quality of life (QOL) has received a lot of attention in the developed world (HIC) but only recently in Africa, specifically Nigeria (Akinpelu et al., 2009; Akosile et al., 2013; Ezejimofor et al., 2016). Since the burden of stroke is expected to increase significantly in LMIC, there is a need for a better understanding of the condition (O'Donnell, 2010; Norrving & Kissela, 2013; Virginia et al., 2016); this indicates a knowledge gap in the literature.

According to Feigin et al. (2014), out of 119 studies (58 from HICs and 61 from LMICs) conducted between 1990 and 2010 on the global and regional burden of stroke, the age-standardised incidence of stroke decreased by 12% in HIC while increasing in LMICs. Other studies on the global prevalence of stroke and its risk factors in 188 countries from 1990 to 2013 revealed that data from the GBD 2013 report was used to estimate the burden of stroke by age and sex using stroke-related disability-adjusted life years (DALYs) risk factors and the population-attributable fraction (PAF). According to the findings, 90 per cent of the global burden of stroke in 2013 was due to the cumulative impact of all modifiable risk factors studied, with behavioural and metabolic factors accounting for most of the burden. In addition, LMICs had substantially higher levels of air pollution, environmental hazards, cigarette smoke, dietary risks, and High Blood Pressure (HBP) than HICs. However, studies have

shown that most countries' epidemiological data are incomplete (Yusuf et al., 2014), so it is possible that this resulted in a higher proportion of the stroke burden being attributed to risk factors. Other research was also unable to model the different trends of specific risk factors and percentage changes in DALYs attributable to risk factor clusters due to this lack (Ezejimofor et al., 2016). NICE guidelines (2012) and the World Health Organization (WHO) (2014) both highlight the disparity in stroke reports between HICs and LMICs and suggest that more measures are needed to increase understanding of how to improve quality of life and health care, as there is growing concern that stroke survivors in LMICs are being disadvantaged.

1.3.1 Statement of Purpose

Even though several studies have been conducted on the impact of stroke on the quality of life of stroke survivors in Nigeria (Akosile et al., 2013; Ezejimofor et al., 2016), particularly within the affluent parts of the country, there is still very little research in this area in the poorer aspects of the country such as the SE regions. Stroke incidences have reduced by 42% over the last 4 decades (1970-2008) in HIC, whilst the stroke incidence rates in LMIC have increased by 100%. (Owolabi et al., 2015). Areas such as SE regions of Nigeria are particularly affected due to poverty and minimum health care resources (Ezejimofor et al., 2016). Despite the shorter life expectancies and the increase disability adjusted life years (DALY), should this trend in stroke incidences continue and aging of the population continue, deaths from stroke in LMIC will increase over the next decade by 20% and the burden of stroke may soon become unbearable for the LMIC (Vincent-Onabajo, 2018). Therefore, the purpose is to contribute to building resources in terms of research in the poorer communities of Nigeria. (Ezejimofor et al., 2016; Vincent-Onabajo, 2018). Quality of life in the context of this research study refers to how an individual feels about their current situation in life. This includes the perception of the individual's wellbeing, such as goals, expectations, and concerns.

Furthermore, to my knowledge, there is no mixed method study using Interpretative phenomenological analysis (IPA) that has been conducted in the SE region of Nigeria to examine stroke knowledge and experiences regarding the quality of life from the perspectives of stroke survivors. This identifies yet another gap in the literature. As a result, important questions arise, which this study intends to address:

1.4 Research Question

What is the impact of stroke on the quality of life of stroke survivors in the SE communities of Nigeria?

How has this affected their daily lives?

1.4.1 Aims of this research study

1. To identify variables that predict the impact of stroke on the quality of life of stroke survivors in SE Nigeria (using the outcome measure, the health-related quality of life in stroke patients – HRQOLISP).
2. To explore (using semi structured interviews) the perceptions, attitudes, knowledge, cultural approaches to improving quality of life and beliefs of stroke survivors in the SE communities.

1.4.2 Objectives of the research study

- To describe the epidemiological profile of stroke survivors in the SE communities of Nigeria
- To assess the HRQOL of stroke survivors (using the HRQOLISP questionnaire) and identify associated determinants.
- To conduct semi – structured interviews to ascertain detailed perceptions concerning QOL in stroke survivors.
- To engage in field observation to gain more insight into behaviours and attitudes of participants to enhance field notes.

1.5 Rationale of the Study

There has also been increasing concern about the exponentially growing burden of non-communicable diseases in Africa. Africa has, over the years, seen non-communicable diseases take the place of communicable diseases (Feigin et al., 2016; Obembe et al., 2013; Onwchekwa et al., 2014); the reduction in communicable diseases has been linked to improved medical facilities, services and basic amenities, and the socioeconomic status of the population of these regions (Ezejimofor et al., 2016). One such non-communicable disease that has emerged as part of this transition is hypertension, which has resulted in strokes (Feigin et al., 2016). Stroke cases among hypertensive patients have become a significant public health burden in Africa. (This is discussed further in the study). Notably, strokes have increased the percentage of paralysed patients in the Nigerian population (Obembe et al., 2013; Onwchekwa et al., 2014).

However, despite the public health burden of stroke in LMICs such as Nigeria, there are relatively few studies on the condition (Enwereyi et al., 2014; Owolabi et al., 2013; Akinpelu et al., 2012; Badaru et al., 2015; Ezejimofor et al., 2016). Studies on the quality of life of stroke survivors are also scarce, especially in the SE regions (Akosile et al., 2013; Badaru et al., 2015; Vincent-Onabajo et al., 2018), with roughly 70% of the few studies being conducted in the country's affluent south-west (Akosile et al., 2013; Badaru et al., 2015; Vincent-Onabajo, 2018). With a rise in the number of stroke survivors in Nigeria's Southeast communities, the lack of rehabilitation facilities and experts exacerbates the situation. Social support in the healthcare system and healthcare infrastructure are equally sparse, which places a burden on the healthcare system and has a devastating effect on the survivors' quality of life (QOL). The lack of development in the healthcare sector has heightened the interest in this area concerning the quality of life. However, due to the lack of rehabilitation facilities and experts, social and health support, lack of development in the healthcare sector, poverty / lack of health resources in the SE urban communities of Nigeria, it is imperative to accept solutions that contribute to strengthening the country's healthcare system to maximise QOL for these patients. This necessitated the exploration and incorporation of the views of stroke survivors in the research (Onabajo et al., 2018; Abubaker et al., 2012; Akosile et al., 2013).

1.5.1 The Positioning of the Researcher and a Personal Reflection

My Nigerian parents, who immigrated to England in the mid-1960s, often narrated the story of the Biafran War (1967–70), which focused on the Igbo people. The Igbos lived in the Southeast of Nigeria (known as the state of Biafra) and sought secession. I remember my parents discussing the events with such passion and talking about their participation as Igbos here in the UK. My father always elaborated on one aspect, which was that the UK Igbo community took it upon themselves to protest in 1967 along the streets of London to Trafalgar Square as they petitioned the UK government to intervene in the war and help to save the Igbos, who were practically defenceless. He always emphasised one scene that unfolded during a rally that became rather rowdy. Dad told me that one day, he and my mother had attended the protest with me in a pushchair, but due to the rowdiness, he had to carry me. He said that a police officer who noticed my father's difficulty grabbed me from my father and placed me on his shoulders so that I would not be crushed by the crowd. A reporter then took a photograph of me on the shoulders of the police officer. My father reported that, the next day, I appeared on the front cover of the local newspaper, sitting on the shoulders of a police officer, with

the caption: “Biafran baby girl” and police officer in protest for the Biafran War.’ My father remembers the incident decades later with the same clarity as if it had occurred yesterday. This struck a chord in me. Even as a child, I felt a deep passion for these Igbo people, especially as I understood what they had gone through during the Biafran War (discussed further in Chapter 4). My worldviews and perspectives have been shaped by these feelings. This was to become clear during the research study.

As I was growing up, I developed a strong passion for helping people; as a physiotherapist, I had a keen interest in neuromusculoskeletal conditions, particularly stroke. In 2009, my mother had an ischaemic stroke while she was on holiday in Nigeria. Fortunately, she was flown back to the UK, where immediate investigations and rehabilitation took place. One year later, my mother was left with no residual effects, and she is still alive 14 years later. Therefore, with the right resources and support in place, this was possible.

Unfortunately, a female relative of my mother who lived in Nigeria experienced a similar stroke that same year. She was significantly younger than my mother and shared a dense left hemiparesis (a severe physical disability). Regrettably, she died a few years later from the stroke. From that point, I became curious as to why this often occurs in LMICs. This was the beginning of my mission, as I set out to gain an in-depth understanding and knowledge of the effects and impact of stroke from patients’ perspectives in Nigeria.

National and International guidelines (WHO, 2015; Feigin et al., 2016) are very much concerned about the discrepancies between HIC and LMIC and suggest that more measures must be taken to gain further understanding of the issues, with the aim of improving QOL and health care. This is crucial in areas such as the SE region of Nigeria, where stroke incidence may be set to double in the coming years (WHO, 2015; Feigin et al., 2016; Owolabi et al., 2017). A deep understanding of the issues and the impact of stroke on the lives of survivors in this region is paramount to comprehending how the condition affects people’s QOL.

1.6 The Gap and its Significance

Quality of life-related to stroke is a significant healthcare issue that has not received sufficient attention in Nigeria (Akosile et al., 2013; Badaru et al., 2015; Vincent-Onabajo et al., 2018), and stroke causes an adequate decrease in quality of life. (Lai et al., 2020; Owolabi MO et al., 2008).

Even though various studies on the burden of stroke in sub-Saharan Africa have been conducted, the following information is still missing from the literature. The review reveals that there is a scarcity of nationally representative data on stroke prevalence, incidents, and case casualties and correlates in sub-Saharan Africa, which hinders generalisation (Owolabi et al., 2018; Feigin et al., 2016). In addition, there is a shortage of data on stroke survivors' HRQOL in sub-Saharan Africa, notably in Nigeria and its poorer communities (Ezejimofor et al., 2017; Owolabi et al., 2018). Consequently, little is known about the impact of stroke on the QOL of the survivors.

Studies have also revealed there is a lack of access to quality health care and education, as well as a lack of knowledge about the risk factors that may lead to hypertension and non-communicable diseases (Ezejimofor et al., 2017; Owolabi et al., 2018). Furthermore, there is a scarcity of data on the use of mixed method approaches to investigate survivors' experiences and quality of life in Nigeria (Feigin et al., 2016; Gbiri et al., 2012; Ezejimofor et al., 2017). This suggests that there is a need to investigate the lived experiences of stroke survivors in relation to their quality of life. Mixed method approaches have been known to balance out the limitations in each method and also help to provide stronger evidence with more confidence in the findings.

Even though studies have shown that the incidence of stroke is increasing in these communities due to poor education, poor infrastructure, poor health professional input, and a lack of stroke facilities, there has been no study that has voiced the perceptions of stroke survivors in the SE communities using a phenomenological approach to capture detailed perceptions about their QOL. Therefore, understanding the impact of the condition, on the quality of life, from the perspective of the survivors in this community is imperative to promoting maximal QOL, improving the effectiveness of rehabilitation and better supporting the needs of these individuals locally and nationally.

1.7 A Brief Overview of the Methodology

The methodology for this study is discussed in detail in Chapter 5. However, to give a brief overview, this study used an explanatory sequential mixed methods approach and incorporated a cross-sectional design with convenience sampling. Thus, the study is explanatory and interpretive in nature. The work also uses a phenomenological methodology with purposive sampling. The study comprises two phases: Phase 1 employs a quantitative approach, and Phase 2 a qualitative approach. This thesis, which describes the study, consists of eight chapters.

The impact of stroke is measured using the health-related quality of life in stroke patients (HRQOLISP) tool, an outcome measure with a scale from 0 to 40. The tool was developed to assess the impact of stroke / disability on the quality of life of the stroke survivors. It had been validated and is deemed reliable for assessing a patient's QOL after a stroke (Owolobi et al., 2011; Sampane-Donkor, 2014). Quality of life is a key outcome. It is important that the effectiveness of interventions is measured and valued in ways which are fully reflective of the quality of life amongst the stroke survivors. The tool had been utilized in similar studies such as Owolabi et al., (2011); and Sampane-Donkor, (2014). The HRQOLISP encompasses two dimensions and seven domains. The physical dimension covers the physical, psychological, cognitive/intellectual, and eco-social / active daily living (ADL) domains, while the spiritual dimension comprises the soul, spirit, and spiritual interaction domains. (This is explained in detail in Chapter 5.)

The HRQOLISP captures a survivor's experiences in these domains and thereby demonstrates the impact of stroke on different aspects of HRQOL by identifying the characteristics that predict these changes. Researchers have reported that the use of validated QOL assessment instruments is necessary to help improve the effectiveness of rehabilitation programmes for patients with stroke (Badaru et al., 2015; Vincent-Onabajo, 2018).

Perceptions, attitudes, and cultural approaches were explored through the performance of semi-structured interviews. This approach was chosen to aid in the detailed capture of the individuals' perceptions concerning their QOL. It is believed that this method would also uncover the participants' behaviours, 'thought patterns, and opinions to provide further insight into the problem' (Onwuegbuzie et al., 2009).

1.8 Knowledge Contributions

The analysis and interpretation of data from Phase 1 (quantitative) and Phase 2 (qualitative) will result in a more comprehensive and holistic knowledge of the impact of stroke on the quality of life of stroke survivors in South-eastern Nigeria. Understanding the impact of this condition on quality of life would aid those who are essential to providing care for this population in terms of service provision, education, resource allocation and planning.

The research study will demonstrate the repertoire of needs of stroke survivors in the SE community of Nigeria. In addition, the study will expose stroke's physical, emotional, intellectual, eco-social, and

spiritual effects and how individuals construct their life after stroke by adapting to conditions such as noncommunicable diseases (hypertension).

The interplay of quantitative and qualitative findings can produce theoretical statements leading to an understanding that will benefit both practitioners and survivors. This will promote better sensitivity in the design of rehabilitation programmes for the affected population.

The information from the thesis will also allow physiotherapists and healthcare professionals to better support this group's needs, as accurate and up-to-date information on stroke and its burden is required for the development and evaluation of adequate care and rehabilitation programmes for patients with stroke in SE Nigeria. Based on the findings of this study, a new model approach (ADIG Approach) has been developed to aid in this incorporation in SE Nigeria (See Discussion chapter).

As stated earlier, little is known about the QOL of stroke survivors in Nigeria's SE communities. Therefore, for the literature, the study would contribute to the increased knowledge, awareness, and understanding of varied cultures and attitudes of stroke survivors in LMICs. Knowledge from the research study has been disseminated through the publication of two manuscripts, as seen above.

1.9 Thesis Overview and Organisation

This research study is made up of two phases and consists of eight chapters as said earlier. Phase 1 uses a quantitative approach, whilst Phase 2 uses a qualitative approach.

1.9.1 Chapter 2: Literature Review

This chapter establishes a solid theoretical foundation for the research study by referring to the problem statement, aims, and objectives stated in Chapter 1. It examines and synthesises a diverse range of primary and secondary source material on stroke concerns internationally, in Sub-Saharan Africa, Nigeria, and the country's SE communities. The chapter situates the research study within the ongoing debate on the impact of stroke and QOL in stroke survivors. The gaps in the field are noted and explored. A summary concludes the chapter.

1.9.2 Chapter 3: Post colonisation Review

This chapter presents an overview of contemporary Nigeria in terms of post-war reconstruction, the health care system and its impact on the Nigerian SE community. The chapter investigates the impact of the Biafran conflict concerning health-related diseases such as stroke and non – communicable

diseases (NCD). It discusses the implications of early childhood malnutrition and its relationship with NCD. The chapter ends by highlighting the African traditional medicines and their influence on health in the Nigerian community.

1.9.3 Chapter 4: Theoretical Framework

This chapter discusses the conceptual framework that draws on theory, research, and experience to give conceptual cohesion to the research project. The chapter provides a guiding framework that monitors the study and plays a significant role in analysing the quantitative and qualitative findings. The chapter discusses the relationship between the biopsychosocial, medical, and social models and highlights the concepts, ideas, and variables identified in the research study.

1.9.4 Chapter 5: Methodology

This chapter describes the methodological reasoning used in the quantitative and qualitative phases of the research study. It situates the research work within a certain methodological tradition while offering justification for the methodologies used. A mixed method approach with a triangulation effect was suggested in accordance with pragmatism. The chapter closes by emphasising all components of the research study's chosen design and processes.

1.9.5 Chapter 6: Quantitative Findings

This chapter organises, presents, and reports the research study's main statistical quantitative findings, which is taken from the HRQOLISP questionnaire for phase 1. A step-by-step flow chart breaks down the analysis process, describing the various tests used for the study. The chapter concludes with a discourse of the variables and relationships that predict the impact of stroke on the QOL of the stroke survivors in SE communities of Nigeria.

1.9.6 Chapter 7: Qualitative Findings

This chapter presents the study's main qualitative findings in phase 2 of the study. The methodological framework, Interpretative Phenomenological Analysis (IPA) was chosen to outline the process of this second phase. The section details the four-step analytical process. An interpretative mapping of the process is described in detail, followed by the three emerging main master themes and corresponding sub-themes. The chapter concludes with a review of the data gathering and analysis, which embodies the criteria.

1.9.7 Chapter 8: Discussion, Conclusion, Recommendations and Reflexivity

This chapter highlights the significant findings in light of the research question, literature review, and conceptual framework, as well as bringing together the work performed by emphasising the findings of stage 1 and stage 2 of the study. The results are displayed side by side to integrate them and utilise triangulation. It discusses the contributions made in the field of physiotherapy, followed by the development of the ADIG approach model. The chapter then highlights the various concluding comments and recommendations. It ends with a dialogue of the strengths, limitations, and implications for practice, followed by a reflection on the research journey.

The following chapter, a literature review, will place the study from the perspective of past research on the subject. It will give a critical synthesis of empirical literature while justifying how the research fills a gap in the literature.

CHAPTER TWO

Literature Review and Background

2.1 Introduction

This chapter reviews a growing body of current literature on stroke and related disorders. The review considers the following areas: the historical perspectives of stroke; its pathology, prevalence, and the epidemiology of stroke. It will discuss the experiences of living with a stroke in Sub – Saharan Africa (SSA), whilst addressing the concepts of health and HRQOL along with social determinants of health in developed and developing countries. It also deliberates on the risk factors associated with stroke including stroke rehabilitation globally.

The research strategies however, used in the study provided an overview of current knowledge, allowing the researcher to identify relevant theories, methods, and gaps in the existing literature, which was adhered to in the study. We searched for electronic databases – CINAHL, Medline, PubMed and Academic, search complete and the peer -reviewed journal implementation science to identify relevant studies. With the use of keywords, database and other sources the researcher found and selected the most pertinent literature for the topic at hand. The review ends with an overall summary of the chapter.

2.2 Stroke: A Brief Historical Perspective

Hippocrates originally recognised stroke in 460–370BC, when he discovered that obstruction of the ‘stout’ carotid arteries resulted in the loss of consciousness (Caplan, 2000; Ashrafian, 2010).

Furthermore, he found that strokes were most prevalent between the ages of 40 and 60. In 1658, Johann Jacob Wepfer observed that apoplexy (convulsions and paralysis) was caused by occlusion of the carotid or vertebral arteries and brain haemorrhage (Ashrafian, 2010). Galen (131–201 AD) later documented the brain's vascular structure through dissections of animals. However, Andreas Vesalius (1514–1564) eventually refuted this in the *Fabrica* based on human dissections (Caplan, 2000).

Following this, Thomas Willis reported on the anastomotic vessels near the base of the brain in *Cerebri anatome* (Caplan, 2000), and in 1828, John Abercrombie clinically classified apoplexy into three categories: primary apoplexy (large intracerebral haemorrhages or infarcts with focal deficits and stupor), subarachnoid haemorrhage (with stupor and headache but no focal deficit), and small

infarcts or haemorrhages (with a focal deficit but no stupor or headache) (Caplan, 2000). However, in the latter half of the twentieth century, the technological revolution resulted in significant advancements in antemortem visualisation of vascular lesions and the identification of novel medical therapy techniques for stroke. Moniz and Seldinger devised angiography, a method that reveals essential details about vascular architecture. Similarly, in the 1970s, Hounsfield and Damadian pioneered Computerised Tomographic (CT) scanning and Magnetic Resonance Imaging (MRI), which enabled the location of brain infarcts and haemorrhages to be defined (Caplan, 2000).

In the intervening years, more sophisticated and powerful tools have been developed to highlight the pathophysiology of stroke (Caplan, 2000). In addition, these advances in stroke have facilitated the establishment of stroke units that offer effective care for patients with stroke and survivors (Sampane-Donkor, 2014). To meet the average standard, however, much more is required.

However, the overall key gaps in the literature, as discussed in the study, is the scarcity of information and knowledge concerning the impact of stroke-on-stroke survivors in sub-Saharan Africa / Nigeria (Owolabi et al., 2008; Norrvinget al., 2013). Knowledge concerning risk factors that influence non – communicable diseases such as hypertension in these regions is equally limited. Followed by the lack of data on the in the use of Mixed method approaches, with no known study that has voiced the perceptions of stroke survivors in the SE communities using a phenomenological approach to capture detailed perceptions about QOL post stroke (Feigin et al., 2016). These are the main concerning factors.

2.2.1 Definition and Pathology of Stroke

The medical term for stroke is cerebrovascular accident (CVA) (Sacco et al., 2013). However, a stroke in the twenty-first century is defined as an abrupt damage to the brain caused by an abnormal blood supply, with a persistent neurological deficit (Sacco et al., 2013; Feigin et al., 2016). This definition excludes subdural haemorrhage, epidural haemorrhage, cortical venous and dural venous sinus thromboses, transient ischaemic attacks (with the only transient neurological deficit), and uncomplicated dissections of carotid and vertebral arteries (Owolabi et al., 2008; Norrvinget al., 2013; Hamza et al., 2014). The clinical manifestations of stroke include a wide range of signs and symptoms, such as paralysis, weakness, numbness, severe headache, slurred speech, cognitive changes, vision problems, and balance issues (Feigin et al., 2016; Gbiri et al., 2012; Ezejimofor et al.,

2017). Strokes can occur on either side of the brain (Gbiri et al., 2012). Those that occur on the left-hand side of the brain are more likely to affect speaking and language. Those that occur on the right-hand side of the brain cause problems like spatial orientation (Gbiri et al., 2012; Hamza et al., 2014). Stroke is the leading cause of neurological admissions and a significant cause of disability, affecting health-related quality of life (HRQOL) (Hamza et al., 2014; Owolabi et al., 2008).

Stroke diagnosis involves a radiological assessment where the clinical diagnosis is uncertain (Warlow, 1998). MRI or CT imaging are reliable methods for identifying stroke subtypes. MRI provides more accurate information and can distinguish between a haemorrhage and a thrombus earlier than CT imaging, despite the fact that CT imaging is more frequently used in the diagnosis of strokes (Caplan, 2000). Unfortunately, in most LMICs, such as Nigeria, CT imaging and MRI facilities are not readily available or affordable – with few institutions offering the service, as costs are often not covered by the primary health system (Owolabi et al., 2008; Norrving et al., 2013).

As mentioned above the loss of blood flow to a portion of the brain is a stroke (Feigin et al., 2009). This occurs when a blood clot obstructs an artery in the brain or when a haemorrhage from a blood vessel in the head causes pressure in the brain. In either situation, brain injury is either temporary or permanent (Swains et al., 2008). Brain cells begin to die in just 3 to 4 minutes without oxygen (Mendis et al., 2013). In other words, the duration between the stroke and treatment affects the severity of brain damage.

Every minute, around two million brain cells are lost (Warlow et al., 1998; Mendis et al., 2008; Swains et al., 2008). The longer one goes without oxygen, the more likely irreversible brain damage occurs (Mendis et al., 2008; Swains et al., 2008). However, depending on the area of the brain that is deprived of oxygen, a person may suffer from loss of movement, function, memory, and speech, as well as other disabilities (Swains et al., 2008). If blood flow is restored or pressure is relieved quickly through medical treatments, the brain may fully recover (Mendis et al., 2013; Feigin et al., 2009). A stroke that is treated quickly may result in temporary arm or leg paralysis. A more severe stroke that is not treated promptly may result in permanent paralysis on one side of the body or speech/memory loss (Mendis et al., 2013; Feigin et al., 2009). Strokes are classified into two types (explained further in the thesis).

There are several types of strokes; however, for the purposes of this research study, the focus is on the two most common types, Ischemic and haemorrhage as shown below.

2.2.2 Ischemic Stroke:

This occurs when a blood clot blocks the flow of blood to the brain. This may have formed inside an artery that supplies blood to the brain and is called a thrombus (Bandford et al., 1991; Warlow et al., 1998). Ischaemia stroke also refers to when the blood supply stops because of a blood clot (Sampane-Donkor, 2014). This happens when a blockage cuts off the blood supply to the brain. It is also often referred to as a clot (Connor et al., 2007). Ischaemia results in hypoxia and hypoglycaemia, which sets up a vicious cycle. This can be caused by a clot forming in an artery leading to the brain or within one of the small vessels deep inside the brain. This accounts for 85% of all cases (Owolabi et al., 2008; Sampane-Donkor, 2014). However, a situation where the blood supply to the brain is temporarily interrupted is known as a transient ischaemic attack.

A transient ischaemic attack (TIA) is defined as a neurological deficit lasting less than 24 hours, attributed to focal cerebral or retinal ischaemia (Connor et al., 2007). However, the TIA Working Group proposes a new definition: 'A TIA is a brief episode of neurological dysfunction caused by focal brain or retinal ischemia, with clinical symptoms clinically lasting less than 1 hour and without evidence of acute infarction. The corollary is that persisting clinical signs or characteristics of imaging abnormalities define infarction which is a stroke (Owolabi et al., 2008; Sampane-Donkor, 2014). For clinical studies, the most recent definition of stroke is symptoms that last longer than 24 hours or radiological evidence of a recent vascular brain injury with swiftly fading symptoms, described as cerebral infarction with transient symptoms (Connor et al., 2007). However, when symptoms persist for more than 24 hours but disappear within three weeks, reversible ischaemic neurological impairment is occasionally used, even if a genuine infarction may have occurred. For example, a completed stroke occurs when the maximum deficit occurs within six hours, whereas a stroke in progress occurs when symptoms and signs worsen for 24 hours from onset (Sampane-Donkor, 2014).

2.2.3 Haemorrhagic Stroke:

This refers to when a blood vessel in the brain breaks or leaks due to weakness in the vessel wall, and blood flows into or around the brain causing swelling and pressure. This bleeding (or

haemorrhage) damages brain cells and tissue (Sampane-Donkor, 2014). Such strokes include, as mentioned above, subdural haemorrhage, epidural haemorrhage, cortical venous and dural venous sinus thromboses, transient ischaemic attacks (with the only transient neurological deficit), and uncomplicated dissections of carotid and vertebral arteries.

Studies have reported that haemorrhagic stroke accounts for 20%, while ischaemic stroke accounts for 80% of strokes globally (Owolabi et al., 2008; Sampane-Donkor, 2014; Feigin et al., 2016). Recent epidemiological data indicate the proportions of ischaemic and haemorrhagic strokes in Africa are 66% and 34%, respectively, compared to 91% of ischaemic and 9% of haemorrhagic stroke in high-income countries (O'Donnell et al., 2010; Feigin et al., 2016). Poststroke complications are the leading cause of death in Nigerian patients with ischaemic stroke; these include medical and neurological complications (Wahab et al., 2008). In Nigeria, mortality rates are quite high, with a range of 21%–45%, but in HICs, the mortality rates have been reported to be approximately 40–46% lower (Ekeh et al., 2015). Various studies have found predictors of stroke mortality. For example, Ekeh et al. (2015) stated older age (age > 60 years) is a predictor of mortality. This was not the case in another study (Bennett et al., 2007). Some studies have noted that females have increased mortality and lower one-year survival (Ekeh et al., 2015), while Barret et al. (2007) noted the male sex to be a poor predictor (Barret et al., 2007). Similar further studies had inconclusive results (Ekeh et al., 2015; Sampane-Donkor, 2014).

There are two types of haemorrhagic strokes: intracerebral and subarachnoid haemorrhage. These are the main types of strokes that are being dealt with in this research study. Intracerebral haemorrhage is the most common type of nontraumatic intracranial haemorrhage and accounts for 80% of haemorrhagic strokes and 10%–15% of all strokes (Caplan, 2000). Intracerebral haemorrhage is mainly caused by uncontrolled hypertension leading to the rupture of small vessels. The rupture leads to an avalanche-type effect, with breakage of nearby vessels resulting in haematoma expansion in up to 40% of cases (Caplan et al., 2000; O'Donnell et al., 2010). Subarachnoid haemorrhage is mainly due to aneurysms and arteriovenous malformations in a ratio of 3:1 (Owolabi et al., 2008; Sampane-Donkor, 2014). This is also often associated with medications such as anticoagulants. About 65% of subarachnoid patients survive, but half remain disabled primarily due to severe cognitive deficits (Sampane-Donkor, 2014). Owolabi et al. (2008) reported that, on average, in Black Africans, non-embolic cerebral infarction accounts for about 60%, embolic infarction 5%, cerebral

haemorrhage 20%, subarachnoid haemorrhage 10%, and ill-defined stroke 5% or more (Feigin et al., 2016). In studies on stroke epidemiology and treatment trials, stroke mortality serves as a crucial outcome indicator. As a result, data on mortality is essential for tracking illness patterns and developing public health interventions. This will result in a decrease in stroke death and disability.

The brain is the primary organ injured by stroke; it is metabolically active and requires regular and steady blood flow and oxygen (Mozaffarian et al., 2016). The blood flow to the brain is managed by two internal carotids anteriorly and two vertebral arteries posteriorly – the circle of Willis (Kuriakose et al., 2020). As stated above, when blood flow is reduced below a particular threshold, brain cell function is severely impaired, and some neurons cannot survive below a specific level (Kuriakose et al., 2020). The brain's regulating mechanism tries to restore homeostasis by raising blood pressure, but the increased intracranial pressure pushes cerebrospinal fluid out, creating circulation problems (Mozaffarian et al., 2016; Kuriakose et al., 2020).

Stroke is a medical emergency requiring prompt and precise treatment (Swains et al., 2008). The sooner a person receives care for a stroke, the less likely it is that permanent damage will occur. An emergency medical team should be immediately notified if a stroke is suspected (Dombrowski et al., 2013).

The acronym FAST stands for the primary physical signs of a stroke (face, arms, speech, and time). FAST is used as a memory aid to detect and improve a stroke patient's response to demands (Dombrowski et al., 2013). The Act FAST programme encourages everyone to take action as soon as they notice stroke symptoms in order to save lives (Dombrowski et al., 2013).

- **Face** – the face may drop (drooping face)
- **Arms** – inability to raise arms due to arm weakness.
- **Speech** – this becomes slurred or garbled, or the person may not be able to talk at all.
- **Time** – it is time to call for medical emergency help.

This was developed in the United Kingdom in 1998 by medical professionals (Lecouturier et al., 2010). Campaigns were launched around the time, and data revealed that stroke admissions to hospitals dropped by about 12% (Dombrowski et al., 2013). Public Health England (PHE), with the support of the Stroke Association, relaunched several years later, with data indicating an increase in stroke incidence reduction (PHE, 2021). In addition, variables indicating the diagnostic accuracy of

strokes by paramedics and emergency medical technicians have been reported in studies, with positive predictive values ranging from 64% to 77% (Lecouturier et al., 2010).

The campaigns helped raise awareness of stroke symptoms by assuming that public knowledge about common stroke symptoms and the need for emergency response was lacking (Lecouturier et al., 2010). As this is also the case in LMICs, such campaigns involving FAST should be incorporated and launched in these countries to raise awareness of stroke risk factors (this is discussed in further detail in chapter 8).

2.2.4 The Epidemiology of Stroke

The burden of stroke encompasses data on its prevalence, incidence, risk factors, mortality, and morbidity. Stroke is a major cause of morbidity and mortality worldwide (Fiegins et al., 2017; Katan et al., 2018). There are 1.2 million stroke survivors in the UK; 1 in 53 people in the UK is a survivor (Wang et al., 2013). Despite having several stroke survivors, England has the lowest percentage of stroke survivors per head of the population, approximately 1.3 million compared to LMICs (Wang et al., 2013). Nevertheless, stroke is one of the most common causes of death in LMICs, such as in Nigeria (Owolabi et al., 2008; Norrving et al., 2013; Hamza et al., 2014). Due to ongoing epidemiological transition, stroke is a significant cause of morbidity and mortality in Africa, where it accounts for 0.9%–4.0% of hospital admissions and 3%–4.5% of total deaths (Ojiniet al., 2003). In a three-year review of adult neurological admissions in University College Hospital, Ibadan, stroke constituted 50% of cases (Talabi et al., 2003). However, this was more than what was previously reported in a similar study in Ibadan but was comparable to a reported study in Lagos (Owolabi et al., 2008; Norrving et al., 2013).

The prevalence of stroke survivors in a community depends on the incidence and case fatality, which have different determinants. In Nigeria, the community prevalence of stroke varies from 58/100,000 to 400/1,000,000, with an annual mortality rate of about 70/100,000 per year (Owolabi et al., 2008; Norrving et al., 2013). Enwereji et al. (2014) found that the crude prevalence of stroke in rural Nigeria was 1.63 (95% confidence interval 0.78–3.00) per 1,000 population. The crude prevalence of stroke in males was 1.99 (95% CI 0.73–4.33) per 1,000, while that for females was 1.28 (95% CI 0.35–3.28) per 1,000 population. The peak age-specific prevalence of stroke was 12.08 (95% CI 3.92–28.19) per 1,000, while after adjustment to WHO world population, the peak was 1.0 (95% CI 0.33–2.33) per

1,000(Owolabi et al., 2008; Norrving et al., 2013). These study results are comparatively higher than reported in previous community-based studies in Nigeria (1.63 versus 1.14, 0.58, and 0.68 per 1,000) (Danesi et al., 2007) but lower than reported in Aiyete, Southwestern Nigeria (4.43 per 1,000). However, unlike their study and earlier Nigerian studies conducted in predominantly low-income rural communities, Danesi et al.'s study was conducted in a mixed-income urban community (Owolabi et al., 2008). Also, the proportion of the population at particular risk for stroke (45 years and above) was higher in the study than that of Danesi et al. (24.73% versus 15.24%). This may be partly explained by the common practice in Nigeria of urban-to-rural migration after retirement (67% of retirees) (Adebo et al., 2012). Owolabi et al.'s (2017) systematic review of the epidemiology of stroke in Africa indicates the prevalence rates of stroke survivors range from 15 per 100,000 in Ethiopia to 963 per 100,000 in Egypt and 1460 per 100,000 in the Niger Delta region of Nigeria (Khedr et al., 2014; Owolabi et al., 2015). It has been suggested that the wide disparity in these figures could reflect the uneven methodological rigour of the studies (Owolabi et al., 2017). The study highlights incident rates that ranged from 25 per 100,000 person-years in Lagos, Nigeria, to 250 per 100,000 person-years in Egypt in 2007 (Khedr et al., 2014; Owolabi et al., 2015). Again, it has been reported that this wide discrepancy is likely caused by variability in methodological rigour and case ascertainment (Khedr et al., 2014). However, the latter study was more rigorous, while the Lagos study was only for one year, with an underrepresentation of patients with stroke (Owolabi et al., 2017).

2.3 Experiences of Living with Stroke in sub – Sahara Africa, Nigeria

Surviving a stroke can be a long-term process that affects several aspects of a person's life, with long-term consequences. Epidemiological studies of stroke in Nigeria have focused on mortality and risk factor profiles but not on quality of life which is a significant health care issue (Abubakar et al., 2007; Wahab et al., 2008; Okosile et al., 2013; Badaru et al., 2015; Vincent-Onabajo et al., 2018). Stroke causes a significant decrease in quality of life even among those with no residual effects (Lai et al., 2020; Owolabi MO et al., 2008).

The social, psychological, and medical contexts in Africa differ from those in Western countries (Heikinheimo et al., 2015). Several studies have described poststroke QOL in sub-Saharan Africa (Owolabi et al., 2013; Owolabi et al., 2015). Studies from Nigeria have concluded that determinants of HRQOL in patients with stroke are stroke severity, functional recovery, laughter, and frequency of negative feelings or depression (Heikinheimo et al., 2015). A study involving 100 patients with stroke

and 100 healthy adults in Nigeria and Germany more than a month after stroke divided QOL into physical and spiritual spheres (Owolabi et al., 2013; Owolabi et al., 2015). The physical sphere reflected the negative impact of stroke on QOL and involved sensory and motor function, mood, and interpersonal intersections. The spiritual sphere, which included self-esteem, personal autonomy, and idealistic aspects of human life, remained stroke resistant among the Nigerian participants (Busch et al., 2017). A Tanzanian study of 58 patients, 58 controls, one to five years after the stroke incident, found the most vital factors that correlated with QOL were age, depression, anxiety, physical disability, motor function, and involvement in social events (Jones et al., 2012). Contrary to a study in Kenya of young stroke survivors, gender made a difference; men had better QOL than women (Bello et al., 2021).

A literature review by Badaru et al. (2015) explored the quality of life of Nigerian stroke survivors in Ibadan, Nigeria. The review identified a total of 14 studies published between 2007 and 2014. The studies revealed that 10 (71.4%) were conducted in the Southwest region of Nigeria, 2 (14.3%) in the Northwest region, 1(7.1%) in the Southeast region, and 1(7.1%) in the South-South region of Nigeria. This implies most studies of Nigeria stroke survivors were conducted in the SW region (the affluent region of the country), with the mean ages between 54.4 years and 62.8 years. However, a decade ago, there were few or no published studies on the quality of life of stroke survivors in the country.

2.3.1 Health Related Quality of Life

HRQOL, validated by WHO (2001), is used as an essential parameter for measuring outcomes in modern medicine globally (Salter et al., 2008; Obembe et al., 2013). HRQOL assessment is multi-dimensional and focuses on the patient's quality of life and disability. It is, therefore, essential to know how different HRQOL dimensions vary over time among survivors (Hamza et al., 2014).

Quality of life (QOL) is defined as 'an individual's perception of their position in life in the context of the culture and value systems in which they live, and concerning their goals, expectations, standards, and concern' (WHOQOL Group, 1996). QOL is an important health outcome used to measure stroke, as it gives a holistic insight into the wide-ranging effects that stroke can have on a person's physical, social, and emotional health (Norrving & Kissela, 2013). According to the WHO (1999), this is the individual's perception of their position in life in the context of the culture and value system in which they live and concerning their goals, expectations, standards, and concerns.

The World Health Organisation (WHO) has defined health as 'a state of complete physical, mental and social well-being and not just the absence of disease or infirmity. However, this was reviewed in 1993 by the WHO, defining quality of life as 'an individual's perception of their position in life in the context of the culture and value systems in which he/she lives and concerning his/her goals, expectations, standards, and concern' (Owolabi et al., 2010).

In Nigerians, stroke impairs all facets of HRQOL and has a major impact on its survivors (Owolabi, 2011). The results of various studies show that the severity of impairment correlates with stroke severity. However, poststroke disability is of great challenge to the patients, the family, and the larger society, with a significant cost burden on the health facilities and the informal care workers (Olufemi et al., 2016). It is a serious health and societal issue across the person's quality of life, and its associated health care and welfare expenditures are enormous for both the family and the national economy (Olufemi et al., 2016; Gbiri et al., 2015). Olufemi et al. (2016) emphasised the importance of estimating the degree of disability among stroke survivors, as this will not only provide information on the magnitude of the problem but also help improve goal setting during stroke rehabilitation to reduce the burden of stroke by improving self-reliance and productivity after stroke. Further studies have reported that a third of stroke survivors have a moderate-to-severe disability and another third have a mild disability (Olufemi et al., 2016). Compared to controls with the same comorbidities, stroke survivors had a 32.8% prevalence of poststroke impairment, according to the reports (Gbiri et al., 2015). However, in HICs, stroke is attended to as emergency care, emphasising early intervention. Stroke care in LMICs, such as in Nigeria, does not attract the needed adequate care due to low levels of awareness and inadequate facilities for care (Oyewole et al., 2016).

Studies have recommended that determining the subjective impact of stroke on survivors in LMIC countries is critical to discover the elements that predict poor QOL so that these aspects can be improved (Gbiri et al., 2012). The data generated will highlight the need for allocating health resources for the prevention and management of stroke at the community and national levels in low-income countries (Feigin et al., 2007; Gbiri et al., 2012; Norrving & Kissela, 2013). To the researcher's knowledge, few longitudinal studies that have measured or determined the impact of stroke on the QOL of stroke survivors have been conducted in Nigeria. Owolabi (2014) stated that stroke studies in Nigeria are mainly hospital-based cases and indicated that these cannot provide prevalence or incidence estimates because the population at risk is unknown. However, recent epidemiological data

show that the proportions of ischaemic and haemorrhagic strokes in Africa are 66% and 34%, respectively, compared to 91% of ischaemic strokes and 9% of haemorrhagic strokes in high-income countries (O'Donnell et al., 2010). Studies have also stated that the proportion of strokes in Africa ranges from 29% to 57% in comparison with 16% to 20% in North America (Owolabi et al., 2010). Conversely, ongoing studies by Owolabi et al. (2008) and Owolabi and Ovbiagele (2013) have reported that roughly six Africans have a stroke per minute and that research has revealed that the age-standardised incidence of stroke reduced by about 12% in high-income nations between 1990 and 2010 (Hall et al., 2012). However, the burden of stroke in Africa is increasing – especially in Nigeria, disproportionately afflicting young and middle-aged adults (Owolabi, 2011).

Studies on the incidence rate of stroke, which includes mortality and morbidity, have been linked to national per capita income. For example, a study by O'Donnell (2010) found that between 1970 and 2008, there was a 42% decrease in stroke incidence in high-income countries. In contrast, LMICs, such as in Africa, experienced a 100% increase in stroke incidence.

A study by Akosile et al. (2013) recruited 103 volunteer stroke survivors (53 males and 50 females) from various hospital settings. It adopted a quantitative approach using the Stroke-Specific Quality of Life (SS-QOL) scale to assess QOL. The study aimed to investigate sex differences in the stroke survivors' QOL domains and set out to provide preliminary data on Nigerian stroke survivors. The findings suggested that overall QOL scores were not significantly different for males and females in all the domains. Participants' best scores were in vision, thinking, mood, and language, whereas the worse scores were in the social role domains. Gbiriet al. (2009) investigated the QOL of stroke survivors and healthy individuals in SW Nigeria, Owolabi et al. (2009) reviewed the HRQOL profile of Nigerian stroke survivors equally and Hackett et al. (2000), who studied HRQOL among long-term stroke survivors, all presented similar results.

Conversely, Owolabi and Ogunniyi (2009) argued that QOL may not be severely affected in milder forms of stroke and suggested that acquired coping strategies may minimise the effects of stroke on QOL. It was also argued that the good scores obtained in the vision, thinking, mood, and language domains might reflect a low visual field presence and cognitive function impairment among study participants. Participants may have also recovered from some of these comorbid conditions, as their strokes were long-standing.

Gbiriet al. (2009) explored the prevalence, patterns, and impact of depression on the QOL of stroke survivors. The findings revealed that the prevalence and severity of depression declined considerably over six months for individuals with acute stroke. However, the study excluded stroke survivors with severe affectation and those who did not comprehend English. Therefore, these findings cannot be generalised to such individuals. In addition, the accuracy of the data may have been affected, as information on stroke diagnosis was obtained through patients and family sources and not directly from the doctor or consultant.

Hamza et al. (2014), in a one-year study of 233 stroke survivors recruited from three hospitals in the Northern region of Nigeria, adopted a quantitative approach. The study examined predictors of poststroke HRQOL in Nigerian stroke survivors, aiming to identify the predictors in the different aspects of quality of life and measure the changes in functional status over time. Specific scales were used to measure the changes that occurred in the various aspects at six months and then one year later. During the healing phase, functional impairments were dramatically decreased. The presence of depression, disability, and motor impairment were independent predictors of HRQOL. The mean average for the respondents was 58.76 ± 13.24 . Studies such as Owolabi et al. (2008), Abukakar et al. (2012), and Gurcay et al. (2009) have all presented similar findings. It was argued that the study could not identify how early the stroke survivor started to receive rehabilitation, which may have affected the results. Furthermore, prospective longitudinal studies have found that Nigerian stroke survivors experience significant recovery of functional abilities from stroke onset up to and beyond six months (Abubakar et al., 2012; Badaru et al., 2015; Akinpelu et al., 2009).

Gbiri et al. (2012) followed sixty-five participants (33 male and 32 female) in a one-year quantitative study. The study aimed to examine the QOL of Nigerian stroke survivors during the first 12 months poststroke. Participants were recruited within 72 hours of stroke onset. Assessments of QOL and depression took place monthly. The findings revealed that QOL improved significantly from onset to six months but non significantly from six months to 12 months, where nearly 85.2% of the stroke survivors had depression at one month. At three months, family support was shown to have a significant positive influence on QOL. At 6, 9, and 12 months, marital status, family support, education qualification, and occupational status significantly positively influenced QOL. The equal distribution of male and female participants in the study suggests that stroke affects both sexes equally in Nigeria.

Conversely, studies have argued that the incidence is usually greater in men than in women under 65 (Akinpelu et al., 2009). Although the findings suggest that the QOL of the participants improved significantly over the 12 months, it remained lower than the total obtainable score throughout the 12 months. However, these findings show similarities with other studies (Owolabi et al., 2010; Obembe et al., 2013; Murray et al., 2012).

Olaleye (2013) studied the factors affecting patients' participation in outpatient stroke physiotherapy exercises using semi-structured interviews. The researchers recruited eight male Nigerian stroke survivors for the study. The findings suggested personal internal, experimental, and external factors were important factors for this small group of Nigerian men poststroke. However, due to the small sample size, this is not representative of the population at hand.

Several studies have demonstrated poor community awareness and knowledge of stroke and reduced reintegration into the community, particularly in low-income countries and the Nigerian communities (Sampane-Donkor et al., 2014). Ezejmofor et al. (2016) highlighted that there is currently a stroke epidemic and reiterate that this reflects the poor community awareness of stroke and its risk factors. It has been suggested that evaluating and addressing perceptions of stroke survivors is crucial in combating and controlling this epidemic in Nigeria as a whole. The goal of rehabilitation has shifted from the mere survival of a victim to how well a survivor can be effectively reintegrated into the community. Studies have suggested that community reintegration is the most important and, ironically, the most underestimated area of stroke rehabilitation (Bhagal et al., 2003; Sampane-Donkor et al., 2014; Ezejmofor et al., 2016).

One study by Obembe et al. (2013) examined community reintegration in stroke survivors, focusing on motor function and depression. Ninety participants (56 men and 34 women) who attended physiotherapy clinics at selected hospitals in SW Nigeria were recruited for the study. The Reintegration to Normal Life Index (RNLI) was used to assess community reintegration, and motor function was assessed using the Motor Assessment Scale (MAS). The Hamilton Depression Scale (HDS) was used to assess depression. The findings suggested that the higher the community reintegration, the higher the motor function and the lower the depression. It was concluded that motor function and depression influence community reintegration and should be appropriately assessed and adequately treated before survivors return to the community. However, it is argued that the findings of

this study may not be generalised to stroke survivors who cannot mobilise independently, as the survivors in the study could. Moreover, the study used convenience sampling – demonstrating sampling bias, as the participants were recruited consecutively based on the study criteria.

More recently, Akosile et al. (2016) studied community reintegration and related factors in a Nigerian sample group. This was a cross-sectional survey comprising 71 volunteers (35 males and 36 females). The study aimed to determine the level of community reintegration and factors that may either influence or be related to it among community-dwelling stroke survivors from SE Nigeria. The findings showed that community reintegration was generally poor for community-dwelling stroke survivors. Participants had deficits in community reintegration, either mild/moderate (52%) or severe (47.9%). The study argued that rehabilitation focus should be targeted at enhancing mobility functions and vocational and social skills. However, due to the study's sample size, it can be argued that this may not be representative of the stroke survivor population (Olufemi et al., 2016).

It is difficult to draw any conclusion on the impact of stroke on QOL of stroke survivors in Nigeria since the results are scanty and not fully representative of the country. Recent studies have suggested that critical information on aspects of stroke care is very much lacking in Nigeria and needs to be updated (Vincent-Onabajo et al., 2016; Ezejimofor et al., 2016). It has also been suggested that collaboration between experts from resource-rich nations and Nigeria will be of tremendous benefit in generalising much-needed data on the extent of the disease and its management in various regions of the country, as this is particularly important when attempting to validate any developed guidelines (Ezejimofor et al., 2016; Vincent-Onabajo et al., 2018, Hamza et al., 2014) This calls for health education in these regions of the country. Consequently, this emphasises the need for further studies, especially from the SE region of the county, which is the aim of my study.

In Nigeria as a whole, there is currently a stroke epidemic (Ezejimofor et al., 2016). This is partly a reflection of the poor community awareness of stroke and its risk factors. Therefore, evaluating and addressing perceptions in LMIC is crucial in combating and controlling this epidemic in Nigeria, particularly in the Eastern parts. The available literature has revealed a lack of community awareness of and information about stroke and its risk factors, particularly in low-income neighbourhoods. (Sampane-Donkor et al., 2014). Other African studies (Cossi et al., 2012; Ayanniyi et al., 2006) have

presented similar difficulties, with high-risk participants unable to accurately identify each of the primary stroke risk factors (Obembe, 2013; Sug Yoon et al., 2001; Aly et al., 2009).

This study aims to investigate and assess survivors' perceptions, knowledge, and cultural awareness of stroke and its risk factors, as evidenced by studies such as Akinyemi et al. (2009). Thus, this aims to address the gaps in the literature, such as poor community awareness concerning risk factors, reduced literature within the poorer communities of Nigeria, and a lack of quantitative studies concerning lived experiences from the survivors' perspectives.

In summary, as the burden of stroke is expected to rise in LMICs and poor communities due to ongoing epidemiological transitions (Ezejmofor et al., 2017), studies have suggested that community-based stroke research is needed in African countries, particularly Nigeria, to aid in addressing these gaps in the literature as stated above (Vincent-Onabajo et al., 2018; Hamza et al., 2014; Owolabi et al., 2018). The overall aim is to gain a thorough understanding of the impact of stroke on the quality of life of stroke survivors. This will also aid in identifying specific rehabilitation goals, health care, and social needs to support long-term stroke recovery among Nigerian survivors effectively.

2.3.2 The Concepts of Health and HRQOL – (Living with a 'Long term' condition)

The number of people who survive a stroke and live with its consequences is increasing because of new medicines, particularly in the Western world. In the United Kingdom, approximately 1.3 million stroke victims now survive. In other words, around 1 in 53 people in the United Kingdom live with a stroke. The increase in stroke patient survival necessitates the assessment of health outcomes related to stroke prevention, treatment, and rehabilitation. Studies in HICs that have explored QOL indicate that outcome measures are crucial in identifying determinants of good and poor prognosis in patients with stroke. Jaracz et al. (2003) found that HRQOL was relatively good for patients with stroke compared to the control group. Despite ongoing physical disability, patients with stroke appeared to adjust well psychologically to their disability. In contrast, Clarke et al. (2002) demonstrated a multidimensional impairment across all HRQOL categories, except for autonomy and purpose of life. A similar study found that even after stroke survivors were thought to have recovered, their daily living activities and participation were continuously impaired by stroke (Lia et al., 2002; Owolabi et al., 2009). A stroke had a multifaceted impact on HRQOL in a Nigerian study, with the most evident effects in the physical, psychological, cognitive, and social interaction domains (Owolabi

et al., 2015). This emphasises the necessity of learning more about the factors that influence stroke survivors' HRQOL.

In modern medicine, the idea of health-related quality of life (HRQOL) is used as an essential indicator for monitoring outcomes. It is critical in assessing the complex impact of disease on a patient's life and in evaluating the disability associated with various health statuses (Owolabi et al., 2011). Assessment of HRQOL following stroke is becoming more prevalent, as it has been recognised that therapy evaluation should consider both quality and quantity (Ezejimofor et al., 2016). In addition, quality of life (QOL) studies has been beneficial in obtaining a better understanding of patients' reactions to sickness, strengthening supportive care, and determining the efficacy of treatment approaches (Mahesh et al., 2020).

HRQOL measures encompass emotional, physical, social, and subjective feelings of well-being. Hence, they can be used to identify and prioritise areas of need of individual patients and patients with special needs (Ezejimofor et al., 2016). HRQOL measurements can also assess the efficacy and cost-effectiveness of various preventative, therapeutic, and rehabilitative therapies, both old and new (Mahesh et al., 2020). The World Health Organisation (WHO) defines QOL as the 'individual's perception of their position in life in the context of the culture and value systems in which they live and concerning their goals. Recent global recommendations have stated that domain structures for QOL tools for LMICs should be context-specific (Yan et al., 2016; Ezejimofor et al., 2016). According to the WHOQOL Group (1995), "in addition to the physical, mental, and social aspects of QOL, there is now a recognition that spiritual and religious aspects are required to be included in health-related quality of life", which was not previously the case. Furthermore, epidemiological characteristics, living context, and expectations of stroke are prone to vary even within LMICs and HICs (Ezejimofor et al., 2016). The group has consequently urged the development of HRQOL tools to incorporate dimensions such as economic expenses, spirituality, and family concerns (Pietersma et al., 2013; Ezejimofor et al., 2016; Saladin, 2000).

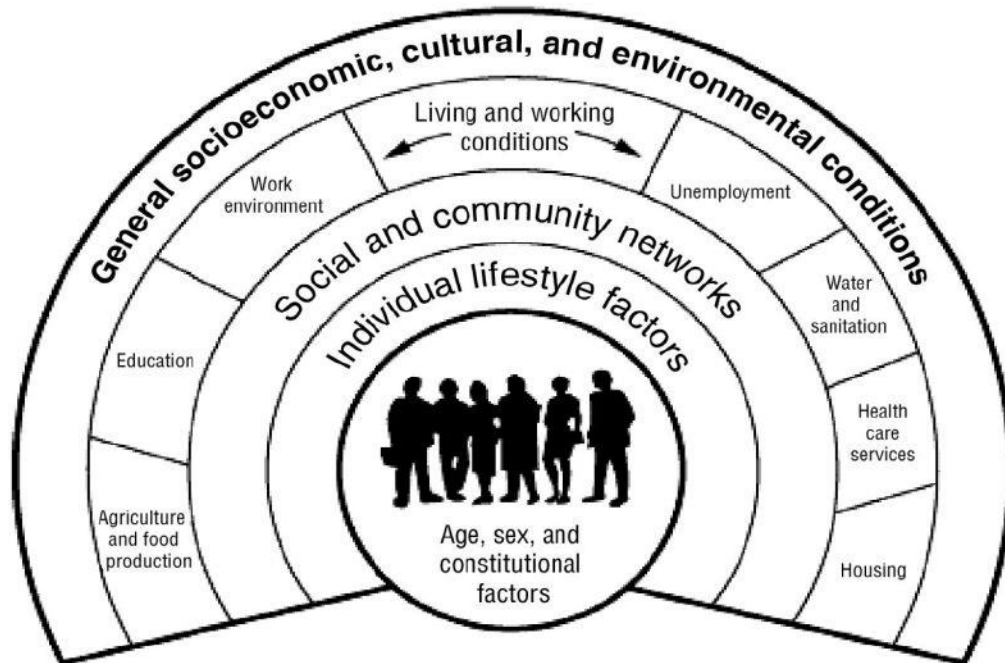
2.3.3 Social Determinants of Public Health

Social determinants are the social and economic conditions that influence the individual and group differences in health status (WHO, 2015). The environments in which people are born, grow, work, live, and age are the primary causes of chronic disorders and are referred to as social determinants.

These factors can affect a wide range of health and quality of life risks and outcomes. (WHO, 2015). Individuals under the age of 75 with three or more social determinants of health, such as unemployment, poor diet, and lack of exercise, are nearly 2.5 times more likely to have a stroke than those who do not have any of the factors (WHO, 2015).

To fully comprehend the social determinants of health inequalities within a country, it is necessary to make another conceptual leap and concentrate on the pathways and mechanisms by which the recognised health determinants in the model Dahlgren and Whitehead operate (2021). (See Figure 1). This model remains one of the most effective illustrations of health determinants and has had widespread impact in research on health, inequality, and influences. It is simply a model of visual representation of the concept of the main determinates of the health populations (Marmot et al., 2020)

Figure 1: Social Determinants of health



Source: Dahlgren and Whitehead (2021)

In this widely used socioeconomic "rainbow", the social determinants of health and potential policy interventions are arranged on five hierarchical levels. Dahlgren and Whitehead (1991) talked about the layers of influence on health. They map out the relationship with the individual, their environment, and chronic diseases. As seen in the above diagram the individuals are at the centre surrounded by influences of health. The model provides a perspective on the interconnectedness and interdependence of socio-economic, cultural environmental living and working conditions, social and community networks and lifestyle choices which contribute to a survivor's health and wellbeing (Katikireddi et al., 2020). This is similar in nature to a model that will be discussed in Chapter 4 (Biopsychosocial model) which aims to provide an interdisciplinary approach to an understanding of the key social, psychological, and biological factors that impact on health emphases. This continues to be in line with the research study's main question, "What is the impact of stroke on the QOL of stroke survivors in the SE communities of Nigeria?". The WHO (2003) defined health as a state of complete physical, mental, and social wellbeing and not the absence of disease. It is therefore obvious that determinants of health are three-fold, namely physical, psychological, and social factors (Alhassan et al., 2017). (To be discussed further in Chapter 4).

This model has many advantages and is useful because it broadens people's perspectives and encourages them to consider factors other than just health services, such as local environmental factors and societal factors. Professionals and policy makers working in diverse sectors have found this helpful (Marmot et al.,2020). It is also useful in the collaboration of people from different sectors of life to achieve a common goal in promoting health and reducing inequalities. For example, socio-economic and ethnic inequalities emerging with the Covid-19 pandemic. This evidence demonstrated that more disadvantaged groups in the UK have had greater exposure to Covid-19 because of the jobs they do, and overcrowded living conditions (Katikireddi et al., 2020).

The pandemic has raised public awareness of the country's substantial health inequities. As a result, the places where people live, work, learn, and play impact their health and are referred to as social determinants of health. Controlling and treating established stroke risk factors, such as hypertension and diabetes, may be especially critical for individuals whose life circumstances may help to exacerbate stroke risk, according to the REGARDS study. Therefore, it has been suggested that doctors devote special attention to patients with many socioeconomic health determinants (Evgeniya Reshetnyak, 2020).

Individuals are assigned to different social positions based on their social setting. Differential exposure and vulnerability to the risk or cause of sickness result from these social positions. As a result, the likelihood of surviving the condition is determined by risk exposure. Living with a particular disease has social and economic implications. While the social repercussions particularly concern the individual's exclusion from society, the economic effects are dependent on the severity of the illness's impairment and the society's environment and social policies (Evgeniya Reshetnyak, 2020). The social and economic implications may feed back into the etiological pathways, contributing to the disease progression in an individual or causing a drop in the individual's socioeconomic level. As stated above, the notion of health-related quality of life (HRQOL) will be used to illustrate the process by which social and economic implications feedback to the development of sickness in an individual or lower an individual's socioeconomic level (Evgeniya Reshetnyak, 2020).

Social determinants, however, include the availability of social services, employment and working conditions, income and wealth distribution, access to quality health care, and the ability to obtain a quality education. A recent study by Reshetnyak (2020) discloses the findings of a study that explores

the cumulative effect of social factors on individual stroke risk. According to the findings, having one social determinant of health raised stroke risk by 26%, having two increased it by 38%, and having three or more increased it by 51%.

2.3.4 Social determinants of public health in Sub – Saharan Africa (SSA)

Over and above education, training, and experience, health is a crucial component of human capital (Alhassan et al., 2017). Health is so important that it has been declared a fundamental human right in most of the UN member states (Sach et al., 2012). The health of the world's population has generally improved over the past fifty years, according to a review of the global health indicators. The world's life expectancy at birth increased from 53 years in 1960 to 65 and 70 years in 1987 and 2012, according to HDRs (1990) and (2013). According to the reports, in contrast, Sub-Saharan Africa (SSA) made little to no progress and had the worst health indicators up until this point of any other region (Alhassan et al., 2017). This is because the SSA's life expectancy at birth moved to only 54.9 years in 2012 from 40 and 46 in 1960 and 1975, respectively. This is like the reports revealed in Nigeria, where the nations' life expectancy, according to reports, is increased slightly to 52.3 years in 2012 from 40 and 46 in 1960 and 1975 respectively. As a result, even though Nigeria is known as the "Giant" of Africa, its citizens have poor health (Alhassan et al., 2017). However, given the breadth and depth of the nation's poverty, it is not surprising that the nation's health is in poor shape. The consequences of investments in health human capital are allegedly health disparities in health indicators (Alhassan et al., 2017). The developing world makes poor or minimal investments in health due to high levels of poverty, compared to the developed world's massive health investments (Sach et al., 2012).

As stated above, it is apparent that the primary factor that determines the health of the people is not the medical treatment or choice of lifestyle but the conditions the people are experiencing (Alhassan et al., 2017). This is in line with the aims and objectives of this research study concerning the lived experiences that stroke survivors in SE Nigeria have daily. Certain health behaviours such as smoking, drinking, poor nutrition, or lack of exercise can have a significant effect on a person's health, similarly a person's income, wealth, educational achievements, race and ethnicity, workplace and community can equally have a profound effect on health (Alhassan et al., 2017). This is discussed further in the research study when the quantitative and the qualitative findings are revealed.

There have been many empirical studies on social determinants of health in the world. However, studies in Nigeria concerning social determinants of health have been minimal. Those available have focused on maternal or children's health. Nevertheless, research by Imam and Koch (2004) and Ogunleye (2012) looked at 38–40 sub-Saharan African nations. According to Imam et al. (2004), education reforms and rising GDP per capita have an impact on mortality rates in the SSA, whereas Ogunleye (2012) discovered that, in SSA, all other variables and the availability of food and alcohol determined life expectancy, while urbanisation, carbon emissions, and alcohol consumption determined child mortality. Another study by Visser (2011) examined the environment determinants of children's health in Nigeria. The results revealed that sources of drinking water and sanitation facilities were the strong determinants of children's health in the country (Adewara et al., 2013). Ichoku and Nwosu (2011) examined the health inequalities among regions in Nigeria. It uncovered the realities of regional health inequality, with SE worse hit by the problem. However, Ichoku et al., (2011) found that the difference in wealth accounted for 58% and caused 33% of the differences in child nutritional and underweight status between the poor and non – poor in the county.

An investigation into the factors influencing health status in Nigeria was made by Alhassan et al. (2017) using Ilorin Metropolis of Kwara State as a case study. The study found that household age, access to safe and improved drinking water sources, and type of residence were all important health determinants. Based on the results, the authors suggested that interventions be made to improve the health status of ageing households through social protection, increase the population in rural areas with access to a source of safe drinking water, and encourage home ownership, especially in the country's poorer regions.

2.3.5 The Features of a Good HRQOL Measure for Stroke

The most currently utilised HRQOL tools were created in HIC and may not adequately reflect resource-constrained countries' features such as LMIC (Mahesh et al., 2020). Studies have highlighted that they do not consider factors such as environmental effects (user-friendliness and safety of household items), economic factors (e.g., financial security), spiritual well-being, and soul development (self-esteem, personal growth, and autonomy), even though they have been proved to affect overall QOL (Mahesh et al., 2020; Pietersma et al., 2013; Ezejimofor et al., 2016).

Studies have identified the differences between HICs and LMICs in the expectations of the people due to the difference in salary scales and standards of the household environment (Yan et al., 2016; Mahesh et al., 2020). Therefore, it is important to consider the social, spiritual, and economic impacts that arise from a stroke based on the current argument that it is necessary to provide high-quality rehabilitation programmes (Mahesh et al., 2020).

Concerning LMICs, stroke-related literature has been scarce. Hence, most of the evidence on stroke rehabilitation comes from Western settings and might not apply to LMICs such as Nigeria. Therefore, developing new HRQOL tools for stroke survivors would enable more context-related quality HRQOL measurement (Thrift et al., 2012; Yan et al., 2016; Pietersma et al., 2013). However, the selection of the HRQOL measure must be based on its psychometric attributes, which include feasibility, validity, reliability, and sensitivity to change (Daiva Rastenyte et al., 2006)

To select the most appropriate HRQOL instrument for the research project, the researcher had to become acquainted with the advantages and disadvantages of the various instruments (Saladin, 2000). Haan et al. (1993) state that the choice of suitable quality-of-life instrument should be based on not only psychometric properties but also careful considerations of the research questions, the relevance to the objectives of the study, the feasibility of the instrument, and the specific characteristics of the patients with a stroke under study.

Most instruments used to measure patients' QOL are generic. However, disease-specific tools are considered better than generic tools for being sensitive in picking up the changes in patients with stroke (Yan et al., 2016; Ezejimofor et al., 2016). Generic scales are not developed for a specific target population; they are often used with many patient populations. A major strength of these generic scales is the possibility of detecting the relative effects of disease and treatment on different life domains (Yan et al., 2016). They also allow for the comparison of QOL results across the patient population. However, a significant limitation is that they are not always sufficiently focused on the specific problems of any given patient population. Disease-specific scales exist for stroke. Such scales do not allow cross-disease comparisons but are often more sensitive to the QOL issues particularly relevant to a specific population of patients (Haan et al., 1993).

Out of the many health-related QOL tools, the two most common tools that could have been chosen for the study are the Short Form 36 (SF-36) Health Survey and the European Quality of Life 5-

dimensional (EQ-5D) tool (Mahesh et al., 2020). These tools have been validated for several disease conditions (including stroke), as validation is necessary to improve the effectiveness of rehabilitation. The European Quality of Life tool was created as a standardised generic scale used to evaluate patient health. EQ-5D consists of six items and covers six domains. It comprises a descriptive system and an EQ–visual analogue scale (VAS) for responders' self-rated health. SF-36 is a 36-item questionnaire completed by the patient. The item is grouped into eight domains which embrace an extensive range of physical activities and psychosocial cognition and include the evaluation of general health status. There are, however, several limitations to the generic scales. Instruments that are affected by 'ceiling effects' (many persons with a very high score for a specific test) and 'floor effects' (when the QOL scores are recorded as very low) lack the necessary sensitivity to distinguish among patients. There are also questions concerning the validity and reliability of the generic scales (Haan et al., 1993).

2.3.6 Review of Existing Health related quality of life in stroke patients (HRQOLISP) Measures for Stroke

The HRQOLISP, as stated above, is a standardised, robust health-related quality-of-life questionnaire for patients with stroke and validated by the WHO (2004). It was administered to each participant who met the inclusion criteria in the preferred locations that were geographically local to the participant. It is a measurement of the health status of individuals and can be used in identifying and prioritising areas of need of individual patients and patients with special needs. Often used in LMIC due to the sensitivity and compactibility of the items suggested (Owolabi et al., 2018). This outcome measure is also vital in determining the determinants of good and poor prognosis in patients with stroke (Obembe et al., 2013). It was first used in the second half of the twentieth century to assess QOL (WHO, 2001). The WHOQOL group 1993 defined quality of life as 'an individual's perception of their position in life in the context of the culture and value systems in which they live' (Obembe et al., 2013).

Prior to selecting this outcome measure (HRQOLISP), I considered a number of generic and stroke specific HRQOL measures for the study, but I wanted to record each stroke survivor's unique subjective perspective or voice of their stroke experience in a third-world setting. The HRQOLISP was thus considered to be a suitable instrument for the goals of this study. (See Chapters 1 and 5).

