

**HEALTH-RELATED QUALITY OF LIFE AMONG STROKE  
SURVIVORS IN KANO, NIGERIA: A MIXED-METHOD STUDY**

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## **Dedication**

This work is dedicated to the memory of my late father  
Alhaji Hamza M. Turabu (FFAN) 1945-2006

And to

The Nigerian stroke survivors for they are,

Much excluded and abnegated  
Much maligned yet little understood

May we work together to remove their barriers for life participation and unlock the  
vast potentials of people with disabilities in general

## Abstract

**Background:** Cerebrovascular accident or stroke is currently the main cause of neurological disability in Nigeria with devastating impact on the person's physical, psychological, and social functioning. Some stroke survivors are able to adapt to their disabilities while others are devastated even by a minor sequelae. In the Nigerian healthcare model, the focus is on survival only, thus overshadowing all other, broader Quality of life (QOL) issues. This study aims to determine the factors that have an impact on the quality of life of stroke survivors and to highlight why and how these individuals retain or lose their sense of wellbeing after stroke in Kano, Nigeria.

**Method:** This is a mixed-method study conducted in three phases on 233 stroke survivors in Kano, Nigeria. Phase I is the validation of the primary tools for the measurement of QOL and social support. Phase II (quantitative phase) is a longitudinal study to identify the domain specific covariates (predictors) of QOL at 6 months and 1 year after stroke. In Phase III (qualitative phase), data were collected via in-depth interviews with 15 participants with the aim to explore the factors identified in Phase II. Correlations and stepwise linear regression model were used to determine the domain specific covariates (predictors) of QOL, whilst thematic analysis using constant comparative methods aided by NVivo 9 software was used to analyse the qualitative data. Finally, an integration of the phases for an overall presentation of the health-related quality of life of these survivors was discussed.

**Results:** The 16-item Hausa (language) version of the Stroke Impact Scale (Hausa-SIS) 3.0's 8 domains (strength, hand function, mobility, activities of daily living (ADL), emotion, memory, communication and social participation) was found to be psychometrically fit and have good coverage of Quality Of Life (QOL) construct. In the final analysis, a parsimonious model was obtained with two items for each of the 8 constructs. The 11-item Hausa version of the Multidimensional Scale of Perceived Social Support (Hausa-MSPSS) was found to be reliable and acceptable for the assessment of perceived social support among stroke survivors in Nigeria. A two-factor model with Family and Friends as the two domains was found to be acceptable. Phase II results showed that among the eight dimensions of QOL, all dimensions excluding the emotional domain, showed significant improvement at 1 year after stroke. However, social support was significantly decreased from 6 months to 1 year after stroke

( $p < 0.005$ ). Linear regression showed that the factors found to be most predictive of satisfactory QOL at 6 months after stroke are being employed, enough income, presence of a caregiver, acceptance at work place, higher level of education, side of stroke, less dependency in conducting activities of daily living (Barthel Index Score), urban residency, lower degree of disability (Modified Rankin Score), and higher degree of social support. The factors “reasonable hospital treatment charges” and “perceived social support by friends” were found to be additional predictors of satisfactory QOL at 1 year after stroke. Withdrawal of support by significant others was the sole factor associated ( $p < 0.05$ ) with unsatisfactory QOL at both 6 months and at 1 year after stroke. The qualitative study revealed that in addition to the factors above, the availability and accessibility of spiritual and religious resources as well as the ability to perform sexually and other functions and the received social support helped the stroke survivors to improve the emotional domain of their QOL.

**Conclusion:** Stroke has debilitating consequences affecting many aspects of functioning and living. To improve the QOL of the stroke survivors, it is recommended that programs that focus on meeting their needs such as re-employment, religious and socio-cultural activities plus continual social and financial support should be developed and given to them as part of a holistic rehabilitation program for stroke patients and survivors.

**Keywords:** stroke survivors, quality of life, satisfaction, mixed-methods research design, Nigeria

## Abstrak

**Latar belakang:** Penyakit angin ahmar atau strok adalah antara penyebab utama ketidakupayaan neurologikal di negara Nigeria. Ketidakupayaan ini boleh mengakibatkan impak yang amat teruk kepada seseorang pesakit dari segi aspek fizikal, psikologikal dan keupayaan sosial. Ada pesakit berjaya mengadaptasi ketidakupayaan mereka tetapi ada juga yang menghadapi masaalah untuk meneruskan kehidupan walaupun ketidakupayaan yang dialaminya sedikit sahaja. Dalam perkhidmatan kesihatan di Nigeria, fokus utama masih tertumpu kepada menyelamatkan nyawa pesakit strok, dimana kualiti kehidupan pesakit tersebut selepas sembuh kurang di titikberatkan. Objektif kajian ini adalah untuk mengenalpasti faktor-faktor yang mempunyai impak keatas kualiti hidup (QOL) pesakit dan implikasi nya kepada polisi dan strategi untuk meningkatkan kualiti hidup pesakit selepas strok di Kano, Nigeria.

**Kaedah:** Ini adalah penyelidikan secara majmuk (gabungan kualitatif dan kuantitatif) yang telah dijalankan dalam 3 peringkat atau fasa yang melibat 233 pesakit selepas strok di Kano, Nigeria. Dalam Fasa 1, validasi alat-alat primer untuk mengukur QOL dan sokongan sosial telah dijalankan. Dalam Fasa II (fasa kuantitatif), satu kajian prospektif telah dijalankan untuk mengenalpasti domain yang boleh meramal/mempredik QOL pada 6 bulan dan 1 tahun selepas strok. Fasa III (fasa kualitatif) ialah penyelidikan menggunakan teknik temuduga keatas 15 pesakit strok bertujuan untuk meneroka faktor-faktor yang telah dikenal pasti dalam Fasa II. Ujian korelasi dan regresi linear telah digunakan untuk menentukan covariates khusus domain (ramalan) kualiti kehidupan (QOL), manakala analisis tematik menggunakan kaedah perbandingan dibantu dengan perisian NVivo 9 digunakan dalam analisa data kualitatif.

**Keputusan:** Soal selidik Stroke Impact Scale (Hausa-SIS) versi bahasa Hausa yang mempunyai 16 item dan 8 domain (kekuatan, fungsi tangan, pergerakan, keupayaan menjalankan aktiviti seharian (ADL), emosi, memori, komunikasi dan penyertaan sosial) didapati “psychometrically fit” dan mempunyai liputan yang menyeluruh keatas konstruk Quality Of Life (QOL). Setelah analisa tamat, satu model telah diperolehi dengan dua item per konstruk bagi setiap 8 konstruk. Malah, soal-selidek Versi Skala Hausa (11 item) untuk mengukur Persepsi Sokongan Sosial (Hausa-MSPSS) juga telah dibuktikan boleh diguna (“reliable”) untuk menilai sokongan sosial di kalangan pesakit strok di Nigeria. Model yang mengandungi dua faktor dengan Keluarga dan Kawan

sebagai dua domain utama didapati boleh digunapakai. Keputusan Fasa II menunjukkan bahawa dari lapan domain QOL, semua domain tidak termasuk domain emosi, menunjukkan peningkatan yang ketara pada satu tahun selepas strok. Manakala, sokongan sosial telah menurun dengan ketara dari 6 bulan hingga 1 tahun selepas strok ( $p < 0.005$ ). Ujian regresi linear menunjukkan faktor-faktor berikut mempunyai kaitan dengan kepuasan kualiti hidup (QOL) pada 6 bulan selepas strok ialah: mempunyai pekerjaan, pendapatan yang mencukupi, kehadiran penjaga, penerimaan di tempat kerja, tahap pendidikan yang lebih tinggi, bahagian badan yang terlibat, kurang dependasi menjalankan aktiviti kehidupan harian (Barthel Indeks Score), tahap kecacatan (Modified Rankin Score) dan kekuatan sokongan sosial. Selain daripada faktor yang telah disebut, “caj rawatan di hospital yang berpatutan” dan “sokongan sosial oleh rakan-rakan” adalah ramalan tambahan QOL yang memuaskan pada 1 tahun selepas strok. Penarikan balik sokongan oleh orang lain yang penting dalam kehidupan pesakit strok merupakan satu-satunya faktor berkaitan ( $p < 0.05$ ) QOL yang tidak memuaskan di kedua-dua 6 bulan dan pada 1 tahun selepas strok. Penyelidikan kualitatif telah menunjukkan selain dari faktor-faktor yang telah disebut diatas, kemudahan dan akses pesakit strok kepada sokongan dari aspek keagamaan dan spiritual adalah yang paling memberi kepuasan kualiti hidup selepas strok. Juga keupayaan menjalankan aktiviti seksual dan aktiviti lain serta sokongan sosial yang berterusan bolih meningkatkan kualiti hidup dalam domain ‘emosi’.

**Kesimpulan:** Strok boleh mengakibatkan kesan ke atas pelbagai aspek fungsi dan kehidupan harian. Kajian ini telah berjaya mendedahkan faktor-faktor yang boleh meningkatkan kepuasan QOL dikalangan pesakit strok yang seharusnya menepati apa yang mereka perlu. Dengan itu, disarankan agar program-program seperti program kembali kepada pekerjaan, program keagamaan dan program yang bolih meningkatkan sokongan sosial dan kewangan dikalangan pesakit-pesakit strok, dibangunkan dan dijalankan secara holistik dalam aktiviti pemulihan pesakit.

**Kata kunci:** Pesakit strok, kualiti kehidupan, kepuasan QOL, penyelidikan kaedah majmuk, Nigeria

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## List of Publications and conferences

### Publications from the theses

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2. **A. M. Hamza**, A. S. Nabilla, S. Y. Loh. (2012) Evaluation of Quality of Life among Stroke Survivors: Linguistic Validation of the Stroke Impact Scale (SIS) 3.0 in Hausa Language. *South Journal of the Nigeria Society of Physiotherapy* 20:52-59. (SCOPUS)
3. **A. M. Hamza**, A. S. Nabilla, S. Y. Loh. (2013) The Importance of Social Relationship and Support System after Stroke: A Qualitative Inquiry. *Journal of Medical Rehabilitation* 16(2): Vol. 16, No 2 (2013), Available at <http://www.njmr.org.ng> (SCOPUS)
4. **A. M. Hamza**, A. S. Nabilla, S. Y. Loh. (2013) What Improves Quality of Life-Views from Post-stroke Survivors in Kano, Nigeria. *Malaysian Journal of Public Health Medicine (MJPHM)*, Vol. 13 (Suppl 1) 2013 (SCOPUS)
5. **A. M. Hamza**, A. S. Nabilla, S. Y. Loh, N. K. Jahan. (2014) Health-Related Quality of Life among Stroke Survivors in Kano, Nigeria. *Biomed Research International* vol. 2014, Article ID 350281, 7 pages <http://dx.doi.org/10.1155/2014/350281>. (ISI)
6. **A. M. Hamza**, A. S. Nabilla, S. Y. Loh, K. Chinna (2014) Validity and reliability of the Hausa (Nigerian) version of Multidimensional Scale of Perceived Social Support (MSPSS) index. *Iranian Red Crescent Medical Journal* (Accepted for publication). (ISI)
7. **A. M. Hamza**, A. S. Nabilla, S. Y. Loh, K. Chinna (2014) Reliability and Validity of the Nigerian (Hausa) version of the Stroke Impact Scale (SIS) 3.0 index. *BioMed Research International* (Accepted for publication). (ISI)

### Conference

1. **A. M. Hamza**, A. S. Nabilla, S. Y. Loh A Qualitative Study of the Factors Influencing the Quality of Life among Stroke Survivors in Kano, Nigeria, 3<sup>rd</sup> International Public Health Conference & 20<sup>th</sup> National Public Health Colloquium 28-29 August 2013-Riverside Majestic Hotel, Kuching, Sarawak Malaysia

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## **List of symbols and abbreviations**

ADL	Activities of Daily Living
AIC	Akaike Information Criterion
AMOS	Analysis of Moment Structures
ANOVA	Analysis Of Variance
AVE	Average Variance Extracted
AVM	Arterio Venous Malformation
BDI	Beck Depression Inventory
BI	Barthel Index
BMI	Body Mass Index
CFA	Confirmatory Factor Analysis
CR	Censored Regression
CVA	Cerebro Vascular Accident
CVD	Cerebro Vascular Disease
CT	Computed Tomography
CI	Confidence Interval
DMA	Drugs Management Agency
df	Degree of freedom
DALY	Disability Adjusted Life Years
ECG	Electro Cardio Gram
HIV	Human Immunodeficiency Virus
HMB	Hospital Management Board
HRQOL	Health Related Quality of Life
IADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning

ICIDH	International Classification of Impairment, Disability and Handicap
MSPSS	Multidimensional Scale of Perceived Social Support
MRS	Modified Rankin Scale
MDG	Millennium Development Goals
NIMH	National Institute of Mental Health
PHC	Primary Health Care
QOL	Quality of Life
RMSEA	Root Mean Square Error of Approximation
SEC	Socio Economic Class
SF	Short Form
SE	Standard Error
SAH	Sub Arachnoid Haemorrhage
SIS	Stroke Impact Scale
TLI	Tucker-Lewis Index
TIA	Transient Ischemic Attack
UK	United Kingdom
US	United States
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life Group

## **Definitions of Key Research Variables**

**Stroke or Cerebrovascular Accident** -World Health Organization (WHO) state it as: “a 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”(WHO MONICA Project Investigators, 1998).

**Adult Stroke Survivors**-For this study, adult stroke survivors are defined as all individuals at 18 years of age or older who have had a stroke and has not died from it, and has returned home.

**Quality of Life (QOL)** -Defined per the World Health Organization Quality of Life Group (WHOQOL) as the “individuals understanding of their position in life related to their goals, expectations, standards, and concerns, culture and value systems in which they live” (Buck et al., 2000; WHOQOL group, 1995). QOL issue is tied to health and emphasized variables such as happiness, personal well-being, life satisfaction, and impact of illness on social, emotional, occupational, and family domains (Larson et al., 2008).

**Health-Related Quality of Life (HRQOL)** -HRQOL refers to the aspects of QOL affected by a disease (Carod-Artal et al., 2009; Larson et al., 2008; Sturm et al., 2004), or the impact of the health condition or health care intervention on the individuals’ subjective experience of their in functional, cognitive, social and psychological processes (Doyle et al., 2004; Hung et al., 2007).

**Mixed-Method Study** - Mixed-Methods are an evolving philosophical assumption of the research process (Creswell & Plano-Clark, 2011), in which a researcher combines elements of quantitative and qualitative research approaches for the purpose of breadth of understanding or corroboration (Johnson et al., 2007). This approach is particularly useful to understand the complexity of factors affecting the QOL of the stroke survivors.

## **CHAPTER ONE: INTRODUCTION**

This chapter presents the background of the study, its problem statement, rationale, scope and delimitation of the study followed by the presentation of a conceptual framework that was used to guide the study. Finally the significance and contribution of the study is discussed.

### **1.1 Introduction**

Cerebrovascular accident or stroke remains one of the global public health problems today (Carod-Artal et al., 2000; Geyh, 2007; Geyh et al., 2004; Hackett et al., 2000; Yu et al., 2013). The World Health Organization (WHO) reported that cerebrovascular accident (CVA) or stroke is a global leading cause of morbidity and mortality with negative impact on health-related quality of life (HRQOL) and it is projected to worsen in developing countries over the next two decades (Owolabi, 2008; Wahab, 2008). In the more developed countries of the world, it's the third most common cause of death after heart disease and cancer (Ogun et al., 2005; Sangkaew, 2007). However, developing countries have some of the highest stroke mortality rates in the world that account for over two-thirds of stroke deaths worldwide (Brainin et al., 2007). WHO projected that by the year 2030, low and middle income countries which currently accounted for 85.5% of stroke deaths globally will account for 80% of all strokes (O'Donnell et al., 2010; Wahab et al., 2008). Evidence in Sub-Saharan Africa indicates higher case fatality rates for stroke than those in industrialized societies (Lemogoum et al., 2005 ). The epidemiological transition contributed by the adoption of western lifestyles has impacted the burden of the disease. Stroke is currently the main cause of neurological disability in Nigeria (Ogunrin & Unuigbe, 2008; Owolabi, 2008; Wahab et al., 2008). In most tertiary hospitals in Nigeria, stroke accounted for 0.92 – 4% of

hospital admissions, 2.83 – 4.52% of total deaths and is reportedly the leading cause of neurological admissions (Njoku & Aduloju, 2004; Ogunrin & Unuigbe, 2008).

For the stroke survivors, the impact of stroke can be devastating, and unlike other slow developing disabling conditions, it has a sudden onset leaving the individual and the family ill-prepared to deal with its residual impairment of physical, psychological, and social functions (Hackett et al., 2000; Lai et al., 2003; Patel et al., 2007). But until recently, stroke research has been largely focused on survival. The notion of quality of life (QOL) among researchers studying the consequence of stroke has gained increasing popularity in health care research following the increased need to improve the quality of lives saved. Although there is no clearly approved definition of QOL, but as a construct, it has been accepted that it is a multidimensional consideration of physical, functional, psychological, and social health. The residual physical consequences are not necessarily associated with QOL (Clarke, 2003a; Clarke et al., 2002) as some individuals emerge capable to adapt to their residual disabilities and impairment in order to preserve their sense of wellbeing after stroke while, others are ravaged by minor consequence (Clarke, 2003a). Clarke (2003) further reported that there is no explicit association between the severity of functional limitations and wellbeing after stroke.

Using both quantitative and qualitative strategies, the aim of this sequential explanatory, mixed methods study was to identify the predictors of QOL and to understand the issues influencing stroke survivors' QOL in Kano state, Nigeria. A quantitative approach was designed to identify the correlates of QOL at 6 months and 12 months after stroke. Qualitative design on the other hand was undertaken in order to explain the underlying meaning and processes by which QOL is affected after stroke and highlight aspects of

the stroke experience that may not be covered or unexplained by the quantitative findings.

## **1.2 Background of the study**

Today, there is a growing number of stroke survivors due to advancement in the treatment of the disease. As a result, a large proportion of survivors are left with significant residual physical, cognitive, and psychological impairments (Clarke, 2003a; Geyh, 2007; Owolabi, 2010; Rogers & Holm, 1998). Strategies on how best to minimise stroke-related disabilities and health risks are a major concern for healthcare providers in the field of preventive medicine and rehabilitation. Efforts to prevent stroke onsets, as well as to prevent post-stroke disabilities and to maximize quality of life for stroke survivors (or people who have suffered the consequences of stroke) should be maximized (Geyh, 2007; Owolabi, 2010; Rogers & Holm, 1998). Treatment of a disease may prolong life and seems effective, but poor adaptation and poor psychological functioning contributing to ill-health, warrants that the outcome of a treatment should be carefully considered based on the quality as well as quantity of continued existence (Buck et al., 2000). It's therefore important to know the nature of that extended life (Buck et al., 2000).

It has become increasingly obvious that assessments of neurological function and disability are not sufficient to evaluate the impact of stroke on patients (Duncan, 2000).

It was eventually considered crucial to add measures of HRQOL that do not only target on stroke-related deficits or impairments, but also consider the fact that QOL is inherently an attribute of the patient's self-perception rather than a measure of various aspects of the health status (Suenkeler et al., 2002). From a rehabilitative perspective, outcomes may be measured at the levels of: (i) Body functions or structure



(impairment): problems in body function or structure as a significant deviation or loss. (ii) Activities: the execution of a task or action by an individual and (iii) Participation: the involvement in a life situation (Barak & Duncan, 2006), provides a more comprehensive assessment for therapy specialists to intervene.

The definition of QOL is still debated despite decades of research. It has been generally and collectively construed and believed to be multidimensional consisting of physical, functional, psychological, and social health (Buck et al., 2000; Carod-Artal et al., 2000; Haacke et al., 2006; Larson et al., 2008). The concept of quality of life is indicated at both the level of WHO's framework of participation and activity (Barak & Duncan, 2006). Quality of life (QOL) as defined by the World Health Organization Quality of Life Group (WHOQOL) is the individuals understanding of their position in life related to their goals, expectations, standards, and concerns, culture and value systems in which they live (Buck et al., 2000; WHOQOL group, 1995). Health related quality of life (HRQOL) on the other hand denotes the aspects of QOL affected by a disease (Carod-Artal et al., 2009; Larson et al., 2008; Sturm et al., 2004), or the impact of the health condition or health care intervention on the individuals' subjective experience of their functional, cognitive, social and psychological processes (Doyle et al., 2004; Hung et al., 2007). Quality of life (QOL) issue is tied to health and emphasize variables such as happiness, personal well-being, life satisfaction, and impact of illness on social, emotional, occupational, and family domains (Larson et al., 2008). The following section examines the various dimensions of QOL in more depth, in order to understand the qualitative needs of stroke survivors.

The physical dimension (main component) in QOL refers to the disease related symptoms (Carod-Artal et al., 2000) and depending on the presentations may include:

motor impairment, spasticity, ataxia, dysarthria, dysphagia, and pain, sleep disturbances and fatigue (Carod-Artal et al., 2009). This component is believed to be the necessary requirement of basic healthiness, or the ability to engage in activities that leads to satisfaction in health (Sangkaew, 2007). The functional dimension includes mobility and care (Carod-Artal et al., 2009) and the ability to carry out different work and family roles (Carod-Artal et al., 2000). Psychological or mental dimension is concerned with the feeling of self-satisfaction of physical and mental wellbeing, body image as well as the reaction to disease diagnosis, management and the environment (Sangkaew, 2007). It comprise aspects related to emotional and cognitive variables (e.g. post stroke depression and vascular dementia) (Carod-Artal et al., 2000). It may also include coping, mood and cognition (Carod-Artal et al., 2009) as well as subjective experience of health and life satisfaction (Carod-Artal et al., 2000). Social dimension comprises of work, social network, social and familial contacts (Carod-Artal et al., 2000; Carod-Artal et al., 2009).

Health status measures generate comparable results and are therefore used to assess the burden of a disease on a patient as well as functioning and health in the form of profile or summary scores (Geyh, 2007). Health status measures can emphasise focal areas for necessary interventions, reveal expected or unexpected changes, discriminate patient groups, can be useful to explain or predict health states, and may allow conclusions on the effectiveness, efficacy, safety or benefit of treatments (Geyh, 2007). In addition, health status measures are applied for a great variety of purposes including clinical, research, management, and policy settings (Geyh, 2007). Following stroke, health status measures might also be used for the examination and description of stroke impact, for monitoring, intervention evaluation, and quality management, surveys, for individual as well as macro level health care planning and decision making (Geyh, 2007). In the area

of research on stroke, several measures are utilised to assess the broad extent of the event's impact and outcome (Geyh, 2007; Geyh et al., 2004). Many of the current generic health-status measurement instruments obtainable are restricted in the scope to which they measure precise areas of functioning commonly impacted by stroke and may fail to grab clinically essential changes in such areas during recovery or as a result of intervention (Doyle, 2002). In addition, several of the most commonly utilised stroke outcome tools (e.g., the FIM™ instrument, Barthel Index, Rankin scale) are behavioural evaluation scales that solely target on the measurement of functioning (Doyle, 2002; Geyh, 2007; Robinson, 2007). It is only lately that all-inclusive measures of patient-reported functioning and well-being have been developed specifically to evaluate the health status of stroke survivors (Doyle, 2002; Geyh, 2007; Robinson, 2007). Their usage suggests a growing awareness and more acceptance that the patient's view or perspective is fundamental and need to be addressed by health care providers and researchers (Geyh, 2007).

Generic measures are the most commonly used measures to assess QOL in stroke, especially for comparisons across different health conditions. Yet, they also have been criticized to be defective in their application with regard to the special population of stroke survivors (Buck et al., 2000; Duncan, 2000; Geyh, 2007). To overcome these challenges, stroke-specific health status measures integrating the patients' perspective are progressively being developed (Barak & Duncan, 2006; Geyh, 2007). They are expected to play an important role in stroke measurement, as in management, epidemiological research, clinical, and drug trials. QOL assessment is needed to extensively capture stroke outcome (Barak & Duncan, 2006; Duncan, 2000; Geyh, 2007).

### **1.3 Rationale of the Study**

Considerable depth of knowledge can be gained by advancing the study of stroke experience from both philosophical perspectives (Casebeer & Verhoef, 1997; Clarke, 2003a, 2009; Curry et al., 2009; Lempp & Kingsley, 2007; Morgan, 2007; Sale et al., 2002; Shah & Corley, 2006). Most of the research on post-stroke QOL were conducted using quantitative approaches administered as survey questionnaires (Carod-Artal et al., 2009; Clarke et al., 2002; Gbiri & Akinpelu, 2012; Haacke et al., 2006; Nichols-Larsen et al., 2005b; Wyller et al., 1998), with relatively very few using the qualitative methods (Backstrom & Sundin, 2009; Curry et al., 2009; Levasseur et al., 2009; Viscogliosi et al., 2011). The implementation and development of public health programs will be greatly improved if robust data are available. While most mixed-method researches on post QOL have been conducted in developed countries, data are very scarce for developing countries. Although the quality of life of stroke survivors in Nigeria has been previously reported (Akinpelu & Gbiri, 2009; Gbiri & Akinpelu, 2012; Gbiri et al., 2010; Hamzat & Peters, 2009; Owolabi, 2008), there is currently no mixed-method research study on post stroke QOL among stroke survivors in Nigeria. Against a backdrop of epidemiological transition and substantial increase in stroke cases, it is important for developing countries like Nigeria to have valid information regarding the factors influencing stroke survivor's quality of life among its people.

### **1.4 Aim and Objectives of the study**

The aim of the study is to examine the factors influencing the quality of life and to conduct an in-depth exploration of stroke survivors in Kano, Nigeria in order to formulate effective public health education and promotion interventions strategies to improve the QOL for stroke survivors in Kano state, Nigeria.

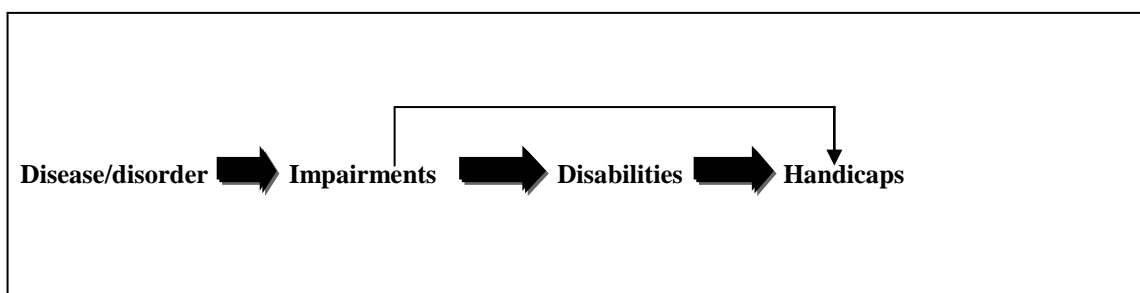
### **1.4.1 Specific objectives**

1. To validate the Hausa language version of the Stroke Impact Scale (SIS) 3.0 and Multidimensional Scale of Perceived Social Support (MSPSS) Hausa versions
2. To identify the domain specific predictors of QOL among stroke survivors at 6 months and 12 months after stroke in Kano, Nigeria
3. To estimate the impact of socio-demographic variables, functional status, level of disability, social support and mood disorders on QOL at 6 and 12 months after stroke among the Nigerian stroke survivors.
4. To explore and elucidate the complexity of factors that influence QOL so as to gain insight into the underlying processes by which QOL is maintained or lost following stroke.

### **1.5 Conceptual framework**

To explain the residual disability, QOL and functional limitations following stroke, a thorough understanding of the progression that results in impaired physical, psychological, and social functions or the disablement process is necessary. The disablement here refers to the impact of stroke as a chronic condition has on the functioning of specific body systems and on the survivor's ability to act in necessary, usual, expected and personally desired ways in their society (Verbrugge & Jette, 1994). Several conceptual models permit the understanding, assessment, measurement and treatment of stroke related disabilities. When considering outcome measurement, working with a framework or model of illness to systematise the data that might be collected is beneficial (Duncan, 2000; Verbrugge & Jette, 1994). The standard and now the generally accepted model of illness is the World Health Organization's disablement model.

A model of disease consequence proposed by the World Health Organization (WHO) known as the International Classification of Impairment, Disability and Handicap (ICIDH) (World Health Organization, 1980) (Figure 1.2) was developed in 1980 to illustrate the pathway from disease to impairments, disability and handicap. The objective was to clarify terminology and generate a model that surpasses a simple medical model with a succession from aetiology to pathology and to presentation (Johnson & Pollard, 2001).



Source: World Health Organization. International Classification of Impairments, Disabilities and Handicaps: A Manual Classification Relating to the Consequence of Diseases. Geneva. WHO 1980.