As stated earlier, the HRQOLISP is a 40-item outcome measure encompassing two dimensions and seven domains. The physical dimension includes the physical, psychological, cognitive/intellectual, and eco-social or ADL domains, while the spiritual dimension comprises the soul, spirit, and spiritual interaction domains. Scores for each domain were summed up and then stratified as severe, moderate, and mild strokes. The arithmetic mean of the various domain scores was calculated and compared at the subscale level. The questionnaires were completed by myself as the researcher and a researcher assistant (who signed an NDA) in line with the participant's choice for each item. This procedure lasted 30–45 mins.

In a nutshell, the empirical data collected in the quantitative phase (Phase 1) provided information used in the qualitative phase (Phase 2) to explore further participants' worldviews or beliefs about some of these domains. The seven domains in the HRQOLISP questionnaire were used as dependent variables in this study, while age, income, gender, stroke type, and physical impairment were used as independent variables. Pearson correlations, independent t-tests, one-way analysis of variance (ANOVA), and multiple regression were utilised to establish associations between these variables to address the study's research questions. (As discussed further in Chapter 5).

2.3.7 Validity, Reliability, Responsiveness, Appropriateness, and Acceptability

Stroke-specific measures are essential to determine the profile of HRQOL in the Nigerian's SE population who had a stroke (Garrat et al., 2020). An ideal stroke specific HRQOL standard must be rigorous, valued, reliable, patient centred, responsive, precise, acceptable, and appropriate and must cover all measurable domains of life and functioning (Garrat et al., 2020). These scales are more valid, patient centred, and suitable for accessing HRQOL in specific diseases and populations (Yan et al., 2016). In addition, they are more responsive than generic measures because they assess domains of particular interest to the persons with the condition, whereby small changes may be more easily detected.

Following the WHOQOL guidelines (Orley et al., 1993), Owolabi et al. (2011) developed a stroke specific HRQOL questionnaire for patients with stroke in Nigeria (LMIC). Studies have argued that investigating HRQOL in stroke without an integrative approach is misleading (Owolabi et al., 2011). This new measure was developed to address the lack of a gold standard measure that specifically targets stroke survivors in Nigeria / Africa. It was established specifically for LMIC's to identify and

prioritise areas of need for stroke victims in developing nations, as well as to solve the shortcomings of existing procedures (Owolabi et al., 2011). As a result, the HRQOLISP was selected for the study.

The HRQOLISP is a holistic, multiculturally validated measure based on an integrative concept of human life (Owolabi et al., 2011) (discussed in detail in Chapter 5). It consists of 102 items in seven domains. It is stroke-specific, patient-centred, and known to be more valid, reliable, and responsive than generic measures. The measure exhibits good face, content, construct convergent, and discriminant validity, with internal consistency and reliability (Owolabi et al., 2011). Unlike traditional depression scales, the full spectrum is captured by the psychological domain of the HRQOLISP. It is also more valid than the SF-23, which has poor validity in the social domain. Furthermore, HRQOLISP exhibits good discriminant validity in all domains except soul, spirit, and spiritual interaction. As mentioned earlier, regarding the absence of floor and ceiling effects, the HRQOLISP has improved its validity. The measure can assess the worst and best health state possible and detect minor improvements and determinants.

2.4 Risk Factors for Stroke (HIC and LMICs)

Stroke prevention is of utmost importance in sub-Saharan Africa (Feigin et al., 2013; O'Donnell et al., 2016). Stroke incidences continue to rise globally – particularly in LMICs, such as Nigeria (where it remains a leading cause of morbidity and mortality) (Owolabi et al., 2018). A wide range of stroke risk factors have been found through epidemiological studies and are essential for both primary and secondary stroke prevention. There are two types of risk factors: modifiable and non-modifiable. The modifiable risk factors include hypertension, diabetes mellitus, high blood cholesterol, obesity, cardiovascular disease, sedentary lifestyle, smoking, and alcohol consumption (O'Donnell et al., 2016; Feigin et al., 2013; Lopez et al., 2006). The nonmodifiable risk factors are relatively few and include age, gender, and genetics (O'Donnell et al., 2016; Feigin et al., 2013).

2.4.1 Non-modifiable Risk Factors

Age is the most vital determinant of stroke, and the risk of stroke doubles every decade above the age of 55 (Caplan, 2000; Lopez et al., 2006). However, in sub-Saharan Africa (SSA), most stroke cases occur in people less than 60 years old, whereas in developed countries, stroke usually affects much older people around 70–75 years (Feigin et al., 2013). (Discussed further in Chapter 3).

However, in an alarming trend, strokes in people aged 20–54 increased from 12.9% to 18.6% of all

cases globally between 1990 and 2016 (Diji et al., 2020). Nevertheless, age-standardised attributable death rates decreased by 36% over the same period (Kuriakose et al., 2020).

Gender, race, and ethnicity have all been linked to increased stroke risk, especially in men, Blacks, and Hispanics. In certain cultures, this is said to be a major cause of death for unknown reasons.

Wang (2013) reported that Black people are twice as likely to have a stroke as White people.

Furthermore, Blacks have a higher risk of cerebral atherosclerosis (Wang et al., 2013).

2.4.2 Modifiable Risk Factors

Hypertension is the most vital risk factor after age, and people with hypertension are about three or four times more likely to have a stroke (Feigin et al., 2016; Owolabi et al., 2015; Gbiri et al., 2012; Ezejimofor et al., 2017). The strong association between hypertension and stroke has been attributed to the powerful effects of hypertension on cerebral circulation (Connor et al., 2009). In cerebral blood vessels, hypertension produces hypertrophy and causes a reduction in the external blood vessels. In addition, a previous stroke can significantly elevate the risk of a subsequent stroke, with a recurrence rate of 5%–25% in one year and 20%–40% in five years (O'Donnell et al., 2010). In a comparative study of stroke risk factors among stroke survivors in Nigeria and Germany, it was observed that smoking, atrial fibrillation, congestive cardiac failure, ischaemic heart disease, and atherosclerosis of the carotids were significantly more common among the German stroke survivors (Owolabi et al., 2015), while hypertension was significantly more common among the Nigeria stroke survivors (Owolabi et al., 2015; Gbiri et al., 2012; Ezejimofor et al., 2017). A study in the UK showed that large vessel atherosclerotic stroke is more common in the White population than in the Black population (Smith et al., 2015; Markus et al., 2007). The interaction of genetic, environmental, nutritional, and socioeconomic determinants has been indicated as the cause of racial differences in stroke risk factors, which has consequences for the distribution of stroke subtypes; while haemorrhagic stroke appears to be more associated with hypertension, ischaemic stroke is more related to factors such as smoking, cardiac disease, and atherosclerosis (Smith et al., 2015). The prevalence of ischaemic stroke in Western populations is due to the widespread occurrence of the latter category of risk factors among White people. Because many African countries have adopted the Western way of life, it is projected that the distribution of stroke risk factors and subtypes in Africa will resemble that of the Western world (Markus et al., 2007; Smith et al., 2015).

Data from the INTERSTROKE study, the most extensive global case-control study on stroke, indicates that five-stroke risk factors – hypertension, current smoking, obesity, a lack of physical activity, and diet – are responsible for more than 80% of all strokes (O'Donnell et al., 2016; Feigin et al., 2013). The Global Burden of Disease study (Feigin et al., 2016) shows global risk factors variations for stroke. The INTERSTROKE study explored risk factors for stroke among Africans using a meta-analysis of the small amount of data available. Still, it revealed no significant association between stroke and important risk factors such as diabetes, cigarette smoking, physical inactivity, and diet. This may have been due to the small number of Africans represented (Owolabi et al., 2018). The prevalence of hypertension in Nigeria is high, and the country's overall awareness of raised blood pressure amongst hypertension cases is low (Adeloye D., 2015). It is estimated that there were about 20.8 million cases of hypertension in Nigeria among people aged 20 years and above in 2010, with a prevalence of 28.0% (24.6%, 31.9%) in both sexes. It has been predicted that, by 2030, there will be an increase of 31.1 million cases of hypertension among people aged at least 20 years old and above, with a prevalence of 30.8% (24.5, 33.7) in both sexes.

2.5 Stroke Rehabilitation – Globally

The British Society of Rehabilitation Medicine defines rehabilitation as a process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimum physical, psychological, and social function (Bernhardt et al., 2017). A stroke can long-term affect the patient's body function, activity, and participation (Lindsay et al., 2014). Therefore, in the absence of any therapy, rehabilitation constitutes the primary mode of therapy to improve the quality of life following a stroke (Bernhardt et al., 2017). The WHO describes rehabilitation as a restorative process that enables people with impairments and activity limitations to attain and maintain optimal function in various domains (WHO, 2001). The World Stroke Organisation recommends that, after a stroke, patients should have access to rehabilitation specialists, including physiotherapists and occupational, speech, and language therapists (Lindsay et al., 2014). However, in lower-resourced environments, developing and delivering rehabilitation services to patients after a stroke is a considerable challenge (Bernhardt et al., 2017) (to be discussed further).

Stroke is now the fourth-leading cause of loss of DALYs (Bernhardt et al., 2017). This increase in stroke survivors potentially living with disabilities burdens survivors' families, the community, and the healthcare system (Bernhardt et al., 2017). Because of the substantial costs and their impact on

society, much attention is paid to preventing stroke worldwide. Moreover, studies have demonstrated that moderate-to-high levels of physical activity are associated with a reduced risk of strokes. Foley et al.'s (2008) review of numerous trials that investigated how stroke therapy/rehabilitation affected patients in long-term facilities revealed that offering stroke therapy / physical rehabilitation might be safe and might increase independence.

Mixed cardiorespiratory and strength training and circuit-class training (English et al., 2010) have improved physical fitness and mobility for patients with moderate stroke. High-intensity therapy, repetitive task practice, and electromechanical gait training have all been found to have positive outcomes. However, uncertain benefits have been noted for rhythmic auditory stimulation of gait and leg strengthening programmes (French et al., 2007). Nevertheless, the conclusions of these reviews could be overturned by a relatively small number of neutral studies. Although body weight-supported treadmill training has shown uncertain benefits, overground–walking training for a patient with mobility deficits and speed-dependent treadmill training as a form of physical fitness training might improve aspects of gait (West et al., 2008).

Stroke rehabilitation is most often delivered by a multidisciplinary team and is defined by the WHO (2001) to encompass the coordinated delivery of interventions provided by two or more disciplines in conjunction with medical professionals (Walker et al., 2017). Furthermore, the team aims to improve patient symptoms and maximise functional independence and participation using a holistic biopsychosocial model as defined by the ICF (WHO, 2001) (to be discussed further in the chapter).

However, other factors contributing to low functional outcomes include the experience of social integration after a stroke. Kwok et al. (2006), in a one-year follow-up of 303 stroke survivors, found that, overall, only 46% of participants achieved independence in all basic ADLs and had a maximum BI score of 20. The researchers measured the participants' functional status at two points– 3 and 12 months –and found that recovery improved with time; survivors had increased (0–1) Barthel scores. Similarly, among the 680 patients in Anderson et al.'s (2004) study, 52 had survived 21 years after their stroke. Of these, only 12% were institutionalised, and 19% required minimal help with their ADLs. It was concluded that one of the long-term effects of stroke is that as stroke survivors get older, the effects of the stroke lead to a further reduction in function.

Pan and Kwok (2008), using the modified Barthel Index and the WHO Health-Related Quality of Life (HRQOL) questionnaire, interviewed 247 stroke survivors at 3, 6, and 12 months and found that HRQOL was independently related to active daily living (ADL) and depression. Young et al. (2002) qualitatively examined physical functioning after stroke and mapped out how individuals readjusted their worldviews and physical place within them to achieve a sense of autonomy. Stroke survivors tend to adjust to their disabilities and impairments to maintain some sense of well-being poststroke (Clarke et al., 2009). These studies provide a narrated interpretative voice to the frustration elicited by an inability to perform certain functions. They also use these feelings to map the path of frustration onto the despair of never being able to regain such functional abilities.

These studies reviewed above collectively outline the crucial interplay between functional abilities, social support, psychological well-being, and depression. Focusing on functional skills and the recovery process, they show that this interaction is crucial in determining the quality of life-related to health. What they fail to demonstrate is how it feels from the patient's perspective. They conclude that functional status and well-being are not necessarily associated since a participant's capacity for doing a task is regarded equally to their ability to do so. Kwakkel et al. (2015), who has revealed that functional recovery is not necessarily an indicator of well-being, stated that the challenge is to identify the other contributing factors and understand them from a survivor's perspective.

2.5.1 Stroke Recovery

This refers to improvements that occur suddenly or during the early stages of recovery when the brain rapidly attempts to heal from its injury (Kwakkel et al., 2015). This is also related to the severity of the stroke. The motor system has been the focus of research on stroke recovery. However, understanding the processes that underpin how recovery is achieved during stroke rehabilitation is of utmost importance (Kwakkel et al., 2015; Duff et al., 2013). An understanding that distinguishes between behavioural restitution and the use of compensation strategies will further direct how patients with stroke are trained to regain the ability to complete meaningful tasks and how interventions should be designed (Kwakkel et al., 2015).

Several systematic reviews have explored whether high-intensity therapy improves recovery (English et al., 2010; French et al., 2007; West et al., 2008). The idea that more intensive training is beneficial is widely recognized, even though there are no clear standards for the ideal levels of practice.

However, an agreement is widespread that rehabilitation should begin as soon as possible after a stroke (Kwakkel et al., 2015). In addition, recovery can continue for months or years after a stroke – well beyond the formal rehabilitation period (English et al., 2010).

The location and magnitude of the initial stroke lesion, as well as the extent of the subsequent healing, affect the long-term effects of stroke. Recovery is a complex process that probably occurs through a combination of spontaneous and learning-dependent processes, such as restoration of the functionality of damaged neural tissues, substitution, reorganisation of partly spared neural pathways to relearn lost functions and compensation, and improvement of the disparity between the impaired skills of a patient and the demands of their environment (French et al., 2007; Kwakkel et al., 2015).

2.5.2 Timeline of Stroke Recovery

A challenge for stroke rehabilitation is determining the optimal timing to implement interventions focused on recovery and repair (Kwakkel et al., 2015; Duff et al., 2013). However, the possibility for behavioural changes even years poststroke is recognised. The current understanding, however, of brain repair processes suggests that most of the behavioural recovery and the rapid changes occur in the first weeks to months poststroke for most people. This time perspective represents an important treatment target to maximise the potential of restorative interventions (Kwakkel et al., 2015). Conversely, several cohort studies have suggested that recovery of body functions and activities is predictable in the first few days after a stroke (Byblow et al., 2015).

2.5.3 Compensation

Compensation is defined as a person's ability to accomplish a goal through substitution with a new approach rather than using their standard pre stroke behaviour repertoire (Byblow et al., 2015). This behaviour does not require neural repair but may necessitate learning. Compensation may be seen in all functional domains. In the motor domain, compensation strategies employ intact muscles, joints, and effectors in the affected limb to accomplish the desired task or goal (Bernhardt et al., 2017). Researchers commonly test interventions that promote compensation rather than behavioural restitution to improve a patient's safety and quality of life.

2.5.4 Rehabilitation in Africa

Stroke is a disease that has tremendous global health, financial, and economic consequences (mainly in terms of rehabilitation expenditures), especially in LMICs. In African countries with low incomes,

these enormous costs can cause severe economic damage to both the individual and the nation (Hamza et al., 2014). Olaniyan et al. (2015) reviewed the costs associated with stroke in LMICs and found that the highest mean direct medical cost was \$8,424 in Nigeria, while the lowest was \$416 in Senegal. However, the best intervention process for managing stroke survivors is still fraught with controversies, mainly as they concern the economic impacts of such interventions (Olaniyan et al., 2015). Despite this, many previous studies have failed to provide information about which treatments are the most efficient in reducing the overall disease burden in Nigeria (Owolabi et al., 2014; Olaniyan et al., 2015). Stroke has recently become one of the leading health conditions accounting for disability and mortality in the country, and studies have reported that the poststroke survival rate is anticipated to increase in HIC due to better treatment and management. Hence, the importance of organising rehabilitation programmes for stroke survivors in the most effective way to enhance their QOL (Hamza et al., 2014)

In the past decade, there have been extraordinary medical advances in stroke treatments. While many may not survive stroke events, a growing proportion will and would still require clinical management. Many people survive stroke because of modern technology, while most still live with impairment, disability, or handicap. Rehabilitation reduces disability and maximises the functional ability of stroke survivors with disabilities (Hamza et al., 2014). Research has indicated that multidisciplinary early and intensive rehabilitation significantly reduces disability (Kaur et al., 2014). Rehabilitation can restore function and prevent permanent disability in patients with stroke (Owolabi et al., 2014). Ultimately, the main goal of stroke interventions is to improve the health-related quality of life (HRQOL) of stroke survivors, ensuring that they are enabled to fulfil their roles and purpose in life after the event (Hamza et al., 2014; Owolabi et al., 2014). Unfortunately, there is an urgent need for improvements in access to rehabilitation for people with stroke in LMICs. In a study examining only physical rehabilitation needs using Global Burden of Disease study data from 2017, years lived with disability data for neurological diseases, including stroke, were proportional to a country's income. The most significant increase in physical rehabilitation needs was found in low-income countries with the most minor rehabilitation infrastructure (Jesus et al., 2017). The WHO estimates that 75% of years lived with disability are linked to health conditions for which rehabilitation is beneficial (Bernhardt et al., 2017; Jesus et al., 2017). Studies have highlighted that the proportion of people with stroke who access rehabilitation is deficient in LMICs compared to in HICs and that access is mainly confined to

the acute period within seven days of stroke (Hamza et al., 2014). Poor or reduced access to rehabilitation services in LMICs can be due to several issues, including the absence of rehabilitation centres in the poor parts of the country, too few dedicated hospitals' stroke units, an insufficiently skilled workforce, cost implications, poor infrastructure, and poor health care services.

The above discourse highlights once again the urgent need for further investigation and research into the impact of stroke on the quality of life of the survivors in LMIC such as SE Nigeria (Akinyemi et al., 2009), as this aims to address the gaps identified in the literature, as stated above.

Issues concerning traditional medicine are still rampant in Nigeria, with misleading cultural beliefs about stroke and the historical use and availability of traditional medicine (Khan et al., 2018). However, Socker et al.'s study (2017) reported that some of the participants suggested rituals and faith-aided recovery after stroke, citing it as a positive influence. The participants reported that spiritual rituals and prayers improved their health function (Soeker., 2017). However, in a quantitative analysis of the influence of religious faith on life satisfaction, Omu, Al-Obaidi, and Reynolds (2012) reported that religious faith does not influence the life satisfaction or self-efficacy of patients with stroke. Dalvandi, Ekman Maddah, and Heikkila (2013), however, reported contradictory findings from their qualitative inquiry and found that participants in their study felt that faith in God assisted them in coping with their emotions and helped improve self-efficacy. (This is discussed further in the Chapter 3).

2.6 Summary of Chapter

The objective of stroke rehabilitation is to enable individual patients to achieve their full potential and maximise the benefits of training to attain the highest possible physical and psychological performance (Peppen et al., 2004). In addition, the goal for many patients with stroke is to achieve a level of functional independence necessary to integrate as fully as possible into community life. Therefore, clinicians are challenged to reliably predict, at an early poststroke stage, the degree of disability the patient will ultimately experience to facilitate optimum stroke rehabilitation. Nevertheless, a gap remains between prognostic research and rehabilitation practice. Therefore, therapists need to formulate their functional goals as precisely as possible. This requires adequate knowledge of the patient and disease characteristics that determine functional outcomes (Kwakkel et al., 2004). As the

body of knowledge regarding stroke recovery and rehabilitation expands globally, more interventions will be developed to achieve genuine rather than compensatory recovery.

This research aims to identify variables that predict the impact of stroke on the quality of life of stroke survivors in SE Nigeria (using the outcome measure, the health-related quality of life in stroke patients – HRQOLISP) and to explore the perceptions, attitudes, knowledge, cultural approaches, and beliefs of stroke survivors in the SE communities. The quantitative findings embrace descriptive analysis of the HRQOLISP questionnaire, whereas the qualitative findings are presented in the form of a narrative interrogation of the impact of stroke on the QOL of stroke survivors generated via in-depth semi-structured interviews.

However, whilst there is a wealth of studies on the QOL of stroke survivors in the HIC countries among stroke survivors (Akinpelu et al., 2009; Akosile et al., 2013), in LMIC such as Nigeria / SE there are still very few studies which have used a mixed method approach. A review by Badaru (2015) in Ibadan, Nigeria, identified 1 (7.1%) study in the SE region of the country. However, there is no study that has used a mixed approach using an Interpretative Phenomenological Analysis (IPA) (Discussed in Chapter 5). Owing to the increasing numbers of stroke survivors in the country, it is imperative that the factors affecting HRQOL in stroke survivors are identified and modulated (Vincent-Onabajo et al., 2018). That is exactly the purpose of this research study. Hence, the need for the study, as it identifies and discusses the gaps in the literature concerning the impact of stroke on the quality of stroke survivors in the SE countries of Nigeria from the survivor's perspective.

Consequently, the overarching aim of the research is not just to explore the impact of stroke on QOL but also to understand the experience of living with stroke, in the Nigeria's low socioeconomic rural and urban populations.

A review of the context of Nigeria and the community in the Southern East is provided in the next chapter which investigates how colonisation affected a nation while considering a number of postcolonial explanations. This contextualises the study broadly and effectively by describing the Nigerian healthcare system using historical analysis.

CHAPTER THREE

Post coloniality: A Review of the Literature

3.1 Introduction

The preceding chapter situated the study in the context of previous research on the impact of stroke upon the QOL of stroke survivors in Nigeria's SE communities. It laid the groundwork for critically analysing data as well as justifying and identifying gaps in the literature relevant to the research study.

This chapter, however, continues in that light and gives a context of Nigeria and the Southern East communities. It looks at post – coloniality as there is a direct relationship between post – coloniality and the biopsychosocial model (a model which looks at the biology, psychology, and socio – environmental factors) in relation to quality of life and disease (Sumuthkochorns et al., 2013).

(Discussed further in Chapter 4). The section explores the impact of colonization on a country and discusses a dependency syndrome which alludes to a biomedical model (discussed in detail in Chapter 4). Additionally, it considers a variety of postcolonial explanations to contextualise broadly and effectively by explaining the Nigerian health care system through an historic analysis.

This chapter also examines the Nigerian / Biafran War (1967 – 1970) and its impact. This involves the Igbos (Southeast individuals), who were subjected to a tactic of hunger. It analyses how this impacted the first generation of post-war children who suffered from malnutrition. (The majority of participants in this research study were affected in this way).

The chapter discusses the link between Post – Coloniality and the consequences of child malnutrition during wartime. A review has been undertaken of Mr Chinua Achebe's (1930-2013) work, a popular author who emphasises the impact of post-colonialization and the effects of the Biafran war on indigenous peoples in SE communities in terms of health and wellbeing. Recent research has demonstrated how these behaviours might negatively impact adult lives and predispose people to chronic and noncommunicable diseases, such as hypertension, diabetes, and stroke conditions later in life as seen in the current research study (Aliasghari et al., 2019; Gomes et al., 2016; Paquereau et al., 2014). Phase 2 focuses on the study's narratives.

3.2 History of Colonialism in Africa / Nigeria – A Historical Perspective

Colonization is the process by which a more powerful nation seizes control of another nation, settles it, seizes political control of the territory, and exploits its resources for its own gain. Postcolonialism is the historical period representing the impacts of western colonialism (Hecrten et al., 2014). It concerns formerly colonised countries, such as Africa (James et al., 2010). It addresses the problems and consequences of the decolonisation of a country, especially relating to the political and cultural independence of formerly subjugated people (Hecrten et al., 2014).

In Nigeria, colonialism started in 1914, and is described as 'control by one power over a dependent area or people' and had a huge impact on the lives of Africans (James et al., 2010). Economic policies were adopted by Europeans who demolished the colonies. European colonialism in Africa had intentions to bring a positive impact – such as religion, which can be used as a spiritual basis for African children (James et al., 2010; Hecrten et al., 2014). Colonial powers introduced Western schools and health care, a resource that often had a positive effect on the lives of the colonised people. However, Africa was distraught economically, politically, and culturally. Africans' traditional lifestyles and cultures were demolished (Onumah et al., 2017; Philips et al., 2018). The goal of postcolonialism was to account for and combat the residual effects of colonialism on culture. In the sixteenth and eighteenth centuries – the precolonial period – Nigeria was dominated by several West African kingdoms, such as the Oyo Empire, the Islamic Kanem–Bornu Empire in the Northeast, and the Igbo (Southeast) Kingdom.

Nigeria was colonised for over 40 years. The conquest of Sokoto was the final act in settling the boundaries of the British protectorates of Northern and Southern Nigeria. In 1914, both protectorates were amalgamated into a single Nigeria (Philips et al., 2018; James et al., 2010).

Nigeria, as a post-colonial country, inherited the biopsychosocial model, which informs how the health care system operates. However, as evidenced by the literature review, a gap remains because this does not address the current situation among QOL of the stroke survivors in the SE communities.

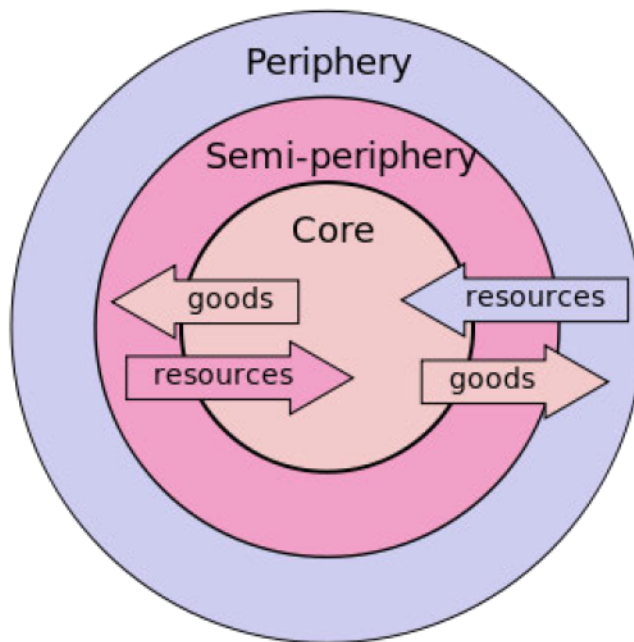
3.2.1 The Impact of Colonialism on a Country

When the British colonised Nigeria, they had the backing of their armed forces, but they governed by enticing a portion of Nigerian society to support the system they installed (Philips et al., 2018). The system had three primary tools.

1. The Christian church
2. Schools that taught a British curriculum
3. The English language

Nigerians who accessed these three systems of knowledge gained access to lucrative administrative roles within the colonial system, while those who did not became increasingly disadvantaged due to their isolation from the British system (Tarantola et al., 2018). However, there was a strong hold on their belief systems – see below.

Figure 2: Dependency Theory



Andre Gunder Frank (2016)

The dependency theory is the belief that resources flow from a 'periphery' of poor and underdeveloped states to a 'core' of wealthy states, enriching the latter at the expense of the former. One of the legacies of colonialism is the dependency syndrome (a theory developed in the late 50s). (Birchnell et al., 1984). (See Figure 1 above). This can be defined as a historical condition that shapes a certain structure of the world economy in such a way that it favours some countries at the expense of others and limits the country's development (Clemens et al., 2010). Colonial powers often used tactics of employing natives to run local government on behalf of the colonial power, rewarding them with money and status for keeping the peace (Gunder et al., 2011). It is argued that such policies enhanced divisions amongst the community groups (Clemens et al., 2010). Other African countries illustrated the 'exploit and extract' mentality the colonial powers had towards their colonies.

Gunder (1971) argued that developing nations have failed to develop not because of 'internal barriers to development' but because the developed west has systematically underdeveloped them, keeping them in a state of dependency. It is also a form of mindset and control, choices of lifestyle which are associated with the biomedical model. A dependency approach 'Doctor tells me what to do attitude' (This will be discussed further in the Chapter 4). This unequal relationship between the colonist and the indigenous populations can lead to immense anxiety, feelings of inadequacy and the need for support (Gunder et al., 2011). Studies have linked dependency with depression or low mood which affects QOL. It is therefore evident that there is a relationship between post – coloniality and the biopsychosocial model, in that the psychological, emotional, and environmental factors impact on an individual's health and wellbeing. Conversely, in alignment with part of the outcomes of this research study, 'the impact of stroke on the quality of life of stroke survivors' (see research findings in Chapter 7) this highlights the importance of the embodied self (self-esteem and self-identity) and its reconstruction that enhances QOL.

3.3 The Biafran War – Historical Review

Following seven years of uneasy peace, the Nigerian / Biafran War broke out in 1967 (James et al., 2010). The war was a culmination of ethnic, economic, and religious tensions among the various peoples of Nigeria (Philips et al., 2018). The Northern armies of the ruling power advanced into Biafra and pushed the Biafrans into a small enclave where food inflows were cut off (Miller et al., 1970; James et al., 2010; Onumah et al., 2018). The result was extensive famine among the Igbos and other minority Biafran ethnicities (Miller et al., 1970).

Biafra's quest to become independent from the Nigeria Federation was directly supported by an odd assembly of six countries that had formally recognised the Republic of Biafra (Philips et al., 2018; Onumah et al., 2017). The Nigerian military formed a blockage around the nation's newly independent Southeast region (Tarantola et al., 2018). It was stated that the Nigerian government ended up directing its military to attack the relief action, which inevitably contributed to the famine that occurred for the Biafrans (Philips et al., 2018). The civil war caused an estimated one million civilian deaths, mostly comprising starving children and the elderly (Hecrten et al., 2014; Onumah et al., 2017). It was the first modern war in sub-Saharan Africa after the independence and one of the bloodiest.

Throughout the conflict, federal aircraft shelled towns and other targets on Biafran territory, frequently inflicting numerous civilian casualties (Onumah et al., 2017; Philips et al., 2018). The postwar result

was extensive famine among the Igbos; this was regarded as one of the great nutritional disasters of modern times. About one to three million Igbos were estimated to have lost their lives. Only a small fraction (10%) died due to military violence (Philips et al., 2018); most succumbed to starvation. The nutritional emergency was most critical in the Biafran enclaves, in which approximately seven million people, mostly refugees, resided (Quayson et al., 2000). [See Figure 2]

Despite Nigeria's effort to suppress reports about such events, the deepening humanitarian crisis of the Biafran populations thrust the conflict into the international spotlight (Quayson et al., 2000). The war was the first postcolonial conflict to engender a transnational wave of humanitarian concern (Sullivan et al., 1967).

3.3.1. Biafra at 50 years on and the Birth of Emergency Public Health

Nigeria was created as a unified territory in 1914 through the amalgamation of Britain's colonial possessions in the region (Philips et al., 2018). After its independence in 1960, Nigeria was widely considered one of sub-Saharan Africa's most promising postcolonial states (Zachernuk et al., 1994). Nigeria was comprised of several separate tribes before colonisation. The different tribes had not only different indigenous beliefs but also had different experiences with colonisation, as the British favoured some groups over others (Onumah et al., 2017). However, Nigerian writers were able to appeal to a large audience by showing the paradoxes that resulted from the most common elements of colonisation (James et al., 2010). For example, Chinua Achebe's *Things Fall Apart* (1958) (to be discussed further in section 3.4.1) questions the colonial assumption that Nigeria was wild and ungoverned before colonisation. He painted a story of a functional society that was torn apart by the introduction of the colonisers, tools of religion, language, and education. His work remains intentionally self-reflective and highlights some of the cruel aspects of Igbo culture (James et al., 2010).

Established as a federal state, postcolonial Nigeria was split into three main regions, each dominated by one or two ethnic groups: Hausa–Fulani in the North, Yorubas in the West, and Igbos in the East (Quayson et al., 2000). The Southeast was predominantly Christian, whereas the North was widely Islamic dominated. When the British unified the tribes, there was no common language, religion, or culture. When Nigeria won its independence from the British in 1960, the country was still divided by ethnic distrust.

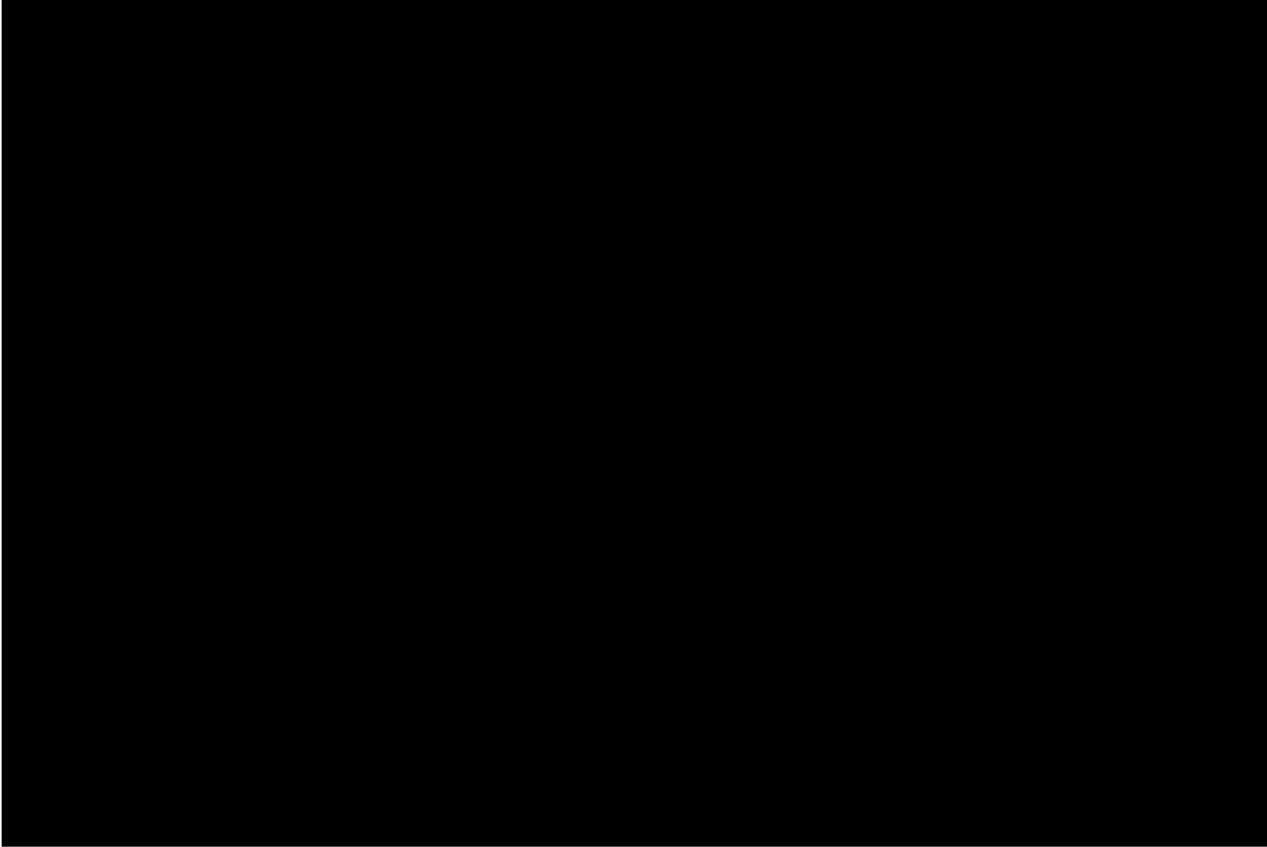


Figure 3: Ethnic groups in Nigeria (2016)

3.4 The Impact of the Nigerian / Biafran War

The underlying causes of the Nigerian war are complex; however, the Biafra war is ranked as one of the greatest nutritional disasters of modern times.

3.4.1 The Post Coloniality and the consequences on the mindset of individuals

Chinua Achebe (1930–2013), a well-known postcolonial writer of the novel *Things Fall Apart*, presents the mind sets of the indigenes within the novel on post colonialism. It portrays 160 tribal lives before the coming of the British towards the end of the nineteenth century. His novel gained global attention in the late 1950s as it focused on the traditions of Igbo society, the effect of Christian influences, and the clash of Western and traditional African values during and after the colonial era. His style of writing relies on the Igbo oral tradition, which combines narration with representations of folk stories, proverbs, and oratory (Sumuthkochorns et al., 2013).

The main character of the novel, Mr. Okonkwo, is exposed to change and desperately tries to hold onto the traditional values and practices of his Igbo society. However, he does so during an alien European invasion which ultimately disintegrates this traditional African society (Sumuthkochorns et al., 2013). Before the writing of his novel, Achebe had become disturbed by the works of European

writers that portrayed Africans as noble savages. According to Willene Taylor (1998), these writers believed that colonialism was an agent of enlightenment to primitive people without a valid value system or civilisation of their own (Sickels et al., 2011). Africa was pictured as the 'Dark Continent' inhabited by childlike, superstitious, and fearful people only too ready to welcome and worship the White man. Achebe was particularly disturbed by Joseph Conrad's *Heart of Darkness*. He felt that Conrad painted an inaccurate and demeaning picture of African people. It was the kind of image that fed the whole myth of White superiority.

As a postcolonial writer, Achebe's mission in the novel was to present a composite picture of traditional African society sealed off from any influences of Western civilisation (Sumuthkochorns et al., 2013). The primary purpose of the novel was to present a precolonial past free of the distortions and stereotypes imposed in European accounts (Sumuthkochorn et al., 2013). The African experience in the novel, represented by the Igbo ethos of communal living, is brought into full focus by the author. It also highlights the fact that the novel is a classic study of cross-cultural misunderstanding and the consequences to the rest of humanity when a belligerent culture takes it upon itself to invade another culture or civilisation out of ethnocentrism (Sumuthkochorn et al., 2013). In *Things Fall Apart*, the Western culture is portrayed as being arrogant and ethnocentric, insisting that the African culture needs a leader (Sickels et al., 2011). As it had no kings or chiefs, Umuofia culture was vulnerable to invasion by Western civilisation. It felt that the repression of the Igbo language at the end of the novel contributed greatly to the destruction of the culture (Sickels et al., 2011). This was part of the legacy of Colonialism. However, in terms of medical health and well-being, the practice of a medical model was prevalent during this era, as disability is viewed as a medical condition in the medical model, and, as such, doctors are the specialists who treat and eliminate both the symptoms and the illness (McTigue et al., 2015).

However, according to this viewpoint, disability explains the limited functioning perceived as a deficiency due to body impairment (body function, structure, and mind) (Haegele and Hodge et al., 2016). As a result, the medical model holds that people are considered disabled because they are unable to function as 'normal' people do; this is critical because how disability is defined and viewed influences people's perceptions, expectations, and behaviours toward people with disabilities (Brandon & Pritchard et al., 2011). Unfortunately, the mindset, attitudes, and beliefs of the health

professionals in the country remain firmly entrenched at this level (Haegele and Hodge et al., 2016). This will be further discussed in Chapter Four.

3.5 Exposure to Famine in Early Life



Figure 4: MALNOURISHED BIAFRAN CHILDREN (ONUMAH ET AL., 2017)

For the first time, the massive impact of warfare on a civilian population could be witnessed on television worldwide. Tarantola et al. (2018) reported that the media displayed images of starving and dying children who were bloated with kwashiorkor (a form of malnutrition caused by protein deficiency in the diet, typically affecting young children), (see Figure 3), while others were barely surviving with nutritional marasmus (undernourishment causing a child's weight to be significantly low for their age) and were referred to as 'Shrimp' babies. In the summer of 1968, the globe witnessed the emergence of a new 'third world': the 'Biafran babies' – starving children in the secessionist Republic of Biafra (Waters et al., 2002). This kind of tragedy was new to television viewers. Most had not seen a starving child looking like a matchstick with a protruding stomach, with reddish-brown hair that signals a slow death from starvation (Waters et al., 2005). Biafran was the first war, according to literature, where the enemy used famine among its people as a weapon against its enemy (Tarantola et al., 2018). It was noted that the French Red Cross, the United States, and over 30 agencies from many countries provided early relief efforts. Several French doctors volunteered with the French Red Cross to work in hospitals and feeding centres in besieged Biafra. After entering the country, the volunteers, in addition to Biafran health workers and hospitals, were subjected to attacks by the Nigerian army

and witnessed the murders and starvation of civilians by the block-adding forces (Waters et al., 2005; Tarantola et al., 2018; Philips et al., 2018). In the early 1970s, after two and a half years of fighting, the remaining secessionist regime surrendered, but this did not end the suffering. Neither the relief action nor the Nigerian government had adequately planned for Biafra's collapse. Genocide did not happen; however, mass nutritional adversity continued long after the war was ended (Philips et al., 2018). However, from the standpoint of my research study, it should be noted that some of the participants in this study are not only stroke survivors, but also possibly Biafran war survivors. (Discussed further in the study).

Recovery interventions began after the war, enabled by an oil boom that occurred in the 1970s. This provided an expansion in government resources (Tarantola et al., 2018). The Nigerian government and international agencies attempted to reintegrate the war-affected populations, repair the damage to physical infrastructure (including health and educational facilities), and restore social services and public utilities to war-affected regions (Ukpong et al., 1975).

3.5.1 Early Childhood Malnutrition and Its Impact on health

Starvation is a legitimate weapon of war, and we have every intention of using it against the rebels

Quote by Mr. Ayida (1968)

The level of starvation in Biafra was three times higher than the starvation reported during World War II in Stalingrad and Holland (Alade and Mustell et al., 1977). Malnutrition has been identified as a common problem in patients with ischaemic stroke (Gomes et al., 2016) and is associated with increased poor outcomes, such as mortality, morbidity, length of hospital stays, and disability. About 62% of patients with stroke have been shown to have experienced malnutrition in the past (Gomes et al., 2016), with approximately 25% of them ending up being more malnourished within the first few weeks of experiencing a stroke. Stroke is often more prevalent in people who have faced several risk factors of malnutrition, including chronic diseases, dysphagia, and physical and psychological impairment (Gomes et al., 2016; Zhang et al., 2015). Malnutrition may intensify the neuroinflammatory responses and impair the recovery of ischaemic brain injury by inhibiting the expression of axon terminal proteins (Paquereaus et al., 2014). However, to accelerate recovery, high-risk patients should be identified and referred for further assessment and appropriate nutritional intervention (Zhang et al., 2015).

This, therefore, highlights the need for the early assessment of nutritional status and the factors associated with it in patients with stroke (Tarantola et al., 2018). It also highlights the possible link between malnutrition and stroke.

3.5.2 The Effects of Malnutrition on Stroke Survivors

The mismatch between the environment that people in urban Nigeria now live in, characterised by a high calorie/high carbohydrate diet, and the one within which they evolved during the Biafran famine may therefore be largely responsible for the present increase in disease risks (Johansson et al., 2007, Gomes et al., 2016; Zhangs et al., 2015). It is unclear whether malnutrition is a consequence of dysphagia or vice versa. Aliasghari et al.'s (2019) study of the impact of premorbid malnutrition and dysphagia on ischaemic stroke outcomes in patients early reveals the importance of nutritional status in the early management of patients with stroke, as well as significant correlations among nutritional status, biochemical tests, stroke outcomes, and length of hospital stay. The study also suggests that dysphagia is more prevalent in patients with malnutrition. However, ongoing recent studies have shown that nutritional status assessed at admission may be associated with mortality and disability at discharge and three months follow-up (Aliasghari et al., 2019; Gomes et al., 2016; Zhangs et al., 2015). It has also been suggested that patients with ischaemic stroke with baseline undernutrition would be undernourished during hospitalisation (Paquereau et al., 2014). This is common in the first few months after stroke, where malnutrition may contribute to poor short- or long-term stroke outcomes. Aliasghari et al.'s study demonstrated a strong correlation between premorbid malnutrition at admission and three-month MRS scores. The findings are comparable to those of Zhang et al. (2015), where premorbid malnutrition may predict three months of poor outcomes in patients with stroke during hospitalisation. Aliasghari et al.'s (2019) study poses several limitations and therefore may not be entirely reliable. It failed to assess patients' body compositions due to their disabilities, the researchers did not monitor the changes in nutritional state and dysphagia in the patients, and data for the subtypes is unavailable.

Studies have identified the links or correlations with undernutrition amongst pregnant women that may contribute to the exposure to noncommunicable diseases later in adult life (Miller et al., 1970; Johansson et al., 2007). Studies have also highlighted the link between poor foetal nutrition and later adult cardiovascular diseases in different countries (Barker et al., 2002; Barker and Robinson et al., 1992). The development and forming of the phenotype that occurs in utero responses to the

environment, nutritional perturbations may lead to reduced functional capacity. This explains why adults born small are at an increased risk for cardiovascular diseases, such as stroke conditions. The biological literature also suggests that if the undernourished baby experiences a diet high in fat and sugar later in life, then he or she is at risk of obesity, diabetes, and cardiovascular diseases such as stroke (Barker and Robinson et al., 1992).

The Biafran famine was characterised by a severe scarcity of proteins, manifested in the vast number of infants and children suffering from kwashiorkor (Miller et al., 1970). Experimental models suggest that protein deficits in utero may programme abnormal glucose homeostasis and vascular endothelial dysfunction (Miller et al., 1970; Johansson et al., 2007). However, besides the nutritional insult, pregnant women in former Biafra were living under conditions of war; such stress for mothers and infants could also have contributed to higher blood pressure in later life (Hult et al., 2010; Johansson et al., 2007).

The importance of early childhood health stems from the fact that physiological and neurological development is especially rapid during these years due to plasticity, the concept that shock change the developmental path by altering tissue structure as well as metabolic and endocrine processes. (Water et al., 2005; Johansson et al., 2007; Barker et al., 2002). Moreover, early childhood is a period of rapid growth that makes young children particularly sensitive to nutritional deprivation (Water et al., 2005)

Previous studies have indicated that nutritional insults during gestation or the first few months of postnatal life may be important for later outcomes and disease risk. It can also be presumed that foetal and infant malnutrition is a significant contributor to the increasing prevalence of hypertension and glucose intolerance in other parts of sub-Saharan Africa (Johansson et al., 2007).

3.6 Hypertension

Hypertension accounts for about half of the deaths from stroke and heart disease and 12.8% of the total all-cause deaths globally. It also ranks first among the noncommunicable disease in Nigeria (Ejiroghene et al., 2020). This research study has also highlighted that hypertension is one of the key risks factors to developing stroke (see Chapter 6, Table 6.2). However, the global distribution of hypertension burden is uneven, as most of the deaths occur in LMICs (Okwuonu et al., 2014; Ogah et al., 2012). Incidentally, there is a decline in the prevalence of hypertension in many developed

countries because of improved awareness and better treatment and control. The opposite appears to be the situation in LMICs, such as in Nigeria (Ejiroghene et al., 2020).

Conversely, it is now accepted that there is a connection between hypertension and Post Traumatic Stress Disorder (PTSD) highlighted by recent studies (Bronze, 2022). PTSD is a mental health condition that is triggered by a terrifying event which is brought on by experiencing or witnessing it. The symptoms may include flash backs, nightmares, and severe anxiety as well as uncontrollable thoughts of event (Howard et al., 2018). PTSD has been associated with an increased risk of hypertension which can lead to stroke. In a current issue of hypertension, Howard et al., (2018) provided insight into the underlying mechanisms of hypertension by revealing a correlation between chronicity of PTSD (present in a high proportion of 42% of subjects) and subsequent development of high blood pressure. Similarly, Stewart et al., (2015) in a study found that the US army had 3846 wounded US military service members had reported increased incidence rates of hypertension from 6%-15% according to the degree of severity of the initial injury post war.

Interestingly, although both severity of initial injury and duration of PTSD contributed to the risk of hypertension and possible stroke, this appeared to operate independently.

Hult et al.'s (2010) study reviews the legacies of the Biafran War famine concerning hypertension, diabetes, and overweight to determine the risks of the noncommunicable disease 40 years after foetal and infant exposure to the famine that affected Biafra during the Nigeria Civil War (1967–1970). The study reveals evidence that the children of Biafra were more exposed to noncommunicable diseases in adult life. The results identify that higher BP and higher glucose followed by increased weight were observed in middle-aged Nigerian people exposed to severe malnutrition in utero and during infancy. The starving pregnant women and foetus or infants affected by malnutrition/famine were also associated with significant increases in the prevalence of hypertension (from 9% to 24% approx. 140 mmHg) and several cardiovascular diseases. Thus, famine in early childhood was also associated with an increased prevalence of hypertension in adults (9.5%–16%). The results of the study are in line with those of previous studies that have suggested that foetal undernutrition contributes significantly to cardiovascular disease risk and stroke in adult life (Aliasghari et al., 2019; Gomes et al., 2016; Paquereau et al., 2014; Zhang et al., 2015).

A community-based study of rural and semi-urban populations in Enugu (SE Nigeria) (the former capital of Biafra) aimed to assess the level of knowledge and practice of lifestyle modification among

hypertensive adults. It reports the prevalence of hypertension in SE Nigeria at 32%. This is comparable to the results of a noncommunicable disease survey in Abia state, which indicates a prevalence of 31.8% among 2,999 participants (Okwuonu et al., 2014).

Adeloye et al.'s (2015) systematic review further disclosed that the pooled awareness rate of hypertension in Nigeria was only 17.4% between 1980 and 2013, while Ogah et al.'s (2012) systematic review indicate the pooled prevalence of hypertension in Nigeria increased from 8.6% to 22.55% between 1970 and 2011.

Despite all that is known about its adverse health consequences, high blood pressure (HBP) is still poorly controlled in Nigeria (Okwuonu et al., 2014; Ejiroghene et al., 2020). The awareness level and practice of lifestyle modification in blood pressure control among the people living in Southeast Nigeria is poor; therefore, concerted strategies are needed to improve these. Interventions such as lifestyle modifications, with their advantages, are often overlooked. Awareness campaigns and practice of these measures aid in blood pressure control (Ejiroghene et al., 2020; Feigin et al., 2016; Owolabi et al., 2013; Owolabi et al., 2018). It is hoped that this study will contribute to informing the appropriate public health responses towards reducing this burden.

3.7 Primary Health Care in Nigeria (PHCN)

African traditional medicine practitioners provided the earliest medical care in Nigeria (Chinawa et al., 2015; Fatusi et al., 2015). Medical services came to Nigeria with the advent of British colonisation (Scott-Emuakpor et al., 2010). Beforehand, traditional herbalists were curing and healing the sick in Nigeria. The WHO recognises the need to integrate traditional medicine with orthodox medicine, as they define it as 'the total combination of knowledge and practices, whether explicable or not, used in diagnosing, preventing or eliminating physical, mental or social disease'. Traditional health care is still prevalent, as it forms a part of the health care delivery system in both rural and urban centres in Nigeria (Scott-Emuakpor et al., 2010). There are claims by Traditional Medicine practitioners that since orthodox medicine cannot cure all diseases, they can intervene in the areas where it is weak (Elujoba et al., 2005).

In Nigeria, health care services are classified into three types: Orthodox or Western medicine, African traditional medicine, and spiritual healing. These are the three main areas that will be discussed further in the research study in order to gain a better understanding of the origins of PHCN.

The Alma-Ata Declaration of 1978 emerged as a major milestone of the twentieth century in the field of public health, and it identified primary health care as the key to the attainment of the goal of health for all (Omoleke et al., 2000). The declaration, cosponsored by the WHO (1987), is a brief document that expresses 'the need for all development workers and the world community to protect and promote the health of all the people in the world'. They called for a global commitment to achieving health for all by 2000 based on the principles of equity and community participation in health planning and policy making (Omoleke et al., 2000).

The document states that primary health care is essential health care based on practical, scientifically sound, and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation at a cost the community and country can afford (WHO, 1987). The declaration notes that traditional medical practitioners and birth attendants are found in most societies (Chinawa et al., 2015; Fatusi et al., 2015). They are often part of the local community, culture, and tradition and continue to have a high level of social standing in many places, exerting considerable influence on local health practices (Omoleke et al., 2000).

Part of the Alma Ata Declaration is that health is a fundamental human right, and the government should be responsible for the health of the people (Omoleke et al., 2000). However, health is rarely seen as a fundamental human right by policymakers in Nigeria. Hence the inability to implement the Abuja Declaration, for which African heads of state pledged to set a target of earmarking at least 15% of their annual budget to improve the health sector (Chinawa et al., 2015; Fatusi et al., 2015).

The first record of modern medical services in Nigeria was during the various European expeditions in the early- to mid-nineteenth century, at the time World War I (1914–1918) was ending. Nigeria was born by the amalgamation of the Northern and Southern regions (Omoleke et al., 2000). It was stated that the first health care facility in the country was opened in 1880 by the Roman Catholic Church in the Southeast region of Nigeria (Obosi) (Chinawa et al., 2015; Fatusi et al., 2015), after which emerged several others in the neighbouring towns and cities in the Southeast region (Scott-Emuakpor et al., 2010). Medical health care in Nigeria at the turn of the century was controlled by the colonial masters. This was the first centralisation of control of health services in Africa. In Nigeria, medical services developed and expanded with industrialisation (Omoleke et al., 2000).

Increasing investment in the health of the people has been a challenge for decision-makers, despite evidence confirming the link between health and economic development (Chinawa et al., 2015; Fatusi et al., 2015). Nigeria's health care system was constructed haphazardly; it is poorly developed and has suffered severe backdrops, especially at the local government levels. Hence, there are inherent disparities, a dysfunctional care emphasis, and a negative social distance from users and communities. Only a portion of the post-independence policies designed to address issues has been put into practice (Abubakar et al., 2022). Nigeria's gross domestic product is the largest in Africa, but its per capita income of approximately ₦770,000 (1.32 million) is low, with a high inequitable distribution of income, wealth, and, therefore, health (Abubakar et al., 2022). Nigeria's population health outcomes are poor, with national statistics masking drastic differences between the rich and the poor and between urban and rural populations. Nigeria is a picture of poverty amidst plenty (Adeyi et al., 2016).

Approximately 74.85% of Nigerian citizens pay for their health care services, and 70% is spent as an out-of-pocket expenditure which is a barrier to healthcare (Abubakar et al., 2022). Unfortunately, the system has faced several major challenges to achieving universal health. Although significant progress was made in the first two decades after the country's independence in 1960, the economic downturn resulting from the plummeting oil price, which Nigeria is dependent on, led to a series of twists and turns in the health sector (Abubakar et al., 2022).

However, against the backdrop of poverty and disarray that resulted from the Biafran War, many of the Igbo people who are stroke survivors in the region struggle to afford services such as physiotherapy rehabilitation. Nonetheless, organisations such as Stroke Action Nigeria (SAN) founded by chief Rita Melifonwu, aims to assist. It was established in 2000 after the UK Department of Health 1999 funded the Mary Seacole Nursing development and Leadership Award for stroke prevention research, which has supported the move toward the building of affordable stroke rehabilitation centres in SE Nigeria.

Health outcomes such as life expectancy continue to improve in the HIC thanks to improved social, psychological, and medical health care conditions (Adeyi et al., 2016). However, these improvements mask a widening gap between the health outcomes of the wealthiest and the most deprived countries and communities such as SE communities in Nigeria (Abubakar et al., 2022).

According to Eze et al (2019), 19% of all stroke survivors' cases occurred in adults in SE communities of Nigeria in 2013. However, as previously stated, there are few studies on stroke and QOL in the country's Southeast due to the reasons mentioned in chapters one and two. Therefore, it is against this background that the researcher embarked on this research study to determine the impact of stroke on the QOL of its survivors in this deprived community in Nigeria.

3.8 Traditional Medicine / Healing

Over the years, the use of complementary and alternative medicine in both rural and urban areas across Nigeria has increased (Abdullahi et al., 2011). Although western medicine and health care systems have been introduced in Africa, many Africans still rely on traditional health care (Asare et al., 2017). Despite the 150 years of introduction of Western-style medicine to Nigeria, traditional healing and medical practices remain a visible part of the complex health care system in Nigeria today (Chukwuma et al., 2015). Ransome-Kuti (1987) demonstrated the relevance of TM as follows:

"The health services of Nigeria have evolved through a series of historical development, including a succession of policies and plans which had been introduced by previous administrations. The health services are judged to be unsatisfactory and inadequate in meeting the needs and demands of the public as reflected by the law of the state of health of the population".

A casual survey performed in Benin City (1988) by Ebeigbe et al. (2013) reveals that for every signpost for a Western-style clinic or office, there are three that indicate a traditional doctor. Although this traditional system existed separately, there is a great deal of philosophical and conceptual similarities. However, before the introduction of cosmopolitan medicine, traditional medicine (TM) was the dominant medical system available to millions of people in Africa, in both rural and urban communities (Abdullahi et al., 2011). The arrival of the Europeans marked a significant turning point in the history of this age-long tradition and culture (Hillenbrand et al., 2006). Traditional medicine, otherwise known as folk medicine, native healing, or complementary and alternative medicine (CAM), is the oldest form of health care system that has stood the test of time. It is also strongly believed that traditional health care still serves most people not only in Africa but worldwide (Cook et al., 2009; Elujoba et al., 2005; Harris et al., 1994). Nigeria has a rich tradition of herbal medicine with its diverse cultures and traditions. Nigeria is rich in traditional medicines and has eminent and respected traditional healers involved in taking care of the indigenes.

Nevertheless, the relationship between culture and its healing rituals can be rather complex (Tribe et al., 2007). Tribes' study introduced Health Pluralism (biomedicine) traditional medicine and alternative medicine. However, it refers to health pluralism a diverse range of explanatory health benefits as well as a varied range of designated healers. Tribes' study argued that working with individuals and resources who have lived through extreme events such as the Biafran civil war may be more appropriate in assisting communities than Western models of diagnosis and therapy (Tribe et al., 2007). The study concluded that health pluralism is a more appropriate alternative to western models of therapy in the context of conflict.

According to WHO, about three-quarters of the world population depends upon traditional remedies for health care. Traditional herbal remedies are particularly used in the developing world, where they offer a more widely available and affordable alternative to pharmaceutical drugs (Ekeanyanwu et al., 2011). In Africa, 80% of the population depends on TM, according to WHO estimates. Studies have shown that a large portion of society would select herbal medicine as the first choice for home treatment remedies (Chukwuma et al., 2015; Ekeanyanwu et al., 2011).

The reason for the increasing acceptability of traditional medicine in developing countries is partly due to the inaccessibility of orthodox medicine, but the major contributing factor is that it blends readily into the sociocultural life of the people in whose culture it is deeply rooted (Chukwuma et al., 2015). Many people also believe that it is safer and more natural than pharmaceuticals (Hillenband et al., 2006). However, investigations have demonstrated that not all-natural products are safe and that some poisons are naturally occurring (Ansari, Inamder, et al., 2010). The issues related to TM are associated with the administration of TM care. There is great concern for its safety and efficacy, as well as control, and this poses a great challenge for health authorities and the public (Chukwuma et al., 2015). It is reported that herbal medicines on the market can also cause serious illnesses (from allergies to liver or kidney malfunction, cancer, and even death (Chukwuma et al., 2015), as most herbal products have not been subjected to a drug approval process to demonstrate their safety and effectiveness (Ansari, Inamder et al., 2010). For example, a prospective study by Harris and Cullinan et al. (1994) demonstrated that 25% of childhood blindness in Nigeria and India is associated with the use of traditional eye medicines. However, difficulties regarding the quantifiability of its medications, dosage, manufacture, documentation, storage, and potency, as well as the identification of side effects, must be addressed. Conversely, once these shortcomings are rectified, African TM has a lot

to offer in saving the lives of African citizens (Harris and Cullinan et al., 1994; Hillenband et al., 2006). However, the elite African who has adequate knowledge about the scientific cause of illness also incorporates traditional and spiritual factors when dealing with illnesses (Asare et al., 2017).

This section aligns with part of the research study's aims and objectives, which is to investigate the perceptions, attitudes, knowledge, cultural approaches, and beliefs of stroke survivors in the SE communities of Nigeria, and gain a better understanding of the participants' behaviours, mindsets, and feelings regarding the impact of stroke on QOL.

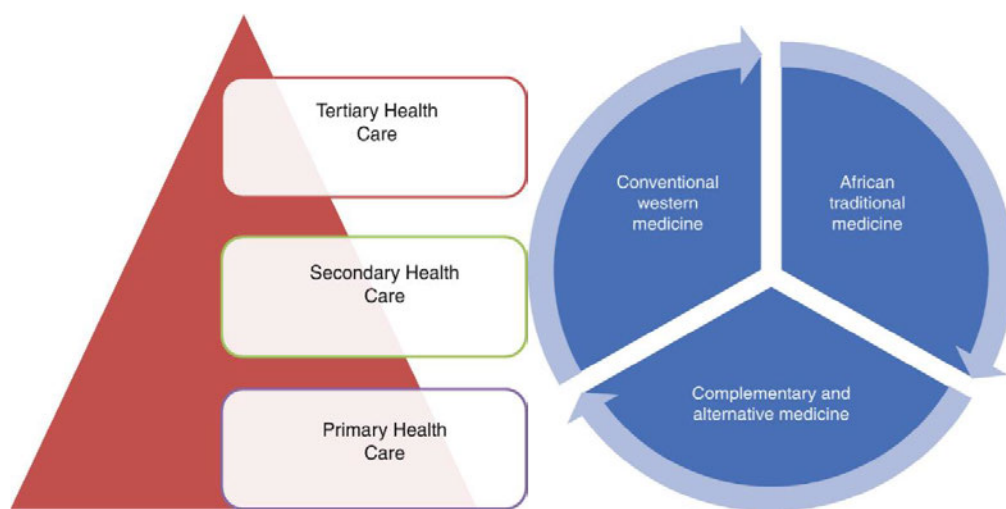


Figure 5: ORGANISATIONNL STRUCTURE OF the HEALTH CARE SYSTEM IN NIGERIA (Fatusi et al., 2015)

3.8.1 The African Traditional Medicine Practitioner

An African traditional medicine practitioner is a person recognised by his or her community as competent to provide health care through herbal medicine, which contains aerial or underground parts of plants or other plants materials in the crude state and mineral resources (Awolowo et al., 2013).

Several African countries, including Nigeria, have heavily relied on the spiritual and practical skills of traditional medical practitioners who are either faith healers, herbalists, and/or herb sellers (Chukwuma et al., 2015).

The origin of diseases in Africa is simplistic; it is either an enemy has cast a spell on a person, or the person is being punished by divine powers for his or her sins (Awolowo et al., 2013; Chukwuma et al., 2015). Interestingly, African traditional healers are consulted not only for sickness or disability but also

for good luck, for the security of lives and property, and for warding off any imminent evil or demonic attacks (Awolowo et al., 2013). These methods are based on the social, cultural, and religious background, as well as the knowledge, attitudes, and beliefs prevalent in the community concerning physical, mental, and social well-being and the causes of diseases and disability (WHO 1987). It is also noted that the community indigenes had built a trust relationship with the traditional healers within the community as this was the original form of healing for the locals during the precolonial days.

There are several types of traditional medical practices, and each system has its methods. Healers are addressed as *babalawo* among the Yoruba-speaking people, *dibia* among the Igbos, and *boka* among the Hausa-speaking tribe (Cook et al., 2009). In the various local communities, the traditional doctors are well known for treating patients holistically (Awolowo et al., 2013). They usually attempt to reconnect the social and emotional equilibrium of patients based on community rules and relationships (Awolowo et al., 2013). As highlighted earlier, they often act in part as an intermediary between the visible and invisible worlds and between the living and the dead or ancestors. They sometimes do this to determine which spirits are at work and how to bring a sick person back into harmony with the ancestors (Ratzan et al., 2000).

One important factor that traditional medical practitioner manifest in their profession is a better awareness of the culture and norms of the community within which they work (Omoleke et al., 2000; Elujoba et al., 2005). This is primarily due to the trust relationship that has developed over time between the indigenous peoples of the community and the traditional healers. There is, however, less emphasis on this in orthodox medicine. For example, research has demonstrated that Nigerian Fulani pregnant women do not physically express delivery pains because it is taboo to feel or do so, whereas an orthodox doctor might assume that the woman is not responding to labour if such a doctor is not sociologically aware of such a taboo (Omoleke et al., 2000). Conversely, there is an urgent need, as stated above, for appropriate legal frameworks to checkmate the quacks and charlatans in the practice of TM for the regulation of the bodies (Ekeanyanwu et al., 2011; Omoleke et al., 2000; Ratzan et al., 2000).

3.9 Nationwide Health Care Plan in Nigeria

In the 1960s, there was no strong focus on the development of health systems (Ukpong et al., 1975). The PHC was presented almost four decades ago as a pragmatic answer to the public health

challenge of Nigeria. The first colonial development plan for health care services spanned from 1945 to 1955 (Ransome-Kuh et al., 1987). The following subsequent plans revealed the formulated goals for national health care services in Nigeria. The overall policy for nationwide health care services was clearly stated in a 1954 Eastern Nigeria government report stating national health services for all (Ransome-Kuh et al., 1987). The Third National Development Plan was introduced in 1975, more than 20 years after the above report. The development trends in the health sector have not been marked by any spectacular achievements during the past decade (Ukpong et al., 1975). The Fourth National Development Plan (1981–1985) addressed the issue of preventative health services. This involved the establishment of three levels of health care facilities.

1. Comprehensive health centres (CHCs) serve communities.
2. Primary health centres (PHCs) to serve communities of 5,000–20,000 persons.
3. Health clinics (HCs) to serve 2,000–5,000 persons.

These institutions were to be built and financed by the federal government (Scott-Emuakpor et al., 2010). The Federal Ministry of Health is the planning and coordinating body for health service issues (Ransome-Kuh et al., 1987; Scott-Emuakpor et al., 2010). The federal government provides the bulk of the money for the local governments to provide delivery of health care to the masses. Nigeria has up to 36 states and over 500 local government areas (Ukpong et al., 1975). Unfortunately, the programme did not achieve its goals due to implementation challenges; therefore, services were not delivered across Nigeria. However, some improvements in medical health have been made. Today there are 26 medical schools in Nigeria compared to 1 in 1960, 2 in 1965, 6 in 1984, and 18 in 2005. There are also 13 universities with physiotherapy schools in Nigeria, with courses lasting approximately five years (Ransome-Kuh et al., 1987; Scott-Emuakpor et al., 2010).

Nigerians transitioned into the 21st century with one of the weakest health systems in the sub-Saharan Africa region (Scott-Emuakpor et al., 2010). The 2000 WHO ranking of the health systems of member nations placed Nigeria as 187 of 191 countries – only ahead of three countries (Scott-Emuakpor et al., 2010). As the ‘Giant of Africa,’ this is a poor rank. The current state of PHCs in Nigeria is appalling, with only approximately 20% of the 30,000 PHCs across Nigeria in working order (Chinawa et al., 2015; Fatusi et al., 2015). Primary health care in Nigerian needs strengthening and revitalisation, as currently, most PHCs cannot provide essential health care services and have

additional issues, such as poor staffing, inadequate equipment, poor distribution of health workers, poor quality of health care services, and poor condition of infrastructure. However, problems with the implementation of PHCs in Nigeria are related to handover issues in the 1980s by the new military government that took over in 1993, and the establishment that successful implementation of PHCs in any country requires adequate financial resources. This brought an end to the giant strides recorded under the leadership of Professor Ransome-Kuh from 1985 to 1992. Many African countries, including Nigeria, have fallen short of the Abuja Declaration of 2001, despite the pledge by heads of state of African Union countries (Elujoba et al., 2005). Conversely, the Alma-Ata Declaration has been successfully implemented by other countries, such as Thailand, Cuba, China, and Mexico (Scott-Emuakpor et al., 2010).

3.9.1 Summary of Chapter

This chapter examined how postcolonial characters vary and align across sectors, geographies, and health care histories in Nigeria. It highlights the impact of colonialism on a country via the lens of the dependency theory demonstrating a biomedical model. A snapshot of the Nigerian / Biafran civil war was discussed; this triggered a massive humanitarian crisis in Southeast Nigeria which led to famine-like conditions and a particularly severe shortage of proteins and calories. It was found that exposure during childhood to the war had adverse consequences on the health of women and men, most especially in adult life. Furthermore, mothers exposed to the war had children who suffer from higher mortality rates or, conditional on surviving, suffer worse health and education outcomes in the long run.

The section has also established a strong link and correlation between childhood malnutrition and adult health problems related to cardiovascular diseases, potentially predisposing patients to other chronic noncommunicable diseases (such as hypertension, diabetes, and ultimately, stroke complications) later in adult life. This was confirmed by the survivors / first generation of post-war children who served as the subjects of this research study.

There is a growing body of evidence that suggests that the increased susceptibility to chronic diseases in adulthood has a developmental basis originating in foetal life (Barker et al., 2002). Subjects born between 1965 and 1967 were classified as having experienced early childhood starvation. Those born between 1968 and 1970 (the war's end) were classified as having been exposed to hunger during their foetal and early childhood lives (Gomes et al., 2016). About 70% of

the participants in Phase 1 (quantitative research study) who actively filled in the questionnaire (HRQOLISP) and 5 of the 10 participants involved in Phase 2 (qualitative research study using semi-structured interviews) were classified as having been exposed to starvation during their early infancy. The remaining 30% were people born before 1968 or after the 1970's, as the participants in the research study ranged in age from 16 years old to 85 years old. These interconnected frames highlight the influence of childhood malnutrition on adult life.

Therefore, the prevention of foetal and infant (who are possibly the adults in the study) malnutrition should be given high priority in national health, education, and economic agenda to limit the increase of noncommunicable diseases in many African countries (Eze et al., 2019). Given that studies have identified that the highest risk for hypertension is found in those undernourished in early life and those with excess weight, it is appropriate to consider that preventative measures such as awareness and education with reduction of excess weight in later childhood may be as important for reducing adult ill health (such as stroke conditions) in adult life.

The following are some of the drawbacks that come with a colonial ideology. Nonetheless, colonization is the process by which a more powerful nation seizes control of another nation (James et al., 2009). In Nigeria colonization commenced 1914, the ideology often portrayed a negative effect on the community especially concerning access to health amongst stroke survivors in the poorer communities. (Hecrten et al., 2014). Access to health care is critical to survival and achieving favourable functional outcomes in stroke patients. Stroke survivors experienced difficulties in accessing health services in rural and urban areas in LMIC (Onumah et al., 2017; Philips et al., 2018).

The Nigerian stroke organisation (NSO) recommended that all stroke patients should be managed in a stroke unit (Lindsay et al., 2014). A global survey reported that only 18% of LMIC had stroke units, compared to 91% of HIC (Lindsay et al., 2014).

Stroke unit coverage in Nigeria remains limited most especially in the poor communities of the country, with only a few centres having stroke units. Equally, most health services in Nigeria are paid for out of pocket, with close to 97% of the population without any health insurance coverage (Owolabi et al., 2021), while the minimum wage in Nigeria is 30,000 Niara (Equivalent to £35). Reasons for delayed onset – to – arrival time, includes a lack of awareness of symptoms and the belief that stroke is a 'spiritual attack' that is better treated using spiritual and herbal remedies (Nweke et al., 2019).

Also, the challenges to accessing health care include complex pathways to care, physical mobility related to stroke, long travel distances and limited transport options (Nweke et al., 2019). Potential challenges to establishing more stroke units and improving the few existing ones include cost, human resources and the incompatibility with existing systems (Owolabi et al., 2021). However, despite the various reforms to increase the provision of health to the Nigeria people, health access is less than 43.3% (Owolabi et al., 2021; Akinyemi et al., 2021)

At the level of government, advocacy for the establishment of more strokes unites and easier access to health care and treatment will be beneficial in the long term for stroke survivors in the poor communities (Owolabi et al., 2021; Akinyemi et al., 2021).

Based on the post-colonial discussions seen above highlighting the various adopted approaches used in conflict, environmental and health conditions, followed by the gaps in the literature observed in Chapters One and Two, highlighting the gap of social and psychological integration, there is a need to look at a conceptual framework that pulls these aspects together. This is undertaken in the following chapter.

In line with the aims of this research study concerning the impact of stroke on the QOL of survivors in SE Nigeria, and the ability to capture the individuals detailed perceptions concerning their QOL, it is evident that without the use of a biopsychosocial approach individuals are more at risk of diseases such as NCD and stroke. In the following chapter, these issues are addressed by looking at the rationale, pro and cons of the conceptual framework that can be used to inform the research study.

CHAPTER FOUR

The Theoretical Framework

4.1. Introduction

The preceding chapter provided context for Nigeria and the SE in relation to post colonialization and the state of the health care system. It investigated the impact of colonisation on indigenous peoples' health and well-being. In this chapter I will be looking at the International Classification of Function (ICF) model. This is an international standard for framing, describing, recording, and measuring functioning and disability (WHO 2001). I will also review historical perspectives of the various models, such as the medical model, holistic approaches, social and biopsychosocial models in relation to Africa and concerning the health care system in Nigeria. I will examine how the models evolved historically through the lens of the International Classification of Function (ICF). The chapter ends with a summary that highlights the positive and negative factors in relation to Health care in Nigeria.

This chapter intends to establish a guiding theoretical framework that will act as a springboard for the data analysis, result interpretation, and discussion of the research study's findings.

4.2 The History of the development of models via the ICF

Disability is a complex phenomenon that is difficult to define and measure (Dantas et al., 2020). However, according to the World Health Organization (2001), disability is any physical or mental condition (impairment) that makes it more difficult for the person with the condition to perform tasks (activity limitation) and interact with their environment (participation restriction) (Dantas et al., 2020). Disability has frequently been evaluated using medical and social theories. However, scholars have critiqued these models for focusing exclusively on disability as a medical or social paradigm (Kivunja et al., 2018). Conversely, to address these challenges, the World Health Organisation (WHO) developed the ICF. Before that, WHO introduced the International Classification of Impairments, Disabilities, and Handicaps in the 1980s. This was a novel international system to classify the consequences of diseases. Researchers argued about its biomedical orientation and disregard for the role of the physical, social, and attitudinal environments in the disablement process (Kivunja et al., 2018). Subsequent modifications and upgrades occurred throughout the 1990s. This resulted in the development of the ICF by the World Health Assembly in 2001. The ICF is based on the principles of universality, parity, neutrality, and consideration of context. The parity denotes that the ICF does not

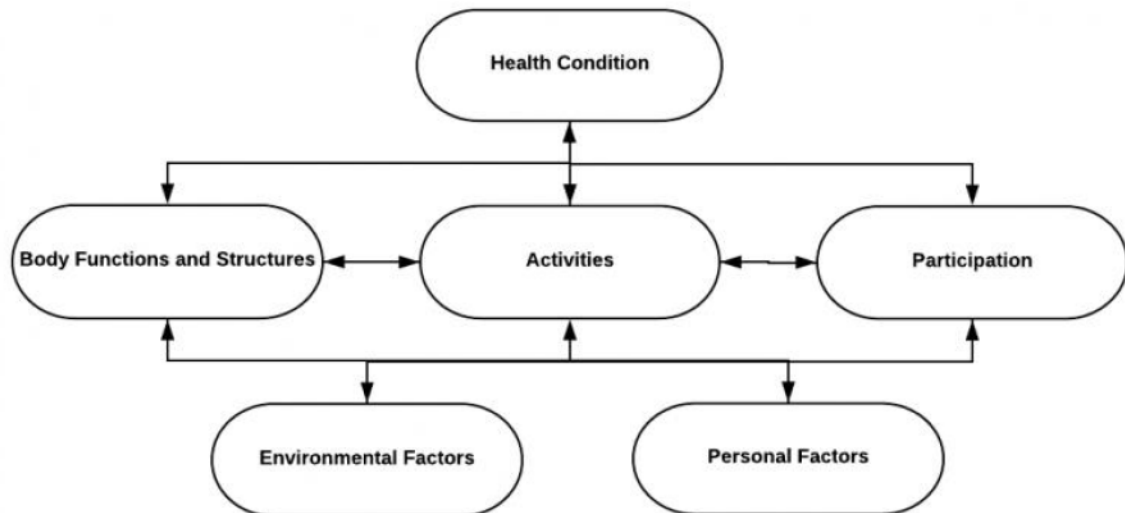
discriminate against health conditions based on aetiology and provides a neutral ground for comparing various health conditions and health-related states (McDougall et al., 2011). This issue is essential, especially in the context of LMICs, such as in Nigeria, where people with disabilities are often categorised and labelled based on their health problems. However, unlike previous models of disability, the ICF provides the opportunity to explore the experience of disability by taking the unique features of the individuals, as well as the physical, social, and attitudinal environments, into consideration (WHO, 2013). In Nigeria, for example, some of the significant challenges people with disabilities encounter include environmental barriers such as inaccessible buildings and transport, work and social barriers such as negative attitudes and beliefs towards disability (Sango et al., 2013; Me et al., 2006).

Both in HICs and LMICs, users have employed the ICF as a conceptual model for research, outcome measuring instruments, management planning, and data gathering (McDougall et al., 2011). It has been used at various health levels and has been a standard reference for health and disability-related legislation, the evaluation of needs and services, and disability certification (McDougall et al., 2011). The ICF represents one of the most significant paradigms shifts in rehabilitation science and practice (Jelsma et al., 2009). It has introduced significant innovations that sealed inherent loopholes within the dominant concepts of disablement: the medical and social models.

The WHO accepts and uses the models as part of its ICF (see Figure 1). The ICF places social attitudes, injustice, and discrimination as one of environmental factors affecting individuals with disabilities (Roush and Sharby, 2011). The ICF is a tool that guides practitioners, service users and policy makers within the field of disability. However, medicalisation of disability persists in LMICs, such as in Nigeria; in a study involving national baseline survey of people with disabilities, both the ICF and the social model were unutilised, and the survey drew mainly from the medical model of disability (Sulaiman et al., 2021). The recommendation of the ICF to member countries by the WHO is yet to fully take effect. However, another study of ICF use revealed that a limited number of studies have utilised the ICF in LMICs compared to in high-income countries (Jelsma et al., 2009). This underutilisation of the ICF could be due to the limited emphasis of disability research and the medicalisation of disability in LMICs such as Nigeria. The ICF impacts how data on disability is conceptualised, collected, and analysed, especially in HICs. Its use in LMICs is limited and needs to

be actively encouraged; this could change the way disability-related issues are viewed and addressed in these regions, such as Nigeria (Sulaiman et al., 2021).

Figure 6: International Classification of Impairments, Disabilities, and Handicaps (ICF)



Source: Blake et al (2018)

There are, however, various limitations of the ICF that have been reported in the literature, such as the lack of a robust theoretical underpinning, clarification between components of activities and participation, systematisation of personal factors, and subjective dimensions, such as well-being and quality of life (McDougall et al., 2011). Imrie (2004) argued that, theoretically, ICF does not delineate the nature and contents of functioning and disability, which may limit its potential to inform users about the nature of functioning and disability. Researchers, therefore, suggest that some aspects of ICF require further conceptual clarification and development. Moreover, despite the comprehensive nature of ICF, there is a lack of clarity about its essential assumptions, viewing disability as a dynamic process rather than a unique feature. However, although it is important to acknowledge any shortcomings in the ICF, these limitations are unlikely to have any significant impact on its utility in LMICs, where models with grave limitations are commonly employed (Sango et al., 2013).

The ICF has many unique qualities (including being multinational, interactive, and comprehensive), which place it above other models for exploring disablement (McDougall et al., 2011). It is the most widely accepted conceptualisation of disability which provides a standardised framework and language of communication to professionals and other users (Jelsma et al., 2009). Despite the

advantages and limitations of the ICF, it surpasses both the medical and social models of disability by synthesising what is true in the two models to portray the disablement process on a biopsychosocial spectrum (Sango et al., 2013; McDougall et al., 2011). The unique features of the ICF make it an invaluable tool for understanding human experiences in various contexts.

4.2.1 Historical Perspectives

Since prehistoric times, human beings have been faced with the dilemma of the relation between the mind and the body. The classic biomedical paradigm is founded on the Cartesian divide of mind and body and views disease as largely a failure of the soma caused by injury, infection, or inheritance (Alonso et al., 2004). However, the first response to the mind-body question was proposed by Descartes (1641). He identified the mind with consciousness and self-awareness and distinguished it from the brain. Interestingly, Larmer (1986) argued that minds are entirely separated from bodies and material objects of any kind. This is known as Cartesian dualism (which is associated with a Biomedical model), a philosophical position that asserts that the mind (thinking thing) is distinct from the body (unthinking thing). Amoroso (2010) suggested that the body can be seen as a machine and be repaired by a medical doctor who acts as an engineer that mends broken bones. Thompson et al. (2016) stated that, since disabilities are considered diseases, practitioners and other experts need to work on the development of universal criteria, methods, and treatments to identify the 'malfunction' and effectively 'repair' the problem. Interestingly, Nettleson (2006) argued that the above approach has led to the ideology that a specific identifiable agent causes every disease. Descartes also debates that the body cannot exist without a mind; however, the mind can endure the annihilation of the body to which it is paired (Bennett, 2007). Cartesian dualism holds that minds and bodies interact casually despite their radical distinctiveness. Cartesian dualism uses three primary arguments based on doubt, simplicity, and clear perception. Descartes's argument regarding doubt holds that an individual can doubt the existence of the body, such as in a hemiparesis (partial stroke), but not the mind. Conversely, it is clearly understood from the medical model that people with disabilities are abnormal, and to reduce, if possible, the abnormality, the knowledge, and skills of medicine and medical professionals are necessary (Thompson et al., 2016).

In my personal experience as a neuro-physiotherapist, the biopsychosocial model is frequently the preferred model in clinical practice. It is now widely accepted that illness and wellness are the results of a combination of biological, psychological, and social elements (Nicholl et al., 2010). In late

Victorian England, the forerunners of the Chartered Society of Physiotherapists – the Society of Trained Masseuses (STS) – established a series of strategies with the medical community to govern the quality of practitioners (Dixon et al., 2003). This followed the adoption of a biomechanical view of the body, which was then established (Nicholls and Cheek et al., 2006). This biomechanical discourse encompassed a 'Cartesian' view of the body and favoured an objective, bioanatomical, depersonalised approach. This endured for more than a century and appeared as a consistent reference point for the identification of physiotherapy practice in commonwealth countries (Anderson et al., 1977; Dunstan et al., 2006). The body is conceptualised in the current physiotherapy literature. According to Nicholl et al. (2010), it is stressed that the relevance of the body in physiotherapy is crucial and that a renewed interest in the meaning of the body in physiotherapy is long overdue.

Biomechanical discourses appear in the profession's preference for objectives and value-neutral research paradigms, and these lie at the heart of physiotherapists' theoretical and practical approaches; these surface in many places in contemporary physiotherapy (Darnel et al., 2007). Broberg et al. (2003) claimed that the body is at the 'core' of and is the starting point of physiotherapy. However, scholars have argued that the machine metaphor that lies at the heart of the biomechanical body has contributed to a quality-of-care crisis in health care (Marcum et al., 2004). This approach has been both necessary and productive for physiotherapy practice and has limited physiotherapists' ability to fully account for and respond to the breadth of health and illness experienced by embodied persons (Marcum et al., 2004). Physiotherapists have largely ignored the social, political, cultural, economic, geographical, and psychological dimensions of health and illness. Rather than taking a holistic view of the body, physiotherapists have always been highly selective, focusing on biomechanical understandings of the body whilst marginalising others such as cultural, economic, political, and social. Only recently have practical models that promote the idea of a more inclusive form of physiotherapy practice emerged (Broberg et al., 2003) – at a time when the profession is under pressure to reform and show that it is considering new models of practice and responding to the demands of future health care (Nail et al., 2006; Higgs, Jones, and Edwards et al., 2003). It may seem that physiotherapists have been slow to adopt the more 'holistic' dimensions of health care that are now being demanded by funding agencies and the public. These dimensions are vital if the profession is to thrive. Physiotherapists' historically dispassionate approach to patient care is now being challenged, hence the new biopsychosocial approach to practice.

This model can be divided into three main aspects: biomedical (capturing the physical elements of the body), social (including cognitive, emotional, motivational, and behavioural symptoms), and psychological (the effects of perceived social contacts on health) (Bennett et al., 2007). Concerning the research study, these three aspects of the model play a role. However, one of the most criticised consequences of adopting the biomedical model is a partial definition of the concept of health. It is argued that health must be the state in which somatic signs and symptoms are not present as previously discussed in Chapter 2 (The social determinants of health).

4.2.2 Medical Model

The term 'biomedical' refers to a patient's acute medical and nursing care requirements. The biological dynamics capture the physical elements of the body that affect and determine health (Lehman et al., 2017). Disability in the medical model is viewed as a medical condition, and, as such, doctors are the specialists who treat and eliminate both the symptoms and the illness (McTigue et al., 2015). The view is that disability explains the limited functioning seen as a deficiency because of body impairment (body function, structure, and mind) (Haegele and Hodge et al., 2016). Hence, the view of the medical model is that people are considered disabled as they are unable to function as 'normal' people do; this is crucial because the way disability is defined and viewed affects the perceptions, expectations, and behaviours of people towards people with disabilities (Brandon & Pritchard et al., 2011). Up until the 1980s, the United Kingdom viewed disability as a dysfunctional body. This conception of disability concluded that the disability is the actual impairment of a person, and this person is viewed as incomplete, flawed, or broken (Duncan et al., 2013).

This model reiterates the provision of health care and rehabilitation services to individuals based on the degree and severity of impairment. It is of considerable advantage in the diagnosis and planning of the patient's care, which traditionally underpins medicine (Engel 1980). For example, the cardiovascular system is central to the health of the entire body, and the neural systems, such as the neurological system, are important for understanding how psychological and physical domains affect health for a neurological attack such as a stroke. Each of these systems is formed by a complex interconnected set of structures and cells; therefore, the neurological system not only operates to deter disease but also interacts with other biological dynamics, such as the circulatory system, and with social and psychological dynamics (Lehman et al., 2017). Conversely, Engel advocated for a biopsychosocial approach – arguing that the biological model provides little place for psychological,

social, and behavioural elements of sickness, thereby obstructing an apparent holistic approach to treating the individual and their illness. A significant criticism of the medical model is that although medical experts should be held responsible for treating and curing disabilities, as they have expert knowledge, their power should be limited only to the medical aspects of disabilities. Haegele and Hodge et al. (2016) suggested that medical experts should not have any control or authority over the lives or perceptions of others. Another significant drawback is that it leads to 'paternalism, pathologizing and benevolence', as seen above. It has also been suggested that the medical model often views disability as being pitiable and disempowered, thereby casting a negative image of people with a disability rather than considering disability a social, environmental, and/or political problem. The medical model has likewise been criticised by people with disabilities who report that it is the society that disables people and not their impairments by excluding them from full involvement and participation in society. This view posts that disability is not impairment but the societal factors that restrict people with disabilities, including prejudice and discrimination (McTigue et al., 2015). Moreover, people with disabilities emphasise they are fully capable of participating both in society and in the workplace if only there is adequate support from society and government (McTigue et al., 2015). However, its advantages are that the model is simple and easy to follow, but it inappropriately focuses on what is wrong with the person rather than what the individual may need by focusing on limitations.

4.3 The Holistic Approaches / Perspectives

"Health, and what makes people healthy, can only be fully understood by exploring the myriad of interactions and influences that emerge out of the complexities of human experiences and the various inter-relationships of the mind, body, and society."

Quoted by Yuill (2010)

This perspective holds to the idea that biological, psychological, and social processes are integrally and interactively involved in physical health and illness. In the last three decades, applied research across a range of subjects has affirmed the value of the biopsychosocial perspectives and demonstrated how biological, psychological, and social processes operate together to affect physical health outcomes (Suls et al., 2004).

Theoretical frameworks or models have been used to capture a communal understanding of health and illness (Allonso et al., 2004; Amoroso et al., 2010). Each model varies in its emphasis on biomedical, cultural, and psychosocial determinants of health. These models have served a variety of purposes and offer distinct perspectives on health. These three key models have been applicable for this research study, each with a specific role.

The aim of the holistic models is to try to make the disabled person as less disabled, by changing them and their impairment. The benefit of the holistic model revolves around the promotion of lifelong learning; the models are motivating and allow for the formation of cohesive communities and researchers can assess multiple factors that may contribute to a psychological problem. The disadvantages are that it may be time consuming and costly due to limited resources, with inadequate training in care knowledge (Amoroso et al., 2010).

4.3.1 Social Model

According to the social model, disability is defined as the social exclusion of disabled persons rather than their inability (Hutchinson et al., 2016). Therefore, 'impairment' and 'disabilities' are different terms, as impairments are functional limitations due to physical, mental, or sensory impairment, while a disability refers to exclusion from social participation through limited opportunities compared to others due to physical and social barriers (Hutchinson et al., 2016). Mike Oliver developed the social model in 1983 (McKenzie and Lorenzo, 2015; Kumbier and Starkey, 2016). It is directly relevant to populations with disabilities and employment, and it identifies societal negative attitudes and exclusion as the main contribution to the inferior position in which people with disabilities are. The social model aims to improve health by reducing the health inequities that lead to illness.

Improvements have been made regarding the recognition and diagnosis of disabilities, with a variety of new treatments and intervention programmes. Oliver (1983) argued that physical, economic, and social barriers faced by the population with disabilities are not a result of their mental or physical impairments but are constructed by the social, cultural, and ideological beliefs and attitudes that result in environmental barriers (Depoy and Gilson, 2015). This model clarifies that discriminatory societal policies and inadequate infrastructure adaptations limit the full participation of individuals with disabilities in society. The model also advocates that the structure, practices, and policies of societies and organisations need to change to accommodate diverse groups of people from all disabled works of life. When the changes take place, the needs of various groups will be met instead of directly

applying treatment to a disabled individual (Counts et al., 2015). This model of health examines all the factors which contribute to health, such as a person's culture, environment, and belief system. Social models of health recognise that health is influenced by a wide range of individuals, as well as interpersonal, organisation, and social-environmental factors. It has broadened its scope to include a human rights component, which comprises the right to health care, education, and social participation. Another important aspect of the social model is that it portrays the term disability as part of human diversity (physical, cognitive, sensory, or emotional), stressing the normality among diverse groups and not their social exclusion and discrimination (Gallagher et al., 2014). Oliver (1983) acknowledged that disability is not an individual medical problem but that the problems people with disabilities face are due to the negative response of society (Gallagher et al., 2014). It is felt that society imposes barriers and limitations deriving from discrimination, resulting in isolation, separation, poverty, and unemployment of people with disabilities (Gallagher et al., 2014).

Shinohara and Wobbrock (2011) found that society views people with disabilities as different from other members of society due to their impairments; consequently, people with disabilities are viewed as weak, dependent, and incapable. The researchers identified that others perceive people using assistive technology as disabled and incapable of functioning when not using these technologies. The assumptions, however, are invalid, as the fundamental concept is for people with disabilities to have the same access to technology, services, and information as everyone else (Shinohara and Wobbrock, 2011). This model influences the development of public policies regarding the population with disabilities, including education and employment, both in the European context and internationally (Anastasiou and Kauffman, 2013). People with disabilities have assumed that sometimes a socially hostile and discriminatory environment might be much worse than their physical impairments themselves (Anastasiou and Kauffman, 2013). However, although this model is viewed by many as the new paradigm, it is still not universally accepted. There are still various versions of the model, and societies view the model's principles differently (Sulaiman et al., 2021).

A study by Heavy et al. (2013) in Kings College London revealed that people in the UK perceive disability not only as a physical reality but also as a social construction because society inevitably stigmatises populations with disabilities, treating them with inequity and prejudice. Heavy et al. (2013), in their qualitative study, concluded that three interlinked definitions and meanings of disability exist: disability as an official status, a person's inability, and a stigmatising mask. Correspondingly, Halfon,

Larson, and Newacheck (2012) revealed that there has been no progress in reducing socioeconomic disparities in disability over the past half-century since people with disabilities are still considered of lower social status and receive lower income in contrast with people without disabilities. Unlike the medical model, the social model suggests that disability can be reduced or eliminated in that various people with impairments might not be disabled if society supports them (Bailey et al., 2015). Carlisele (2000) investigated health inequalities and conceptual frameworks and recognised that the model addresses injustices that contribute to ill health by analysing determinants of illness. Germor (2014) argued that social models of health imply that there is a social responsibility to ensure that people have healthy living and working environments. Nevertheless, the concept that sickness may be better understood by examining the larger social, psychological, and cultural circumstances is the foundation of this model. One of the identified weaknesses of the model is neglecting impairment as an essential aspect of people with disabilities' lives. Both the medical and social models of disability dominate the conceptualisation of disablement in the twentieth century; however, researchers have criticised these models for narrowing disability to one of their aspects (Carlisele et al., 2000). One perhaps valid critique of the social model is that it completely separates impairments from disability, which is a central part of people with disabilities' lived experiences (Gallagher et al., 2014).

One of the most significant factors is the fact that the social model increases the awareness and perceptions of people with disabilities themselves – as this philosophy supports them the way they are, teaching them that it is the society that needs to change and not themselves (Meyers et al., 2014). The model discourages the notion that impairment is something negative or worthy of pity, as it is just a description of a person's body structure (Goering et al., 2015). Studies have stressed the fact that the experiences of people with disabilities because of their impairments are significantly essential and affect their interaction with society. Therefore, although disability problems still exist for various people, such as patients with stroke, these can be viewed as obstacles that can be overcome through physical and mental support both by society and the government. Unfortunately, legislation amendments aimed at decreasing socioeconomic differences are seen to be ineffective in changing social perceptions and attitudes (Meyers et al., 2014; Goering et al., 2015).

4.3.2 Biopsychosocial Model

This study therefore proposes a biopsychosocial model concerning the impact of stroke on the quality of life of stroke survivors in a Nigerian community. The perspective is based on the idea that

biological, psychological, and social processes are integrally and interactively involved in physical health and illness (Bolton et al., 2019). The biopsychosocial model emerged from the need for a better understanding of the human being as a unit and an exploration of an individual's biological, psychological, and sociological perspectives. The biopsychosocial perspective expressed in the ICF recognises the interactive influence of physical, psychological, and social factors and the relevance of understanding the individual's viewpoint concerning their health and well-being – as reflected in this research study, according to the quantitative and qualitative findings (McDougall et al., 2011). Nordenfelt (2016) described the notion of health expressed in the ICF as the most outstanding contribution to the health care system, marking a focal shift from disability to ability.

The biopsychosocial model has been extensively described in the literature; however, the model itself and its practical applications have been poorly defined and especially lacks theoretical explanations of the interaction of biological, psychological, and social factors in producing long-term conditions or noncommunicable diseases (Lehman et al., 2017; Bolton et al., 2019).

Engel proposed the 'biopsychosocial' (BPS) model of disability in the 1980s. It was regarded as one of the most important developments in medicine in the 20th century. Unlike the medical model, as stated above, the BPS approach posits that biological, psychological, and social factors play a significant role in disease causation and treatment (Bolton et al., 2019). The model proposes a philosophy that incorporates the social and medical models of disability (Penney et al., 2013). It strives to acknowledge patients' health perceptions in the context of their specific circumstances. The model aims to link both the social and the medical models by presenting a consolidated approach. It is said that the biopsychosocial model forms a more integrated and comprehensive concept around disability, encompassing elements from both the social and medical models (McCrosky and Lawson, 2014). Therefore, this model is based on the fact that disability is an interaction between three sets of factors: physical (such as age and gender), psychological (such as behaviour), and social (such as cultural environments) (Bath et al., 2014).

The biopsychosocial model is commonly used in chronic pain situations, such as neurological conditions (i.e., stroke), with the view that the pain is a psychophysiological behaviour pattern that cannot be categorised into biological, psychological, or social factors alone (Lehman et al., 2017).

There are suggestions that physiotherapy should integrate psychological treatment to address all components comprising the experience of chronic pain.

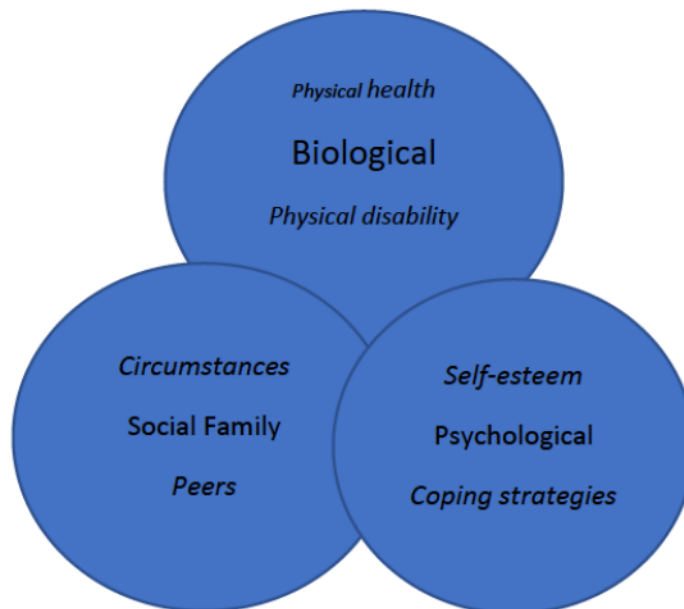


Figure 2: THE BIOPSYCHOSOCIAL MODEL OF HEALTH. (LEHMAN ET AL., 2017)

Suls and Rothman (2004) emphasised the importance of continuing to apply the biopsychosocial (BPS) model to its full potential and highlighted four areas to ensure the continued evolution of the BPS model. These initiatives involved research, training, practices, and intervention. The suggested recommendations emphasise the need to better understand and utilise linkages among biological, psychological, social, and multicultural valuables. Additionally, Nicassio et al. (2011) investigated the links between physical, psychological, and social aspects and health-related quality of life (HRQOL) and disability in patients with rheumatoid arthritis. The findings highlight the need to address psychological aspects in the clinical management of patients to improve HRQOL. The researchers suggested that future research into the area should highlight whether psychological factors predict functional outcomes over time while controlling for prior levels of disease activity.

Alonso (2004) conducted a thorough study of medical researchers' attitudes towards biopsychosocial health concepts. None of the 52 papers examined in the study provided a positive and repeatable definition of health (Alonso, 2004). There were changes towards more holistic notions of health, but

no significant changes in psychological dimensions in measures of a 'healthy state' were found. According to the findings, nursing and allied health workers employed a biopsychosocial approach to patient care and assumed responsibility for the patient's well-being. Conversely, physicians who embraced a biomedical approach to patients focused on the medical features of patients.

Engel formulated the biopsychosocial model as a dynamic, interactional, but dualistic view of human experience in which there is the mutual influence of mind and body (Alonso et al., 2004). The model emphasises the need to balance a circular model of causality, and he needed to change the clinician's stance from an objective detachment to reflective participation, thus infusing care with greater warmth. Engel intended to broaden the scope of the clinician's gaze. His biopsychosocial model was a call to change the way of understanding the patient and to expand the domain of medical knowledge to address the needs of each patient (Alonso et al., 2004; Amoroso et al., 2010). It is perhaps the transformation of the way illness, suffering, and healing are viewed that may be Engel's most durable contribution. Engel did not deny that mainstream biomedical research had fostered important advances in medicine, but he criticised its excessively narrow (biomedical) focus for leading clinicians to regard patients as objects and for ignoring the possibility that the subjective experience of the patient was amenable to scientific study (Engel, 1997; Epstein, 2004). Engel argued that to fully understand and respond adequately to patients' sufferings and to give them a sense of being understood, clinicians must attend to the biological, psychological, and social dimensions of illness simultaneously. He offered a holistic alternative to the prevailing biomedical model that had dominated industrialised societies since the mid twentieth century (Engel, 1997).

Gatchel et al. (2015) highlighted the fact that the biopsychosocial model of disability not only involves impairments and pathophysiological reasons but also includes psychosocial and lifestyle factors. This point of view partly opposes the medical and social models of disability, as it views these models as incomplete (Gatchel et al., 2015; McGeary and Lippe, 2014). Professionals, academics, clinical practitioners, and researchers adopt the biopsychosocial model to better understand the pain and discriminatory issues derived from biological, psychological, and social factors (Gatchel et al., 2014). Regarding the differences between the medical and social models of disability, it is believed that both are necessary and can contribute to understanding disability, as they might be seen as two sides of the same coin (Haegele & Hodge, 2016). The medical model considers disability a medical phenomenon – perceiving the individual as faulty and deficient, with limited functioning naturally

disabling a person. However, the social model refers to disability as a social construct – separating impairments and disability, which is viewed as an abnormality of the body (impairment) and a disadvantage caused by society and perceiving the individual as unique (Haegele & Hodge, 2016). Moreover, the medical model places the insufficiency on the individual but the social model on the surrounding external environments (including society) that fails to accommodate people with disabilities (Haegele & Hodge, 2016).

Recently, Bolton and Gillett (2019) examined the past, present, and future of the biopsychosocial paradigm (Frazier et al., 2020), providing an overview of four decades of research. The authors concluded that the BPS paradigm lacked clinical, scientific, and philosophical merit. Even though their book is timely and well written and intends to highlight flaws that could drive science and practice forward, their criticisms are not fully convincing and are open to debate (Frazier et al., 2020). The lack of scientific data to support or disprove the BPS model and a narrow appraisal of its worth only in terms of aetiology and therapeutic application are among the flaws highlighted (Frazier et al., 2020). He discovered a lack of clarity in the authors' viewpoint and the criticisms they made, as well as a hazily described reworking of the BPS model to address the flaws Bolton and Gillett introduced. Frazier eventually concluded that their philosophical approach to the BPS model ignores the fact that it has been and continues to be the main approach for health professionals and research, as well as for most health professions (physiotherapy, nursing, occupational therapy, counselling, and social work).

Studies have highlighted and investigated the link between physical, psychological and social aspects and the HRQOL in patients with stroke (Alonso et al., 2004; Nicassio et al., 2011). The findings of this study (seen in chapters 6 and 7) suggest the need to address psychological aspects in the clinical management of patients to improve HRQOL. The biopsychosocial model emerged from the need for a better understanding of the human being as stated in the research study. It is known that physical, emotional, cognitive, and psychological problems may result from stroke and affect quality of life and work / physical activities (Gatchel et al., 2015). The model examines how the three aspects, biological, psychological and sociological factors occupy roles in the quality of life of stroke survivors in our study (Alonso et al., 2004). Therefore, evaluating the relationships using a biopsychosocial approach in understanding the impact of stroke on QOL of the stroke survivors may help us improve our understanding of who is more at risk from poor quality of life and inactivity. Understanding the

factors that most influence quality of life in stroke survivors may contribute to reducing barriers to good quality of life and physical activity and at the same time reduce rates of recurrent stroke and associated morbidity and mortality in the SE communities of Nigeria (Gatchel et al., 2015; Haegele & Hodge et al., 2016).

An advantage of the use of this model is that it is a class of trans -disciplinary behaviour, which looks at the interconnection between biology, psychology, and socio-environmental factors. According to Wade D and Halligan et al., (2017) they suggest that the framework accepts that illness and health are the results of an interaction between the factors. The approach understands that the systems overlap and interact to impact the individual's wellbeing. Understanding these systems can lead to more effective rehabilitation.

The model is also beneficial for clinical practice and rehabilitation as it allows health professional to treat people who have diseases and not just the diseases people have, this allows for the ability to understand people beyond their biological functioning and to view human health in its fullest context (Ghaemi et al., 2011). The model also includes the mind body connection. Health is a state of complete physical, mental, and social well-being and not simply the absence of disease as defined by the WHO (World Health Organization)

The model recognises the Importance of patient self-awareness, relationships with the health professionals in the health care system and individuals' life context (Ghaemi et al., 2011). This is relevant concerning the research study as the model was used as the basis for the mixed method approach in relation to the HRQOL questionnaire and the semi structured interviews.

However, research and critics have concern that the model is not scientific enough and feel it has not met the 'Gold standard' of being validated through randomized trails. Another criticism on the pragmatic side of things (Ghaemi et al., 2011). By being all – inclusive. It is argued that the health professional who adopts the BPS is in real danger of losing boundaries regarding their knowledge and expertise, are health professionals expected to now understand everything? As the general trend in medical science is towards specialisation and not broadening one's perspective (Ghaemi et al., 2011).

4.4 Biopsychosocial Model in relation to Africa

In Nigeria there is an adage that states “Health is everything, health is wealth” meaning whoever has good health has everything (Akintunde et al., 2006). As previously mentioned in chapter three, the health care systems of Nigeria emerged from colonial medical services that emphasised costly high – technology, urban based care (Asare et al., 2017). When Nigeria gained independence in 1960, she inherited health-care systems modelled on those of the industrialised western nations that had colonised them (Chukwuneke et al., 2012.)

Because of different understandings of what disease is, primarily due to ignorance, limited knowledge of health, and poverty, health models of care in Africa are influenced by culture, behaviour, beliefs, and attitudes (Asare et al., 2017; Chukwuneke et al., 2012). Primary Health Care (PHC) is the accepted model for delivering basic health care to LMIC such as Nigeria. The PHC programmes in Nigeria appear to have a theoretical framework which possesses new challenges for understanding health (Chukwuneke et al., 2012). Understanding of health problems and their causes varies from community to community, society to society within the community, religion to region, and culture to culture in Nigeria, as in most African countries (Asare et al., 2017).

The presence of the concepts of biomedical, psychological, and social environmental factors in African medical approaches demonstrates that the historical trajectory of modern health care points to holistic approaches (Asare et al., 2017). As a result, an effort should be made to deepen the dynamic connections and interrelationships between physiological, psychological, and socio-environmental factors - a dynamic overlap that should serve as the foundation of all levels of health care and health promotion (Chukwuneke et al., 2012). The health theory and practice produced by efforts toward patient-centeredness, respect for the individual, value awareness, and narrative sensitivity are all biopsychosocial in nature. A study by Margalit et al. (2007) argued that presentation of illness cannot be considered in isolation from their psychosocial causes and consequently, therefore, the individual’s disease cannot be divorced from the psychosocial, personality and environment.

Some theoretical appraisals endorse the biopsychosocial model as allowing “illness to be viewed as a result of interacting mechanisms at the cellular, tissues, interpersonal and environmental levels” (Fava et al., 2008). Similarly, the sub – Saharan African (SSA) landscape has adopted and recommended the biopsychosocial model with varying levels of integration (Fava et al., 2008). There

have been some experimental and observational requirements for normalising the biopsychosocial model in SSA. Comparative studies have investigated both the biomechanical and biopsychosocial aspects of health in East, West, and South Africa. One such study published in 2017 on the predictors of chronic low back pain disability in Nigeria, reported that the psychosocial factors such as illness perception and fear – avoidance beliefs were more important than the biomechanical factors like pain intensity (Igwesi et al., 2017). These results were found to be in contrast with the existing management based on the dominant biomedical model. A qualitative study by Nkhoma et al., (2021) in Malawi has recommended the BPS model for planning health interventions especially in chronic care management. Another study in Zimbabwe by Chigangaidze et al. (2012) reported that public health and social work researchers have endorsed the BPS model for policy and practice in disasters and outbreak management in the context of Covid-19. These conceptual and observational studies highlight the fact that the field of health has a quest for holistic approaches in SSA (Asare et al., 2017).

4.4.1 Culture, Religion, and health care in Low middle class income Countries

The constitution of Nigeria guarantees religious freedom. Hence there are many religions that are practiced in Nigeria (Chukwuneke et al., 2012). Christians predominately live in the SE /SS areas of the country whereas the Muslims are largely based in the Northern parts of Nigeria. As stated previously in earlier chapters, Nigeria has the largest population in Africa with over 250 ethnic groups and more than 510 languages (Igwesi et al., 2017). As a result, the country has become a complex society with various cultural and religious practises that reflect the people's attitudes, behaviours, and understanding of their health. Extended families are still the norm and the backbone of Nigeria's social system (Igwesi et al., 2017). Grandparents, cousins, aunts and uncles, sisters, brothers, and in-laws all work together to overcome life's challenges. Hierarchy and seniority govern the family unit. Members of families frequently turn to one another for help in times of need and are expected to support the existing system (Chukwuneke et al., 2012). Consequently, in certain situations, one does not have the authority to make health decisions without the input of family members. With the spread of Western culture in most urban areas, the role of the extended family system is gradually diminishing, but a strong tradition of mutual caring and responsibility among members remains (Chukwuneke et al., 2012). Most individuals, however, particularly those in the community, believe that diseases are frequently caused by supernatural forces, bad luck, witches, and wizards (as

discussed in chapter three). As a result, there is an under representation of primary health care service utilisation, because most people do not accept the health care system models that are provided for them. The biopsychosocial model, as discussed earlier in the chapter, is defined as an interdisciplinary model that examines the interconnections between biology, psychology, and socio-environmental factors (Asare et al., 2017).

4.4.2 Health seeking behaviours and the impact on culture in Africa

Age, gender, culture, religion, occupation, illness, levels of education, general attitudes, and knowledge about the presenting illness are all factors that influence people's health-seeking behaviours (Obionu et al., 2006). Other enabling factors include health-care availability and accessibility, financial resources, social networks and support services, and perceptions of disease severity. However, to understand behaviours, these factors must be contextualised. Understanding human behaviour is required to change behaviour and improve health practises (Obionu et al., 2006). Experts in health interventions attribute this to cultural influences, as culture and personal beliefs play important roles in people's health-seeking behaviours, particularly in most rural areas of Africa (Chukwunke et al., 2012). For example, Hausman - Muela et al. (2017) described how malaria and witchcraft can be linked in illness interpretations. They claim that Tanzanians believe that witchcraft can prevent 'biomedical' treatment from working on malaria parasites by creating a barrier between the body and the outside world: the person in question would obviously seek treatment from a witch doctor before seeking western medicine. To increase Nigerians' health-seeking behaviour, service providers should be properly structured to understand and appreciate the need for health outreach programmes, particularly in rural communities (Hausman – Muela et al., 2017). As previously stated, the local government, private and public health providers should establish a communication network that connects health care institutions, stroke survivors, families, and local faith communities.

Asare et al. (2017) conducted a study of the African belief system in relation to existing health models. The study concluded that spiritual doctors / traditional medicine is the first to be confronted with difficult health conditions. They argue that spiritual beliefs in the community give people hope, so they should not be rejected, but rather encouraged by health providers to guide and facilitate the individual's recovery from illness. As stated in Chapter 3, the combination of traditional and western medicine can help to speed up illness recovery. As a result, when compared to the biopsychosocial

model in Western culture, the new health model in African culture can be the biopsychosocial model - with the representing spiritual practice (Asare et al (2017).

Africans' behaviour is motivated by what they believe, which in turn is based on what they experience (Frazier et al., 2020; Asare et al., 2017). The current Western model of biopsychosocial model is used to explain health and illness. Health is considered to comprise physical, mental, emotional, and social factors. However, for the Africans, well-being is not just about the healthy functioning of the body system through proper health care and lifestyle; it goes beyond scientific causes to include spiritual involvement, as seen in the main findings of this study. One cannot stop Africans from believing in supernatural powers. The continued existence of spiritual beliefs among Africans suggests the heritability of these beliefs. According to studies, this is because it is passed from one generation to the next through parenting and education (Danquah et al., 2014). Modification of the biopsychosocial model to include spiritual factors is best suited to the African culture, as spiritual beliefs offer hope (Asare et al., 2017).

4.4.3 The Problem with the Integration of the Biopsychosocial models in Sub-Saharan Africa

The essence of complete care and hope for a framework in which holistic care can be incorporated into a health system structure is the importance of the BPS model. The problem is that it has yet to be successful (Frazier et al., 2020; Asare et al., 2017). The west debates that BPS integration has a completely different history than SSA. Engel (1977) questioned medical theories in the medical field that left little room for psychological content. The question was whether those disciplines belonged in any way to the scientific field of medicine. African traditional medicine and its practitioners, on the other hand, historically provided the earliest health care in SSA (Asare et al., 2017). As a result, the globalisation of western health systems was successful in introducing the BPS in SSA. However, there was a lack of cross-cultural exchange between western medicine and African traditional medicine.

It is explained that the introduction of western medicine and culture gave rise to 'cultural philosophical clash' which had created an unequal power – relation that practically undermined and stigmatised the traditional health care system in Africa because of the overriding power of the western medicine (Ratzan, et al. 2000). It is said that western medicine prescribes specific drugs for a disease. In contrast, traditional medicine focuses on treating the person rather than just their symptoms. It is

believed in the African culture that the western medicine only occupies one function – which is getting rid of the symptoms of an illness whereas the African medicine performs three distinct functions (Ratzan, et al. 2000).

- Getting rid of the symptoms
- Identifying and removing the causes of the illness
- Maintaining a holistic balance (including spiritual) in the patient.

This practice of medicine has evolved over time and many people refer to these two distinct approaches as traditional and western (Ratzan, et al. 2000).

Ratzan (2000) reports that the traditional medicine can provide crucial links between disease and behaviour as well as effective treatment not found in the western medicine. Therefore, there is the need for African leaders to pay serious attention to global trends in TM discourses for the benefit of all. This would require that both traditional and western health professionals acknowledge their areas of strengths and weaknesses in order to minimize the current distrust and the perceived paranoid between western and traditional medicine. It is only then that these current distrust between traditional and modern medicine can be accomplished for the benefits of millions of people who depend on TM in Africa.

Part of the issues concerning cross – knowledge exchange between western medicine and traditional medications is very much culture, attitudes, and belief. For example, a study by Oyelakin et al (2009) highlight the issues of the Yoruba / Nigeria culture and medicine and argue that the integration of Yoruba traditional medicine into Orthodox medicine is unnecessary. They argue that culture is the totality of the ways of life and a totality of people belief and practices (Oyelakin R.T.,2009).

However, in the quest to evolve to a better and a more resilient global health system, where the attention is directed to sources of knowledge which include the traditional and western medical systems (Abdullahi, A.,2011). There is a growing awareness of the fact that traditional and western medicine can contribute to higher acceptability amongst the population rather than relying solely on one system (Abdullahi, A.,2011). This calls for a pluralistic health system which is one where a variety of diverse providers, serves and organisations co-exist and communicate with one another to provide health care to a community / population (Abdullahi, A.,2011). Bridging the gaps between western and

traditional knowledge systems is now considered an important imperative for improved health and outcomes (Please see the Adig Model of health care –discussion chapter).

As previously stated, there is a need to focus on health outreach programmes, the interrelationship of health models (as seen above), communication networks, training and enlightenment campaigns among health providers and institutions in Africa, particularly in the most vulnerable parts of Africa, such as Nigeria, the African giant.

4.4.4 Summary of Chapter

This biopsychosocial model has provided a theoretical health care framework that considers both positive and negative factors both in the western world and the developing world. It is hoped it provides clarity in understanding the impact of stroke on the quality of life of stroke survivors in the poor communities of Nigeria. Studies have recommended applying the ICF in LMICs, such as Nigeria, where less robust disablement models are still being used to explore disablement (Sango et al., 2013). However, the three models in this chapter coexist as three complementary methods that contribute to the framework's overall strength in exploring the various aspects of health and illness.

As a guiding framework, the biopsychosocial model has proved remarkably successful, as it has enabled health professionals to be at the forefront of efforts to forge a multilevel, multisystem approach to human functioning, globally. In the context of this research study, the BPS model was applied to better understand the disease process, its causes, and the effects of stroke on the quality of life of stroke survivors. Chapter 5 situates the study within a specific methodological tradition by describing and emphasising the rationale for the methods used in this mixed method study.

CHAPTER FIVE

Methodology

5.1 Introduction

The previous chapters have set the background to this research and have described my approach as a researcher. However, this chapter presents a discussion of the beliefs that underpin the research and my views and beliefs on epistemology and ontology which in turn have led me to adopt a mixed methods (MM) methodology to the research. It also discusses why, within MM, I have chosen, in the qualitative phase 2, a phenomenological method influenced by Heidegger, and his hermeneutic phenomenology with the use of IPA method. This methodological approach is used to examine the impact of stroke on the quality of life of stroke survivors in Nigeria's SE communities. Inquiries were conducted from December 2019 to January 2021.

5.1.1 Qualitative and Quantitative methodology

There have been two main research methodologies used in research, described as quantitative and qualitative; however, traditionally researchers from social sciences were influenced more by quantitative and positivist stances (Creswell et al., 2017). Since the early 1980s, though, there has been an increase of interest in qualitative, naturalistic approaches to research. It is claimed that qualitative, naturalistic methods are preferable within the social sciences, with authors arguing that qualitative methods may gather data about human behaviour that is impossible to obtain by quantitative methods (Creswell et al., 2017; Clark et al., 2009).

5.1.2 Definitions of Terms

Quantitative / positivists research methodology tests the importance of the hypotheses of studies. It is deductive and systematic in nature, often presents in numbers with the use of experiments, therefore involving mathematical calculations, surveys, and stimulations (Clarke et al., 2009). Data are often analysed numerically and interpreted relatively easily. This helps the researcher identify the cause of the experimental results or observations. The strength of quantitative methodology involves the provision of precision as measurements are considered to be reliable. It presents good controls through design and data sampling. It also provides sophisticated analysis with the use of statistical techniques (Flick, 2017). Its limitations, however, involve the loss of knowledge of human experience and therefore the variables are no longer under the researcher's control. It also produces insignificant

findings of minor situations and does not take into account the individual's unique ability (Creswell et al., 2017).

Qualitative, naturalistic research methodology is inductive and descriptive in nature. Its aim is to understand the experience and to evaluate knowledge, attitudes, behaviours, and opinions of individuals concerning a specific research topic (Flick, 2017). Observations and description are crucial in this methodology. The method is based on the quality of the phenomenon and focuses on feelings, viewpoints, and behaviours. (Creswell et al., 2017). The strength of this method is that it is descriptive in nature with the findings. Its limitations are that reliability and validity can be of some concern if not managed well.

The one key similarity between the two methodologies is the logical search to find a solution to the research problem. However, in contrast, a difference between the two methodologies is the positioning of the researcher (Flick, 2017). The researcher in quantitative research acts as a removed 'observer', where the influence in the data generation is minimal or at least minimised, whereas the researcher in qualitative research is involved in the attempting to understand and interpret the social world through the eyes of the participants (Creswell et al., 2017, Clark et al., 2009).

Therefore, the rationale for the use of a mixed methods (MM) approach for this research study (as mentioned in earlier chapters) is to understand the synergy between the two types of findings that reflect participants' points of view (Creswell et al., 2018). This gives voice to the study participants, ensuring that study findings are grounded in participants' experiences. It will also ensure the combination of paradigms, allowing investigations from both the inductive and deductive perspectives which will enable the researcher to combine theory generation within a single stance. Onwuegbuzie et al. (2009) and Creswell et al., (2018) discussed the relevance of using a MM approach and have suggested that its strength lies in the ability to gather, analyse, and integrate data concerning the same phenomenon, and to explore convergence or corroboration of results for the purpose of eliminating the inherent bias associated with the use of only one method.

It is suggested that the choice of methodological approach taken for one's own research is heavily influenced by one's philosophical belief regarding the assumptions relating to the most general features of the world (Creswell et al., 2017 and 2019). Essentially the researcher either has a belief in

a naturalist or a positivist philosophy or both. As stated in earlier chapters this study adopts an MM approach because it is congruent with my world views, and it fits with the current research question.

Therefore, in summary, I chose a pragmatic approach as seen in the above study; this is a practical approach that allows and encourages me to choose the most appropriate methods available to answer the research question effectively and thoroughly (Creswell et al., 2019). The logic behind mixing methods is because neither qualitative nor quantitative methods were significant in themselves to capture details of the phenomenon concerning the impact of stroke on the quality of life of stroke survivors in the SE communities of Nigeria. According to Creswell et al., & Braun et al., (2011), they report that mixed methods combine the elements of the qualitative and the quantitative to effectively answer the research question. This helps to gain a more complete picture than a stand-alone study, as it integrates benefits of both methods. It also creates increase comprehensiveness and confidence in the findings of the study (Creswell et al., 2019). It was also important to give voice to the voice less or be the voice of my study participants to ensure that the findings of my research study were grounded in their lived experiences.

5.2. Philosophical Paradigms

It is generally assumed that quantitative and qualitative research are based on different philosophical paradigms (Flick, 2017). Positivism or post positivism for quantitative research and constructivism / interpretivism for qualitative research. Positivist or quantitative researchers believe in a single reality, in other words a reality that can be measured and understood, whereas the interpretivism paradigm or qualitative researcher asserts the existence of numerous realities suggesting that human behaviour is complex and cannot be easily controlled (Manson, 2006; McGee, 2017). The post positivism paradigm which is concerned with the subjectivity of reality purports that there is only one absolute reality out there. However, as reiterated above, this study chose a Pragmatism paradigm, based on a MM approach, which incorporates both positivism and interpretivism within a single study (McGee, 2017).

5.2.1 Ontology – What is the nature of reality?

What we know, and how we come to accept what we believe to be our reality are questions which researchers must consider as part of the methodological preparation for their research as it has implications for the framework which they will choose to adopt (Flick, 2017). This is especially

important in phenomenology as each different phenomenological approach has its own underlying assumptions which the researcher must be careful about (Creswell et al., 2019).

Reality as described by Lincoln and Guba (1985) can be classified as objective, perceived, constructed, or created. Individuals create their own realities which they can then choose with whom, and when, to share with others. I am contented with this constructed reality belief in that, I accept that each individual will have their own interpretation of events that they have experienced, and each individual experience will be unique to them. I am also comfortable with the objective reality where reality can be measured, therefore, creating either single or multiple ways of knowing the truth. I will not attempt to understand these experiences from the participants' perspectives; rather, I will attempt to understand what they have told me through my own values and beliefs system, which shapes my interpretations. (Discussed further in Chapter 6, hermeneutics phenomenology and IPA).

I believe that reality is something that can be measured and generalised and is unique to each person. By approaching the study from both philosophical perspectives, a greater depth of knowledge can be obtained concerning the impact of stroke on the quality of life of the stroke survivors in the SE regions of Nigeria.

Therefore, when choosing my approach to research and data generation, I needed to choose a framework and method that would allow the following (Creswell et al., 2019):

- A framework which allows action, intervention, and constructive knowledge.
- A framework where participants share their own experiences with me.
- A framework that finds the most workable solutions to define concepts and explain phenomena.

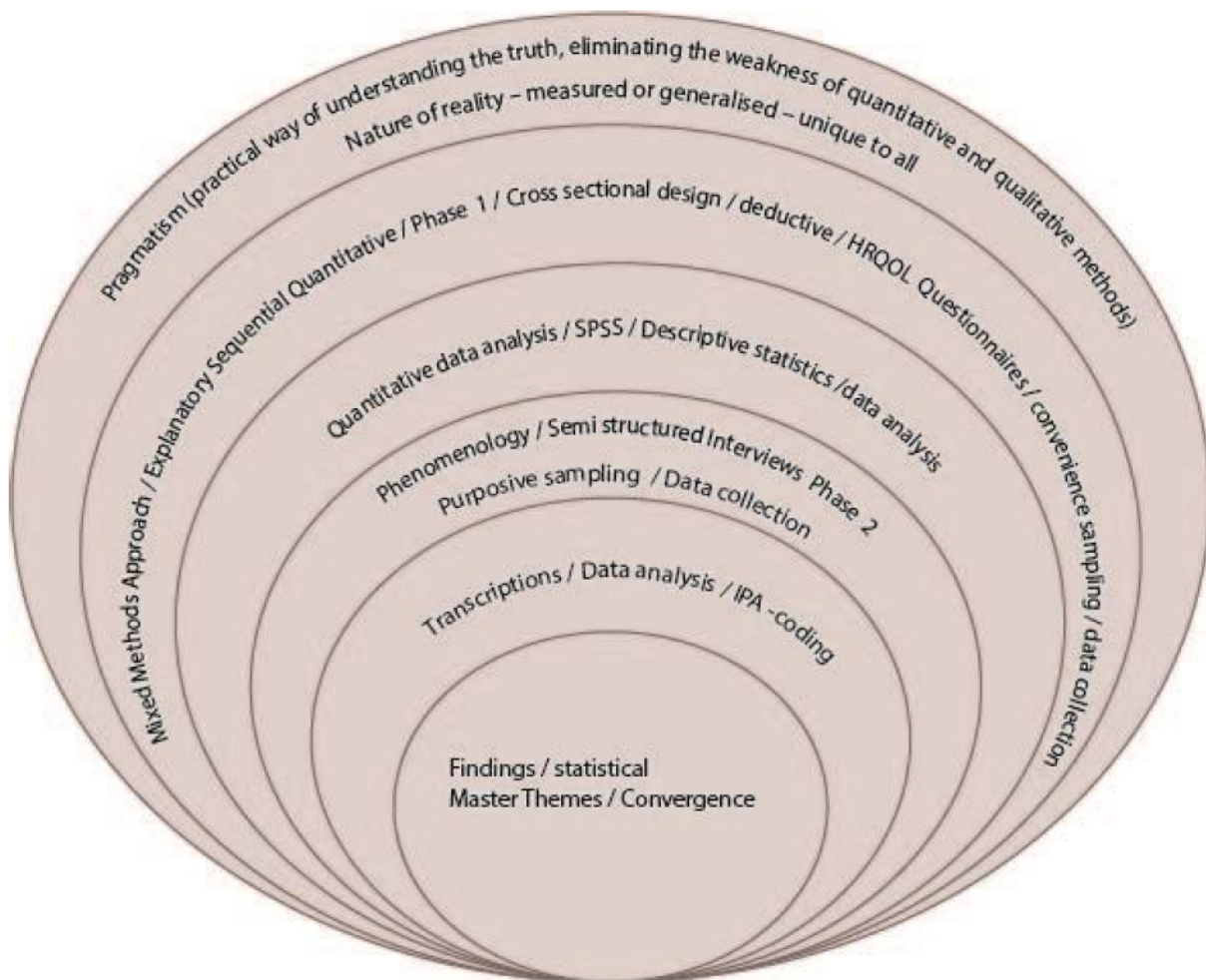
All the above criteria fit within the pragmatic view of ontology and within hermeneutic phenomenology and my chosen methods.

5.2.2 Epistemology – what can we know?

What one knows (epistemological views) is shaped by one's ontological views (our beliefs about what is real) (Creswell & Plano Clark, 2011). Within the positivist view knowledge is asserted, hence, research should be carried out in an objective (or value free) manner (Creswell et al., 2019). As discussed above, based on my ontological view, this is not possible for me as a researcher, as my

preconceptions will influence my interpretation and therefore understanding of knowledge generated. So, for this reason my epistemological views do not sit comfortably alone with the positivist view. However, with the interpretivist claim to knowledge, the aim of the researcher is to understand a phenomenon rather than to attempt to explain it (Flick, 2017). These ontological and epistemological views and beliefs which together form part of my world views led me to adopt a pragmatic approach to this research using MM methods (Taskakori and Teddie, 2010). Therefore, in line with the pragmatic framework chosen, I am contented having a pragmatic view to knowledge.

Figure 7: Research Triangle Framework



Source: Editor. Based on The Research Onion Triangle. (Creswell JW., 2019)

This above research triangle layers give a more detailed description of the stages of the research process. It also provides an effective progression that involves the development of my research work (Creswell et al., 2019).

5.3 Objectives of the research study

- To describe the epidemiological profile of stroke survivors in the SE communities of Nigeria
- To assess the HRQOL of stroke survivors (using the HRQOLISP questionnaire) and identify associated determinants.
- To conduct semi – structured interviews to ascertain detailed perceptions concerning QOL in stroke survivors.
- To engage in field observation to gain more insight into behaviours and attitudes of participants to enhance field notes.

A non-experimental (no experiment) explanatory sequential mixed method approach was chosen for the research study as it combines quantitative and qualitative data collection and analysis in a sequence of phases as seen above in the research triangle framework and in former chapters of the research study (Creswell & Plano Clark., 2018).

5.4 Mixed Method Approach (MM)

5.4.1. Introduction

The MM approach involves the collection and analysis of both quantitative and qualitative data within a single study (Creswell et al., 2019). MM is defined as an approach to inquiry in which the researcher connects qualitative and quantitative data in order to provide a unified understanding of a research problem. Clark et al. (2009) suggested that both methods must be clearly articulated in the design, and each should illuminate how they answer the research question. However, Creswell et al. (2019) discuss the evolution and fusion of quantitative and qualitative methods for the purpose of addressing complex problems. The employment of both quantitative and qualitative methodologies to investigate a single research question has sparked debate and is still very unusual in physiotherapy research (Clarke, 2009). The growing popularity of mixed method research has reignited debates over whether (and how) quantitative and qualitative approaches should be used. The conflict between standalone qualitative and quantitative approaches began in the mid - nineteenth century (Beeker and Geer, 1957). Today, mixed method research has spawned a 'burgeoning field' of methodological and

theoretical debates (Flick, 2017) over the qualitative-quantitative divide and method integration (Manson, 2006; McGee, 2017). However, when attempting to comprehend the understanding of a chronic disability condition, such as stroke, and its impact on the quality of life of survivors from the perspective of the participants, a mixed-method approach is likely to provide the most thorough picture. It was critical for me to be able to explain and contextualise the quantitative findings using qualitative data for this study, as the benefits of a mixed method approach for this study revolved around three key concepts.

Generalisability- The study's interviews used a small sample size, which cannot be used to generalise the population of stroke survivors in SE Nigeria (Creswell et al., 2020). As a result, using quantitative data allows one to see how interviews can be applied quantitatively to a larger audience, which is beneficial to the study. **Conceptualization –** The mixed method approach enabled the researcher to contextualise the two sets of findings (quantitative and qualitative), adding richer detail to the conclusion (Polit and Beck et al., 2014). **Credibility –** Using various methods to collect data on the same subject can improve the credibility of the results. In the case of this study, for example, the quantitative and qualitative data converged at some point, inevitably strengthening the study's validity in a process known as triangulation (Creswell et al., 2017; Clark et al., 2009). (For more information, see Section 5.4.3.) The next section reveals the philosophy behind mixed method approaches.

5.4.2 Pragmatism – ‘The Paradigm War’

A mixed method research design informed by the pragmatic position (Creswell & Plano Clark, 2011) was considered to provide the most appropriate design for this research project and its question. A currently widespread view within the mixed methods community is that pragmatism is the appropriate philosophical paradigm for mixed method research. However, the assumption that paradigms can be positioned side by side (e.g., within the same research study) without conflict has been described as the ‘paradigm war’.

Pragmatism is considered the paradigm that provides the underlying philosophical framework for mixed method research (Taskakori and Teddie, 2010). Both approaches combined lead to a better understanding of the research purpose. Pragmatism is an approach that has been associated with mixed methods – in other words, the flexibility to see the merits of both methods and adapt to the research at hand. Pragmatism has also been described as a deconstructive paradigm that advocates

the use of MM in research; it side-steps the contentious issues of truth and reality (Feilzer, 2010). Pragmatism carries an everyday meaning as being practical (Rorty, 1982). It is believed that knowledge is consequential – that is, generated after action and reflection in action – even if we can use what we know to guide our actions (Dewey, 1931/1982). Dewey intended to differentiate between the everyday experience of the world and intelligent action. As human beings, we are often faced with problems to which we do not know how to respond, which means that we need to continually generate knowledge to adapt to a changing world. However, concerns about the use of mixed approaches have been the subject of continuous debate (Flick, 2002; Silverman, 2005). According to some researchers, qualitative research falls within the 'interpretive paradigm' – which claims the world is in a constant state of change, with different subjective realities (Guba and Lincoln, 1989). As a result, quantitative methodologies are viewed as suited for deductive analysis by some. Toombs (1987), however, reported that this could result in a situation in which 'illness or disease' effectively reflects two distinct realities, each with a considerably and fundamentally varied meaning.

Furthermore, Bryman (1988) questioned whether the connection between epistemology and methodology is exaggerated, while Howe (1985–1988) argued that the qualitative–quantitative dispute is a result of positivist presuppositions. Howe (1985), along with an increasing number of other pragmatists, argued that value-laden qualitative methods and descriptive quantitative methods result from uncritical acceptance of positivist epistemology. Howe's postpositivist perspective is similar to that of the philosopher Quine (1951), who was the first to reject the positivist assumption that empirical evidence and related laws and theories have a precise relationship. All knowledge is viewed as theory-laden rather than as reality subdivided. According to Haase and Myers (1988), both interpretations of reality's nature are compatible and necessary for understanding human experiences. While similar experiences might yield numerous meanings, they can also be combined to establish broad principles upon which to base one's understanding of the universe (Haase and Myers, 1988). The paradigm battle raged on into the 1970s and 1980s. By the end of the paradigm war, many authors and researchers felt that quantitative and qualitative research methodologies are compatible. The new paradigm gained acceptance in the late 1980s (Gage et al., 1989).

However, in terms of advantage, this philosophy emphasises activity rather than ideas – 'learning by doing'. The truth is that no philosophy is always true or correct, but pragmatist philosophy does not treat truth as permanent and objective. Instead, all truths are relative to time and space. There are

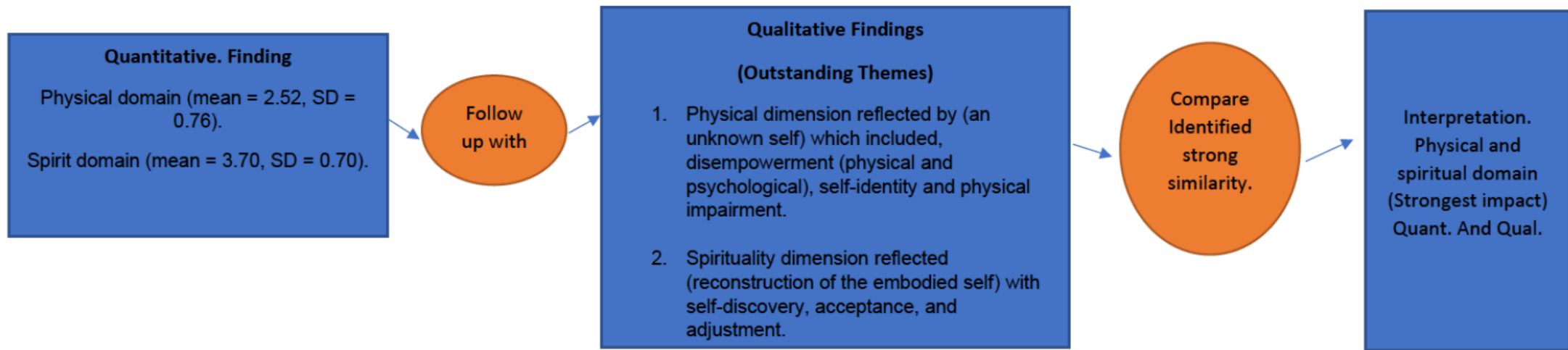
also limitations of learning through doing, as many facts known to an individual are acquired from another person. It is almost impossible for one individual to experience every fact known to them (Hammond et al., 2013). Generally speaking, no single research methodology is inherently superior to any other (Jogulu and Pansiri, 2011). This philosophical level of research methods focuses on assumptions relating to the most general features of the world, encompassing aspects of the mind. It is recognised that there are many ways of interpreting the world and undertaking research, as the principle is that there is no single 'point of view' that can ever give the entire picture (Creswell & Plano Clark, 2011). This approach coincides with my own ontological and epistemological perspective that reality is something that can be measured and generalised and is unique to each person (as discussed above). By approaching the study from both philosophical perspectives, a greater depth of knowledge can be obtained about the impact of stroke on the QOL of the stroke survivors. Nevertheless, Creswell et al. (2017) highlight the choice of adopting MM design as a medium for arriving at triangulation – arguing that the researcher needs to move away from such practice, as it devalues the MM approach.

5.4.3. The Triangulation Designs

This combined convergence model / explanatory sequential approach represents the traditional model of a mixed-method triangulation design (Creswell, 2017). The purpose was to obtain different but complementary data on the same topic (Creswell, Plano Clark et al., 2003) to best understand the research problem, considering the researcher plans to directly compare or contrast quantitative statistical results with qualitative findings.