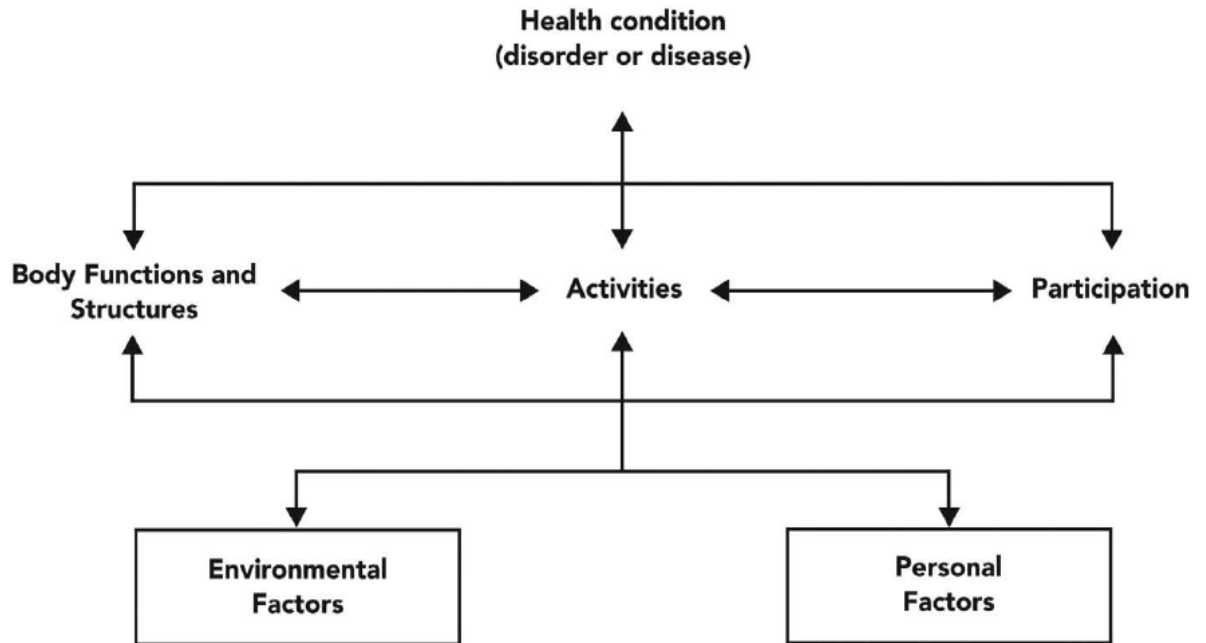
**Figure 1.1: The International Classification of Impairment, Disabilities and Handicaps (ICIDH), 1980**

The ICIDH model suggests that disability is the result of impairment, which in turn is the result of disease or disorder. Handicap results from disability or impairment. The basis of the pathway is *pathology or disease disorder*, which is defined as any abnormality of macroscopic, microscopic or biochemical structure or function affecting an organ or organ system (Ferucci et al., 2007; Verbrugge & Jette, 1994). The second stage is *impairment*, defined as any abnormality of structure or function at the whole organism level, irrespective of any definite environment, sign or symptoms (Ferucci et al., 2007; Verbrugge & Jette, 1994). The third stage is *disability*, which evolves from the interaction between the organism and the environment and is defined as restriction or lack of ability to perform activities and accomplish at the level of the individual

(Ferucci et al., 2007; Johnson & Pollard, 2001; Verbrugge & Jette, 1994). Lastly, *handicap* is defined as a disadvantage and role limitation or any alteration in an individual's status or roles in a society (Ferucci et al., 2007; Johnson & Pollard, 2001; Verbrugge & Jette, 1994). The model offered a pathway of consequence from impairment to disability or handicap or directly from impairment to handicap. Each stage of the pathway should be considered as independent and may or may not be established by the preceding stage and/or accounted for the subsequent stage. This concept evoked criticisms based on the rhetoric and on the social validity of the model (Johnson & Pollard, 2001) and for numerous arguments; it was considered to be overly medically oriented, disregarding the psychological and social dimensions, the negative implication of the term 'handicap' and it ignored environmental factors.

Hence, in 2001, the WHO released a revision of the classification called the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) (Figure 1.2). The objective of the revised classification which is based on the "biopsychosocial" model of disablement (Khan & Pallant, 2007; Robinson, 2007) is to produce a common language for interpreting functional states related to health in order to enhance the communication between the health care workers, others in the public sectors, and people with disabilities (World Health Organization, 2001); Geyh et al., 2004; Khan & Pallant, 2007; Robinson, 2007). The framework is aimed to enable a rigorous comparison of data across countries, disciplines, and services. It can also be utilized as a means for designing research, gathering data, establishing social policy, or for clinical judgement and education (World Health Organization, 2001); Geyh, 2007; Geyh et al., 2004; Khan & Pallant, 2007; Robinson, 2007). The ICF model opposed the notion that disability is an aftermath of disease or aging and focuses on human functioning as factors of health. The ICF has revised important terms, such as

“disability” has become “activity”, and “handicap” has become “participation” (World Health Organization, 2001).



Source: World Health Organization. International Classification of Functioning, Disability and Health. Geneva. WHO 2001.

**Figure 1.2: The International Classification of Functioning, Disability and Health (ICF) 2001**

The primordial conceptions within this biopsychosocial model are functioning and disability (Geyh, 2007). Functioning refers to the positive or neutral consequence of the bidirectional complex interaction between an individual with a health condition and his or her setting/context (Geyh, 2007). Disability is a comprehensive term referring to impairments of body functions and structures, activity limitations and participation restrictions. It is the negative outcome of the interaction between an individual with a health condition and his or her context (Geyh, 2007). According to ICF model, activities and participation are affected by environmental and personal factors (referred to as contextual factors within the ICF) (World Health Organization, 2001).



**Table 1.1: an overview of International Classification of Functioning, Disability and Health**

Components	<u>Part 1: Functioning and Disability</u>		<u>Part 2: Contextual Factors</u>	
	<u>Body functions and structures</u>	<u>Activities and participation</u>	<u>Environmental factors</u>	<u>Personal factors</u>
Domains	Body functions	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body functions (physiological)	Capacity: executing tasks in standard environment	Facilitating or hindering impact of features of the physical, social and attitudinal world	Impact of attributes of the person
	Change in body structure (anatomical)	Performance: executing tasks in the current environment		
Positive aspect	Functioning and structural integrity	Activities and participation	Facilitators	Not applicable
Negative aspect	Impairment	Activity limitation	Barriers/hindrances	Not applicable
		Participation restriction		

Source: World Health Organization. International Classification of Functioning, Disability and Health (ICF). Geneva. WHO 2001.

The model relates to each of the other six components of health: the health condition, body functions and structures, activity, participation, environmental factors, and personal factors. It's divided into two parts namely (Barak & Duncan, 2006; Robinson, 2007): 1) Body functions and structures; and 2) Activities and participation. Body functions and structures are the physiological functions as well as the anatomical parts of the body, i.e., organs and limbs. Activities on the other hand are the individual's execution of tasks or actions (Robinson, 2007). The second part of the ICF includes environmental and personal factors, which influence the state of an individual's health and functioning (Robinson, 2007). Environmental factors are external to the person and make up the physical, social and attitudinal environment in which people live their lives but are associated with health conditions at all levels (body structure and function,

everyday activities and participation in society) (Khan & Pallant, 2007). These factors are common to all people (disabled or not), and interrelate with the individual's health conditions in a peculiar manner to yield different disability outcomes (Khan & Pallant, 2007).

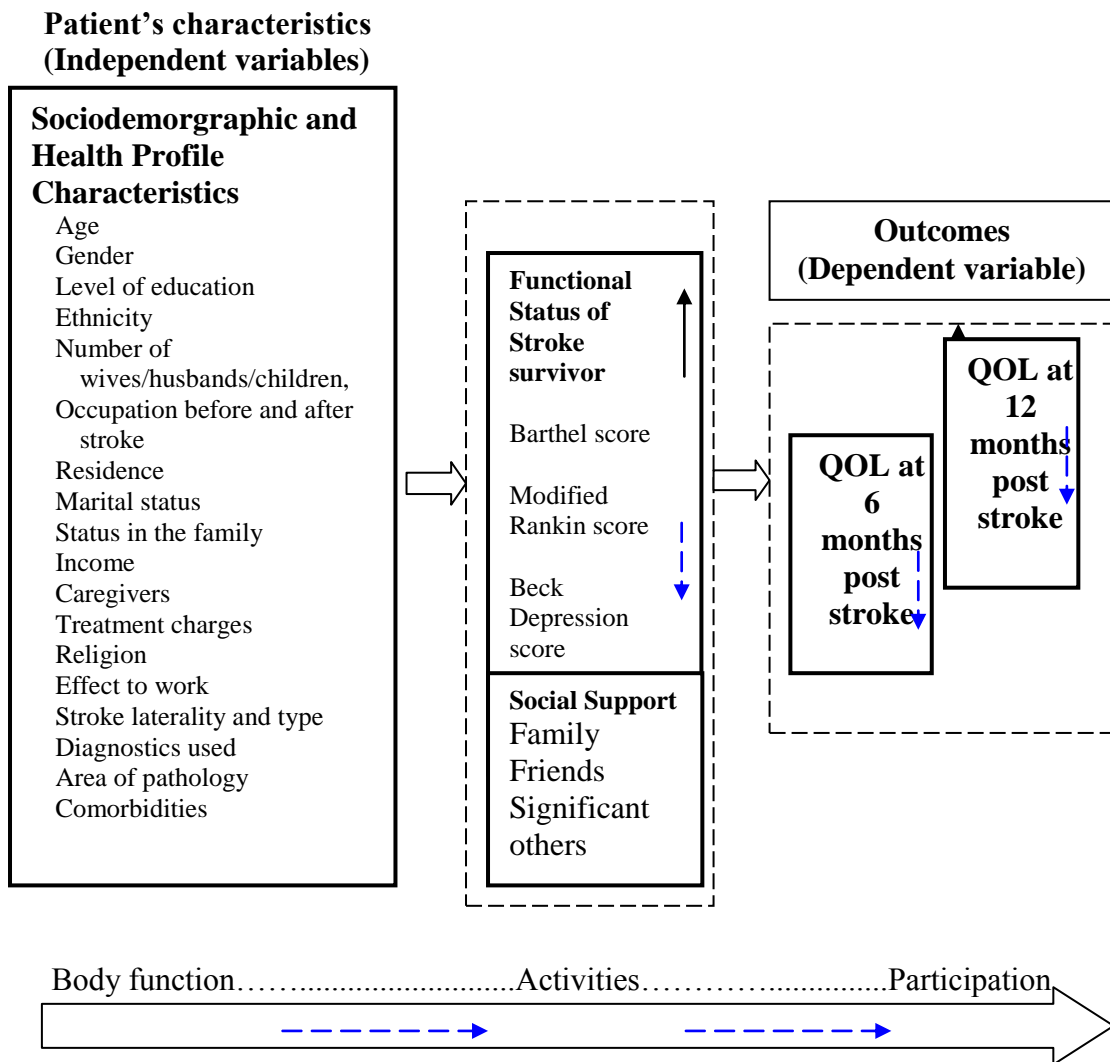
The theoretical framework that this study utilized is thus based on the ICF conceptual model which outlines the numerous inherent factors influencing the QOL of the stroke survivors. The model (see figure 1.3) delineates that the patient's characteristics (independent variables) have an influence on the QOL of the stroke survivors. The patient's characteristics as shown in the model are divided into two parts: the socio-demographic and health profile characteristics; functional status and social support.

The socio-demographic and health profile characteristics of the patients correspond to the body function of the ICF framework and have been reported to influence the QOL of the stroke survivors and include: age, sex, income gender, stroke laterality, comorbidities etc. The functional status which corresponds to the activities function of the ICF framework is shown to influence the QOL of the stroke survivors and include: mobility and self care as measured by the Barthel Index (BI), functional independence as measured by the MRS and the level of depression as measured by the Beck Depression Index (BDI). Perceived social support from family, friends and significant others also correspond to the activities function of the ICF framework and have also been reported to have an impact on the stroke survivors QOL.

Finally, in the outcomes (dependent variable) section, the QOL of the stroke survivors at 6 months and at 1 year after stroke which corresponds to the participation section of the ICF framework can be described by examining the impact of the socio-demographic

and health profile characteristics of the participants, physical, mental as well as social health and experiences on the perceived wellbeing (QOL) of the stroke survivors.

This study was designed to provide information that is not available in other studies. Many studies on the determinants of QOL and the stroke survivor's experience after stroke are either cross-sectional or follow-up studies conducted over a shorter period of time, thus lacking the ability to examine the dynamic multidimensionality of the stroke experience. By utilizing a mixed-methods study and, first by employing a longitudinal design examining data at six months and one year after stroke and subsequently followed by qualitative design, this study captured the multidimensionality of the stroke survivor's experience in addition to examining change over time. A thorough investigation of the dynamic changes in handicap in the subacute phase of stroke (from discharge at 6 months to 1 year) is needed to determine its immediate trajectory and to identify determinants that can be included in public health policy and community rehabilitation programmes.



Body function.....Activities.....Participation

**Figure 1.3: Quality of Life Measurement approach for the study**

## **1.6 Significance of the study**

Knowledge of the factors influencing the QOL among stroke survivors and perception of their wellbeing is needed, so that, healthcare professionals can better prepare stroke survivors, their caregivers and collaborate with their healthcare colleagues on how best to improve survivor's overall long-term health. As Clarke et al (2003) noted, there is no one-to-one correlation between functional limitations and QOL. The understanding of the real need (from patients' perspectives), rather than assumed need (staff's perspectives) is essentially critical for the growing number of stroke survivors (due to improved treatment outcomes and greater life expectancy). There is a dire need for more detailed information about the long-term effects from surviving a stroke, and this demands more research efforts particularly on Nigerian stroke survivors.

This study is thus important for several reasons:

Firstly, the need for a philosophical shift in stroke treatment needs to attend beyond medical treatment to reflect the need to treat not just the disease, but also the management of the late effects. Secondly, in order to formulate Nigerian-specific health policies on long-term care of the stroke survivors, it's necessary to identify and understand the determinants of QOL of survivor's perception of their wellbeing and experiences after stroke. Adopting a quantitative and qualitative mixed components study design, this extensive study may set up the foundation for knowledge about the determinants of QOL that may be used to develop and refine standards for the care of stroke survivors including how secondary risk factors can best be managed. The findings from this study will inform the developers of clinical guidelines and support the work of the healthcare professionals which will ultimately have an impact on the health and QOL of the stroke survivors.

An explanatory sequential mixed-method study was conducted in order to elicit data for an extensive and indepth understanding of the factors influencing the QOL of the stroke survivors. A longitudinal study was conducted to identify the domain specific predictors of QOL at 6 months and 1 year after stroke, followed by a phase utilizing a qualitative design to explore the reasons for the pattern observed from the quantitative findings. New insights, meaningful description, and theoretical relationships about how best stroke survivors define their QOL and what they do to manage their lives emerged from the study. This study also provides information about the support needs of stroke survivors at six months and one year after the event.

The potential implication of the research findings can be used for the development of effective health strategies aimed towards improving the quality of life of stroke survivors in Kano state, Nigeria in the following ways: 1. prioritising problems; 2. facilitating communication; 3. screening for potential problems; 4. identifying preferences; 5. monitoring change or response to treatment; 6. training new staff; 7. clinical auditing; and 8. clinical governance (Bielli et al., 2004). Following stroke, health status measures may also be used for the examination and description of stroke impact, for monitoring, intervention evaluation, and quality management, surveys, for individual as well as at the macro level of health care planning and decision making (Geyh, 2007). Information acquired from QOL studies can help in assisting the planning of rehabilitation services (Owolabi, 2008) especially in Kano which do not have stroke rehabilitation centres. Moreover, assessment and evaluation are valuable in ascertaining the patients' problems, establishing treatment priorities, administering interventions, overseeing disease period, and for health economists and planners in designing new ideas and solutions to the discovered problems (Ones, 2005).

## **1.7 Structure of the thesis**

Chapter 1 outlines the research premise through the general introduction, background for this thesis and provides the significance and the purpose of the study followed by the presentation of the conceptual framework for the study. Next, the objectives of the study are presented and finally the contribution of the study is discussed.

Chapter 2 starts with an introduction to Nigeria's health care system followed by a description of the services available for stroke patients in Nigeria. Epidemiological related stroke studies including rehabilitation are discussed in detail. Finally the measurement approach and the predictors of HRQOL (patient's factors, disease functional status and social support factors) are reviewed and discussed.

Next, chapter 3 presents the philosophical discussion, rationale for choosing mixed-methods research design and the stages for the explanatory sequential mixed-methods design.

Chapter 4 presents the findings obtained from the phase I validation of study/measuring instruments; findings from the phase II quantitative longitudinal survey to identify the domain specific predictors of QOL at 6 months and 1 year after stroke; and findings from the phase III qualitative design to explore the reasons for the observed pattern in the quantitative phase.

Chapter 5 includes a discussion on the findings and addresses the limitations and the strengths of the study. Finally, Chapter 6 concludes with a summary of the findings, recommendations arising from the study and future research directions.

## **CHAPTER TWO: LITERATURE REVIEW**

This chapter provides a detailed review of stroke epidemiology and studies on quality of life after stroke. It starts with describing the Nigeria's health care system followed by a description of the services available for stroke patients in Nigeria. Stroke studies and its epidemiology including rehabilitation are discussed in detail. Finally the predictors of HRQOL (patient's factors, disease functional status and social support factors) are reviewed and discussed.

### **2.1 Health Care System in Nigeria**

The health care services in Nigeria are provided by the three tiers of government: the Federal Government; State Governments and Local Governments. The federal government manages the university teaching hospitals, the state governments control the general hospitals and the local governments coordinate the dispensaries (Asuzu, 2004; Scott-Emuakpor, 2010). Nigeria practices a mixed-economy and so private health care delivery; individual, corporate and missionaries-based centers also contribute immensely to the health care delivery system (Federal Republic of Nigeria, 2009). The Nigerian health care system also comprises a set up of primary, secondary and tertiary health care facilities (Asuzu, 2004). Primary health care is provided by the health clinics distributed throughout the country. The secondary care is delivered by the health care and maternity centres. Tertiary care is rendered by the university teaching hospitals (Abdulraheem et al., 2012; Asuzu, 2004). Primary Health Care (PHC) which is supposed to be the foundation of the Nigeria's health care system is currently catering to less than 20% of the potential patients (Abdulraheem et al., 2012; Asuzu, 2004). Most of the Nigeria's PHC facilities are at different stages of collapse, obsolete equipments, and dilapidated infrastructure and barely non-existent referral system (Abdulraheem et al., 2012; Asuzu, 2004).



The Federal Ministry of Health in Nigeria have eight departments committed to various aspects of health care including:

1. Public Health
2. Family health
3. Hospital services
4. Human resources
5. Planning, research and statistics
6. Food and drugs services
7. Procurement
8. Finance and account

These eight departments together with other ministries, development partners and other relevant stakeholders function to develop, coordinate and implement policies and strategies with the aim of increasing the life expectancy of Nigerians, providing them with sustainable and improved health care services to improve nutritional status and to reduce maternal and infant mortality rates. Other functions include enhancing the sexual, reproductive, maternal, and neonatal and child health care (Federal Ministry of Health of Nigeria). Currently, the department of public health services supervises 23,636 health care facilities of which 62% (14,607) are public facilities and the rest (9,029) are private facilities all over the country (Federal Ministry of Health of Nigeria). Access to health care services is limited for Nigerians especially those living in rural areas. In 2006, it was reported that only 55.1% of Nigerians had access to medical services. The same report also reported that there is a geographical disparity in accessibility to medical services. Only 47.8% of the rural residents have access to medical services in comparison to the urban residents (70.9%)(Federal Ministry of Health of Nigeria).

## **Kano State**

The Kano state Ministry of Health develop, coordinate, implement and supervise national and state policies and oversee the functions of the other health facilities owned by different organizations within the state. The ministry also coordinate and control the authorities of agencies and institutions in the health sector owned by the state. The Kano state Ministry of Health is accountable for the 666 public health care facilities (637 primary health care centres and 27 secondary health care centres), 15 private health care centres and two tertiary health care centres (Federal Ministry of Health of Nigeria).

Kano state ministry of health comprises of five directorates and each of the directorate is subdivided into specialized departments and units. These are:

1. Directorate of Primary Health and Disease Control
2. Directorate of Medical and Health Care Services
3. Directorate of Administration and General Services
4. Directorate of Nursing Services
5. Directorate of Planning, Research and Statistics

Aside from the Ministry of Health, there are two semi-independent parastatals, the Hospital Management Board (HMB) and Drugs Management Agency (DMA). The HMB is accountable for the recruitment, training, remuneration, promotion, discipline of the state government-owned staff as well as the coordination, supervision of zonal hospitals management committees, purchase, renovation and rehabilitation of the hospital equipments. The HMB is headed by the Executive Secretary and has two boards of directors. Its two sub directorates include the Administration & General services and Hospital Services. The directorate also consist of professionals in the fields of Medicine, Public Health and Nursing each headed by the Head of Department (HOD). The DMA is headed by the General Manager. The functions of the DMA

include the procurement, production and supply of high quality drugs for the government hospitals at a reasonable price. The DMA also ensures sustainable supply of drugs based on a revolving fund.

Kano is blessed with abundant human and natural resources. However, the state is confronted with enormous problems that hamper its ability to achieve the Millennium Development Goals (MDGs) (Kano State Economic Empowerment and Development Strategy (K-SEEDS), 2004). More than 75% of Kano people live in rural areas but the state is experiencing increased rural-urban migration, unemployment, poor infrastructure, electric power and water supply (Kano State Economic Empowerment and Development Strategy (K-SEEDS), 2004).

## **2.2 Burden of stroke in Nigeria**

In Nigeria, *stroke* is reported as the leading cause of hospital neurological admission and it is projected to be on the increase (Njoku & Aduloju, 2004; Ogunrin & Unuigbo, 2008). Although the burden of *stroke* in Nigeria is substantial (Onwuekwe et al., 2008), the exact incidence of *stroke* has not been established and previous hospital-based reports could be representing only the tip of the iceberg and are therefore unreliable (Ogungbo et al., 2005). Wahab (2008) reported that the current prevalence of stroke in Nigeria is 1.14 per 1000 while the 30-day case fatality rate is as high as 40%. In the south western region of Nigeria, ischemic stroke was commonest (56% ischemic and 44% haemorrhagic) and another study found 48% ischemic and 40.7% due to haemorrhage (Njoku & Aduloju, 2004). In agreement with the findings of many conducted studies, females were not as affected as men (Njoku & Aduloju, 2004; Onwuekwe et al., 2008), with the male to female ratio of 2.5:1, 2.4:1 and 1.27:1 as

reported at the University of Maiduguri Teaching Hospital and University of Nigeria Teaching Hospital Enugu respectively (Onwuekwe et al., 2008).

The disease management is notably conservative owing to the lack of adequate diagnostic, treatment, rehabilitation, and support services, human and material resources with little or no funding for quality research (Ogungbo et al. 2005; Wahab, 2008). It accounted for about 0.92-4% of hospital admissions and 2.83-4.52% of total deaths and is believed to be taking a substantial proportion among noncommunicable diseases (Ogunrin & Unuigbe, 2008). In addition, hospital-based studies in Nigeria has also documented that stroke accounts for 45% of all neurological admissions and 5-17% of medical deaths and a high case fatality rate of 40% (Wahab et al., 2008). Ogun et al (2005) reported that stroke appears to be an enormous problem in Nigeria and places a major financial burden on the already inadequate health services in the country.

The problem of stroke in Nigeria seem to be neglected by the government as there is no official publication documenting the economic and financial burden as well as its impact on the health of the nation (Ogungbo et al., 2005). Studies have reported hypertension as the main risk factor for Stroke in Nigeria (Amu et al., 2005; Njoku & Aduloju, 2004; Ogunrin & Unuigbe, 2008). Other risk factors have not been thoroughly studied as observed in most developed countries. However, a few studies have reported obesity, infections including HIV infection, anaemia, hydration under nutrition and congestive cardiac failure as major stroke risk factors in Nigeria (Amu et al., 2005; Ogunrin & Unuigbe, 2008). Although its implication has been proven, smoking has not been reported as a major risk factor for stroke among Nigerians (Amu et al., 2005; Ogunrin & Unuigbe, 2008). The families and the communities are overburdened, owing to prolonged hospitalisation and the failure of many stroke survivors to return to work

(Njoku & Aduloju, 2004). In Nigeria, stroke is also commonly looked upon as a spiritual disease which demands spiritual cure rather than hospital management (Njoku & Aduloju, 2004).

## **2.3 Epidemiology of Stroke**

Stroke as reported by the WHO is the second commonest cause of mortality globally and the leading cause of severe disability and therefore most common reason for rehabilitation (Geoffrey et al., 2007). WHO (2001) revealed that 15 million people worldwide develop stroke yearly, out of which 5 million die and another 5 million are left permanently disabled (Green & King, 2009). In 1999 two-thirds of the global stroke mortality occurred in less developed countries and the number of deaths reached 5.54 million (Feigin et al., 2003). Brain lesion is often the leading cause of mortality during first week following stroke afterward cardio respiratory causes (Ann, 1997). Most epidemiological studies particularly thus that are prospective provide the most robust data. These studies have not been able to distinguish stroke caused by haemorrhage from those caused by infarction, or the ischemic subtypes (Hugh, 2008). Although achievement has been recorded in stroke prevention and management leading to its reduction, the surge in the aging population and increasing prevalence of obesity and diabetes will increase stroke incidence during the next decade (Green & King, 2010).

Stroke incidence was reported to be markedly higher among Afro-Caribbeans in the UK and in African-Americans than among Caucasians, with an increased intracerebral haemorrhage and ischemic stroke – due partly to the severity of hypertension in these populations (Green & King, 2009; Hugh, 2008). In the UK, stroke mortality is higher in South Asians than in Caucasians; this may partly be a consequence of greater central obesity, insulin resistance and diabetes. The distribution of stroke subtypes appears to

vary between ethnic groups; for example, intracranial disease is often reported in Chinese than in European Caucasian stroke patients (Hugh, 2008). The number of stroke cases will increase immensely in the next 20 years in the developing countries - largely due to the increase in the aging population (Geoffrey et al., 2007). Truelsen (2010) reported that, an estimated 80% of all first-ever strokes occur in Africa and that 5% of the 30 million stroke survivors globally live there. An increase in the prevalence of stroke might be witnessed in the future due to the changes in exposure to major stroke risk factors and improved prevention and control of infectious diseases (Truelsen, 2010).

There is a global difference in the prevalence among young adults (socioeconomically active age group). However, ischemic strokes rarely happen in patients younger than 45 years (<5%). When it occurs, this may lead to a life time of medical complications and the young persons and have to live with disabilities for a longer period of time (Fahmi, 2007). The percentage of mortality as a result of stroke reported in western countries is 10–12% and people under 65 years represent 12% of these deaths. In a community-based study in Nigeria, the prevalence of stroke was found to be 1.14 per 1000 in males with 0.69 per 1000 in females (Wahab, 2008). These rates are lower than what what is reported from most developed countries and it's postulated that this could be as a result of high case fatality rates from the disease (Owolabi, 2008). The frequency increases with advancing age with prevalence rate of 24.14 per 1000 in thus more than 65 years, though this is low when compared with 70 per 1000 in thus similar age groups in most European countries (Wahab, 2008). The frequency of ischemic, hemorrhagic and their respective aetiologies also vary in different regions of the world (Owolabi, 2008; Wahab, 2008). In Nigeria, previous reports showed that infarctive stroke is commoner than hemorrhagic stroke (64% and 25% respectively), however, a changing pattern with

an increasing frequency of hemorrhagic stroke has been suspected (Owolabi, 2008; Wahab, 2008).

In 2002, disabilities related to stroke were the sixth most reported common cause of reduced DALYs (Geoffrey et al., 2007). Another report by the WHO in 2001 revealed that low and middle income countries contributed to the 85.5% of the global mortality due to stroke and reported seven times higher loss of DALYs than high income countries (Feigin et al., 2009). Population based epidemiological studies provide the most revealing estimate of stroke burden (Lavados et al., 2007). The association between the resultant population stroke mortality and the prevalence of hypertension has been reported by the latest retrospective review of eight surveys on hypertension (Giuseppe, 2004). In the past 50 years there was consistent decrease of about 1% per year of stroke mortality in developed countries until the late 1960s where a sharp decline of about 5% per year was reported, largely due to risk factors control particularly pertaining to hypertension and cigarette smoking coupled with consistent improvement in the standard of living which is not the case in the developing countries (Geoffrey et al., 2007). Stroke as a condition differ in recovery ranging from day recovery, incomplete recovery, severe disability to death. The consequence of stroke is greater and often in women than men. Women have less likelihood of recovery due to their established longer life expectancy and elevated incidence at older ages. However, age specific stroke rates are higher in men with the exception of subarachnoid haemorrhage although there is little evidence supporting stroke subtype or severity with regards to sex difference (Reeves et al., 2008).

In a study which spanned over a 7-year period, sampled households that consisted about 15,792 adults aged 45 to 64 years, it was observed that of all the stroke occurrence,

ischemic strokes accounted for almost 83% with haemorrhagic and intracerebral haemorrhagic strokes comprising the remainder and representing 7% and 10% respectively (Giuseppe, 2004). The number of people in a community surviving stroke is dependent upon the incidence and case-fatality which most of the times are not inspired by the same factors. Therefore incidence information is needed in order to describe for any differences in occurrence related to time or place of likely explanations. Moreover, in most case control studies there may be bias in prevalent cases due to underrepresentation of fatal cases compared to incident cases (Chang et al., 2002). Stroke is currently the biggest cause of disability (neurological) in developing countries including Nigeria. This is largely due to adoption of western life style and epidemiological transition (Owolabi, 2008). By the year 2020, stroke and coronary artery diseases are projected to be the leading cause of lost healthy life-years (Feigin et al., 2003). Most stroke and myocardial infarction events happen in the lower socioeconomic groups supporting the assertion that their events increase as countries develop (Chang et al., 2002).

## **2.4 Clinical features of Stroke**

Oedema is the first main feature following all cases of stroke irrespective of its aetiology. However, the site, size of underlying pathology, length of occlusion or haemorrhage, presence and lack of collateral circulation, body temperature and blood pressure are among the factors affecting the final magnitude of a stroke event (Fatahzadeh & Glick, 2006). Stroke clinical indices differ based on the location and the size of the brain pathology (Fatahzadeh & Glick, 2006). Based on the study conducted by NIMH, the stroke signs and symptoms appear abruptly and frequently with more than one symptom at the same time. These signs and symptoms may include sudden confusion, dizziness, inadequate balance/coordination, sudden weakness/numbness



more importantly on one side of the body and sudden relentless headache with unknown aetiology (Hugh, 2008). Among the more common advanced neurologic impairment include sudden seizure, vomiting and headache and prompt changes in mental status. In addition, focal death classic of ischemia occur less than with haemorrhagic strokes (Charles et al., 2003). However, stroke signs and symptoms are many and may involve dizziness, vomiting, hemiparesis, arbitrated eye movement, sensorimotor dysfunction, visual fault, memory disturbance, compromised mental status, language problem deafness, hypoesthesia and hemiplegia (Fatahzadeh & Glick, 2006).

## **2.5 Brief classification and Pathogenesis of Stroke**

The key pathogenic pathway for stroke is the disturbance in blood communication and conveyance of oxygen and glucose to the brain tissue. For the brain to function effectively, it needs 60-70mL of perfusion/100g of tissue/minute because it does not store glycogen. Moreover, a lag in the communication of blood to 25mL/100 g/minute may principally lead to enormous disturbances including neuronal ischemia, energy failure, and neurologic symptoms and should ischemia persist this will be accompanied within minutes by irreversible tissue damage (Fatahzadeh & Glick, 2006). Many studies reported gender as a factor for stroke as documented that men have higher risk for stroke compared to women. This is attributed to the fact that, women live longer than men and may be older when they have stroke making them more likely to die from it although pregnancy related hormonal changes, childbirth and menopause heightened their risk for stroke (Feigin et al., 2003). The association between risk of stroke and pregnancy has also been reported (Feigin et al., 2003). There is difference among ethnic and racial distribution of risk for stroke in the six weeks postpartum following childbirth (Fatahzadeh & Glick, 2006).

Stroke is caused by ischemia, infarction or interactional haemorrhage. Ischemia and infarction account for 85 to 90 per cent of stroke in western countries while 10 to 15 per cent are due to intracranial haemorrhage. Most CVA present as a sudden onset of focal neurologic deficit but it can upset the whole body although it is disease of the brain (Geoffrey et al., 2007). Among the eventual disabilities that can accompany stroke may comprise emotional complications, cognitive disturbances/deficits, fatigue, paralysis, speech difficulties and problems with ADL (Hugh, 2008). Cerebral ischemia which may precede for some seconds or few minutes is caused by inadequate blood flow and infarction of the brain resulting in a generalized reduction in cerebral flow to systemic hypertension (EG cardiac arrhythmias myocardial infarction or haemorrhagic shock) usually producing syncope, infarction in the boarder zones between the major cerebral artery distributions or widespread brain necrosis depending on the duration of hypertension (Ellen & Benoit, 2002).

Focal ischemia on the other hand is usually caused by emboli from a proximal cardiac artery. Intracranial haemorrhage may occur into the brain parenchyma, the subarachnoid space. Subdural or epidural hematomas are usually the result of trauma not cerebrovascular disease (Paolucci et al., 2000). The majority of intracranial haemorrhages are associated with hypertension. Spontaneous haemorrhage, arteriovenous malformation (AVM) and bleeding into a neoplasm are less common causes. Subarachnoid haemorrhage (SAH) is usually due to ruptured secular aneurysms or less commonly, an AVM. Sometime the source for the haemorrhage cannot be found (Feigin et al., 2003).

## 2.6 Diagnosis of Stroke

There are many other medical conditions that can have similar features as stroke features thereby making diagnosis difficult because, focal neurological deficits are not only distinctive to stroke, as it may also appear in the circumstance of an epileptic seizure attack or an acute hypoglycaemic episode. Other conditions that may mimic stroke signs and symptoms may include brain neoplasm, acute sepsis, infectious encephalitis, multiple sclerosis, prolonged migraneous aura, and severe metabolic imbalances. Therefore, basic knowledge cardinal to stroke occurrence allows the application of effective preventive and therapeutic interventions unique to it (Fatahzadeh & Glick, 2006). The approach that may be used in stroke diagnosis may involve holistic neurological and physical examination, clinical history and accessory tests. The neurological examination makes it possible for mapping stroke topology and may be employed in confirming neurological focality when suspected and necessary (Ustrell-Roig & Serena-Leal, 2007). In addition, other factors important to the diagnostic operation include among others clinical appearance, mundane profile of the event, position of the infarct, stroke subtype, patient age, medical history and exact aetiology (Fatahzadeh & Glick, 2006).

These data, when used alongside other diagnostic modalities such as general physical examination, laboratory findings, ECG, chest X-ray, emergency cranial CT and cardiac auscultation can reveal valvular or rhythm abnormalities, conduction problems, and a late myocardial infarction (Fatahzadeh & Glick, 2006). Other diagnostic procedures that may be employed include the use of non-invasive imaging technique e.g. Magnetic Resonance (MR) angiography, CT angiography and digital subtraction angiography (Charles et al., 2003). Prior to commencing emergency management, it is imperative to consider diagnosing haemorrhagic stroke, since history and clinical examinations alone

are not always reliable. Techniques such as vascular testing in the form of cerebral angiography or Doppler ultrasonography were recommended because of their ability to reveal the nature, position, and the extent of vascular pathology in substantial vessels of the head and neck (Fatahzadeh & Glick, 2006). In addition, when subarachnoid haemorrhage or meningitis is suspected, lumbar puncture may aid in excluding the established aetiologies. When septic embolus accompanying infective endocarditis is suspected, echocardiography and blood cultures can be employed (Hugh, 2008). Other laboratory tests that can be carried out may include test for blood sugar, urinalysis, complete blood count and chemistry, serum electrolytes, erythrocyte sedimentation rate, screening for hypercoagulability, serologic tests for syphilis, cholesterol, and lipid levels (Fatahzadeh & Glick, 2006).

## **2.7 Risk Factors (Stroke and QOL)**

Most epidemiological studies (particularly prospective design, which provides more robust data than cross-sectional designs) have been unable to distinguish stroke caused by haemorrhage from that caused by infarction, let alone differentiate ischemic subtypes. Therefore, most risk factor data apply to stroke syndrome as a whole (Hugh, 2008). Primary stroke prevention focused on the risk factor modification in the whole population are based mainly on several epidemiologic studies that have identified many predisposing factors in relation to stroke (Fatahzadeh & Glick, 2006). On the other hand, many observational epidemiological studies in the form of case-control and cohort studies have reported a significant number of risk factors associated with stroke e.g. claudication which cannot possibly be on the etiologic pathway (Warlow, 1998).

Among the identified risk factors that are non-modifiable are heredity, sex, age and ethnicity while risk factors that are modifiable include hyperlipidemia, hypertension,

cardiovascular disease, diabetes mellitus, cigarette smoking and abuse of alcohol (Giuseppe, 2004). Many studies however, reported an increase in risk for stroke with regards to cigarette smoking as dose dependent and a risk factor independent for stroke (Lavados et al., 2007). Credible evidence from the 32 published meta-analysis studies reported an extreme risk of stroke among cigarette smokers with a relative risk of ~1.5 (95% CI, 1.45–1.98) among smokers compared to non-smokers (Giuseppe, 2004). Diabetes mellitus is a risk factor associated with both large vessel disease and carotid atherosclerosis and has a relative risk of two for stroke (Hugh, 2008). As compared with individuals without diabetes, the relative risk for thromboembolic stroke in patients with diabetes was 2.0 (95% CI, 1.4–3.0) as reported by the Honolulu Heart Program (Giuseppe, 2004). Moreover, this finding upholds the hypothesis that independent of blood pressure, diabetes may grant an increased risk of stroke. Although the association between total cholesterol and low density lipoproteins as risk factors for ischemic heart disease was reported to be strong, the relationship with stroke appears weaker (Hugh, 2008).

Socioeconomic status as measured by income level, education level and occupation is considered as an independent risk factor for stroke morbidity and mortality has infrequently being studied in Caribbean and Latin America, but reported steady increased occurrence of stroke and mortality in low socioeconomic groups in different populations (Lavados et al., 2007). High BMI although partly through other factors such as diabetes and hypertension was variously reported as a risk factor for stroke. Additional case control and cohort studies have reported an established relationship between lack of exercise and heightened risk for stroke (Fatahzadeh & Glick, 2006). Other risk factors – migraine (particularly with aura) and the oral contraceptive pill (particularly oestrogen-containing preparations) are risk factors for stroke.

Reportedly, immediately after its initiation hormone replacement therapy also seems to be associated with amplified risk of stroke. This may have a prothrombotic mechanism (Hugh, 2008). There is a causal association between inflammation, infection and stroke. Chronic infection and inflammation may predispose to atherosclerosis and stroke. Several studies have suggested that acute infections may precipitate onset of stroke. There is an established relation between socioeconomic status and stroke risk, though this may be complicated by factors such as lack of exercise and smoking (Lavados et al., 2007). The incidence of stroke is greater among Afro-Caribbeans in the UK and in African-Americans compared to Caucasians. Both intracerebral haemorrhage and small vessel ischemic stroke are particularly increased; this may partly relate to the greater prevalence and severity of hypertension. In the UK, stroke mortality is higher in South Asians than in Caucasians; this may partly be a consequence of greater central obesity, insulin resistance and diabetes. The distribution of stroke subtypes appears to vary between ethnic groups; for example, intracranial disease is more common in Chinese than in European Caucasian stroke patients, supporting ethnicity as a probable risk factor for stroke (Hugh, 2008).

## **2.8 Stroke Rehabilitation and Quality of Life (QOL)**

Consequent to the growing social and political emphasis on disability, currently stroke rehabilitation does not only focus on functional outcomes, but also integrate the developing issues of psychological wellbeing and independent living (Clarke, 2009; Duncan, 2000; Duncan et al., 2005). The objectives of stroke rehabilitation is to is to prevent complications, recognize, and manage co-morbid medical conditions, reduce impairments, facilitate social function, maximize functional independence, optimize psychosocial adaptation of patients and families, enhance emotional adaptation and facilitate resumption of prior life roles and community reintegration depending on the

degree of disability and recovery potential (Duncan et al., 2005; Kwakkel et al., 1999; Lavados et al., 2007; Yagura et al., 2003). According to Duncan and colleagues (2005), early commencement of effective rehabilitation interventions following stroke can enhance recovery and minimize functional disability, increased functional outcomes and patient's general satisfaction and reduce potential costly long-term care expenditures. In view of this, improving QOL can be regarded as the primary goal of the stroke rehabilitation practice.

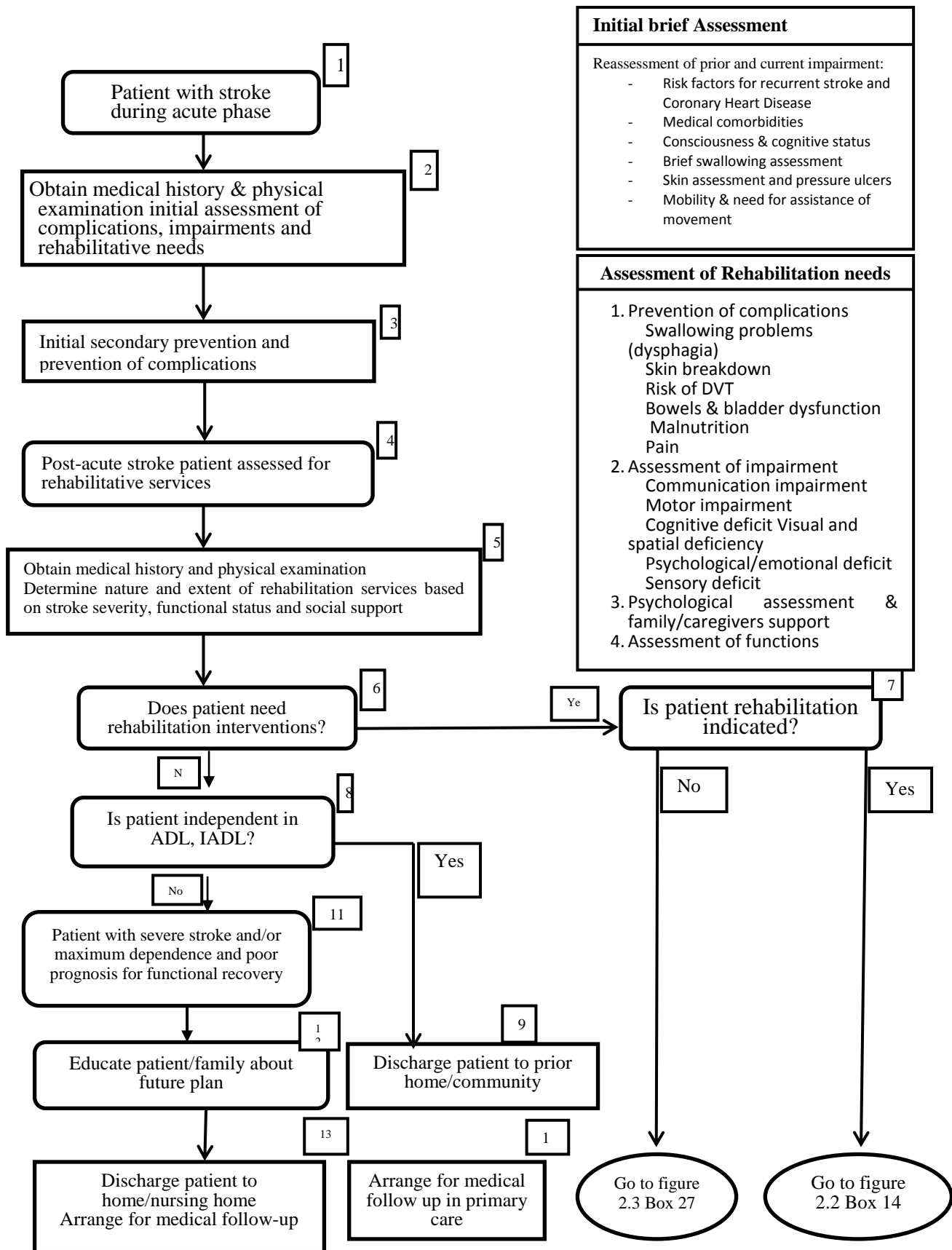
Stroke rehabilitation is a continuous and multi-disciplinary team approach that is holistic, comprehensive, and dependent on multiple inputs and a range of skills and expertise including repeatedly applied treatment modalities to improve quality of life after stroke (Fung, 2004; Kwakkel et al., 1999; Long et al., 2003; Nair & Wade, 2003). The stroke rehabilitation team comprises the coordinated efforts from nursing, rehabilitation professionals including physiotherapists, occupational therapists, language and speech pathologists/therapists, physicians trained in rehabilitation medicine, pharmacists, psychologists and social workers with different skills and working collectively in order to help the patient (Fung, 2004; Lees, 2002). Stroke rehabilitation encompass a set of activities whereby patients with disabling stroke receive treatment (both short term and long term) to help them regain and relearn as much as possible the skills of everyday living so as return to normal life (Fung, 2004; Green & King, 2010). Rehabilitation consists of a broad array of biomedical, psychological, social, educational, and vocational interventions that can be rendered in a variety of institutional and community based settings (Kwakkel et al., 1999).

Stroke rehabilitation uses learning theory graded levels of task difficulty opportunities for repetition of skill performance, professional supervision and feedback thereby

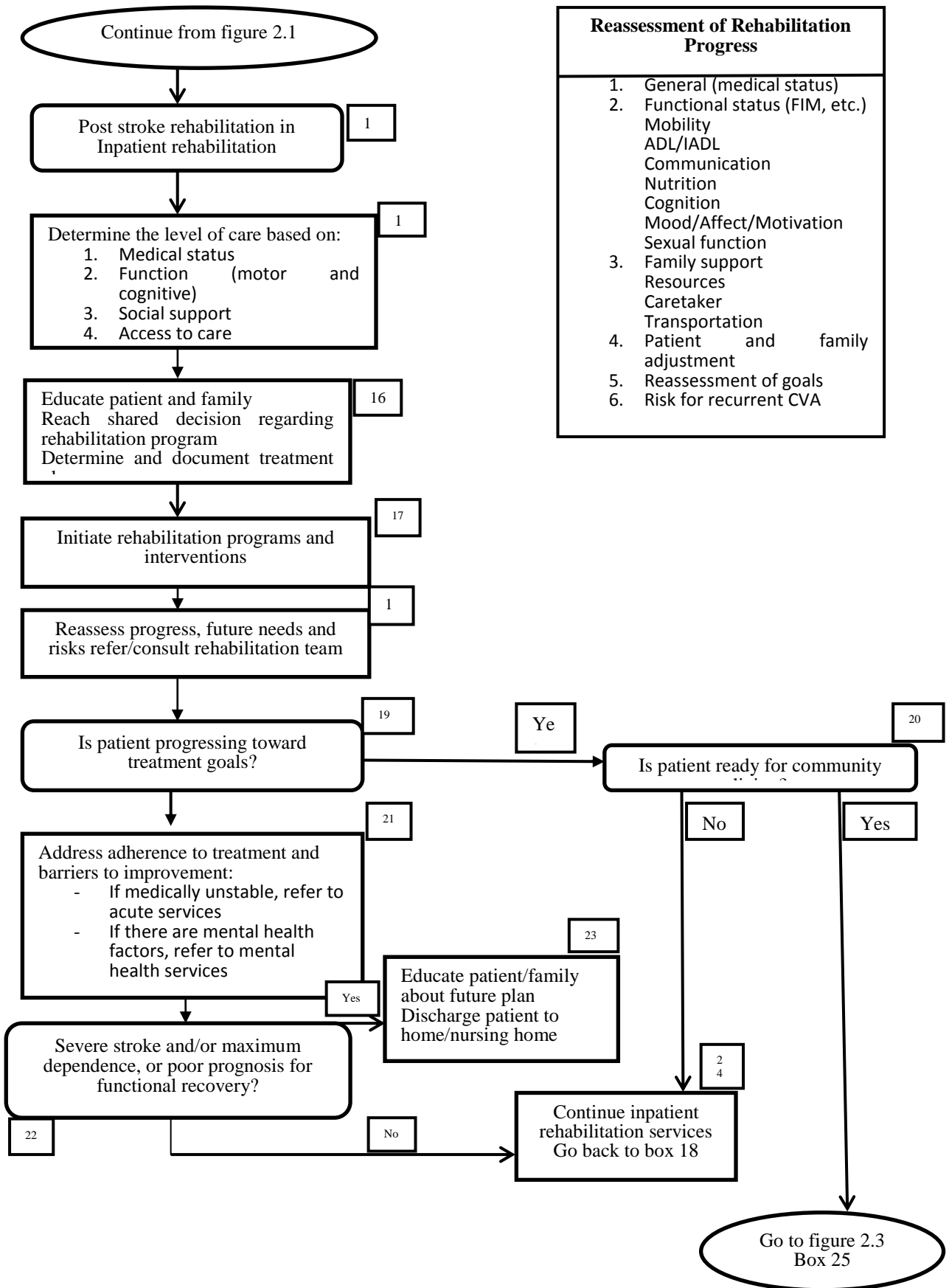
reducing mortality and morbidity following stroke (Kwakkel et al., 1999; Lavados et al., 2007). Medical rehabilitation has been established to modify compensatory learning, self-care, and adjustment mechanisms and as fundamental neural recovery. Moreover, recognising beyond neural recovery that has the potential of improving function following stroke is a growing interest (Robinson-Smith et al., 2000). Stroke rehabilitation interventions may include functional skills training to address personal care skills, mobility activities and instrumental activities of daily living. Interventions may include therapeutic exercises, spasticity management, treatment of aphasia and depression (Ann, 1997). Other interventions may include patient education, family and caregiver education, behavioural techniques, supportive counselling and recruitment of community resources (Ottenbacher, 2005). Therefore, the principle behind stroke rehabilitation is to address: psychosocial issues, involve family participation, recruit community resources, promote functional activities and generally attend to quality of life issues.

The developed algorithms by the VA/DoD Stroke Rehabilitation Working Group adapted from Duncan et al. (2005, page e100-e143) provides an essential scientific evidence-based clinical practice guideline for the management of stroke rehabilitation practice interventions and evaluations summarized as Figure 2.1-2.3. The developed guideline provide for evidence-based practice in organising the necessary facilities to put in a holistic stroke care delivery to achieve maximum functionality and independence and improve patient/family quality of life (Duncan et al., 2005).

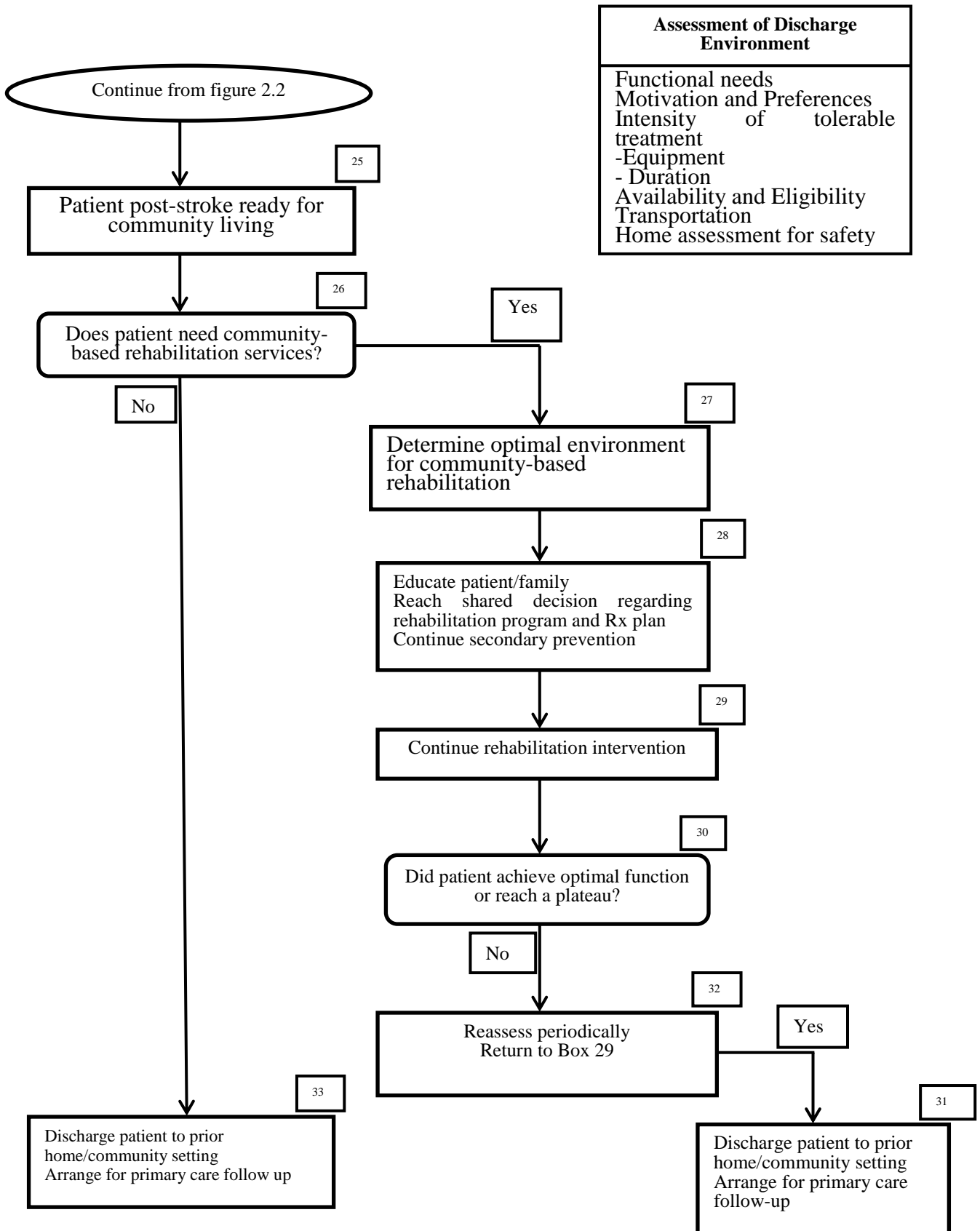




**Figure 2.1: Assessment (flowchart adapted from (Duncan et al., 2005))**



**Figure 2.2: Inpatient Rehabilitation (flowchart adapted from (Duncan et al., 2005))**



**Figure 2.3: Community-Based Rehabilitation (flowchart adapted from (Duncan et al., 2005))**

## **2.9 Stroke survivors and functional status**

Functional status measures are conceptually connected to the activities and participation component of the ICF and are basically involved with measuring an individual's capability to carry out ADL and fulfil social roles (Geyh, 2007). Functional ability is defined as an individual's ability to execute the usual activities that people do in order to meet basic needs, fulfil social roles, and protect their health (Haas, 1999). Assessing stroke recovery at the impairment, activity, and participation levels allows for the determination of the impact of changes in impairments on changes in activity and perceived QOL (Barak & Duncan, 2006). It's often unclear what to assess when evaluating functional status but, the common approach used in rehabilitation is to evaluate independence in performing functional activities, namely, Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) (Duncan, 2000; Rogers & Holm, 1998). ADL pertains to daily self-care activities concerning functional mobility and personal care such as feeding, swallowing, grooming, dressing, bathing, continence, toileting and mobility (Geyh, 2007; Owolabi, 2010; Rogers & Holm, 1998). IADL on the other hand pertains to a series of life activities comprising home management tasks and functions necessary for independent living in the community such as cooking, using a telephone, handling money, laundry, shopping, using transportation, maintaining a household, working, participating in leisure activities, managing medicine etc. (Geyh, 2007; Owolabi, 2010; Rogers & Holm, 1998). Health status measures generate comparable results and are therefore used to assess the burden of a disease on a patient as well as functioning and health in the form of profile or summary scores (Geyh, 2007). Health status measures can emphasise focal areas for necessary interventions, reveal expected or unexpected changes, discriminate patient groups, can be useful to explain or predict health states, and may allow conclusions on the effectiveness, efficacy, safety or benefit of treatments (Geyh, 2007). In addition,

health status measures are applied for a great variety of purposes including clinical, research, management, and policy settings (Geyh, 2007). Following stroke, health status measures may also be used for the examination and description of stroke impact, for monitoring, intervention evaluation, and quality management, surveys, for individual as well as macro level health care planning and decision making (Geyh, 2007).

## **2.10 Social support and Quality of life (QOL)**

During the sub-acute phase of stroke, when potential for further functional gain is limited, the psychosocial consequences of stroke become increasingly important determinants of health-related quality of life (Katherine et al., 2010; Lyncha et al., 1999). Although about one-third of individuals with stroke may develop post stroke depression, perceived social support may prevent either onset or duration of depressed mood (Salter et al., 2010). In stroke survivors, social support is believed to affect the quality of patient care and disease outcome, as well as patient's physical and psychosocial well-being (Lyncha et al., 1999; Tsouna-Hadjis et al., 2000). Studies have consistently demonstrated a link between low levels of social support and poor mental and physical health outcomes and have subsequently fuelled the development and evaluation of interventions designed to improve social support for those deprived of this resource (Brenda et al., 2002; Bruwer et al., 2008; Katherine et al., 2010; Lyncha et al., 1999). Apart from disability, psychosocial factors such as emotional responses and social support determine health related quality of life (HRQOL) in stroke survivors (Owolabi, 2008; Yu et al., 2013). In the broadest sense, social support cuts across any process through which social relationships might promote health and well-being (Kolella & King, 2004) and moderates the impact of functional status on well-being (Clarke et al., 2002; Tsouna-Hadjis et al., 2000). Improvement of accessible social support could be an essential plan in mitigating psychiatric distress and averting post

stroke depression (Salter et al., 2010). The role of social support as a coping resource, in addition to its association to stressors and mental and physical wellbeing has generated increased interest in recent years (Bruwer et al., 2008).

## **2.11 Review of Outcomes Measurement Tools used in Stroke**

In the field of stroke, several tools exist to measure stroke outcomes. The measures are applied for a variety of purposes in clinical research, policy and management issues (Buck et al., 2000; Daina & Daiva, 2006; Kasner, 2006). Quality of life measurement tools can be divided into generic and disease specific scales. Generic scales address general health concepts not specific to any age, disease or treatment (Furmonavicus, 2004; Haacke et al., 2006; Lima et al., 2009). Disease-specific measures on the other hand, are more valid, patient-centred, responsive and more useful for measuring HRQOL in specific diseased population (Bowling, 1995; Duncan et al., 2000; Kasner, 2006; Haacke et al., 2006; Lima et al., 2009).

### **2.11.1 Generic measures of HRQOL**

Many generic and disease specific health-status measurement instruments have been developed for use in clinical trials evaluating various medical therapies, but their use in examining the impact of stroke and stroke interventions has been limited (Doyle, 2002; Lima et al., 2009). Examples of the generic measures are Short-Form-36 Health Survey (SF-36) (Gurcay et al., 2009; Lai et al., 2003), the European Quality of Life Instrument (EuroQol) (Buck et al., 2000; Dorman et al., 1999), Nottingham Health Profile (NHF) (Buck et al., 2000; Kasner, 2006), COOP Charts, and the 136-item sickness impact profile (SIP) (Buck et al., 2000; Dorman et al., 1997; Dorman et al., 1999; Hobart et al., 2002). While both the SF-36 and EuroQol correlate closely in the physical domain, their poor correlation in the psychological domain may be due to difference in content, validity or reliability of one or both of these instruments in these domains (Hobart et al.,

2002). The SF-36 correlates well with measures of the physical and mental domains but poorly with measures of social functioning suggesting that a supplemental measure may be required for this domain (Buck et al, 2000; Dorman et al., 1999; Hobart et al., 2002). Despite the fact that generic measures can allow for comparisons between groups with various kinds of illnesses, they cannot address the problem associated with a specific diseased condition and may not be responsive to significant adjustment in QOL (Buck et al., 2000).