The quantitative and qualitative data of the research study were collected and analysed separately based on the same phenomenon, as to be seen in chapters six and seven of the research study. This design and its purpose of converging different methods has been discussed extensively in the literature (Green et al., 1987; Morse et al., 1991). See Figure 5.2.

Figure 8: Triangulation of Findings



Quantitative/qualitative mapping of the impact of stroke on the quality of life of stroke survivors in the SE communities of Nigeria

Source: Author

In this study, as stated earlier, data were collected sequentially (Creswell et al., 2017). The intention was to maximise the combined results by seeking ways in which the two sets of findings expand, collaborate, or contradict their respective empirical findings. Greene et al. (1989) argued that these methods are particularly useful when they are similar (such as scaled quantitative questionnaires combined with semi-structured qualitative interviews) and when they examine different facets of the same phenomenon (Creswell et al., 2017). Working with both forms of data allows the researcher to integrate findings or use them to complement each other, thus gaining a deeper understanding of the phenomenon under investigation (Denscombe et al., 2011; Cohen et al., 2011). The research available has concentrated on the delivery of health care, outcomes, and treatment, but there is a paucity of philosophical and empirical research on the impact of stroke on the quality of life of stroke survivors in Nigeria, and even fewer studies employing an MM approach (Hamza et al., 2014; Olufemi et al., 2016). Hence, it is critical to conduct research in this area.

Aside from comprehensiveness, there are numerous justifications for using this approach, including increased confidence in the findings, ensuring that disempowered groups in various countries and communities are heard, and the ability to incorporate both quantitative and qualitative data collection techniques (Creswell and Plano, 2011). MM can also be used to enrich a study, as it uses more than one form of data collection and analysis (Tashakkori & Teddie, 2003). The MM approach addresses several critical issues with theoretical and methodological practices. It impacts the study's aims and outcomes as it provides a reasonable agreement between theories with methodologies. It also ensures the reliability and validity of the overall research findings. However, several studies have argued that a common shortcoming can be the failure to comprehensively integrate findings, thereby limiting the transferability of the MM approach (Bryman et al., 2007; Patton et al., 2011), whilst other studies reiterate that the integration of MM findings remains a challenge for most researchers (Creswell et al., 2017; Denscombe et al., 2011; Patton et al., 2011).

Nevertheless, this study aims to arrive at a useful and transparent presentation of both quantitative and qualitative findings with the use of an explanatory sequential–sectional mixed method approach. Quantitative and qualitative data were collected sequentially. The use of quantitative and qualitative strands facilitates a holistic understanding of the phenomenon under study and promotes data triangulation (Creswell et al., 2018). The quantitative findings of 101 HRQOL questionnaires comprise

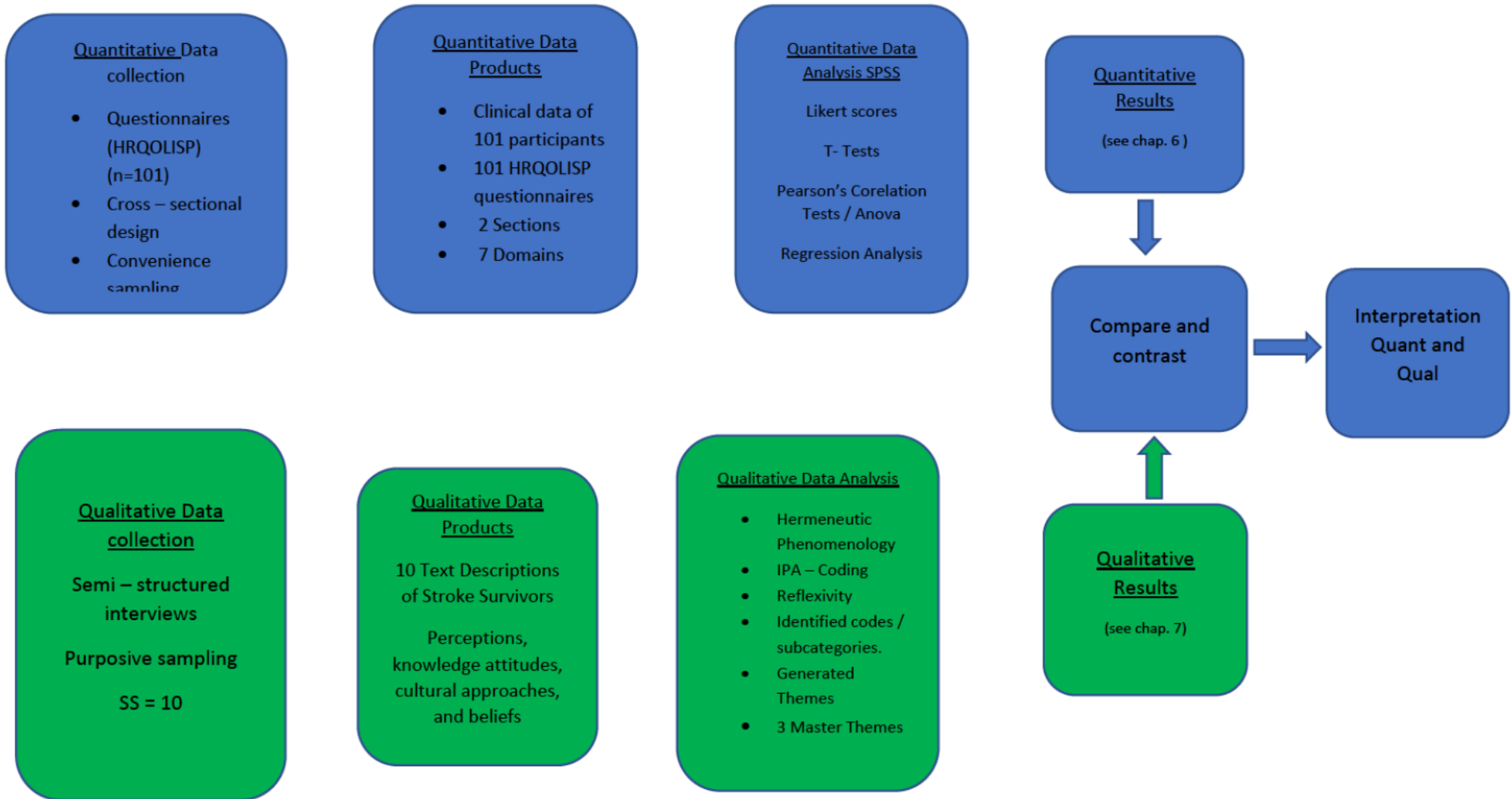
the electronic documentation of the clinical assessment of the stroke survivors. The qualitative findings are in the form of a narrative interrogation of 10 semi-structured interviews with stroke survivors.

5.5 Research Methods

The research study utilised an explanatory sequential mixed method design and is divided into two phases. The quantitative phase (Phase 1) uses a cross-sectional design with convenience sampling. This approach addressed Aim 1 of the study. The qualitative phase (Phase 2) used a hermeneutic phenomenological approach with purposive sampling. This approach addressed Aim 2.

An explanatory sequential design is an approach that combines in sequence, quantitative and qualitative data collection and analysis in a sequence of phases as seen in the methodology chapter (Creswell et al & Clark et al., 2018). The quantitative data collection was performed first in my research study, as the qualitative data explained and contextualised the quantitative findings. Whereas in a convergent mixed method design, this would involve the collection of both qualitative and quantitative data simultaneously, analysing them separately and then merging the results together. This was not the case with the above research study.

Figure 5:4 Mixed method chart design



5.6 The Quantitative Phase (Phase 1)

5.6.1 Definition of Cross-sectional designs

This is described as the use of empirical research to describe a population at a particular point in time. The population with stroke was of particular interest in the investigation. Alternatively, data on individual characteristics such as risk factor exposure and results can be obtained with this approach. This contributes to achieving Aim 1 of the research study, which is to identify characteristics and variables that predict the impact of stroke on the quality of life of stroke survivors in SE Nigeria.

This approach promotes the integration of quantitative and qualitative findings and data, thus providing a more comprehensive source of knowledge (Zheng et al., 2015). This is characterised by the collection and review of relevant data at a given time. It also investigates the situation in a single population and analyses data from that population (Bethlehem, 1999). Rather than using a list to get information on the target population in SE communities in Nigeria, the researcher collected data from a small section of a population with stroke found within four individual medical institutions (see above), using convenience/availability sampling to make inference about the population (Millet et al., 2013).

In this study, the cross-sectional design highlights the results from the quantitative data, demonstrating general trends and relationships amongst the various domains, whilst the qualitative results provide in-depth personal perspectives of the stroke survivors in the SE communities of Nigeria. The approach has not only facilitated a more complete understanding than what would have been provided by each database alone but also enabled validating one database with the other (Zheng et al., 2015)

5.6.2 Rationale for the Cross-Sectional Design

Cross-sectional, cohort and case-controlled designs are collectively referred to as observational studies (Mann et al., 2003). Individuals are observed, and outcomes are measured. The researcher observes the behaviour of the individuals in the study without trying to influence the outcome of the study (Mann et al., 2003). In other words, no treatment is given to the individuals. These studies also draw inferences from a sample to a population where the independent variable is not under the control of the researcher (Barria et al., 2018). The following designs were considered for the research

study, but the cross-sectional design proved to be the most suitable in terms of answering the research question.

In a cohort design, data are often already available. The design describes incidences and the natural history of a study. The design measures events in temporal sequences, thereby distinguishing causes from effects. The study is often performed post hoc and is 'followed up' retrospectively. The study period may take many years, but the time to complete it is only as long as it takes to collate and analyse the data (Barria et al., 2018). However, in comparison, these designs are much cheaper to run, as the data have already been collected. A single study is said to be able to examine various outcome variables, and its lack of bias attribute is promising, as the outcome of current interest was not the original reason for collecting the data. Nonetheless, because the cohort was originally constructed for another purpose, it is unlikely that all the relevant information would have been rigorously collected. The design presents with limitations, such as issues surrounding confounding variables, which acts as a major weakness that would affect the analysis of the cohort designs. It is also quite expensive to run, with issues related to ethics. Subject selection and loss of follow-up are other major potential causes of bias (Mann et al., 2003).

In contrast to cohort and cross-sectional designs, case-control studies are often retrospective in nature. The subjects with the outcome of interest are matched with a control group. Some of the subjects would have also been deliberately chosen because they have the disease (Mann et al., 2003). Case-control designs are much more cost efficient than cohort and cross-sectional designs. These types of designs determine the relative importance of a predictor variable in relation to the presence or absence of the disease. The advantages are that they are simple, quick, and inexpensive to organise. They can be used for the generation of hypotheses, with the requirement of fewer subjects; hence, more resources are available to study each subject in depth (Robert et al., 2015). They are quite common in research and are particularly good for studying infrequent events. The use of previously collected data is also efficient and inexpensive. However, with data being collected in a standardised way, this permits comparisons over time and between different countries. The design's major limitation is bias, and validation of information is a problem. The selection of an appropriate group for comparison can also be difficult (Barria et al., 2018).

The cross-sectional design was chosen as it aids in the provision of descriptive estimates of the population at a specific moment in time, as well as the documentation of changes since the last observation (Levin et al., 2006). The design is frequently used to estimate the prevalence of the desired result in a particular population, usually for public health planning objectives. This is one of the most effective ways to determine the prevalence and study the associations of multiple exposures and outcomes in a study. This is important in this study as the design identifies the number of people in the study with similar characteristics of interest and the proportions of persons with a particular disease or attribute at a point in time. All the required measurements are administered to the set population at the same time, with different variables accessible at the same time. Many cross-sectional designs are performed using questionnaires and/or interviews. The HRQOLISP, for example, was used in this study.

In this approach, the researcher simultaneously assesses the subjects' outcomes and exposures. This is in contrast to the case-control and cohort designs, which selects subjects based on their result status. However, based on the exposure status, the subjects in a cross-sectional design are simply chosen from an available population of potential relevance to the study question (Sedgwick et al., 2014). The design's strengths lie in being relatively quick and inexpensive to conduct, allowing the researcher to quickly obtain extensive information. Since the subjects are not treated or exposed, ethical issues are rare. Due to the absence of follow-up, less usage of the resource is needed to conduct this design. Data can be obtained on various variables to know how differences in the independent variables might correspond, correlate, or associate with the dependent variables. This is critical for the current study, as one of its aims is 'to identify variables that predict the impact of stroke on the quality of life of the stroke survivors in the SE communities of Nigeria'.

However, limitations of this design are issues surrounding non-responders. It is important that efforts are made to maximise the numbers who do respond to the questionnaires (Sedgwick et al., 2014). This is an actual problem when the characteristics of non-responses differ from those of responders. The issue of non-responders was handled in this study by the researcher and team engaging closely with each participant. The individuals were also conveniently chosen, limiting the non-responder effect, as only those subjects who were available completed the questionnaire (Mann et al., 2003). Studies have also reported that it is difficult to determine whether the outcome that followed the

exposure within the time, resulted from the outcome (Spector et al., 2019), whilst other studies have argued that it is often difficult to check for incidents and stated that associations could become difficult to interpret (Sedgwick et al., 2014). Another limitation is that the design does not allow for relationships between the cause and the outcome (cause and effect). However, because this research employed a mixed method approach, the use of qualitative/interpretive methods (Phase 2) enabled the narrative collection of data, highlighting cause and effect from the subjects' perspectives. It is argued that cross-sectional studies are susceptible to sampling bias because, unlike studies starting from a series of patients, cross-sectional studies often select samples from a large and heterogeneous study population (Spector et al., 2019).

5.6.3 Study Design and Sampling

The study used a cross-sectional method approach to collect data, analyse, and interpret the quantitative data on 101 study participants. Convenience sampling (also referred to as availability sampling) was applied. The approach reflects the multifaceted nature of the above aims and objectives. Phase 1 was designed to promote generalisability of the results related to the impact of stroke on the QOL of stroke survivors in SE Nigeria.

5.6.4 Definition of Convenience sampling

There are several different sampling methods that can be used in research such as snowball sampling (or chain referral sampling). It is often used in qualitative studies as it is effective in getting numbers (Patton et al., 2002). However, its advantage is that they are ideal for hard-to-reach groups or specific groups. Its disadvantage includes very limited potential (Smith et al., 2009). The convenience sampling method, is one of the most used sampling methods, also referred to as availability sampling; this was the sampling of choice for the study, as participants were made available for the study within each of the institutions in the SE communities of Nigeria. The advantages are that the method saves time, money, and effort (Patton et al., 2002). However, its disadvantage is that it lowers credibility and has something of a 'bad reputation' (Schreier et al., 2018).

5.6.5 Study Population and Recruitment

Convenience sampling was used to recruit one hundred and one (101) stroke survivors from the following medical health institutes/clinics: As the phase 1 of the study uses a descriptive cross –

sectional study the sample size of 101 has been predetermined and has not been calculated based on the expected prevalence (P) which is 13.4/100,000 – 10.8/100,000 in the South and Southeast regions of Nigeria.

The first hospital of availability was Amaku Chukwuemeka Odumegwu Ojukwu University Teaching Hospital based in Awka. This is the main teaching hospital within the community; it was re-opened in 2010 following a hospital reconstruction. The second medical hospital was Nnamdi Azikiwe University Teaching Hospital (NAUTH), Nnewi, Anambra, which opened in 1991. This was constructed by the federal government of Nigeria. The third organisation was Stroke Action Nigeria (SAN), which was founded by Rita Melifonwu, a nurse (CEO), in Onitsha (2000). This is a non-profit organisation dedicated to stroke survivors, with the mission of ensuring that everyone affected by stroke receives holistic care. Stroke rehabilitation, self-management and well-being clinics, health checks, management, and preventative clinics are among the services offered. It was fascinating to come across a centre such as SAN in SE Nigeria, as the state lacks any comparable centre. Participant recruitment for the research study took place between December 2019 and January 2021.

Convenience sampling, which was used as a recruitment tool, is a specific type of nonprobability sampling method that entails data collection from members of the population who are readily available to participate in the study. In other words, these participants were patients who visited the clinics and were approached and invited to participate. To participate, all subjects who met the inclusion criteria were invited and contacted. This sampling method was chosen not only because it was the most convenient but also because it was the only option available at the time the study was conducted as discussed above. It appeared to be one of the simplest sampling techniques and was relatively inexpensive to implement at the time. However, due to the inability to generalise research findings and the high levels of selection bias and sampling error, this may serve as a constraint on the study and erode its credibility (Millet et al., 2013).

I travelled to Nigeria for the data collection at the time. However, due to the lockdown restrictions caused by the COVID-19 pandemic, I was unable to return to Nigeria to complete data collection for the final stage. Unexpected changes had to be made; hence, I applied for ethical approval from the University of East London for data collection to take place online via Microsoft Teams and Zoom. Approval for ethics was granted in July 2020.

Participant data was obtained with permission from the central offices of the registries of the above institutions. Letters of consent were provided for the administrative directors. Volunteers who matched the inclusion criteria were contacted by mobile phone. Participants were presented with the patient information and informed consent sheets.

Table 1: Inclusion Criteria

- Patients with definite clinical and radiological stroke diagnosis.
- Patients involved in a stroke rehabilitation programme.
- Patients who had a stroke within one or two years prior to the time of contact with the investigator.
- Patients who can communicate verbally and in the English language.
- Patients who are independently mobile with or without an aid, such as a scooter, wheelchair (powered or nonpowered), Zimmer frame, walking stick, or cane.

Table 2: Exclusion Criteria

- Patients who do not fulfil the inclusion criteria.
- Patients with other medical conditions that are neither risk factors for nor complications of stroke but could interfere with HRQOL.
- Patients who are acutely ill and cannot withstand the rigour of a robust questionnaire or interview.
- Patients with ambiguous stroke diagnosis.
- Patients who are unable to communicate effectively for interview purposes.

5.6.6 Justification for the Use of the HRQOLISP

HRQOL assessment following stroke is becoming more prevalent as it is recognised that therapy evaluation should consider both quality and quantity (Ezejimofor et al., 2016). Not only have quality of life (QOL) studies been beneficial in acquiring a better understanding of patients' reactions to sickness and in strengthening supportive care, but they have also proved beneficial in determining the efficacy of treatment approaches (Mahesh et al., 2020). The majority of currently utilised HRQOL tools were created in high-income countries and may not adequately reflect resource-constrained countries'

features (Mahesh et al., 2020). Studies have highlighted that they do not consider factors such as environmental effects (user friendliness and safety of household items). Economic factors, for example (financial security). Spiritual well-being and soul development, such as (self-esteem, personal growth, and autonomy) even though they are proved to impose an impact on the overall QOL (Mahesh et al., 2020; Pietersma et al., 2013; Ezejimofor et al., 2016.).

The World Health Organisation (WHO) defines QOL as the 'individuals' perception of his/her position in life in the context of the culture and value systems in which they live and in relation to their goals'. Recent global recommendations have stated that domain structures for QOL tools for LMICs should be context specific (Yan et al., 2016; Ezejimofor et al., 2016). The WHOQOL group (1995) stated that 'in addition to the physical, mental and social aspects of QOL, there is now a recognition that spiritual and religious aspects are needed to be included in health-related quality of life'. Epidemiological characteristics, living context and expectations of stroke are prone to vary even within LMICs and HICs (Ezejimofor et al., 2016). They have consequently urged the development of HRQOL tools to incorporate dimensions such as economic expenses, spirituality, and family concerns (Pietersma et al., 2013; Ezejimofor et al., 2016; Saladin, 2000).

Studies have identified the differences between HICs and LMICs in the expectations of the people due to the difference in salary scales and standards of household environment (Yan et al., 2016; Mahesh et al., 2020). Therefore, it is important to consider the social, spiritual, and economic impacts that arise from a stroke, based on the current argument that it is necessary to provide high-quality rehabilitation programmes (Mahesh et al., 2020).

Stroke-related literature in relation to LMICs has been scarce. Hence, most of the evidence on stroke rehabilitation come from western settings and might not be applicable to LMICs such as Nigeria. Therefore, the development of new QOL tools for stroke survivors would enable more context-related quality QOL measurement (Thrift et al., 2012; Yan et al., 2016; Pietersma et al., 2013). However, the section of the QOL measure must be based on its psychometric attributes, which include feasibility, validity, reliability, and sensitivity to change (Daiva Rastenyte et al., 2006)

To select the most appropriate HRQOL instrument for the research project, the researcher should become acquainted with the advantages and disadvantages of the various instructions (Saladin, 2000). Haan et al. (1993) stated that the choice of suitable quality of life instrument should be based

not only on psychometric properties, but also on careful consideration of the research questions, the relevance to the objectives of the study, and the feasibility of the instrument and the specific characteristics of the patients with stroke under study. (Discussed further in Chapter 6 Quantitative findings).

Most instruments used to measure patients' QOL are generic, whereas disease-specific tools are considered better than generic tools for being sensitive in picking the changes of stroke patients (Yan et al., 2016; Ezejimofor et al., 2016). Generic scales are not developed for a specific target population, and they are often used with many patient populations. A major strength of these generic scales is the possibility of detecting the relative effects of disease and treatment on different life domains (Yan et al., 2016). They also allow for comparison of QOL results across patient populations. However, a major limitation is that they are not always sufficiently focused on the specific problems of any given patient population. Disease-specific scales exist for stroke. Such scales do not allow cross-disease comparisons but are often more sensitive to the QOL issues particularly relevant to a specific population of patients (Haan et al., 1993).

Out of the many HRQOL tools, the two most common tools that could have been chosen for the study are SF-36 and EQ-5D (Mahesh et al., 2020). These tools have been validated for several disease conditions, including stroke, as validation is necessary to improve the effectiveness of rehabilitation. The European quality of life is created as a standardised generic scale used for the evaluation of patient health. EQ-5D consists of six items and covers six domains. It comprises a descriptive system as well as an EQ-visual analogue scale (VAS) responders' self-rated health. SF-36 is a 36-item questionnaire completed by the patient himself / herself. The item is grouped into eight domains which embrace a large range of physical activities and psychosocial cognition and includes the evaluation of general health status. There are, however, several limitations to the generic scales, instruments that are affected by 'ceiling effects' (large number of persons with a very high score for a specific test) and 'floor effects' (when the QOL scores are recorded as very low) lack the necessary sensitivity to distinguish among patients. There are also questions concerning the validity and reliability of the generic scales (Haan et al., 1993).

The stroke-specific measures are important to determine the profile of HRQOL in Nigeria stroke patients. An ideal stroke specific HRQOL measure must be rigorous, valued, reliable, patient centred,

responsive, precise, acceptable, and appropriate and must cover all measurable domains of life and functioning (Garraat et al., 2020). These scales are more valid, patient centred and appropriate for accessing HRQOL in specific diseases and populations (Yan et al., 2016). They are more responsive than generic measures because they assess domains of particular interest to the persons with the condition, whereby small changes may be more easily detected.

Following the WHOQOL guidelines (Orley et al., 1993), a stroke specific HRQOL questionnaire for patients with stroke was developed in Nigeria by Owolabi et al. (2011). Studies have argued that investigating HRQOL in stroke without an integrative approach is misleading (Owolabi et al., 2011). This new measure was developed in the lack of a gold standard measure that specifically targeted stroke survivors in Nigeria / Africa. It was established to identify and prioritise areas of need for stroke victims in developing nations, as well as to solve the shortcomings of existing procedures. As a result, the HRQOLISP was selected for the study.

The HRQOLISP is a holistic multiculturally validated measure based on an integrative concept of human life (Owolabi et al., 2011). It consists of (102 items in seven domains). Being stroke specific and patient centred it is known to be more valid, reliable, and responsive than generic measures. The measure exhibits good face, content, construct convergent and discriminant validity, with internal consistency and reliability (Owolabiet et al., 2011). Unlike traditional depression scales, the full spectrum was captured by the psychological domain of the HRQOLISP. It is also more valid than the SF- 23 which has poor validity in the social domain. Furthermore, HRQOL exhibits good discriminant validity in all the domains except in the soul, spirit, and spiritual interaction domains. As mentioned earlier with the absence of floor and ceiling effects, the HRQOLISP has improved validity. The measure would be able to assess the worse and the best health state possible and detect small improvements and determinants.

5.6.7 Data Collection (the Instrument – HRQOLISP)

The HRQOLISP is a standardised robust HRQOL questionnaire for patients with stroke and has been validated by the WHO (2004). This was administered to each participant who met the inclusion criteria within the preferred above locations that was geographically local to the participant. It is a measurement of the health status of individuals and can be used in identifying and prioritising areas of need of individual patients and patients with special needs. This outcome measure is also important in

the identification of the determinants of good and poor prognosis in patients with stroke (Obembe et al., 2013). It was first used in the second half of the twentieth century in the assessment of QOL (WHO, 2001). The WHOQOL group in 1993 defined quality of life as 'an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives' (Obembe et al., 2013). Several generic and stroke specific HRQOL measures including the international classification of functioning, disability, and health framework (ICF) were examined for the study prior to deciding on this outcome measure. However, the objective was to capture the stroke survivors' individual subjective view of their stroke experience in a third-world environment. I believe that the HRQOL was a more appropriate instrument and tool for this study's purpose.

The HRQOLISP is a 40-item scale outcome measure and encompasses two dimensions and seven domains. The physical domain includes physical, psychological, cognitive / intellectual, and eco-social or ADL domains, while the spiritual dimension comprises of soul, spirit, and spiritual interaction domains. Scores for each domain will be summed up and then stratified as severe stroke, moderate stroke, and a mild stroke. The arithmetic mean of the various domain scores will be calculated and compared at the subscale level. The questionnaires were completed with the researcher and researcher assistant (who signed an NDA) in line with the participants' choice for each item. This procedure lasted approximately 30–45 min.

The empirical data collected in Phase 1 provided information used in Phase 2 as a springboard for delving deeper into participants' worldviews or beliefs about some of these domains. The seven domains as discussed in Chapter 2 (The features of a good HRQOL measure for stroke survivors) and above in the section (Justification of the use of HRQOLISP) were used as dependent variables in this study, while age, income, gender, stroke type, and physical impairment were used as independent variables. Pearson correlations, independent t-tests, one-way analysis of variance (ANOVA), and multiple regression were used to determine the relationships between these variables.

5.6.8 Quantitative Data Analysis

(For Further Details, See Chapter Six: 'Quantitative Findings')

Data were analysed using customary routine methods reported in the HRQOL literature (Bruce et al., 2009; Onwuegbuzie et al., 2009; Owolabi et al., 2009; Patton et al., 2002; Tengs et al., 2003).

Quantitative analysis is a scientific method that involves numerical data measurement. As a result, as shown below, customary routine methods in quantitative analysis are the standard methods that are commonly used to measure and analyse numerical data. These methods are widely accepted and have been used in a variety of fields for many years. SPSS version 22 was used to analyse the data, described as follows:

- Epidemiological profile - Demographic variables (continuous and interval scale variables) HRQOLISP were summarised using arithmetic means and SDs. Categorical variables were summarised using frequency tables. Stroke risk factors, subtypes and other clinical parameters of stroke participants were described by prevalence rates and frequencies. SD of the various domains scores and variables in both domains were collated, i.e., item responses were summed without weighting or standardisation. By finding the arithmetic mean, the overall HRQOL score was computed using a scale 0 to 100, with 0 indicating worst QOL and 100 best QOL.
- The measurement of independent variables using Pearson correlations was used to measure the strength of the association between the variables and to inform the direction of the relationships.
- Multiple regression was performed to determine the most significant difference, and identify which variable was the strongest predictor of the HRQOLISP for the current study. The independent variables included age, income, gender, stroke type and physical impairment.
- The significance of the predictive effect (determinants) was evaluated using linear regression.

5.7 Qualitative Methodology

As stated in Chapter 1 (rationale for mixed method approach), the qualitative phase 2, used ten semi-structured interviews to collect data on stroke survivors' perceptions, knowledge, attitudes, and cultural approaches. Thus, encouraging participants to talk through specific experiences allows them to focus on events and situations which have taken place in their lives (Sims and Wright, 2002). This will create further deep in-depth insight into the stroke survivor's perception of their experiences and how they make sense of their experiences.

All the interviews were transcribed and analysed using a four-step interpretative phenomenological analysis process. Identical and interconnected themes emerged from the interviews, permitting synthesis into a single organising framework with three superordinate master themes and several

subthemes that capture the key issues noted by the 10 participants concerning the quality-of-life post-stroke.

5.7.1 The Qualitative Phase (Phase 2)

Hermeneutic phenomenology (using semi-structured interviews) addressed aim 2 of the study. The qualitative (Phase 2) predominated, as it allowed for rich and detailed descriptions of the stroke survivors' experiences. Hermeneutic phenomenology is particularly useful to this study as it allows for an exploration of meaning by interpretation, in which the very production of meaning occurs through a circle of reading, reflective writings, and interpretations (Smith et al., 2015).

5.7.2 Rationale for the Use of Semi-Structured Interviews

The most commonly used qualitative methods in health care research are interviews and focus group discussions (Gill et al., 2008). Interviews can be used to explore the views, perceptions, experiences, and beliefs of individual participants, whilst focus group discussions are often used to explore group dynamics to generate data (Creswell, 2019). The study could have used one of the three styles of interviews: structured, semi-structured, or unstructured. Structured interviews were omitted from the study since they are essentially verbally presented questionnaires that allow for little variance but do not allow for follow-up questions on responses that may have deserved additional investigation (Creswell, 2019). Unstructured interviews were also ruled out of the study because they lack organisation and are difficult to manage and participate in. Further, they lack planned interview questions, which could make the interview extremely confusing to the participants (i.e., the stroke survivors) and are time demanding (often lasting for several hours) (Creswell, 2019). Since stroke survivors frequently experience exhaustion, this style of questioning would have been inappropriate.

Further, focus group discussion was not chosen due to its resemblance to less structured interviews. It is extremely possible that the survivors would withhold their candid and genuine opinions on the subject at hand out of guilt and shame (Borg, 2006). Stroke survivors may also be hesitant to express their true thoughts, as studies have reported that one-third of stroke survivors feel embarrassed in social situations (Moawad et al., 2021).

The semi-structured approach was again chosen because it facilitated the interviewer's ability to 'build a relationship with the participants' (Borg, 2006). This enables rapport and empathy and allows

greater flexibility of coverage. It also allows the interview to go into novel areas and generate richer data. However, on the downside, this form of interview reduces the control the researcher has over the situation, which was demonstrated once or twice during the interview stage. It may also take longer to carry out and is often a lot harder to analyse; however, this method was the best option to use to answer my research question. All the interviews were transcribed and analysed using a step-by-step interpretative phenomenological analysis (IPA) process. It is believed that interaction in a social situation will create a more relaxed environment to explore and evaluate the second part of the question, as the interviews took place in the patient's environment of choice. This allowed me to gain a considerable degree of flexibility since the participants were asked to reflect on both their present and past experiences (Sim & Wright, 2002). This method uncovered attitudes and behaviours, trends in thoughts and opinions of the participants, giving further insight into the problem (Onwuegbuzie et al., 2009).

5.7.3 Semi-Structured Interviews

Ten semi-structured interviews were conducted. The selection of 10 participants was based on the philosophy of IPA. Smith et al., (2009) argued that between 3-12 participants is a reasonable size for analysing the similarities and the differences between participants in IPA.

The participants were selected from the main ethnic group in SE Nigeria (Igbos) and were between 29 and 75 years old. Semi-structured interviews are a common method of data collection in qualitative research. A hermeneutic phenomenological approach using semi-structured interviews was adopted. This was considered to have the flexibility to probe a bit more or a bit less in response to varying replies. Smith et al. (2009) argued that this is key to gaining a deeper understanding of the topic of interest. According to Denzin and Lincoln (1994), this approach enables the researcher to gain insight and explore the depth, richness, and complexity inherent in the phenomenon.

A schedule for the interview was created and used to guide rather than restrict the conversation. The open-ended questions capture the participants' thoughts and perceptions in detail concerning their quality of life (Sim and Wright, 2002). The interview questions incorporated the use of prompts as recommended by Denzin and Lincoln (2005).

During the interview, questions were not asked in the order of the schedule; instead, the schedule was used as a guide that prompted participants to discuss their quality of life and experiences. Prior

to commencing each interview, I reminded the participant of the reasons for the study (aims) and gave the participant time to ask any questions they might have. The next step involved collecting the signed consent forms from the participant and explaining what happens to the data and the participants' right to stop at any time during the interview. The interviews lasted between 30 and 45 minutes. The questions are composed of core questions and some associated questions related to the central questions (see sample questions below).

The interviews were audio recorded to make it easier for the researcher to focus on the interview context and the verbal prompts, thus enabling the transcriptionist to generate a 'verbatim transcript' of the interview (Denzin & Lincoln, 1994). The audio recording and the transcripts were kept in a locked safe. The transcripts were read and compared to the audio tape recording, and the field notes several times to verify accuracy. Each transcript's text was divided into meaning units and then subdivided into condensed meaning units. From the condensed meaning units, codes (descriptive units) were developed (see Chapter 7 - coding section).

A reflective diary was kept prior to the interviews and immediately afterwards. This enabled the documentation of feelings and biases that had been evident during the interview process and any surprises about the environment (see section 8.9). This was considered useful for being able to park any concerns felt by the researcher and focus on the interview participant, as advocated by Smith et al. (2009) and Finlay et al. (2011), bearing in mind that 50% of the interviews took place online through Zoom / Microsoft Teams. Further, the diary provided useful data for the interpretative stage and, finally, the data acted as evidence to check ethically sensitive issues, which according to studies (Smith et al., 2009; Finlay et al., 2011) are considered important.

As phenomenological data are collected through in-depth semi-structured interviews supported by a reflexive account from the researcher, it has been suggested that 5–20 interviews are required to provide meaning to the phenomena under investigation (Finlay et al., 2011; Liamputtong et al., 2013; Creswell et al., 2019). Ten semi-structured interviews were conducted in the preceding study. Smith et al. (2009) suggested that a sample size of three to six is a reasonable size for analysing the similarities and differences between participants in IPA. They argued that if the sample is too large, the vast amount of data becomes overwhelming. According to Liamputtong et al. (2013) and Creswell

et al. (2019), in IPA, one foregoes breadth for depth. This allowed for reflection on the data in a new way.

According to the IPA interviewing procedure, the researcher will have a set of questions such as seen below. The interview is guided by the schedule rather than be dictated by it.

The development of the semi – structured interview questions was informed by the IPA approach, where the overall focus was to address pertinent issues concerning QOL in stroke survivors. Topics were addressed in the most appropriate sequence (Smith et al., 2007). Semi – structured interviews allow for the researcher and participants to engage in a dialogue whereby initial questions are modified in the light of the participants' responses and the researcher can explore interesting and important areas which arise. Hence, probes and prompts followed on from some of the answers.

The sample interview questions below emerged from information transmitted from the quantitative findings of the research study (Phase 1). Semi-structured questions are designed to be more open-ended and less straightforward in nature; as a result, the interviewer only asks a few prepared questions.

5.7.4 Sample of the Interview Questions

- What has your experience of stroke been like for you?
- Can you tell me your understanding of the stroke condition?
- Can you explain how you've coped with this condition?
- What is your understanding concerning rehabilitation?
- Can you tell me what your stroke care is like now?
- What are some of the things you may consider as good preventative practices?
- How has this condition affected your hobbies?
- How has your role changed as a father / mother, brother / sister, husband, or wife?

5.8 Rationale for the Hermeneutic Phenomenological design

There are several qualitative research designs commonly used in research. Phenomenology (hermeneutic phenomenology) was used in this research study, as it aligns with the researchers' ontological and epistemological philosophical positions, which are consistent with Heidegger's (1962) thinking. Hermeneutic phenomenology aims to highlight the experience under exploration as close as

possible to how it was lived by the participant. The following material justifies the study's use of phenomenology. Grounded theory was proposed as a possible methodology for the research investigation. This theory is an exploratory method that is well suited for investigating social processes that have attracted little previous research attention, where previous research is lacking in breath, and a new point of view on familiar topics appears promising (Glaser & Strauss, 1967). The theory emphasises the process of developing a theory from the evidence gathered during a study. The disadvantage, however, is that the theory frequently generates a significant volume of data that is difficult to manage. Additionally, the researcher's ability to apply theory is critical. Furthermore, it is well known for being time-consuming and challenging to conduct. Milliken et al. (2010) explained that there is no universally accepted method for categorising objects, which can result in confusion in the analysis.

Another qualitative research design option for this research study is ethnography. This is a research approach where you look at people in their cultural settings with the goal of producing a narrative account of that culture against a theoretical backdrop (Boyle et al., 1994). This is a method that is precisely about individuals, societies, and their culture, focusing on the behaviour of people with respect to the social setup they live in. However, the theory is limited in that the research design is time-consuming and requires a well-trained researcher. Studies have also suggested that short-term studies are at a disadvantage with this design, as it takes time to build trust with the informants to facilitate full honest discourse (Morse et al., 1994; Boyle et al., 1994).

The third qualitative design considered in relation to the research study is discourse analysis. This design is often used to study different situations and subjects. It is known as the analysis of language 'beyond the sentence' (Goulding et al., 2003). Its strength lies in its ability to recreate and characterise real-world communication processes. It provides additional information to assist in resolving tough circumstances and facilitates the collection of sensitive data through a variety of methods (Morse et al., 1994; Smith et al., 2009). However, one of its drawbacks is that collecting and analysing data requires a significant amount of time and work. According to previous studies, this method focuses primarily on language and lacks methodological rigour (Turhan et al., 2019; Goulding et al., 2003).

Edmund Husserl established the philosophy of the phenomenological approach, in which he asserted that the researcher must adopt a phenomenological attitude and set aside or bracket prior knowledge

or presuppositions (Finlay et al., 2011). However, the ideas from the hermeneutic / interpretative approach based on Heidegger's concepts are based on the principle that 'reduction' is impossible and, thus, rejects the idea of suspending personal opinions in favour of interpretations of experience. The background, culture, history, and preconceptions of the researcher align with this philosophy, whereby applying research reflexivity has been paramount.

5.8.1 Phenomenology

Phenomenology (as briefly explained above) is an umbrella term that refers to both a philosophical movement and a variety of research approaches. According to previous studies, it seeks to explore patterns and relationships (Finlay et al., 2011; Liamputtong et al., 2013; Creswell et al., 2019). This enables an in-depth understanding of a small number of subjects through extensive engagement (Creswell et al., 2019). It aims to describe as opposed to explain, the intention being to make 'voices heard' (Liamputtong et al., 2013). It is defined as 'describing a common meaning for several individuals of their lived experience of a concept or phenomenon' (Creswell et al., 2019). It relies on borrowing people's lived experiences so that the researcher can better understand the meaning or the significance of the event by seeking to 'remain as faithful as possible to the phenomenon and to the context in which it appears in the world'. This is one of the main philosophies that guide knowledge generation in qualitative research (Liamputtong et al., 2013). Implementing phenomenology as a framework for conducting the research might be challenging, as the approach is philosophical and not constrained by a method-structured step.

5.8.2 Hermeneutic Phenomenology Underpinned by Heideggerian Philosophy

Hermeneutic phenomenology was considered as a vehicle for exploring Phase 2 of the research study to understand and explore the perceptions, attitudes, knowledge, cultural approaches, and beliefs of stroke survivors in the SE communities of Nigeria. The philosophy is translated into a methodological framework, as the methodological approach facilitates the answers to the research question.

Studies have alleged that phenomenology and hermeneutic phenomenology are often misunderstood and state that the ideas and theories underpinning this methodology are 'dynamic and evolving' (Finlay et al., 2011; Creswell et al., 2019); hence, researchers have avoided this philosophy due to the difficulty in understanding the complexities of German-based language.

The thinking that underpinned Martin Heidegger's philosophy was based on constructing my reality from my own experiences and belief. Heidegger's idea has been integrated into the research study, as the concepts highlighted have been chosen and are used to couch our questioning and understanding of the data generated in Phase 2 of the research study. It should be remembered that the appraisal of Heidegger in this context is not entirely about philosophy but also about meshing relevant philosophical standpoints into a usable methodological framework. The rationale for using Heidegger to underpin Phase 2 of the study is that the philosophy permits and encourages the exploration and inclusion of preconceptions of the researcher as legitimate components of the research. Therefore, my experiences both as a practitioner and a researcher, are woven together to produce a shared understanding of the phenomena or 'fusion of horizon' (Gademer et al., 1975)



Figure 9: Fusion of Horizon (Gademer et al., 1975)

5.8.3 Development of the Heideggerian Phenomenology

Phenomenology was one of the first genuine moves away from the positivist paradigm, where the subjectivity of human experience becomes valued. The father of phenomenology was Edmund Husserl, who developed 'Transcendental phenomenology' (Chapman et al., 1994; Crotty et al., 1996). His philosophy and belief were that to generate valid data. It was first necessary for the researcher to put aside any preconceptions that they may have in relation to the research question; he termed this 'Bracketing' (Chapman et al., 1994; Crotty et al., 1996). However, Martin Heidegger, a student of Edmund Husserl, challenged this idea or belief, suggesting that the researcher is as much a part of the research as the participant and that their ability to interpret the data was reliant on previous

knowledge; he called this prior knowledge 'fore-structure' (Heidegger et al., 1962). He postulated that there is no such thing as interpretive research that is free of the judgement or influence of the researcher (Steiner et al., 1978).

Heidegger's philosophy sees the researcher as being in the world of the participant and research question (Heidegger et al., 1962). In other words, Heidegger's message was simple: 'understanding is never without preconceptions. He added that the only true way for the researcher to conduct a hermeneutic enquiry is to have prior knowledge and some 'fore-structure' to ensure that the questions asked are pertinent (Steiner et al., 1978). The goal, therefore, of hermeneutic research in line with Heidegger's thinking is to enter the world of the person and interpret the meaning they assign to the experience. The researcher endorses this viewpoint because of the likely influence of the researcher's own experiences, culture, values, beliefs, and prior knowledge and understanding, which are all regarded as significant in interpreting and making meaning of a participant's experiences in this research study (Vanscor et al., 2017).

5.8.4 Acknowledging the Argument against Heidegger

The choice of philosophy is determined by its relevance to a study, not simply by the philosopher as a person judged by a set of life choices, as earlier stated. Initially, I was apprehensive about adopting Heidegger's philosophy based on the controversies surrounding him, especially the debates centred around his involvement in Nazism (Steiner et al., 1978; Dreyfus et al., 1991). I agree that fascist, antisemitic beliefs have no place in research studies. However, being mindful of this, I believe that many areas of Heidegger's thinking remained relevant to generating thoughts in my research study, regardless of his life choices.

Choosing an appropriate methodology when one delves into research is paramount, as there is a raft of approaches available (Creswell et al., 2014; Smith et al., 2009; Finlay et al., 2011). Knowledge of the philosophical foundations of the methodology chosen is critical. Phenomenology by Heidegger is useful in my research study's second phase.

5.9 Rationale for Performing IPA

The two most prominent methods for analysing qualitative data are content analysis and thematic analysis. Both terms have been defined in a variety of ways and are used to refer to a wide variety of

phenomena (Neuendorf et al., 2018). The following information validates the study's decision to employ IPA rather than content and thematic analysis.

Content analysis is a systematic coding and categorising approach used for exploring large amounts of textual information to determine trends and patterns of words used (Power & Knapp, 2006).

Content analysis dates to the early twentieth century, with chiefly quantitative techniques used (Smith, 2000; Neuendorf, 2019). Nonetheless, more recently, variations have introduced qualitative content analysis. Content analysis may be applied to any message content. However, studies have argued that the analysis is complex and often time-consuming (Joffe & Yardley et al., 2004).

Braun and Clarke (2013) defined thematic analysis as a 'way of seeing' and 'making sense' out of seemingly unrelated material. It has been suggested to be the first qualitative method that should be learnt, as it provides core skills that will be useful for conducting many other kinds of analysis. The goal is to develop a story from the texts of interest by developing patterns and themes, with the result highlighting the most salient 'constellations' of the meaning present in the texts (Joffe, 2012). Braun and Clarke (2006) presented a six-phase process for thematic analysis. Thematic analysis dates to the 1970s, developed from within a more constructivist paradigm, with an emphasis on the interpretative approach to largely qualitative techniques. However, researchers have argued that thematic analysis is positivist in its requirement and that assertions ought to be supported with evidence (Vaismor et al., 2013). The two sets of methods provide different types of conclusions, with content analysis providing quantitative objective, reliable measures about messages and thematic analysis most typically resulting in qualitative inductive conclusions about themes in the message content.

Thematic analysis has been classified as a method rather than a methodology, which means that, unlike many other qualitative approaches, it is not bound by any epistemological or philosophical viewpoint. This, however, makes it a very flexible method (Braun & Clarke, 2013). Nevertheless, due to the wide variety of analysis applications made available, this often makes the analysis confusing and challenging. For this research study, I have chosen thematic analysis, which involves the use of interpretative phenomenological analysis (Creswell et al., 2019). IPA uses a type of analysis that moves from a detailed within-case to a cross-case thematic analysis (Smith et al., 2009). Studies have suggested that the use of content analysis and basic thematic analysis is suitable for

researchers who wish to employ a relatively low level of interpretation in contrast to hermeneutics phenomenology, in which a higher level of interpretative complexity is required. IPA is a flexible and user-friendly approach to phenomenological research that aims to provide a comprehensive and in-depth account that prioritises the individual. It, therefore, enables the researcher to hear and understand the experiences of the participants, which is the intent of the research study.

This chosen analysis (IPA) allowed the exploration of a chief research question of the thesis (the impact of stroke on the quality of life of stroke survivors in SE Nigeria). It was particularly attractive for this study because of its commitment to explore, describe, interpret, and situate the participants' sense-making of their experience (Hefferon et al., 2011). IPA is helpful as it enabled the participants to recount an account of their experiences as fully as possible. However, this requires high-level skills from the interviewer, a combination of strong emphatic engagement able to probe further into interesting and important aspects of the collected narrative data (Hefferon et al., 2011). The small sample size of most IPA enables micro-reading of the participant's account. (Seen in Chapter 7. Qualitative findings). The inquiry is then sharpened by IPA's inductive, interpretative analysis with emphasis on information that is grounded, consequently, sacrificing breadth for depth. The process of IPA not only uses phenomenology but also incorporates a hermeneutics inquiry (Creswell et al., 2013), which means it is interested in capturing individual and subjective accounts, as well as more global patterns of collectively shared accounts of private experiences. It makes the basic ontological assumption that when trying to make sense of their experiences, people offer narratives that are structured into reoccurring patterns of interpretations (Hefferon et al., 2011). The interpretations of the individuals concerned may reflect the context of how they are experiencing a particular phenomenon at present in their life cycle. Therefore, interpretations become relative to the experience within the context and time of the individual's life.

As with any other qualitative research, IPA acknowledges the active participation of the researcher in the generation of analytical findings yet allows the researcher to arrive at a map of prevalent meanings across a body of data and present them as themes – a label given by the researcher to express interpretations of meaning. This is known as the 'double hermeneutic' in which interpretations are made about the participants' interpretations. Therefore, the researcher assumes a central role in the analysis and the interpretation of the participants' experiences (Creswell et al., 2013) The

dynamism of the interpretation and reflection resonates excellently with the hermeneutic circle model that deals with the dynamic relationship between the meanings (Smith et al., 2009). There are key analytic steps (see Chapter 5 Qualitative findings and results) that the researcher needs to follow as detailed in the qualitative analysis process when making sense of participants' experiences and reflections.

5.9.1 Interpretative Phenomenological Analysis (IPA)

This analytical step of the research study is driven by phenomenological principles, as described by IPA (Smith & Osborn, 2004; Creswell et al., 2013). The previous section described the theoretical and historical underpinnings of phenomenology philosophy and phenomenological methodology from which interpretative phenomenology analysis has evolved.

One of the main theoretical underpinnings of IPA is hermeneutics, which is the art and science of interpretation and meaning. IPA believes that Heidegger's concept of the appearance of being captures the essence of interpretation well. It is believed that there is a phenomenon out there ready to be explored but requiring detective work of the researcher to bring it to light using prior experience, assumptions, or preconceptions to make sense of the experience once it is revealed (Smith et al., 2009). This is an integrative hermeneutic phenomenology; the approach is phenomenological in that it involves a detailed examination of the participants' life. It attempts to explore personal experiences and is concerned with an individual's perception of an event as opposed to an objective statement (Vanscor et al., 2017).

The aim of IPA is to explore in detail how participants 'make sense' of their experiences. It is argued they do this through their own personal and social world by assigning meaning to those experiences and events from the perspective of the participants (Smith et al., 2009). It also aims to develop an understanding of participants' experiences with the themes that are identified from the personal interaction with and interpretation of the interview data, regardless of the strategy one has chosen.

The researcher becomes involved in the process of information creation (described as the hermeneutics circle) and the knowledge statements that emerge, according to a standard statement in qualitative research (Vanscor et al., 2017). The IPA theoretical underpinnings are phenomenology, hermeneutics, and ideography.

IPA has two primary aims: to look in detail at how an individual makes sense of life experience and to give a detailed interpretation of the account to understand the experience (Creswell et al., 2013).

Participants' voices were reflected in this research study through narrative accounts; these accounts were to be analysed using the systematic protocol that allows the data to be deconstructed to facilitate the development of themes. It recognises that the researcher plays a critical role in making sense of the participants' personal experiences (Smith, 2004). It is this feature that sets it apart from Husserl's more descriptive phenomenological approaches (1925).

In reference to the use of a mixed method approach, IPA can be used as part of a mixed method approach, especially if the goal is an in-depth understanding of the participants' perspective on the issues in question. Mixed method researchers are generally less label – oriented and more purpose driven (Vanscor et al., 2017; Creswell et al., 2019).

Successful analysis of IPA seeks to be reflexive, which is considered 'Obligatory' in an IPA approach (Creswell et al., 2013). A reflexive diary to capture feelings and intuitive thoughts throughout the data collection and analysis period was planned. Previous studies advise that the more detailed the diary the more interpretative the final analysis becomes (Creswell et al., 2013; Smith et al., 2009).

However, the steps involved at the analysis level (See chapter 7 for more detail) involve, collecting data, reviewing initial notes and or comments (Smith, 2004). Finding connections and clustering experiential statements, compiling the table of person experimental themes. Clustering and compiling the cases and writing up the study (Creswell et al., 2013; Smith et al., 2009).

5.9.2 Interpretative Phenomenological Analysis (IPA) Criticisms

The IPA approach has been criticised for being fraught with inconsistencies and lacking in regulation (Braun et al., 2013). However, studies have argued that the main vigorous criticism is that the methodology suffers from several major theoretical and practical limitations. One is that the methodology is always intertwined with language, whereas its primary focus should be to gain insight into the experience. Studies have also raised concerns as to whether IPA can accurately capture the experiences and meanings of the experiences rather than opinions about them. It has also been suggested that participants and researchers may not have the requisite communication skills to successfully communicate the nuances of experiences (Smith et al., 2009). It is argued that IPA's emphasis on perceptions is problematic and restricts the understanding because phenomenological

research aims to comprehend lived experiences but does not attempt to explain why they occur (Braun et al., 2013).

However, Smith et al. (2009) have argued that IPA uses hermeneutic, ideographic, and contextual analysis to understand the cultural position of the experiences of the people. Consequently, as a researcher, it is important to be aware of the criticisms and to take extra care to collect rich and in-depth data from participants.

5.9.3 Trustworthiness and Rigour of Research

To expose the transparent nature of the data generated and the interpretation process, it is necessary to discuss how and why the findings generated can be considered reliable and truthful. Morse et al. (2002) proposed that, to maintain consistency with conventional paradigms, quantitative and qualitative, researchers should adopt the same terminology, thereby reducing confusion. They argued that concepts such as validity and reliability 'can be appropriately used in all scientific paradigms', regardless of the methods used.

Lincoln and Guba's (1985) criteria of credibility, dependability, conformability, transferability, and more recently authenticity was used to establish trustworthiness in this research study. It is stated that to build trustworthiness in qualitative research, the above characteristics must be considered (Polit & Beck, 2014). The most crucial of the five criteria is credibility (Polit & Beck, 2014). Credibility indicates confidence in the truth of the data and its interpretation. In this study, methodological coherence and researchers' responsiveness were the strategies for achieving this. Methodological coherence is reflected throughout the process of the study in a nonlinear way as the researcher moves back and forth between framework and application to guarantee congruence amongst deciding on a research question. My responsiveness was achieved by sustaining truthfulness, staying open, and being sensitive while listening to each participant's story to ensure their perspective was noted and represented as clearly as possible. The use of direct quotes upheld from the used text allows the reader to partake in the validation of the data. Prior to the interviews, participants were briefed and, upon request, had a brief question and answer session following the interviews, as they were aware that the researcher was also a physiotherapist by profession. Furthermore, constant reflective journaling was used, which included the collection of field notes and the keeping of a reflective diary

throughout the data collection and analysis. Before and after each interview, reflective notes were written.

The second criterion is dependability – the stability of data over time and conditions, like reliability in quantitative research. This is difficult to maintain in qualitative research, according to a previous study (Creswell et al., 2017). Nonetheless, constant debriefing, sharing, and debating portions of the data and study with the supervisory team was the technique used in the research study. Confirmability, which is like objectivity in quantitative research, in that it refers to the consistency and reproducibility of findings, was the third criterion. Coherent with hermeneutic phenomenology, I did not hold an objective position alone as it was a mixed methods approach that included my preunderstandings as stated earlier. The objectivity in hermeneutics can be comprehended as being open to the study text. Confirmability was also achieved in the research study by taking detailed notes on most of the study's major decisions and discussing them with the supervisory team at one point to eliminate bias from a single individual's viewpoint (Polit & Beck, 2014).

The third criterion was transferability, which refers to the degree to which the results of qualitative research can be generalised or transferred to other settings or contexts, or the generalisability of the data (Polit & Beck, 2014). This is comparable to the concept of validity and reliability in quantitative research. However, triangulation is also a process seen as a way of ensuring the validity of the findings through comprehensiveness and the convergence of patterns; this enables the generalisability of the findings (Polit & Beck, 2014). Additionally, at various stages of the analysis, the supervisory team was involved. However, as part of the study was one of hermeneutics, the idea was not to generalise the findings but to provide a deep description of the phenomenon from the participants' perspective. The fifth criterion was authenticity, which refers to the integrity of findings. This was established in the research study by the clear application of the findings and the demonstration of clear communication with the supervisory team (Creswell et al., 2017).

5.9.4 Ethics

For the research study to result in benefits and minimise the risk of harm, it had to be conducted ethically (Creswell et al., 2019). There are several main principles that guided the conduct of this research study such as social and clinical value, scientific validity, fair subject selection, informed consent, and respect for the participants. These are discussed further in each section. However,

ethical approval for both phases of the study were obtained from the University of East London (see Appendix 2). Participants have the right to know who has access to their data and what is being done with it. The aim of ethical review is to protect participants; however, ethical reviews also help to protect the researcher. By obtaining ethical approval, the researcher demonstrates that he or she has adhered to the accepted ethical standards of a genuine research study. Ethical approval for this research investigation was obtained in advance from the appropriate authorities. In third-world countries such as Nigeria, ethics are slightly different. According to the constitution of the Federal Republic of Nigeria (Promulgation), Act Chap 23 (2004) instructs that all institutions adhere to the NITDA data protection guidelines. Hence, the data is protected and owned by Nnamdi Azikiwe University according to this code of practice and according to the data protection legislation of Nigeria (1999). Permission to access patient records were obtained from the heads of Stroke Action Nigeria, Amaku Teaching Hospital Nigeria, and Nnamdi Azikiwe University. The heads of the households and individual subjects gave informed written and/or oral consent. Informed written consent was also obtained from spouses or close relatives of those subjects who were incapable of giving their informed written consent. Participants were informed about the purpose, aims, and length of the study and that they could withdraw from the study at any time without any adverse consequences to themselves. They were informed that information obtained would be held strictly confidential and anonymised.

Transcripts and other data were kept in a locked safe, and electronic data securely kept in a password-protected computer system. The researcher's contact details were readily available to the participants should they need to access the results of the study or discuss it at any point. The researcher adhered to the seven Caldecott principles concerning data protection.

NHREC ethical approval for the research was facilitated by Professor Akosile (PhD supervisor – advisory capacity), Nnamdi Azikiwe University Teaching hospital (NAUTH), Nnewi.

5.9.5 Ethic approval was obtained from the following institutions (see Appendix 3).

- University of East London (2019 & 2020)
- Stroke Action Nigeria, Onitsha, Anambra State (2020)
- Chukwuemeka Odumegwu Ojukwu University Teaching Hospital, Amaku, Awka (2019)
- Nnamdi Azikiwe University Teaching Hospital, Nnewi, Anambra State (2019)

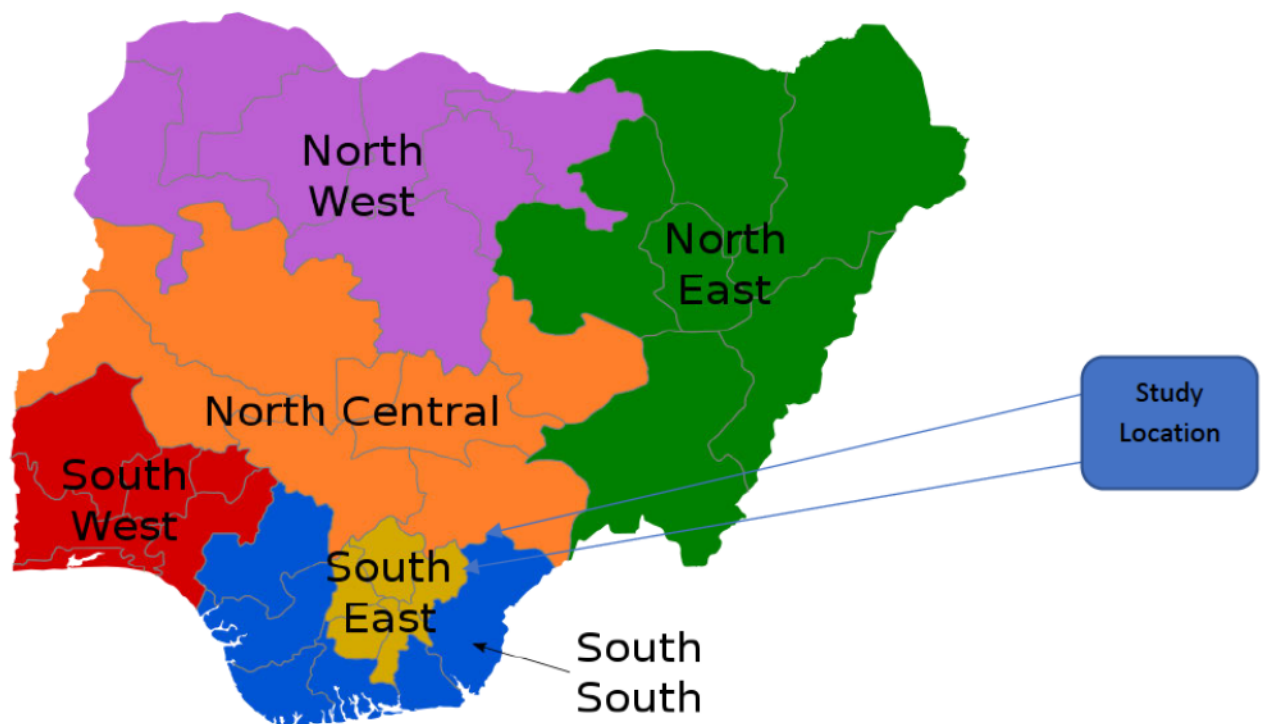


Figure 10: MAP OF NIGERIA SHOWING THE REGION OF STUDY LOCATION

5.9.6 Summary of Chapter

The two phases of this mixed method approach addressed the research question by creating broader, deeper, and more useful information from the data.

- The numerical data ensured validity and credibility that further helped verify the quantitative and the qualitative data through means of triangulation (Bruce et al., 2009).
- It provided quality, convergence, and a corroborative link between the two methods concerning the 'impact of stroke on the quality of life of stroke survivors in the SE communities of Nigeria'.
- It demonstrated insight into their perceptions of living with a stroke and what this meant to them (see the qualitative findings/results in Chapter Five)

Feilding (2012, pp. 125–126) wrote, 'Rather than mixing because there is something intrinsic or distinctive about quantitative data or qualitative data, we mix to integrate the two fundamentals' ways of thinking about a social phenomenon'. However, the limitations evolved around the qualitative aspect concerning generalisability is due to subjective data quality, data rigidity and small sample

size as seen in the phase 2 of the research study. Conversely, qualitative research does not provide statistical representation, it's focus is about the deeper understanding and conceptualisation of a particular phenomenon where the experience and interpretations can be transferable to other populations (Creswell et al., 2017).

In other words, despite all the complexities concerning mixed method research, there is still the potential for a better understanding of social scientific problems when both qualitative and quantitative methods are used together.as seen in its triangulation approach (Discussed above in the triangulation design section).

The statistical results of Phase 1 (quantitative analysis) of this exploratory sequential mixed method research study are presented in the following chapter.

CHAPTER SIX

QUANTITATIVE FINDINGS – PHASE 1

6.1 Introduction

The previous chapter focused on the beliefs that underpin this research and discussed the rationale for using a mixed method approach in this study. This chapter on the other hand, focuses on the study's quantitative main findings, including the presentations of relevant quantitative statistical data that emerged from the HRQOLISP questionnaires.

The chapter includes a step-by-step flow chart which describes the analysis process and explains the various tests used for this phase of the study.

In alignment with the objectives of the research study this chapter examines the HRQOL of stroke survivors in the SE communities of Nigeria and studies the associated determinants.

The study aims to:

1. Describe the epidemiological profile of stroke survivors in the SE communities of Nigeria.
2. Identify variables that predict the impact of stroke on the quality of life of stroke survivors in SE Nigeria (using the outcome measure HRQOLISP).
3. Assess health-related quality of life in stroke survivors (using the HRQOLISP) and identify the associated determinants.

Four main levels of analysis were performed in this chapter. The demographic variables (continuous and interval scale variables) were used to show the epidemiological profile of the stroke survivors.

The measurement of independent sample T tests and ANOVA were used to describe the factors associated with the HRQOL domains. The use of Pearson correlations was to measure the strength of the association between the variables and the multiple regression analysis was used to examine the determinants of HRQOL domains.

An explanatory sequential mixed method approach was used for phase 1 of the study, emphasising the quantitative phase followed by the quantitative phase, which will be presented in the following chapter. (Creswell & Clark, 2017).

6.1.1 Study Design

This cross-sectional / nonexperimental technique was used to collect data, evaluate, and interpret the data. The approach reflects the multifaceted nature of the aims and objectives of the study (See Chapter 1, Section 4). Phase 1 promotes generalisability of the results related to the impact of stroke on the QOL of the stroke survivors in the SE Nigeria.

6.1.2 Data Collection

The questionnaire used in this study was a standardised HRQOLISP validated by the WHO (2004). This was administered to each participant who met the inclusion criteria (see Chapter 5, Table 1) within the preferred above locations that were geographically local to the participant. The instrument measures the health status of individuals and can be used to identify and prioritise areas of need of individual patients and patients with special needs. This outcome measure is also important in the identification of the determinants of good and poor prognosis in patients with stroke (Obembe et al., 2013). It was first used in the second half of the twentieth century in the assessment of QOL (WHO, 2001). In 1993, the WHOQOL Group defined quality of life as 'an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives' (Obembe et al., 2013). Prior to selecting the chosen outcome measure, several generic and stroke specific HRQOL measures were considered, including the ICF (See Chapter 2, section 6). However, given the methodological difficulties found in some studies from different countries, the measurements to be used must be chosen depending on the research question and considering the specific clinometric properties of the assessment scale (Mcarthur et al., 2013; Obembe et al., 2013; Garret et al., 2020; Owolabi et al., 2017). Nevertheless, my objective was to capture the stroke survivors' individual subjective and specific cultural views of their stroke experiences in a third world environment. Based on the literature review it is believed that the HRQOL is an appropriate instrument and outcome measure for this study's purpose (Owolabi et al., 2017; Obembe et al., 2013; Garret et al., 2020).

The HRQOLISP is a 40-item scale outcome measure and encompasses two dimensions and seven domains (Owolabi et al., 2011). The physical dimension includes the physical, psychological, cognitive/intellectual, and eco-social or ADL domains, while the spiritual dimension comprises the soul, spirit, and spiritual interaction domains. Scores for each domain are summed up and then

stratified as severe, moderate, and mild strokes. The arithmetic mean of the various domain scores is then calculated and compared at the subscale level (Onwuegbuzie et al., 2009; Owolabi et al., 2009).

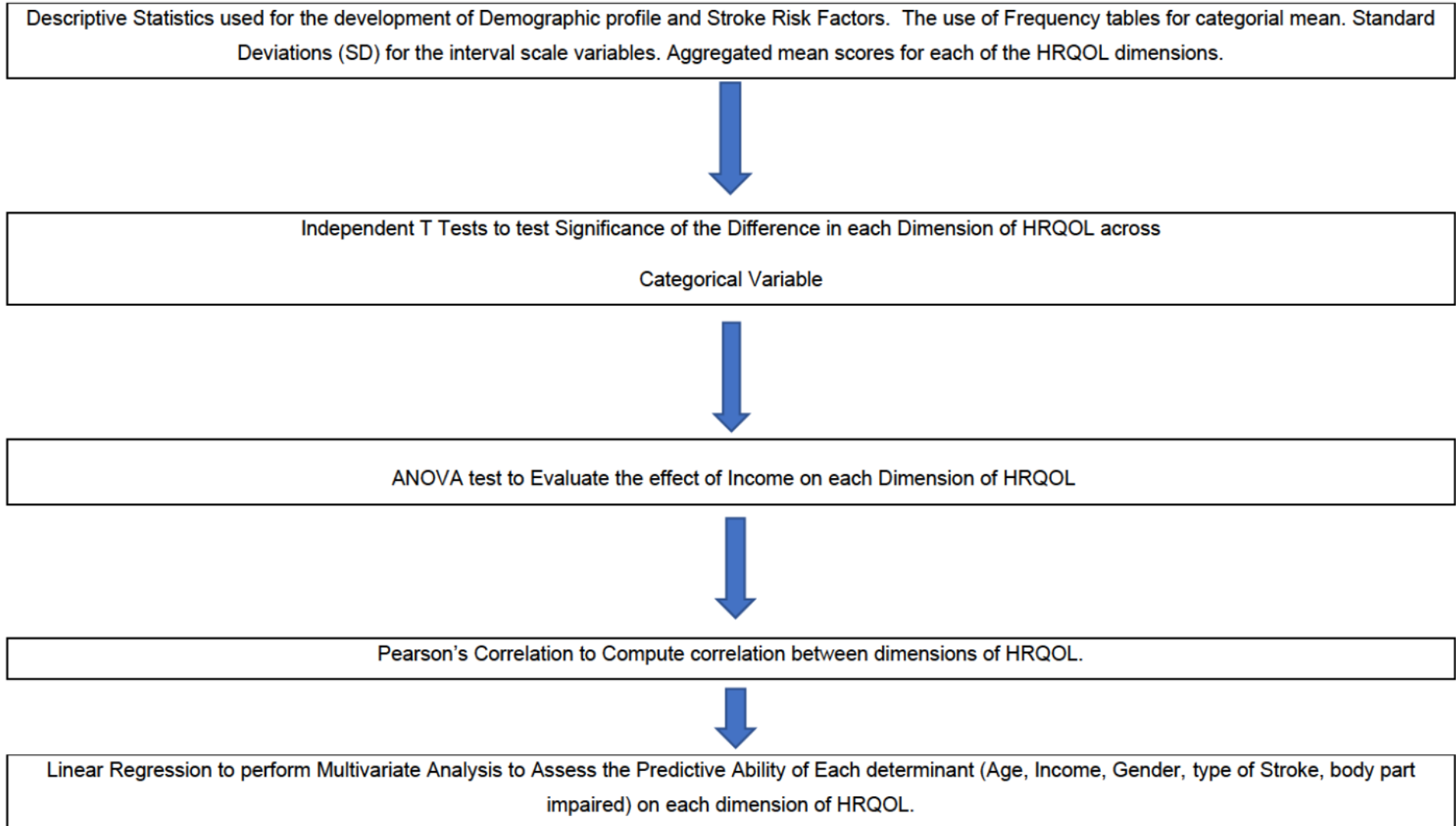
The questionnaires were completed with the researcher and a research assistant (who signed a nondisclosure agreement) in line with the participant's choice for each item. This procedure lasted approximately 30–45 min. The empirical data collected in Phase 1 provided information that was used in Phase 2 as a springboard for delving deeper into participants' worldviews or beliefs about some of these domains. The seven domains were used as dependent variables, while age, income, gender, stroke type, and physical impairment were used as independent variables. Independent t-tests, one-way analysis of variance (ANOVA), Pearson correlations and multiple regression were used to determine the relationships between these variables (Bruce et al., 2009; Onwuegbuzie et al., 2009). Please see Figure 6.1: Flow Chart, this demonstrates the sequence of the statistical tests involved in the analysis of the HRQOLISP / quantitative phase 1.