Examples of generic measurement tools used to measure post stroke QOL **in only one single domain of QOL** include Karnofsky Performance Status Scale (Buck et al., 2000; Dekker et al., 1998), Life Satisfaction Index Nottingham version (Buck et al., 2000; Kasner, 2006), Geriatric QOL Questionnaire (Buck et al., 2000; Kasner, 2006), Mini Mental State Examination (MMSE) (Kasner, 2006), Functional Life Scale (Buck et al., 2000), Hospital Anxiety and Depression Scale (Buck et al., 2000; Visser et al., 1995), Ryff Measure of Psychological Wellbeing for the psychological domain (Hobart et al., 2002). However, little information is available about their psychometric and other properties (Buck et al., 2000).

**Utility measures** are direct measures of personal preference regarding health status. They are developed for health economic evaluation and derived from a specific body of economic theory (Buck et al., 2000). They incorporate preferences for health states and produce single numerical indices (Haacke et al., 2006; Sangkaew, 2007). The utility of a health state is rated between 0 [death] and 1 [perfect health], though some health states are opined by some to be worse than death (Buck et al., 2000; Hobart et al., 2002). Utility is determined directly using the standard gamble method, time trade-off model, category-rating scale or visual analogue scale (Haacke et al., 2006; Kasner, 2006;

Sangkaew, 2007). Utility measures include EuroQol (Buck et al., 2000; Duncan et al., 1997), London Handicap Scale (LHS) (Buck et a., 2000; Fitzpatrick et al., 1998), Health Utilities Index (HUI) (Fitzpatrick et al., 1998), Visual analogue scale (Kwa et al., 1996), standard gamble technique (Buck et al., 2000), time trade-off, and global scale (Duncan et al., 1997; Fitzpatrick et al., 1998).

**A disability measure** assesses basic and instrumental daily functioning. Basic activities of daily living include feeding, swallowing, grooming, dressing, bathing, continence, toileting and mobility while instrumental/extended activities include using the telephone, handling money, shopping, using transportation, maintaining a household, working, participating in leisure activities, etc. Example of the disability measurement tools include modified Rankin Scale, Barthel Index, The Lawton and Brody Scale, and American Heart Association (AHA) Stroke Outcome Scale (Carod-Artal., 2009; Kasner, 2006); Lai et al., 2009). The limitation of these measures of ADL is that no ADL measure can sufficiently represent these factors in each person (Carod-Artal, 2009; Kasner, 2006)).

The Short Form-36 (SF-36) is the extensively used generic measure of HRQOL tool that assesses physical, psychological, and social functions, but was discovered to suffer high floor and ceiling effects in some domains (Gurcay et al., 2009; Lai et al., 2003) and thereby diminishing its capability to detect adjustments with regards to QOL (Gurcay et al., 2009).



**Table 2.1: Table of evidence of the psychometric and other properties of generic measures used in stroke QOL research (Modified from Buck *et al.* 2000; Daina & Daiva, 2006)**

Measure	No. Of items	Reliability	Validity	Response to change	Suitability for use with proxies	Mode of administration	Floor/ceiling effects
SF-36	36	Yes	Yes	Yes	Yes	Interview or self	Large ceiling effects
NHP	38	Yes	Yes	Yes	No	Interview or self	Not reported
EuroQol	6	Yes	Yes	No	Yes	Interview or self	Not reported
HUI (HUI 2/HUI 3 combined versions)	4-6	No	No	No	Yes	Interview or self	Not reported
LHS	6	Yes	Yes	No	No	Self	Not reported
SIP	136	Yes	Yes	Yes	Yes	Interview or self	Not reported

### 2.11.2 Stroke-specific measures of HRQOL

Due to the limitations associated with the generic measures of HRQOL, stroke specific measures were developed to deal with elements peculiar to stroke patients (Daina & Daiva, 2006). In addition, because of their power to locate significant modification in QOL, stroke specific measures therefore emerge more appropriate in measuring post stroke QOL (Daina & Daiva, 2006; Salter *et al.*, 2008). Stroke-specific measures include the Niemi QOL scale which is designed for use four years after stroke and assesses working conditions, activities at home, family relationships, and leisure activities (Buck *et al.*, 2000; Neimi *et al.*, 1988). However it was not developed with patient-centred methods. The Ferrans and Power QOL Index-Stroke version is a 38-item measure of health and functioning, socioeconomic, psychological, spiritual and family functioning (Buck *et al.*, 2000; King, 1996). Other examples of stroke-specific measures are the Stroke Impact Scale (SIS) (Carod-Artal *et al.*, 2009), Frenchay Activities Index

(FAI), Viitanen Life Satisfaction Interview (for long-term survivors), Ahlsio QOL Interview, Stroke Rehabilitation Outcome study, the 30 item Stroke Adapted Stroke Impact Profile (SA-SIP30), Stroke and Aphasia Quality of Life Scale -39 (SAQOL-39) (Buck et al., 2000; King, 1996), Newcastle Stroke-Specific Quality of Life Measure (NEWSQOL) and the Stroke-Specific Quality of Life Scale (SSQOL). The CQOL (change in quality of life scale for stroke) and the ECVI-38 are also stroke specific measures recently developed in Taiwan and Cuba respectively (Daina & Daiva, 2006; Salter et al., 2008). These measures have been preliminarily evaluated in stroke patients but require further studies to ascertain their psychometric suitability particularly in multicultural settings. So far, none of them represents a fully reasonable and complete operationalisation of the concept of HRQOL (Daina & Daiva, 2006; Salter et al., 2008). Among these stroke specific measures of QOL, only the FAI and SIS has evidence indicating suitability for use with proxy respondents, and only the SIS, FAI and SA-SIP30 can be both self-and interviewer-administered (Daina & Daiva, 2006).

**Table 2.2: Table of evidence of the psychometric and other properties of stroke-specific measures used in stroke QOL research (Modified from Buck *et al.* 2000; Daina & Daiva, 2006)**

Measure	No. Of items	Reliability	Validity	Response to change	Suitability for use with proxies	Mode of administration	Floor/ceiling effects
FAI	3	Yes	Yes	Yes	Yes	Interview or self	Not reported
Neimi QOL Scale	4	Yes	Yes	No	No	Interview	Not reported
Ferrans and Powers QOL Index-Stroke Version	4	Yes	Yes	No	No	Interview	Not reported
Ahlsio QOL Interview	Not specific	No	No	No	No	Interview	Not reported
SA-SIP30	8	Yes	Yes	No	No	Interview or self	Not reported
Stroke Rehabilitation Outcome Study	3	No	Yes	No	No	Not reported	Not reported
Viitanen Life Satisfaction Interview	7	No	Yes	No	No	Interview	Not reported
Stroke Impact Scale (SIS)	59	Yes	Yes	Yes	Yes	Interview and Self	No ceiling and floor effects

The stroke impact scale (SIS) was chosen for this study because it's the only stroke specific measure utilising a patient-centred approach in its development (Duncan et al., 2003; Gurcay et al., 2009; Salter, 2008). It was developed as an extensive measure of outcome in stroke survivors from the viewpoint, perception, position and contributions of stroke patients, caregivers, and health professionals with stroke expertise (Duncan et al., 2003; Gurcay et al., 2009; Kamel et al., 2010). Past studies reported that SIS 3.0 indicated substantial improvement in most SIS 3.0 domains in patients recovering from mild and moderate stroke (Daina & Daiva, 2006; Duncan, 2000; Lai et al., 2003). It was designed to improve the capture of the broad range of post stroke physical limitations

including hand function, ADL, IADL, and mobility. In addition, SIS 3.0 do not have any ceiling and floor effects. SIS 3.0's participation domain adequately assesses the ability of a wide variety of post stroke patients to participate in activities that are meaningful to their life without some limitations of the generic measures such as the SF-36 SF domain (Lai et al., 2003). SIS 3.0 also integrates relevant dimensions of functions and HRQOL into one self-report instrument (Kamel et al., 2010). Compared to other stroke specific measures of QOL, SIS have more advantages including a link to the web site that allow for data entry, thereby generating a summary statement of every patient (Daina & Daiva, 2006).

## **2.12 Features of a good HRQOL measure**

The characteristic SIS 3.0 include 59-items in eight domains (strength, hand function, mobility, physical and instrumental activities of daily living (ADL/IADL), memory and thinking, communication, emotion and social participation) (Carod-Artal et al., 2008; Carod-Artal et al., 2009; White et al., 2007). Apart from covering all measurable life domains and functioning, a good stroke-specific measure of HRQOL should have the essential and rigorous psychometric properties including validity, acceptability, responsiveness, sensibility, proxy suitable, sensibility and minimal clinically important difference (MCID) (Barak & Duncan, 2006; Buck et al., 2000).

### **Validity**

Like any outcome measure, verification of the validity is essential for QOL measures in order to guarantee self-reliance of their scientific robustness (Buck et al., 2000). It is the ability of an instrument to measure what it is proposed to measure (Barak & Duncan, 2006; Buck et al., 2000; Owolabi, 2010). The validity of an assessment tool is enhanced by the absence of floor and ceiling effect (Owolabi, 2010).

*Content validity* is defined as the extent to which a measure represents all domains of interest in a given construct (Buck et al., 2000; Owolabi, 2010). Content validity requires experts on the subject matter to evaluate whether test items assess defined content and require more statistical tests than does the assessment of face validity (Barak & Duncan, 2006).

*Construct validity* refers to the specification of the factors that account for the discrepancy or inconsistency in the intended measures and the theoretical association between them. A hypothesis regarding the probable strength and direction of the possible relationship is stated (Owolabi, 2010). Validity is supported when the correlations are in agreement with prior hypotheses (Owolabi, 2010). Other forms of construct validity include convergent (concurrent) validity which is obtained when different measures of similar fashion are rationally associated and extremely correlated. On the other hand, discriminant validity, which is another form of construct validity, is manifested when dissimilar measures/domains are not as eminently correlated (Barak & Duncan, 2006; Owolabi, 2010).

*Criterion validity* is defined as the performance of the instrument as compared to the existing gold standard or outcome that the measure was intended to assess (Barak & Duncan, 2006; Owolabi, 2010). Predictive validity (a form of criterion validity) and is referred to as the extent to which a test can tell about how well an individual will do in a later position (Barak & Duncan, 2006).

## **Reliability**

This is the extent to which a score is free of random error such that measurements for the same individual on independent occasions or by different observers produce comparable or approximate results (Barak & Duncan, 2006; Buck et al., 2000).

*Internal consistency reliability* is the most commonly used estimate of the reliability of an outcome measure. It is the average degree of association among the items on a test

(Barak & Duncan, 2006). Cronbach's coefficient 'alpha' is used to evaluate the extent of equivalence and association between responses to items/questions tapping the same concept (Owolabi, 2010). Excellent internal consistency is reported at 0.80, adequate is 0.70– 0.79 and poor is 0.70 (Barak & Duncan, 2006). Cronbach's coefficient alpha is directly proportional to the number of and the correlation between items tapping the same concept. An acceptable level (Nunnally's) of alpha has been defined as 0.70 or more (Owolabi, 2010).

*Test-retest reliability* is the measure of correspondence between scores achieved by the same person at two different times (Owolabi, 2010). A suggested minimum test–retest reliability of 0.90 is proposed to evaluate the on-going progress of an individual in a treatment condition (Barak & Duncan, 2006). The problem is in ascertaining whether observed changes are due to chance or improvement/deterioration over time (Barak & Duncan, 2006; Owolabi, 2010).

*Inter-rater reliability* pertains to the extent of correlation obtained between two or more observers that assess the same respondent (Barak & Duncan, 2006; Owolabi, 2010). Generally, 80% agreement between observers is the least required (Barak & Duncan, 2006).

## **Responsiveness**

Responsiveness of a QOL measure is essential when ascertaining the effect of a treatment on the patient's health (therapeutic effect) (Barak & Duncan, 2006; Houlden et al., 2006). It's the ability of HRQOL measure to reveal even small differences within an individual over time. Responsiveness is also referred to as **sensitivity to changes** within patients over time (Barak & Duncan, 2006; Houlden et al., 2006). Disease-specific measures can be more responsive than generic measures, resulting from their ability to measure domains of particular interest in a person with the condition, thereby allowing for detection of small changes. Responsiveness is most commonly evaluated

through correlation with other scores, effect sizes, standardized response means, relative efficiency and sensitivity and specificity of change scores (Barak & Duncan, 2006; Owolabi, 2010). Responsiveness of a measure can be established by using the paired t-test statistic for within-subject changes. It can also be calculated as effect size, which is the change in mean score from baseline to follow - up divided by the standard deviation of baseline scores (Owolabi, 2010).

### **Acceptability**

For this study and as similarly reported by Buck et al. (2000), acceptability is determined by pretesting with patients in terms of wording, response options, and general layout and suggested by the high response rate (Buck et al., 2000; Owolabi, 2010). Instruments with brief completion time, simplicity, brevity and small number of items enable acceptability but may concede content validity, precision and responsiveness (Buck et al., 2000; Owolabi, 2010).

### **Mode of Administration**

Self-administered measures tend to be less resource intensive, but may be especially difficult if not impossible task for patients with cognitive or language difficulties that may affect concentration and comprehension. Equally, applying interviewer administered questionnaires may be difficult to some stroke patients with speech problems (dysphasia) and incapable to respond to an interview (Buck et al., 2000; Owolabi, 2010). Depending on the practical solution, it's therefore essential to determine whether QOL measure can be either self, interviewer-administered or both (Barak & Duncan, 2006; Buck et al., 2000).

### **Proxy suitability**

Use of proxies is applicable when there will be agreeable correspondence of responses from patients, their close relation or significant other (in answering questions as he or she believes what the patient would). It is essential to utilize proxy owing to the

difficulties that the stroke patients may encounter when communicating or understanding research questions (Barak & Duncan, 2006; Buck et al., 2000; Owolabi, 2010). In order to limit selection bias and where crucial, the use of proxies may be favoured than omitting more severe cases from trials, particularly because such individuals may probably have a considerably decreased QOL (Buck et al., 2000; Owolabi, 2010).

## **Sensibility**

Sensibility is one of the major determinants of success or failure of clinical measures. The chosen outcome measures must not be cumbersome to the patient, and must also correspond to the goals of the intervention and the study (Barak & Duncan, 2006; Houlden et al., 2006). It's also referred to as the overall appropriateness, importance, and ease of use of an instrument (Barak & Duncan, 2006; Houlden et al., 2006).

## **2.13 Predictors of HRQOL after stroke**

### **2.13.1 Patient Factors**

**Age:** Following stroke, residual disability affects the QOL. Elderly persons that were subordinate in seeking for personal aid with regards to the Activities of Daily Living graded their HRQOL lower than the others (Forsberg-Warleby et al., 2004; Gosman-Hedström et al., 2008). Poor QOL in the physical and mental domains were associated with increasing age (Nichols-Larsen et al., 2005b). On the contrary, Patel et al (2007) found that age was inversely associated with mental health at 1 year after stroke and with physical health at 3 years after stroke. Younger patients reported worse mental and physical domains of QOL. Owolabi (2008) reported that age, gender, socio-economic class (SEC), post-stroke duration, side, type and number of strokes, SLS, modified Rankin scale (mRS), social support, and Likert-graded responses to laughter and negative feelings frequencies had no significant impact on QOL. Reportedly, old age,



home residence, lack of physical exercise, and the need for the use of soft diets or tube feeding were both connected with poor QOL and handicap (Kwok et al., 2007). Gurcay et al (2009) found that age and functional status were the main independent determinants affecting HRQOL in patients 3 months after stroke. **Sex:** One of the factors that were consistently reported to be present at the onset of stroke that independently predicted HRQOL at 1 years post stroke was female sex (Carod-Artal et al., 2009; Patel et al., 2007; Sturm et al., 2004). Suenkeler et al (2002) reported that male sex at 3 and 6 months after stroke was identified as predictor of favourable QOL at 1 year post stroke ( $p < 0.05$ ). On the contrary, Owolabi (2008) found gender to have no significant impact on QOL. However, a research by Gray et al (2007) revealed that females inclined to score less than males across all QOL domains (apart from general health); significant lower scores were observed for physical functioning (OR: 0.58, 95% CI: 0.47 to 0.72), vitality (OR: 0.79, 95% CI: 0.64 to 0.98), and mental health (OR: 0.75, 95% CI: 0.61 to 0.93). Petrea et al (2009) found that at 3 to 6 months post-stroke women were more disabled, most probably to be single, and 3.5 times likelihood to be institutionalized ( $p < 0.01$ ). Carod-Artal et al (2009) found no significant differences detected by age, years of education, disability (as measured by BI and/or Lawton scale) or functional status (as measured by m-RS) among males and females. **Marital Status:** Forsberg-Warleby et al in 2004 found that compared with their life before stroke, the spouses' general life satisfaction, leisure situation, everyday occupation, sexual life, partner relationship and social contacts were reduced 4 months after stroke. In addition, no substantial change in life satisfaction was observed between 4 months to 1 year post stroke (Forsberg-Warleby et al., 2004). Interestingly, in a follow-up study at 6 and 12 months after stroke, Kwok et al (2007) reported that being married was associated with a significant decrease in QOL. **Education Level:** Education was found to be associated with almost all the domains of QOL at 6 months and 1 year after stroke (Aprile et al.,

2006; Clarke et al., 2002; Jeong et al., 2012). The buffering or moderating effect of education on the QOL of the stroke survivors was documented in various studies (Clarke, 2003b; Clarke et al., 2002; Hopman & Verner, 2003). Aprile et al (2006) found that the physical aspects of the QOL appeared to be diminished in patients with lower educational level and living with family while, the mental aspects appeared to be declined in patients with higher educational level and living alone. Contrary to this finding, Carod-Artal (2000) found lower educational status not correlated with lower QOL and there was poor correlation between increased educational level and better QOL. **Ethnicity:** There is paucity of research on the relationship between quality of life and ethnicity. Nichols-Larsenet al (2005b) discovered poorer HRQOL in the physical domain to be related to non-white race at 3-9 months post stroke. **Social Class:** Very few studies have identified the relationship between social class and quality of life after stroke. Owolabi (2008) found socioeconomic class to be associated with social support ( $p = 0.003$ ,  $r = -0.350$ ) but it had no substantial effect on HRQOL. **Financial status:** Few studies have identified the relationship between financial status and quality of life after stroke. Financial hardship was found to be associated with poorer psychological QOL either directly by the loss of work-related income and cost of formal care or indirectly by loss of income of family caregivers (Clarke & Black, 2005; Gurcay et al., 2009; Kwok et al., 2006; Lynch et al., 2008; White et al., 2008). **Self-care self-efficacy:** Robinson-Smith et al (2000) reported self-care self-efficacy to be strongly related to depression and quality of life in their study of the predictors of post stroke QOL in older Chinese adults. Lee et al (2009) reported that self care efficacy at an early stage had a constant role in post stroke QOL. **Caregiving:** Although this area has not been widely explored, there is some evidence that caregiving can have positive benefits to the stroke survivors which may include feeling a sense of accomplishment, increased sense of hope and meaningfulness (Thompson, Bundek, & Sobolew-Shubin, 1990). Other

benefits may include good physical health and satisfaction with services (Hodgson et al., 1996). **Occupation:** Vestling et al (2003) found that a total of 41% had returned to work, although employers had to make adjustments regarding assignments and working hours. Those who had returned to work demonstrated a significantly higher level in subjective well-being and life satisfaction. The ability to walk meant an enormous opportunity of going back to work (odds ratio = 3.98) followed by white-collar worker (odds ratio = 2.99) and having preserved cognitive capacity (odds ratio = 2.64) in a minimum of 6 months post stroke subjects. Rotter (2002) found that patients having a hobby and returning to work demonstrate a higher QOL. In a study which analyzed QOL after stroke for a sub sample of people aged <65 years, failure to recover the ability to work is associated with low QOL (King, 1996). In their study of clinical determinants of QOL after stroke, Patel et al (2007) reported that at 1 year after stroke, non-manual workers reported a better QOL than manual workers ( $p<0.033$ ).

### **2.13.2 Disease Factors, Functional Status and Social Support**

**Depression:** Depressive symptoms were reported to be related to poor functional status and quality of life in stroke patients (Altindag et al., 2008; Haacke et al., 2006). A study by Berg et al reported that male stroke survivors had significantly more depressive symptoms ( $p<0.001$ ) at more than 18 months after stroke (Berg et al., 2003). Some studies have consistently found significant relationships with female survivors reporting more depressive symptoms (Carod-Artal et al., 2009; Cassidy et al., 2004; Chiu et al., 2005; Leentjens et al., 2006). At 1 year post stroke, variables associated with depression were status as a housewife, female sex, incapable to work owing to disability, and reduced social activity ( $p<0.0001$ ) (Carod-Artal et al., 2000). A study by Kwok revealed that depressive mood had a fundamental and broad adverse effect on QOL between 3 months to 1 year post stroke (Kwok et al., 2007). Carod-Artal et al (2009) found mood disturbance to be a stronger and independent predictor of HRQOL among Brazilian

stroke survivors. In addition, post-stroke depression was associated with female sex, disability, and lower cognitive functioning ( $p < 0.001$ ). Motor impairment, disability, and mood disturbances (depression) were consistently reported as independent predictors of HRQOL (Carod-Artal et al., 2009; Carod-Artal et al., 2000; Sturm et al., 2004).

**Comorbidities:** Nichols-Larsen et al (2005b) found that stroke survivors with more comorbidities reported poorer HRQOL in the area of memory and thinking at 3-9 months post stroke. Other studies have also reported comorbidities as determinant of quality of life in stroke survivors (Carod-Artal et al., 2009; Hopman & Verner, 2003; Owolabi, 2008). Suenkeler et al (2002) reported that absence of diabetes at 3 and 6 months after stroke was identified as a predictor of favourable QOL at 1 year post stroke ( $p < 0.05$ ). Stroke survivors with comorbidities who were restricted in their physical and cognitive functions were more likely to report worse mental health (Clarke et al., 2002). In their study of clinical determinants of QOL after stroke, Patel et al (2007) reported that at 1 year after stroke, diabetics were worse than non-diabetics ( $p < 0.001$ ).

**Side of stroke:** Decreased QOL especially the communication domain have been observed among stroke survivors with left hemispheric lesion (right sided hemiplegia) (Barker-Collo, 2007; Carod-Artal et al., 2009; Kamel et al., 2010 ; Moon et al., 2004; Nichols-Larsen et al., 2005b; Patel et al., 2007). Findings by Barker-Collo (2007) suggested that individuals with left hemisphere lesions may be particularly at risk of developing depression and anxiety after stroke. Younger individuals are also at heightened risk of depression during the 3 months post stroke. Moon et al (2004) found that at 2 months following stroke, severe sub cortical gray matter lesion and depressive symptoms in the acute phase of stroke were of significance in predicting low QOL.

**Type of stroke:** Kauhanen et al (2000) found that QOL was poorer for patients with mild to moderate impairment 3 months poststroke caused by brain infarction . Azita et al (2001) found subarachnoid haemorrhage survivors fare as well as or better than

intracerebral haemorrhage survivors at 6 months after stroke. **Functional status:** Carod-Artal (2000) identified functional status as a predictor of quality of life at 1 year post stroke. Clarke et al (2000) found that an improvement in motor disability was found to be related to progress in quality of life throughout the first year of recovery. However, Robinson-Smith et al (2000) found that functional independence and quality of life to be improved over time, while depression was reduced. Functional independence was sufficiently correlated with quality of life at 6 months following stroke, but not at 1 month after stroke. Bosworth et al (2000) discovered that the patients' evaluations of their health status during the early first year after stroke were very steady over time, with only slight progress at 6 months, followed by an insignificant decline at 12 months. Carod-Artal (2000) reported that post stroke disability was a stronger predictor of low QOL than post stroke depression 1 year after stroke. Patients with severe/moderate disability reported lower QOL than depressed patients. It was reported that poor mental health and physical and cognitive difficulties were associated with reduced sense of QOL (Hopman & Verner, 2003; Patel et al., 2007). **Language impairment:** An indirect relationship with QOL - difficulty with aphasia is associated with lower QOL or life satisfaction in stroke survivors (King, 1996; Patel et al., 2007). The ability to communicate was rated as a highly important predictor of QOL after stroke (King, 2006; Kwok et al., 2007). Communication impairment was perceived as devastating and was a source of stress leading to loneliness (Michallet et al., 2003; Natterlund, 2010). Aphasia affected the biopsychosocial wellbeing of the stroke survivors including their participation in activities of daily living, in social activities, the ability to work, and their emotional status leading to development of depressive symptoms (LaPoint, 2005; Pound et al., 2001). **Dependency at Discharge:** Robinson-Smith et al (2000) found functional independence to be reasonably associated with quality of life at 6 months after stroke, but not at 1 month after stroke. Other studies had also reported that

vigorous rehabilitation enhanced functional outcome, and consequently influence depression positively (Appelros & Viitanen, 2004; Clarke et al., 2000). Hopeman and Verner (2003) discovered that significant gains in HRQOL during inpatient stroke rehabilitation may be followed by equally considerable decrease in the 6 months following discharge. Lee et al (2009) et al reported that length of hospital stay after admission for stroke was identified to have an independent effect on QOL at 6 months after stroke. **Disability:** as measured with Barthel *Index (BI)* was a predictor of HRQOL for all SIS 3.0' physical and social participations domain (Carod-Artal et al., 2009). On the contrary, Moon et al (2004) found that the level of neurological dysfunction, as measured by BI was not associated with the QOL status 2 months after stroke. In another study, Kwok et al (2007) found that there was substantial progress in BI, but QOL pertaining to social relationships and environment diminished between 3 and 12 months after stroke. Researcher also found improvement in functional status, between 3 and 12 months after first stroke, but QOL deteriorated considerably in terms of psychological health, social relationships, and perceived living environment (Kwok et al., 2007). Carod-Artal (2000) reported that women had a lower BI score both on admission and at 1 year after stroke and reported a reduced QOL. In a follow-up study at 6 and 12 months after stroke, Kwok et al (2007) reported that despite significant improvement in the BI score, the QOL in terms of cognitive function increased but social relationship and environment decreased. In their study of clinical determinants of QOL after stroke, Patel et al (2007) reported that at 1 year after stroke, patients with pre-morbid BI <15 were worse than those with BI 15-20 ( $p < 0.021$ ). **Modified Rankin Scale (mRS)** was found to be substantially correlated ( $-0.65 < r -0.42$ ,  $P < 0.001$ ) to the physical, psychological, intellectual and social domains of the QOL (Owolabi, 2008). Carod-Artal (2009) also reported that the mean scores of the SIS 3.0 domains were significantly higher in the patients more affected by stroke as assessed by mRS.

Appelros and Viitanen (2004) found that a low functional outcome as measured by mRS predicts depression, which also has a major impact on life satisfaction one year after a stroke. **Social environment:** In stroke survivors, social support is believed to affect the quality of patient care and disease outcome, as well as patient's physical and psychosocial well-being (Lyncha et al., 1999; Tsouna-Hadjis et al., 2000). Apart from disability, psychosocial factors such as emotional responses and social support determine HRQOL in stroke survivors (Owolabi, 2008; Yu et al., 2013). Studies have consistently demonstrated a link between low levels of social support and poor mental and physical health outcomes and have subsequently fuelled the development and evaluation of interventions designed to improve social support for those deprived of this resource (Brenda et al., 2002; Bruwer et al., 2008; Katherine et al., 2010; Lyncha et al., 1999). Living alone, being institutionalized, reduced physical function, and depression were independently linked to lower levels of patient's satisfaction over time (Bosworth et al., 2000). Social supports and educational resources moderate the impact of functional status on well-being (Clarke et al., 2002). In a study of QOL among Chinese patients, Kwok et al (2006) reported a decrease in environmental and social interaction HRQOL after 1 year of stroke.

## **CHAPTER THREE: RESEARCH METHODOLOGY**

This chapter describes and explain the methodology of the mixed-method research study and methods used. Methodology implies to the philosophical framework, while method is the research techniques and procedures for conducting the research (Wilkins & Woodgate, 2008). The subtopics in this chapter describe the study area, mixed-method research design and the rationale for using it. Next, the topics describe the research design and research procedures in accordance with the individual phases of the study. Phase I is the instruments validation phase; Phase II, is the quantitative component and; Phase III is the qualitative component. Finally, sampling methods, research instruments and statistical methods used are described where appropriate.

### **3.1 Methodology**

This section introduces the study setting, design and sampling and the philosophical foundation of mixed-method research and the justification why mixed-methods was opted as an appropriate methodology for explaining the complexity of factors associated with QOL among stroke survivors.