Note: *Spirit domain refers to the understanding of one's faith, levels of faith, attending church and being involved in church activities.*

Eco social refers to Activities of daily living (ADL's such as feeding, bathing and toileting).

Spiritual domain refers to one's relationship with God, one's closeness and connectivity with God.

Figure 11: Flow Chart



6.2 Findings of the Epidemiological Profile of the study

The epidemiological profile and health-related quality of life of stroke survivors revealed above, feature the demographic features of the study participants. The sample comprised of 101 participants (males 52% and females 47%). Age distribution was from 16 to 85 years old, with a mean age of 61.01 years (SD = 12.74). About 30% of the participants had university degrees, while the remaining had primary and secondary education. About 85% of the participants were married, whereas 5% were single. Over 50% of the participants had income between 10K and 100K (£20–£200), with a quarter of the participants indicating low income (between 0 and 10K [£0–£20]). Haemorrhage accounted for 23.8% of the strokes, while Ischaemic accounted for 68.3% of the strokes.

Note: Currency is in Naira (1 Pound = 930 Naira)

K=One Thousand Naira

Table 6.1 presents the summary of the demographic profile and type of strokes of the participants in this study.

Table 3: Demographic profile and Type of Stroke Suffered by Subjects

Variable		n	%	Mean	SD
Age range (yrs)	16 - 85	101	100	61.01	12.74
Gender	Male	53	52.5		
	Female	48	47.5		
Education	Primary	32	31.7		
	Secondary	20	19.8		
	College	12	11.9		
	University	30	29.7		
	Others	5	5.0		
Marital status	Single	5	5.0		
	Married	85	85.0		
	Divorced	1	1.0		
	Widowed	8	7.9		
	No response	2	2.0		
Income	0 – 10 K	25	24.8		
	10K – 50K	35	34.7		
	50K – 100K	18	17.8		
	100K +	14	13.9		
	No response	9	8.9		
# Spouses	0	9	8.9		
	1	90	89.1		

2 2 2.0

Type of stroke	Haemorrhage	24	23.8
	Ischaemic	69	68.3
	N/S	1	1.0
	Unknown/Missing	7	7.0
# Strokes	1	81	80.2
	2	17	16.8
	3	1	1.0

Note: Currency is in Naira (1 Pound = 930 Naira)

K=One Thousand Naira

More than 80% of the patients had one stroke, while 16.8% of subjects suffered two strokes, and one patient had three strokes. Out of one hundred and one of the stroke survivors, (80%) had experienced stroke once, 17 (16.8%) had two stroke episodes, and one (1.0%) had three stroke episodes. The two main types of strokes the participants encountered were haemorrhagic (23%) and ischaemic (68.3%).

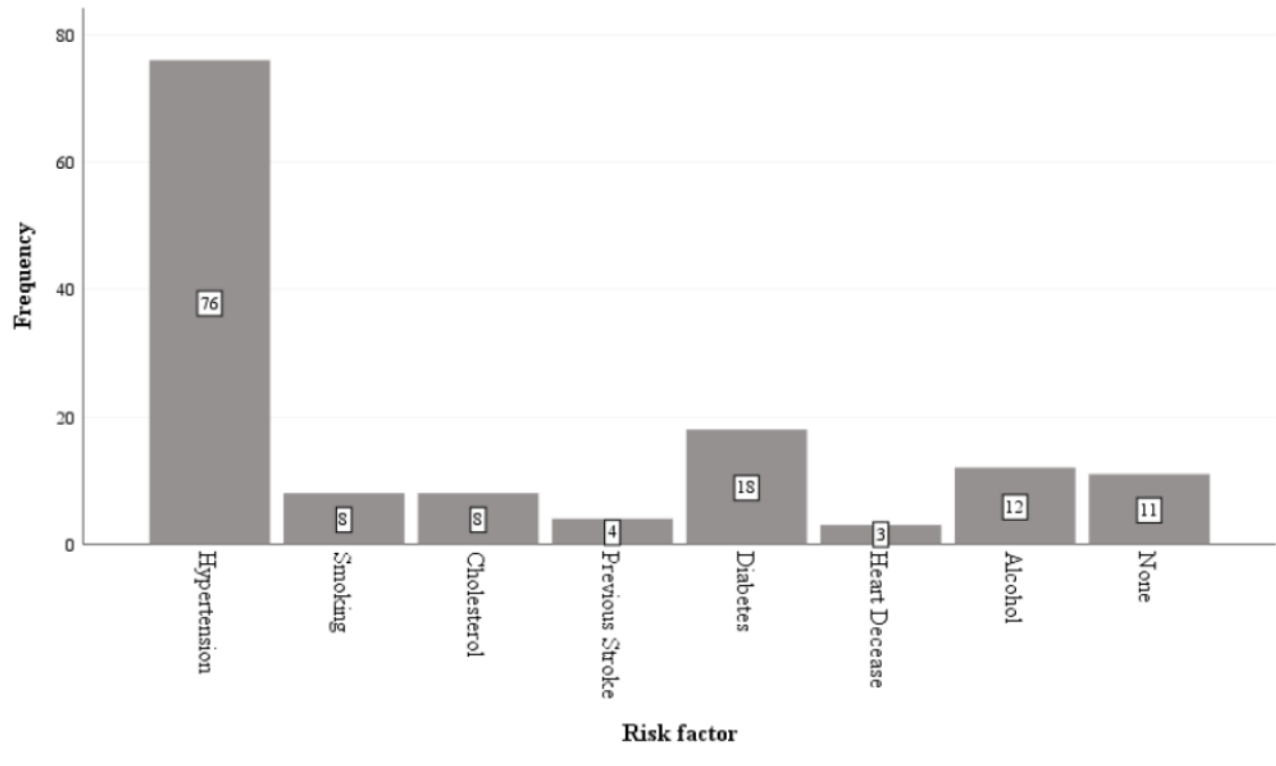
Tables 6.2 and 6.3 present the distribution and the bar plot of the risk factors associated with stroke.

More than three-fourth of the subjects (n=76, 76.8%) had hypertension, followed by diabetes (n=18, 28.2%) alcohol (n=12, 12.1%) smoking and cholesterol (n= 8, 8.1%) previous stroke (n=4, 4.0%). A small proportion of the subjects (n= 11, 11.1%) indicated none of these risk factors.

Table 4: Distribution of stroke risk factors amongst SE Nigerians.

<i>Risk Factors associated with stroke</i>		
Risk Factor	N	Percentage
Hypertension	76	76.8%
Smoking	8	8.1%
Cholesterol	8	8.1%
Previous Stroke	4	4.0%
Diabetes	18	18.2%
Heart – Disease	3	3.0%
Alcohol	12	12.1%
None	11	11.1%

Table 5: Bar Plot of risk factors of stroke indicated by stroke survivors in SE Nigeria



Overall, hypertension was the most common risk factor (76%), followed by diabetes (18%), alcohol consumption (12%), and high cholesterol and smoking (8% each). The least prevalent risk factor was heart disease (3%).

6.2.1 Clinical Parameters and Stroke Risk Factors

The risk factors / predictors associated with stroke revealed that 76.8% had hypertension and 28.2% had diabetes, followed by alcohol (12.1%) and smoking and cholesterol (8.1% each). A small proportion (11.1%) indicated none of the risk factors. The drugs used by the patients with stroke were mainly antihypertensives and pain killers, and none of the participants had thrombolytic therapy. Overall, hypertension and diabetes presented as the main determinants of stroke for the study.

6.3 Descriptive Statistics of the HRQOLISP

Table 6.4 depicts the descriptive statistics of the seven domains (dependant variables): physical, emotional, intellectual, soul, eco-social, spiritual interaction, and spirit. The HRQOLISP scores for each domain ranged from 1 to 5, with the higher scores reflecting greater quality of life and the lower scores reflecting poor quality of life. The arithmetic mean of the various domains scores was calculated. The descriptive statistics of each dimension indicated relatively low mean score for the physical dimension of the HRQOLISP (mean = 2.52, SD = 0.76), with the mean values for other dimensions being comparable. Specifically, the spirit and soul domains reported relatively higher mean values (mean = 3.70, SD = 0.70).

Table 6: Descriptive Statistics of Quality-of-Life Dimensions

	N	Min.	Max.	Mean	SD
Physical	101	2.22	4.33	2.52	.76
Emotional	101	2.00	5.00	3.40	.66
Intellectual	101	2.00	5.00	3.39	.53
Soul	101	2.50	5.00	3.68	.56
Spirit	101	1.00	5.00	3.70	.70
Eco Social	101	2.50	4.67	3.47	.40
Spiritual	101	1.67	5.00	3.50	.64
Interaction					

The lowest scoring domain demonstrating poor quality of life was the physical domain (mean = 2.52, SD = 0.76), whereas the highest scoring domain demonstrating the better quality of life was the spirit domain (mean = 3.70, SD = 0.70). This demonstrates that the physical, emotional, and intellectual domains were the most affected HRQOL domains for stroke survivors and had the utmost impact on their quality of life in the Southern East communities of Nigeria.

6.4 Pearson correlation matrix

Pearson's correlations were used to assess the significance of the relationships between the HRQOL domains. Table 6.5 presents the correlation matrix of the HRQOL domains.

Table 7: Correlation matrix of Health-Related Quality-of-Life Dimensions

	Physical	Emotional	Intellectual	Soul	Spirit	Eco-social	Spiritual interaction
Physical							
Emotional	.051						
Intellectual	.111	.647**					
Soul	-.140	.598**	.458**				
Spirit	.043	-.181	-.280**	-.210*			
Eco-social	-.058	.247*	.273**	.249*	-.140		
Spiritual	.170	-.122	-.078	-.174	.360**		
Interaction							

Note: *significant at .05 level, **significant at .01 level, ***significant at .001 level

The correlation analysis indicates that the physical dimension did not significantly correlate with any other dimension ($p \geq .05$). However, the emotional (psychological) dimension ($p = .051$) had a significant positive correlation with the intellectual ($p = .647$) and soul ($p = .598$) dimensions. The intellectual (cognitive) dimension significantly correlated with the soul ($p = .458$) dimension and had a significant positive correlation with the eco-social (ADLs) ($p = .273$) dimension but a negative correlation with the spirit ($p = -.280$) dimension of HRQOL. The spiritual interaction was significantly associated with the spirit dimension. The emotional (psychological) dimension had a significant positive correlation with the intellectual (cognitive) and soul dimensions, suggesting that high scores for the emotional (psychological) dimension is associated with high scores for the latter two dimensions. The intellectual (cognitive) dimension had a significant positive correlation with the soul, spirit, and eco-social (ADLs) dimensions, which suggests high intellectual (cognitive) scores is associated with high eco-social (ADLs) scores. However, the intellectual (cognitive) dimension had a negative significant correlation with the spirit domain, which suggests that increased intellectual (cognitive) ability is not associated with spiritual ability. Therefore, high intellectual (cognitive) scores were not associated with the spiritual dimension.

6.4.1: Independent T Tests

Independent samples t-test was used to test the significance of the difference in the mean score of each dimension of the HRQOL construct between males and females. Figure 6.2 is the box plot of each dimension of the HRQOL construct for males and females.

Figure 12: Box plot of HRQOL dimensions for male and female subjects

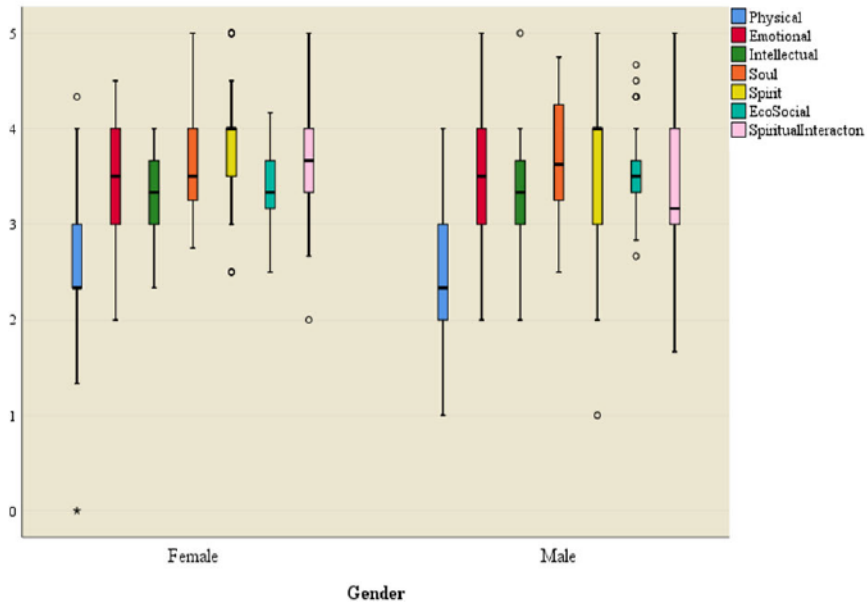


Table 6.6: presents a summary of the results of the comparison of each dimension between the male and female groups.

Table 8: Effect of Gender on Dimensions of Health Quality of Life

					t	df	p	95% CI for Mean difference
	Gender	N	Mean	SD				
Physical	Male	52	2.44	.70	-1.17	98	.24	(-.48 .12)
	Female	48	2.62	.83				
Emotional	Male	53	3.39	.66	-.13	98	.90	(-.28 .24)
	Female	47	3.40	.66				
Intellectual	Male	53	3.41	.54	.31	98	.76	(-.18 .25)
	Female	47	3.38	.53				
Soul	Male	53	3.72	.61	.65	99	.52	(-.15 .29)
	Female	48	3.64	.51				
Spirit	Male	52	3.67	.76	-.32	98	.75	(-.32 .23)
	Female	48	3.72	.64				
Eco Social	Male	52	3.54	.41	1.78	98	.08	(-.02 .30)
	Female	48	3.40	.38				
Spiritual	Male	53	3.43	.73	-1.26	98	.21	(-.42 .09)
Interaction	Female	47	3.59	.53				

Results of the independent samples t-test indicated that there is no significant difference in the mean score of each dimension of the HRQOL construct between male and female groups ($p \geq .05$). Gender did not have a significant effect on any dimension of the HRQOL construct.

6.4.2: ANOVA Test

A single factor ANOVA model was constructed and tested to assess the effect of income on dimensions of HRQOL.

Table 6.7 presents descriptive statistics of the different dimensions of HRQOL along with a summary of the results of the ANOVA test.

Table 9: Effect of Income on dimensions of quality of life

Dimension	Income	N	Mean	SD	F	P
Physical	0 - 10K	25	2.68	.93	.846	.472
	10K- 50K	34	2.36	.60		
	50K - 100K	18	2.46	.79		
	100K +	14	2.51	.74		
Emotional	0 - 10K	25	3.34	.61	3.171	.028
	10K- 50K	34	3.16	.57		
	50K - 100K	18	3.69	.75		
	100K +	14	3.54	.63		
Intellectual	0 - 10K	24	3.37	.41	4.124	.009
	10K- 50K	35	3.20	.45		
	50K - 100K	18	3.61	.60		
	100K +	14	3.60	.49		
Soul	0 - 10K	25	3.57	.51	0.621	.603
	10K- 50K	35	3.65	.63		
	50K - 100K	18	3.70	.56		
	100K +	14	3.82	.42		
Spirit	0 - 10K	25	3.70	.82	0.266	.849
	10K- 50K	35	3.69	.71		
	50K - 100K	18	3.69	.55		
	100K +	13	3.88	.77		
Eco Social	0 - 10K	24	3.32	.42	1.641	.186

	10K- 50K	35	3.52	.34		
	50K - 100K	18	3.56	.46		
	100K +	14	3.44	.40		
Spiritual Interaction	0 - 10K	25	3.53	.55	0.748	.527
	10K- 50K	35	3.43	.59		
	50K - 100K	17	3.55	.72		
	100K +	14	3.71	.63		
	Total	91	3.52	.61		

Note: Currency is in Naira (1 Pound = 930 Naira)

K=One Thousand Naira

As a reminder: see section 1.

Note: *Spirit domain refers to the understanding of one's faith, levels of faith, attending church and being involved in church activities.*

Eco social refers to Activities of daily living (ADL's) such as Feeding, bathing and toileting).

Spiritual domain refers to one's relationship with God, one's closeness and connectivity with God.

The results of the ANOVA test indicated that there was no significant difference in mean scores across income levels for the physical, soul, spirit, eco-social, and spiritual interaction dimensions of HRQOL. This reveals that there is no significant effect of income on the dependent variables – the HRQOL dimensions mentioned above. However, the emotional and intellectual dimensions (see figure 6.3 and figure 6.4) of HRQOL revealed a significant difference across income levels for the emotional, $F(3, 87) = 3.171, p = .028$, and intellectual dimensions, $F(3, 87) = 4.124, p = .009$.

Figure 13: Mean of emotional dimension of quality of life.

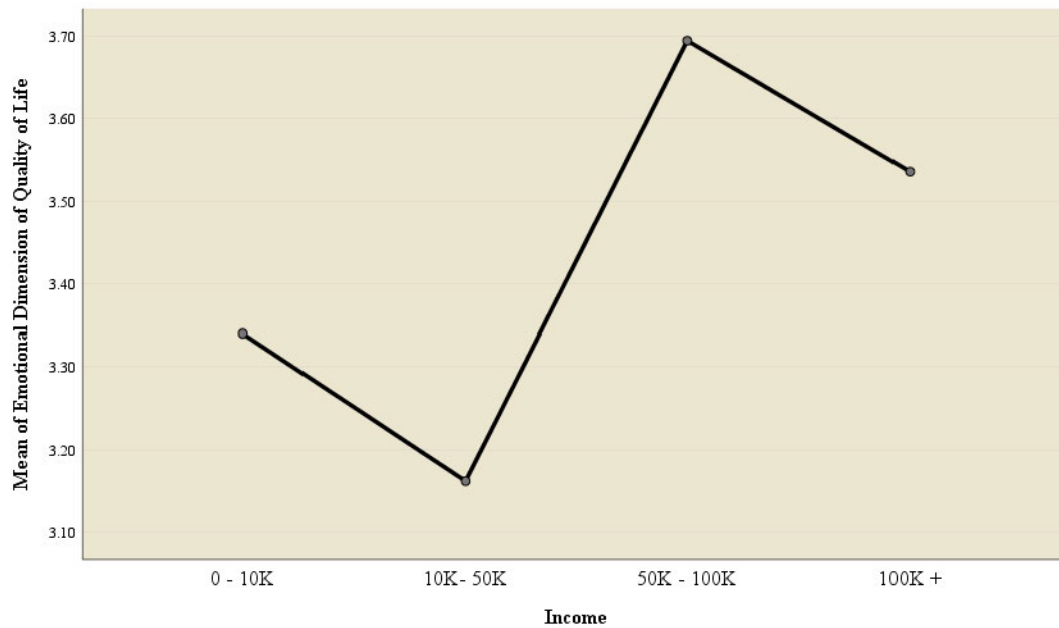
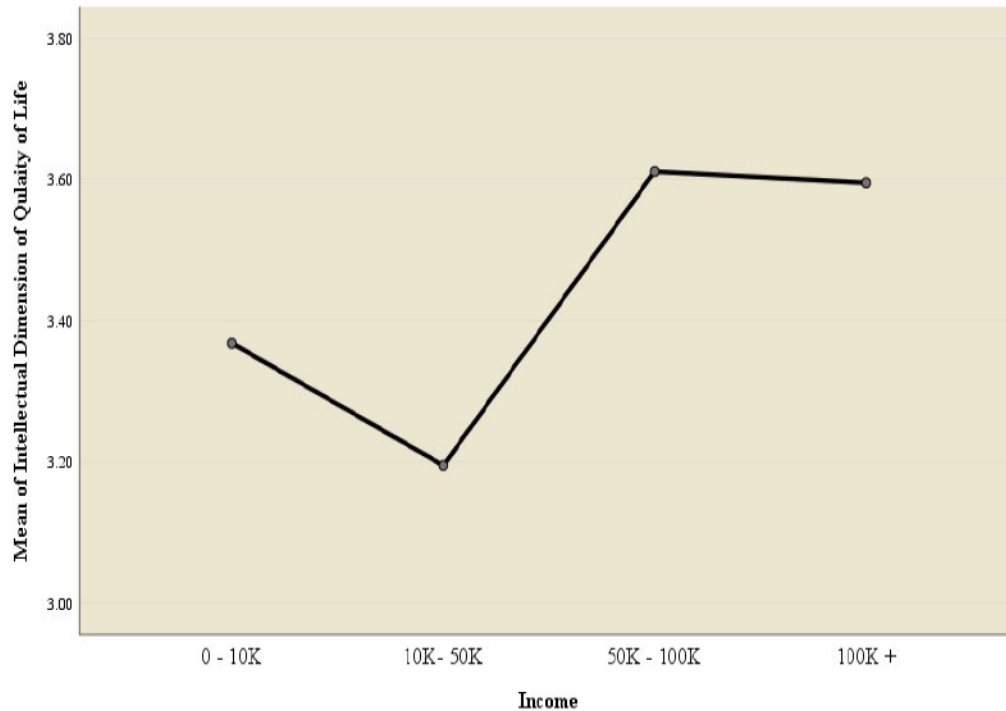


Figure 14: Mean plot of Intellectual dimension of quality of life across income levels.

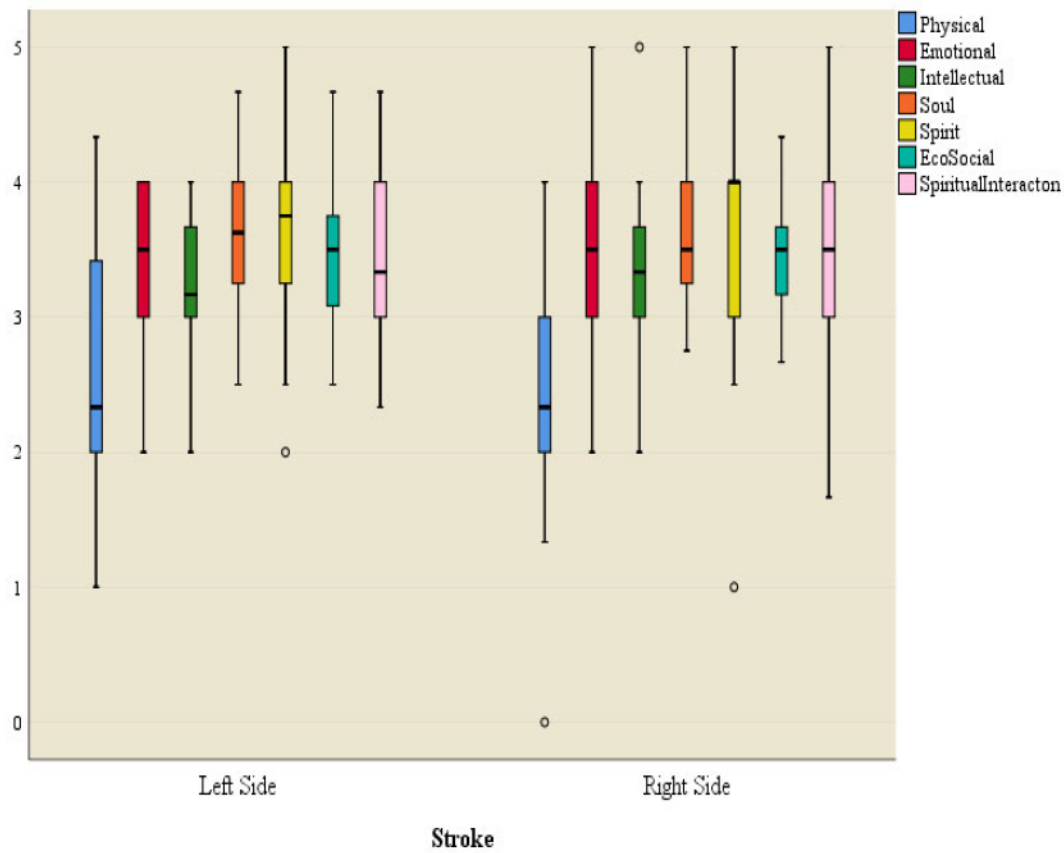


The Scheffe's post hoc test was used to make possible contrasts between group means and for unplanned comparisons. The results of the test indicated significant differences in the emotional and intellectual dimensions of HRQOL between the N10K–50K and N50K–100K (N= Naira, Nigerian currency) Nigerian income levels. Specifically, regarding the emotional dimension (see figure 3 and figure 4) the mean score for subjects in the N10K–50K income level ($M = 3.16$, $SD = .57$) was significantly lower (mean difference = -0.532 , 95% CI: -1.056 to -0.009) than that of subjects in the N50K–100K income level ($M = 3.69$, $SD = .75$). Furthermore, concerning the intellectual dimension, the mean score for those in the N10K–50K income level ($M = 3.20$, $SD = .45$) was significantly lower (mean difference = -0.416 , 95% CI: -0.810 to -0.022) than that of the subjects earning N50K–100K ($M = 3.61$, $SD = .60$).

6.4.3 Independent samples T Tests - testing the significance of the difference in the mean scores between affected sides of stroke.

Independent samples t-test was used to test the significance of the difference in the mean scores of each dimension of HRQOL construct between the sides affected by the stroke (stroke orientation). Figure 6.5 is a box plot of each dimension of the HRQOL construct for the two sides (left and right hemiparesis).

Figure 15: Box plot of dimensions of Quality of Life for Left and Right-Side Hemiparesis



The independent samples t-test results showed that there is no significant difference in the mean score of each dimension of the HRQOL construct between the left and right hemiparesis affected by the stroke. The side of the body affected by the stroke did not show a significant effect on any dimensions of the HRQOL construct.

Table 6.8 demonstrates the effect of stroke orientation on the dimensions of HRQOL, revealing that there is one significant difference in the mean score of each dimension of the HRQOL between left and right hemiparesis.

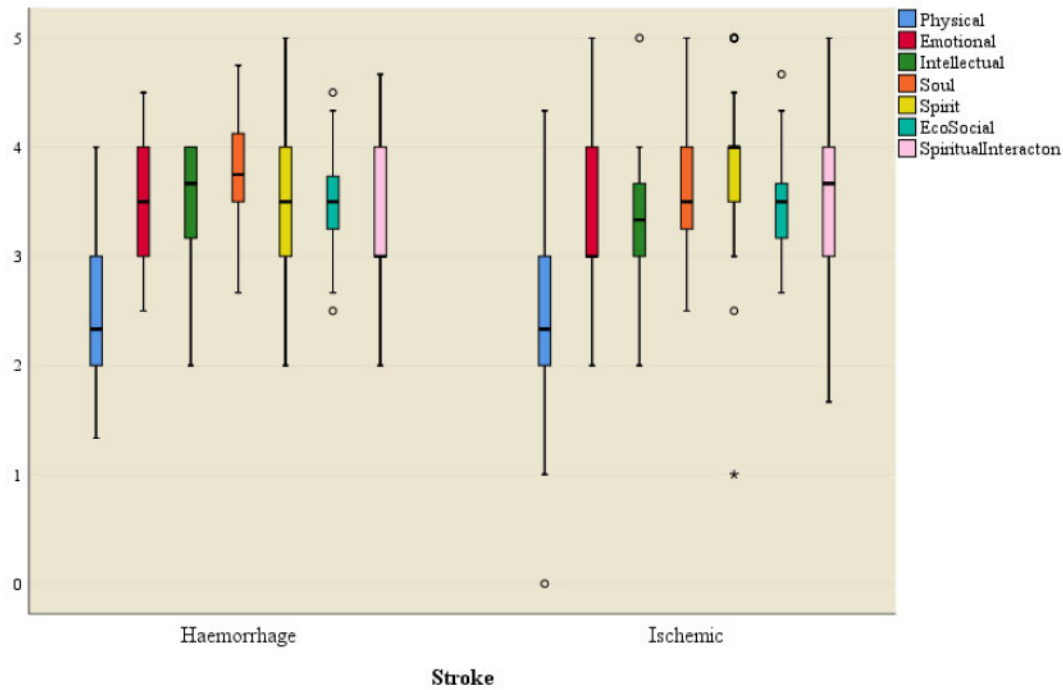
Table 10: Effect of Stroke Orientation (Affected Body Side) on dimensions of quality of life.

					t	df	p	95% CI for the mean difference	
	Part	N	Mean	SD					
Physical	Left	34	2.64	.85	1.30	92	.20	(-.11	.54)
	Right	60	2.43	.72					
Emotional	Left	33	3.33	.54	-.67	92	.51	(-.37	.18)
	Right	61	3.43	.69					
Intellectual	Left	34	3.28	.54	-1.53	92	.13	(-.37	.05)
	Right	60	3.44	.47					
Soul	Left	34	3.64	.58	-.73	93	.47	(-.33	.15)
	Right	61	3.73	.55					
Spirit	Left	34	3.71	.66	.15	92	.88	(-.28	.33)
	Right	60	3.68	.74					
Eco Social	Left	33	3.48	.53	.14	92	.89	(-.16	.19)
	Right	61	3.47	.32					
Spiritual	Left	34	3.50	.58	.06	93	.95	(-.26	.28)
Interaction	Right	61	3.49	.66					

6.4.4: Independent samples T Tests - testing the significance of the difference in the mean scores between the haemorrhagic and ischaemic stroke type.

Figure 6.6 is a box plot of each dimension of the HRQOL construct for the two types of strokes. Independent samples t-test was used to test the significance of the difference in the mean score of each dimension of the HRQOL construct between the haemorrhagic and ischaemic stroke types.

Figure 16: Box plot of dimensions of Quality of Life for types of strokes



The results of the independent samples t-test indicate no significant difference in the mean scores of each HRQOL dimension construct between haemorrhagic and ischaemic types of strokes. The type of stroke did not have a significant effect on any dimension of the QOL construct. Table 6.9 shows the dimensions of the two types of strokes on the quality of life.

Table 11: Effect of Type of Stroke on dimensions of quality of life.

					t	df	p	95% CI for mean difference	
	Stroke	N	Mean	SD					
Physical	Haemorrhage	24	2.45	.86	-1.4	90	.89	-.38	.33
	Ischemic	68	2.48	.70					
Emotional	Haemorrhage	24	3.54	.49	1.33	90	.19	-.10	.53
	Ischemic	68	3.33	.72					
Intellectual	Haemorrhage	24	3.50	.50	1.27	90	.21	-.09	.42
	Ischemic	68	3.34	.55					
Soul	Haemorrhage	24	3.80	.51	1.15	91	.25	-.11	.42
	Ischemic	69	3.65	.58					
Spirit	Haemorrhage	23	3.52	.70	-1.55	90	.12	-.60	.07
	Ischemic	69	3.78	.70					
Eco Social	Haemorrhage	24	3.48	.48	.03	90	.98	-.18	.19
	Ischemic	68	3.47	.36					
Spiritual	Haemorrhage	24	3.31	.64	-1.69	90	.09	-.55	.04
Interaction	Ischemic	68	3.56	.63					

6.5: The Regression model to evaluate the significance of the effect of the independent variables.

A linear regression model was constructed and tested to evaluate the significance of the predictive effect of age, gender, income level, type of stroke, and body side affected due to stroke. Specifically, a general linear model (GLM) was applied, taking gender, income, type of stroke, and body side as categorical predictors and age as a continuous predictor.

The results of the GLM analysis revealed significant models and predictors of the spiritual interaction dimension of HRQOL. The R squared value was 0.179, indicating that 17.9% of the variance in the spiritual interaction dimension can be explained by the predictors. Among the predictors, gender and income were statistically significant but with small effects ($\eta^2 < 0.20$) on the spiritual interaction dimension for gender, $F(1, 75) = 4.341, p = .041$, and income, $F(3, 75) = 4.067, p = .010$. Specifically, adjusting for the effect of other predictors, the mean spiritual interaction level was significantly higher for females compared with males (mean difference = .277, $t(75) = 2.083, p = .041$, 95% CI for mean difference: 0.012–0.542).

For income levels, Bonferroni adjusted comparisons indicated that the subjects in the high-income group of 100K or more had significantly higher mean spiritual interaction scores compared with subjects in the 10K–50K income group (mean difference = 0.701, 95% CI for mean difference: 0.156–1.247).

Table 6.10 below presents the results of the GLM model (with model effects of each predictor, along with the test for its significance).

Table 12: Predictive effect of Age, Gender, and Stroke side on Dimension of Quality of Life

Dimension of QOL	Predictor	β (SE)	p	95% CI of β	η^2	R ²	Adj. R ²
Physical	Gender (female)	.08(.18)	.66	(-.28, .45)	.003	.095	.009
	Age	-.01 (.01)	.09	(-.03, -.002)	.039		
	Income						
	0 – 10K	.07 (.28)	.79	(-.48, .63)	.001		
	10 K – 50 K	-.28 (.28)	.31	(-.83, .27)	.014		
	50K – 100K	-.14 (.30)	.64	(-.74, .46)	.003		
	Body impaired (left)	.20 (.18)	.27	(-.16, .59)	.02		
	Type of stroke (Haemorrhage)	-.26 (.20)	.21	(-.65, .15)			
Emotional	Gender (female)	.03 (.16)	.83	(-.28, .35)	.001	.135	.053
	Age	-.003 (.01)	.61	(-.02, .009)	.003		
	Income						
	0 – 10K	-.27 (.24)	.26	(-.74, .20)	.017		
	10 K – 50 K	-.36 (.23)	.13	(-.83, .11)	.031		
	50K – 100K	.17 (.26)	.52	(-.35, .68)	.006		
	Body impaired (left)	-.13 (.15)	.42	(-.43, .18)	.009		
	Type of stroke (Haemorrhage)	.21 (.17)	.22	(-.13, .56)	.02		
Intellectual	Gender (female)	-.02 (.11)	.86	(-.25, .21)	.001	.151	.071
	Age	-.001 (.004)	.82	(-.01, .01)	.001		
	Income						
	0 – 10K	-.23 (.17)	.19	(-.57, .12)	.023		
	10 K – 50 K	-.32 (.17)	.06	(-.66, .02)	.046		

	50K – 100K	-.05 (.19)	.79	(-.42, .32)	.001		
	Body impaired (left)	-.19 (.11)	.09	(-.41, .03)	.037		
	Type of stroke (Haemorrhage)	.18 (.13)	.17	(-.08, .43)	.026		
Soul	Gender (female)	.01 (.14)	.92	(-.26, .29)	.001	.053	.035
	Age	-.005 (.005)	.36	(-.02, .006)	.011		
	Income						
	0 – 10K	-.26 (.21)	.23	(-.68, .17)	.019		
	10 K – 50 K	-.13 (.23)	.63	(-.55, .29)	.005		
	50K – 100K	-.11 (.23)	.63	(-.57, .35)	.003		
	Body impaired (left)	-.12 (.14)	.40	(-.85, .40)	.010		
	Type of stroke (Haemorrhage)	.14 (.15)	.37	(-.17, .45)	.011		
Spirit	Gender (female)	.16 (.18)	.38	(-.20, .51)	.011	.060	.029
	Age	.002 (.007)	.79	(-.01, .02)	.001		
	Income						
	0 – 10K	-.28 (.28)	.32	(-.84, .27)	.014		
	10 K – 50 K	-.37 (.27)	.18	(-.92, .18)	.024		
	50K – 100K	-.23 (.30)	.46	(-.83, .38)	.008		
	Body impaired (left)	.19 (.18)	.28	(-.16, .54)	.016		
	Type of stroke (Haemorrhage)	-.33 (.20)	.11	(-.74, .07)	.035		
Eco-Social	Gender (female)	-.17 (.09)	.08	(-.37, .02)	.042	.093	.007
	Age	.0001 (.004)	.92	(-.008, .007)	.0001		
	Income						
	0 – 10K	.055 (.15)	.72	(-.24, .35)	.002		
	10 K – 50 K	.25 (.15)	.09	(-.04, .54)	.039		
	50K – 100K	.23 (.16)	.16	(-.09, .55)	.027		
	Body impaired (left)	-.06 (.11)	.51	(-.26, .13)	.006		

	Type of stroke (Haemorrhage)	.10 (.11)	.35	(-.11, .31)	.012		
Spiritual Interaction	Gender (female)	.28 (.13)	.04	(.01, .54)	.055	.179	.102
	Age	.01 (.01)	.16	(-.003, .017)	.026		
	Income						
	0 – 10K	-.48 (.20)	.021	(-.89, -.07)	.069		
	10 K – 50 K	-.70 (.20)	.001	(-1.10, -.30)	.139		
	50K – 100K	-.49 (.22)	.029	(-.99, -.05)	.062		
	Body impaired (left)	.15 (.13)	.270	(-.12, .41)	.016		
	Type of stroke (Haemorrhage)	-.29 (.15)	.053	(-.58, .004)	.049		

SE = standard error, η^2 is the measure of effect size associated with the model parameter.

Note: Currency is in Naira (1 Pound = 930 Naira)

K=One Thousand Naira

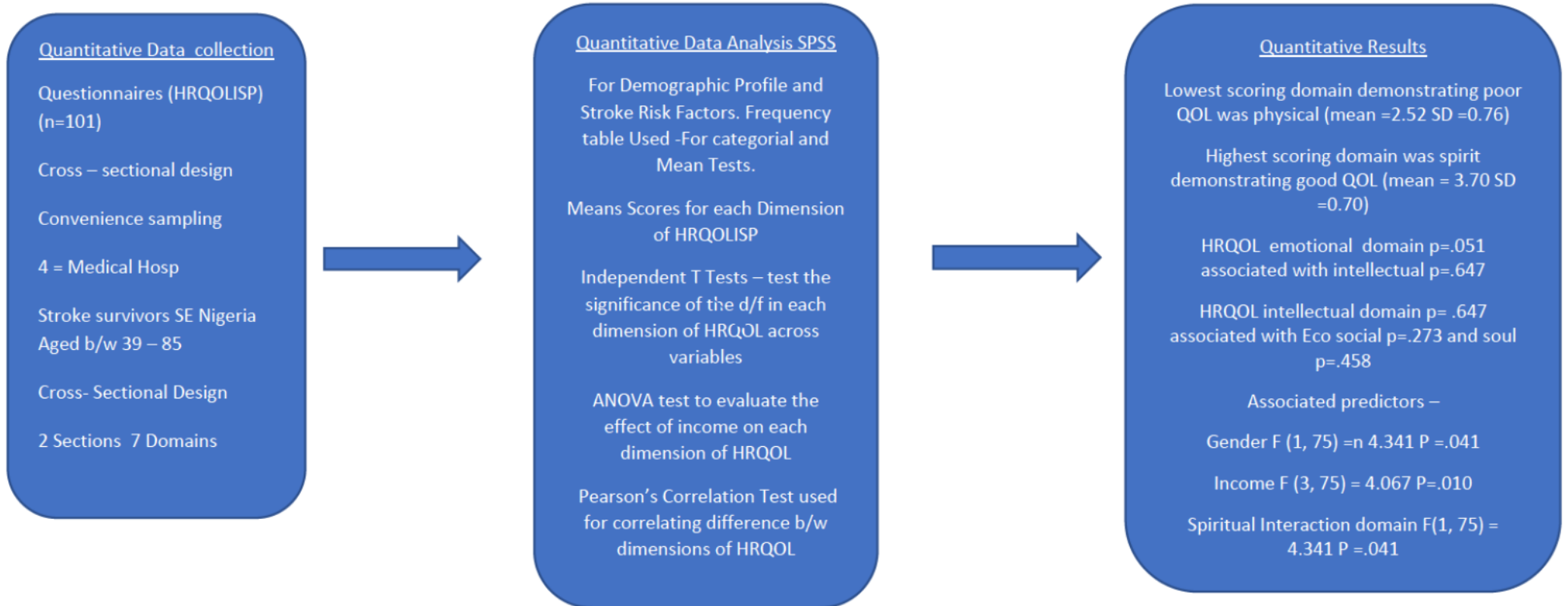
The GLM analysis indicated that the models for the physical, emotional, intellectual, soul, spirit, and eco-social dimensions of QOL were statistically not significant. This implies that none of the predictor variables had a statistically significant effect on these dimensions of the HRQOL construct.

The results of the GLM analysis revealed a significant effect of gender and income on the spiritual interaction dimension of the quality of life of subjects. Age, gender, income, type of stroke, and body side affected by the stroke failed to show a significant predictive effect on the physical, emotional, intellectual, soul, spirit, and eco-social dimensions of quality of life.

6.5.1: Overall Process

Figure 6.7 presents a summary of the process surrounding the quantitative data collection, its analysis, and findings with the use of SPSS version 22

Figure 17: The progression of the quantitative methods in phase 1



6.6 Discussion

The HRQOLISP tool was used to attain the QOL scores for each domain. The assessment tool captured multidimensional impacts of stroke on the quality of life of survivors from the perspective of the stroke survivors, which is clinically important information for rehabilitation services. Demographic and stroke risk factor information (continuous and interval scale variables), age, and quality of life scale score were summarised using arithmetic means and using standard deviations (SDs). The statistical analysis of the data included both descriptive and inferential methods. Categorical variables (gender, education, marital status, ethnicity, type of stroke, income level, body side affected by the stroke) were summarised using frequency tables.

The independent samples t-test was used to test the significance of the difference in the dependent variables: the physical, emotional, intellectual, soul, spirit, eco-social, and spiritual interaction dimensions of the quality of life (QOL) construct. Differences regarding (i) gender (ii) type of stroke, and (iii) body side affected by stroke were tested. The independent samples t-test assumes equality of variance of the variable between two of the groups being compared.

Pearson's correlations were used to measure the strength of the associations between variables and to inform the direction of the relationships. Multiple linear regression analyses were performed to determine the most significant difference, thereby identifying the strongest predictors of HRQOL for the study.

Single factor ANOVA was used to test the significance of the difference in the physical, emotional, intellectual, soul, spirit, eco-social, and spiritual interaction dimensions of the quality of life (HRQOL) construct between income levels.

The significance of the predictive effect of age, gender, type of stroke, income, and body side affected by stroke on the physical, emotional, intellectual, soul, spirit, eco-social, and spiritual interaction dimensions of the QOL construct was evaluated using linear regression analysis. Specifically, a general linear model (GLM) was constructed, including gender, income, type of stroke, and body side affected by stroke as categorical factors and age as the continuous predictor.

6.7 Summary of Chapter

The variables and relationships that predict the impact of stroke on the quality of life of stroke survivors in Nigeria's SE communities are illustrated in the following results.

Stroke had a twofold effect on QOL in this study: good or poor influence. The descriptive statistics for HRQOL revealed that the lowest scoring domain that demonstrated a poor quality of life was the physical domain (mean = 2.52, SD = 0.76), whereas the highest scoring domain that demonstrated a good quality of life was the spirit domain (mean = 3.70, SD = 0.70). This shows that the physical, followed by the emotional (psychological) and intellectual (cognitive) domain is the most affected of the HRQOL domains of the stroke survivors. This ultimately had the most impact on the quality of life of the stroke survivors in the SE communities of Nigeria.

The Pearson's correlation used to analyse the relationships between the variables revealed that the emotional (psychological) domain ($p = .051$) is associated with the intellectual (cognitive) domain ($p = .647$). This means that high scores for the former are associated with high scores the latter. The intellectual (cognitive) domain is also associated with the eco social (ADLs) ($p = .273$) and soul ($p = .458$) domains, which suggests that high scores of the intellectual (cognitive) domain are associated with high scores for the latter two.

The intellectual (cognitive) domain was negatively correlated with the spiritual domain. In other words, when stroke survivors improved their intelligence (cognitive capacity), they appeared to lose their spiritual orientation.

A significant difference was observed between the emotional (psychological) and intellectual (cognitive) domains for both the 10K–50K and 50K–100K income levels. Regarding the intellectual (cognitive) domain, the mean score of the subjects in the 10K–50K income level ($M = 3.20$ $SD = 0.45$) was significantly lower than the mean score for those earning 50K–100K ($M = 3.61$ $SD = 0.60$), with a mean difference of -0.416 (95% CI = -0.0810 to -0.022).

The general linear regression test analysed the associated predictors and revealed that the predictors gender, $F(1, 75) = 4.341$ $p = .041$, and income, $F(3, 75) = 4.067$, $p = .010$, had a statistically significant effect ($n^2 < 0.20$) on the spiritual interaction domain, $F(1, 75) = 4.341$ $p = .041$.

The results of the GLM analysis revealed predictors of the spiritual interaction domain of the HRQOL – with the R squared value being 0.179, indicating 17.9% of the variance in the spiritual interaction domains. This suggests that the GLM analysis revealed that income and gender were the determinants of HRQOL in this study, most particularly the spiritual interaction domain.

6.8 Reflection

Reflection is critical because it helps researchers to analyse their practices and the impact they have on others, themselves, and their findings (Creswell et al., 2017). When I first arrived in Nigeria to begin collecting quantitative data, I was faced with the dilemma of where to begin. I had already determined the three medical centres I had planned to collect data from but was unaware of the difficulties I would face in obtaining informed written consent from the institutions and patients, even though I had previously received ethical approval from the various medical institutes. Despite the fact I am of Nigerian descent, I still felt like a foreigner at times and was often treated as such. I quickly learnt to conform to each setting and staff's expectations during the process of gathering quantitative data (HRQOLISP questionnaire) from the medical institutes.

The first few questionnaires administered appeared to drag on interminably. I had not anticipated that each questionnaire would take such a lengthy time to complete. In addition, most stroke survivors had developed a slower pace in their behaviour – having mild or moderate cognitive difficulties, which had a negative impact on speed.

The quantitative data collection process was divided into two stages. Thirty-five questionnaires were compiled during my first visit to Nigeria, which took place between December 2019 and March 2020. The goal was to return to collect the remaining sixty-six questionnaires in September 2020. However, the COVID-19 pandemic occurred in March / April 2020, which was unfortunate. As a result of travel restrictions and social distancing, I had to make alternate arrangements for collecting the remaining questionnaires for Phase 1 of the study (see chapter 5 section 6). By the end of 2020, the remaining questionnaires had been collected with the assistance of my PhD supervisor (Professor Asokile) based who is based in the University of Nsuka Nigeria. Phase 1 and the derived database, in retrospect, were necessary for me to comprehend how stroke survivors in Nigeria's SE region respond to questions about the impact of stroke on their quality of life.

After collecting a total of 101 questionnaires on paper, I was faced with the task of transferring the data to an electronic database (an Excel sheet) so that the data could be viewed in terms of variables that could produce statistical evidence of the impact of stroke on the quality of life of stroke survivors in Nigeria's SE communities. This was a lengthy process; I needed to shift my perspective from clinical readings to statistical data to deal with it.

The following stage was to construct the database, ensuring that it was compatible with both software and hardware and, finally, to trial the database that generated the data in this phase. This sequential approach resulted in the formation of an electronic database (SPSS version 22) that served as the foundation for the quantitative portion of this study's methodological development. The data collected formed a separate database from which tests and analyses could be conducted to address the study question, which focused on the impact of stroke on the quality of life of stroke survivors in Nigeria's SE communities.

The overarching goal of this study is to investigate the impact of stroke on the QOL of stroke survivors through the participants' lived experiences. The quantitative phase 1 findings of this study resulted in a biomedical approach, whereas the following chapter, which presents the study's qualitative findings for phase 2, will focus on the social and cultural perspectives, with both phases working together to produce insights into the impact of stroke on the participants' QOL. As a result, phase 1 revealed that the physical domain, demonstrated a poor quality of life (mean = 2.52, SD = 0.76), whereas the highest scoring domain that demonstrated a good quality of life was the spirit domain (mean = 3.70, SD = 0.70). It therefore remains critical that we gain a more comprehensive understanding of the concepts and phenomenon of the impact of stroke on QOL through the verbal narratives of the participants, which is what the findings of qualitative phase 2 intends to do.

CHAPTER SEVEN

QUALITATIVE FINDINGS – PHASE 2

7.1 Introduction

The previous chapter has concluded with a discourse of the variables and relationships that predict the impact of stroke on the quality of life of the stroke survivors in the SE communities of Nigeria. However, this chapter presents the study's main qualitative findings for phase 2 of the studies data analysis. This phase sets out to examine in depth the impact of stroke on the quality of life of the stroke survivors in SE Nigeria. At times, the work is written in the first person. This is the style of the researcher, and in so doing, I aim to show ownership of my work about the interpretative, subjective facet of the study (Creswell et al., 2016).

This chapter presents the narrative findings from the Interpretative phenomenological analysis (IPA) of the interview transcripts of ten (10) stroke survivors (aged 29-72 years) who had a stroke for more than one year; these were transcribed verbatim. In some of the themes and subthemes, I use the narratives of one to four participants. This does not mean that the other participants did not tell or share the same experiences; the participants' extracts are the most powerful. The chapter begins with a narrative introduction to each master theme and subtheme, followed by supporting extracts, interpretative analysis, a discussion, and a reflective element to close.

7.2 Qualitative Data Analysis

Interpretative phenomenological analysis (IPA) was used to conduct semi-structured interviews with ten individuals. The purpose of IPA was to elucidate the process by which stroke survivors 'make sense' of their experiences. A four-step IPA analysis approach was used to record and analyse all interviews. Similar and interconnected themes emerged from the participants, allowing for the synthesis of the data into a unified organising framework with three superordinate master themes and multiple subthemes encapsulating the 10 participants' primary concerns about quality-of-life following stroke. All the participants in the study gave permission for their transcript extracts to be used in this way. Summary of the analytical process is shown below.

7.2.1 The Analysis Phase in IPA

The section that follows provides an overview of the IPA data analysis process. This is provided in great detail in order to promote process transparency. I used a systematic process to analyse the data, thereby aiding the development and interpretation of themes to demonstrate the significance of the phenomenon under examination. This technique aided in contextualising the impact of stroke-on-stroke survivors' quality of life.

7.2.2 Reflexive Exercise

My process of analysis began with a reflexive exercise, and this is also seen in each section through the study (Creswell et al., 2017). Studies advise researchers to reflect on their relationship to the research topic as part of a reflection exercise to spot any assumptions they may have (Finlay et al., 2011; Crowe et al., 2016). Following that, the researcher may think about how all of this might impact research processes and how this might be managed. I found that doing this exercise allowed me to think about my past experiences of working with stroke survivors in clinical settings as well as my hopes and expectations for the study's findings.

Phase 1 – Familiarisation (Multiple reading and Making Notes)

I began the process of immersing myself in the data by reading and re-reading the transcripts, whilst listening to the audio recording (Smith et al., 2009). However, to aid clarification, all notes taken during the interviews and reflections on the interviews were read in conjunction with the transcripts. Throughout this process, it became clear that each reading revealed new insights (Crowe et al., 2016; Smith et al., 2015). Some of the comments attempted to summarise the participants' experiences, whilst some were associations or connections that occurred to them, and others were primarily interpretations (Smith et al., 2015). However, all interviews were then transcribed into a Microsoft Word document. (This made it easier to cut and paste clusters, superordinate / sub themes and main themes generated at a later stage of the analysis.) The analysis was conducted using the qualitative software Quirkos (See Chapter 5). This is a simple software tool for exploring qualitative data and is flexible and easy to use. I uploaded the 10 scripts onto the software and became as familiar with the accounts as possible, noting initial impressions (Smith et al., 2015). At this point I recorded my first reactions to the data (Smith et al., 2015). This suggests that researchers may find themselves feeling overwhelmed by ideas and possible connections at this stage. One of my first reactions to the data

I was aware of the tensions, particularly the need to stay true to the interpretative aim of IPA by adding depth and sophistication to the analysis by moving it beyond the superficial, while also ensuring that my interpretations were closely tied to the text. This process involved going back and forth the text in order not to lose the essence of what the participants were saying, this procedure was repeated until saturation was reached (Smith et al., 2009). However, the use of field notes assisted in making sense of the participants' sense making process as I reflected on my initial thoughts.

Phase 3 – Theory Building (Seeking Relationships, Emergent and Clustering Themes)

This stage entailed capturing, reflecting on, and comprehending the notes as well as the psychological essence of the text (Smith et al., 2009, Finlay et al., 2011). It was a process of description and interpretation, as the participants' original words and thoughts, as well as the analyst's interpretation, were reflected. Appendix 7 offers an example of the analysis process of some of the participants. I created a list of all the emergent themes that had been identified in the participants account (see Appendix 7). These themes are cut and pasted into a word document to form clusters of related themes (see Table 7.1). To form the clusters, I used abstraction (where like is put with like and a new name is given), subsumption (where an emergent theme helps bring together a series of related themes), and polarisation (where emergent themes have opposing relationships). (Tables 7.1-7.3).

Choosing which themes to focus on necessitated me becoming selective considering these two aspects: the richness of the passages which highlight the themes and how the themes help illuminate other aspects of the text (Crowe et al., 2016). This phase presented me with several challenges. Moving away from the participants' direct accounts and back to my own analysis made me question my interpretations. I remained reflexive in developing and naming the emergent themes, constantly questioning whether they were grounded in the data and how much my meaning making reflected my own experiences and values.

The creation of a table which brings together the clustered themes with their related quotes is an important part of this step of the analysis (Smith et al., 2015). The table unifies the emergent themes directly with the transcript. Viewing these together without the exploratory notes was a significant step in the analysis for me. I often felt that my interpretative leap was too far from the participants'

experiences. I wondered if my analysis had been impacted by my presuppositions and expectations as I seemed to be looking for matching examples in the data. (See Appendix 7)

Phase 4 – Data Refinement and Analysis (Writing Up an IPA study)

Smith et al. (2015) argued that during this phase, the analyst must be creative to draw together the emergent themes, and that not all the emerging themes must be included. During this phase, my aim was to write down each participant's account in a textual format. This leads the reader through various descriptions and levels of interpretation, whilst always maintaining transparency between the participants' words and the researcher's analysis. The analysis process entailed interpreting the data at a more theoretical level, transitioning from a 'cluttered' participant account to a more coherent narrative. The narrative reflects both subjective and collective experiences, which is central to the IPA process (Finlay et al., 2011; Smith et al., 2015).

The difficulties of my large body of data became clear at this point in the analysis. Smith et al., (2015) and Creswell et al., (2017) argued that measuring recurrence across cases is important for larger studies and can improve the rigour of the findings. I was concerned that by setting a higher target for recurrence, the richness of the understanding of the phenomenon would be lost, and that setting a lower target would make the analysis unmanageable.

Appendix 11 shows the recurrence of each superordinate and sub theme. This stage of the process struck me as a powerful illustration of the IPA hermeneutic circle: the whole is understood as its parts, which are then understood in relation to the whole (Creswell et al., 2017). I eventually ended up with superordinate themes, which contained several sub themes, from where the three main themes emerged. This is illustrated in Table 7.5: (The three overarching Main themes and subthemes), in the section below. This final phase was completed when the characteristics that made each case unique (Idiographic) were identified and shared experiences between participants emerged.

Following the completion of this phase, two presentations emerged. The first section contained the narrative accounts, which included my interpretations with verbatim extracts from the transcripts to serve as proof of my interpretations. The second section was a discussion that focused on examining the analysis considering existing literature to demonstrate how the participants' experiences contributed

new insights into existing knowledge on the impact of stroke on the QOL of stroke survivors through lived experiences.

7.3 An Example of the Analysis Process of One theme - from Data Extract to Main theme

The following is an example of the process from data extract to coding, to clusters, to sub themes / superordinate, to main theme. I use the first theme – An Unfamiliar self which consists of the sub themes.

1. Self- identity
2. Disempowerment
3. Physical disability

In performing the analysis for the study, I initially coded each transcript after transcribing prior to uploading on the Quirkos qualitative system. This is to ensure that I remained immersed in the data and codes are closely linked to the data as stated earlier.

The Quirkos Initial coding format (see Figure 7.1) included establishing connections, where bubbles were dropped into each other and presented as codes. Codes were classified into categories which appeared to address similar issues, then grouped into clusters, then superordinate's / sub themes and then finally Master themes. In this example, the data set is one extract but usually you will have more than this.

The right-hand margin of the software was used for making initial codes and comments of significant interests identified by myself.

As defined earlier, a theme is a pattern that captures something significant about the data (Braun & Clarke). It is reported that there are no hard and fast rules about creating a theme. If you have a small data set such as in this study, there may be considerable overlap between the coding stage and the stage of identifying the preliminary themes as seen in this study.

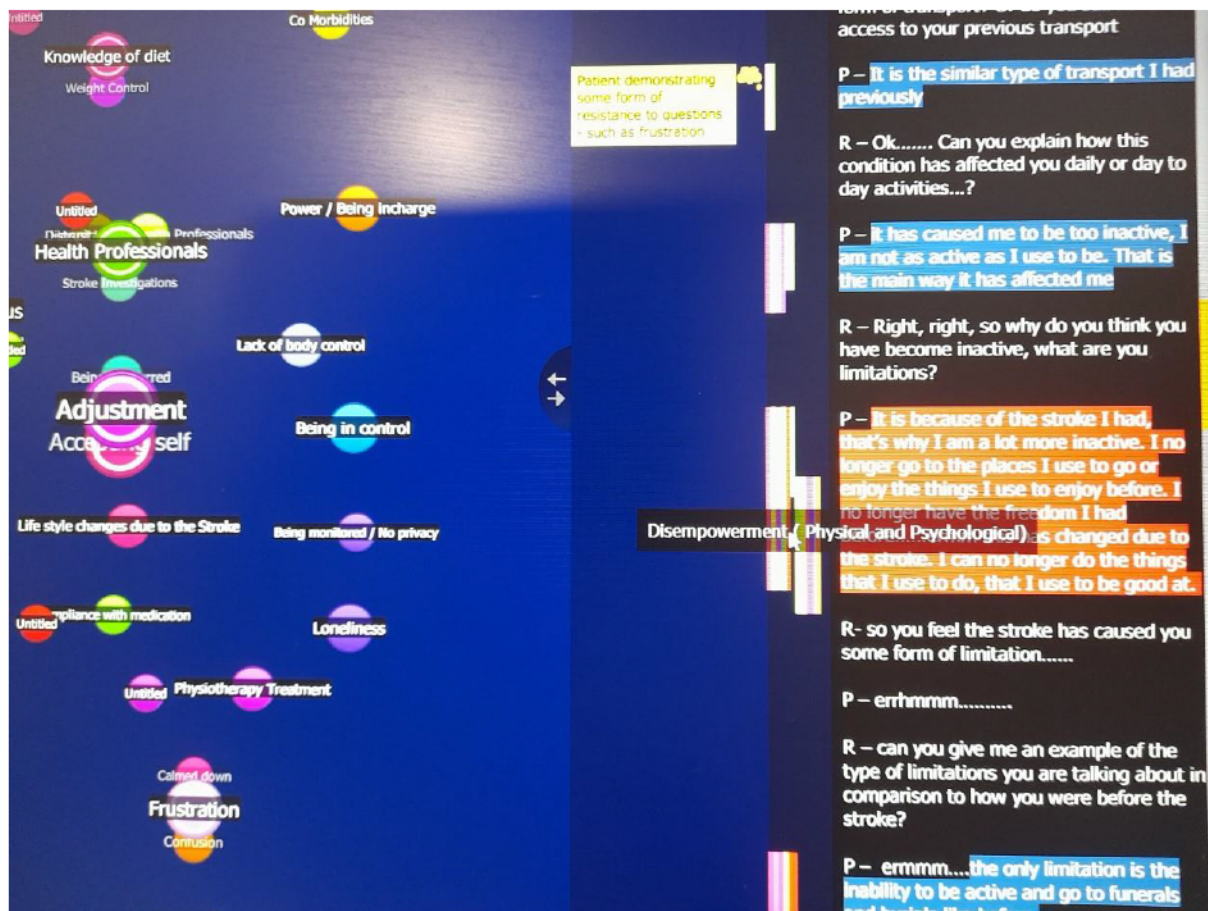
In this example 'An unfamiliar Self', the codes and clusters were examined, and some of them clearly fitted together into a theme. For example, there were several codes that related to perceptions of an unfamiliar self – from the observations and field notes, this was viewed as an unpredictable body. The sub – themes, self – identity, disempowerment, and physical disability (see tables below), were all collated into the example theme.

Figure 19: Comparison patterns from one participant narrative highlighting self-identity

The image displays a software interface with two main panels. The left panel is a conceptual map with a dark blue background and various nodes connected by lines. The nodes include: 'Co Morbidities', 'Knowledge of diet', 'Weight Control', 'Power / Being Incharge', 'Health Professionals', 'Stroke Investigations', 'Lack of body control', 'Being in control', 'Adjustment', 'Accommodate self', 'Life style changes due to the Stroke', 'Being monitored / No privacy', 'Loneliness', 'Physiotherapy Treatment', 'Frustration', and 'Cautious'. A central node is labeled 'Self Identity'. A text box over the map reads: 'There seems to be a gap between not walking and Self Identity. The sudden loss of ability to walk can be a major impact on ones self esteem and mental well being. I wonder how the women is handling this.' The right panel shows a transcript of a conversation between P and R. The transcript is as follows:

P (00:03:11-14)
R okay, so
P now I am walking, I am walking well but that time I was not walking, I was not able to walk is just that I make use of walking stick
R alright
P my hands is not fully okay
R hmm okay okay, please as you had this stroke did you did you know it was stroke you were going to have
P I did not know is just that it is doctor that told me it was stroke
R okay
P I did not know because I have not had the experience it before I did not know, I did not understand
R okay
P I don't know what is stroke but I have been seeing others that are going through the experience, I have not had the experience it is the doctor that told me that it was stroke that I should go for CT scan
R hmm, okay you said that you are, that you are, that you are taking drugs for bp(blood)pressure, why did you start taking, why are you taking drugs for bp?

Figure 20: Comparative patterns from one participant narrative highlighting disempowerment



data as possible. Revisiting the original data ensures further immersion in the data and encourages new interpretations of the participants' narrative.

The codes emerged from an increased number of similar texts from the main transcript; it also shows the overlapping nature of the commonalities and variations identified. I came up with the theme – An unfamiliar self, as I felt it worked in this example as seen above in (Table 7.1). The participants in the study had referred to this cluster as being unpredictable and hence an unfamiliar self, arose as a theme. There had been a lot of data to support it, followed by overlaps with the three superordinate's / sub themes.

Table 13: Unfamiliar Self (Theme 1) Clusters 1, 3 8 and 9 (see appendix 9)

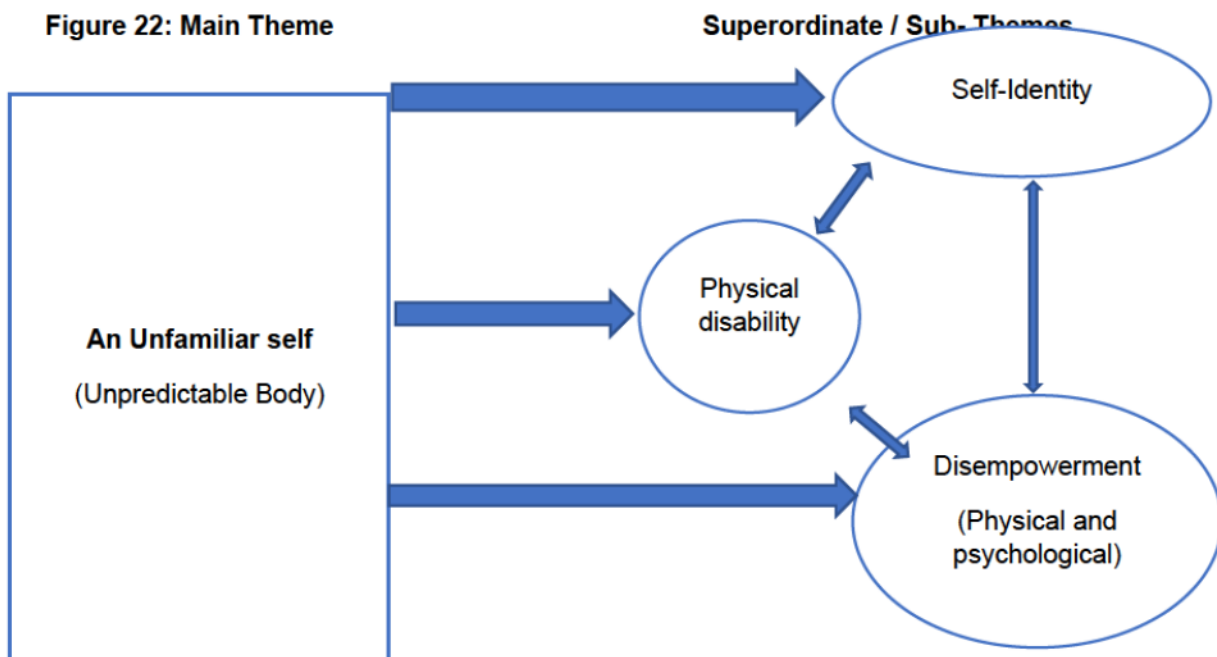
Cluster 1	Cluster 3	Cluster 8	Cluster 9
Impact of stroke on QOL (64) (10)	Impact on normal function (56) (9)	Telling the story (46) (9)	Lifestyle changes due to stroke. (54) (9)
Disempowerment 48 (Physical and psychological)	Physical disability (66)	Sadness (51)	Frustration (56)
		Act. before stroke (47)	Being anxious (46)
Physical disability (66)		Emotional response (34)	Being reassured (12)
Self – identify (52)			
Loneliness (62)		Confusion (7)	Distrust in health professionals (11)
Unbelief / In denial (58)			
Frustration (56)			
Sadness (51)			
Lack of body control (43)			
Dependency (35)			
Low mood / unhappy (35)			
Confinement (20)			
Reduced activities (17)			
Challenges post stroke (11)			

Table 7.1 displays some of the preliminary themes that are identified in part of the text, alongside clusters and codes. Most codes are associated with one theme although some are associated with more than one.

Table 14: The first overarching Master theme and Subsequent Sub-themes

Master theme 1. An unfamiliar self refers to the unpredictability of the stroke condition. Its component subthemes feature the role of self-identify, alongside disempowerment (physical and psychological) and the impact of physical disability.

Figure 22: Main Theme



At the end of each step the codes had been organised into broader themes that seemed to say something specific about the research question 'The impact of stroke on the quality of lives of the stroke survivors. The themes were predominately descriptive. i.e., they described patterns in the data relevant to the research question.

The remaining tables 7.2 and 7.3 highlight the process of emerging codes and clusters which capture the data analysis stages to make sense of the participants' perceptions and create a coherent narrative about the impact of stroke on the quality of life of stroke survivors in SE Nigerian communities.

Table 15: Recovery of embodied Self (Theme Two) Clusters 4, 5 and 6

Cluster 4	Cluster 5	Cluster 6
Poor Management of BP (58) (9)	Understanding of stroke (68) (9)	Traditional Drugs Native Doctors (48) (6)
Worrying about BP machine (41)	Stroke risk factors (34)	Cultural beliefs (42)
	Knowledge of diet (27)	
	Being education on the condition of stroke (25)	Faith and religion (26)

Blood pressure management (40)	Lack of knowledge (20)	
Medication (26)	Awareness of stroke (20)	
Compliance with medication (3)	Rehabilitation 40	

The theme 'recovery of embodied self' shows an increase in the number of similar texts about management / education, faith and religion / culture and rehabilitation.