#### **3.1.1 Setting**

This research was carried out in Kano, one of Nigeria's main cities, which has attracted an influx of in-migration owing to its political and economic significance. Kano state is the most populated state in Nigeria with the current estimated population of over 12 million people (Galadanci et al. 2010), although the 2006 census puts Kano's population at 9,383,682 with an almost equal distribution of male (51%) and female (49%) (Federal Ministry of Health of Nigeria; Galadanci et al. 2010; Kano State Economic Empowerment and Development Strategy (K-SEEDS), 2004). The state is divided into 44 Local Government Areas, 40 State Constituencies, 24 Federal



Constituencies and 3 Senatorial Districts (Federal Ministry of Health of Nigeria; Galadanci et al., 2010; Kano State Economic Empowerment and Development Strategy (K-SEEDS), 2004). It is geographically situated at 12°00'N 8°31'E and occupies an area of 20,131km<sup>2</sup> with a population density of 466/km<sup>2</sup>. The climate of Kano is generally dry and wet with annual rainfall of about 850-870mm (Kano State Economic Empowerment and Development Strategy (K-SEEDS), 2004). The average temperature is about 27°C and varies from warm to hot throughout the year. Historically, Kano has been a commercial and agricultural state and is famous for its production of groundnuts and solid mineral deposits (Kano State Economic Empowerment and Development Strategy (K-SEEDS), 2004). Kano state is situated in the North-Western part of Nigeria and was created on May 27, 1967 from the Northern Region (Kano State Economic Empowerment and Development Strategy (K-SEEDS), 2004). Kano city, the state capital, is a manufacturing centre producing processed foods, textiles, furniture, cement, rolled steel and light trucks. It borders Katsina state to the north-west, Jigawa state to the north-east, and Bauchi and Kaduna states to the south. The primary inhabitants of the state are the Hausa/Fulani people who are predominantly of Islamic faith and Hausa language is commonly spoken in the state but there are also Nigerians from other parts of the country and foreigners (Galadanci et al., 2010; Kano State Economic Empowerment and Development Strategy (K-SEEDS), 2004). The people of Kano are known to be very enterprising and industrious (Galadanci et al., 2010; Kano State Economic Empowerment and Development Strategy (K-SEEDS), 2004). The state is crossed by the main (Lagos-Nguru) railway and by highways that link it to Kaduna and Bauchi states. Kano city also has an international airport. Kano is endowed with wooded savannah in the south and scrub vegetation in the north and is drained by the Kano Chalawa-Hadejia river system. The state's light sandy soils are excellent for growing peanuts (groundnuts), which is a major export. Other crops include cotton,

onions, indigo, tobacco, wheat, and gum Arabic; Millet, sorghum, beans, cowpeas, and corn (maize) are subsistence crops. Cattle, horses, goats, and sheep are grazed, and hides and skins are exported. Tin and columbite are mined. Life expectancy in Kano State is 51 years for male and 52.2 years for women (Galadanci et al., 2010; Kano State Economic Empowerment and Development Strategy (K-SEEDS), 2004; "Status of Emergency Obstetric Services in Six States of Nigeria- A needs Assessment Report,"). The infant mortality rate is 110 per 1000 live birth and maternal mortality is 1700 per 100,000. The literacy rate is 35% and 75% of the population live in rural areas. There is a gender bias with regards to access to education. Compared to 76.6% of male children, only 31% of the female children have access to education. Primary school enrolment rate is 90%, secondary school enrolment rate is 80% and tertiary institutions enrolment rate is 60% (Galadanci et al., 2010; "Status of Emergency Obstetric Services in Six States of Nigeria- A needs Assessment Report,"). Overall, the women enrolment is lower with primary school enrolment of 40%, secondary school enrolment of 35% and tertiary institutions enrolment of 20% (Galadanci et al., 2010; "Status of Emergency Obstetric Services in Six States of Nigeria- A needs Assessment Report,"). Only 37.6% have access to piped water supply (Federal Republic of Nigeria, 2009; Galadanci et al., 2010).

This study was conducted at three stroke referral hospitals that are dedicated to the rehabilitation and neurologic disorders in Kano, Nigeria. These hospitals were Aminu Kano Teaching Hospital, Murtala Mohammad Specialist Hospital and Mohammad Abdullahi Wase Specialist Hospital. Patients with a diagnosis of stroke who were admitted or seen as outpatients at the neurology and physiotherapy clinics in these three hospitals between December 2010 and January 2012 were included in the study.



**Figure 3.1: Map of Kano, Nigeria (Insert- Nigeria map)**

### **3.1.2 Philosophical Foundation of Mixed-Methods Research**

Mixed-Methods are an evolving philosophical assumption of the research process (Creswell & Plano-Clark, 2011), in which a researcher combines elements of quantitative and qualitative research approaches for the purpose of breadth of understanding or corroboration (Johnson et al., 2007). This approach is particularly useful to understand the complexity of factors affecting the QOL of the stroke survivors.

Johnson et al (2007) refers to the methodology utilized in this mixed-method study as “pragmatism of the middle”. Johnson and colleagues uphold that pragmatism allows for the mixed-method research to exist side-by-side with philosophies of quantitative research which has been historically synonymous to post-positivist world view; and the qualitative research which has been historically synonymous with constructionist worldview (Giddings & Grant, 2006). Pragmatic philosophy argue that truth is “what works” for judging answers to the research questions presented (Johnson et al., 2007). The main assumption of pragmatism is that quantitative and qualitative methods are compatible rebuffing the view that they are opposing paradigms.

The methodological division result from the view points that each design conform to a distinct epistemological paradigm (Clarke, 2003a, 2003b, 2009; Lempp & Kingsley, 2007; Sale et al., 2002). Consistent with this point of view, quantitative research falls within a positivist paradigm, which speculates that the world is typically stable and predictable, complying with conventional standards and norms. Conversely, qualitative research is considered by a number of researchers to fall within the interpretive paradigm, and hypothesises that the world is in a changing form of transition with varied individual realities. Quantitative approach is therefore considered as convenient for deductive explanatory analysis under standardized and controlled situation, while qualitative strategies are applied to examine research inquiry inductively under uncontrolled natural conditions (Clarke, 2003a; Curry et al., 2009; Lempp & Kingsley, 2007; Shah & Corley, 2006). A number of researchers urged that instead of engaging in a philosophical debate, it is preferable to recognize quantitative and qualitative approaches as a continuum in research methods and each is best suited according to the research objective. They uphold that both approaches are essential in understanding

human experience (Casebeer & Verhoef, 1997; Clarke, 2009; Curry et al., 2009; Lempp & Kingsley, 2007; Morgan, 2007; Shah & Corley, 2006).

### **3.1.3 Rationale for the Mixed-Methods Design**

This study needed the mixed-method approach because corroboration of associations in quantitative studies have failed to explain the underlying reasons why and how individuals retain or lose their sense of wellbeing after stroke (Lempp & Kingsley, 2007; Sale et al., 2002; Shah & Corley, 2006). Against this background, Clarke (2003, 2009) further asserted that a considerable depth of knowledge could be gained by advancing the study of stroke experience from both quantitative and qualitative perspectives.

Mixed-methods research design is used because neither quantitative nor qualitative methods are independently sufficient to obtain the essence and course of an event or occurrence, such as understanding the complexity of factors affecting the QOL of stroke survivors. Mixed-methods design contributes to an extensive understanding of an issue than a single method design and it can compensate the flaws in each of the methods utilized. It can report bias in the manner of interpreting a phenomenon, and can reinforce assimilation and applicability of data (Giddings & Grant, 2006).

The use of a mixed-method approach in a single research design is increasingly becoming a common practice in clinical medicine and health services research (Clarke, 2003a; Curry et al., 2009; Lempp & Kingsley, 2007; Sale et al., 2002). The quantitative research paradigm which has long been the emphasis of medical research now increasingly considers qualitative research methods as a way to broaden the scope of evidence-based medicine (Green & Britten, 1998; Lempp & Kingsley, 2007). Quantitative research emphasizes on the importance of measurement and analysis of

causal relationship between variables (Leff & Goldstein, 2003; Lempp & Kingsley, 2007; Shah & Corley, 2006). However, the corroboration of associations in quantitative studies failed to explain the underlying reasons why and how individuals retain or lose their sense of wellbeing after stroke (Lempp & Kingsley, 2007; Sale et al., 2002; Shah & Corley, 2006). In stroke studies, qualitative paradigm underscore the individual's viewpoint of their stroke experience and discovered that stroke survivors describe their losses and improvement according to their subjective interpretation of crucial or important activities in life instead of the standard definition of disability (Clarke, 2009; Gubrium et al., 2003; McKeivitt et al., 2004; O'Connell et al., 2001). Therefore, qualitative study may help us explore the nature and reasons why and how stroke affects the individual's wellbeing (Clarke, 2009; Curry et al., 2009; Sale et al., 2002).

## **3.2 Method**

This section describes the research design that was utilized to obtain information rich data, design consideration and procedures. The role of the researcher and ethical considerations are also discussed.

### **3.2.1 Research Design**

The research design was formulated based on the research objectives. This study utilized mixed-methods research design which is a procedure for collecting, analysing and “integrating” both quantitative and qualitative data at some point of the research processes within a single study.

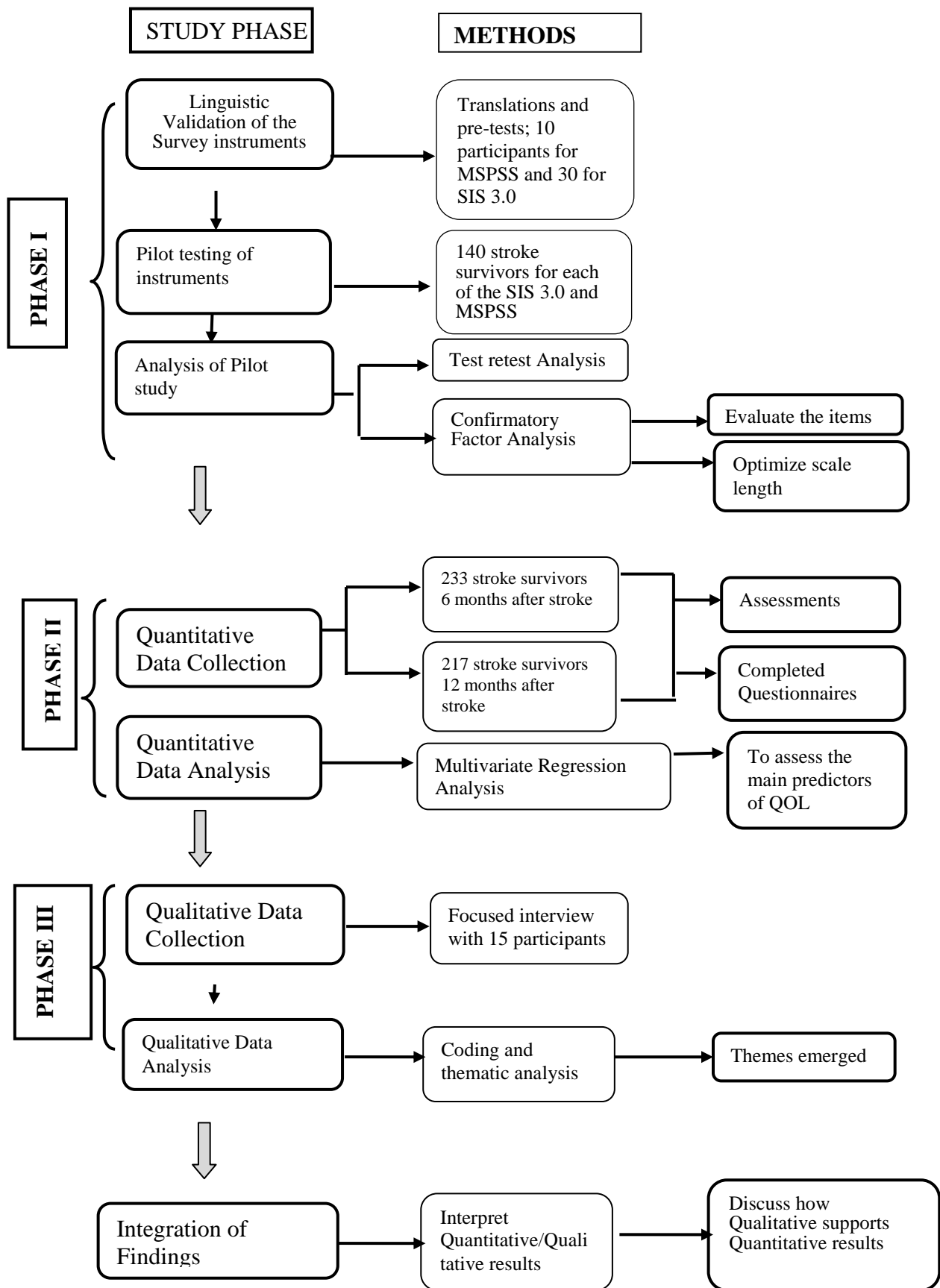
### **3.2.2 Design Considerations**

When designing a mixed method study three issues are taken in to consideration: (1) *Priority* refers to which of the method, quantitative or qualitative (or both) had more emphasis, (2) *Implementation* refers to the sequence of the quantitative and qualitative data collection and analysis, and (3) *Integration* refers to where mixing of the

quantitative and qualitative approaches occurred in the study (Wilkins & Woodgate, 2008). A visual representation of the study was also developed to guide and to ensure a better conceptual understanding of the design in accordance with the research questions and methodological discussions in the literature (Creswell, 2003). **Priority:** Priority was given to the quantitative methods. This study utilizes mixed methods research design essentially for the purpose of elaboration where quantitative approaches are first used in order to identify the domain specific predictors of QOL at 6 months and 12 months after stroke, followed by a qualitative phase, which aims to explore the mechanism or the necessary reason for the recognized patterns. **Implementation:** The study was generally conducted in three phases. Phase I was conducted in order to validate the adopted instruments, because there were no developed tools or translated scales for the measurement of quality of life and assessment of social support among stroke survivors in Nigeria. Since SIS 3.0 and MSPSS were developed in English (see Figure 1 & 2), it is essential to carry out linguistic and psychometric validations of the instruments. Phase II (quantitative phase) identified the patterns and correlates of QOL at 6 months and 12 months after stroke. The Third phase (qualitative phase) explained the underlying meaning and processes by which QOL is affected after stroke. **Integration:** Triangulation is the most common purpose of mixed-method researches where quantitative and qualitative methodological approaches could be mixed, so that results from the two approaches are applied to compliment the validity of the findings by the process of corroboration or searching for concurrence (convergence) in findings across designs (Clarke, 2003b; Teddlie & Tashakkori, 2003). Alternatively, the findings from one approach can again be applied to elaborate on or augment the findings from another method (Clarke, 2009). This study utilizes mixed methods research design (sequential explanatory strategy) essentially for the purpose of elaboration where quantitative approaches are first used in order to identify the patterns and correlates of QOL at 6

months and 12 months after stroke, followed by a qualitative phase, which aims to explore the necessary reason for the recognized patterns. *Visual Model*: Without a graphical representation of the procedures used in the study, it will be difficult to understand the multi-phase nature of a mixed-method research. A visual representation of the mixed-method procedure helps conceive the ordering of data collection, priority of the method and the mixing point of the methods within a study. Figure 3.2 illustrate the sequence of data collection and analysis of the sequential explanatory procedure, priority of the quantitative phase, connection between the quantitative and the qualitative phases and where integration or mixing of the results of both quantitative and the qualitative occurs.





**Figure 3.2: Procedures for Explanatory Sequential Mixed Method Study**

### **3.3 Ethical approval**

Approval for the conduct of this study was obtained from the Medical Ethics committee of the University of Malaya (Eth. Comm. /IRB Ref number 830.7), Ministry of Health Kano state, Nigeria (HMB/GEN/488/11) and Aminu Kano Teaching Hospital, Nigeria (AKTH/MAC/SUB/12A/P3/IV/801) which were in accordance with the principles of the Declaration of Helsinki. Refer to Appendix A for the respective approval certificates. Data collection commenced soon after ethical approval and access was secured. Written informed consent (see Appendix B) was also obtained from each patient or from their proxies prior to participation. All interviews were audiotaped with the permission of the respondents.

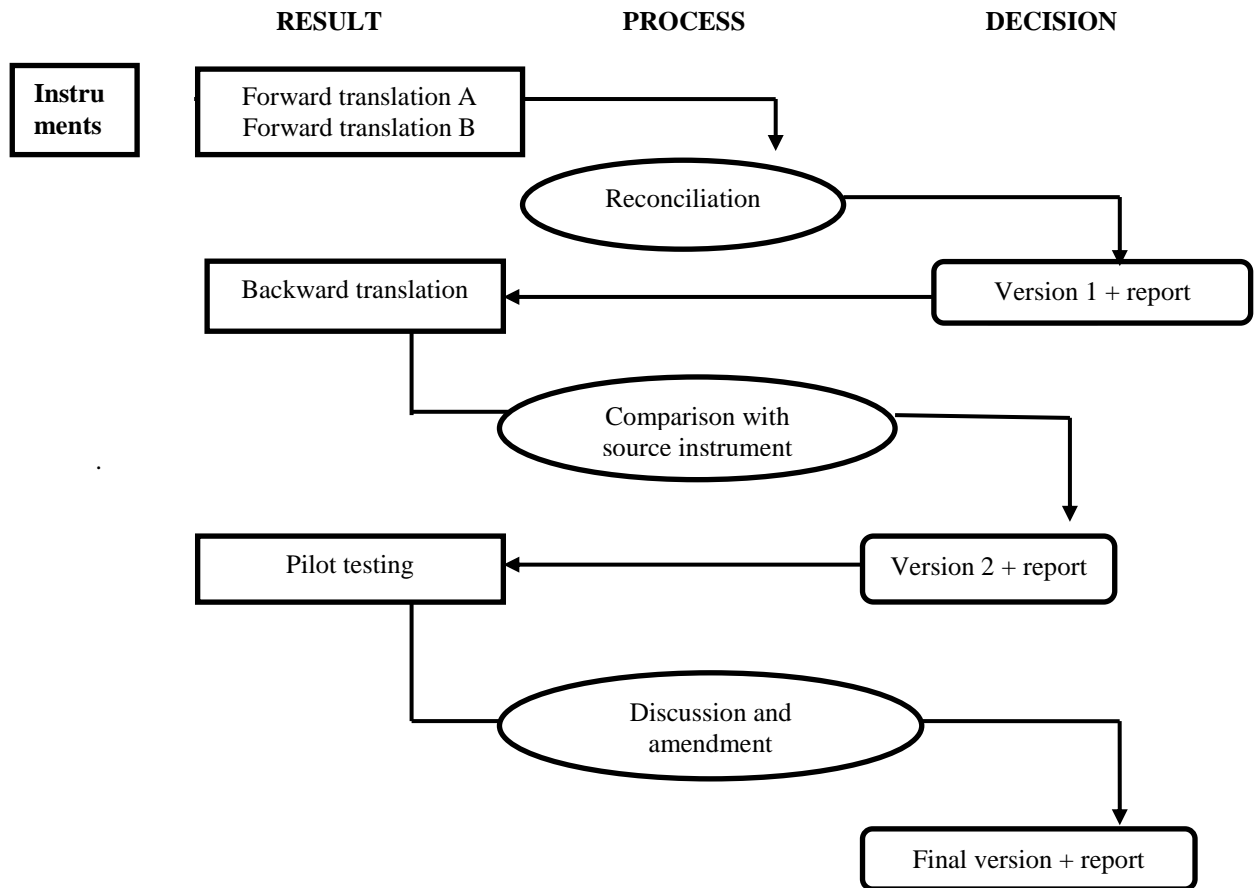
### **3.4 Role of the Researcher**

The researcher's engagement in the collection of quantitative and qualitative data for the study is described as follows. In collecting the quantitative data, the researcher segregated variables using a questionnaire and causally related them to determine the changes that occur over time and identify the domain specific predictors of health-related quality of life among stroke survivors. The researcher performed rigorous statistical analyses and explained the results based on the established values for statistical significance. For the qualitative data, the researcher performed an in-depth interview. During the interview, the researcher assumed a more participatory role and became immersed in the interview data.

### **3.5 PHASE I: INSTRUMENTS VALIDATION PHASE**

This section details the procedure involved in the linguistic and psychometric validations, study sample, data collection methods, and approach to data analysis of the SIS 3.0 and MSPSS for future use in clinical research and practice in Nigeria. Ethical issues considered during the planning and conducting of this phase are addressed.

Mapi's five stage recommendation (Acquadro et al., 2004) for cultural and linguistic validation which is also similar to Beaton et al (2000) guidelines for cross-cultural adaptation of self-report measures was used (figure 3.3). In the guidelines, a five stage process is recommended: translation, synthesis, back translation, expert committee review and pilot testing, the adaptation of the concepts to the identified target population's culture and to the original connotative meaning. Permission for the use and validation of the scales were obtained from the copyright owners. The translations and validations of MSPSS and SIS 3.0 were conducted in close collaboration between the translation committee that consisted of five experts from University of Malaya, Bayero University Kano, Nigeria and professional translators of the Freedom Radio Nigeria *muryar jama'a 99.5FM* (an independent radio) and the copyright owners/developers of the questionnaires (see Appendix C for the approval certificate).



**Figure 3.3: Algorithm of the linguistic validation processes**

### 3.5.1 Validation of the Stroke Impact Scale (SIS) 3.0 index

While the use of outcome measures has generated increased interest in recent years (Carod-Artal et al., 2009; Doyle, 2002), the use of stroke specific measures such as the SIS 3.0 is also receiving a growing motivation in its use to evaluate QOL among stroke patients across cultures (Duncan et al., 2003; White et al., 2007). At the moment, there is no tool developed in Hausa language for the evaluation of QOL among stroke survivors. Since SIS 3.0 is written in the English Language, it is necessary to carry out linguistic validation of the MSPSS in Hausa language and further evaluate its psychometric properties so that it can be used in clinical research and practice in Nigeria.

The development of the Hausa version of the SIS 3.0 (see Appendix G) involved linguistic translation and testing of the psychometric properties of the Hausa-SIS 3.0. These cognitive processes are deemed important to make sure that the Hausa-SIS 3.0 was measuring the same concept as the original English version. This is important if comparisons are to be made on the QOL outcomes between different cultures.

### ***Description of the Study Instrument***

The Stroke Impact Scale (SIS) version 3.0 (Appendix D3) is a stroke specific measure of QOL that has undergone extensive psychometric testing and reported excellent internal consistency, with Cronbach's alpha values ranging from 0.93 reaching to close to 1 (Altindag et al., 2008; Carod-Artal et al., 2008; Carod-Artal et al., 2009; Duncan et al., 2003; White et al., 2007). SIS 3.0 was developed based on the viewpoint, perception, position and contributions of stroke patients, caregivers, and health professionals with stroke expertise (Duncan et al., 2003). It is a psychometrically robust 59-item stroke-specific self-report measure developed to assess a number of dimensions of QOL. It consist of 8 domains: strength, hand function, mobility, physical and instrumental activities of daily living (ADL/IADL), memory and thinking, communication, emotion and social participation. Scores for each domain range from 0 to 100, where higher scores indicate better QOL. The items in Strength subscale measure physical strength. The items in memory and thinking, communication, ADL/IADL, mobility and hand function subscales measure the level of difficulty. Items in the emotion and social participation subscales are rated in terms of frequency. The SIS 3.0 also includes a question (item 60) to assess the patient's global perception of recovery. The respondent is asked to rate his or her percentage of recovery on a visual analogue scale of 0 to 100, with 0 meaning no recovery and 100 meaning full recovery.

Past studies indicate substantial improvement in most SIS 3.0 domains in patients recovering from mild and moderate stroke (Daina & Daiva, 2006; Duncan, 2000).

The aim of the forward translation step was to obtain a Hausa language version of SIS 3.0 with conceptual, semantic and operational equivalence to the original U.S. English version. The SIS 3.0 was translated into Hausa by two professional translators from the Freedom Radio Nigeria *muryar jama'a 99.5FM* (an independent radio station). The translators were selected based on their experience and track record of success in linguistic translations. Their mother tongues were Hausa and they were proficient in English. The two bilingual translators worked independently, so that neither of them would influence the translation of the other. One of translators had some experience in working as a professional translator in health related areas and was well acquainted with the aims and general ideas that were being assessed by the instrument. The other translator had no any prior knowledge of the instrument's objectives. Upon the completion of the translations, comparison and reconciliation of the translations was done in a series of meetings between the investigators and the translators. Linguistic issues that were raised were resolved by way of further consultations and consensus. The first reconciled version was developed in Hausa based on these two forward translations and the reconciliation.

The second step involved a backward translation of the reconciled language version to the source language (U.S. English). This was done by a third translator, a professional who was a native Hausa speaker and fluent in English and had no prior knowledge of the instrument. The backward translated version was compared with the original SIS 3.0 by five multidisciplinary team members. The translation discrepancies that resulted

were rectified during this process to ensure semantic and conceptual equivalence of the Hausa version.

Pilot testing and cognitive debriefing was conducted with a sample of 30 stroke patients. The respondents, with mean age of 57.7 years, took an average of about 15-20 minutes to complete the questionnaire. The cognitive testing was conducted to ensure that the Hausa version was understandable, acceptable and the language used was simple and appropriate for its intended future use. This preliminary test was done by face-to-face interviews with the patients in order to obtain feedback (remarks and suggestions) for the Hausa scale. After some essential revisions, the final reconciled Hausa version, the Hausa-SIS, was produced based on the results obtained from the clinicians' review and respondents' feedback. At each stage of the above processes, a summary report was organised and reports were sent, verified and accepted by Mapi research Institute in Lyon, France, on behalf the copyright owners. For test-retest reliability analysis, the final Hausa-SIS 3.0 was administered among 35 stroke patients and they were reassessed a week after the first evaluation.

Subsequently, the psychometric properties of the Hausa-SIS 3.0 was tested using a sample of 140 stroke surviving patients, aged between 35 to 82 years old, selected consecutively from the three stroke referral hospitals in Kano, Nigeria. Besides testing the questionnaire, the feasibility of administering the questionnaire under field conditions was also noted. In the confirmatory factor analysis (CFA), the AMOS version 18 software was used to test the instrument validity. CFA categorically tests a priori hypotheses about relations between observed variables and latent variables or factors (Brown, 2006; Jackson et al., 2009).

### **3.5.2 Validation of the Multidimensional Scale of Perceived Social Support (MSPSS) index**

In view of the role of social support as a coping resource, and its association with stressors and mental and physical wellbeing (Bruwer et al., 2008), there is a growing impetus in the use of the Multidimensional Scale of Perceived Social Support (MSPSS) to evaluate perceived social support across cultures (Cheng & Chan, 2004). Although MSPSS was initially designed to assess social support in adolescents to assess perceptions of social support adequacy among adolescents from three different sources: family, friends, and significant others, a growing body of research about the utility of the MSPSS revealed that it's a useful measure for many populations including cardiovascular disease populations and the elderly (Canty-Mitchell & Zimet, 2000; Edwards, 2004). There are no developed tools or translated scales in Hausa language for the assessment of social support among stroke survivors in Nigeria. Since MSPSS was developed in English (see Figure Appendix D2), it was necessary to carry out a translation and trans-cultural adaptation of the questionnaire where it was intended to be used. Therefore, the aim is to carry out linguistic validation of the MSPSS in Hausa language and further evaluate its psychometric properties for future use in clinical research and practice in Nigeria.

The procedure involved in the development of Hausa version of MSPSS (see Appendix H) involved the process of linguistic and psychometric validations of the Hausa-MSPSS. These cognitive processes were to ensure that the Hausa-MSPSS was measuring the same concept as the original scale, thereby enabling comparisons between different cultures.



### ***Description of the Study Instrument***

**MSPSS** (Appendix D2) is a well validated and psychometrically rigorous 12 items concise instrument used for measuring the hierarchical structure of perceived social support from family (items 3, 4, 8 and 11), friends (items 6, 7, 9, and 12), and a significant others (items 1, 2, 5, and 10) (Zimet et al., 1988). Though not developed specifically for stroke patients, MSPSS was designed to address several issues concerning social support. MSPSS has a number of properties which suggest that it may be a valuable tool for use in research in a variety of populations, including cardiovascular disease and the elderly (Canty-Mitchell & Zimet, 2000; Cheng & Chan, 2004; Cheng & Chan, 2004; Edwards, 2004). Previous studies have indicated MSPSS to have good internal consistency, test-retest reliability, and strong factorial validity in addition to good construct validity (Bruwer et al., 2008; Canty-Mitchell & Zimet, 2000; White et al., 2007). The perceived social support is measured on a 7-point likert-type scale (1 very strongly disagree; 2 strongly disagree; 3 mildly disagree; 4 neutral; 5 mildly agree; 6 strongly agree; 7 very strongly agree).

The forward translation of the English version of the MSPSS to Hausa was carried out by 2 independent professional translators of the Freedom Radio Nigeria muryar jama'a 99.5FM (an independent radio). The aim of the forward translation step was to obtain a version in Hausa language with conceptual, semantic and operational equivalence to the original U.S. English version. The MSPSS was translated to Hausa by two bilingual translators, whose mother tongues were Hausa and proficient in English. The two bilingual translators worked independently, so that neither of them would influence the other's translation. One of them, with experience working as a professional translator in health related areas, was familiar with the aims and constructs being assessed by the instrument, whereas, the other was not, nor had any prior knowledge of the instrument's

objectives. A series of five meetings were conducted by a multidisciplinary expert committee for review and comparison of the two drafts. After reconciliation, the translation that was more equivalent to the original English version and appropriate for Hausa was selected.

The second step involved backward translation of the draft Hausa-MSPSS questionnaire in to English. The backward translation of the reconciled Hausa language version was done in the source language (U.S. English) by a professional translator who was a native Hausa speaker and fluent in English, and had no prior knowledge of the instrument. The backward translated version was compared with the original MSPSS by the multidisciplinary team and an initial version of Hausa-MSPSS was proposed. During the translation process, translation discrepancies and linguistic issues were taken into consideration and modifications were made accordingly.

Cognitive debriefing and patient testing was conducted with a non-random sample of 30 stroke patients. Respondents with mean age of 58.76 years took an average of about 5-10 minutes to complete the questionnaire. The cognitive testing was to ensure that the final Hausa version was understandable, acceptable and the language used was simple and appropriate for the intended future use of the questionnaire. This preliminary test was done by face-to-face interviews in order to acquire feedback remarks and suggestions on the Hausa scale from the interviewees. Based on the clinicians' review and respondents' feedback the initial Hausa version was revised. A summary report on the revisions was sent to the copyright owners and it was accepted by them.

The final version of the Hausa-MSPSS questionnaire was administered among 35 stroke patients. These patients returned to the clinic again to complete the Hausa MSPSS a

week after the first evaluation. The data collected were used in reliability and test-retest reliability analyses.

Finally, the psychometric properties of the translated Hausa-MSPSS were assessed using data collected from 140 consecutive stroke survivors from the three stroke referral hospitals in Kano, Nigeria. The age of the patients ranged from 40 to 80 years old. Using AMOS 18, a series of CFA was performed to examine the nature of and relations among latent constructs. CFA categorically tests a priori hypotheses about relations between observed variables and latent variables or factors (Brown, 2006; Jackson et al., 2009). Besides testing the questionnaire, the feasibility of administering the questionnaire under field conditions was also noted.

### **3.5.3 Data Analysis**

The psychometric properties of the Hausa-SIS 3.0 and MSPSS were tested through test-retest reliability, content validity, face validity, criterion validity, construct validity and internal consistency. Double data entry was carried out and cross-checked to assure the consistency and quality of the data. Most analyses were carried out using the statistical program SPSS for Windows version 20.0. Descriptive statistics were obtained for demographic variables; means and standard deviations for continuous variables and frequency and percentages for categorical variables. The face and content validity were tested through a pilot test involving stroke patients during the linguistic validation process by the experts in quality of life measures, public health and stroke rehabilitation. The criterion validity of the Hausa-SIS 3.0 and MSPSS were assessed for their ability to measure what they were intended to measure (Field, 2009). Confirmatory factor analysis (CFA) was performed using AMOS version 18 to determine if the number of factors and the loadings measured (indicator) variables on them conform to

what is expected on the basis of pre-established theory (Brown, 2006). In the CFA, the 8 and 3 constructs with their respective indicators were tested for SIS 3.0 and MSPSS respectively.

### ***Test-retest Reliability Analysis***

Test-retest reliability measures stability over time and was achieved by re-administering the questionnaires a week later to the same participants. This interval was chosen so that reliability estimates are not overestimated due to memory effect (Garson, 2012). Reliability on the other hand, refers to the reproducibility of the measurement when it's randomly repeated for the same study participants.

The present study used the Cohen's Kappa ( $k$ ) in the reliability analysis. Kappa is the commonly used technique for estimating the paired inter-rater agreement for nominal and ordinal data (Fleiss, 1981). With ordinal variables (likert scale), one must select weights arbitrarily to calculate weighed kappa. Maclure and Willet (1987) reported that, a weighed kappa measures the agreement between 2 raters, where disagreement involving distance values are weighed more heavily than disagreements involving more similar values. For example, the ability to carry out the ADL on 5-point rating scale (1=could not do at all, 2= very difficult, 3=some-what difficult, 4=a little difficult and 5=not difficult at all) denote how capable they are in carrying out the activities during a typical day. For weighed kappa, a rating of 1, 2 and 5 on a 5-point Likert scale would be weighed more heavily whereas ratings of 3 and 4 for the same variables (a minor disagreement) would have a low weighting. Therefore, weighed kappa is appropriate for ordinal scales (Lantz, 1997).

Below are the criteria for test-retest reliability according to Landis and Koch (1977):

- Poor agreement less than 0
- Slight agreement 0.01 to 0.20
- Fair agreement 0.21 to 0.40
- Moderate agreement 0.41 to 0.60
- Substantial agreement 0.61 to 0.80
- Almost perfect agreement 0.81 to 1.00

### ***Internal Consistency***

Internal consistency measures the degree to which item responses obtained at the same time correlates highly to each other. Reliability of an instrument is a necessary condition for the validity of the measurement, as it indicates that the construct is truly measuring the intended dimensions. Therefore, construct reliability must be established before a construct validity (Hair et al., 2010). The internal consistency of items in the scale was estimated using Cronbach's alpha, also referred to as the reliability coefficient. Cronbach's alpha was computed for each factor domain. Garson (2012) reported that the widely accepted cut-off for social science studies is alpha 0.70 or higher for a set of items to be considered a scale, but some use 0.75 Or 0.80 while others are more lenient lowering it to 0.60 for studies using large sample size. ***Confirmatory Factor Analysis*** (CFA): CFA is a tool to either 'confirm' or 'reject' a pre-conceived theory (Hair et al., 2010). The aim of CFA is to identify models that can provide statistically acceptable fit and theoretically meaningful interpretation of the data. If the result indicates a lack of fit based on the substantive evidence, the model can be corrected. The CFA provides additional diagnostic information that may suggest the need for adjustment to improve the model's test of measurement theory (Hair et al, 2010). This is performed by removing from the model all straight arrows connecting

latent variables, adding curved arrows representing the covariance between every pair of latent variables and leaving the straight arrows from each latent variable in its indicator variable as well as leaving straight arrows from error and disturbance terms to their respective variable. Model correction was based on the analysis of the standardized factor loadings and the value of the Consistent Akaike's Information Criterion (CAIC) (Choo et al., 2013). Nonetheless, in developing a theory and modifying the models, the content of the theory is equally essential when making a decision whether to retain or include a statement (item) (Choo et al., 2013)

A series of CFA was performed to confirm the factor structure in order to support the validity of the scales (Worthington & Whittaker, 2006). The CFA was performed using the maximum likelihood estimation (MLE) in AMOS 18 on 140 samples different from the study samples in the quantitative phase. In accordance with the proposal by Clark and Watson (1995) the number of items in an instrument determines the sample size to be used in the psychometric testing. For an instrument with 20 items or less, a sample size between 100 and 200 subjects is deemed to be adequate (Clark & Watson, 1995; Yusof & Jaafar, 2012). Byrne (2010) stated that another requirement of CFA is that one hypothesizes beforehand the number of factors in the model and then test this hypothesized structure statistically to define the adequacy of its goodness-of-fit to the sample data.

In CFA both the 8 constructs of the SIS 3.0 with a total of 59 items and the 3 constructs of the MSPSS with 12 items were assessed. CFA was conducted in a two-step procedure. First, a one factor congeneric measurement model was conducted on each construct. The congeneric measurement model is a measurement model that hypothesizes no covariance between or within construct error variance meaning they are

all fixed at zero (Hair et al., 2010). The procedure begins by listing the constructs that comprises the measurement model. Second, confirmatory factor models were investigated for one factor congeneric models to assess the measuring model overall fit. Hair et al (2010) reported that it was also recommended to have a minimum of 3 items or more per factor. In this step, all individual construct come together to form the overall measurement model.

Assessment of construct validity involves the measurement of a relationship between items and constructs known as a path estimate. The indicator of path estimates is based on the factor loadings which should be at least 0.5 and ideally 0.7 or higher. If loadings is 0.5, the factor is explaining half the variation in the item with the other half being error variance. Factor loadings greater than 0.6 are considered to be significant and do not load high if the coefficient is below 0.4 (Hair et al., 2010). Loadings of this size or larger confirm that the indicators are strongly related to their associated constructs and are an indication of construct validity (Hair et al., 2010).

Goodness-of fit indices were used to determine the overall fit of each other factor model. Hair et al (2010) reported that models with good fit are deemed to adequately represent the data and can confidently be generalized to the entire population. AMOS prints 25 different goodness-of-it measures. It was suggested that at least one measure from each classification from the goodness of fit indices should be employed (Hair et al., 2010). Seven fit statistics tests were chosen for this study to assess the overall fit of the model. First, the non-significant chi square ( $X^2$ ). However, Joreskog and Sorbom (1993) stated that the chi square test may provide inaccurate model of fit if the sample is too large or is a violation of multivariate normality. The normed chi square test ( $X^2/df$ )

therefore is used to supplement the result of the chi square test. The normed chi square index should be below 3 (Bentler, 1990).

Two measures on the absolute fit classification were used. A goodness-of-fit index (GFI) greater than 0.9, represent a good model fit (Joreskog & Sorbom, 1984). The root mean square error of approximation (RMSEA) is a common measure of fit notably because it does not require comparison with the null model. RMSEA assess the lack of fit of the model to the population covariance matrix. Browne and Cudeck (1993) reported that RMSEA index values up to 0.80 indicate a reasonable fit and at least less than 0.10 as an acceptable model fit.

The Comparative Fit Index (CFI) and Normed Fit Index (NFI) were used in the CFA given their appropriateness as indicators of global fit with a small sample size (Byrna, 2010). CFI and NFI index values greater than 0.90 indicates a satisfactory fit (Bentler, 1990). The Akaike Information Creteion (AIC) was used for model comparison, a model that that fits with the smallest values of the AIC being the most parsimonious fitting mode (Byrna, 2010).

A model is considered a good fit if the value of the chi square test is insignificant, and at least one incremental fit index (e.g. CFI, GFI, AGA, TLI etc) has an index of <0.9 and one poor fit index (e.g. RMSEA, SRMR, RMR etc) has an index <0.08. The squared multiple regression coefficients ( $R^2$ ) associated with the latent variable of QOL domain was used to evaluate the effectiveness of the model explaining the variance observed in the participant's QOL.



Bootstrapping procedure was performed as an aid to non-normal data. Hayes and Preacher (2010) stated that bootstrapping is an attractive alternative for inference when assumptions of commonly-used statistical methods are not met. The shape of the sampling distribution of the statistic is unknown or standard error of the statistical index is difficult or impossible to derive analytically. The re-sampling method has more accurate Type I error rates and power than single method that assumes a normal distribution (Hu, 2010). In this study, SIS 3.0 domains assessed HRQOL data were positively skewed and therefore, bootstrapping replicates 1,000 samples were applied to obtain normal distribution. All other assumptions of statistical multivariate were met with variance inflation factors of less than 2.0 and tolerance of more than 0.50 indicating no issue with collinearity.

During the conduct of CFA, missing data was expected to be minimal for most variables and if such occurred will be imported with a series of means. The assumption of univariate normality was assessed through variable skewness and kurtosis. All skewed values should be less than 1 magnitude to assume symmetry of individual values. The Mardia statistics for multivariate normality is calculated and the CR value should be less than 5 in magnitude for multivariate normality to be assumed.

## **3.6 PHASE 2: METHODOLOGY FOR QUANTITATIVE COMPONENT**

This prospective longitudinal observational study was carried out in the Department of Medicine and Physiotherapy of Aminu Kano teaching hospital and two specialist hospitals (Murtala Muhammad Specialist Hospital and Muhammad Abdullahi Wase Specialist Hospital) of Kano state of Nigeria, The hospitals are the major centres for admission and or referral of most of the stroke patients in the state. This section details the research design that was applied to the study sample, data collection methods, and approach to data analysis. Ethical issues considered during the planning and conducting of this phase of the mixed methods study are addressed.

### **3.6.1 Research design**

A prospective longitudinal observational study design was appropriate to answer the research question. The investigator was interested in identifying the predictors of QOL at 6 months and 12 months after stroke.

### **3.6.2 Sample size**

The sample size for the study was estimated using OpenEpi version 6 based on the physical health exposure factor with Odds Ratio (OR) of 0.58. The selected exposure factor for the physical health is based on previous study. Using the physical health as exposure factor with CI 95%, power of the study 80%, ratio of unexposed to exposed in a sample is 1, % of exposed with outcome is 3, a sample size of 3082 is required to detect an odds ratio of 0.58. However, due to time constraint and the reported 30 days case fatality of 40%, it is not possible to get the 3082 sample size within the time period. Therefore, the sample size for the study was estimated according to the procedure put forward by Tabachnick and Fidell (2007) where: for simple linear and multivariate regression, a minimum sample size of 104 is required. Field (2009) and Hair et al (2009) suggested that an addition of 5 cases for every addition of predictors is

needed. In this study and at baseline comparison, there are 25 predictors. Thus, the sample size in this study is computed as:  $n = 104 + 25(5) = 104 + 125 = 229$ .

### **3.6.3 Sample recruitment**

Following approval, study respondents were consecutive stroke survivors, who were admitted or referred for stroke in the aforementioned hospitals between 1<sup>st</sup> November 2010 until 31<sup>st</sup> January 2011. A total of 233 respondents were recruited for the study. Of these number, 106 (45%) were from Murtala Mohammad Specialist Hospital; 90 (39%) from Aminu Kano Teaching Hospital; and 37 (16%) from Narrarawa Specialist Hospital.

#### ***Inclusion criterion***

Patients were included if they were: Kano state residents and aged 18 years and over, able to communicate in Hausa language with first-ever stroke diagnosed by a neurologist.

#### ***Exclusion criterion***

Patients with history of recurrent stroke attack and persistent deficits or thus with underlying psychotic and mental disorders, those who were handicapped before the stroke event as well as patients with comorbidities that would significantly affect HRQOL and limit life expectancy (e.g. class III or IV heart failure, peritoneal dialysis or hemodialysis) were excluded.

In the end, a total of 233 patients were recruited after they consented to participate in the study and had completed all instruments. Only 217 participants eventually completed the interview at 1 year after stroke. The attrition rate at 1 year after stroke was 6.87% (16 out of 233) because of death (n=9, 3.86%) or unavailability for the follow-up interview (n=4, 1.72%). Two people refused to continue their participation in

the study (0.86%) and one was away from Kano and had changed his phone number (0.45%).

### **3.6.4 Data Collection, variables measured and instruments**

Data were collected using a prepared close-ended questionnaire. The variables measured in this study included a baseline socio-demographic and clinical characteristics (see Appendix D1) created by the researcher. Baseline socio-demographic and clinical characteristics of the respondents at 6 months after stroke were collected from medical and nursing records, and from attending doctors if needed. Stroke severity, functional activity, depressive symptoms, perceived social support and stroke-specific quality of life were measured using the validated instruments to measure the changes that occur in different aspects of stroke-specific health related quality of life. The follow-up clinical examinations were performed at 6 months and 12 months after stroke by interviewing the patients or their reliable proxies.

#### ***3.6.4.1 Dependent variables***

The QOL at 6 and 12 months after stroke was utilized as the dependent variable for this study. Participants' QOL were prospectively assessed by the investigator by interviewing the patients or their reliable proxies using the validated Hausa version of the Stroke Impact Scale (SIS) 3.0 index. Refer to appendix G (Hamza et al., 2012a).

**Stroke Impact Scale (SIS) version 3.0** (Appendix D3) SIS 3.0 has undergone extensive psychometric testing and reported excellent internal consistency (range, .93–1.00, cronbach's alpha=0.94) are sufficient (Altindag et al., 2008; Carod-Artal et al., 2008; Carod-Artal et al., 2009; Duncan et al., 2003; White et al., 2007). It was developed based on the viewpoint, perception, position and contributions of stroke patients, caregivers, and health professionals with stroke expertise (Duncan et al., 2003). It is a psychometrically robust 59-item stroke-specific self-report measure developed to

assess a number of numerous physical domains and other dimensions of HRQoL. It consists of 8 domains: Strength, Hand function, Mobility, Physical and instrumental activities of daily living (ADL/IADL), Memory and thinking, Communication, Emotion and Social participation (Carod-Artal et al., 2008; Carod-Artal et al., 2009; White et al., 2007). Scores for each domain range from 0 to 100 with higher scores indicating better HRQOL. Four of the subscales (strength, hand function, ADL/IADL and mobility) can be merged into an aggregate physical domain. The Strength items are rated in terms of strength but the; memory, communication, ADL/IADL, mobility and hand function items are rated in terms of amount of difficulty. The emotion and social participation items are rated in terms of frequency. The SIS 3.0 also includes a question (item 60) to assess the patient's global perception of recovery. The respondent is asked to rate his or her percentage of recovery on a visual analog scale of 0 to 100, with 0 meaning no recovery and 100 meaning full recovery. Researches indicated that most SIS 3.0 domains sensitively displayed improvement in recovery in patients with mild and moderate stroke (Daina & Daiva, 2006; Duncan, 2000). The SIS 3.0 was adapted and validated for the Nigerian (Hausa) population. Permission for the use and validation of the scale were obtained from the copyright owners. Below are the description of the SIS 3.0 and the scoring criterion of dimensions.

*Description of the SIS 3.0*

<b>Dimensions</b>	<b>Number of Items</b>	<b>Cluster of Items</b>	<b>Items Reversion</b>	<b>Direction of Dimensions</b>
Strength	4	1a-1d	No	Low score = High impact on QOL
Hand function	5	7a-7e	No	
Mobility	9	6a-6i	No	
Activities of daily living	10	5a-5j	No	
Emotion	9	3a-3e, 3g	No	
		3f, 3h, 3i	Yes	
Memory	7	2a-2g	No	
Communication	7	4a-4g	No	
Social participation	8	8a-8h	No	
Stroke recovery*	1	9	Not applicable	

\*Item 9 (Stroke recovery) does not belong to any of the dimension

## Scoring of dimensions

<b>Item scaling</b>	5-point scale from 1 to 5
<b>Weighting of items</b>	No
<b>Extension of the Scoring Scale</b>	0-100
<b>Scoring procedure</b>	<p>• <b>Scores by dimension (except for Stroke recovery):</b>  Final score = [(Raw score –Min)/(Max-Min)] * 100  With Min=1; Max =5  Raw score = Mean of non-missing items</p> <p>• <b>Stroke recovery:</b> Final score = Item score</p> <p>• <b>Emotion domain score</b>  There are 3 items that change polarity in the emotion domain, 3f, 3h, and 3i. The SIS scoring database takes this change of direction into account when scoring, however, if you are scoring manually, you must reverse the scores, i.e 1 becomes 5, 2 becomes 4, 3 remains the same, 4 becomes 2, and 5 becomes 1, prior to manual calculation. For these items, use the following equation to compute the individual’s score:  item score = 6 – individual’s rating</p> <p>• <b>Physical domain score:</b> Strength, Hand function, Mobility and Activities of daily living may be combined into one Physical domain:  Physical domain score = Mean of final scores of the four domains</p>
<b>Interpretation and Analysis of missing data</b>	<p>• For a particular subject, if <math>\geq 50\%</math> of the items in a dimension are missing then the domain score is missing</p> <p>• If less than 50% item responses are missing in a dimension:  Score = [(Mean –Min)/(Max-Min)] * 100  Score = Dimension score for a particular dimension  Mean = Mean of non-missing item scores within that dimension  With Min=1; Max =5</p>
	<p><b>Question 1:</b> If patient says, “I don’t have an affected side”, then instruct them to score using their perceived weaker side. If they still insist there is no affected, or weaker, side instruct them to score using their dominant side.</p> <p><b>Question 4:</b> If patient says s/he does not do any or all of the items listed, code item(s) as <i>Extremely Difficult</i>.  (Item f) If patient does not call but is handed the phone this is OK. (Item g) If patient cannot hold a phone book, if they can read it this is OK. This item addresses whether the patient is able to initiate a phone call, look up the number, and dial this number correctly.</p> <p><b>Question 5:</b> If patient says s/he does not do any or all of the items listed, code item(s) as <i>Cannot do at all</i>.  (Item a) If person is on pureed food, even if they feel they could cut the food, code as <i>Cannot do at All</i> (Item c) Bathing oneself does not include getting into the tub.  (Item e) This question is associated with movement. Does the</p>

<p><b>Interpretation and Analysis of ‘non-concerned’ answers</b></p>	<p>person have the physical ability to get to the bathroom quickly enough? (Item f) Losing a little urine/dribbling is considered an accident. If person has intermittent catheter and is having no leaking problems code them as per report. If person has an indwelling Foley catheter, code as <i>Cannot do at all</i>. (Item g) Constipation is not counted here person has to have an accident. (Item i) “Shopping” means any type of shopping and does not include driving.</p> <p><b>Question 6:</b> If patient hasn’t done any of the items in the past two weeks code as <i>Cannot do at all</i>. (Item h) If patient hasn’t “climbed several flights of stairs” in two weeks, they may be prompted by saying “have you gone up and down one flight of stairs a couple of times in a row.” If they still say they have not done it then they must be coded as <i>Cannot do at all</i>. (Item i) If the patient wants to know what kind of car say “your car” or “the car you ride in most.”</p> <p><b>Question 7:</b> If patient says “I don’t have an affected side”, then instruct them to score using their perceived weaker side. If they still insist there is no affected, or weaker, side instruct them to score using their dominant side. (Item a) If the patient says s/he has not been to the grocery store say “have you carried anything heavy with that hand.” (Item d) This item is to tie a shoelace/bow using both hands.</p> <p><b>Question 8:</b> If patient does not do any of the specific items (and has never done), code interference as <i>None of the time</i></p>
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### 3.6.4.2 Independent variables

Variables examined included the baseline socio-demographic and clinical characteristics of the patients in the previous 6 months after stroke were obtained and assessed using a questionnaire (appendix D1), medical and nursing records, and attending doctors’ reports if required. Information collected included: age at the time of stroke, sex, ethnicity, marital status, residency, education, and occupation before stroke, occupation after stroke, income, and type of stroke, side of stroke (laterality), status in the family, caregiver, return to work and hospital treatment charges. Ethnicity was determined based on self-described categories including Hausa, Yoruba, Igbo or Other. Marital status was coded into four categories as single, married, widowed and divorced/separated. Residency was categorized into two groups namely, urban and rural. Educational status was coded based on the self-reported highest level of



education completed and were recategorized into four groups, that is tertiary, secondary, primary or none. Occupation before and after stroke were categorized into seven groups including government employees, businessmen, retiree, farmers, labourers, traders or unemployed. Income was self-reported and coded under three categories as “enough and save”, “just enough” or “not enough”. Effect on work was categorized in to five groups comprising “normal”, “less flexible”, “change work”, “can’t return to work” or “became unemployed”. Care giving was determined based on self-described categories including by the couple, child, in-laws, cousin or employee. Hospital treatment charges was categorized into six groups including subjects charges being catered by self-support and able, friends, government support, social security, life insurance or for free.

Clinical variables examined (Appendix D) included type and side of stroke, the degree of disability was assessed using the modified Rankin Scale (mRS) (Banks & Marotta, 2007; Carod-Artal et al., 2008; Carod-Artal et al., 2009; Haacke et al., 2006; White et al., 2007). Activities of Daily Living (ADL) assessment was performed using the Barthel Index (BI) (Carod-Artal et al., 2009; Haacke et al., 2006; Sangkaew, 2007). The level of depression was measured using Beck Depression Inventory (BDI) (Altindag et al., 2008; Bruwer et al., 2008) and perceived social support was assessed using the validated Hausa version of the Multidimensional Scale of Perceived Social Support (MSPSS). Refer to appendix H (Hamza et al., 2012b). These clinical examinations were performed at the baseline 6 month and 12 months after stroke through interview of patients (80%) and proxies. Proxy interviews involves asking/interviewing the family caregiver to complete/answer the patient’ study questionnaire on behalf of the stroke survivor who was having communication difficulties. In this study 48 proxies were used (20%).

## ***Instruments***

**Barthel Index (BI)** (Appendix E1) is a well validated tool for the assessment of 10 items of ADL associated with mobility and safe care (Carod-Artal et al., 2009; Haacke et al., 2006; Sangkaew, 2007). It assesses the extent of self-reliance in the activities of daily living related to safe care and mobility. It gives a score ranging from 0 (total dependence) to 100 (total independence). The measured items are bowel and bladder controls, grooming, toilet use, feeding, transfer, mobility, dressing, climbing stairs, and bathing. Each grouping of the BI is valued in a scale of 0 (unable to carry out a task) to 5 (denoting complete independence). The mean BI score of < 20 was classified as total dependence and demanding “institutional care”; 21-60 as severe dependence; 61-90, moderate dependence; 91-99 as mild independence and 100, as fully independent.

**Modified Rankin Scale (MRS)** (Appendix E2) has been extensively utilized for international stroke research to assess disability after stroke in terms of global functional independence, and hence evaluate recovery from stroke (Banks & Marotta, 2007; Carod-Artal et al., 2008; Carod-Artal et al., 2009; Haacke et al., 2006; White et al., 2007). It measures the competence of the ability of the patient to carry out activities they had carried out earlier and determine any assistance in doing so. The validity and interrater reliability of the MRS has been well documented. It uses 6 distinctive grades: 0 indicating no symptoms; 1 (regardless of symptoms, no significant disability); 2 denoted as slight disability (patient unable to carry out all prior activities although competent to look after own affairs without assistance); 3 moderate disability (patient unable to walk unaided, but need some assistance); 4 moderately severe disability (patient incapable to walk unaided and unable to attend to his bodily needs if denied help); 5 severe disability (patient is bedridden, incontinent, and needs requires persistent nursing care and attention); and 6 dead.

**Beck Depression Inventory (BDI)** (Appendix E3) is 21 items self-report 4-point likert-type functional measurement inventory that measures the severity of depression and that suggest attitudes and symptoms associated with depression (Altindag et al., 2008; Bruwer et al., 2008). It proved exceptional internal consistency for psychiatric and non-psychiatric populations. The severity of the symptom is defined about an ordinal continuum from absent or mild (a score of 0) to severe (a score of 3). The severity of the depression scores are created by adding the scores of the items subscribed from each item set. The current guideline suggested categorizing the severity scores as follows: 0-9, minimal; 10-16, mild; 17-29, moderate; and 30-63, severe. The items precisely reflect increase in appetite, increase in sleep, agitation, and psychomotor retardation.

**Multidimensional Scale of Perceived Social Support (MSPSS)** (Appendix D2) is a well validated and psychometrically rigorous 12 items concise instrument used for measuring the hierarchical structure of perceived social support from family (items 3, 4, 8 and 11), friends (items 6, 7, 9, and 12), and a significant others (items 1, 2, 5, and 10) (Bruwer et al., 2008; Canty-Mitchell & Zimet, 2000; White et al., 2007; Zimet et al., 1988). It was developed for adolescents, but is suitable for other groups. It has a number of properties which suggests that it may be a valuable tool for use in research involving a variety of populations, including cardiovascular disease populations and the elderly (Canty-Mitchell & Zimet, 2000; Cheng & Chan, 2004; Cheng & Chan, 2004; Edwards, 2004). Studies indicate that MSPSS has a good internal reliability, test-retest reliability, and strong factorial validity. In addition, good construct validity of the significant other, family, and friend subscales was also demonstrated (Bruwer et al., 2008; Canty-Mitchell & Zimet, 2000; White et al., 2007). The perceived social support is graded on a 7-point likert-type scale (from very strongly disagree to very strongly agree) as follows:

respondents are required to circle 1, very strongly disagree; 2 strongly disagree; 3 mildly disagree; 4 Neutral; 5 mildly agree; 6 strongly agree; 7 very strongly agree.

### **3.6.5 Data Analysis**

The data were, substantiated and analysed using Statistical Package for Social Science (SPSS) version 20. Data were cleaned and normality was checked with normality test Kolmogorov-Smirnovtest before analysis. Descriptive statistics are used to summarize the socio-demographic and clinical characteristics of the study population and are presented as means (standard deviations), or as numbers, percentages and 95% confidence intervals (CI) as appropriate. The mean scores and standard deviations of each specific dimension of the SIS 3.0 were calculated for stroke survivors. Paired samples *t*-test was used to calculate the changes in scores of functional status and social support and QOL from 6 month to 1 year after stroke. The results of the *t*-statistics were considered significant at the 0.05 level. Forward stepwise linear regression model was then used to identify the factors that predict the changes in the physical, mental, and social dimension of the health-related quality of life taking in to cognizance the possible confounding and interaction effects between variables. The value of  $R^2$  is the amount (%) of variation in QOL (by domains) that is explained by the regression model.  $R^2$  lies between 0 and 1, with values of 1 being a perfect model was used to indicate how well the variables predicted the QOL (by domains). The *p*-values and confidence intervals are presented as statistical coefficients. In this study, BI is the independent variable and ADL, mobility and composite physical domain of SIS are the dependent variables. The regression models were run separately. When collinearity, was checked between two independent variables, was checked; the value of Variance Inflation Factor (VIP) and Tolerance- were both 1 i.e. there is no multi-collinearity. Multiple linear regression analyses were performed separately for each of the QOL domains and the potential confounders with the log of QOL as the dependent variable. Log of QOL domain was

obtained using the data transformation of the QOL domain. The log of QOL domain, rather than the QOL domain, was used to ensure a straight line adequately described the relationship between the dependent and independent variable.

### **3.6.6 Ethical Considerations**

Approval for the conduct of this study was obtained from the medical ethics committee of the University of Malaya (Eth. Comm. /IRB Ref number 830.7), ministry of health Kano state, Nigeria (HMB/GEN/488/11) and Aminu Kano Teaching Hospital, Nigeria (AKTH/MAC/SUB/12A/P3/IV/801) which was in accordance with the principles of the declaration of Helsinki. Refer to Appendix A for the respective approval certificates.

Data collection commenced once ethical approval and access was secured. Written informed consent (see Appendix B) was also obtained for each patient or their proxies prior to participation.

Participants were made aware that their participation was voluntary and that they can withdraw at any time without any penalty. If a potential participant was not interested in participating, his/her participation was not pursued. While the names of the participants were known in order to get their written informed consent for the interview, only the researcher had access to the participants' names. Identity number was also used for all sources of data. Hence, no one will be able to identify any individual member of the study. Hard copies of questionnaire were kept in separate files and will be destroyed after eight years. Data was used only for the purpose for which it was requested and no hospital specific reporting of data was performed. No known harm to study participants was apparent. Study participants received no compensation for their participation.