Table 16: Reconstruction of the embodied Self (Theme Three) Clusters 7

Cluster 7
Reconstruction of the embodied Self / Familiar Self
(63) (10)
Adjustments (64)
Accepting Self (59)
Family support / History (42)
Self-discovery (41)
Being in control (48)
Having Hope (45)
Encouragement to new ss (29)
Maintaining dignity (23)
Reassurance (9)
Goals re stroke (5)

The theme 'reconstruction of embodied self' shows an increase in the number of similar texts about adjustments, accepting self / self-discovery. The above three tables develop into the three main master themes, the superordinate, and subthemes – see Table 7.5.

A successful IPA strives to maintain a reflexive mindset throughout the study, which is deemed 'obligatory' in IPA (Creswell et al., 2013). Preconceptions (personal prejudices or understandings) are updated as the researcher continues to study and interpret evidence. While using the hermeneutic circle, one often attempts to make personal biases and judgements explicit by writing them down during the research project before data are analysed. In this case, I decided to write them before and during the qualitative analysis.

Table 17: The Three overarching Master and Subsequent Subthemes

Master Themes	Superordinate / Subthemes
<p>1. An unfamiliar self</p>	<p>Unpredictable body</p> <p>Self-identity Disempowerment – physical and psychological Physical disability</p>
<p>2. Recovery of the embodied self</p>	<p>Transitional Stage</p> <p>Rehab / physical therapy Education / management of condition Faith / religion and cultural beliefs</p>
<p>3. Reconstruction of the embodied self</p>	<p>My new life after stroke</p> <p>Familiar self Self-discovery Adjustment and acceptance</p>

Source: Author

Master theme 1. An unfamiliar self refers to the unpredictability of the stroke condition. Its component subthemes feature the role of self-identify, alongside disempowerment (physical and psychological) and the impact of physical disability.

Master theme 2. Recovery of the embodied self refers to the transitional stage of the stroke condition. Component subthemes include rehab / physical therapy, management of the condition by means of education, and the impact of faith / religion.

Master theme 3. Reconstruction of the embodied self refers to a new way of life after the stroke. Its component subthemes feature a familiar self, self-recovery, and the impact of adjustment and acceptance of the stroke survivors.

Figure 7.4 demonstrates an overall interpretative mapping of the findings identifying the impact of stroke on the quality of life of the stroke survivors.

Table 7.4 demonstrates the participants' demographic data using pseudonyms, whereas Figure 7.6 gives a synopsis of each participant of the research study.

Figure 23: An Interpretative mapping of the impact of stroke on quality of life of stroke survivors.

Source: Author

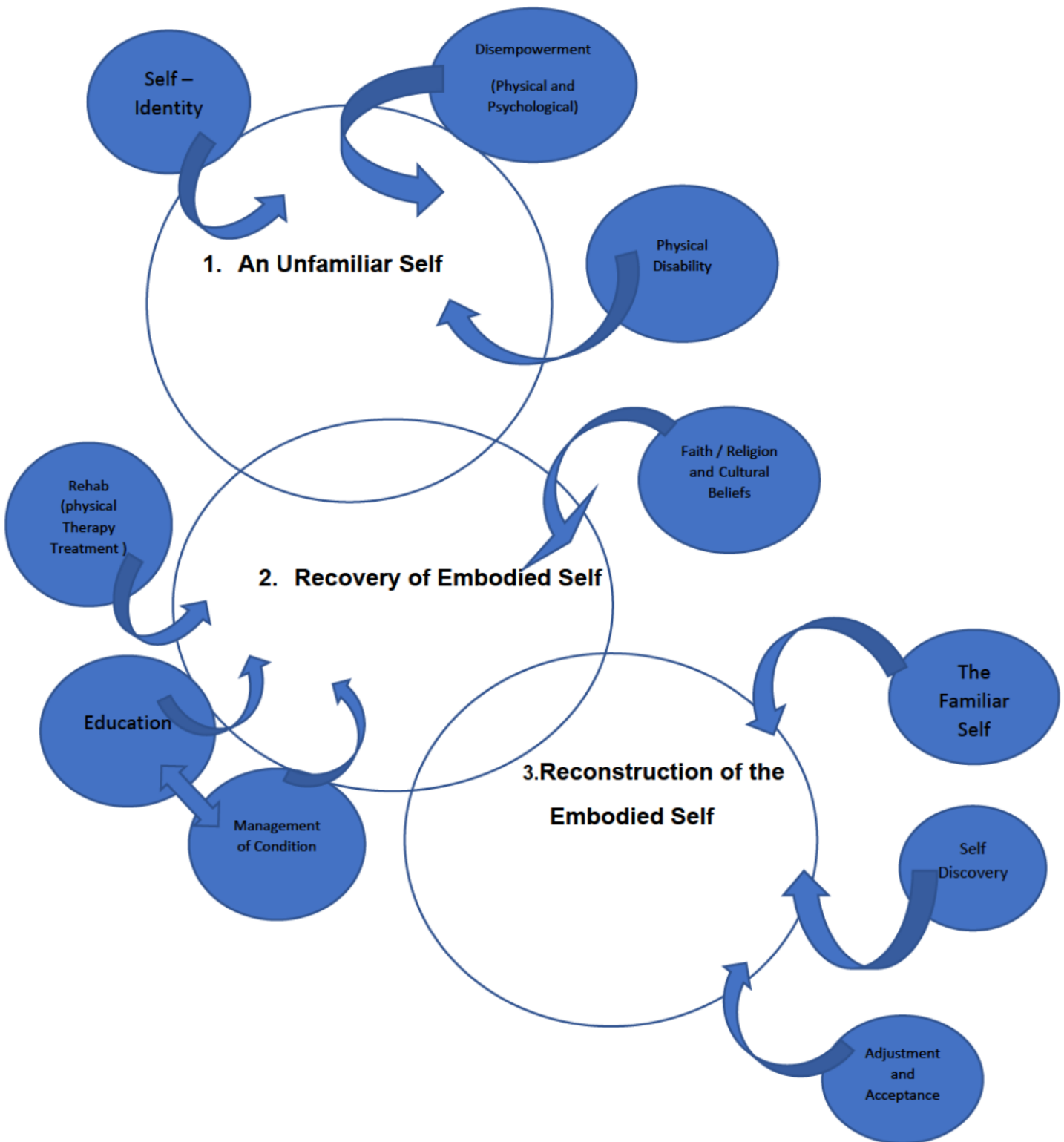


Table 18: Participants' DEMOGRAPHIC DATA': pseudonym, age, year of stroke, and number of children

Study ID	Pseudonym	Age	Gender	Year of stroke
Participant 1	Buchi	72	Male	2018
Participant 2	Emeka	54	Male	2019
Participant 3	Amaka	53	Female	2012
Participant 4	Meka	58	Male	2017
Participant 5	Ouchi	62	Male	2018
Participant 6	Enosi	55	Male	2018
Participant 7	Bisi	29	Female	2015
Participant 8	Joko	61	Female	2015
Participant 9	Jopadi	64	Female	2015
Participant 10	Tobichi	58	Male	2018

Figure 24: Synopsis of the Participants

Mr Buchi, 72-year-old male, suffered a stroke in 2018. He states being a former businessman who took pride in his work. He states he has now ceased trading. He lives alone following the death of his wife several years ago. He is the father of six children and several grandchildren. He remains involved in certain aspects of his business because he believes he must maintain control. A man who is both proud and respectable.

Mr. Emeka, a 54-year-old man, had a stroke in 2019 that caught him off guard. He states he is married with four children and believes he will fully recover from his condition, as he states that no one in his family has ever had a stroke. He is a devout Christian who prays on a regular basis. According to his beliefs, he believes it was a spiritual attack by his adversaries.

Mrs. Amaka, a 53-year-old woman, experienced a stroke in 2012. Amaka is a mother of four children. She reports having worked as a chemistry teacher in the past and enjoyed cooking. At the time of the stroke, Amaka was working on her master's degree. This, she says, has been put on hold.

Mr. Meka is a 58-year-old gentleman. In 2017, had a stroke. He states he has five children and is married. A cab driver who had to work all hours of the day and night to make a living. Regularly attends church with his family and enjoys family outings. Very softly spoken and is serious about his workout routine. He expects a full recovery because he does not believe in strokes.

Mr. Ouchi is a 62-year-old gentleman. In 2018, he suffered a stroke and reports being married with five children. Prior to his stroke, he worked as a mechanic. A cheerful family man who looked after his loved ones. He is now worried as he was the breadwinner of the family as his wife did not work. He is eager to put in a lot of effort into his recovery.

Mr Enosi, a 55-year-old male. Reports being married with four children when he suffered a stroke in 2018. He works as a businessman; he is self-assured and devout. When he was diagnosed with a stroke, he was taken aback. During the interview, his responses were rather abrupt, refusing to go into detail. He is a little oblivious to the fact that he has had a stroke.

Mrs Bisi is a 29-year-old mother of one child. She states she suffered a stroke in 2015 just after her daughter was born. At the time of her stroke, she was a housewife, very knowledgeable of what a stroke is. She is currently separated from her husband. She loves reading and has great goals for the future. Anticipating a complete recovery.

Mrs Joko is a 61-year-old female. In 2015, she reports she suffered a stroke. She is married and has seven children. She previously worked as a market woman (a lady who sells food items at the market). She enjoyed her work and was always quite busy. She is devout but believes that her anxiousness contributed to her stroke because she was always on the go. She believes her recovery is delayed and feels low about it.

Ms Jopadi is a 64-year-old female. She suffered a stroke in 2015 as she reports. Jopadi is a widow with five children who reside with her mother most of the time. Prior to the stroke, she worked as a cook and enjoyed it. She describes herself to be a Christian and believes she is the victim of a spiritual attack. Jopadi is somewhat overweight and intends to lose weight to speed up her rehabilitation.

Mr Tobichi is a 58-year-old male who suffered a stroke in 2018. He states he is married without children. Due to his health, he lost his job as an *okada* (commercial motorcycle) rider and now lives with his wife

at the family home. He enjoys family vacations with his wife and is focused on a full recovery, as he plans to start a family in the future.

Table 7.5: presents the themes that emerged from the analysis of the ten in-depth semi-structured interviews. It also shows the complexities and overlapping nature of the commonalities and variations identified. The interpretative story that follows is about the subjective experiences of the impact of stroke on the quality of life of the survivors. Three overarching themes emerged as central to these survivor narratives.

The following narratives are taken directly from the interviews with the participants. As the three themes emerged, the impact of stroke on the quality of life of stroke survivors became clear. The first theme was 'an unfamiliar self', which illuminated the altered body due to physical and physiological changes poststroke.

7.4. Master Theme 1: An Unfamiliar Self

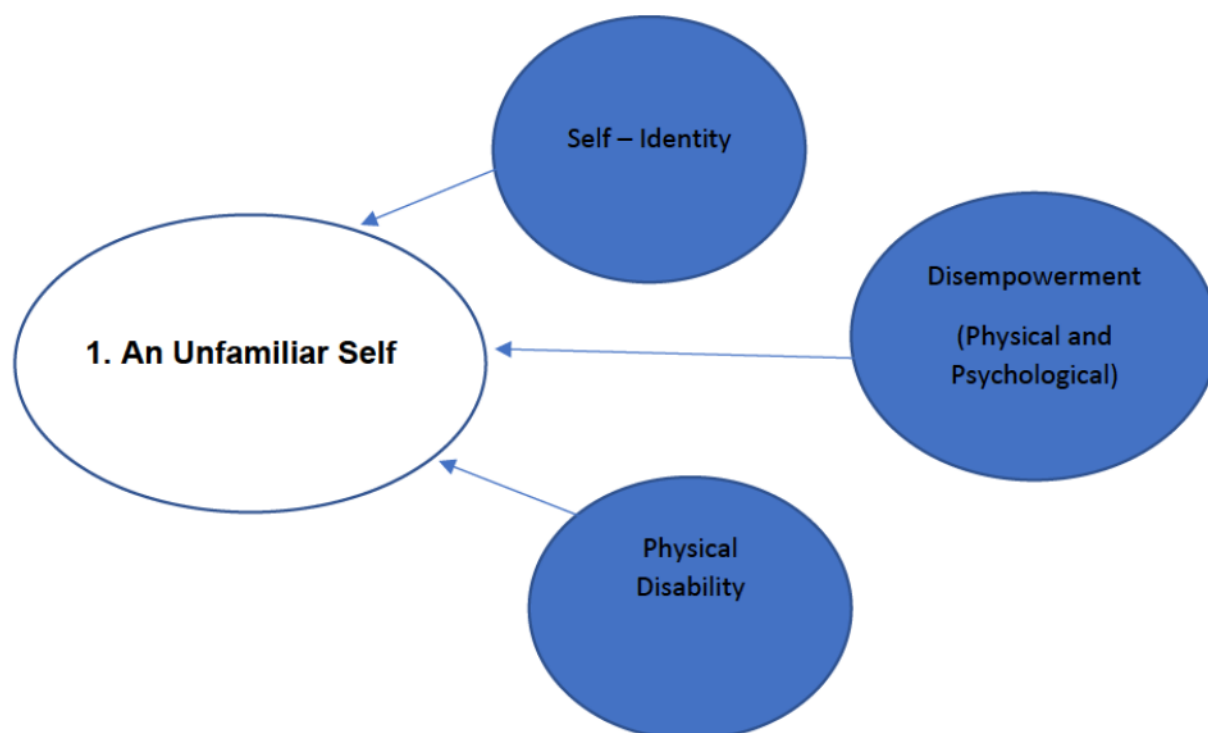
7.4.1 Introduction

In the context of this study, physical changes following a stroke can be interpreted as living with an altered sense of self or an unfamiliar self. According to studies, stroke survivors view their bodies as fragile, unfamiliar, and unreliable. Most of the participants in the study struggled with not being who they were and repeatedly referred to themselves as the person before and after the stroke. They described their bodies as being distant and in conflict with their previous and current self-concepts.

Although most of the participants described their self-awareness as remaining constant throughout their recovery following stroke, they all addressed their bodies as becoming unpredictable, strangely foreign, and effortful. Figure 7.7 displays the most common theme 'unfamiliar self', which refers to the unpredictability of the stroke condition, and its component subthemes: the role of self-identify, disempowerment (physical and psychological), and the impact of physical disability.

These long-term and often permanent consequences of bodily weakness may turn stroke survivor's intentionality inwards, away from external activities, projects, and relationships with others.

Figure 25: An unfamiliar self and sub themes
Source: Author



7.4.2 Disempowerment (Physically and Psychologically)

Disempowerment or loss of independence due to various functional disabilities was considered the most important factor that had an impact on the quality of life (QOL) of stroke patients in the study. This was one of the major themes discussed by eight out of 10 participants. This category conveys the participants' loss of physical and functional abilities. The participants often highlighted how they had never particularly thought about how they connected with their bodies before the stroke – 'it was simply normal'. The experience of stroke made the participants increasingly aware of their bodies because of its unfamiliarity. The loss of independence is deeply felt by the participants in the study, perhaps mainly due to the stigma associated with disability and paralysis in this community / culture, as seen in Chapter 2. Stroke survivors are even often reduced to tears over the state of dependency due to pride associated with the culture.

Being unable to move or feel parts of their bodies evoked uncanny feelings of not being the owner or their body parts. The sudden loss of functional ability presents itself in the form of physical limitation resulting from a form of neuronal lesion of the stroke event. Participants Emeka, Ouchi and Amaka highlight the sudden physical changes that occurred during the incident.

"Then suddenly, noticed my leg and arm become very heavy and my mouth started twisting, that's all I could remember "
(Emeka 54 years old)

" it become so ...soft, my mouth started to twist ...just like this....so, I couldn't walk again, even...on the chair I was sitting i almost fell off" (Ouchi, 62 years old)

"they took me to the hospital. On my get there, I could not get down from the vehicle again"(Amaka 53 years old)

The above quotes demonstrate how a stroke affects the use of both lower limbs in carrying out an activity that was accomplished before the stroke, owing to muscular weakness and sudden neurological changes.

The individual aspects reflected on Emeka's, Ouchi and Amaka's struggle to cope with and adapt to the sudden impact of stroke during the process of requiring power and control of their lives. When they referred to body parts that did not function, words often used expressed detachment as if the body part were seen as a strange object from out-side. Empowerment is a complex concept and may easily be recognised by its absence: for example, powerlessness, loss of control and subordination. The discussions demonstrated that Buchi's, Tobichi and Amaka's experience reflected individual aspects of lack of control and disempowerment.

"I was asked if I could walk upstairs on my own, I said no, and I was aided" (Buchi 72 years old)

"because all the while I was going there, I no dey walk, in short, I no dey get up unless they take wheel chair carry me" (Tobichi 58 years old)

Amaka states:

" Because of my stroke, my school had to aid me, tell people to aid me in teaching my course. I am a chemistry teacher".

As a former chemistry teacher, Amaka emphasises her loss of independence. She reiterates that she is now referred to as someone who seeks assistance. Functional difficulties disrupted Amaka's known, comfortable way of doing things and living her life, lowering her perceived QOL. Amaka's reflection on a past self is a loss of the simple things in life, the things that defined who she was, a physically fit woman who had been proud of working and taking care of her responsibilities. Amaka feels cheated by her loss of independence, and her pain can be heard as she talks about how her

employers now feel concerning her dependency. This is interpreted as a need to recover part of her life and a loss of her independence.

Amaka, Enosi, Joko and Tobichi state the following:

"I entered the vehicle myself, but on reaching the hospital, I could not come out of the vehicle again" (Amaka, 53-year-old)

'If you observe properly, I couldn't drive again, so I parked my car, my car is now parked" (Enosi 55-year-old)

"I feel somehow, because I wasn't at on my normal condition, but at least I try but sometimes somebody will carry me" (Joko 61 years old)

"That is no walk that I am walking, when they hold my hands, I can take small steps whilst biting my teeth while I move"(Tobichi 58 years old)

These long-term and frequently permanent consequences of physical weakness may cause the participants to intentionally withdraw from external activities and projects, as well as from interpersonal relationships as stated in the text. Participants Bisi, Amaka and Tobichi report the following:

"I'm not going anywhere any more since my attack" (Bisi 29 year old)

"I was going out before, but since I have not been well, I have just been at home"(Amaka 53 year old)

"I am feeling sad that there is no one that I am going to see again, I'm feeling sad like a person" (Tobichi 58 years old))

The participants state that the impact of stroke has contributed to the withdrawal from previous activities in the society leading to isolation. Life for the participants is now one of disability and isolation.

Stroke has had two major effects on the participants in the study, firstly, the inability to do physical tasks; secondly, the illness has a socially disabling impact on participants' life and identity. The participants cannot participate in that aspect of the Nigerian culture that gives them a sense of belonging. This way of thinking is frequently associated to depression.

Joko emotionally states:

"It is because of the stroke I had, that why I am a lot more inactive. I no longer go to the places I use to go to, which I enjoyed and loved. I no longer have the freedom I had beforeermm, this has all changed due to the stroke. I can no longer do the things that I use to do, that I use to be good at "(Joko, 61 year old)

This is interpreted as reduced social participation of the participants in the community, with perceived causes including physical disability, communication disability, fatigue, lack of access and the stigmatising attitudes of others.

This is viewed as a decrease in individuals' social participation in the community, attributed to a variety of factors such as physical disability, communication, impairment, fatigue, lack of access and other stigmatising attitudes as seen in the text. Joko's low mood emphasises the sadness of her condition, emphasising loss of independence, reduced social participation and signs of fear with an unfamiliar self.

The withholding from a patient relevant information and excluding that person from decision making concerning their health is another form of disempowerment. Lack of control of a situation, whether financially, physically, emotionally, psychologically, enhances helplessness, dependency, low self-esteem as expressed by most of the participants.

"...or have an idea of what is happening around me"(Meka 58 years old)
"...doctors were with me 24hrs of the day, monitoring my condition.".(Ouchi 62 years old)
"it dawned on me that this was serious because there is no other way....." (Ouchi 62 years old)
"and I couldn't leave my bed again, at all (that was all I knew)"(Buchi 72 years old)
"I said no, and they agreed and brought a chair, erm stretcher and helped me to the stretcher..." (Buchi 72 years old)
"I could not drive again ...so I parked my car..." (Emeka 52 years old)
"...because of my stroke, my school had to aid me, tell people to aid me in teaching my course."(Amaka 53 years old)
"I am a chemistry teacher by course..." (Amaka 53 years old)

These statements can be interpreted as a lack of control of everyday situations due to the stroke. The above participants reiterate their grief post-stroke of situations that would have usually been effortless. Meka narrates his loss of awareness during the stroke attack and how scared he felt. Ouchi

highlights the severity of his condition as the doctors surrounded him 24 hours of the day. The ability for the above participants to talk about their losses demonstrates part acceptance to depend on other people for support. After stroke, part of the cycle of life is firstly accepting the loss of control and receiving help from others, which some of the participants in the study struggled with initially. The financial burden in the family of a stroke survivor can cause considerable anxiety and stress particularly during rehabilitation / recovery. The loss of a job or the inability to fulfil previously valued financial roles, therefore failing to provide for the family at once, often leads to sadness and frustration. The stroke usually meant a sudden end to employment or part employment. Employment is regarded as one of the most important predictors of quality of life. Stroke survivors who are employed report a better quality of life, less health service usage, and better health status than non-employed survivors as mentioned in the text from some of the participants. This may result in financial strains, making it more challenging to support the children and family. Emeka narrates the following:

"when somebody wake up, you cannot have anything to feed their children will lead you to thinking..." (Emeka 52 years old)

In the Nigerian culture, the man is viewed as the primary provider for the family and is frequently regarded as the family's head. The transition from breadwinner to non-breadwinner was difficult for most individuals and could result in despair.

Amaka and Emeka express the effect of financial strain, demonstrating helplessness.

"...once you don't have cash in the hands, when you are hungry for something, and you can't buy it, that is a bigger problem to me..."(Emeka 54 years old)

"And when your children ask you about something you cannot provide it....ehh that's my main problem " (Amaka 53 years old)

This could be interpreted as a lack of power and independence over their financial condition. In the Nigerian community, having money is considered important because it earns you respect. However, due to the way Nigerian society is structured, people find it difficult to ask friends or relatives for financial support out of pride.

7.4.3 Self-Identify

This section highlights the participants' accounts of issues concerning self-identify. This is frequently linked to a cohesive body-self and an enduring self-identity. The participants in this study indicated that they experienced being socially isolated and were often restricted to their homes. This is a

common theme in studies of life after stroke, where the body is always present as one's perception of the world, and therefore self must be embodied. This was discovered to have a huge influence on the participants' self-identity.

Joko, Enosi, Tobchi, Buchi and Amaka, state the following:

"there is nothing I am doing, just stay home and do my exercises" (Joko 61 years old)

"those places I can't attend, have to do without me as I can only do what I can considering my situation" (Tobichi 58 years old)

'when I get better, I can start going out'(Amaka 53 years old)

These statements can be interpreted as the survivors' perception of their inability to participate in social or recreational activities in the same way they did previously. The activities highlighted were mainly linked to engagement in religious or spiritual activities such as attending church or going to funerals as Buchi states.

"The main limitation is the ability to be active and to go to funerals and burials like I use to before" (Buchi 72 years old)

As a result of their incapacity to participate in some activities, participants developed anxiety about their Christian faith. This can also be understood as their bodies becoming untrustworthy, with a break in the link between the body and the self. Most survivors believed that their bodies threatened their self-esteem and identity, which can be stressful and perplexing. Furthermore, the ready availability of social support in Nigeria is primarily due to the deeply rooted culture of solid kinship ties, communal living, and good neighbourliness. For example, Enosi described himself as an active person before his stroke; he was busy but now inactive. However, the physical restrictions caused by his stroke, including muscle weakness, incoordination, and fatigue, makes him spend much more time sitting alone at home. The participants made it quite evident that they had deteriorated since their stroke and voiced no hope of recovery. This in turn resulted in participants expressing feelings of uselessness and sadness, where a loss of movement was linked to a lack of recovery. Other participants, however, described having an enduring self-identity despite their inability to match their body's current abilities and characteristics with their pre-stroke sense of self. The presence of an enduring identity appeared to minimise the degree of bodily strangeness that the participants in the research study experienced.

7.4.4 Physical Disability

Stroke can affect many areas of life, but, for most of the participants in this study, physical disability and/or impairment was reported to limit active daily living (ADLs). For the participants, this seemed to have essential and devastating social consequences.

This was emphasised by all the study's participants, indicating a negative effect on the participants' quality of life. Participants described their poststroke body as effortful to move and far more demanding of their concentration than prior to the stroke. Amaka expressed her anger about how physical limitations led to role changes (e.g., being unable to cook).

"yeah, it has changed me, because before the stroke, I use to cook in my house, but now I cannot without help. Now I need support to cook" (Amaka 53 years old)

Other participants expressed feelings of embarrassment, frustration, and difficulty in mobilising.

Participants state the following:

"I was going, as I wanted to climb the stairs, but I fell on the floor" (Meka 58 years old)
"I started limping on the leg, so I went to seek help." (Meka 58 years old)
"I could not move at all from the bed or use my legs to the private toilet " (Emeka 54 years old)
"Then I suddenly, noticed my leg and arm become stiff and heavy". (Emeka 54 years old)
" at times I don't even know or have an idea of what was happening around me, I later tried to move with energy, I couldn't walk, I no longer feel myself it just psychosocial" (Buchi 72 years old)

This can be interpreted as a complete loss of control over one's movement. The incapacity to carry out actions in the same manner as before. The humiliation of becoming powerless, followed by a sense of hopelessness was rather daunting for the participants. However, other participants saw this as a challenge to be overcome by their effort, and they believed it was their job to recover from the physical consequences of stroke and developed personal coping strategies, as seen in the text below.

Joko and Jopadi state the following:

"I now walk, I just hold their hands and I walk little" (Joko 61-year-old)
"Walking bit by bit, I now use a walking aid" (Jopadi 64-year-old)

The participants expressed a change in roles because of their condition. The inability to resume previous roles resulted in dependency and a lack of interest in previous activities. The ability to continue roles such as the family income provider, homemaker, protector, carer, normal mobility and

function, parent or decision-maker was also a concern issue experienced by the participants in the study.

"I facing some problems like with my finances because I cannot take care of my children and family as I use too...."(Meka 58 years old)

"I have a lot of experience, like I cannot walk like I use to walk before, and my system is not normal as it used to be before.."(Emeka 54 years old)

"and I couldn't leave my bed again, at all (that was all I knew)....."(Amaka 53 years old)

"life after the stroke is not the same with life before the stroke..." (Amaka 53 years old)

"asked if I could walk upstairs on my own, I said no and was aided....."(Buchi 72 year old)

Within this construct, the aspect of loss, uselessness, and sadness are highlighted. The participants clearly state that they were worse off since they had experienced a stroke and no perception of recovery was expressed. This lack of recovery left the participants feeling in shock, in denial and lost. The loss of upper or lower limb movements (Functional inability) is linked to a lack of recovery. The participants also linked the lack of recovery to being dependant on others for specific tasks.

"I don't know, when you say stroke, I don't believe"(Meka 58 years old)

"it hit me and hit me, then I thought ohhh...and started going to lyienu hospital..."(Amaka 53 years old)

"or have an idea of what is happening around me" (Bushi 72 years old)

"like a, something just strike my face, and the key I was holding just fell from my hand..."(Ouchi 62 years old)

"I'm coping with the assistance of my wife and my brother taking care of me..."(Emeka 54 years old)

"...it made me to drop some of my plans for the future...before the stroke, I was doing my masters but immediately after, I had to drop it to relieve the stress..." (Amaka 53 years old)

"I feel discouraged about life, I feel depressed but thank God by the grace of God I'm getting better" (Amaka 53 years old)

Physical disability was one of the main dominant sub- themes. Physical limitation was seen to have important and devastating social consequences. It is clear from the above narrations that participants saw physical disability as challenges to be overcome by their own individual efforts and beliefs. The loss of independence is keenly felt, probably because of the 'stigma' associated with disability and paralysis in the culture. Patients who have suffered a stroke are frequently brought to tears by their dependence.

7.5 Master Theme 2: Recovery of the Embodied Self (Transitional Stage)

7.5.1 Introduction

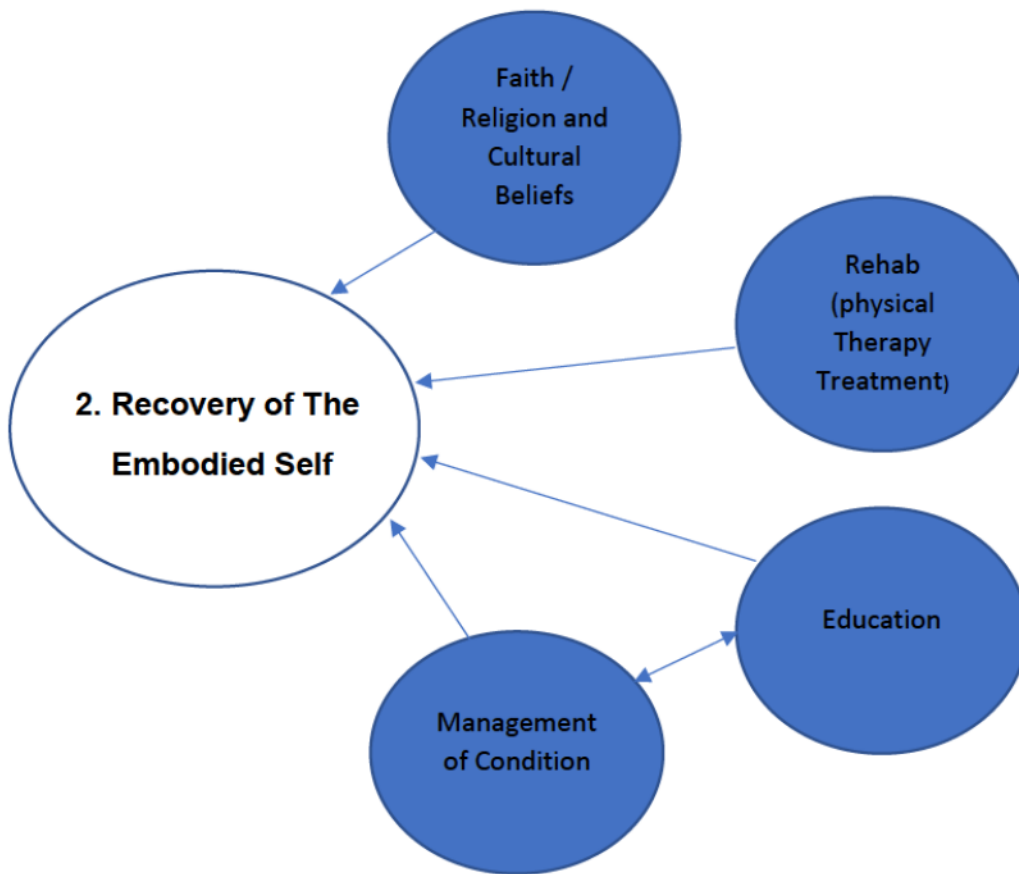
This theme refers to the transition to actions to adopt a healthier lifestyle. It embodies the transitional stage of the survivor's experience and is seen as the phase of transitioning from the unfamiliar-self to the embodied-self of healing. Figure 7.8 displays the recovery of embodied self and its component subthemes. Rehab /physical therapy treatment, management of the condition by means of education followed by the impact of faith / religion.

This is the stage at which the survivor acquires a better understanding of their sickness and begins to show signs of progress through rehabilitation and physical therapy, education, and improved management of their condition, all of which are infused with religion and spirituality.

The term 'embodiment' in the context of this study is used to refer to how people live in and experience the world through their bodies. Nine out of the ten participants recognised their persistent functional problems and talked about slowly adjusting to the new situation. This consisted of rehabilitation and physical therapy, education and knowledge, better management of the condition and faith.

Figure 26: Recovery of embodied self and sub- themes

Source: Author



7.5.2 Rehab / Physical Therapy

It was noted in the study that the stroke survivors attempted to re-establish familiarity with their bodies through a life-long project of testing their limits. The participants experienced an overly emphasised focus on rehabilitation of physical needs to regain power and control of their lives. Accomplishing significant tasks enables them to develop a stronger sense of self. Participants reported a need for active participation in their rehabilitation, which was achieved through an awareness of their situation and by being engaged in independent activities, which gave them a feeling of control of their situation as demonstrated in the following text.

The participants stated the following:

"I believe my arm will raise up, because before I was not raising it, because before... errh the only thing was the finger, but I am using it little by little. I can now straighten it up to hold something" (Emeka 54 years old)

"They say it did not touch my bones, it was only soft tissue ie my muscles and nerves. (Meka 58 years old)

"Yes, I don't exercise for one week, I start to feel bad, exercise is very good for stroke". (Amaka 53 years old)

' I have started to get up, I can now stand and sit" (Tobichi 58 years old)

"The exercises have helped me a great deal A great deal"; (Enosi 55 years old)

"I can not walk for 2 hours, as before but a lot better " (Buchi 72 years old)

"It helped me a bit, but not ready to stand up and walk"(Tobichi 58 years old)

"They are happy to see that I am walking better" (Bisi 29 years old)

This can be interpreted as participants feeling good about themselves in terms of recovery. However, the best practice in stroke rehabilitation must address all factors that are important to the patient.

The lack of ability to engage in usual activities was expressed by most of the participants. The impairment of body function was a factor that caused the inability to engage in usual activities and in previous roles. The participants expressed the importance of exercise and encouraged the activity prior to having an attack or stroke. Physical exercise post-stroke is highly recommended as physical inability is a risk factor for stroke.

Meka offers guidance on rehabilitation and exercise, emphasising the necessity of physical activity as exercise is not ingrained in Nigerian society.

"my advice to everyone is to exercise, exercise....lack of exercise is a problem on its own..."

"i will recommend physical exercise before stroke, but not after stroke, you better exercise before"

"lack of exercise.... you know our people does not know what it means to exercise..."

The following are testimonials from survivors who have experienced the benefits of physical activity after a stroke.

"the Stroke Action has helped me a lot, cause before, normally, I was not doing some exercises....."(Ouchi 62 years old)

"because, I was not walking before, to go far places, but now, I am walking a bit better, I can go far places,..." (Ouchi 62 years old)

"I'm getting better, eh....i believe that I will finally better one day..."(Emeka 54 years old)

"yes, if I don't exercise for 1 week, I started feeling bad, the exercise is very good for stroke people.." (Amaka 53 years old)

7.5.3 Education

Some of the participants in the study expressed a need for additional knowledge and individual information about stroke. Stroke survivors' quality of life is negatively impacted by a lack of awareness or education about the disease. They sought information to help themselves during the recovery process and to enhance their quality of life. New knowledge helped participants to make sense of why they were experiencing their body differently after the stroke and this understanding often provided reassurance. The participants especially wanted information to help them understand stroke recovery and the rehabilitation process. Participants explained how information helped them to understand rehabilitation goals and to recognise when they were making progress. This provided reassurance that rehabilitation was working, whereas insufficient provision of information prevented them from taking an active part in their rehabilitation. The lack of information is said to result in a feeling of just 'sitting and waiting for something to happen'.

The following participants shared their experiences of unawareness.

" I know now, I must stop thinking, there is nothing that will annoy me anymore, what I know now is that I will manage being upset" (Meka 58 years old)

" your diet matters a lot, some people do no eat right" (Buchi 72 years old)

"I avoid anything that has too much oil in it, we are advised to watch what we eat eg avoid high cholesterol"(Emeka 54 years old)

" its HBP and Diabetics, that mainly lead to stroke, but I'm not a diabetic and I don't think I was hypertensive" (Bisi 29 years old)

" I still have more... relief since that day till now, the things I didn't know, now I know" (Meka 58 years old)

These statements suggest that the survivors had learnt a great deal more about stroke disease, particularly the risk factors, and that this knowledge will help in the more effective management of the condition. Education and management of the condition appear to go hand in hand, as participants mention how increased knowledge of the condition enables better and improved condition management.

7.5.4 Management of the condition

Hypertension is one of the most important risk factors for stroke and is the risk factor with the highest population-attributable risk. The risk factor profile for the participants in the study was similar to what is recorded in older individuals in developed countries, with hypertension being the most prevalent risk factor as seen in Chapter 6 section 2. However, most of the study participants talked about a lack

of frequent HBP health examinations and disease control, which in some cases, brought on the condition.

Participants discussed their lack of previous knowledge and its effect.

" I suffer from HBP, now I often take my medication. But prior to the stroke I had not taken my medication for a week and some days' (Enosi 55 years old)

" everything before now, my BP was very high and the nurses and doctors tried to bring it down"(Buchi 72 years old)

" I took the BP medication and my BP normalised" (Emeka 54 years old)

' because I am now taking my meds regularly and checking my BP and sugar levels as I do not want my BP to be more than 100 over something. You know they explain all these things to you to better manage the condition"(Emeka 54 years old)

" I'm advising everyone that are at risk of stroke to go for regular health check-up, stabilise your BP.... Go to for you physiotherapy and do not waste time." (Emeka 54 years old)

" I will be checking my BP often and try to keep my weight down" (Jopadi 64 years old).

" now that I have had stroke, I will advise anyone who do not have stroke that they should be careful with their health, they should regularly go for BP check-up if they are at risk as this condition is not a joke. Checking BP regularly so they do not fall into this type of condition" (Jopadi 64 years old).

The above statements are interpreted as poor control of the strongest risk factor (hypertension). Prior to his stroke, Enosi claimed he was inconsistent in taking his HBP medicine since he felt his condition was not as critical due to diminished HBP symptoms. Hypertension is known to be a silent killer as some of the participants described lack of serious warning signs prior the attack of stroke. Buchi reported that his blood pressure was consistently high, and that the medical community fought to bring it under control at one point several weeks before his stroke. Emeka emphasises his newfound understanding of the need to maintain his blood pressure and diabetes, and he is now much more cautious in his maintenance. Jopadi emphasises the necessity of maintaining a healthy weight and getting regular blood pressure readings.

7.5.5 Spirituality

Spirituality is centred on values and can be viewed as a source of meaning and purpose for what humans do. In the Nigerian culture, this is a key component of a person's daily occupation, and having one's spiritual needs met is, therefore, an essential engagement and empowerment. This subtheme had one of the strongest significant positive impacts on the quality of life of the survivors. It is an important component and may be a key factor in how survivors cope with the illness and achieve a sense of coherence. According to majority of the participants in the study, faith in God was crucial to overcome the disease.

Most of the participants interviewed in the study had a firm religious belief, and this could be based on their cultural heritage.

Emeka stated the following:

"calling God to help us ...only body that can help us is God. Is only God can do anything that you want in your life..."
"Is only God that can do anything that you want in your life. With God anything can be possible just living by the help of other people now, without my junior brother, I don't think how far I would have gone by now because he helped me a lot and he took me to many places to make sure I got better. So, I'm thanking God for that"

This is interpreted as the conviction that only God can assist him, and that God will eventually heal him. He consoles himself by reminding himself that God is in control of his circumstances. He expresses gratitude to God for the continued support he receives from his family, particularly his brother.

Spirituality can provide vulnerable people who have chronic health conditions with peacefulness, reasons for living, a sense of purpose, and a sense of harmony.

Joko and Jopadi reiterate the following:

"with God anything can be possible just living by the help of other people now....."(Joko 61 years old)
"So, I am thanking God for that, it is the help of God..."(Jopadi 64 years old)

This is interpreted as an expression of thankfulness to God for a situation that could have been far worse. It is the notion that God is capable of anything, which is why the survivors continue to hope and believe, which is a significant component of Nigerian culture. This was reflected in the quantitative section concerning spirit and soul, demonstrating complementary findings (see Chapter 6 section 6.3).

Increased spirituality and spiritual support can serve as critical coping mechanisms for people who are ill or dying, as demonstrated in the text. This can also assist individuals living with chronic illnesses in accepting their illnesses and living meaningful lives despite their health challenges.

The following statements from Bisi, Joko and Emeka, summarise the preceding passage.

"I feel discouraged about life, I feel discouraged hmm, I feel depressed but thank God by the grace of God, I am now getting myself, I am now recovering... (Bisi 29 years old)
"i myself, I don't have it, so I just know. I just telling my God, I do not want to have, I don't have it. I tell him, I don't want anything like this in my body..."(Emeka 54 years old)
"then she was like you wont die, she started praying for me, I said okay, I don't know what is happening but all I know is that am alive...(Bisi 29 years old).

"I am asking God that I can start walking, it should not happen to someone else..."(Joko 61 years old)

Most of the participants were conversant with herbal traditional interventions post-stroke. Traditional medicine refers to a set of health care practices that are part of a country's own tradition. It is quite common to find people who fall back on traditional medicine, especially if their illness concepts are poor.

Traditional/herbal medicine and its practices play a major role in the health care of the community of Nigeria. In some cases, the native doctor (Babalawo) and the local herbalist (Eleweomo) are the only practitioners available for the treatment of illness. Even in the communities where allopathic medicine is available the limited facilities it offers and its cost, make many patients rely on traditional methods. Prior to the introduction of cosmopolitan medicine, traditional medicine used to be the dominant medical system available to millions of people in Africa in both rural and urban communities. Several participants in the study resorted to herbal medicine for treatment because they believed it would help them recover faster and because they couldn't afford their drugs and physiotherapy.

Some of the participants reported that spiritual rituals and or TM improved their health, whereas, in contrast, patients are frequently disappointed and upset because their relatives believe they have been 'affected' by occult or black magic, which can lead to additional loneliness, isolation, and the longing for their former existence.

Buchi, Emeka, Joke and Bisi stated the following –

"yeah...herbal medicine. Yeah, they used razor blades to cut my arms and gave me some medicine..."(Buchi 72 years old)

"he gave me some medicine because I was not walking before, then I started walking slowly ..."(Emeka 54 years old)

"he used the medicine and he gave me the medicine and I drank it. It get some massage he gave me using some things and hot water to my legs....."(Joko 61 years old)

"Because when I got there, there were people that it was serious issues that ere treated and got better, there were people it was very serious for them and they are getting better there..."(Joko 61 years old)

"it helped me sha, in the sense that my hands was in a fist form before, but after taking the TM it stretched out a little"...(Bisi 29 years old)

The preceding statements demonstrate that spiritual rituals and TM aided in their health improvement. Buchi recalls how the indigenous doctor sliced open his arms with razor blades and inserted herbal remedies into the wounds. Emeka recounts his initial incapacity to walk, but after receiving the TM, he was able to gradually rise to his feet and walk. According to Joko, she was given TM to drink and had

her injured leg massaged, which aided her with walking. Bisi reports that her affected hand was in the shape of a fist prior to taking the TM, which then began to spread out afterward.

Interestingly, it was also common to find individuals who, while acknowledging that the hospital is the appropriate place to seek assistance in the event of a stroke, continue to use traditional practices.

Amaka and Jopadi describe their unpleasant encounter with the 'native doctor' / TM.

"it's just God that help me because I for take the medicinethat placeit was, I was, my own husband that saved me because he has a medical doctor friend..."(Amaka 53 years old)

"it's not getting better...because of place I was first, if I had gone to a physiotherapist / doctor and that's the next day...."
(Amaka 53 years old)

"use local medicine to take, and those local medicines don't work for your BP and erm..so if care are not taken, somebody can get another strong thing..." (Amaka 53 years old)

"I really don't like it, what ever has to do with 'native doctor', I really didn't like it..."(Jopadi 64 years old)

"take doctors' advice and physiotherapist advice...don't take these side advice because it made my own not to get....to linger up till now..."(Jopadi 64 years old)

The above statements are interpreted as the following. Amaka talks about how she almost went to a native doctor and how taking TM does not always work, especially for individuals who have HBP. She reports that it can often make one's situation worse. Jopadi shows her disbelief in native doctors while clinging to the mainstream medical advice she received from her doctor and physiotherapist.

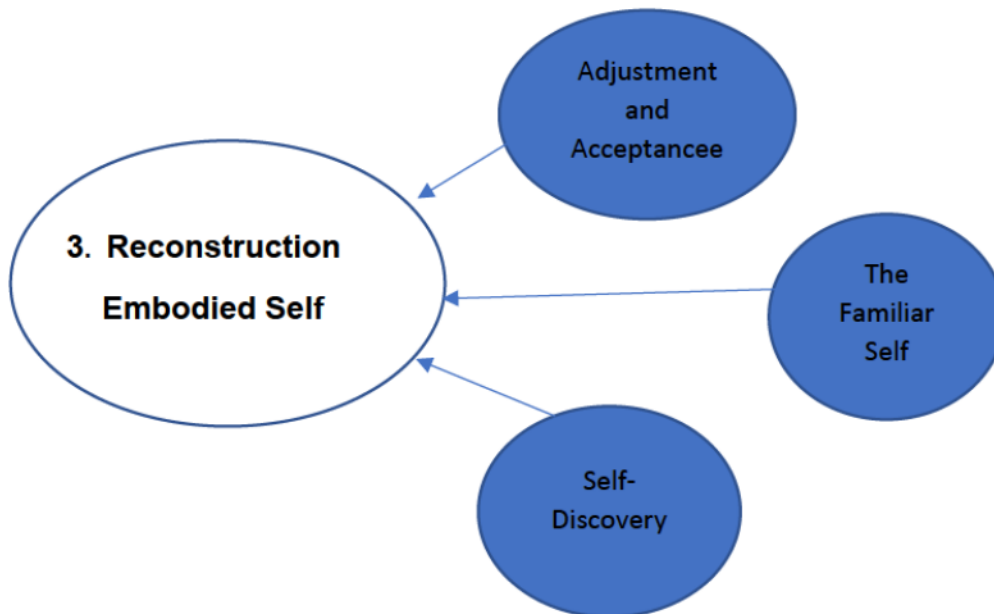
7.6 Master Theme 3: Reconstruction of the Embodied Self

7.6.1 Introduction

The reconstruction of the embodied self and quality of life can be a continuous and interconnected process of 'being, doing, belonging, and becoming'. The narratives in this session lead to "I can" whereas previously, it was "I cannot" and referred to the participants' body and ability to move, perceive, reflect, and be aware. This third and final theme indicated in Figure 7.9: reconstruction of the embodied self, has had a huge impact on the quality of life of survivors with subthemes such as the familiar self, which reflected 'restoration of the self-body'. Self-discovery reflected 'enhance knowledge and control'. At the same time, adjustment and acceptance reflected 'adaptation and settlement' of the condition.

Figure 27: Reconstruction of the embodied self and sub themes

Source: Author



7.6.2 The Familiar Self

Unlike the strange and unfamiliar sensations and emotions similarly threatened by the union of body and self when one's own bodily utterance cannot be recognised, the familiar self is the restoration of most of the loss function. This subtheme was popular amongst the participants of the study and had a positive impact on the quality of life of the survivors. The continuous positive change in their self – awareness, which is driven by a lack of restrictions in functional ability was shown to be part of recovery. It is, however, assumed according to collected data, that an awareness of the inter-relationship between world, body and self will contribute to a better understanding of how bodily experiences after stroke influence the perception of self.

The participants who had restored some of their function reflected upon a returned normality, both generally in life and themselves as a person.

Enosi and Amaka stated the following:

"but now I walk slightly independently, sometimes with a walking aid but hope soon to walk without any help or aid...so to me this is a big achievement". (Enosi 55 years old)

"It's getting better ...its becoming better" (Enosi 55 years old)

"things that will prevent me of not having another stroke again, I'm now always taking my medication and I try and avoid eating all those spices / artificial type foods. I'll stick to natural foods and try to stop taking too many carbohydrates and anything that will cause me to add weight" (Enosi 55 years old)

"yes, if I don't exercise for 1 week, I started feeling bad, the exercise is very good for stroke people.." (Amaka 53 years old)

Quality of life is central to rehabilitation; however, as seen in the text, this is accompanied by complex multifaceted phenomenon. Conversely, Amaka, Meka and Tobichi express the following:

"I'm getting better, eh...I believe that I will be finally better" (Amaka 53 years old)

"I know how my system was before, but it is transforming gradually.."(Meka 58 years old)

"I can now walk inside my compound with more confidence..."(Tobichi 58 Years old)

The participants' physical environment also anchored them to a particular bodily experience following stroke. The rehab environment had a pervasive effect on Emeka's experiences of his body post-stroke. For Emeka this environment and the physical surroundings influenced how he experienced his body and how effectively he plans to improve in his recovery. He states the following:

"when I first came to the rehab club, I saw some people who had worse conditions than myself, I just knew then I was going to get better" (P2)

7.6.3 Self-Discovery

This subtheme self-discovery had a positive impact on the quality of life of the survivors. The knowledge of one's own body by discovery in a common world opened the possibility to understand the body in more depth. Participants' knowledge of their post-stroke bodies allowed them to modify everyday activities to allow for changes in their bodily limits, such as the monitoring of fatigue or the use of aids in certain situation, Emeka highlights the following:

'after doing a lot of exercises, I have more strength than before...errh, this has helped me a lot to get to this level in my recovery".

"when I first came to the rehab club, I saw some people who had worse conditions than myself, I just knew I was going to get better"

Self-discovery is also linked with regaining control which is interpreted as the participants' experience of bodily control and their sense of control over their lives in general. Most of the participants expressed how their stroke had influenced their sense of control until they were able to discover means of bodily wholeness. Emeka and Amaka state the following:

"I can cope a lot better now with this condition". (Emeka 54 years old)

"I believe my arm will raise up again, because before I was not raising it, because before..errh the only thing was the finger but I am using the finger and shoulder small, small and often straighten it to hold something". (Emeka 54 years old)

"I feel like I am getting better" (Amaka 53 years old)

These statements are interpreted as feelings of great achievement, hope, perseverance, and belief.

The participants express that they are on the road of recovery because of self-discovery.

Joko express the following:

"the improvement I have seen so far in my body is that the difference is clear. I am trying hard to stand up and walk independently, the massage is great, I really like it"

Jopadi emphasises the importance of maintaining a positive outlook on the future concerning recovery. Each participant discussed their own approach to stroke recovery, which often related closely to how they interpreted their bodily experiences. Jopadi and other participants exhibit an optimism that was prevalent throughout the interviews which was frequently tied to discussions about the difficulties they encountered with their poststroke bodies.

"what I am now thinking is my goal is that I will now take better care of my health very very well, unlike before I use to play with my heath, I will not let this happen to me again".(Jopadi 64 years old)

7.6.4 Acceptance and Adjustment

The reconstruction of the embodied self illustrates a process interconnected with acceptance, progress, adjustment, and managing of life. This sub-theme had a positive effect on the quality of life of the survivors and improved the participant's experience. Adjustment and acceptance amongst most of the participants gradually moved forward to a more settled, adapted embodied self. Studies highlight that adjustment and acceptance are interwoven with recovery. Participants in the study

attributed their ability to adjust to several factors such as personal characteristics, diet, lifestyle changes and environment.

Bisi and Emeka stated the following:

"During the sessions I do, I do it with all my ability and strength and I feel I am doing a good job because of all the improvements I have made in my recovery. I feel confident that with time, things will be a lot better for me"(Bisi 29 years old)

"I'm coping with the assistance of my wife and brother taking care of me" (Emeka 54 years old)

Other participants emphasised the fact that after having a stroke one needs to take things slowly whilst also keeping busy. Bisi stated:

"people should rest and take things easy, eat good food especially fruits and vegetables. Do those things that make you happy, as I started doing these things recovery started to happen a lot faster"

"Because when you have a stroke, if you become a stroke victim, you will start afresh like a baby and learn how to talk and walk and how to do things. But after I came here, they taught me a lot of things I know now"

"My BP is now checked every morning. All thanks to the Doctors and nurses, I now feel a lot healthier".

The above statement can be interpreted as acceptance and adjustment after stroke being variable over time. Stroke acts as a sudden and disturbing event for people and its impact on the people can be ongoing, sometimes moving in and out of salience in different contexts.

A challenge remains for us as health professionals is to find ways of helping stroke survivors to regain a positive perception of self, despite changes in bodily functions, social positions and roles, in the community.

Bisi reported that:

"the experiences I have now, is that I can't do those things I use to do easily".

The situation of dependency undermines the emotional stability and identity of stroke victims, evoking feelings of futility and failure. The person feels sad, hopeless, and less interested in activities that were once enjoyable, slowing the process of recovery of physical and mental health as stated above by the survivor.

7.6.5 Summary of Chapter

Six male and four female stroke survivors participated in the study, whose mean age was 57 years, most of whom were married and had children. Most participants were working-class and, on average, had minimal to average monthly wages. The three master themes and subthemes that emerged from the preceding text indicate the impact of stroke on the quality of life of stroke survivors in Nigeria's SE region.

Interpretative analysis of the impact of stroke on their quality of life was marked by situations of loss of independence, reduced self-identity, physical impairment, rehabilitation/physical therapy, education, management of the condition, spirituality, self-discovery, acceptance, and adjustment. Experiencing a stroke suddenly moved people to a state of dependency, where they lacked control over their daily lives according to some of the participants in the study. Several studies have reported the value of independence and autonomy to participants (White et al., 2015).

Most of the participants said that they had, at some point, sensed that something was wrong but thought at the time that it would get better. On the day of the stroke, the perceived symptoms were described as sudden headache and / or loss of control of the lower limbs, with an inability to move or stiffness or numbness of the upper limb and mouth twisting. Some of the participants sought traditional / native medicine for assistance, whilst others attended local hospitals for orthodox medicine. Following hospital treatment, most returned home with clinical changes such as hemiparesis or hemiplegia and became dependent on others to perform activities of daily living. Most of the participants expressed fear and concern of becoming dependent on others to perform activities of daily living, most especially the men. These feeling generated a sense of hopelessness among participants due to the disabilities imposed by the stroke attack.

The WHO's initial definition of health in 1946 has attracted some level of criticism for being physically orientated (Whittaker et al., 2004). Social factors play an important role in the definition of health and how the individual comes to view their own health. As a result of these social factors, together with religion and spirituality, the individual develops ideas of health, as well as controls aspects of their health. Most participants in the research study initially expected to recover to their pre-stroke selves; however, participants' attitudes about change in general (whether they accepted change as a part of life) have been said to have an impact on their recovery (Roman et al., 2006).

According to some studies (Pedersen et al., 2019; Peoples et al., 2010; Sampane-Donkor et al., 2014; Badaru et al., 2015), stroke has an impact on all aspects of health-related quality of life (HRQOL), particularly domains in the physical sphere (physical, cognitive, psycho-emotional, and eco-social (ADLs). However, this research study indicated that the physical domain (an unknown self) had the greatest impact on the quality of life of stroke survivors in Nigeria's SE communities. Disempowerment (physical and psychological), self-identity, and physical impairment are all examples of this. Spirituality, self-discovery, acceptance, and adjustment were the next most impactful themes (reconstruction of the embodied self), having equal impact on the quality of life of the stroke survivors. This will be discussed in detail during the ending discussion.

7.6.7 Reflection

A process of self-examination is defined as reflection or reflexivity. In this instance, I, as a researcher, reflected on my engagement and communication with the participants, my judgments, and the following analysis of the gathered data. I began a research journal the day data collection began, and a reflective diary was initiated when the ten participants' semi-structured interviews commenced. Five of the interviews were first performed in Nigeria, while the remainder were conducted via Zoom several months later. All data protection safeguards were adhered to. I continued to capture thoughts and ideas throughout the process, both before and after the interviews.

When I was conducting the interviews, I thought I had everything under control and had developed enough skills to perform the interviews; however, an extract from one of my journals says otherwise, as I questioned what I was not doing right.

(I cannot believe that I allowed this gentleman to lead the interview process. He talked almost throughout the interview without allowing me to prompt him at certain stages. I now feel [I was] less in control of that interview. This is how I feel, however. I may be wrong. Maybe it was a good interview after all, as I was able to ascertain a lot of information from the participant (Author's diary entry, Monday, January 20th, 2020)

I spent some time after this interview pondering on what I did wrong, what I could have done better, and how I could improve. This was a lesson for me that made me evaluate my interview skills; however, as the interviewing process continued, I noticed I was more aware of the process and felt significantly more in control of subsequent interviews. I also learnt that reflexivity is not about beating

oneself up when something does not go to plan; instead, it is a practice that relies on noting, accepting, and integrating learning as a way of moving forward.

The COVID-19 pandemic necessitated travel restrictions. I had planned to travel back to Nigeria to complete the remaining data collection but was unable to do so. I then applied for ethics approval to conduct my remaining five interviews via Zoom conferencing on social media. I was unsure how this would work out, and then shockingly, my first online interview lasted only 35 minutes. I attempted to stretch it a bit further, but it appeared as though the participant was not ready to open up fully.

(I was not expecting this interview to be so brief; the participant clearly did not want to open completely to me, whether due to a lack of trust or because I was not physically in front of him. After this interview, I was a little perplexed. (Author's diary entry, Monday, Nov 9th, 2020)

What is most striking about my response to the fact that the first online interview lasted barely 35 minutes is what I assumed: I expected all participants to want to speak with me merely because we shared some cultural similarities.

(I quickly realised that if I concentrated exclusively on my Nigerian origin when approaching participants, I risked losing my impartiality during these interviews, so I need to be conscious of the delicate balance that exists. (Author's diary entry for Monday, November 16th, 2020)

I had assumed that being part Nigerian, I would have found the interview process quite straightforward. However, it was through striking this balance of understanding that I was able to conduct ten semi-structured in-depth interviews that provided insight into the impact of stroke of the participants' quality of life.

The IPA approach and its hermeneutic notion allowed me to communicate my preunderstandings, personal assumptions, experience, and expertise during the data analysis process as a physiotherapist with Western knowledge and education. Reflection and reflexivity are crucial tools in the examination of qualitative data in this process.

However, part of the challenges of this project, as a researcher, often related to my personal experience and knowledge of the discipline: 'when to suspend this' and 'when to utilise it' as a physiotherapist. My subject knowledge was useful in communicating with participants but was a potential distraction at times. From the outset, I was open about my background but found it useful to emphasise my role as a student-researcher rather than a researcher with professional experience.

Still, I was often referred to as the physio doctor. However, as the interviews progressed, I developed a trusting relationship with some of the participants. Having to constantly repeat processes during the data collection and interviews enhanced my skills and confidence. Furthermore, with the data generated and having to heavily rely on my reading and interpretation of the text just to avoid jeopardising trustworthiness and validity of the data was daunting, as I still felt like a baby researcher working on her personal preconceptions. This was a challenging adventure but with great lessons learnt and good relationships built.

My insider / outsider approach as deliberated in the study of Serrant – Green (2002) is an attempt to make sense of the contradictions, presumptions, and responsibilities I had to face as a black female researcher in the (SE communities of Nigeria). However, the issue of outsider / insider in research can be seen to be a complex one (Serrant – Green., 2002).

Nonetheless, my role as a researcher required me to become immersed in the daily lives and experiences of the participants in my study, which I needed to do in accordance with the methodological approaches used in my study. (Creswell et al., 2019).

Interpretative phenomenological analysis with the hermeneutic notion allows me, based on M Heidegger philosophy, to construct my own reality from my own experiences and beliefs. (Finlay et al; Creswell et al., 2019).

As a researcher and physiotherapist with prior knowledge, beliefs, preconceptions, understandings, and culture based on my philosophical stance, have rendered me an insider from the perspective of my research (Serrant – Green., 2002).

However, an outsider would consider bracketing or putting aside one's preconceptions. As a researcher, this would have been extremely difficult for me because I do not believe I would have been true to myself, as it is impossible to put aside all my biases (Vanscor et al.,2017). This is a contentious issue with multiple points of view (Serrant – Green., 2002).

Finally, in striving to ensure trustworthiness in my study, I found that collaborating with my supervisors regularly during the analysis process allowed me to tap into multiple perspectives and often made it easier to see variations in the data (Vaismoradi et al., 2013), thereby enhancing the quality of the qualitative findings, as well as contributing to the rigour of the study. I also found that the integration of

my data commenced not only during the discussion phase but also whilst I was gathering and analysing the qualitative data.

The following concluding chapter intends to discuss the key findings in light of the research question, literature review, and conceptual framework. The chapter will compile the findings from both phases of the study. The discussion of the findings is presented side by side to demonstrate the complementarities of the results obtained by triangulation. The chapter includes my concluding statements and recommendations, as well as personal contributions to the field of stroke and physiotherapy. The chapter closes with a discussion of the study's strengths, limitations, and implications for practice, followed by an overall reflection on the research journey.

CHAPTER EIGHT

DISCUSSION

8.1 Introduction

This chapter discusses the results in light of the study's research question and objectives. Research Question - What is the impact of stroke on the quality of life of stroke survivors in the SE communities of Nigeria.

Objectives for the research study

- To describe the epidemiological profile of stroke survivors in the SE communities of Nigeria.
- To assess the HRQOL of stroke survivors (using the HRQOLISP questionnaire) and identify associated determinants.
- To conduct semi-structured interviews to ascertain detailed perceptions concerning QOL in stroke survivors.
- To engage in field observation to gain more insight into behaviours and attitudes of participants to enhance field notes in the community.

The chapter provides in depth interpretations and analysis of the quantitative phase 1 and the qualitative phase 2 findings. This addresses the above objectives of the study which expands on the contribution to answering the research question. The chapter reviews health and stroke in the summary of Chapter four (Theoretical framework). This is accomplished by exploring the theoretical ideas of phenomenology through the lens of a biopsychosocial approach – which is essential, as it highlights the effects of stroke and its underlying causes – as well as what is important from the perspective of the stroke survivor. It discusses stroke knowledge, attitudes, and practices in the community in relation to objectives 3 and 4 of the research study. The chapter highlights the limitations and strengths and discusses the recommendations considering the new model suggested (The Adig Model). It finally concludes with contributions to literature and clinical physiotherapy practice with a reflexivity that looks back at the journey of the research study.

8.2 Discussion of the Quantitative Findings – Phase 1

8.2.1 Stroke Prevalence and Correlates (Epidemiological profile)

This section discusses the key findings for stroke prevalence and its correlates, it focuses on addressing objective 1. The sample population of this study comprised 101 participants. Chapter six, table 1, displays the demographic profile and types of strokes suffered by subjects, including the gender-specific, age-specific, and age-adjusted prevalence of stroke (WHO world population) (Feigin et al., 2016). There were more male ($n = 52$) than female participants ($n = 48$). The age distribution was 16–85 years, with a mean age of 61.01 years ($SD = 12.74$). According to the data, 60%–65% had primary and secondary school qualifications, while only 30% of the sample population possessed a bachelor's degree. About 85% of the participants were in partnerships, and 5% were single.

A significant finding for this aspect of the study was related to the stroke survivors' mean average age of 61.01 years in SE communities of Nigeria. This is comparable to studies such as Owolabi et al. (2018) and Ezejimofor et al. (2017). These results build on existing evidence; for example, in Southwestern Nigeria, utilising hospital-based data demonstrated similar mean ages of stroke survivors (60.7 versus 59.4 and 61.5 years, respectively). However, it is argued that hospital-based studies are more likely to experience selection bias (Ezejimofor et al., 2017). Danesi (2007) reported a mean age of 63.4 years for stroke survivors, which is higher than in my study by 1.9 (age group: 74–84 years), versus 1.00 (age group: 55–63 years) per 1,000 population. The literature review (Chapter 2) reports the low average age of a stroke has been attributed to a variety of factors, including decreased life expectancy and a high prevalence of fatal stroke in developing countries (Ezejimofor et al., 2017; Owolabi et al., 2018; Feigin et al., 2016). In contrast, the mean age and peak prevalence of stroke in developed countries have been reported to be higher than those in developing countries (Owolabi et al., 2018; Feigin et al., 2016). In a German population, the mean age for stroke survivors was greater – 69 years. This disparity may be due to the relatively long-life expectancy in developed communities (Owolabi et al., 2018). Male prevalence of stroke noted in my study is comparable to data obtained in sub-Saharan African studies (Ezejimofor et al., 2017; Owolabi et al., 2018; Feigin et al., 2016).

Africa, however, appears to have the highest incidence, prevalence, and case fatality rates of stroke (Feigin et al., 2016). The age-specific stroke incidence is relatively higher in younger age groups in sub-Saharan Africa, as noted in my research study. It is further argued that people of African descent experience strokes at a younger age and have worse outcomes (Akpalu et al., 2015; Agyemang et al., 2012).

Overall, the findings of this aspect of the study suggest that the prevalence of stroke is high in the SE communities of Nigeria, which partly answers the research question. This is significant as these findings have met my expectations, as I anticipated, based on the literature, that there will be higher incidences and prevalence of stroke within a LMIC. This has been confirmed and is comparable to other similar sub-African studies (Ezejimofor et al., 2017; Owolabi et al., 2018; Feigin et al., 2016). The findings demonstrate that the indigenes in the SE communities of Nigeria are more likely to experience a stroke at a younger age, in comparison to indigenes that live in HIC who have a mean age of 65 years and above for stroke survivors (Owolabi et al., 2018; Feigin et al., 2016). This may be as a result of bad health habits, high cholesterol, diabetes and hypertension as discussed in Chapter 2 section 4. Nonetheless, this research study also identifies the possible chance of the Biafran war equally playing a role in exposing indigenes to non-communicable diseases such as hypertension and stroke. All of this contributes to the impact of stroke on the QOL of stroke survivors in Nigeria's Southeast communities.

This section assists in describing and addressing objective 1 of the study (the epidemiological profile of stroke survivors in Nigeria's SE communities). It has highlighted the relevance of a better understanding of noncommunicable diseases, cardiovascular disease, poor health habits, hypertension, and stroke is required. It is, therefore, highly recommended that health officials and policy makers pay more attention to the prevention and control of stroke in this region. As stated in Chapter 2, 70% of stroke and stroke-related deaths and disability-adjusted life years occur in LMICs because of risk factors such as hypertension (Ejiroghene et al., 2020).

8.2.2 Risk Factors Associated with Stroke

This aspect of the discussion further addresses objective 1. As hypertension is the primary risk factor for cardiovascular and non-communicable diseases, it has become a significant public health concern in both economically developed and developing countries (Okwuonu et al., 2014; Owolabi et al.,

2017). This study established that hypertension was the most significant stroke risk factor, as seen in Chapter 2, Table 2 and Figure 6.4 ('Distribution of Stroke Risk Factors amongst the Sample Population'). The study reveals that more than three-quarters of the subjects ($n = 76$, 76.8%) had hypertension, followed by diabetes ($n = 18$, 28.2%). This is similar to other Nigerian studies that have reported approximately 87% of patients with hypertension. Studies in sub-Saharan Africa have also shown that hypertension is a major risk factor of stroke. For instance, in Ethiopia, hypertension accounted for 52%–65.6% of stroke cases (Alemayehu et al., 2013; Owolabi et al., 2018). In Mozambique, 86.6%–96.0% of patients with stroke have hypertension before hospital admission (Damasceno et al., 2010). An estimate of the prevalence of hypertension in Nigeria was obtained through systematic research of population-based studies conducted between 1980 and 2013 (Adeloye et al., 2015). According to the survey, there is a significant incidence of hypertension in Nigeria, but there is poor general knowledge of high blood pressure among hypertension sufferers in the country. Interestingly, according to the findings of the research, there is also an alarmingly high prevalence of undiagnosed hypertension, as well as a low rate of adherence to antihypertensive treatment (Ejiroghene et al., 2020; Owolabi et al., 2018). The global incidence of hypertension has been rising, and as a result, studies indicate that there will be approximately 23 million deaths from cardiovascular disease by 2030, with 85% of those fatalities occurring in LMICs (Ejiroghene et al., 2020).