In addition, to minimise invasion of privacy, recruitment of the participants took into account the potential participant's right to refuse without the researcher knowing his/her

decision. This action allow for the potential participants to make independent choices other than imposing choices on them.

### **3.7 PHASE 3: METHODOLOGY FOR QUALITATIVE COMPONENT**

The overall plan of this phase was directed by the findings from the preceding quantitative part. The aim of this phase was to explore the necessary reasons for the observed patterns in the quantitative phase, understand the mechanism by which stroke affects the QOL of the individuals and elucidate the nature of the stroke experience that may not be covered during the study or concealed in the quantitative findings. The chapter details the research design utilized to obtain information-rich qualitative data for the mixed-method study, selection of the research participants, interview guides, data collection methods and analysis. Ethical issues and methodological rigour considered during the planning and the conduct of this phase of study were addressed.

#### **3.7.1 Sampling**

The sampling method, sample size, criteria for sample selection and processes for participants' selection are described.

##### **Sampling strategy**

A purposive sampling technique was used in conducting the study. Participants for this component were selected from the population of stroke survivors who participated in the quantitative study in order to generate the richness of individual's experiences (Speziale & Carpenter, 2003). The aim of this technique was to select appropriate information which will address the research question and serve to best inform the study (Clarke, 2009; Speziale & Carpenter, 2003). A range of variation was sought across age,

marital status, socioeconomic status, education, and occupation (Clarke, 2009; Speziale & Carpenter, 2003).

### **Sample size**

A total of 15 stroke survivors participated in the qualitative phase of this study. The aim of the study recruitment was to obtain a sample size capable enough to generate the richness of the individual's experiences (Speziale & Carpenter, 2003). Data were collected until redundancy occurred and when the researcher realizes no new relevant data were emerging (theoretical saturation had been achieved) (Clarke & Black, 2005). A total of 15 interviews were conducted.

### **Criteria for sample selection and recruitment**

Based on the finding that increasing age was identified to be associated with lower sense of wellbeing in most of the domains of quality of life following stroke and in order to conform to the demographics of the study sample, participants were selected from the sample of the stroke survivors with varying age in order to fully explore the effect of different ages on wellbeing following stroke. Owing to the repeated influence of physical and cognitive functions for QOL that was identified in the quantitative findings, stroke subjects were sampled with varying level of residual impairments and disability in order to fully explore the effect of different levels of functions on QOL. Seven of the subjects chosen had difficulty carrying out ADLs due to considerable hemiplegia, while eight subjects were sampled because they had a higher level of function as a result of less severe impairment. Occupation was repeatedly identified as an important factor for a number of domains of quality of life in the quantitative phase, thus subjects of varying occupations were sampled in order to fully capture the effects of different kinds of occupations on wellbeing following stroke. Results from the quantitative phase also indicated the importance of care giving and social supports on a number of dimensions of QOL; therefore, subjects with a varying range of social

supports were sampled in order to fully understand the underlying reasons for the relationship between social resources and QOL. Therefore, nine subjects with very supportive spouses, children and family members were selected, while six subjects with low supports (widowed, with unsupportive spouses and family members) were also sampled. Accordingly, participants with different socioeconomic resources were recruited since income and education were identified as essential for a number of dimensions of wellbeing in the quantitative result. Subjects with different education level (formal and informally educated) and with varying socioeconomic status (low and middle class background) were also sampled in order to fully explore the effects of different levels on wellbeing following stroke. Participants were excluded if they have severe communication problems (i.e. aphasia) or cognitive impairments that would limit their ability to reveal their subjective experiences. The functional status of each of the respondents was assessed using MRS and BI scales (see appendix E2 and E1) respectively. .

### **3.7.2 Interview guides**

In conducting a qualitative research, the researcher is the primary instrument who collects, observes analyses and interprets the research data. The interview guide (appendix F2) as reported by Patton in 1987 (Patton, 1987) are commonly used to assist in these processes. The reason for using the interview guide was to ensure that the interviewer examine similar issue in the distinct groups which is based on the need to identify the factors influencing stroke survivor's quality of life. The interview guide which included open-ended in-depth interview questions was produced based on the findings developed during the quantitative phase by the investigator and adhered to more closely. Interviews were conducted in Hausa language and so the interview guide was translated into Hausa for use with the consented subjects.



### **3.7.3 Data Collection Methods**

Data were collected using a demographic form and a guided semi-structured interview. Interviewing techniques are described. Field notes were kept.

#### **Demographic form**

The demographic form was used to obtain a demographic and health profile of the study participants (see appendix F1). Data collected from the demographic form include: name, age, sex, stroke laterality, date of stroke, date of interview. The demographic form took less than 3 minutes to complete.

#### **Semi-structured Interview**

Data was collected using the technique of semi-structured in-depth interview (Clarke, 2003b, 2009), which is the most common type of interview and specially devised to detail the mechanism underlying an already examined pragmatic association (Speziale & Carpenter, 2003). The interview was carried out from 27<sup>th</sup> February 15<sup>th</sup> April, 2012. An interview guide was developed (appendix F2) to help participants articulate their feelings about their personal stroke experiences and how they manage their lives. The questions were guided semi-structured and allow participants to develop conversations in ways most relevant to their situation. Additional questions (probes) were developed for each of the main questions but, were only asked when there was a need to stimulate discussion.

Using the interview guide, the researcher carried out in-depth interviews with the 15 selected stroke survivors in their homes and at a time that was suitable for them. Preparatory work included selection of an appropriate place, contacting the participants prior to the interviews and gaining their consent was ensured before entering the field. The process of conducting the interview was thorough and at the end of the first in-depth interview, the researcher identified where the probing was needed. Moreover, the

researcher did not phrase the questions in the same way each time, or follow the question sequence in a stringent manner thereby enabling the discussion to evolve with the study participants. Interview guide serves as a rough checklist of the points for discussion but each interview builds upon the particular issues that were brought about by each respondent. During the in-depth interview, few notes were taken (field notes) to document something important that needed to be clarified, aid formulate question or as a note if probing was required. During the discussion sessions, participants were encouraged to give their views and probes were used to stimulate discussion whenever there were prolonged pauses during the conversation. Interviews were commonly concluded between 40 and 80 minutes, and all interviews were audiotaped with the permission of the respondents in order to obtain an accurate record of what was said and transcribed verbatim.

#### **3.7.4 Data analysis**

Thematic analysis using constant comparative methods was aided by Nvivo 9 software for the data analysis. The collected data were transcribed verbatim and translated into English. Data analysis of the interviews occurred concurrently and interactively with data collection (Speziale & Carpenter, 2003). Verbatim transcripts texts were imported into NVivo 9 qualitative data analysis and management software package and was read word by word and many times in order to find the emergence of an intriguing pattern which would clarify the research question and open coded line-by-line for concepts and themes (Charmaz, 2006). The researcher developed intimate knowledge of the data by constant handling and reading of the data. Open coded line-by-line for concepts and themes (Charmaz, 2006). A coding system described by Miles and Huberman (Miles & Huberman, 1994) which involved scrutinizing through the codes and reflective notes was used to identify connections, differences and associations between factors. In an iterative process of going back to the data and comparing it with emerging codes and

creating new codes, emergence of identical or related and new concepts was looked for in consequent interviews, sequentially generating comparisons between the coding pattern and interview transcripts (Clarke, 2003a; A. Strauss & Cobin, 1998). Emerging themes were identified and discussed so that any pattern across the interviews was noted. This process enabled constant focusing of ideas and also validated respondent's narrations (Hammersley & Atkinson, 1995). As interviews progressed, themes were refined leading to several additions and alterations to the coding memo and finally the coding categories were condensed, based on similarities and differences of contents. A system of sifting and comparison enabled patterns in the data to be clarified. There were 19 themes coded from the transcriptions. These were regrouped into 7 categories of which 4 categories have further break downs and 3 were independent issues.

### **3.7.5 Methodological Rigor**

Rigor is an important aspect in the practice of a good qualitative research (Speziale & Carpenter, 2003). While reliability and validity are used to evaluate the practicality of the quantitative study, qualitative research on the other hand is evaluated by its "trustworthiness", or its ability to portray the experience being studied (Lincoln & Guba, 1985). The four primary criteria for establishing trustworthiness, namely, credibility, dependability, confirmability and transferability as proposed by Lincoln & Guba (1985) proved helpful in establishing the credibility of this research.

#### **Credibility**

Credibility is defined as a process whereby the researcher is satisfied that the findings of the study are meaningful and reflect the current experiences. In this study, credibility is achieved by:

- Reaching a theoretical saturation

- Member checking: Interview transcripts were returned to all participants for them to check and encouraged to comment on the transcripts (Charmaz, 2006) and ensured that its participants driven (Hennessy et al., 2010). Their comments were incorporated in to the transcripts for data analysis.
- Peer review and debriefing: debriefing discussions of the emergent themes were also conducted between the researcher and his supervisors to increase the credibility of finding (Maley et al., 2010) (Denzin & Lincoln, 2003; Hennessy et al., 2010).
- Prolonged engagement in the topic such that data collection took adequate time and the researcher's engagement in general conversation with the participants before and after the interview (Denzin & Lincoln, 2003).
- A Strauss and Corbin criterion was also used to balance between objectivity and sensitivity by becoming totally immersed in the data during collection and analysis (Strauss & Corbin, 1998).

### **Dependability**

Dependability relates to the clarity of the research (Lincoln & Guba, 1985). In this study, dependability has been actualized through a thorough audit trial. The audit trial enables another researcher to effortlessly follow the decision trial used by the researcher to achieve a similar conclusion. As part of auditing the study, the researcher and his supervisors independently review a selection of the interview transcripts to see if there was some prior agreement to the emerging themes.

### **Confirmability**

Confirmability is concerned with confirming that the explanations are derived from the data and not the researcher's personal conception (Lincoln & Guba, 1985). Confirmability in this study was achieved by:

- Using direct quotes
- Strictly complying to the data analysis process
- Peer review and debriefing

### **Transferability**

In qualitative studies, the task of transferability rests with the users of the research and is concerned with the possibility that the findings of a study may have meaning for others in similar circumstances (Lincoln & Guba, 1985). Transferability in this study was addressed by detailing the processes used for the study including the methodological decisions and context of the interviews.

### **3.7.6 Ethical Considerations**

Ethical clearance supplied forms (see appendix B) were distributed to the study participants prior to the interview. Participants were given as much time to review the consent form. Participants were also encouraged to ask questions regarding anything they did not understand or if they required a better explanation. Participants signed the consent forms in front of the researcher and the witness. This approach to consent ensures mutual participation and takes into cognizance the possibility of unexpected events or changes in circumstances (Speziale & Carpenter, 2003). Participants were made aware that their participation is voluntary and that they can withdraw at any time without any penalty. If a potential participant was not interested in participating, his/her participation was not pursued.

While the names of the participants were known in order to get their written informed consent for the interview, only the initials were assigned to the interview transcripts. Only the researcher had access to the participant's names. Code numbers and pseudonyms were also used for all sources of data. Moreover, only the researcher and

his supervisors read the interviews and in presentations and publications, no one will be able to identify any individual member of the study. Hard copies of data (demographic and interview transcripts) were kept in separate files and will be destroyed after 8 years.

To minimise invasion of privacy, recruitment of the participants took into account the potential participant's right to refuse without the researcher knowing his/her decision. This action allow for the potential participants to make independent choices other than imposing choices on them.

Some participants became more aware of their feelings given the opportunity to talk about their experiences. Respect, caution and sensitivity were exercised when interacting with participants in order to prevent the possibility of unwarranted stress. If the participants expressed signs of increased distress, the interview was stopped and only resumed when the participants felt comfortable.

## **CHAPTER FOUR: RESULTS**

This chapter presents the findings of the study according to the individual phases of the study; Phase I is the instruments validation phase; Phase II, quantitative component and; Phase III is a qualitative component.

### **4.1 PHASE I- INSTRUMENTS VALIDATION**

In phase I, the findings of the validation of the SIS 3.0 and MSPSS for use in clinical research and practice in Nigeria are presented accordingly.

#### **4.1.1 Results for the validation of the Hausa-SIS 3.0**

Content and face validity testing of the Hausa-SIS 3.0 (Appendix G) was performed by the experts to ensure that the Hausa-SIS had achieved conceptual, semantic and operational equivalence with the original index. During translation and where required, expressions used in the items were subjected to more culturally acceptable linguistic equivalents similar to concept and meaning to the original items. A pre-testing and pilot study with 30 stroke survivors additionally verified the face and content validation of the Hausa-SIS 3.0. The time taken to answer the questionnaire was also acceptable i.e. 15-20 minutes. The feasibility of administering the instrument under field condition was also verified. The instrument was found to be easily conceivable, simple, clear and appropriate for the assessment of QOL among this group of stroke survivors.

##### **4.1.1.1 Linguistic Validation**

###### ***Title of the Instrument: "Stroke Impact Scale (SIS) 3.0"***

The term "stroke" ("the act of striking or a blow") in Hausa language, literally translates to "*sare, buguwa*". The term which is more of an expert terminology, is not clearly comprehensible in spoken Hausa language. The literal translation of the instrument's title was not viable in Hausa language; hence, the title was substituted by a medically, yet culturally agreeable linguistic equivalent in Hausa. Accordingly, the title "Stroke

Impact Scale” was translated to “*Sikelin Awon Tasirin Bugun Jini*” as agreed by the translation committee.

### ***Domain description***

Some issues were raised regarding the sentences or terms describing the domains within the questionnaire. Of the 8 sentence describing the domains, only one appeared to be problematic. The sentence describing the second domain “These questions are about your memory and thinking” tended to be misinterpreted. Respondents assumed that the sentence describing the domain was referring to the “process” not the “act” of memory and thinking. The sentence was therefore made to be more culturally appropriate and translates as “*Wadannan tambayoyi sun shafi yadda kake/kike ji dangane da sauyin da ka/ki ka samu na yanayin walwala da kuma yadda kake/kike iya shawo kan damuwarka/ki bayan samun mutuwar barin jiki*”. Moreover, Description of the item 60 “Stroke recovery”, where a patient is asked to assess his/her global perception of recovery was consistently reported as not specific, The description of the item was therefore rendered to “The Process of your Stroke Recovery” which translate as “*Yadda ake samun sauki daga matsalar ta bugun jini*”.

### ***Instructions***

Participants in the cognitive debriefing did not identify any practical misconceptions regarding specific instructions for each of the 8 domains including item 60 where a patient is asked to assess his/her global perception of recovery.

### ***Response options***

There were no difficulties encountered regarding the response options throughout the linguistic validation process.



### *Terms and reflections within the items*

Culturally sufficient equivalents had to be found for the following terms and expressions which were identified as problematic by the committee and replacement were agreed upon.

- é Burden T that which is borne with difficulty (*babban nauyi*)
- é Concentrate T to bring one's faculties to bear (*mayar da hankali kan abubuwa*)
- é Conversation T the spoken exchange of thoughts (*hira*)
- é Nervous T fraught with or showing anxiety (*tsoro*)
- é Blame T accuse (*Dorawa kai laifi*)
- é Mood T Frame of mind (*walwala*)
- é Bowels T entrails (*bayan gida*)

Additionally, as in response options, most of the reflection used within items cannot be rendered to “literal translation” in Hausa, and; they were subjected to culturally acceptable linguistic equivalents. Respondents easily comprehend the meaning of the expressions when they are alternatively stated as the phrases following the arrows as illustrated below:

é Item 11: Solve every day problems? T Solve your routine predicaments?

(*Warware matsaloli na yau da kullum?*)

é Item 16: Blame yourself for mistakes that you made? T Guilty of your wrong

doings? (*Dorawa kai laifi a kan kurakuran da ka aikata?*)

é Item 18: Feel quite nervous? T Feeling of unease or frightened? (*Jin tsoro?*)

é Item 19: Feel that life is worth living? T Hopeful despite challenges? (*Jin in*

*dai da rai akwai rabon za a iya samun lafiya?*)

é Item 25: Participate in a conversation with a group of people? T Get in to

conversation with others? (*Shiga cikin hira da sauran jama'a?*)

é Item 28: Cut your food with a knife and fork? T Eat with cutlery sets? (*Yanka abinci da wuka da cokali mai yatsu?*)

é Item 33: Control your bladder (not have an accident)? T Ability to control the passage of urine efficiently? (*Iya rike fitsari ba tare d kuskure ba?*)

é Item 34: Control your bowels (not have an accident)? T Ability to control the passage of faeces efficiently? (*Iya rike bayan gida ba tare da kuskure ba?*)

é Item 38: Stay sitting without losing your balance? T Sit upright without reclining? (*Iya zama daram ba tare da jirkicewa ba?*)

é Item 39: Stay standing without losing your balance? T Stand upright without leaning? (*Iya tsayuwa kyam, ba tare da karkacewa ba?*)

é Item 54: Quiet recreation (crafts, reading)? T Indulge in simple, pleasurable chores like reading or artistry? (*Ayyukan nishadantarwa masu sauki, (kamar karatu da yar karamar sana 'ar hannu)?*)

é Item 55: Active recreation (sports, outings, travel)? T Indulge in pleasurable, energy demanding chores like exercise and long walk? (*Ayyuka Nishadantarwa masu bukatar kuzari (kamar wasannin motsa jiki da tafiya mai nisa)*)

é Item 58: Your ability to control your life as you wish? T Run your life as you desire? (*Yadda kake/kike iya tafiyar da rayuwar ka/ki bisa son ranka/ki?*)

### ***Pilot testing***

The 30 respondents that participated in this process did not encounter problems with understanding the contents of the Hausa version of the SIS 3.0, but raised concern on some of the terms used in the items. They provided some suggestions and a consensus was reached and we retained the items by providing supplementary explanatory sentences as previously discussed under the “Terms and reflections within the items”. The instrument was found to be easily conceivable, simple, clear and appropriate for the evaluation of quality of life among stroke survivors.

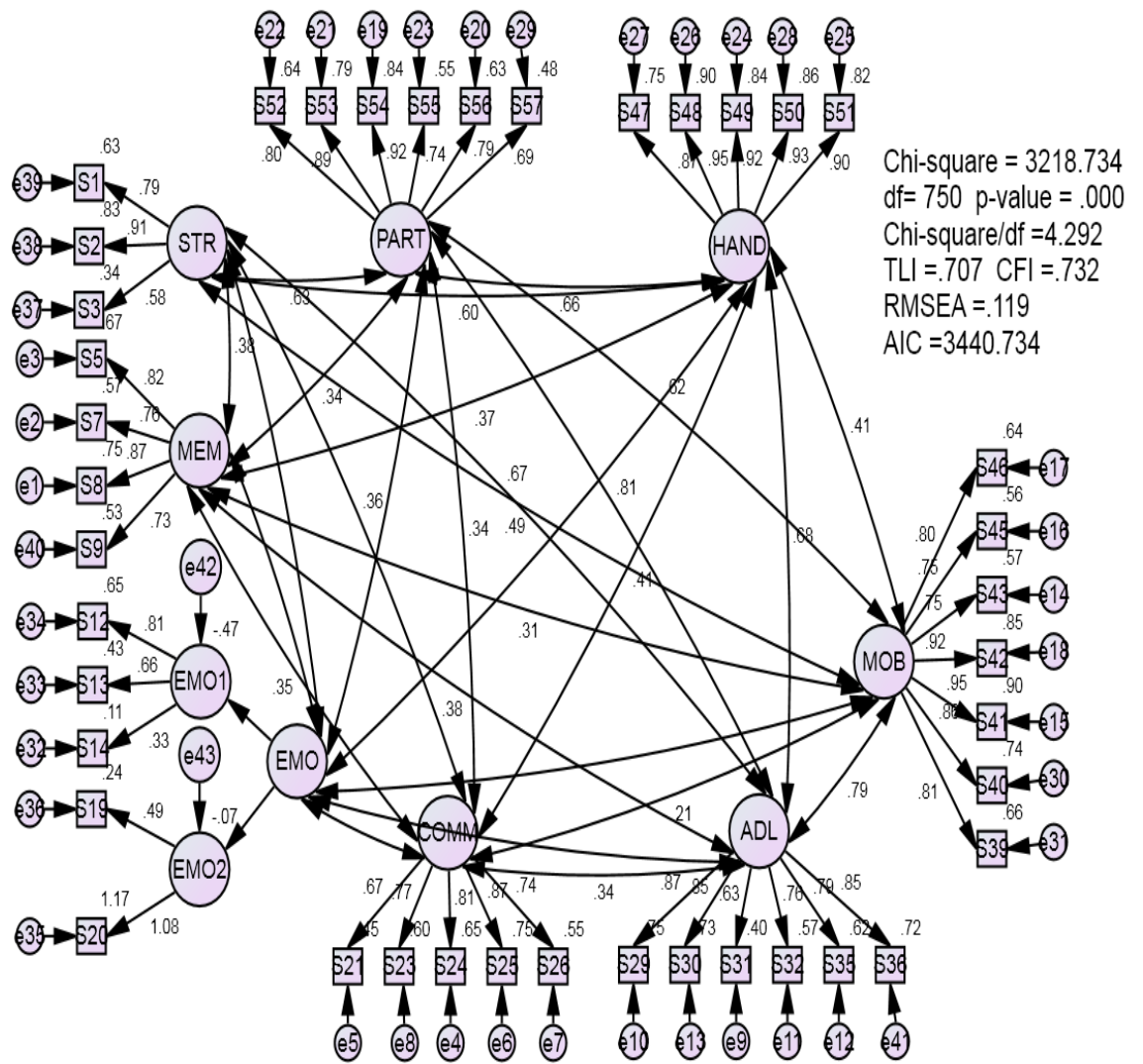
All the 140 stroke survivors who were selected agreed to participate. There were 73 females and 67 males in the study and their ages ranged from 35-82 years with a mean age of  $57.7 \pm 13.8$  years. In the sample, Cerebral Ischemic stroke was detected in 48 (34.3%) patients, cerebral haemorrhage in 11 (7.9%) and indeterminate in 81 (57.9%) patients. 63 (45.0%) patients had left hemispheric lesions, whereas 77 (55.0%) had affected right hemisphere. In the sample 107 (76.4%) were urban residents.

#### **4.1.1.2 Reliability analysis**

In reliability analyses, the Cronbach's alpha values for the internal consistencies for the items in strength, hand function, mobility, ADL/IADL, memory and thinking, communication, emotion and social participation domains were 0.801, 0.916, 0.898, 0.781, 0.845, 0.886, 0.584, and 0.736, respectively.

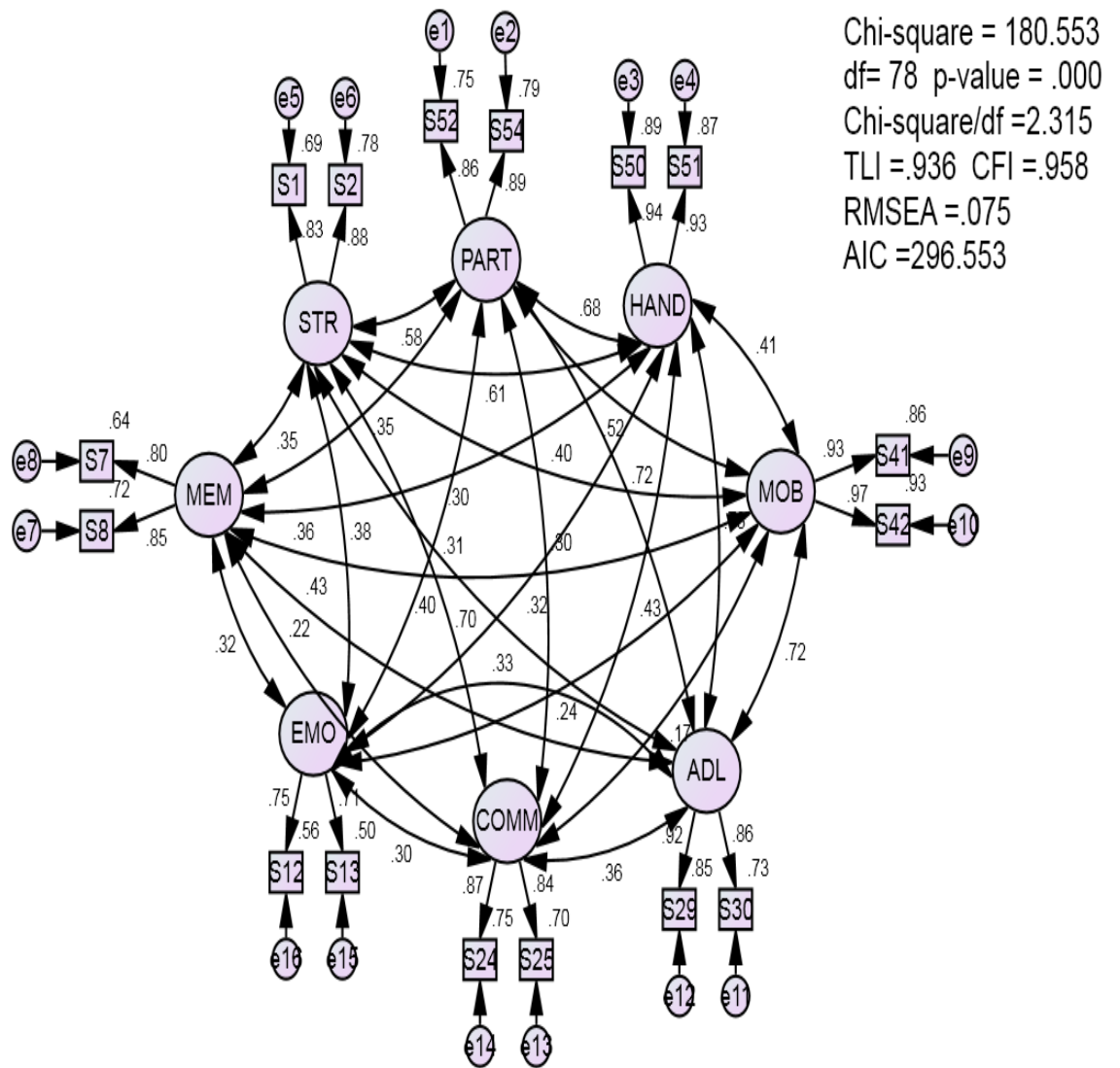
#### **4.1.1.3 Confirmatory Factor Analysis**

In CFA, the 8-factor model (Figure 4.1-1) did not fit well [Chi-square/df > 3, TLI and CFI < 0.9 and RMSEA > 0.08]. Guided by modification indices option in AMOS, the model was corrected of shortcoming in discriminant validity.



**Figure 4.1: Initial tested model**

In the final analysis, a parsimonious model (Figure 4.1-2) was obtained with two items per construct for the 8 constructs [Chi-square/df < 3, TLI and CFI > 0.9 and RMSEA < 0.08].



**Figure 4.2: The final model**

The unstandardized regression weights and the factor loadings (standardized regression weights) are shown in Table 4.1. All the factor loadings are more than 0.7 and the average variance extracted (AVE) for all the constructs are more than 0.50.

**Table 4.1 Regression Weights**

		Unstandardized Estimate	S.E.	C.R.	P	Standardized Estimate
S50	<--- HAND	1.000				.943
S51	<--- HAND	1.190	.053	22.466	***	.934
S1	<--- STR	1.000				.830
S2	<--- STR	1.038	.081	12.761	***	.882
S8	<--- MEM	1.000				.850
S7	<--- MEM	.821	.058	14.144	***	.798
S41	<--- MOB	1.000				.927
S42	<--- MOB	.961	.043	22.166	***	.967
S30	<--- ADL	1.000				.857
S29	<--- ADL	1.143	.062	18.402	***	.922
S25	<--- COMM	1.000				.837
S24	<--- COMM	1.043	.125	8.331	***	.869
S13	<--- EMO	1.000				.709
S12	<--- EMO	1.111	.115	9.637	***	.746
S52	<--- PART	1.000				.863
S54	<--- PART	.963	.066	14.651	***	.891

The pairwise correlation coefficients between the constructs are provided in Table 4.2. Since the highest correlation value is less than 0.85, there is no sign of multicollinearity (Hair et al., 2010). Further test on discriminant validity was done by comparing the AVE and the R-squared values between constructs, pairwise. There is sufficient discriminant validity i.e. the AVEs are more than the R-square value (Fornell & Larcker, 1981). Based on the results as summarized in Table 4.2, there is sufficient discriminant validity between the constructs.