However, although hypertension is the strongest risk factor after age, according to literature (Gbiri et al., 2017; Ezejimofor et al., 2017; Feigin et al., 2016, Owolabi et al., 2015). In contrast to my findings, age is known to be the most vital determinant of stroke, with the risk of stroke doubling every decade above age 55 in HIC (Caplan, 2000; Lopez et al., 2006). Interestingly, in sub-Saharan Africa (SSA), most stroke cases occur in people less than approximately 60 years old, as stated above, whereas in developed countries, stroke usually affects much older people around 70–75 years (Feigin et al., 2013; Ezejimofor et al., 2017; Owolabi et al., 2018).

This research study also observed other potential stroke risk factors, such as smoking (8.1%), cholesterol (8.1%), heart disease (3.0%), and alcohol (12.1%). However, in comparison with studies in the UK and Germany (Owolabi et al., 2015; Feigin et al., 2016), the prevalence of cardiovascular disease, high cholesterol, and ischaemic diseases amongst patients with stroke is approximately (20%–30%), much higher than what was observed in the participants with stroke in the SE

communities of Nigeria. This is interesting, as this disparity indicates that the geographical distribution of subtypes of stroke has an important effect on stroke (Owolabi et al., 2015; Feigin et al., 2016). Because of the limited data that this research produced, it was not possible to investigate the relationship between stroke risk factors and stroke subtypes. However, evidence from other studies have shown that haemorrhagic stroke is more associated with hypertension, whereas ischaemic stroke is more affiliated with smoking and cardiac disease (Feigin et al., 2016; Owolabi et al., 2013; Owolabi et al., 2018). However, this contradicts the data in the current study, which indicate that ischaemic stroke (68.3%) was more prevalent than haemorrhagic stroke (23.8%). Although hypertension is more commonly associated with haemorrhagic stroke, it also causes an ischaemic stroke. Nevertheless, additional research is required to understand the aforementioned. However, the higher prevalence of ischaemic stroke in my study, may be due to the adoption of the Western lifestyle, as stated in Chapter 2, the indigenes of the SE communities have been migrating from rural settings to urban/semi-urban cities over the years for greener pastures. This is significant because it affords that attitudes and behaviours can affect quality of life as a result of developing bad habits (addressing objectives 2 and 4 of the research study).

As stated earlier in Chapter 2, HIC have more Ischemic type strokes cases than haemorrhage type strokes. Ischemic type strokes are more often associated with lifestyle changes such as smoking, being overweight, binge drinking, leading a sedentary lifestyle, and having cardiovascular disease. Returning to the research question, this is significant as it demonstrates an impact on the quality of life of stroke survivors in Nigeria's Southeast communities.

Overall, this study found that hypertension and diabetes were the main determinants of stroke, as demonstrated in the findings (Chapter 6). This addresses the research question in relation to objectives 1 and 2. These findings are similar to previous studies (Ejiroghene et al., 2020; Owolabi et al., 2018; Sampane -Donkor, 2014); It has been shown that about 54% of strokes worldwide is attributable to hypertension and that by appropriate blood pressure control measures, up to 45% of stroke cases can be prevented (Ejiroghene et al., 2020; Owolabi et al., 2018; Sampane -Donkor, 2014; Feigin et al., 2016; O'Donnell et al., 2010). As a result, LMIC and poor communities have high rates of cardiovascular disease that lead to stroke.

Because of a lack of awareness, knowledge and understanding, the Indigenes of Nigeria's SE communities are and have been exposed to high stroke risk factors such as hypertension, diabetes, noncommunicable diseases, and post-war effects, according to my findings in this section, all of which have predisposed these individuals to stroke. As stated previously in the study the best way to manage expectations is through communication by providing education and knowledge as one of the participants in the study had mentioned.

"My Bp is now checked every morning. All thanks to the Doctors and nurses, I now feel a lot healthier" (Bisi, 29-year-old)

However, to manage these issues, campaigns aimed at educating the public and education programs at the community level need to be implemented by the government and health policymakers within the community. The epidemic of hypertension and its complications can be successfully addressed if a sufficient degree of awareness, a new and updated model and suitable drive is maintained.

8.2.3. Associated Determinants of Stroke

This aspect addresses objective 2 of the research study. As demonstrated in Chapter 3, Section 3, in addition to the primary risk factors for the study, this study had identified a possible link between foetal undernutrition or famine in early childhood (such as those who experienced the Biafran War) can predispose one to an increase in hypertension and cardiovascular diseases in later life, which can lead to an increase in stroke incidences (Aliasghari et al., 2019; Zhang et al., 2015). This explains why adults born small are more likely to develop cardiovascular diseases such as stroke (Gomes et al., 2016). According to the biological literature, if an undernourished baby later in life consumes a high-fat, high-sugar diet, he or she is at risk of obesity, diabetes, and cardiovascular diseases such as stroke (Barker and Robinson et al., 1992). However, due to the lack of literature in this area, this is not substantial. Nevertheless, it has been proposed that the Biafran war that took place 56 years ago, this was around the time most of the participants in the study were either infants or foetal.

The country, Nigeria, has become a complex society with various cultural and religious practises that reflect the people's attitudes, behaviours, and understanding of their health (Asare et al (2017).

Extended families are still the norm and the backbone of Nigeria's social system (Igwesi et al., 2017).

However, most of our people, particularly those in the community, believe that diseases are frequently caused by supernatural forces, bad luck, witches, wizards and demons (Asare et al

(2017). Misconceptions about the cause of disability often stems from cultural and or spiritual beliefs or punishment or fate from God. (as discussed in chapter 3). As a result, attitudes and knowledge are influenced. Lack of understanding and awareness regarding disabilities and their resulting characteristics due to cultural, family relationships / spiritual beliefs are also a factor (Obionu et al., 2006).

Other influencing factors include health-care un-availability and accessibility, financial resources, social networks and support services, and perceptions of disease severity. However, to understand behaviours, these factors must be contextualised. Understanding human behaviour is required to change behaviour and improve health practises and beliefs (Obionu et al., 2006).

Discriminatory legislation and polices reinforce prejudice and or discrimination while the segregation of people with disabilities perpetuates negative stereotypes (Hausman – Muela et al., 2017).

To increase Nigerians' health-seeking behaviour, service providers should be properly structured to understand and appreciate the need for health outreach programmes, particularly in rural communities (Hausman – Muela et al., 2017).

This is pertinent in the context of addressing our research question, which is to identify the characteristics and determinants that predict the impact of stroke on the quality of life of stroke survivors in the Southeast communities of Nigeria. However, due to the minimal research in this field, it is suggested that more studies be commissioned to confirm the preceding (Gomes et al., 2016; Aliasghari et al., 2019).

8.2.4. Factors (Stroke Type) Influencing the QOL of Stroke Survivors

The aim of this key section was to identify whether stroke type influenced quality of life of stroke survivors in the SE communities of Nigeria as part of further addressing objective 2 of the research study. As seen above the findings of this study revealed no significant influence or correlation between stroke types. In contrast to other studies such as Gbiri et al.'s (2010) study, haemorrhagic stroke survivors had considerably higher QOL during poststroke periods. However, Owolabi et al. (2010) and Owolabi et al. (2008) found no significant correlation between stroke type and QOL in their respective studies. The findings of this study correspond with these findings. The current study also aligns with a Ghanaian study (Sampane-Donkor, 2014) in which ischaemic strokes accounted for 78% of all cases; however, in contrast, studies in England and Wales (Xu Xm et al., 2018), which was an

international study of 3,000 cases found the incidences of haemorrhagic and ischaemic infarctions to be 22% and 78%, respectively. This may have been due to several factors such as high numbers of participants used for their study and the environment (HIC compared to LMIC).

8.2.5 Descriptive Statistics of Quality-of-Life Dimensions (Quality of life of stroke survivors)

This aspect of the discussion continues to address objective 2 of the research study, and the data contributes a clearer understanding of the impact of stroke on the quality of life of stroke survivors in SE Nigeria.

Generally, little is known about health-related quality of life of stroke survivors globally, as the affected domains appear to vary culturally. Chapter 6, Section 2 presents the descriptive statistics of the seven domains (dependant variables): physical, emotional, intellectual, soul, eco-social, spiritual interaction, and spirit. The HRQOLISP scores for each domain ranged from 1 to 5, with the higher scores reflecting greater quality of life and the lower scores reflecting poor quality of life. The arithmetic mean of the various domains scores was calculated. The descriptive statistics of each dimension indicated relatively low mean score for the physical dimension of the HRQOLISP (mean = 2.52, SD = 0.76), with the mean values for other dimensions being comparable. Specifically, the spirit and soul domains reported relatively higher mean values (mean = 3.70, SD = 0.70).

The findings in this section of the study indicate that the physical and the spiritual domain had the utmost impact on the QOL of the stroke survivors in the SE communities of Nigeria. These findings are consistent with findings by Akosile et al., 2013; Hamza et al., 2014; Owolabi et al., 2011. It has been recommended that health professionals involved in stroke management should focus their attention on interventions and strategies that may enhance physical and functioning abilities in stroke survivors. A study by Pinkney et al (2017) also found high scores in the spiritual interaction domain. The means that spiritual belief in Africa is strong (Asare et al., 2017). It suggests that drawing on one's faith or religion throughout the time of recovery is essential since doing so has the ability to aid healing. This is consistent with similar studies in the field (Sabogal et al., 2016). Studies have also shown that worries generated by chronic illness can slow the illness recovery process. It is considered that belief can provide hope in medical treatment and enhance the success of rehabilitation and the recovery of illness.

The findings in this section also identify that emotional, and intellectual domains were affected HRQOL domains and had an impact on the quality of life of stroke survivors. This is consistent with findings by Hamza et al., (2014) and Donkor A et al. (2018). This continues to imply the need to improve physical therapy / rehabilitation approaches using personalised and multimodal strategies tailored to the specific needs of each patient. Also, the need for interdisciplinary team approach to help with the regaining of old skills and the relearning of new skills, see The Adig model in the recommendation section? of this chapter. Previous studies have demonstrated variability in scores regarding domains. Nevertheless, in contrast to the current study, Pedersen et al.'s (2020) findings reveal more problems in the cognitive, social, and emotional domains than the physical one. The study's Norwegian and Danish population suggests that the participants are from an HIC with adequate rehabilitation facilities and infrastructure, which may be one cause.

Another study (Safaz et al., 2010) found personality and thinking (intellectual) to be among the domains with the highest scores, while some Nigerian studies (Owolabi et al., 2011; Akosile et al., 2013) have revealed that 'social, family and physical functioning' are areas of quality of life most affected. Hamza et al. (2014) revealed the area most severely affected by the quality of life are 'emotions. It was highlighted in the study by Hamza (2014) that this may be as a result of the lack of emotional rehabilitation. However, in contrast, the findings of a study conducted in Sweden by Guidetti et al. (2014) indicated that concerns about functioning were more widespread in the physical domains than they were in the cognitive and social domains. However, one potential reason for these discrepancies may be related to the contrasts and similarities that exist in the fact that these countries are HICs in comparison to LMICs. Due to a lack of access to rehabilitation services, it is now obvious that patients with stroke in these LMICs receive very modest therapeutic treatments to aid with recovery. This is only one possible explanation. However, discrepancies in HRQOL ratings may also be attributed to the range of patient groups evaluated, in addition to the diverse recruitment techniques employed by the various stroke hospitals and research organisations (Guidetti et al., 2014).

8.2.6 Correlation Matrix of Health-Related Quality of Life Dimensions

This part of the discussion further addresses objective 2 of the research study, as it found that the emotional (psychological) domain ($p = .051$) had a significant positive correlation with the intellectual (cognitive) ($p = .647$) domain. The findings suggest that the physical, emotional, and intellectual

domains were most negatively impacted by stroke. This therefore proposes that emotions and intellect are related. Consequently, these domains had the biggest impact on the overall quality of life of the survivors in the research study. The fact that this is the case provides support for the hypothesis that emotional and intellectual experience are related. This is in accordance with studies such as Pinkney et al. (2017), which reported that the cognitive domain is one of the two domains most significantly affected by stroke. However, Pinkney et al. (2017) proposed that 30% of stroke victims have CT findings showing atherosclerotic changes in small vessels or have white matter disease. These white matter changes are often implicated in intellectual (cognitive) decline (Brookes et al., 2014; Pinkney et al., 2017). It would have been interesting to know the outcomes of the CT scans performed on the stroke survivors who participated in the current research study. To be more specific, it would have been intriguing to determine whether the lack of white matter alterations in these individuals may explain their poor HRQOL. This work may be beneficial for future research by targeting people who have already had CT scans or who have the financial means to do so, as most patients in SE Nigeria cannot afford a CT scan. There was a significant association found between the spiritual interaction domain and quality of life when analysing the HRQOL component that pertains to one's spirituality. In Pinkney et al.'s (2017) study, stroke survivors had significantly reduced HRQOL scores across the board, apart from the category of spiritual engagement.

The effect of age, gender, income, afflicted body side (stroke orientation), and stroke type on the mean score of each dimension of the HRQOL construct, except for gender, showed no significant difference. The results build on existing evidence from studies such as Owolabi et al. (2013) and Sampane-Donkor et al. (2014), who suggested that gender has no significant effect on HRQOL. However, female patients with stroke had better HRQOL in the spirit and spiritual interaction domains than their male counterparts in the above studies. Other similar studies have equally shown that gender has no influence on their quality of life (Owolabi et al., 2011). Contrarily, Enato et al. (2011) found that Nigerian women had a significantly poorer quality of life when compared to men based on activities of daily living. Further studies are required using comparable instruments and methodologies to clarify the effect of gender on different HRQOL domains (Owolabi et al., 2013; Sampane-Donkor et al., 2014).

As previously discussed briefly in Chapter - 2, HRQOL associations may vary over time after stroke; this may depend on whether different aspects or components of the multidimensional HRQOL are being considered. Chapter 6, section 3, the correlation analysis, indicates that the physical dimension did not significantly correlate with any other dimension ($p \geq .05$). This may be due to the small sample size used for the study. However, this agrees with other studies that have identified reduced correlation with other dimensions (Pinkney et al., 2017; Owolabi et al., 2017; Olaleye et al., 2013; Gbiri et al., 2012). Therefore, in summary, stroke has a multifaceted effect on HRQOL, being more pronounced in the physical and spiritual domains as discussed above. The analysis of the study revealed that none of the independent variables had significant relationships or correlations with the dependent variables. This may be due to the cross-sectional design of the study, which necessitated a larger sample size. Indeed, additional research on the linkages and correlations between the variables is required. The link between the two methods is emphasized in the summary of the quantitative findings (Chapter 6 section 8) to avoid repetition, as now the focus is on discussing the qualitative findings of the research study.

8.3 Discussion of Qualitative Findings – Phase 2

8.3.1 Explaining the Themes

The three main themes interpreted in this research study were.

1. An unfamiliar self (disempowerment, self-identify, and physical disability).
2. Recovery of the embodied self – transitional stage (rehabilitation and physical therapy, education, management of the condition, and faith / religion).
3. Reconstruction of the embodied self (familiar self, self-discovery, and adjustment / acceptance).

8.3.2 Discussion of Themes in Relation to Existing Literature - The Main Themes

In this section, the three main themes are considered in the context of existent literature. Interpretative phenomenological analysis (IPA) was the chosen methodology for Phase 2. (See Chapter 5, section 9 for rationale). IPA aims to provide detailed examination and analysis of the narrative accounts. The IPA discussion plans to identify the 'essence' of what each theme is about (Braun & Clarke, 2006), what the theme is saying and how the subthemes interact and relate to the main theme in each section. For clarification, in this study, the IPA narrative is divided into separate

themes. For each theme, there is a discussion of the impact of stroke on the QOL of the stroke survivors, followed by an interpretation (which is grounded within the text rather than being imported from outside). The identified theme is then related to the literature with reflections included at the end of each section.

Participants' experiences are reflected on within a wider context where the relationship between the researcher and the participant are interwoven. Consequently, IPA involves a 'hermeneutic'

*where the researcher is trying to make sense of the
participant, who is making sense of their world*

Smith and Osborn et al. (2003)

8.3.3 Master Theme 1: An Unfamiliar Self

This section of the theme's discussion will concentrate on addressing objective 3 of the research study. In the context of the findings, 'an unfamiliar self' refers to the unpredictable nature of the stroke situation. Its component sub-themes include 'self-identity', 'disempowerment (physical and psychological),' and 'physical disability'. The majority of the participants in the study regardless of stroke types, stroke severity or impairment characteristics, stated that their poststroke body was not only different but rather strange to them. This is in alignment with other studies (Pedersen et al., 2019; Timothy et al., 2016). Most of the participants in the study viewed their impaired body parts as abnormal and unfamiliar.

"Then suddenly, noticed my leg and arm become very heavy and my mouth started twisting, that's all I could remember"
(Emeka 54 years old)

When the participants referred to body parts that did not function, they often used words that expressed detachment, as if the body part was seen as a strange object from outside (Pedersen et al., 2019). Participants frequently emphasised that, before the stroke, they had never given much thought to how they related to their body; it was simply 'normal'. The experience of stroke, however, had made the participants increasingly aware of their bodies because of its unfamiliarity. Functional difficulties disrupted a well-established, comfortable method of doing things and living life, so impairing their quality of life (Vincent-Onabajo et al., 2016). Each time they laboured with a task, the body manifested itself, and the consciousness of what they were unable to accomplish asserted its existence. The inability to control bodily functions called forth a feeling that the body was acting on its own and could not be trusted (Kitzmuller et al., 2013). Body parts were perceived as opponents rather

than self-evident teammates, according to most of the participants (Vincent-Onabajo et al., 2016). Negative emotions towards non-cooperative and unreliable body parts were seen and expressed by most of the participants in the study. The participants' experience of a different body – self also related to how their post-stroke bodies had become unpredictable (Kitzmuller et al., 2013). Ouchi narrates the following:

'it became so ...soft, my mouth started to twist ...just like this....so, I couldn't walk again, even...on the chair I was sitting....i almost fell off' .(Ouchi, 62 years old)

Ouchi described how his mouth twisted and how his legs became abruptly heavy, as if it were a distinct, insolent entity capable of self-generating behaviour. The participants' lack of control and inability to fully predict how the body would react when required prompted them to be more circumspect in daily activities. In other words, participants indicated that they gradually developed a tolerance for their poststroke 'embodied' experience despite its unpredictability, implying a gradual acceptance of their altered body over time. Conversely, participants reported that physical functioning and coping strategies act as personal issues and suggest that physical limitations and managing the stroke recovery process through positive thinking and religious faith indeed is crucial for an improved QOL. Timothy et al. (2016) reported that a positive attitude helped anchor individuals to a more personally acceptable embodied experience. Tobichi quotes the following:

*"by the grace of God today and tomorrow I will get myself"..."because I know this thing come today, one day it will go"
"I started getting up, learning and standing up, you understand me"(Tobichi 58 years old)*

Some of the participants struggled to accept the change in who they were in the world. The new circumstances were a part of the 'self that was unknown' due to a variety of functional issues that impacted one's quality of life. The participants discussed recovery of physical functioning as being under their individual control.

The participants in the study attempted to reacquaint themselves with their bodies through a life-long project of pushing it to its limits (Timothy et al., 2016; Pedersen et al., 2019). Mastering significant activities, on the other hand, helped individuals enhance their self-concept. As previously noted, research backs up participants' assertions that maintaining a positive attitude is crucial to their recovery (Kitzmuller et al., 2013; Vincent-Onabajo et al., 2016). These findings are consistent with

previous research where participants reported that their bodies felt strange, unfamiliar, and foreign (Kitzmuller et al., 2013; Arntzen et al., 2013; Morris et al., 2015). According to Timothy (2016), the relationship between body and self after stroke is not static, but rather oscillates between divergence and cohesion at different points in time and over time. He argued that the experience of stroke can challenge people's perceptions of the relationship between their body and their self after stroke. He concludes by stating that the bodily experience of stroke is inextricably linked with a person's sense of self. However, according to similar studies such as Arntzen et al., (2013) and Luker et al., (2015), this experience is especially profound during the transition from the hospital to the home, which was similar to some of the stroke survivors experience in the current study.

<p><i>"The main limitation is the ability to be active and to go to funerals and burials like I use to before"</i></p> <p style="text-align: right;"><i>Buchi 72 years old</i></p> <p><i>"Yeah, it has changed me, because before the stroke, I use to cook in my house, but now I cannot without help. Now I need support to cook "</i></p> <p style="text-align: right;"><i>Amake 53 years old</i></p>
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However, this will be clarified further in the conclusion. This section, therefore, partially answers the research question concerning objectives 3 and 4, by demonstrating and discussing the effect of 'an unfamiliar self' on the quality of life of SE indigens in Nigeria.

8.3.4 Reflection of 'An Unfamiliar Self'

My interpretive analysis of this theme has led me to the conclusion that each participant's perspective evolved during the interview process. I believe this is due to a variety of factors including social standing, gender, knowledge of the disease, and willingness to speak up. The participants expressed their thoughts, but, for the first time, I sensed that the participants developed increased awareness of their bodies during the interview process, and it became apparent that each person constructed their own interpretation of the situation differently, which was heavily impacted by the world around them. I also believe that the initial shock of the stroke attack contributed to participants' denial or disbelief that something like that could happen to them, particularly those who emphasised or relied on prayer. Post stroke neglect is common in stroke survivors (Maxton et al., 2013) Studies have reported this to be a major barrier to successful stroke rehabilitation. Emeka quotes the following:

“I myself, I don’t have it, so I just know, I’m just telling my God I don’t want to have it, I don’t have it, I tell him that I don’t want to have anything like a stroke in my body”

I felt that the term ‘stroke’ was avoided to some extent during their initial discussions, which I believe was part of the denial and a desire to avoid association with the term ‘Stroke’ owing to their grasp of its pathology. Some of the participants in the study found it hard to let go of who they used to be in the world before they had a stroke. In their new lives, parts of themselves were strange because their QOL had changed which again partly answers the research question on the impact of stroke on QOL. Most of the participants in the study described unfamiliarity in life and self, whereas participants from other studies described receiving professional help to sustain their self-constructing process by focusing on unfamiliar aspects of self (Pedersen et al., 2019; Timothy et al., 2016). The second theme ‘the recovering of the embodied self’ sheds light on the ‘transitional stage’ of recovery.

8.3.5 Master Theme 2: Recovery of the Embodied Self – Transitional Stage

The term ‘embodiment’ in context of this study refers to how the participant lives in and experiences the world through their bodies (Pedersen et al., 2019). This theme in the research study articulates the transition from the ‘unfamiliar self’ to the ‘embodied self of healing’ concerning the study participants. Its component subthemes are rehabilitation, and management of the condition by means of education, followed by the impact of faith and religion. This current study demonstrated that recovery of the embodied self was related to progress in functional recovery, enhanced knowledge of the condition and particularly one’s faith and spiritually.

The bodily experience of stroke is intimately connected with a person’s sense of self (Timothy et al., 2016; Pedersen et al., 2019). A person’s social and physical environment as well as the survivors’ attributes, can serve to “anchor” that person more comfortably within his or her embodied experience of stroke (Luker et al., 2015; Crowe et al., 2016). The participants in the study had learned to master their changed bodies so that they could still move despite the effort they experienced. Therefore, although the difference of a strange, effortful body remained, participants were able to again become familiar with their bodies after stroke – which was named the transitional stage.

Participants in this current study reported a need for active participation in their rehabilitation. This was achieved through awareness of their situation and by being engaged in independent activities,

where they could regain a feeling of control of their situation (Rhonda et al., 2015). Gaining education and knowledge about their condition helped as a means of controlling their feelings of powerlessness (Pedersen et al., 2019). The participants were eager to learn about all available resources to aid in their total recovery, as most participants in the study, particularly the younger survivors, anticipated a complete recovery post stroke (Timothy et al., 2016; Pedersen et al., 2019). This is consistent with previous research that emphasises quality of life as a negotiation of self and identity (Moeller & Carpenter et al., 2013). In this current study the findings highlight the interrelationships between body and self and quality of life in the recovery process after stroke. Therefore, the embodied self is defined as an interwoven relationship between body and self in which embodiment plays a central role in structuring experience, cognition, and action (Gallagher et al., 2011) as highlighted above. The findings support previous findings that bodily changes influence an individual's embodied self (Kitzmilller et al., 2013; Pallesen, 2014; Timothy et al., 2016).

Education for the participants in the study included general knowledge of stroke physiology and recovery, as well as insights that they gained from their own post-stroke body. The strongest risk factor – hypertension, poses a huge problem in Nigerian communities as reflected in our findings (see Chapter 6, section 2). However, the low prevalence of awareness, treatment, and control of the condition in the country indicates a serious challenge for stroke prevention (Rhonda et al., 2015; Timothy et al., 2016). Therefore, health education and promotion strategies are needed to reduce the risk of stroke in these communities (Rhonda et al., 2015).

Religion and spirituality support the hope for improvements that can be achieved by faith (Fosarelli, 2008; Katerndahi et al., 2008). Spirituality is based on values and can be viewed as a source of meaning and purpose for what humans do especially in Africa (Ekeanyanwu et al., 2011). Religious activities usually improve the survivor's quality of life and reason for living. Religion has been positively associated with better physical and mental health after stroke (Fosarelli, 2008; Peoples et al., 2010). Traditional medicine, known as 'native healing' or complementary and alternative medicine, is the oldest form of health care and has stood the test of time (Healy et al., 1984; Ekeanyanwu et al., 2011). It is an ancient and culture-bound method of healing that humans have used to cope and deal with various diseases that have threatened their existence and survival. Traditional medicine (TM) is broad and diverse; however, the World Health Organisation (WHO, 2000) has provided one of the most acceptable definitions – the sum of the knowledge, skills and practices based on the theories,

beliefs, and experiences indigenous to different cultures whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement, or treatment of physical and mental illnesses (Fosarelli, 2008; Peoples et al., 2010).

However, this form of health care in the traditional society in Africa may involve black magic both as a cause and a cure of disease and may require elaborate rituals (Ekeanyanwu et al., 2011). Reasons for the power of TM in Africa include the restricted field of modern medicine, trust in traditional doctors, and the fact that they share in interpersonal relations (Ekeanyanwu et al., 2011). Although the methods and techniques of traditional medical practitioners are unorthodox according to Western standards, socioeconomic variables have rendered traditional medical practice a faithful adjunct to orthodox medicine, and 'native doctors' are now recognised as a vital component of national health care systems, as further evidenced by the WHO (Padonu et al., 1997; Ekeanyanwu et al., 2011).

The research study findings provided a new insight into the significant impact of stroke on quality of life of the stroke survivors in SE Nigeria. In the quantitative study, the HRQOLISP scores performed very well in the spiritual domains. This suggests that faith and spirituality play a role in illness recovery, particularly in SE communities of Nigeria. The qualitative findings equally highlight the strength of this subtheme (Spirituality and faith) in relation to the research question. So, the question is, 'is there a relationship between spirituality and health?' There is, however, very little scientific evidence linking spirituality with stroke. However, there is a real link between faith and stroke, suggesting that faith has at least some positive influences on stroke recovery (Moawad et al., 2021) as seen in the current study (see Chapter 7, section five).

Spiritual belief provides hope in the Nigerian culture and SE communities; therefore, when combined with Western treatment, this belief can hasten illness recovery (Asare et al., 2017). It is not possible to stop the African from having some form of faith / belief (Asare et al., 2017) as this belief is generational. This links back to the 'dependency syndrome' one of the legacies of colonialism (see Chapter 3, section two). This is a key component of a person's daily occupation, and having one's spiritual needs met is, therefore, an essential engagement and empowerment. This subtheme in this study had one of the strongest significant positive impacts on the quality of life of the survivors, thereby answering the objectives 3 and 4 of the research question. This is an important component and may be a key factor in how survivors cope with the illness and achieve a sense of coherence. According to the majority of the participants in the study, faith in God was crucial to overcome the

disease. This is consistent with other similar studies such as Giaquinto et al., (2010); Pucciarelli et al., (2020); and Moawad et al., (2021). A study by Pucciarelli et al., (2020) aimed to evaluate the role of spirituality between depressive symptomatology and quality of life in stroke survivors. The study's findings demonstrated a positive role for the stroke survivors. The study concluded that greater awareness of the importance of spirituality among clinicians and health professionals may improve cultural competence (see The Adig model in recommendations). However, because the study was conducted in only one European country, the study's generalizability was limited.

The prevailing 'western model', the biopsychosocial model, which considers health to include physical, mental, emotional, and social factors, is used to explain health and illness. However, for the African, wellbeing is more than just the proper functioning of the body system through proper healthcare and lifestyle; it extends beyond scientific causes to include spiritual involvement. As a result, modifying the biopsychosocial model to include spiritual factors is best suited to African culture (discussed in Chapter 4, section 4). This resulted in the creation of 'The Adig Model,' which is seen and discussed in the research study's recommendations. It also answers the research question as to, 'The impact of stroke on the quality of life of stroke survivors in the SE communities of Nigeria'.

8.3.6 Reflection of 'Recovery of the Embodied Self – Transitional stage'.

I have come to understand that the body is more than just flesh and blood; it is a network of cerebral connections, neurons, and cells that extends from the tip of the brain to the toenail. This segment focused on the participant's comprehension of a new way of life and experience of the world via their bodies. Indulging in new activities allowed participants to gain new physical and spiritual insights. This theme, in my opinion, is the most challenging as it covers participants 'embodied' experiences in encounters with medical professionals like physiotherapists, doctors, and nurses. For instance, initiating repetitive sit-to-stand activities during rehabilitation to retrain balance and lower limb function may treat the physical element of a person's stroke, but does not address the subjective feeling of paralysis / hemiplegia. This subjective aspect, as observed in some participants, could be, for instance, distress, shame, curiosity, confusion, or even dissociation, and may influence how these individuals perceive themselves as human beings, how they relate to their post-stroke bodies, and how they engage or do not engage in rehabilitation interventions or daily activities.

Therefore, for the physiotherapist or health care provider, this 'embodied' experience necessitates a greater investment of time and effort in active listening skills to better accompany individuals during

this physical and mental transition. According to Asare et al. (2017), health professionals using Western medical practises in hospitals and clinics should accept African patients' beliefs and use them to increase their compliance and adherence to scientific medical treatment. They should strengthen the spiritual beliefs of patients who already have them and encourage them to use them positively to improve their illness and health care in order to aid in illness recovery.

"It dawned on me that this was serious because there was no other way, later that day things had all changed. It was from then that I realised this was really a serious matter, that this was a stroke, because I never had any symptoms". (Buchi 72 years old)"

Finally, the third theme 'reconstruction of the embodied self' illustrates the new adjusted and accepted life post stroke.

8.3.7 Master Theme 3: Reconstruction of the Embodied Self

Reconstruction of the 'embodied self' encapsulates the familiar self, self-discovery, adjustment, and acceptance. This can be understood as an ongoing and interrelated process of continuing functional development (Sarre et al., 2014; Timothy et al., 2016). The theme illustrates a process interconnected with acceptance, progress, adjustments, and management in life. It is a means of understanding stroke survivors in the recovery process and has clinical value throughout the various stages of stroke rehabilitation (Asare et al., 2017; Sarre et al., 2014). While some participants in the research study expressed gratitude for their present level of recovered OQL, others were able to put their stroke experiences in perspective despite ongoing functional issues. Enosi quoted the following:

" but now I walk slightly independently, sometimes with a walking aid but hope soon to walk without any help or aid...so to me this is a big achievement".(Enosi 55 years old)

Most of the study participants acknowledged their enduring basic issues and discussed accepting and adjusting to the new norm as they went on a path of self-discovery and started to recognise familiar functionality in daily tasks. The participants narrated their stories about the changes that they had been through and described the alterations from feeling sad, upset, annoyed, anxious, or depressed (early in the process) to not responding in this manner at all to their present functional problems. This is illustrated by the following quotes:

"It's getting better ...its becoming better"(Meka 58 years old)

"I'm getting better, eh...I believe that I will be finally better" (Amaka 53 years old)

"I know how my system was before, but it is transforming gradually.."(Meka 58 years old)

"I can now walk inside my compound with more confidence..."(Tobichi 58 Years old)

The findings of this study illustrate the importance of reassuring how stroke survivors manage in life over time and the significance of self-discovery, adjustment, and acceptance. These participants gradually moved forwards to a more settled, adapted 'embodied self'; this increased the participants' experience of QOL as seen above. According to Sarres et al. (2014) it was suggested that adjustment following a stroke is dynamic and varies over time, which has parallels with the literature on resilience, where resilience is observed to be changeable over time. This is in alignment with the study's findings that highlight the participants' attitude to change in general, and reports to influence their views on recovery. Those who no longer experienced restriction in functioning described a continued positive change in their self-awareness during the first few years of their recovery following stroke, as seen above and further in Chapter 7. Their descriptions revealed that earlier functional disruptions, whether to the emotions or to the body, came to the foreground of awareness in different situations (Kitzmilller et al.,2013; Arntzen et al.,2015; Sarres et al., 2014). A similar study by Pedersen et al., (2019) examined the experiences of quality of life in the first year after stroke in Denmark and Norway and discovered that reconstructing the embodied self is a means of understanding stroke survivors during the first year of recovery, supported by an individualised and tailored rehabilitation model. The current study also discovered that among the participants in SE Nigeria, support was critical for change and development following stroke. The dimension of restoration, on the other hand, is associated with a perceptual process of change and development that is dependent on stimulation from others (Hitch et al., 2014).

Adjusting and adapting are linked to a dynamic emergent perspective on identity, which is embodied by the changing self (Wilcock, 2006). This may not always be the case, as in the case of a similar study (Pedersen et al., 2019), in which participants' reconstruction of the embodied self was positively impacted by disabilities being continually challenged through functional restoration. Learning new things and getting involved are thus essential components of the process of reconstructing the embodied self.

According to the literature, the reconstruction of the embodied self is an ongoing and interconnected process (Kitzmilller et al., 2013; Armtzen et al., 2015). Interactions and ongoing close relationships with family, friends, neighbours, and the community emerged as an important aspect for reconstructing the embodied self and improving quality of life (Sarres et al., 2014). This is evidenced by Emeka's comments.

"I'm coping with the assistance of my wife and brother taking care of me".

"Is only God that can do anything that you want in your life. With God anything can be possible just living by the help of other people now, without my junior brother, I don't think how far I would have gone by now because he helped me a lot and he took me to many places to make sure I got better...so I'm tanking God for that"

(Emeka 54 years old)

Several of the participants indicated how they previously performed simple tasks during the early stages of their stroke, such as walking, cleaning, and cooking, but now these tasks need little thought. In other words, as they progressed or continued to recuperate, self-awareness faded into the background. Jopadi elaborates:

"now I am walking, I am walking well but before it was not like that"....

The embodied knowledge in "I can" without too much struggle or thinking brought back some form of normality with a familiar self for some of the participants as seen in Chapter 7. These participants described the same success in regaining normality or familiarity in the embodied self. Nevertheless, the findings of this aspect of the study elaborate on themes that will be helpful for physiotherapists and health professionals working with stroke patients in the community, hospital or clinics. These findings indicate the value of continuity in services to support reconstruction of the embodied self and quality of life of stroke survivors. Hence, professionals may support reconstruction of the embodied self by optimizing restoration of functions, facilitating the development of coping strategies and supporting adjustments in everyday life for the stroke survivors in SE Nigeria

Following a stroke, this aspect of the study demonstrated various aspects of the impact of stroke on the HRQOL of stroke survivors in SE Nigeria. This answers the research question, "The impact of stroke on the quality of life of stroke survivors in Nigeria's SE communities." The recovery of stroke

varied among the stroke survivors; however, the self – reconstruction process emerged as important for QOL for the participants in the current research study.

8.3.8 Reflection of ‘Reconstruction of the Embodied Self’

Once again, the ‘embodied’ experience of stroke manifestly exceeds the physical body. Embodiment is masked and hidden in physiotherapy practice and paradigms; as a result, effective rehabilitation should take these factors of recovery into account. It is stated that effective rehabilitation should involve a biological and psychosocial assessment with a set of interdisciplinary measures that aim to address post-stroke issues to minimise the chances of a new episode of the illness (see Chapter 4, section three - biopsychosocial model of health). The above discussed findings emphasise the need to reassure survivors about their ability to manage in life over time and the critical role of professional support in the structure and manageability of daily life to maximise quality of life. As a physiotherapist, I believe that rehabilitation for survivors is constrained in the sense that we place a greater emphasis on goals connected to physical movements, thereby focusing on illness rather than wellbeing. To better support our patients through this transitional/reconstructive phase, I believe that more emphasis should be placed on active listening practices. This will allow us to incorporate higher-level life goals that will link physical rehabilitation with the recovery of one's own identity after a stroke.

Stroke impacts more than just one aspect of the body; it also affects an individual's sense of self. These participants are not mechanical devices that can be broken and fixed. These participants' lives are complex because of their embodiment of social, physiological, and environmental elements. As a result, when a stroke occurs, it affects all these dimensions of the participants' lives.

In summary, some of the participants in the study seemed to be able to re-establish an adapted self and form new normality through their acceptance, despite their losses in valued activities and social involvement. Previous studies have highlighted QOL as a negotiation of self and identity (Moeller and Carpenter et al., 2013). However, the Phase 2 findings illustrate the interrelations between the body, self, and QOL in the unfolding ‘reconstruction process’ of stroke. The overall ‘embodied self’ is understood as an interwoven relationship of body and self, where ‘embodiment’ plays a central role in structuring experience, cognition, and action (Gallagher et al., 2011). The findings in this phase indicate that bodily changes influence an individual's embodied self, as others have suggested (Kitzmuller et al., 2013; Timothy et al., 2016). As the familiar self, which Chapter 7 conceptualised as the former self,

refers to the preinjury embodied self of an individual; this is seen to have formed the basis for reconstruction of the embodied self.

8.3.9 Embodiment

This part of the discussion highlights the relevance of a biopsychosocial approach in relation to 'embodiment' and address's objective 4. As mentioned in Chapter 3, a biomechanical view of the body lies at the heart of physiotherapy practice. If the profession is to adapt to the changes taking place within health care, it needs to first understand how the body has framed physiotherapy practice historically, philosophically, and socially. This aligns with the theoretical theory – the biopsychosocial model – used in this research study. The embodied view of chronic illness is more straightforward because, unlike acute illnesses, the very definition of chronic illness implies that the person will live an altered life rather than return to their preinjury / pre illness state (Pedersen et al., 2019). Therefore, the health professional's role is one of functioning alongside the person. It has been proposed that investigating the notions of an 'embodiment' may be relevant to the profession and contribute to a clearer understanding of the relationship between health care and the body. Certain aspects of an embodiment provide physiotherapists with great opportunities for professional development. The concept of 'embodiment' refers to knowing the truth of what it is to be 'embodied' rather than just possessing a body. Physiotherapists have an outstanding awareness of movement, as well as the influence that illness and disability have on function. Hence, physiotherapists have a key and essential role to play in the development of a new science referred to as 'embodied movement'. People's poststroke experiences do not occur in isolation from external influences; instead, other individuals, including physiotherapists, can influence (both positively and negatively) people's understanding of their bodies after stroke. The embodied experience of stroke extends beyond the physical body, yet 'embodiment' remains tacit and hidden in physiotherapy practice and models. The findings of this research study indicate the value of continuity in services to support the reconstruction of the 'embodied self' and HRQOL among stroke survivors. The intricacy and uniqueness of 'reconstructing the embodied self' are relevant for a personalised and customised practice to enhance the individual's experience of HRQOL through meaningful characteristics and activities. The findings also highlight the interaction between the mind and the body, revealing a compromised approach to the social and medical models of disability when viewed through the lens of a biopsychosocial model.

8.4 Health / Stroke through a Biopsychosocial Lens

The discussion in this section further addresses objectives 3 and 4. The concept of health remains debatable; however, from the stroke survivors' perspectives in this research study, health is defined in terms of comparison to others or prior to the stroke attack. For example, one who is healthy is able to walk without an aid, is able to perform active daily living activities (ADLs) without assistance, has healthy behaviours (such as paced physical activities and exercising), or is socially active and regularly attends functions such as church or funeral services.

The study participants quote the following in relation to health:

'I was going, as I wanted to climb the stairs, but I fell on the floor'(Meka 58 years old)

'I started limping on the leg, so I went to seek help'

"I could not move at all from the bed or use my legs to the private toilet " (Emeka 54 years old)

"Then I suddenly, noticed my leg and arm become stiff and heavy".

" at times I don't even know or have an idea of what was happening around me, I later tried to move with energy, I couldn't walk.

I no longer feel myself it just psychosocial " (Buchi 72 years old)

"The main limitation is the ability to be active and to go to funerals and burials like I use to before" (Buchi 72 years old)

'when I get better, I can start going out'(Amaka 53 years old)

The stroke survivor's perspective captures a biopsychosocial view of health. In the study, the physical domain demonstrated a negative impact on the quality of life of stroke survivors, which implies the need to improve physical therapy/rehabilitation approaches and strategies tailored to the needs of the stroke survivors. Spirituality, on the other hand, revealed a positive impact on the quality of life of the survivors, which infers that faith/spirituality and or religion improves the quality of life of stroke survivors according to the results of this study as stated above and detailed in chapter seven.

A strong belief in supernatural powers is deeply rooted in African / Nigeria culture. In Nigeria and Ghana for example, there is a spiritual involvement in the treatment of illness and health care (Asare et al., 2017). However, the new health model in the African culture can therefore be considered a biopsychosocial (S) model with the (S) representing spiritual practice – compared to the biopsychosocial model in western culture (Danquah et al., 2014).

Therefore, it is of the utmost importance to encourage the survivors to connect with their diverse faiths, as spirituality also guides health and recovery and is regarded as a divine gift (Asare et al., 2017). In Africa, spiritual belief is a major determinant of the choice of treatment. This belief system originates from the creation history where the Almighty God created the universe and the first man. Spiritual belief is, therefore, part of an African (Danquah et al., 2014). The continued existence of spiritual belief among Africans suggests the heritability of this belief. The explanation, however, for this continuous spiritual belief among Africans is the fact that it is transferred from one generation to the other through the parenting and upbringing of children (Asare et al., 2017). However, there are different kinds of beliefs – the belief in the Almighty God and the belief in other spirits as most herbalists prepare their herbs based on spiritual belief (Asare et al., 2017).

In contrast, this concept has ramifications for health care workers because if stroke survivors believe their health is a gift from God, they may adopt a relaxed attitude and miss or disregard opportunities for health promotion. Conversely, as stated above, is the concept that health is a status that is granted by God, one that is justly deserved as an idea that is closely linked to those that hold a religious belief (Danquah et al., 2014).

However, the belief that health is a gift from God should not be mis understood. However, this is a common religious belief (Hill et al., 2007). Studies suggest that the spiritual gift of healing is given to all believers and is meant to be directed by God (Goh et al., 2023). Spiritual healing is not a talent or magic power. All who have the spirt is given a gift designated by God such as healing, teaching, or wisdom. God also determines the outcome. However, some Christians quote James 5:13-15 when they say that we can all learn to heal. He says, “the prayer of faith will save the one who is sick, and Lord will raise him up’ ’This verse is often misused to support false teaching that God always wants to health every man, which leads to feelings of ‘guilt and disillusionment (Hill et al., 2007).The implication is that the suffering Christan just didn’t quite believe enough or is hiding some sort of sin (Goh et al., 2023) These misunderstanding about faith have destroyed some believers (Hill et al., 2007).

In this research study, the majority of participants aligned a good health status as being granted by God.

As stated by the study participants:

“with God anything can be possible just living by the help of other people now...”(Joko 61 years old)

“so, I am thanking God for that, it is the help of God...”(Jopadi 64 years old)

It is recommended that the belief in African patients should not be rejected but should be used by health care professionals to guide and facilitate patients' recovery from illness. Therefore, when combined with western treatment, this belief can quicken illness recovery (Asare et al., 2017; Danquah et al., 2014).

8.5 Stroke Knowledge, Attitudes, and Practices in the Community

This aspect address's objective 4, where the findings of the study seem to fit with the experiences discussed. Data from this research study indicate that stroke is perceived as a serious illness that is preventable with lifestyle alterations that can be made to reduce its risks (Ejiroghene et al., 2020; Owolabi et al., 2016). During the qualitative aspect of the study, stroke survivors frequently mentioned that medical personal, even those who were very familiar with stroke, demonstrate little understanding of what it “feels like” to experience a stroke (as discussed in Chapter 7). Furthermore, the data suggest that the perspective of participants differ systematically from that of other participants, as QOL is a subjective phenomenon. However, the key results of the study identity that the physical domain and the spiritual domain had the most impact of the quality of life of the stroke survivors. Family support and the community play an important role in the rehabilitation of the individuals who acknowledge that self – management and rehabilitation is the result of awareness and knowledge.

A study by Omodara et al., (2021) explored the impact of cultural beliefs in the self-management of type 2 diabetes among black sub-Saharan African in the UK. The findings highlighted the need to be aware of not only the negative impact of the illness. But also, be aware of the enabling factors and collective practices of family within the community that influence the self-management and health seeking decisions of individuals living with an illness.

An African traditional medicine (TM) practitioner is a person recognised by his or her community as competent to provide health care through herbal medicine (Awolowo et al., 2013).

Regarding cultural approaches to health management, TM was the earliest means of health care in the continent. It's Africanness consist in its uniqueness to Africa which is inherent in its age long practice among the peoples of Africa. However, because of its antiquity, traditional medicine is not just a means of solving health problems but also an important African cultural heritage.

Interestingly, African traditional healers are consulted not only for sickness or disability but also for good luck, for the security of lives and property, and for warding off any imminent evil or demonic attacks (Awolowo et al., 2013). These methods are based on the social, cultural, and religious background, as well as the knowledge, attitudes, and beliefs prevalent in the community concerning physical, mental, and social well-being and the causes of diseases and disability (WHO 1987). It is argued that spiritual beliefs in the community give people hope, so they should not be rejected, but rather encouraged by health providers to guide and facilitate the individual's recovery from illness.

In the various local communities, the traditional doctors are well known for treating patient holistically (Awolowo et al., 2013). They usually attempt to reconnect the social and emotional equilibrium of patients based on community rules and relationships, this has a huge impact on people's values and beliefs in the communities (Awolowo et al., 2013).

One crucial factor that traditional medical practitioner manifest in their profession is a better awareness of the culture and norms of the community within which they work (Omoleke et al., 2000; Elujoba et al., 2005). This is primarily due to the trust relationship that has developed over time between the indigenous peoples of the community and the traditional healers. There is, however, less emphasis on this in orthodox medicine. (support in addressing objective 4 of the research study).

Perceptions, attitudes, and cultural approaches were explored through the research study. This approach was chosen to aid in the detailed capture of the individuals' perceptions concerning their QOL. It is believed that this method would also uncover the participants' behaviours, 'thought patterns, and opinions to provide further insight into the problem' (Onwuegbuzie et al., 2009). However, spiritual cultural approaches and practices as discussed in earlier chapters are still the most common health care cultural practices in Nigeria. Many Nigerians often patronize these traditional herb vendors who are responsible for diagnosing them and then given them concoctions to treat their ailments based on the symptoms they describe. As many traditional health practitioners use this way of diagnosing diseases.

As explained in chapter 3, Nigerians have a rich history of traditional medicine which remains very popular among the population. The traditional health practitioners in Nigeria include native doctors, herbalists, spiritual healers, and herbal doctors. However, the major issue identified is that the use of Nigerian traditional medicine and herbs is the poor-quality control and safety.

The stroke survivor's knowledge of stroke was poor, but in alignment to a good dietary and lifestyle practices. Quotes from a few of the participants:

"I know now, I must stop thinking, there is nothing that will annoy me anymore, what I know now is that I will manage being upset" (Meka 58 years old)

"your diet matters a lot, some people do not eat right" (Buchi 72 years old)

"I avoid anything that has too much oil in it, we are advised to watch what we eat eg avoid high cholesterol"(Emeka 54 years old)

"its HBP and Diabetics, that mainly lead to stroke, but I'm not a diabetic and I don't think I was hypertensive" (Bisi 29 years old)

"I still have more... relief since that day till now, the things I didn't know, now I know" (Meka 58 years old)

In other words, this attributes importance to biomedical knowledge as demonstrated in Chapter 3, section 1.5. These narratives cut across the different levels of knowledge and education of the participants in the study. Interestingly, this is vital information, considering that the majority of the participants expressed reduced knowledge of the condition and its risk factors prior to the experience of a stroke. However, this still indicates that there is low awareness of stroke among the members of the communities of Nigeria and across sub-Saharan Africa. Conversely, Nigerian studies such as Akosile et al. (2013), Badaru et al. (2015), and Vincent-Onabajo et al. (2018) have demonstrated poor awareness of stroke in the communities. Ghanaian studies such as Sanuade (2016) and Sampene-Donkor (2014) have also shown reduced community awareness of stroke. Similar studies outside Africa, such as in Brazil, Australia, and India, have reported poor community knowledge of stroke and its risk factors (Owolabi et al., 2017; Pandian et al., 2006). Studies have shown that increased awareness of stroke risk factors among people at high risk of stroke leads to improved compliance with stroke prevention practices (Ezejimofor et al., 2016; Vincent-Onabajo et al., 2018). Therefore, consistent sensitisation on the need for regular blood pressure checks in the communities may help to detect elevated blood pressure and reduce stroke incidents (Owolabi et al., 2017; Vincent-Onabajo et al., 2018).

As previously indicated, maintaining sufficient resources to support the delivery of care is a fundamental strategy for increasing the quality of care for patients at risk of noncommunicable diseases. However, access to medical infrastructure and logistics is frequently poor in LMICs and has been a source of dispute in developing nations (Ezejimofor et al., 2016; Vincent-Onabajo et al., 2018). These findings have implications for evidence-based planning and allocation of rehabilitation services and health resources in the Southeast areas of Nigeria (for instance, the number of physiotherapists, occupational therapists, and speech and language therapists required for stroke survivors' rehabilitation). For example, the larger impact of stroke on the physical domain justifies the deployment of additional resources for the successful implementation of physiotherapy during stroke recovery.

Spirituality is connected to better physical and mental health outcomes among individuals with disabilities, according to a review of existing studies (Ezejimofor et al., 2016; Vincent-Onabajo et al., 2018; Rhonda et al., 2015). This has been used by many to help them adjust to their limitations and give their life new meaning. In this regard, other facets of spirituality, rather than merely religious views, may be more crucial for a positive adjustment to life changes (Owolabi et al., 2017; Rhonda et al., 2015).

8.6 Limitations and Strengths

Even the best research studies have limitations, which must be acknowledged in order to demonstrate credibility. The present research study was based on quantitative and qualitative data from a mixed-methods approach as stated earlier in the thesis; the rationale for the use of a mixed method approach for this research study was to understand the synergy between the two methodology findings that reflects participants' points of view (Creswell et al., 2018). This gives voice to the study participants, ensuring that study findings are grounded in participants' experiences. It will also allow for the combination of paradigms allowing investigations from both the inductive and deductive perspectives which will enable the combining of theory generation within a single stance.

However, the study's generalisability may be limited to patients with stroke in urban or semi-urban settings and hence may not be truly representative of the population with stroke in rural areas. This is because only stroke survivors from physiotherapy departments, stroke clubs, and university hospitals in each of Southeast Nigeria's capital cities were included in the study. Patients with significant

disabilities poststroke, such as cognitive and language impairment (aphasia), were excluded from the study due to the extensiveness of the questionnaire utilised. Nevertheless, the selected participants may have had diverse experiences that affected the HRQOLISP profile. It is further worth noting that the small population size of the research study, which is characteristic of many studies conducted in sub-Saharan Africa, makes it hard to declare with absolute confidence how these disparities may be explained by statistics. It is argued that the methodologies utilised in stroke epidemiology research in Africa are often erroneous and unrepresentative of the community (Owolobali et al., 2018; Ezejimofor et al., 2017).

Again, those with cognitive and language difficulties who were excluded from the study could have contributed unique experiences. While this study's findings are again restricted to individuals in low- and middle-income nations, the participants confronted a variety of issues connected to their quality of life. Due to the cross-sectional nature of this study, it was impossible to capture changes in participants' characteristics over time. Despite this, the study proved valuable in assessing the impact of stroke on survivors' quality of life in Nigeria's SE region.

Another limitation of the study is that the cross-sectional design does not enable the assessment of changes in HRQOL. The questionnaire provided seven domains' scores rather than an amalgamated score. Such a score would need weighting of the domains, and that would be done as a future extension of this research which would entail a larger scale. However, there was limited descriptive data on the characteristics of the quantitative sample, although this was done to minimise the data collection time. Additionally, when using lengthy instruments, one must consider the burden on patients and staff, as well as the viability in terms of the resources available. The participants were mostly older people with a variety of comorbid illnesses. Given this population's fragility and advanced age, HRQOL instruments should be assessed for their clarity and capacity to distinguish between the impacts of illness and ageing (Hann et al., 1993).

A further limitation of the qualitative findings is the inability to generalise its findings to a larger population due to the inherent nature of the qualitative method used and the limited number of study participants. The fact that the quantitative participants were 60% male and 40% female, while the qualitative participants were 53% male, and 47% female demonstrates male dominance in the study. However, efforts were made to recruit more female than in the previous phase to gain their own

insight in the study. As female experiences and perceptions could have been different from those of the males, particularly since Nigeria is a patriarchal society (Vincent-Onabajo et al., 2016; Mohammad et al., 2013).

One of the study's key strengths is that it incorporates the participants' perspectives in the development of rich data, allowing individuals to communicate their own experiences in an unrestricted manner (Creswell et al., 2018; Polit and Beck, 2014). A notable strength is the production of comprehensive data about participants' personal experiences following a stroke event. Hence, the themes that emerged from this research study were prevalent throughout the entire study – which included probes of distinct HRQOL aspects, followed by narratives. The design explored did not capture changes over time within and between participants during the study. Despite this, the study was useful for further understanding the impact of stroke on quality of life from the perspectives of stroke survivors in the Southeast communities of Nigeria. Thus, there can be confidence that the findings reflect issues that are important to this population.

This mixed method approach provided several design methods choices and a variety of concurrent and sequential strategies – such as words, pictures, and narratives that add meaning to numbers and add deeper, more meaningful answers to a single research question, as seen above in the research study. The approach enabled information to be uncovered that would have otherwise been discarded or unnoticed and provided a more complete and comprehensive understanding of the research problem than undertaking it separately. The combination of the methods has produced integrated knowledge that best informs theory and practice. The design provides stronger evidence for the conclusion of the research study through convergence and corroboration of the findings (principles of triangulation).

8.7 Recommendations

This section of the discussion highlights the various recommendations emanating from the research study. It is crucial to acknowledge the loss that occurs following a stroke and its influence on the quality of life of the individual. There are numerous approaches to researching the impact of stroke on one's quality of life. For this research study, an MM method was adopted which enables a view of life experiences and the impact of stroke from two perspectives which generated corroboration in the

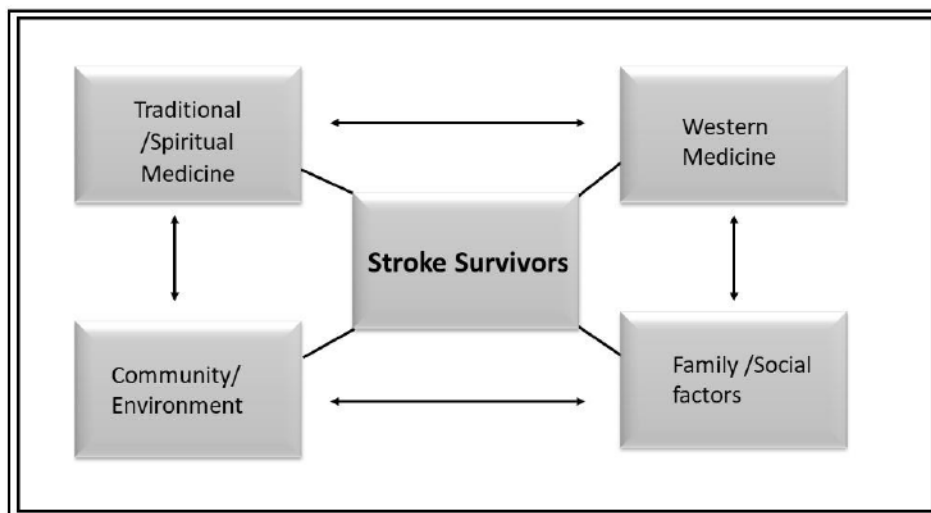
findings (see Chapters 6 and 7). In other words, mixing quantitative and qualitative methodologies can bring value to a single-method approach.

The prevention of occurrence of new strokes is the key solution to the problem of the growing burden of stroke in Africa, and therefore, rehabilitation should focus on what is most meaningful to the individual following stroke (Bernhardt et al., 2020). Professionals can do this by using questions to explore what stroke survivors want to do, what they perceive to be significant barriers, and what skills and support networks are needed (Bernhardt et al., 2020). The findings emphasise the importance of rehabilitation practitioners supporting stroke survivors to engage in meaningful self-selected social activities and the importance of stroke survivors having the freedom and autonomy to set their own goals within rehabilitation (Krug et al., 2017; Olaleye et al., 2017). The individual's ability to adapt their behaviour and attitude by being positive, hopeful, determined, resilient, and courageous is an essential part of pursuing their self-selected valued activities (Krug et al., 2017; Bernhardt et al., 2020). Acknowledging and encouraging the importance of these behaviours and attitudes should be promoted in rehabilitation. Stroke survivors should be informed by their physiotherapists or other allied health practitioners about their prognosis and the benefits of immediate rehabilitation following their hospital diagnosis. With this, stroke-related mortality can be reduced by improving stroke management (Krug et al., 2017; Bernhardt et al., 2020).

Spirituality should be considered in health care / rehabilitation, as there is a faith and a spiritual factor strongly involved in a patient's concept of health and recovery (Owolabi et al., 2011; Owolabi et al., 2017). Spirituality has a positive effect on health behaviour. Consequently, I suggest a simple form of partnership between rehabilitation clinics or hospital-based stroke rehabilitation centres and faith-based organisations / institutions to create a form of synergy, corroboration, and collaboration to enhance and speed up the stroke recovery process of stroke survivors in the Southeast communities of Nigeria. I would also suggest the development of discussion forums between stroke survivors and faith leaders within the community, as this may contribute to the understanding and effective management of stroke care. Discussions such as these could lead to increased awareness of the uniqueness of spiritual beliefs held by participants of stroke in the local communities (traditional healers, spiritual healers, and native doctors) and may assist stroke care health professionals to gain competence in treatment management / rehabilitation and in the unique care of the individuals (Tengs et al., 2001; Owolabi et al., 2011).

This study suggests that stroke survivors should be offered individualised rehabilitation programs that address not only physical activities but also psychological circumstances and existential issues (Lindsay et al., 2014; Kwakkel et al., 2015). Interventions offered to stroke survivors should be unfolded through a pedagogical approach, so the individuals do not feel alienated or need to struggle in isolation. The program should also be able to promote the individual's motivation, the sense of being able to cope, and an optimistic view of life. It has been suggested that a holistic multidimensional approach is required for stroke rehabilitation in SE Nigeria (Akosile et al., 2013; Enwereji et al., 2014; O'Donnell et al., 2016; Ezejimofor et al., 2017; Owolabi et al., 2018). As a result, a new integrated model has been designed and would be appropriate for community validation and improved quality of life for stroke survivors in SE Nigeria. The Adig Model of care is shown below:

Figure 28: THE ADIG MODEL



Source - Author

This model, proposed by the author, reveals the importance of an integrated health system concerning reconstruction of health and QOL of the stroke survivor, as seen in the biopsychosocial model of health. Working amongst individuals suffering from neurological conditions has been a challenge for me as a neuro physiotherapist fortunate enough to live and work in the UK, particularly in terms of determining the most effective form of rehabilitation and the best outcome measure to improve QOL. However, this research has revealed the significance of community, environment,

family, traditional / cultural healing, and social factors in relation to illness recovery. Whilst the belief system in Africa is very strong, health education on medical / scientific causes of diseases cannot abolish traditional, cultural, or spiritual beliefs in Africans (Asare et al., 2017). Traditional medicine and western medicine should be embraced by the health professionals in health care and recovery. Health professionals using western medicine in hospitals and clinics should accept the belief of the individual and utilize their beliefs to increase their compliance and adherence to western medicine (Chukwuma et al., 2015). Health professionals should strengthen traditional beliefs and help direct them to use the belief in a positive manner to improve their illness and health care (Chukwuma et al., 2015). Traditional healers / spiritual healers should also be acknowledged in health care in the community. They should be trained to understand basic medical conditions such as stroke, for them to modify traditional / spiritual practices to meet the needs of the individual (Asare et al., 2017). The WHO recognises the need to integrate traditional medicine with orthodox medicine, as they define it as 'the total combination of knowledge and practises, whether explicable or not, used in diagnosing, preventing or eliminating physical, mental or social disease'. According to them, about three-quarters of the world's population relies on traditional remedies for health care.

According to Tribe et al. (2007), pluralism (the use of traditional and western medicine) the integrated system, can be more appropriate in the recovery of individuals and will most likely be more productive due to certain mind sets, cultures, and attitudes – this is witnessed in the qualitative findings. However, this interrelationship is directly related to the Adig Model of health care in relation to health and wellbeing as seen above.

Health care pluralism is a term that refers to the availability and use of different approaches, treatments and systems of health and illness (Tribe et al., 2007). In the context of this research study, this includes western medicine and or traditional medicine. This often reflects the diversity of beliefs, values and practices related to health and healing in varied cultures and traditions (Sundararajan et al., 2020).

Tribes' study introduced Health Pluralism (biomedicine) traditional medicine and alternative medicine. However, it refers to health pluralism a diverse range of explanatory health benefits as well as a varied range of designated healers. Tribes' study argued that working with individuals and resources who have lived through extreme events such as the Biafran civil war may be more appropriate in

assisting communities than Western models of diagnosis and therapy (Tribe et al., 2007). The study concluded that health pluralism is a more appropriate alternative to western models of therapy in the context of conflict.

The benefits of pluralism in the context of this study are that it promotes tolerance and acceptance of different beliefs, backgrounds and lifestyles which can lead to less health inequalities and discrimination (Sundararajan et al., 2020). It will also encourage the expression and inclusion of many voices to promote quality of care. It will also help preserve unique traditions, identities among culture groups in the communities (Mitchell et al., 2019). Finally, it will help promote intellectual dualism where leadership, economic or political decisions are made through consensus among the members of the community (Mitchell et al., 2019).

The Adig Model of care will help bridge the gap between theoretical understanding and practical implementation (Marmot et al., 2020) It is hoped that the theory concerning the perspectives and various models of health concerning the unfamiliar self, the reconstruction of the embodied self, and the awareness of risks factors will inform application to practice. This provides an understanding of the interaction between empirical and narrative data regarding the impact of stroke and the quality of life of stroke survivors in a Nigerian semi-urban communities seen from the findings in Chapters 6 and 7. The development of "The Adig model," will hopefully usher in a new way of managing stroke recovery and improving the quality of life for stroke survivors in SE Nigeria.

The Adig model has many advantages and is useful because it will broaden people's perspectives and will encourage them to consider factors other than just health services, such as local environmental factors and societal factors. The health Professionals and policy makers working in diverse sectors will find this helpful (Marmot et al., 2020). It will also become useful in the collaboration of people from the varied sectors of life (as seen in the model) to achieve a common goal in promoting health and reducing inequalities (Katikireddi et al., 2020).

Studies have argued that to some extent, colonialism, western religion, and education, as well as the globalisation phenomenon, have negatively affected the perception of TM in Africa (Awolowo et al., 2013; Chukwuma et al., 2015; Ekeanyanwu et al., 2011). Nevertheless, the demand for the use of TM has continued to grow not only in Africa but worldwide. Recent health care studies are realising that traditional practitioners are important players in healing processes, especially in developing countries,

since they continue to provide affordable and accessible health care services for the local communities, especially to those who cannot afford orthodox medicine (Hausmann-Muela et al., 2003; Omoleke et al., 2000). Interestingly, in Osowole et al.'s (2005) study, more than 50% of the traditional healers studied referred patients at least once to modern medicine facilities. Nevertheless, Ratzan et al. (2000) reported that the non-Western medicine can provide important links between disease and behaviour, as well as effective treatment not found in Western medicine. Elujoba et al. (2005) reported that effective health cannot be achieved in Africa by orthodox medicine alone, unless it has been complemented with traditional medicine. The new health agenda in Nigeria and Africa focuses on the institutionalisation of traditional medicine in parallel with orthodox medicine into the natural health care system.

The study also demonstrated that hypertension and diabetes were correlated with stroke in the SE communities of Nigeria (Ejiroghene et al., 2020). The study recommends that tackling hypertension should be treated as a top priority for the Nigerian government. Hypertension and its complications in the environment and communities can be adequately controlled; however, the Ministry of Health and health policymakers need to assist through public enlightenment campaigns and sensitisation programs down to the community level (Ejiroghene et al., 2020; Okwuonu et al., 2014). I would also like to recommend timed regular campaigns, workshops, and seminars in hospitals concerning knowledge/awareness of stroke and its risk factors by stroke organisations/health care practitioners within the community. The study found that the participants' immediate health-seeking behaviour was influenced by both the suddenness of the stroke and their prior knowledge about the disease. Stroke education should be promoted in Nigerian communities to increase the knowledge of warning signs of stroke to ensure early detection and diagnosis.

The study found that the physical domain is associated with HRQOL areas that need to be improved to increase the quality of life for stroke survivors in the SE communities (Timothy et al., 2016). For the participants of the current study, this implies that improvement in their physical health can enhance rehabilitation in other areas of their lives and, in turn, improve their quality of life (Timothy et al., 2016).

A longitudinal approach would be advantageous to fully understand the impact of stroke on the quality of life of survivors, according to this study. This will aid in the development of evidence-based

therapies by allowing researchers to better understand the progression of stroke and its effects across time (Ejiroghene et al., 2020; Okwuonu et al., 2014). Again, future studies need to examine the impact of traditional medicine / herbal medicine (TM) on stroke rehabilitation in comparison to orthodox medicine Ejiroghene et al., 2020; Chukwuma et al., 2015). This recommendation, however, is based on some of the responses of the participants in the study who claimed that they had experienced an improvement in their condition due to TM. Some of the participants mentioned that nonadherence to orthodox medication was due to its cost and a lack of availability within their communities.

At the time of writing this thesis the Covid -19 pandemic was an ongoing global health treatment with implications reaching into virtually all aspects of everyday life. Telemedicine /remote and digital assessments was used in research; this had surged into everyday clinical use as a necessity for safe remote assessments during the pandemic and now has an increasing evolving role in routine clinical research and assessment. The use of telecommunication and information technology to deliver clinical health care research remotely would assist in removing distance barriers with enhanced access to clinical research.

Regarding noncommunicable diseases in Nigeria's SE communities, a well-developed health care system that provides lifelong treatment and follow-up is needed as a result of the Biafran War (Chinawa et al., 2015; Fatusi et al., 2015). A growing number of people in Nigeria are suffering from chronic ailments, which is a huge problem for the already crippled health care system (Chinawa et al., 2015). The Nigerian national health budget and the government's economic plan should also prioritise the prevention of foetal and infant undernutrition – given that the highest risk for hypertension, which commonly leads to stroke, was discovered particularly in the undernourished Biafran children in early life (Chinawa et al., 2015; Fatusi et al., 2015).

8.7.1 Recommendations in summary

The research study recommends a simple form of partnership between the rehabilitation clinics or hospital-based stroke centres, faith – based organisations and institutions to create a form of constructive collaboration and corroboration to enhance and speed the stroke recovery process for the stroke survivors in the SE communities of Nigeria (Mitchell et al., 2019).

The 'Adig Model' of health care has revealed from the above study the importance of an integrated health model regarding the reconstruction of health and QOL of the stroke survivors (where the

Traditional and Western medicine will be embraced by the health professionals working alongside each other, referring and acknowledging each other) in order to achieve the best outcome and improve QOL (Sundararajan et al., 2020).

The study also recommends that the Ministry of health and health policy makers should engage in public enlightenment and education programmes (such as stroke education in the communities to increase the knowledge of warning signs to ensure early detection and diagnosis (Bernhardt et al., 2017). The use of campaigns and sensitization programs should be incorporated down to the community level.

I equally recommend that the Nigerian National health budget and the Governments economic plan should prioritise the prevention of foetal and infant under malnutrition, given that the highest risk for hypertension which leads to stroke, and cardiovascular diseases was discovered among the under malnourished Biafran children in early life (Tarantola et al., 2018; Philips et al., 2018).

The Influencing of the government to implement a campaign against diabetes and hypertension will involve the following -

Writing to the house of representative with a list of tabled requests backed with evidence / signed petitions. And or oral questions for the members of the local house of representative |

The use of Substantive motions or Adjournment motions in the house of representatives.

By raising awareness through public outreach campaigns

The Signing of a petition amongst those family members who are directly or indirectly affected by the conditions.

8.8 Summary of Chapter

The aim of this research was to identify variables that predict the impact of stroke on the quality of life of stroke survivors in Southeast Nigeria, in addition, semi-structured interviews were used to investigate stroke survivors' perceptions, attitudes, knowledge, cultural approaches, and beliefs in the SE communities of Nigeria. Ultimately, understanding the impact of stroke on the HRQOL of survivors is paramount in health care practice and research, particularly in Nigeria, where evidence-based medicine has become a vital priority of the Nigerian health care system.

This doctorate research project has provided valuable information on the impact of stroke on the quality of life of stroke survivors in the SE communities of Nigeria. It clearly shows that there is a high burden of stroke in SE Nigeria.

The research study utilised an explanatory sequential mixed method design and is divided into two phases: the quantitative phase (Phase 1), which used a cross-sectional design / nonexperimental technique to collect, evaluate, and interpret the data with convenience sampling, and the qualitative phase (Phase 2), which employed a hermeneutic phenomenological approach with purposive sampling, followed by an interpretive phenomenological analysis.

The quantitative findings and analysis revealed the impact of stroke has a twofold (positive and negative) effect on the QOL of stroke survivors. The descriptive statistics for HRQOL revealed the lowest scoring domain that demonstrated an inadequate quality of life (negative effect) was the physical domain (mean = 2.52, SD = 0.76) ($p \geq .05$). In contrast, the highest scoring domain that demonstrated a decent quality of life (positive effect) was the spirit domain (mean = 3.70, SD = 0.70) ($p = .28$).

The strength of the relationships between variables was measured using Pearson's correlations. It was discovered that there was a substantial difference in the emotional (psychological) and intellectual (cognitive) HRQOL domains between 10K–50 K and 50K–100K income levels. The mean score for 10K–50K ($M = 3.20$ $SD = 0.45$) in the intellectual (cognitive) domain was significantly lower than that of 50K–100K ($M = 3.61$ $SD = 0.60$) in the spiritual domain. This implies the significance of the predictive effects of the independent variable. Subjects with high-income jobs (100K+) had significantly higher mean values in the spiritual interaction scores compared to subjects earning 10K–50K. This demonstrates the convergence of findings. The qualitative findings revealed that the physical dimension – reflected by an unknown self, which included disempowerment (physical and psychological), self-identity, and physical impairment as subthemes of the measurement – had the most significant negative impact on the QOL of survivors. This finding indicates that the participants in the research study felt more deficient in the physical domain, thereby highlighting the need to improve physiotherapy/rehabilitation approaches.

The spiritual dimension is reflected in the reconstruction of the embodied self, with self-discovery, acceptance, and adjustment as subthemes. This indicates a beneficial impact on the QOL of stroke

survivors in the Southeast communities of Nigeria, suggesting that spirituality/faith improves the recovery of patients with stroke. Consequently, methods that target the spiritual domain and procedures, including 'healing' the spirit, may be advantageous (Owolabi et al., 2017).

The Phase 2 findings involved the intertwined and negotiating processes of the 'unfamiliar self', 'recovery of the embodied self, and 'reconstruction of the embodied self. The last theme is interconnected to ongoing bodily changes and functions throughout the recovery stage of the stroke survivor. This is a means of understanding stroke survivors in the ongoing recovery process and has clinical values throughout the various stages of stroke rehabilitation. Health professionals need to understand the distinct aspects of the 'embodied self', as this is useful for supporting evolution to a known and familiar self-following stroke.

Furthermore, as with any mixed method study that involves IPA, the researcher's prejudices shape the direction and interpretation of the qualitative data; therefore, future readers and researchers will continue to add their understanding of the same data. To make this apparent, my prejudices have been outlined throughout the process.

Though stroke is perceived as a serious and preventable disease in SE Nigeria, community awareness of the risk factors and warning signs is suboptimal. It is postulated that this reflects the trend in the SE communities of Nigeria and is partly responsible for the high morbidity and mortality of stroke in the region. Therefore, community-based education programs, as suggested earlier in the study, are required to increase public awareness of stroke, which could contribute to decreasing the risk of stroke in this urban community.

However, completing this thesis has not only resulted in generating more knowledge and understanding concerning HRQOL but also allowed me, on a personal level, to complete a 'research journey'. While my reflections and views are explicit throughout the thesis, a thought on the end point of my journey is necessary (see 'Reflexivity' below). As is required in phenomenological research, I became involved in Phase 2 of the data. As the Phase 2 themes and the participant-practitioner relationship emerged, I began to reflect on my role in each.

The findings of this research study will be disseminated to the public via stroke rehabilitation centres in SE Nigeria / Africa and various stroke rehabilitation centres in ethnic minority communities in the

United Kingdom. My two publications have already been distributed locally and internationally through conferences, workshops, and seminars.

This may be used to shape future evaluations of stroke rehabilitation models. Furthermore, it will undoubtedly shape my future research. This has, therefore, been a successful journey in allowing me to begin my research career.

Future work will compare the HRQOL of participants with stroke in HICs to the HRQOL of those in LMICs. This will help highlight the impact of various cultures and rehabilitation procedures in stroke rehabilitation institutions of the present day.

Access to healthcare in LMIC is a fundamental human right and a pillar of the country's sustainable development (Ezejimofor et al., 2017; Owolabi et al., 2018). I recommend the improving of local availability of health care services / rehabilitation clinics and clubs for the local stroke survivors.

Lobbying the minister of health concerning the following - Health care accessibility in urban and rural areas in the SE communities. Increase health workers due to imbalances in the work force (Ezejimofor et al., 2017. Transport barriers often hinder health care access in rural areas. Suggesting that the Nigerian government and other international organizations introduce new polices to improve the health and life expectancy of stroke survivors in the urban / rural populations by increasing access to health care (Owolabi et al., 2018).

8.8.1 Thesis Conclusion

The research study showed that the physical domain (an unknown self) and spirituality (reconstruction of the embodied self) had the most significant impact on the QOL of stroke survivors in Nigeria's SE communities, meaning that the stroke survivors' overall quality of life varied. Variables positively associated with stroke survivors' quality of life include being independent and engaging in spiritual activities. A variable negatively related to stroke survivors' quality of life was physical impairment.

This study aimed to understand the impact of stroke on the HRQOL of the stroke survivors and the experience of living with a stroke in low socioeconomic urban communities in Nigeria, using a mixed method approach. The ideologies from this study have revealed the variables that predict the impact of stroke on the QOL of stroke survivors. Collectively, the findings of both data were compared and corroborated, which produced a valid and sound substantiated conclusion demonstrating similarity in the overall findings during the final interpretation (Creswell, 2017). In addition, the study showed how

individuals use a biopsychosocial system in evaluating their health. It also emphasises the value of quantitative and qualitative approaches in helping to better understand the impact of stroke on the HRQOL of stroke survivors.

According to this study, there is a need to pay attention to the complex biopsychosocial disruptions of stroke in the SE communities of Nigeria. Based on the findings of the study, the AGIW model of care has been recommended. There is a request to the government, the Ministry of Health, the local / community leaders, and policymakers to review such.

8.9 Contributions

This research study aimed to address gaps identified in Chapters 1 and 2, sections 1.2 and 2.4 and, in doing so, has made several significant contributions.

8.9.1 Contribution to the Literature / Knowledge

The study's findings build on the current existing available knowledge. The research study has identified the scarcity of literature on stroke survivors' HRQOL in sub-Saharan Africa, notably in Nigeria and its poorer communities (Ezejimofor et al., 2017; Owolabi et al., 2018). There is equally a shortage of information on the impact of stroke-on-stroke survivors and the quality of life after a stroke from the survivor's perspective. Furthermore, there is a lack of data on the use of mixed method approaches to investigate Nigerian survivors' experiences and quality of life (Feigin et al., 2016; Gbiri et al., 2012; Ezejimofor et al., 2017). Therefore, this mixed method explanatory sequential study, which incorporates a cross sectional design and IPA, has not been previously performed in SE Nigeria. This research has bridged the gap between theoretical understanding and practical implementation. It is hoped that the theory concerning the perspectives and various models of health concerning the unfamiliar self, the reconstruction of the embodied self, and the awareness of risks factors will inform application to practice. This provides an understanding of the interaction between empirical and narrative data regarding the impact of stroke and the quality of life of stroke survivors in a Nigerian semi-urban communities seen from the findings in Chapters 6 and 7. The development of a new model, dubbed "The Adig model," will hopefully usher in a new way of managing stroke recovery and improving the quality of life for stroke survivors in SE Nigeria.

8.9.2 Contribution to the Individuals / Survivors

Hypertension is a significant public health concern in both LMICs and HICs and is the primary risk factor identified in this study (Okwuonu et al., 2014; Owolabi et al., 2017). The study reveals that more than three-quarters of the participants in the study (n = 76, 76.8%) had hypertension, followed by diabetes (n = 18, 28.2%). This helps to further understand that individuals in the SE of Nigeria with this condition are approximately four times more likely to have a stroke.

Therefore, the theoretical discussion elicited by the findings will help the stroke survivor and build on the current existing knowledge. In addition, it is hoped that it would further increase sensitivity to the overall risk factors, especially among susceptible persons within the community.

According to the literature and data collected in this study, there is low awareness of stroke and poor general knowledge of high blood pressure among the members of the communities of Nigeria and across sub-Saharan Africa (Akosile et al., 2013; Badaru et al., 2015; Vincent-Onabajo et al., 2018). Therefore, consistent sensitisation on the need for regular blood pressure checks in communities may help to detect elevated blood pressure and reduce stroke incidents (Owolabi et al., 2017; Vincent-Onabajo et al., 2018). However, access to medical infrastructure and logistics is frequently poor in LMICs and has been a source of dispute in these countries (Ezejimofor et al., 2016; Vincent-Onabajo et al., 2018). To manage this issue, the government and health policymakers need to conduct public enlightenment campaigns and sensitisation programs down to the community level. Therefore, with a good awareness level and adequate motivation, the epidemic of hypertension and its complications in the SE communities can be effectively controlled.

A further contribution to knowledge is the growing body of evidence that suggests that the increased susceptibility to chronic diseases, such as noncommunicable diseases (hypertension), in adulthood may be because of undernourishment in early life. It was found that exposure during childhood in the Biafran War had adverse consequences for the health of women and men, most especially in adult life. Those born between 1968 and 1970 (the end of the war) were classified as having been exposed to hunger during their foetal and early childhood lives (Gomes et al., 2016). About 70% of the participants in the research study had been exposed to some form of starvation during their early infancy. However, to corroborate the information given, additional research is necessary.

8.9.3 Contributions to Clinical Physiotherapy Practice / Policies

In this study, the physical domain demonstrated a negative impact on the quality of life of the stroke survivors, which implies the need to improve physical therapy/rehabilitation approaches using personalised and even multi model methods and strategies. Conversely, the spiritual domain demonstrated a positive impact on HRQOL. This implies the need to improve and develop rehabilitation programmes adapted to activities found in the study, such as the capacity to cooperate with institutions of faith, and the application of tactics that will address the spiritual domain in relation to 'healing' and recovery is deemed paramount.

The findings also emphasise the importance of rehabilitation practitioners supporting stroke survivors to engage in meaningful self-selected social activities and have the freedom and autonomy to set their own goals within rehabilitation (Krug et al., 2017; Olaleye et al., 2017). The individual's ability to adapt his or her behaviour and attitude by being positive, hopeful, determined, resilient, and courageous is an essential part of pursuing his or her self-selected valued activities and builds upon the reconstruction of his or her embodied self (Krug et al., 2017; Bernhardt et al., 2020). Acknowledging and encouraging the importance of these behaviours and attitudes should be promoted in rehabilitation. Evidence in the literature shows that improvement in the individual's physical and spiritual health can enhance rehabilitation in other areas of their lives and improve his or her quality of life (Timothy et al., 2016). The above findings build on evidence demonstrated in the literature.

9.0 Reflexivity – Looking Back

Self-reflexivity involves the process of ensuring the integrity and credibility of the researcher (Bolton et al., 2018). This suggests that reflexivity plays an essential part in the amplification of the trustworthiness of the research study (Denzin and Lincoln, 1998). This involves ways of questioning thoughts, attitudes reactions, and habitual actions to understand the role of the researcher regarding others (Bolton et al., 2018). As a novice PhD student, I initially found it difficult to employ reflexivity, but as I advanced through my doctoral studies, I found it to be an increasingly effective tool.

The insightful words of Bechhofer and Paterson (2000) seem to capture the essence of my experience during this research study:

Research design is always a matter of informed compromise

The experience of undertaking this research study has been extremely valuable and informative. Due to my explicit reflections and perspectives during the research study, a look back at my origins is necessary. I had read several articles and books on reflexivity, and the work that caught my attention was Valandra (2012). The tips and guidelines on reflexivity were quite useful in facilitating my reflexivity journey throughout this process. Valandra (2012) offered suggested reflexive questions at every phase of the research study. For example, in the pre-research phase, involved being honest with myself about my biases and limitations and my knowledge, or lack of it, of stroke and the quality of life concerning stroke survivors. It emphasises the potential influence of my ideas and experiences on the study process.

I often tried to engage in self-dialogue to experience the questions that I had about my preconceptions and answer them to highlight my awareness of the research topic: 'the effect of stroke on the quality of life of stroke survivors in SE Nigerian communities'. I wrote down my preunderstanding and knowledge throughout the process, which stemmed from my culture and personal and professional experiences. During the early stages, I kept a diary to capture and document my thoughts, feelings, insights, and field notes, with the majority written by hand; this consisted of jotted notes and mental triggers (personal notes that would remind me of specific things when it came to writing up the notes). However, during this early phase, whilst reviewing the literature, I found myself deeply questioning the reliability and validity of some of the scientific journals. I had come across several instances of contradictory data and was surprised how some of my colleagues appeared to trust the content of peer-reviewed journals. This sparked my interest in the topic of 'publishing bias'. For example, Dawes (2005) argued that although reputable journals adopt a robust peer process, articles can still get published with significant flaws. Furthermore, Webb et al. (2003) highlighted the fact that statistical significance increases the likelihood of a researcher's work being published, which might tempt some researchers to tamper with the data. Journals often have to publish to survive; sometimes, this imperative override the critical review process. At first, I decided to ignore these concerns, but as my literature review progressed, I took a more rigorous approach to identifying relevant journal articles. As a result of these realisations, I found it more efficient to evaluate research using meta-analyses and systematic reviews, as this saved me time from examining various journals. Having published two research papers, I was able to obtain a better grasp of publication requirements.

Reflexivity necessitates awareness of how the researcher's presence in the research environment has affected the acquired data (Creswell et al., 2013). During the analysis and writing-up phases of the research study, reflexive logs were mainly written as side notes on the interview transcript documents (see Appendix Five) and as annotations which were uploaded into the software Quirkos. I found the notetaking process itself helpful, as it ensured that I listened carefully and decoded information. However, the reliability of jotted notes alone can be questionable. For example, the jotted notes were not a direct transcription of what the participants said but consisted of pertinent information. The analysis began during the data collection for the study, where the quantitative data was analysed and informed the qualitative phase. Though 50% of my interviews were performed in Nigeria, whilst the remaining 50% were performed online with ethical approval during the COVID-19 pandemic, the original plan was to return the transcripts to the participants for verification. However, travel restrictions posed an obstacle during that time. I spent considerable time deliberating on whether to do this. The literature appeared to demonstrate opposing views on 'member checking', which is one of the techniques to improve rigour in qualitative studies (Creswell et al., 2013; Caelli et al., 2001; Webb et al., 2003). However, Caelli (2001) proposed returning transcripts to participants to review, clarify, or validate findings depending on one's theoretical stance. Webb et al. (2003) suggested that 'member checking' is unsuited for phenomenology, as there is no edict in interpretive research to verify or generalise findings. This is grounded in the belief that the participant's story is true at that specific time, and, on reflection, their recollections, initial beliefs, and perceptions can change. Therefore, in agreement with this principle, transcripts of the interviews were not returned to the participants for checking. However, participants were asked after the interviews if they wanted to remove any piece of information. Several meetings were held with the supervisory team to ensure that the findings were supported. This enables further insight and depth through challenges and discussions (Creswell et al., 2012; Caelli et al., 2001; Webb et al., 2003).

Throughout this research study, I remain intrigued with how my thinking was changing, demonstrating the continuing researcher development process. It was enthralling to read the information about where the experiences of past researchers had led them, with their end work appearing in a different location than where it had begun. However, there were frustrating times, such as when I had to re-read literature repeatedly, but this made many issues' initial ambiguities clear. I have learned the importance of engaging with the literature and in discussions with my supervisory team and PhD colleagues, I have

developed further insight into the multiplicity of perspectives available on any given issue. I have also been able to develop further understandings through continued critical reading, exercising regular reflexivity through the research process, and incorporating what I have learned from other research processes and interpretations into my understanding of this research study.

In a similar fashion, I have picked up a few essential advanced new skills, such as organisation, time management, and planning. Nevertheless, the pandemic posed a significant burden on most students during this season which was, without a doubt, the most challenging period of my thesis. During this difficult period, I learned how to stay motivated and focused and developed a deeper awareness of my strengths and weaknesses. Consequently, I had to learn to be more resilient (which had previously been one of my weaknesses). However, I was able to stay motivated, thanks to continuous collaboration and communication with the supervisory staff.

In hindsight, I feel I may have benefited from attending more workshops and courses on scientific writing, critical thinking, and analysis to lessen the amount of anxiety that I had. However, towards the end of the research study, I felt a great sense of accomplishment in completing the thesis; the struggle eventually paid off.

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APPENDICE

Appendix 1: Health Related Quality of Life in Stroke Patients, Questionnaire

APPENDIX 1

THE HEALTH-RELATED QUALITY OF LIFE QUESTIONNAIRE IN STROKE PATIENTS (HRQOLISP)

TODAYS DATE

PLEASE RESPOND TO THE FOLLOWING QUESTIONS BY FILLING IN THE SPACE PROVIDED OR CIRCLING THE CORRECT RESPONSE. THE ANSWERS THAT YOU GIVE WILL BE RECORDED AS ANONYMOUS AND KEPT IN STRICT CONFIDENCE.

WHAT IS YOUR GENDER 1. Male 2. Female

WHAT IS YOUR AGE DAY MONTH YEAR

AGE.....

WHAT IS THE HIGHEST FORMAL EDUCATION YOU HAVE RECEIVED?

1. PRIMARY 2. SECONDARY 3. COLLEGE 4. UNIVERSITY OR 5. OTHER (SPECIFY)

WHAT IS YOUR OCCUPATION.....

WHAT IS YOUR HANDINESS 1. RIGHT 2. LEFT.

WHAT IS YOUR AVERAGE INCOME MONTHLY 1. 0- N10,000 2. N10 – N50,000 3. N 50,000 – N100,000 4. N100,000- ABOVE

WHAT IS YOUR MARITAL STATUS? 1. SINGLE 2. MARRIED 3. SEPARATED 5. DIVORCED 6. LIVING WITH PARTNER

7. WIDOWED 8. REMARRIED

NUMBER OF WIVES / HUSBANDS

HOW MANY CHILDREN DO YOU HAVE

1. 0 2. 1 OR 2 3. 3 OR 4 4. 5 OR 6 5. 6 OR 7 6. 7 OR MORE

WHAT IS YOUR ETHNIC RACE 1. IGBO 2. YOROBA 3. HAUSA 4. WHITE 5. INDIAN

WHAT IS YOUR RELIGION 1. CHRISTIAN 2. MUSLIM 3. TRADITIONAL 4. NONE 5. OTHER (SPECIFY)

STROKE TYPE DURATION AND FREQUENCY – 1. ISCHAEMIC 2. HEMORRHAGE

ARE YOU ON ADMISSION CURRENTLY 1. YES 2. NO

WHEN DID YOU FIRST DEVELOP A STROKE

HOW MANY TIMES HAVE YOU HAD A STROKE

DID YOU HAVE ANY OF THE FOLLOWING – (TO BE FILLED IN BY THE INVESTIGATOR)

LOSS OF CONSCIOUSNESS YES NO

HEADACHES YES NO

VOMITNG YES NO

T.I.A YES NO

GRADUAL ONSET OF SYMPTOMS YES NO

ACTIVITY ON ONSET YES NO

HIGH BLOOD PRESSURE NIL/MILD MOD / SEVERE NOT KNOWN

BP<160/100 OR >160/100 MMHG

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WHICH SIDE OF YOUR BODY IS AFFECTED 1. RIGHT 2. LEFT

RISK FACTORS IDENTIFIED (INCLUDING SMOKING AND ALCOHOL).....

C.T SCAN / M.R.I. REPORT: STROKE TYPE, EXTENT AND SITE

CO -MORBID FACTORS IDENTIFIED

PLEASE REPORT THE NEXT SECTION AS (INTACT OR IMPAIRED)

ORIENTATION (IN TIME, PLACE AND PERSON).....

MEMORY (3 ITEM, REGISTRATION AND RECALL, PAST LIFE EVENTS).....

CALCULATION (SERIAL SUBTRACTION FROM 3 – 20).....

JUDGEMENTABSTRACTION (INTERPRETATION OF A PROVERB).....

RISK FACTORS

WHICH OF THE FOLLOWING PERTAIN TO YOU –

HYPERTENSION SMOKING CHOLESTEROL PREVIOUS STROKE

DIABETES HEART DISEASE ALCOHOL NONE OF THE ABOVE

A STROKE AFFECTS WHICH ORGAN OF THE BODY

BRAIN HEART OTHER (SPECIFY)

WHICH OF THE FOLLOWING DO YOU THINK ARE POTENTIAL RISK FACTORS OF STROKE

HYPERTENSION HEART DISEASE FAMILY HISTORY OF STROKE LACK OF EXERCISE

CHOLESTEROL OBESITY STRESS DO NOT KNOW

POOR EATING SMOKING ALCOHOL USE

WHAT ARE THE WARNING SYMPTOMS OF STROKE (YOU CAN CHOOSE MORE THAN ONE)

NUMBNESS (1 SIDE) WEAKNESS (1 SIDE) SHORTNESS OF BREATH VISION PROBLEMS

NUMBNESS ANY WEAKNESS (ANY) HEADACHES DIZZINESS

SLURRED SPEECH PAIN UNSPECIFIED DO NOT KNOW

DO YOU BELIEVE THAT STROKE IS A PREVENTABLE DISEASE –

YES NO DON'T KNOW

LIFE STYLE ALTERATIONS CAN BE MADE TO REDUCE THE RISK OF STROKE

YES NOT SURE NO

STROKE AFFECTS ONLY THE ELDERLY

YES NOT SURE NO

STROKE IS ONE OF THE TOP KILLER DISEASES IN NIGERIA

YES NOT SURE NO

STROKE REQUIRES EMERGENCY TREATMENT

APPENDIX 1

YES NOT SURE NO

WHICH OF THE FOLLOWING SOURCES HAVE PROVIDED YOU WITH YOUR KNOWLEDGE OF STROKE (PLEASE TICK ALL THAT APPLY)

NEVER LEARNED ABOUT STROKE MEDICAL BOOKS TV / RADIO STATION HEALTH CARE PROFESSIONAL
 NEWSPAPER / MAGAZINE SCHOOL INTERNET OTHER (SPECIFY)

HAVE YOU EVER COME ACROSS A STROKE CAMPAIGN AND BEEN INVOLVED. YES NO

WHAT WOULD BE YOUR CAUSE OF ACTION IN THE EVENT OF A STROKE

CALL 999 VISIT THE HOSPITAL VISIT YOUR PHARMACY VISIT THE HERBALIST WAIT AND OBSERVE SYMPTOMS TO SEE IF THEY SUBSIDE OTHER (SPECIFY)

INSTRUCTIONS –

THIS ASSESSMENT ASKS ABOUT HOW YOU PERCEIVE YOUR **CURRENT STATE OF HEALTH, QUALITY OF LIFE,** OR OTHER AREAS OF YOUR LIFE. PLEASE ANSWER ALL THE QUESTIONS HONESTLY. IF YOU ARE UNSURE OF A RESPONSE TO GIVE TO A QUESTION, PLEASE GIVE THE NEAREST MOST APPROPRIATE RESPONSE. PLEASE KEEP IN MIND YOUR STANDARDS, HOPES, PLEASURES AND CONCERNS. **THINK ABOUT YOUR LIFE IN THE LAST TWO WEEKS.** YOU SHOULD CIRCLE THE NUMBER THAT BEST FITS YOUR RESPONSE.

1.1.1.1. PHYSICAL DOMAIN (I,III) TO BE FILLED IN BY INVESTIGATOR

I	BEST MOTOR POWER IN THE DEXTEROUS HAND OR UPPER LIMB	0 NIL	1 FLICKER	2 GRAVITY ELIMINATED	3 AGAINST GRAVITY	4 AGAINST RESIST	5 NORMAL
IIa	BEST MOTOR POWER IN AFFECTED UPPER LIMB	0	1	2	3	4	5
IIb	BEST MOTOR POWER IN AFFECTED LOWER LIMB	0	1	2	3	4	5
III.	SPEECH DEFECT (APHASIA)	NIL. 0	PRESENT. 1				
IV.	MOBILITY	BED BOUND 1		CHAIR BOUND 2	WALKS WITH HELPERS 3	WALKS WITH AIDS FRAME / TRIPOD 4	WALKS UNAIDED 5
		NOT AT ALL 1		A LITTLE 2	A MOD. AMOUNT 3	VERY MUCH 4	EXTERMELY 5
V	TO WHAT EXTENT DO YOU HAVE DIFFICULTY GRIPPING OBJECTS, TURNING DOOR KNOBS, USING CUTLERY, WRITING, OPENING JARS / CANS, CARRY HEAVY OBJECTS?	0	1	2	3	4	
VI	TO WHAT EXTENT DO YOU HAVE DIFFICULTY CONTROLLING YOUR BOWL AND BLADDER?	0	1	2	3	4	
VII	TO WHAT EXTENT DO YOU HAVE DIFFICULTIES SITTING - STANDING WITH OUT LOSING YOUR BALANCE?	0	1	2	3	4	

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VIII	TO WHAT EXTENT DO YOU SEE OBJECTS OFF TO ONE SIDE / REACHING FOR OBJECTS BECAUSE OF EYESIGHT?	0	1	2	3	4
IX	TO WHAT EXTENT DO YOU THINK PHYSICAL PAIN, DISCOMFORT / SENSATION PREVENTS YOU FROM DOING WHAT YOU NEED TO?	0	1	2	3	4
X	HOW MUCH DO YOU NEED MEDICAL TREATMENT DRUGS OR AIDS / AND OR HOSPITAL ATTENDANCE TO FUNCTION IN YOUR DAILY LIFE	0	1	2	3	4
XI	TO WHAT EXTENT HAS YOUR SEX LIFE BEEN ADVERSLY AFFECTED?	0	1	2	3	4
		VERY DISATISFIED 1	DISATISFIED 2	NEITHER SATISFIED OR DISSATISFIED 3	SATISFIED 4	VERY SATISFIED 5
XII	HOW SATISFIED ARE YOU WITH YOUR ABILITY TO PERFORM YOUR DAILY LIVING ACTIVITIES (FEEDING, BATHING, TOILETING, DRESSING AND GROOMING, ETC?)	1	2	3	4	5
XIII	HOW SATISFIED ARE YOU WITH YOUR CAPACITY FOR WORK ?	1	2	3	4	5
XIV	HOW SATISFIED ARE YOU WITH YOUR LOVE LIFE?	1	2	3	4	5
XV	HOW IMPORTANT TO YOU ARE THE ASPECTS COVERED IN SECTIONS IV-XIV	NOT AT ALL 1	A LITTLE 2	MODERATELY 3	VERY MUCH 4	EXTREMELY 5

1.1.1. 2	EMOTIONAL / PSYCHOLOGICAL DOMAIN	NOT AT ALL / NEVER 1	A LITTLE / SELDOM 2	MODERATELY / QUITE OFTEN 3	MOSTLY / VERY OFTEN 4	COMPLETELY ALWAYS 5
I	HOW OFTEN DO YOU HAVE NEGATIVE FEELING SUCH AS, ANGER, DISPEAR, DEPRESSION AND FEAR?	1	2	3	4	5
II	DO YOU HAVE ENOUGH ENERGY FOR EVERY DAY LIFE?	1	2	3	4	5
III	TO WHAT EXTENT ARE YOU ABLE TO ACCEPT YOUR BODILY APPERANCE?	1	2	3	4	5
IV	TO WHAT EXTENT DO YOU ENJOY YOUR WORK?	1	2	3	4	5
V	HOW OFTEN DO YOU LAUGH?	1	2	3	4	5
VI	TO WHAT EXTENT DO YOU ENJOY LEISURE, RECREATION, REST AND RELAXATION?	1	2	3	4	5
VII	HOW SAFE DO YOU FEEL IN YOUR DAILY LIFE?	1	2	3	4	5

APPENDIX 1

VIII	TO WHAT EXTENT HAVE YOU EVER FELT DEATH TO BE BETTER THAN YOUR CONDITION?	1	2	3	4	5
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IX	TO WHAT EXTENT HAVE YOU EVER FELT LIKE ENDING YOUR LIFE?					
		VERY SATISFIED 1	DISSATISFIED 2	NEITHER SATISFIED NOR DISSATISFIED 3	SATISFIED 4	VERY SATISFIED 5
X	HOW SATISFIED ARE YOU WITH YOUR SLEEP? (DURATION AND QUALITY)	1	2	3	4	5
XI	HOW SATISFIED ARE YOU WITH YOUR FEELINGS?	1	2	3	4	5
XII	HOW IMPORTANT TO YOU ARE QUESTIONS I-XI IN THIS SECTION?	NOT AT ALL 1	A LITTLE 2	MODERATELY 3	VERY MUCH 4	EXTREMELY 5

1.1.2	INTELLECTUAL / COGNITIVE DOMAIN	NOT AT ALL 1	A LITTLE 2	MODERATELY 3	VERY MUCH MOSTLY 4	EXTREME / COMPLETELY 5
I	HOW WELL ARE YOU ABLE TO CONCENTRATE?	1	2	3	4	5
II	TO WHAT EXTENT IS YOUR MEMORY IMPAIRED?	1	2	3	4	5
III	TO WHAT EXTENT ARE YOU ABLE TO LEARN NEW THINGS?	1	2	3	4	5
IV	TO WHAT EXTENT DO YOU UNDERSTAND YOUR DISEASE PROCESS?	1	2	3	4	5
V	TO WHAT EXTENT ARE YOU ABLE TO THINK OUT /PLAN PROBLEMS LOGICALLY AND TAKE DECISIONS?	1	2	3	4	5
VI	TO WHAT EXTENT ARE YOU ABLE TO RELAX YOUR MIND?	1	2	3	4	5
VII	HOW AVAILABLE TO YOU IS THE INFORMATION THAT YOU NEED FOR YOUR DAY TO DAY LIFE?	1	2	3	4	5
VIII	TO WHAT EXTENT ARE YOU ABLE TO COMMUNICATE?	1	2	3	4	5
		VERY DISSATISFIED 1	DISSATISFIED 2	NEITHER SATIS. NOR DIS SATISFIED 3	SATISFIED 4	VERY SATISFIED 5
IX	HOW SATISFIED ARE YOU WITH YOUR MEMORY AND ABILITY TO CONCENTRATE?	1	2	3	4	5

X	HOW SATISFIED ARE YOU WITH YOUR ABILITY TO COMMUNICATE?	1	2	3	4	5
XI	HOW SATISFIED ARE YOU WITH YOUR ABILITY TO THINK AND LEARN?	1	2	3	4	5
XII	HOW IMPORTANT TO YOU ARE THE ASPECTS OF YOUR LIFE COVERED IN I-XI IN THIS SECTION?	NOT AT ALL 1	A LITTLE 2	MODERATELY 3	VERY MUCH 4	EXTREMELY 5

1.2.1.	SOUL DOMAIN	NOT AT ALL 1	A LITTLE 2	MODERATELY 3	VERY MUCH 4	EXTREMELY 5
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APPENDIX 1

I	HOW MUCH DO YOU VALUE YOURSELF?	1	2	3	4	5
II	HOW MUCH CONFIDENCE DO YOU HAVE IN YOURSELF?	1	2	3	4	5
III	HOW MUCH CONFIDENCE DO YOU HAVE IN YOUR GOD?	1	2	3	4	5
IV	HOW CREATIVE ARE YOU?	1	2	3	4	5
V	TO WHAT EXTENT ARE YOU INDEPENDENT IN REASONING AND TAKING DECISIONS?	1	2	3	4	5
VI	TO WHAT EXTENT DO YOU BELIEVE YOU HAVE A PURPOSE IN LIVING?	1	2	3	4	5
VII	TO WHAT EXTENT ARE YOU INTERESTED IN FULFILING YOUR PURPOSE FOR LIVING?	1	2	3	4	5
VIII	TO WHAT EXTENT DO YOU ACCEPT OR BELIEVE IN DESTINY / PREDESTINATION?	1	2	3	4	5
IX	TO WHAT EXTENT DO YOU BELIEVE IN FREE WILL?	1	2	3	4	5
X	TO WHAT EXTENT DO YOU THINK YOUR PRESENT CONDITION HAS PREVENTED YOU FROM FULFILLING YOUR PURPOSE IN LIFE?	1	2	3	4	5
XI	TO WHAT EXTENT DO YOU THINK THAT YOUR PRESENT CONDITION HAS ASSISTED YOU IN FULFILING YOUR PURPOSE IN LIFE?	1	2	3	4	5
XII	TO WHAT EXTENT HAS YOUR DREAMS AND VISIONS (IF ANY) PROTRAYED YOUR PRESENT CONDITION BAD?	1	2	3	4	5
XIII	TO WHAT EXTENT ARE YOU INTRUSIVE / INSPIRED ?	1	2	3	4	5

XIV	TO WHAT EXTENT DO YOU RELY ON GOD TO SOLVE YOUR PROBLEMS?	1	2	3	4	5
XV	TO WHAT EXTENT DO YOU RELY ON YOURSELF TO SOLVE YOUR PROBLEMS?	1	2	3	4	5
XVI	TO WHAT EXTENT DO YOU BELIEVE THE DEVIL IS RESPONSIBLE FOR YOUR PRESENT SITUATION?	1	2	3	4	5
XVII	TO WHAT EXTENT ARE YOU OR OTHER PEOPLE RESPONSIBLE FOR YOUR SITUATION MORE THAN GOD?	1	2	3	4	5
XVIII	TO WHAT EXTENT DO YOU BELIEVE IN AFTER LIFE?	1	2	3	4	5
XIX	TO WHAT EXTENT DO YOU BELIEVE IN GOD?	1	2	3	4	5
XX	TO WHAT EXTENT DO YOU PRACTICE YOUR RELIGION / FAITH?	1	2	3	4	5
XXII	HOW STRONG IS YOUR WILL TO LIVE?					
		VERY DISSATISFIED	DISSATISFIED	NEITHER SATISFIED OR DISSATISFIED	SATISFIED	VERY SATISFIED
		1	2	3	4	5
XXIII	TO WHAT EXTENT ARE YOU SATISFIED WITH YOUR FAITH IN GOD?	1	2	3	4	5
XXIV	HOW SATISFIED ARE YOU WITH YOURSELF?	1	2	3	4	5
XXV	HOW SATISFIED ARE YOU WITH YOUR ABILITIES?	1	2	3	4	5
XXVI	HOW IMPORTANT TO YOU ARE THE ASPECTS OF YOUR LIFE COVERED IN QUESTIONS I-XXV IN THIS SECTION?	1	2	3	4	5

APPENDIX 1

1.2.2	SPIRIT DOMAIN	NOT AT ALL 1	A LITTLE 2	MODERATELY 3	VERY MUCH 4	EXTREMELY 5
I	TO WHAT EXTENT DO YOU UNDERSTAND GOD?	1	2	3	4	5
II	TO WHAT EXTENT ARE YOU GUIDED AND MOTIVATED BY GOD IN YOUR DAILY LIFE?	1	2	3	4	5
III	TO WHAT EXTENT DO YOU UNDERSTAND YOUR RELIGION AND FAITH?	1	2	3	4	5
VI	TO WHAT EXTENT DO YOU FEEL GOD IS RESPONSIBLE FOR YOUR PRESENT STATE?	1	2	3	4	5
V	TO WHAT EXTENT DO YOU PERCEIVE YOUR LIFE BEING MEANINGFUL?	1	2	3	4	5
		VERY DISSATISFIED 1	DISSATISFIED 2	NEITHER SATISFIED NOR DISSATISFIED 3	SATISFIED 4	VERY SATISFIED 5
VI	TO WHAT EXTENT ARE YOU SATISFIED WITH DIVINE GUIDANCE IN YOUR LIFE?	1	2	3	4	5
VII	HOW IMPORTANT TO YOU ARE THE ASPECTS OF YOUR LIFE COVERED IN QUESTIONS I-VI IN THIS SECTION?	1	2	3	4	5

2.1	ECOSOCIAL DOMAIN / ADL'S	FULLY DEPENDENT 1	REQUIRES SUBSTANTIAL HELP 2	REQUIRES MIN. HELP 3	REQUIRES NO HELP / BUT NOT BACK TO WORK 4	BACK TO WORK 5
I	ACTIVITIES OF DAILY LIVING (FEEDING, BATHING AND TOILETING)	1	2	3	4	5
		NOT AT ALL 1	A LITTLE 2	MODERATELY 3	VERY MUCH 4	EXTREMELY COMPLETELY 5

II	HOW EASY IS IT FOR YOU TO COMMUNICATE WITH PEOPLE?	1	2	3	4	5
III	HOW MUCH SUPPORT DO YOU GET FROM YOUR RELATIONS?	1	2	3	4	5
IV	HOW MUCH RESPECT DO YOU EXPECT FROM OTHERS?	1	2	3	4	5
V	HOW MUCH RESPECT DO YOU GET FROM OTHERS?	1	2	3	4	5
VI	HOW MUCH SUPPORT DO YOU GET FROM YOUR FRIENDS?	1	2	3	4	5
VII	TO WHAT EXTENT ARE YOU COMPELLED BY OTHERS TO DO WHAT YOU DO NOT CONSIDER SUITABLE FOR YOU?	1	2	3	4	5
VIII	HOW WELL ARE YOU ABLE TO MEET YOUR FINANCIAL NEEDS?	1	2	3	4	5
IX	HOW SURPLUS IS YOUR FINANCIAL RESOURCES?	1	2	3	4	5
X	TO WHAT EXTENT DO YOU HAVE ACCESS TO OPTIMAL HEALTH SERVICES?	1	2	3	4	5
XI	TO WHAT EXTENT DO YOU HAVE ACCESS TO SOCIAL SUPPORT?	1	2	3	4	5
XII	HOW WELL ARE YOU ABLE TO MANAGE YOUR HOME AND PERFORM YOUR DOMESTIC ROLES?	1	2	3	4	5
XIII	TO WHAT EXTENT ARE YOU PERFORMING YOUR OCCUPATIONAL DUTIES?	1	2	3	4	5
XIV	HOW HEALTHY IS YOUR PHYSICAL ENVIRONMENT?	1	2	3	4	5
XV	TO WHAT EXTENT DO YOU HAVE ACCESS TO TRANSPORT FACILITIES?	1	2	3	4	5
XVI	TO WHAT EXTENT DO YOU HAVE OPPORTUNITIES TO LEARN AND ACQUIRE NEW SKILLS?	1	2	3	4	5

APPENDIX 1

		VERY DISSATISFIED 1	DISSATISFIED 2	NEITHER DISSATISFIED OR SATISFIED 3	SATISFIED 4	VERY SATISFIED 5
XVII	HOW SATISFIED ARE YOU WITH YOUR PERSONAL RELATIONSHIPS?	1	2	3	4	5
XVIII	HOW SATISFIED ARE YOU WITH THE SUPPORT YOU GET FROM YOUR FRIENDS?	1	2	3	4	5
XIX	HOW SATISFIED ARE YOU WITH THE CONDITION OF YOUR LIVING PLACE?	1	2	3	4	5
XX	HOW SATISFIED ARE YOU WITH ACCESS TO HEALTH SERVICES?	1	2	3	4	5
XXI	HOW SATISFIED ARE YOU WITH YOUR TREATMENT?	1	2	3	4	5
XXII	HOW SATISFIED ARE YOU WITH YOUR ACCESS TO TRANSPORT?	1	2	3	4	5
XXIII	HOW IMPORTANT TO YOU ARE THE ASPECTS OF YOUR LIFE COVERED IN QUESTIONS I-XXII IN THIS SECTION?	NOT AT ALL 1	A LITTLE 2	MODERATELY 3	VERY MUCH 4	EXTREMELY 5

2.2	SPIRITUAL INTERACTION DOMAIN	NOT AT ALL 1	A LITTLE 2	MODERATELY 3	VERY MUCH 4	EXTREMELY 5
I	TO WHAT EXTENT DO YOU CONSIDER YOURSELF CLOSE TO GOD?	1	2	3	4	5
II	TO WHAT EXTENT DO YOU STUDY OR REVIEW RELIGIOUS BOOKS?	1	2	3	4	5
III	TO WHAT EXTENT DO YOU DISCUSS ASPECTS OF YOUR FAITH / RELIGION WITH OTHERS OF THE SAME RELIGION OR FAITH?	1	2	3	4	5

DID SOMEONE HELP YOU IN FILLING THIS FORM -

INTERVIEWER - 1 . PROXY - 2 . NOBODY - 3

HOW LONG DID IT TAKE TO FILL THIS FORM OUT

DO YOU HAVE ANY COMMENTS ABOUT THIS QUESTIONNAIRE

COULD YOU PLEASE STATE ANY IMPORTANT ASPECT OF YOUR LIFE THAT HAS NOT BEEN ASSESSED.....

THANK YOU FOR YOUR PARTICIPATION IN THIS QUESTIONNAIRE

FULL NAME OF PARTICIPANT -

DOB -

EMAIL -

MOBILE NUMBER -

Appendix 2: UEL Ethics Committee approval



Dear Gloria

Application ID: ETH1819-0012

Project title: Research Question - What is the prevalence of stroke in the Awka community in Nigeria and how disability following a stroke impacts on the quality of lives of these survivors?

Lead researcher: Ms Gloria Adigwe

Your application to Research, Research Degrees and Ethics Sub-Committee meeting was considered on the 23rd of May 2019.

The decision is: **Approved**

The Committee's response is based on the protocol described in the application form and supporting documentation.

Your project has received ethical approval for 2 years from the approval date.

If you have any questions regarding this application please contact the Research, Research Degrees and Ethics Sub-Committee.

Approval has been given for the submitted application only and the research must be conducted accordingly.

Should you wish to make any changes in connection with this research project you must complete ['An application for approval of an amendment to an existing application'](#).

The approval of the proposed research applies to the following research site.

Research site: Nigeria

Principal Investigator / Local Collaborator: Ms Gloria Adigwe

Approval is given on the understanding that the [UEL Code of Practice for Research and the Code of Practice for Research Ethics](#) is adhered to.□□

Any adverse events or reactions that occur in connection with this research project should be reported using the University's form for [Reporting an Adverse/Serious Adverse Event/Reaction](#).

The University will periodically audit a random sample of approved applications for ethical approval, to ensure that the research projects are conducted in compliance with the consent given by the Research Ethics Committee and to the highest standards of rigour and integrity.

Please note, it is your responsibility to retain this letter for your records.

With the Committee's best wishes for the success of the project

Yours sincerely

Fernanda Silva

Research, Research Degrees and Ethics Sub-Committee

Docklands Campus
University Way
London E16 2RD

Stratford Campus
Water Lane
London E15 4LZ

University Square Stratford
Salway Road
London E15 1NF

+44 (0)20 8223 3000
srm@uel.ac.uk
uel.ac.uk



Appendix 3: Ethics approval Nigerian Institutions

**CHUKWUEMEKA ODUMEGWU OJUKWU
UNIVERSITY TEACHING HOSPITAL, AMAKU
AWKA**

(Formerly Anambra State University Teaching Hospital)
PMB 5022 AWKA, ANAMBRA STATE, NIGERIA

Dr. Clement Idigo *BALBCH (Nig)*
Chairman, COOUTH Management Board

Dr. Emmanuel C. Azuike
MB.BS, MPH, FWACP, FMCPH
Deputy Chairman Medical Advisory Committee



Dr. Basil E. Nwankwo *JP, KSM, MB.BS, FWACS*
Chief Medical Director

Dr. Ifeanyichukwu U. Ezebialu
MB.BS, FWACS, FMCOG, Cert. SRHR
Ag. Chairman Medical Advisory Committee

Our Ref: COOUTH/CMAC/ETH.C/VOI.1/0069 Date: 08/5/2019

To whom it may concern

ETHICAL CLEARANCE

**TOPIC: A COMMUNITY BASED STUDY OF STROKE SURVIVORS IN
A SEMI-URBAN COMMUNITY IN EASTERN NIGERIA
USING A MIXED METHODOLOGY**

BY: GLORIA ADIGWE

FOR: THE AWARD OF PhD

The above named research proposal has been reviewed and approved by the Ethical Committee COOUTH Amaku, Awka.

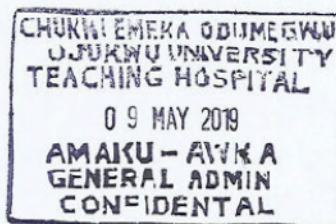
Yours faithfully,

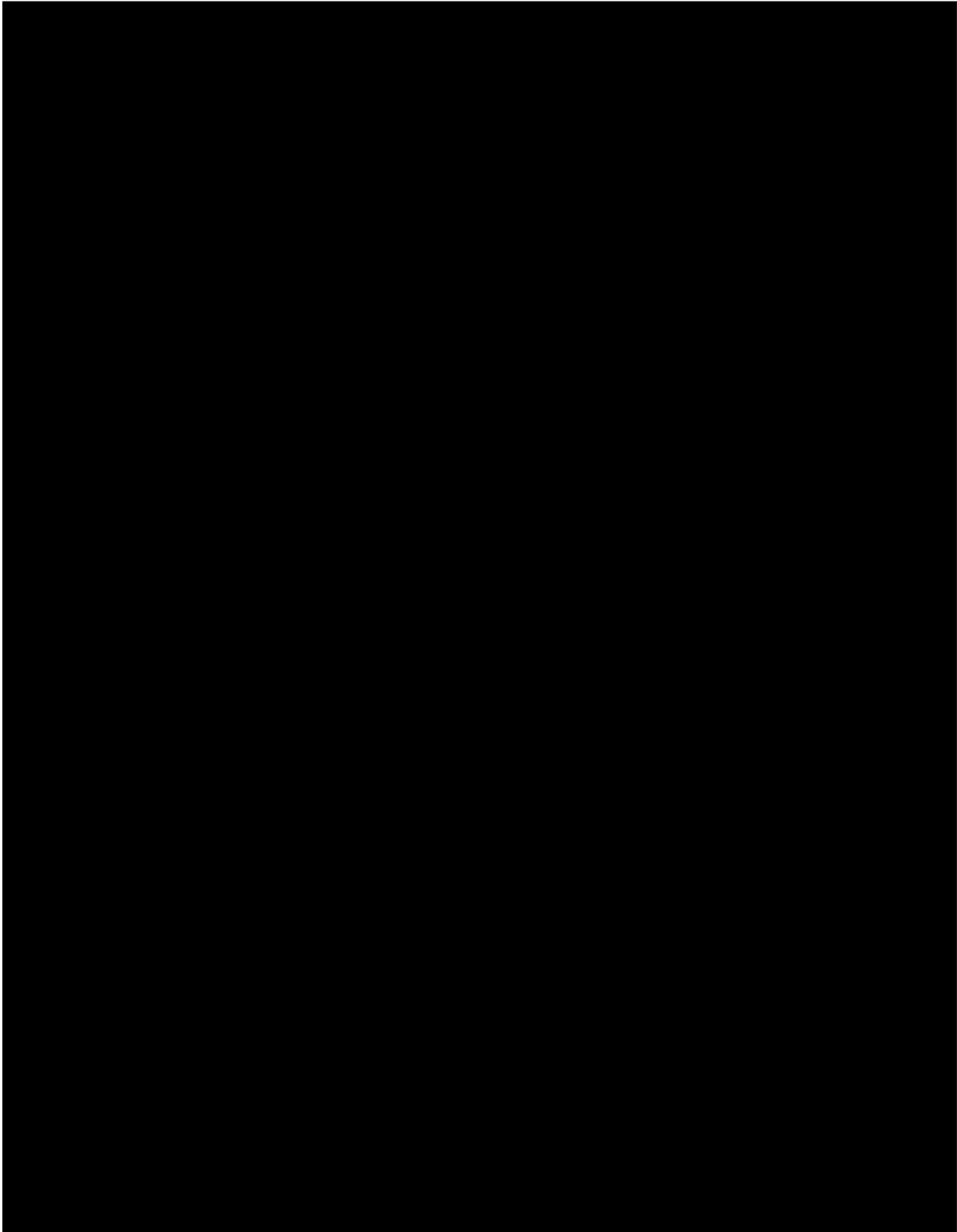


Azuike

(MBBS, MPH, FMCPH, FWACP)

Chairman Ethical Committee





The Stroke Action Nigeria Onitsha Anambra state
Chukwuemeka O O University Teaching Hospital
Nnamdi University Teaching Hospital Nnewi

Appendix 4: Letter of information to participants / Information sheet



UNIVERSITY OF EAST LONDON

University Research Ethics Committee (UREC)

Applications for the Approval of Experimental
Programmes Involving Human Participants

Notes for the Guidance of Applicants

Information to Participants and Forms of Consent and Undertaking: A Model

1. Introduction

- 1.1. The following models are intended to assist you in drawing up a hand-out for the information of participants and a form of consent and undertaking. It is not possible to provide a pro-forma which would be appropriate for all eventualities. It is designed to provide a check-list of points to help you to ensure that you have included what should be included.
- 1.2. You should read carefully the notes for the guidance of applicants to ensure that you prepare forms which are relevant to your participant group. For example, the form of consent required from adults is different to that which is required from children who are not old enough to give consent in their own right, but require the consent of a parent or guardian on their behalf.

2. Information to prospective participants

- 2.1. **Annexe 1** sets out the information which should be included in the hand-outs which you prepare for the information of prospective **participants**. You should use the model as a checklist to ensure that you have included all that is relevant. The points highlighted under the heading 'Project Description' may be not appropriate in all cases nor will all programmes involve remuneration, but it would be unusual for any of the other points highlighted not to be included.

3. Form of consent to participate

- 3.1. **Annexe 2** provides a model form of consent. In the case of experimental programmes involving minors consent is obtained from the parent or guardian on behalf of the child, so the wording should be amended to reflect this.

- 3.2. The model does not provide for the form to be witnessed by a person other than the principal investigator. In most cases the witnessing of the form by an independent third party would not be considered necessary, but in experiments involving some physical exertion or examination (most notably in clinically-related programmes of research) it may be prudent to make provision for the form to be witnessed by a third party.
- 3.3. If participant groups are composed of people who could be considered particularly vulnerable, such as the visually impaired or the elderly and infirm, consideration should be given to whether provision should be made to have the form witnessed by a third party to whom the purpose of the programme has also been explained and who is competent to explain what is required to the participant and ensure that their interests have been protected.

Please do not include these guidance notes with your submission.



Annexe 1
University of East London
[relevant campus address]

Research Integrity

The University adheres to its responsibility to promote and support the highest standard of rigour and integrity in all aspects of research; observing the appropriate ethical, legal and professional frameworks.

The University is committed to preserving your dignity, rights, safety and well-being and as such it is a mandatory requirement of the University that formal ethical approval, from the appropriate Research Ethics Committee, is granted before research with human participants or human data commences.

The Principal Investigator/Director of Studies

[Name(s)]
[Contact Address(es)]
[UEL telephone/email]

Student researcher

[Name(s)]
[Contact Address(es)]
[UEL telephone/email]

[Provide names of any external contractors or partner institutions involved in the research]

[Provide names of any funding bodies or research councils supporting the research]

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study.

Project Title

[full title of the programme]

Project Description

[description of the lay language including aims and objectives]
[explanation of the contribution of the contribution required as participants]

[explanation of what the participants will be asked to do e.g. description of experiments, focus groups, interviews, questionnaires etc]

[description of any hazard or risk]

[description of any likely after-effects, discomfort or distress which might be experienced]

[description of any after-care which might be required]

[For research involving under 16s or vulnerable groups, where true, a statement has been included on all information sheets that the investigators have passed appropriate Disclosure and Barring Service checks]

[A clear statement that where participants are in a dependent relationship with any of the researchers that participation in the research will have no impact on assessment / treatment / service-use or support]

[in the case of patients or participants undergoing treatment explain whether the programme forms of part of their treatment and whether or not any benefit is to be gained from their participation]

Confidentiality of the Data

[If the sample size is small, advice to participants that this may have implications for confidentiality / anonymity]

[If the research involves focus groups this may have implications for confidentiality / anonymity]

[A clear statement that, where possible, participants' confidentiality will be maintained unless a disclosure is made that indicates that the participant or someone else is at serious risk of harm. Such disclosures may be reported to the relevant authority]

[description of how the data will be stored and what steps will be taken to protect its confidentiality]

[explanation of what will happen to the data once the programme has been completed]

[A statement that the data generated in the course of the research will be retained in accordance with the University's Data Protection Policy]

Location

[description of the place at which the research is being carried out]

Remuneration

[give the amount, terms and conditions of any payment that will be made]

Disclaimer

Your participation in this study is entirely voluntary, and you are free to withdraw at any time during the research. Should you choose to withdraw from the programme you may do so without disadvantage to yourself and without any obligation to give a

reason. Please note that your data can be withdrawn up to the point of data analysis
– after this point it may not be possible.

University Research Ethics Committee

If you have any concerns regarding the conduct of the research in which you are
being asked to participate, please contact:

**Catherine Hitchens, Research Integrity and Ethics Manager, Graduate School,
EB 1.43**

University of East London, Docklands Campus, London E16 2RD
(Telephone: [REDACTED] Email: researchethics@uel.ac.uk)

For general enquiries about the research please contact the Principal Investigator on
the contact details at the top of this sheet.

Appendix 5: Introductory letter to participants

UNIVERSITY OF EAST LONDON



Consent to Participate in a Programme Involving the Use of Human Participants.

[Please note that where the study involves different groups of participants, or different activities, e.g. parents, staff, questionnaires, focus groups etc., a separate information sheet and consent form may be appropriate for each]

[Please note that for children under 16 an age-appropriate assent form is required, as well as parental consent]

[Full title of the programme]

[Names of researchers]

Please tick as appropriate:

	YES	NO
I have read the information leaflet relating to the above programme of research in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.		
[If participation is to be audio or video recorded, please state this and ask participants to confirm they consent]		
I understand that my involvement in this study, and particular data from this research, will remain strictly confidential as far as possible. Only the researchers involved in the study will have access to the data. <i>(Please see below)</i>		
I understand that maintaining strict confidentiality is subject to the following limitations: [If the sample size is small, or focus groups are used state that that this may have implications for confidentiality / anonymity, if applicable] [A clear statement that, where possible, participants' confidentiality will be maintained unless a disclosure is made that indicates that the participant or someone else is at serious risk of harm. Such disclosures may be reported to the relevant authority]		
[Specify if anonymized quotes will be used in publications]		
[Specify if participant has the option to be named in publications]		

October 2017



[Give proposed method(s) of publication dissemination of research findings]		
[If applicable, obtain participants' permission to use the data in future research by your team]		
[If applicable, obtain participants' permission to be contacted for future research studies by your team]		
It has been explained to me what will happen once the programme has been completed.		
I understand that my participation in this study is entirely voluntary, and I am free to withdraw at any time during the research without disadvantage to myself and without being obliged to give any reason. I understand that my data can be withdrawn up to the point of data analysis and that after this point it may not be possible.		
I hereby freely and fully consent to participate in the study which has been fully explained to me and for the information obtained to be used in relevant research publications.		

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Investigator's Name (BLOCK CAPITALS)

.....

Investigator's Signature

.....

Date:

October 2017

Appendix 6: Coding data



UEL Data Management Plan: Full

Completed plans **must** be sent to researchdata@uel.ac.uk for review

If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	Gloria Adigwe
PI/Researcher ID (e.g. ORCID)	0000-0002-6336-0375
PI/Researcher email	U9603469@uel.ac.uk
Research Title	A community-based study of stroke survivors in a semi – urban community in South East (SE) Nigeria using a mixed methodology.
Project ID	ETH1819-0012
Research Duration	September 2017-2023
Research Description	<p><u>Research Question</u></p> <p>What is the impact of stroke on the quality of life of stroke survivors in the SE Communities of Nigeria?</p> <p><u>Aims of the Research</u></p> <p>The two specific aims for the research study are -</p> <p>Aim One - Is to determine the impact of stroke on the quality of life of survivors in the SE community of Nigeria. For the purpose of the study this will be measured using the instrument Health related quality of life in stroke patients (HRQOLISP). The HRQOLISP</p>

	<p>encompasses two dimensions and seven domains. The physical domain includes physical, psychological, cognitive / intellectual and eco- social / active daily living (ADL's) domains, while the spiritual dimension comprises soul, spirit and spiritual interaction domains.</p> <p>Aim Two- The researcher intends to carry out ten semi-structured interviews to gain deeper knowledge and understanding of the perceptions of the stroke survivors from the patients perspective. This will aid in capturing the individual's perception in detail concerning their quality of life. It is believed that this method will also uncover attitudes and behaviours, trends in thought and opinions of the participants, giving further insight into the problem (Onwuegbuzie et al, 2009).</p> <p>1. - Is to determine the impact of stroke on the quality of life of survivors in the SE community.</p> <p>2. Explore perceptions, knowledge, attitudes, and cultural approaches with respect to stroke survivors in the SE community.</p> <p>In summary – The study aims to determine the impact of stroke on the QOL of stroke survivors in the SE community of Nigeria. The tool used in this study (Health related quality of life in stroke patients – HRQOLISP).</p>
Funder	Self Funding
Grant Reference Number (Post-award)	
Date of first version (of DMP)	19 th August 2019
Date of last update (of DMP)	30 th October 2019
Related Policies	e.g. Research Data Management Policy
Does this research follow on from previous research? If so, provide details	N/A
Data Collection	

<p>What data will you collect or create?</p>	<p>Data that will be collected will be in two phases.</p> <p>I will avoid collecting personal identifying data. Data will be anonymise immediately with codes such as: for example, year of birth instead of full date of birth. Anonymised data will present in the form of ages and range of ages. The participants will be re – identified using such codes.</p> <p>Phase One – Quantitative data. Ordinal data using HRQOLISP Questionnaire 101 patients. The questionnaires will be created in word format.</p> <p>Phase Two – Qualitative data. Ten Interviews (Semi – structured interviews) Yes. The recording device is SONY IC recorder. Yes, the recording will be transcribed into word. I will perform the transcription. The recording will be transferred from the devise up on to my laptop. Mp3 file format will be created. 5 interviews were face to face but due to the covid challenges, Ethic was granted for the remaining 5 interviews to be performed online. Interview recordings will be transferred on the UEL one drive and will be deleted from the recording device after the study is completed.</p>
<p>How will the data be collected or created?</p>	<p>In the form of questionnaires and interviews –</p> <p>The questionnaires will be administered to each participant in phase one. This will be completed either by the participant or the interviewer.</p> <p>Five interviews performed face to face. The remaining 5 interviews performed online.</p> <p>The 10 participants involved in the interviews (Phase two) qualitative data, will be selected by purposeful sampling.</p>
<p>Documentation and Metadata</p>	
<p>What documentation and metadata will accompany the data?</p>	<p>Quantitative and Qualitative analysis of the data collected. The quantitative data using the HRQOLISP will be analysed using statistical tests such as unpaired t test to observe for differences. Wilcolxon signed ranked test for identifying significant differences and Multiple regression analysis for identifying the strongest predictor. The FIM instrument will be tested using the Friedman</p>

	<p>test to capture the changes in functional status. Unpaired t test to identify the significant differences between groups and domains at sublevel and Mann- Whitney test to compare items at item level. Qualitative data will be analysed using Thematic content analysis.</p> <p>This will include the process of anonymization, it will include blank information sheets and also consent forms for participants. Sample of interview guide questions, are as follows - What has your experience of stroke been like for you?</p> <ul style="list-style-type: none"> • Can you tell me your understanding of the condition stroke? • Can you explain how you've coped with this condition? • What is your understanding concerning rehabilitation? • Can you tell me what your stroke care is like now? • What are some of the things you may consider as good preventative practices? • How has this condition affected your hobbies?
Ethics and Intellectual Property	
How will you manage any ethical issues?	<p>All ethical issues will be managed according to the necessary rules and regulations concerning ethical issues guiding the University of Nigeria Nnamdi Azikiwe Awka. Patients details will be anonymized, information sheets and consent forms will be issued appropriately.</p> <p>Consent will be sought for any form of data sharing – this will be explained in full with the necessary participants.</p> <p>Ethics application has been submitted and approved by the University of Nigeria Nnamdi Azikiwe.</p> <p>As mentioned above patients information will be anonymized using age ranges which will also be coded separately. Patients safely will be adhered too and care will be taken according to the GPDR complaint.</p>

<p>How will you manage copyright and Intellectual Property Rights issues?</p>	<ul style="list-style-type: none"> • Will learn and understand the domestic and global copyright law of the Nigerian research society • All ethical issues will be managed according to the necessary rules and regulations concerning ethical issues guiding the University of Nigeria Nnamdi Azikiwe <p>Nigerian Data Protection Regulation 2019.</p> <p>Data will not be owned by the University of Nigeria Nnamdi Azikiwe.</p>
<p>Storage and Backup</p>	
<p>How will the data be stored and backed up during the research?</p>	<p>Transcripts and other data such as the empirical data generated from the quantitative phase one of the studies will be kept in a locked safe on the system in the UEL one drive (Store data) and electronic data will be securely kept in a password controlled computer system. I and my supervisory team will have access to the data which will be encrypted.</p> <p>Questionnaires will be stored in Word format. Electronically and in paper format.</p> <p>Where will consent forms be stored and in what format? They will be stored in UEL one drive (Store data) in a electronic format.</p> <p>Research will be backed up by using several secure USB's . This will be encrypted for data protection. USB's and soft ware backup systems will be put in place.</p> <p>Personal data and questionnaires will be stored in a separate location which will include the audio recordings. Data will also be stored in UEL's One Drive which is GDPR compliant and will abide by the GDPR/Data Protection regulations.</p>
<p>How will you manage access and security?</p>	<p>The researcher intends to adhere to the 7 Caldecott principles concerning data protection.</p> <p>By making sure the data is encrypted immediately when data is collected. Device must use disk encryption. Power on passwords: will have auto time out. Data will be encrypted prior to storage. Recording tape will be stored on site in fire proof safes with limited access. Myself and my supervisory team will have access to the data.</p>

	<p>As state files containing personal information should be encrypted.</p> <p>Audio-recordings will not be encrypted but will be should be transferred and backed-up on my personal system and The UEL one drive, and then deleted from the device as soon as possible.</p>
Data Sharing	
How will you share the data?	<p>Health Seminars ie (stroke society) Conferences concerning Stroke and Rehabilitation Group meeting, workshops and Hosp in-service training</p> <p>No</p> <p>Data will not be required to be shared with the University of Nigeria Nnamdi Azikwe.</p>
Are any restrictions on data sharing required?	Data will not be shared on the UEL repository as consent was not provided for this
Selection and Preservation	
Which data are of long-term value and should be retained, shared, and/or preserved?	<p>Transcripts will be kept for 5 years for future publication/research then discarded. According to the GDPR laws and regulation.</p> <p>Due to the GDPR laws and regulation, it does not specify retention periods for personal data, so the data will be kept for no longer than is necessary for the purposes for which it was processed.</p>
What is the long-term preservation plan for the data?	<p>5 years reserved retention period.</p> <p>Data will be stored on the Universities net work storage in (UEL on line one drive for Business) and copies kept on remote storage and or on encrypted portable storage with changes of passwords regularly.</p>
Responsibilities and Resources	

Who will be responsible for data management?	I and my supervisory team at UEL will be responsible for the data collected. I and my supervisory team will be responsible for deleting the data after 5 years.
What resources will you require to deliver your plan?	Audio recording and lap top
Review	NB anonymised data should be stored in a completely separate location from any personal identifying and sensitive data including any codes which could re-identify participants
	Please send your plan to researchdata@uel.ac.uk We will review within 5 working days and request further information or amendments as required before signing
Date: 30/10/2019	Reviewer name: <i>Penny Jackson</i>

Guidance

Brief information to help answer each section is below. Aim to be specific and concise.

For assistance in writing your data management plan, or with research data management more generally, please contact: researchdata@uel.ac.uk

Administrative Data

Related Policies

List any other relevant funder, institutional, departmental or group policies on data management, data sharing and data security. Some of the information you give in the remainder of the DMP will be determined by the content of other policies. If so, point/link to them here.

Carly Lightfoot
Scholarly Communications Manager

UEL Data Management Plan: Full
16.07.18

Data collection

Describe the data aspects of your research, how you will capture/generate them, the file formats you are using and why. Mention your reasons for choosing particular data standards and approaches. Note the likely volume of data to be created.

Documentation and Metadata

What metadata will be created to describe the data? Consider what other documentation is needed to enable reuse. This may include information on the methodology used to collect the data, analytical and procedural information, definitions of variables, the format and file type of the data and software used to collect and/or process the data. How will this be captured and recorded?

Ethics and Intellectual Property

Detail any ethical and privacy issues, including the consent of participants. Explain the copyright/IPR and whether there are any data licensing issues – either for data you are reusing, or your data which you will make available to others.

Storage and Backup

Give a rough idea of data volume. Say where and on what media you will store data, and how they will be backed-up. Mention security measures to protect data which are sensitive or valuable. Who will have access to the data during the project and how will this be controlled?

Data Sharing

Note who would be interested in your data, and describe how you will make them available (with any restrictions). Detail any reasons not to share, as well as embargo periods or if you want time to exploit your data for publishing.

Selection and Preservation

Consider what data are worth selecting for long-term access and preservation. Say where you intend to deposit the data, such as in UEL's data repository (data.uel.ac.uk) or a subject repository. How long should data be retained?

Appendix 7: Interview Schedule Agenda

Interview schedule Agenda

Face to Face

Day 1 – 5 of F2F Interviews	Participant 1 -5	Gender Male / Female	Process discussed / Procedure	Time
			Participant Reports to room	
			Meet with researcher and assistant	
			Open statement Introductions	
			Initial 15 mins preparation	
			Interview Questions	
			Questions and answers	
			Closing statement	

Online

Day 1-5 of Online Interviews	Participants 5-10	Gender Male / Female	Process discussed / Procedure	Time
			Participant - set up with computer. device for interview at clinic / club location	
			Initial 15 min preparation	
			Introduction's / Open statement	
			Interview Questions	
			Questions and answers	
			Closing statement	