**Table 4.2: Covariance and correlation**

			Covariance	S.E.	C.R.	P	Correlation
PART	<-->	HAND	.833	.111	7.504	***	.676
HAND	<-->	MOB	.714	.131	5.443	***	.415
HAND	<-->	COMM	.474	.093	5.103	***	.433
HAND	<-->	EMO	.280	.075	3.749	***	.324
ADL	<-->	COMM	.463	.108	4.283	***	.359
COMM	<-->	EMO	.242	.074	3.273	.001	.301
STR	<-->	MEM	.299	.072	4.145	***	.350
PART	<-->	MEM	.384	.092	4.176	***	.346
HAND	<-->	MEM	.316	.083	3.808	***	.299
STR	<-->	EMO	.265	.065	4.066	***	.380
PART	<-->	EMO	.282	.081	3.491	***	.313
PART	<-->	COMM	.341	.094	3.615	***	.298
STR	<-->	ADL	.779	.109	7.136	***	.696
ADL	<-->	EMO	.334	.091	3.694	***	.329
PART	<-->	ADL	1.040	.139	7.475	***	.718
HAND	<-->	ADL	1.015	.127	7.990	***	.732
MOB	<-->	ADL	1.470	.187	7.840	***	.725
MEM	<-->	MOB	.558	.123	4.517	***	.360
MOB	<-->	EMO	.307	.106	2.898	.004	.243
MOB	<-->	COMM	.273	.120	2.271	.023	.171
MEM	<-->	ADL	.536	.105	5.092	***	.430
MEM	<-->	COMM	.217	.081	2.684	.007	.221
MEM	<-->	EMO	.247	.072	3.441	***	.317
PART	<-->	STR	.578	.092	6.288	***	.582
HAND	<-->	STR	.577	.085	6.794	***	.608
STR	<-->	MOB	.561	.112	4.986	***	.404
STR	<-->	COMM	.356	.078	4.556	***	.403
PART	<-->	MOB	.933	.151	6.189	***	.519

In Table 4.3, the average variance extracted (AVE) values are more than 0.5. Thus, there is sufficient convergent validity within the construct. When compared pairwise, all the AVEs are higher than the R-squared values. Thus, there is sufficient discriminant validity between the constructs

**Table 4.3: Test of discriminant validity**

	HAND	STR	MEM	MOB	ADL	COMM	EMO	PART
HAND	0.881							
STR	0.370	0.733						
MEM	0.089	0.123	0.680					
MOB	0.172	0.163	0.130	0.897				
ADL	0.536	0.484	0.185	0.526	0.792			
COMM	0.187	0.162	0.049	0.029	0.129	0.728		
EMO	0.105	0.144	0.100	0.059	0.108	0.091	0.530	
PART	0.457	0.339	0.120	0.269	0.516	0.089	0.098	0.769

*Values in parenthesis are AVEs and the others are the pair-wise R-squared values*

It was found that the 16-item HAUSA-SIS 3.0, which is the short version of the SIS (appendix J), seems to measure adequately the QOL outcomes in the 8 domains.



#### **4.1.2 Results for the validation of Hausa-MSPSS**

The content and face validity testing of the short 16-item or long Hausa-MSPSS index (Appendix H) was confirmed. The Hausa-MSPSS index had achieved conceptual, semantic and operational equivalence with the original index. During translation, and where required, expressions used in the items were subjected to more culturally acceptable linguistic equivalents similar to concept and meaning to the original items. A pre-testing and pilot study with 30 stroke survivors additionally verified the face and content validation of the Hausa-MSPSS index. The feasibility of administering the instrument under field condition was also verified. The instrument was found to be easily conceivable, simple, clear and appropriate for the assessment of social support among this group of stroke survivors. Moreover, the time taken to answer the instrument (5-10 minutes) was acceptable.

##### **4.1.2.1 Linguistic validation**

*Title of the Instrument: “Multidimensional Scale of Perceived Social Support”*

No problems were encountered pertaining to the title of the instrument throughout the linguistic validation process.

*Instruction and reply options*

Cognitive debriefing subjects did not practically identify any misconceptions regarding the instructions including the items

*Terms and expression within the items*

All the terms used within the original items were found to be culturally applicable. However, the expressions used in the items were subjected to more culturally acceptable linguistic equivalents. Respondents were able to better comprehend the meaning of the expressions when they were alternatively stated as the phrases following the arrows as illustrated below:

é Item 1: There is a special person who is around when I am in need T There is always a person taking care of my needs (*Akwai mutum na musamman dake kula da bukatu na*)

é Item 2: There is a special person with whom I can share my joys and sorrows T Have someone I can confide in on my happiness and despair (*Akwai mutumin da ya nake iya fadawa damuwata da farin ciki na*)

é Item 3: My family really tries to help me T My family is doing great in assisting me (*Iyalina na kokari matuka a wajen taimakamin*)

é Item 4: I get the emotional help and support I need from my family T My family show care and concern for all my needs (*Iyali na nuna tausayawarsu a gare ni tare da bani duk wani tallafi da nake bukata*)

é (Item 5: I have a special person who is a real source of comfort to me T (*Ina da mutum na musamman wanda ya kasance yana farantamin sosai*)

é Item 6: My friends really try to help me T My friends are doing great in assisting me (*Abokaina na kokari sosai wajen taimakamin*)

é Item 7: I can count on my friends when things go wrong T I am confident my friends' support even in cases of emergency (*Na amince abokai na zasu tsaya min a duk lokacin da wata matsala ta taso*)

é Item 8: I can talk about my problems with my family T I can discuss my predicaments with my family (*Ina iya tattauna matsalata da iyalaina*)

é Item 9: I have friends with whom I can share my joys and sorrows T I have friends I can confide in on my happiness and sorrows (*Ina da abokai da nake fadawa damuwata da farin ciki na*)

é Item 10: There is a special person in my life that cares about my feelings T I have someone who cares about my life needs (*akwai mutum na musamman a rayuwata da ya damu da bukatuna*)

é Item 11: My family is willing to help me make decisions T My family is ever ready to assist me in whatever I may need to decide (*Iyali na a shirye suke su taimaka min a kan duk wata shawara da nake son yankewa*)

é Item 12: . I can talk about my problems with my friends T I can discuss my problems with my friends (*zan iya tattauna matsalolona da abokaina*).

### ***Pilot testing***

This step aimed to obtain feedback from the experts in the relevant medical field. The feedback was incorporated in to the second Hausa version. Two clinicians with experience in stroke rehabilitation reviewed the second Hausa version of MSPSS. Respondents that participated in this process did not encounter any problems understanding the contents of the Hausa version of the MSPSS, but provided some suggestions and a consensus was reached after providing appropriate supplementary explanatory sentences as previously discussed under the “Terms and expressions within the items”. The instrument was found to be easily conceivable, simple, clear and appropriate for the assessment of social support among this group of stroke survivors.

The validity and reliability study was conducted on 140 stroke survivors. The sample was predominantly Hausa (n=136, 97.1%), 3 Yoruba (2.1%) and 1 Others (0.7%). There were slightly more males (n=75, 53.6%) than females (n=65, 46.4%) and their ages ranged from 40-80 years with a mean age of 58.76 years (SD13.24 years). Lesions in the left hemisphere occurred in 66(47.1%) patients while the remaining 74(52.9%) had lesions affecting the right hemisphere. Cerebral Ischemic stroke was detected in 57 (40.7%) patients, cerebral haemorrhage in 18 (12.9%) and indeterminate in 65 (46.4%) patients. Most of the participants were urban residents (n=102, 72.9%).

#### 4.1.2.2 Reliability Analysis

In reliability analysis, the Cronbach's alpha for the internal consistency for the 12 items was 0.781. In test-retest reliability analysis, the minimum kappa value was 0.673 as shown in Table 4.4.

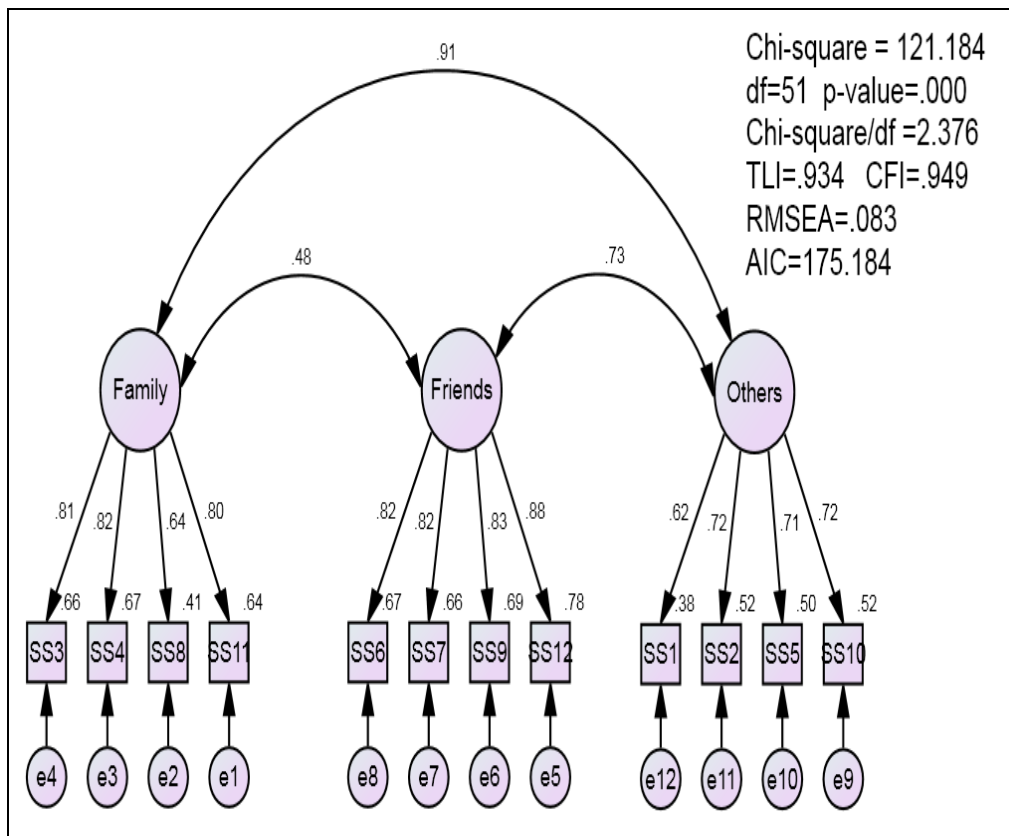
**Table 4.4: Results from pre-post pair test**

Item	Description	$r_s$	kappa
SS1	There is a special person who is around when I am in need.	.883	.673
SS2	There is a special person with whom I can share my joys and sorrows	.949	.806
SS3	My family really tries to help me	.924	.702
SS4	I get the emotional help and support I need from my family	.955	.814
SS5	I have a special person who is a real source of comfort to me	.970	.854
SS 6	My friends really try to help me	.971	.813
SS7	I can count on my friends when things go wrong	.983	.888
SS8	I can talk about my problems with my family.	1.000	1.000
SS9	I have friends with whom I can share my joys and sorrows	.978	.854
SS10	There is a special person in my life that cares about my feelings	.970	.895
SS11	My family is willing to help me make decisions.	1.000	1.000
SS12	I can talk about my problems with my friends.	.922	.711

$r_s$ : Spearman's correlation

#### 4.1.2.3 Confirmatory Factor Analysis (CFA)

In confirmatory factor analysis (CFA), testing the adequacy of a three-factor model, the correlation between family and significant others constructs was 0.91 (Figure 4.3), indicating problem of multicollinearity (Hair et al., 2010) between these two constructs. In such situations, either one of the constructs must be dropped or the items in the two constructs must be combined into one (Fornell & Larcker, 1981).



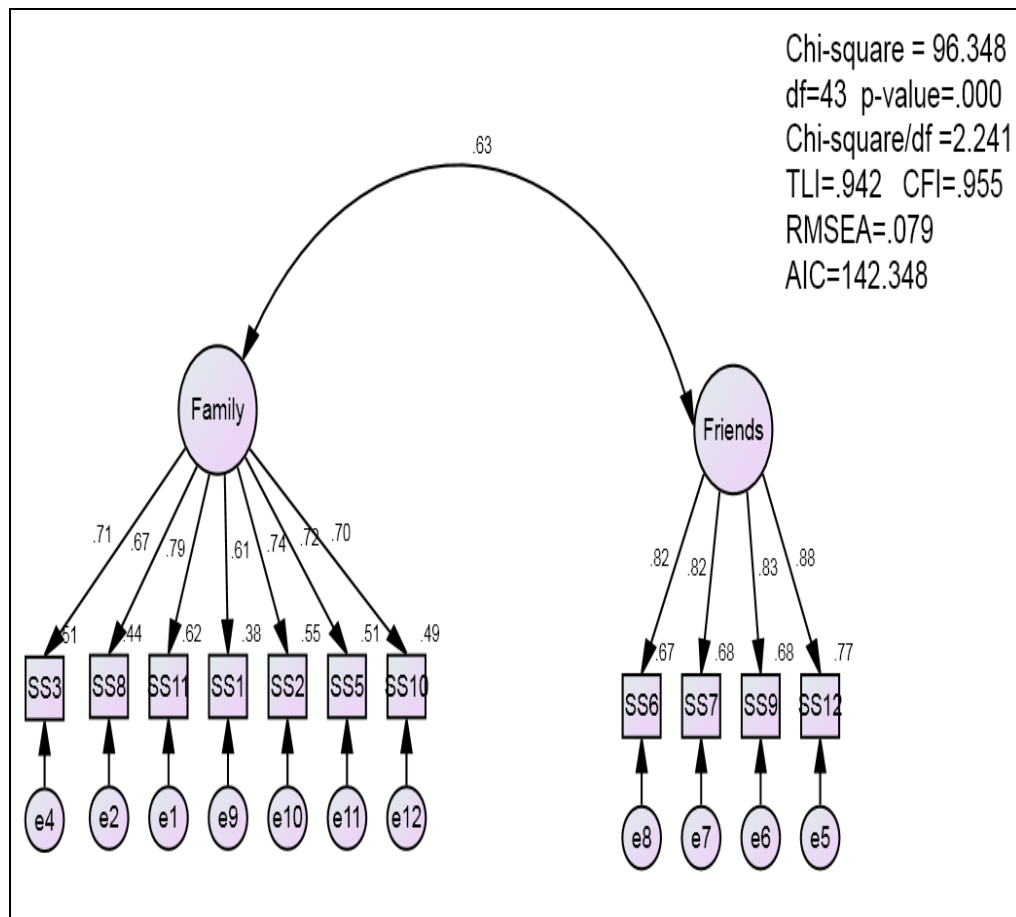
**Figure 4.3: Path diagram for tested three-factor model**

In this study the second option was considered. Items from the two constructs (family and significant others) were combined into one and the name of the construct was maintained as family. Item 4 (I get the emotional help and support I need from my family) lacked discriminant validity and hence it was dropped. The two factor model with just 11 items was found to be acceptable [Chi-square/df < 3, TLI, CFI > 0.9, RMSEA < 0.08]. Cross validity tested using 1000 bootstrap resamples gave satisfactory results (P=0.079). The minimum factor loading in the two-factor model was 0.667. The average variance extracted (AVE) for the Family and Friends constructs were 0.5 and 0.7, respectively. The R-squared value between the two constructs was 0.397. Since the R-squared value is less than the AVEs there is sufficient discriminant validity between the two constructs. The factor loadings for the two constructs are provided in Table 4.5 and the final path diagram is shown in Figure 4.4.

**Table 4.5: Regression Weights for the two-factor model**

		Unstd. Estimate	S.E.	C.R.	P	Std Estimate
SS11	<--- Family	1.000				.787
SS8	<--- Family	.922	.097	9.514	***	.667
SS3	<--- Family	.913	.089	10.251	***	.711
SS1	<--- Family	.907	.105	8.660	***	.614
SS2	<--- Family	1.011	.094	10.798	***	.744
SS5	<--- Family	.967	.093	10.345	***	.717
SS10	<--- Family	1.044	.104	10.054	***	.699
SS12	<--- Friends	1.000				.878
SS9	<--- Friends	.952	.065	14.679	***	.825
SS7	<--- Friends	.957	.065	14.650	***	.824
SS6	<--- Friends	.963	.066	14.517	***	.820

\*\*\* p-value < 0.001



**Figure 4.4: Path diagram for final two-factor mode**

It was conclusively found that the 11-item Hausa-MSPSS (appendix K) index is valid for the assessment of perceived social support among stroke survivors in Nigeria.

## **4.2 PHASE 2- QUANTITATIVE PHASE**

This phase described the socio-demographic and clinical characteristics of the respondents followed by the percentage distribution of the functional status, social supports and Quality of Life (QOL) scores at 6 months and 1 year after stroke. The changes in functional status, social support and QOL at 6 months and 1 year after stroke are described. The factors influencing stroke survivors' QOL with each dimension of QOL at 6 months and 1 year after stroke are also presented.

### **4.2.1 Socio-demographic and clinical characteristics of the study participants at baseline**

As shown in table 4.6, the total number of the study participants was 233 stroke patients, out of which 51% were males and the remaining was females. Their ages ranged from 19 to 82 years with a mean age of 58.76 years (SD 13.24years) indicating that greater incidence of stroke prevailed in the middle aged persons. The individuals of this study were predominantly Muslims (99%) and belonging to Hausa ethnic group. Slightly more than half of the respondents were married and 30% were widowed. They were urban residents (74%) which made them convenient to have easy access to rehabilitation services in the study area. More than half of the subjects received non-formal education. More than one third of the study respondents were self-employed at the time of admission. But after stroke, it was found that slightly more than two third of the respondents had lost their jobs whereas only 22% were unemployed at the time of admission. Only three percent of the study respondents had enough income.

As shown in the table 4.7, using the WHO clinical criteria, 37% suffered from ischemic stroke and 10% were due to haemorrhage but due to lack of the diagnostic facilities and presence of incomplete data, stroke was categorized as indeterminate in 53% cases. Hemiparesis was more common on the right side (53%). The study respondents were



mainly head of the family. Slightly more than half of the survivors were cared for by their children and one fourth by their family members and spouses respectively. Half of the respondents could not return to work and slightly more than one third of them found that their previous work became less suitable after stroke. Close to half of the subject's hospital charges were catered by the family members, although 27% of the hospital treatment costs were paid by the subjects themselves.

**Table 4.6: Socio-demographic characteristics of the study population (N=233)**

Characteristics	Number	Percentage (%)
<b>Age</b>		
<20	01	0.4
20-29	05	2.1
30-39	10	4.3
40-49	38	16.3
50-59	45	19.3
60-69	78	33.5
70-79	38	16.3
>80	18	7.7
<b>Gender</b>		
Male	118	50.6
Female	115	49.4
<b>Religion</b>		
Islam	231	99.1
Christianity	2	0.9
<b>Ethnicity</b>		
Hausa	225	96.6
Yoruba	03	1.3
Others	05	2.1
<b>Marital Status</b>		
Single	05	2.1
Married	139	59.7
Widow/widower	70	30.0
Divorced/Separated	19	8.2
<b>Residency</b>		
Urban	172	73.8
Rural	61	26.2
<b>Education</b>		
Tertiary	22	9.4
Secondary	27	11.6
Primary	48	20.6
Non-formal	136	58.4
<b>Occupation before stroke</b>		
Government	28	12.0
Self employed	86	36.9
Retired	14	6.0
Farming	20	8.6
Laborer	17	7.3
Trading	17	7.3
Unemployed	51	21.9

<b>Occupation after stroke</b>		
Government	10	4.3
Self employed	17	7.3
Retired	18	7.7
Farming	05	2.1
Trading	03	1.3
Unemployed	180	77.3
<b>Income*</b>		
Enough and save	07	3.0
Just enough	101	43.3
Not Enough	125	53.6

\*As defined by the respondents

**Table 4.7: Clinical characteristics of the study population (N=233)**

<b>Characteristics</b>	<b>Number</b>	<b>Percentage (%)</b>
<b>Type of stroke</b>		
Ischemic	86	36.9
Hemorrhagic	24	10.3
Indeterminate	123	52.8
<b>Side of stroke (laterality)</b>		
Right	123	52.8
Left	110	47.2
<b>Status in the family</b>		
Head	227	97.4
Member	6	2.6
<b>Caregiver</b>		
Couple	51	21.9
Children	128	54.9
In-law	02	0.9
Family member*	49	21.0
Employer	3	1.3
<b>Effect to work</b>		
No effect at work	23	9.9
Less flexible	84	36.1
Can't return to work	118	50.6
Became unemployed	08	3.4
<b>Hospital treatment charges*</b>		
Able to pay	63	27.0
Friend	16	6.9
Government	01	0.4
Social work support	10	4.3
Free	31	13.3
Family support**	112	48.1

\*Parent, spouse and children

## 4.2.2 Information about 6-months follow-up

### 4.2.2.1 Incidence proportion of functional status at 6-months after stroke

It was found that at 6 months after stroke (Table 4.8.1), more than one fourth of the stroke survivors had the disability at the moderately severe level and 28% of them had the disability at the moderate level which was measured by the Modified Rankin Scale (MRS). According to the Barthel Index (BI) scale, 42% of the patients were severely dependent in all basic Activities of Daily Living (ADLs) and another 38% were moderately dependent. Only less than one percent of the patients were fully independent. In relation to the Beck Depression Inventory (BDI) scale, 43% of the patients had mild clinically significant depression and none of the patients had severe depression.

**Table 4.8.1: Incidence proportion of functional status at 6-months after stroke**

Functional Measures	Mean	SD	N	%	95% CI
<b>Modified Rankin Scale scores</b>	3.3	1.1			
No symptom			0	0	(0.0, 0.0)
No significant disability			19	8.2	(4.7, 11.6)
Slight disability			33	14.2	(9.5, 18.9)
Moderate disability			66	28.3	(22.7, 33.9)
Moderately severe disability			84	36.1	(29.6, 42.5)
Severe disability			31	13.3	(9.0, 17.6)
Death			00	00	(0.0, 0.0)
<b>Barthel Index scale scores</b>	60.5	25.1			
100 (fully independent)			01	0.4	(2.1, 7.3)
91-99 (mild dependence)			36	15.5	(34.8, 47.6)
61-90 (moderate dependence)			89	38.2	(32.2, 44.6)
21-60 (severe dependence)			97	41.6	(10.7, 20.2)
<20 (total dependence)			10	4.3	(0.0, 1.3)
<b>Beck Depression Inventory scores</b>	12.3	5.0			
0-9 (minimal depression)			80	34.3	(28.3, 40.8)
10-16 (mild depression)			101	43.3	(36.5, 50.2)
17-29 (moderate depression)			52	22.3	(17.2, 27.9)
30-63 (severe depression)			00		(0.0, 0.0)

SD, standard deviation; CI, confidence interval

#### **4.2.2.2 Percentage distribution and Means of perceived social supports at 6-months after stroke**

Percentage distribution of all twelve items of the Multidimensional Scale of Perceived Social Support (MSPSS) is presented in Table 4.8.2. More than half of the patients mildly accepted the presence of special person who is around when he/she needed as a perceived support. The situation is the same regarding the available person around them with whom they could share their joys and sorrows. Slightly less than half of the patients (very strongly and strongly) agreed that their family really tried to help them. Half of the patients were (very strongly and strongly) satisfied with the emotional support that they received from their families. Half of the study subjects mildly agreed to consider different types of support especially support from family, friends and others. Less than one third of the patients (strongly and very strongly) agreed with having a special person as a real source of comfort, whereas one fourth of the overall patients were neutral in agreeing to it. However, 35% of the patients were neutral in accepting that their friends really tried to help them whereas only 19% of them (strongly and very strongly) agreed that their friends really did help.

**Table 4.8.2: Percentage distribution and Means of perceived social supports at 6-months after stroke**

<b>Perceived Support from Family, Friends and Significant Others</b>	<b>Very Strongly Agree</b>	<b>Strongly Agree</b>	<b>Mildly Agree</b>	<b>Neutral</b>	<b>Mildly Disagree</b>	<b>Strongly Disagree</b>	<b>Very Strongly Disagree</b>
1. Special person around when he/she in need	6.9	20.7	57.3	11.2	3.4	0.4	0.0
2. There is a special person whom he/she can share his/her joys and sorrows.	6.0	26.6	52.4	13.3	1.3	0.4	0.0
3. His/her family really tries to help him/her	14.2	32.2	37.8	14.6	1.3	0.0	0.0
4. He/she gets the emotional help and support when he/she needs from his/her family	12.9	37.3	33.5	14.2	2.1	0.0	0.0
5. He/she has a special person who is a real source of comfort to him/her	6.4	21.9	41.6	25.3	4.7	0.0	0.0
6. His/her friends really try to help him/her	2.6	15.9	45.1	34.8	1.3	0.4	0.0
7. He/she can count on his/her friends when things go wrong.	3.9	8.2	51.9	33.0	2.6	0.4	0.0
8. He/she can talk about his/her problems with his/her family.	6.9	16.3	43.3	28.8	4.3	0.4	0.0
9. He/she has friends with whom he/she can share his/her joys and sorrows.	2.1	10.3	43.8	41.2	1.3	1.3	0.0
10. There is a special person in his/her life that cares about his/her feelings.	4.7	17.6	42.5	32.2	2.1	0.9	0.0
11. His/her family is willing to help him/her make decisions.	6.9	21.9	36.1	24.9	9.9	0.4	0.0
12. He/she can talk about his/her problems with his/her friends.	3.0	4.7	53.2	35.6	2.1	1.3	0.0

Slightly more than half of the patients mildly agreed that they can count on their friends when things go wrong but among the remaining, one third were neutral in agreeing to that point. It was found that 43% were mildly satisfied if they could talk to their family about their problems. On the other hand, almost half (44%) of the patients also mildly agreed to have friends as perceived social support whom they can share their joys and sorrows. Even though 36% of the respondents mildly agreed that their family were willing to help them to make decisions, more than half of the patients mildly accept that they could talk about their problems with their friends.

**Table 4.8.3: MSPSS Means, Standard Deviations and Confidence Intervals Estimates (N=233) at 6 months after stroke**

<b>MSPSS Subscales</b>	<b>Number of items</b>	<b>Mean</b>	<b>SD</b>	<b>95%CI</b>
Overall support	12	66.5	8.8	(65.4, 67.7)
Family	4	69.5	11.9	(68.0, 71.2)
Friends	4	62.2	9.7	(61.0, 63.5)
Significant others	4	67.7	10.9	(66.3, 69.2)

SD, standard deviation; CI, confidence interval

As can be seen from the Table 4.8.3, the majority of the patients agreed to perceive presence of family members, friends and significant others like neighbours and sympathizers around them individually and collectively as a significant supports.

#### **4.2.2.3 Incidence proportion of different Quality of Life (QOL) domains at 6-months after stroke**

The incidence proportion of physical activity impairment by different domains at 6 months after stroke is presented in Table 4.8.4. The physical domain is represented by strength, hand function, mobility and activities of daily living. As it can be seen, one third of the patients had no strength at all and another one third had just a little strength at the arm that was affected by the stroke. In terms of grip strength at the affected hand, 37% and 29% had a little strength and no strength at all respectively. Only 21% of the patients had a quite a bit of strength and another 26% had some strength in the leg that was affected by the stroke while 16% had no strength at all. It was found that 35% of the patients had only a little strength in the foot/ankle that was affected by the stroke.

In relation to hand function, 43% of the patients found it very difficult to carry heavy objects such as carrying a bag of groceries and 32% could not even do it at all. More than half of the patients found it very difficult to turn a door knob. Again, more than half of the patients found it very difficult to open a can or a jar. Regarding tying a shoe

lace, 39% of the patients found it very difficult and 38% could not even do that at all while 48% of the patients could not pick up a dime at all.

**Table 4.8.4: Percentage distribution of physical activity domains at 6-months after stroke**

<b>STRENGTH</b>					
<b>In the past week, how would the patient rate the strength of his/her</b>	<b>A lot of strength</b>	<b>Quite a bit of strength</b>	<b>Some strength</b>	<b>A little strength</b>	<b>No strength at all</b>
1. Arm that was most affected by stroke	0.9	12.9	21.0	31.8	33.5
2. Grip of his/her hand that was most affected by stroke	1.7	11.2	21.5	36.9	28.8
3. Leg that was most affected by stroke	1.7	20.6	26.2	35.2	16.3
4. Foot/Ankle that was most affected by stroke	1.7	22.0	18.5	34.9	22.8
<b>HAND FUNCTION</b>					
<b>In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to...</b>	<b>Not difficult at all</b>	<b>A little Difficult</b>	<b>Somewhat difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
1. Carry heavy objects (e.g. bag of groceries)?	7.3	9.0	9.0	42.5	32.2
2. Turn a doorknob?	8.2	2.6	15.5	56.7	17.2
3. Open a can or jar?	6.0	6.0	9.9	54.5	23.6
4. Tie a shoe lace?	4.3	7.3	10.8	39.2	38.4
5. Pick up a dime?	12.9	1.7	15.0	22.7	47.6
<b>MOBILITY</b>					
<b>In the past 2 weeks, how difficult was it to...</b>	<b>Not Difficult at all</b>	<b>A little Difficult</b>	<b>Somewhat difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
1. Stay sitting without losing your balance?	66.1	11.6	8.2	12.0	2.1
2. Stay standing without losing your balance?	37.8	16.3	9.4	13.7	22.7
3. Walk without losing your balance?	47.2	11.2	9.4	9.4	22.7
4. Move from a bed to a chair?	44.2	9.4	9.4	11.6	25.3
5. Walk one block?	29.2	15.9	16.3	15.5	23.2
6. Walk fast?	9.4	14.6	13.3	28.8	33.9
7. Climb one flight of stairs?	15.9	9.5	14.7	16.4	43.5
8. Climb several flights of stairs?	6.0	14.2	12.9	19.7	47.2
9. Get in and out of a car?	16.7	12.9	13.3	14.6	42.5
<b>ACTIVITIES OF DAILY LIVING (ADL)</b>					
<b>In the past 2 weeks, how difficult was it to...</b>	<b>Not Difficult at all</b>	<b>A little Difficult</b>	<b>Somewhat difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
1. Cut your food with a knife and fork?	59.7	8.2	10.7	11.2	10.3
2. Dress the top part of your body?	19.7	15.0	8.2	19.3	37.8
3. Bathe yourself?	16.3	7.7	9.9	24.5	41.6
4. Clip your toenails?	9.4	4.7	6.4	20.2	59.2



5. Get to the toilet on time?	28.3	9.0	14.6	12.4	35.6
6. Control your bladder (not have an accident)?	63.9	10.3	6.0	8.2	11.6
7. Control your bowels (not have an accident)?	64.8	16.3	3.9	8.6	6.4
8. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)?	17.6	12.9	6.0	21.5	42.1
9. Go shopping?	18.9	3.9	9.0	21.9	46.4
10. Do heavy household chores (e.g. vacuum, laundry or yard work)?	8.6	6.9	13.4	19.0	52.2

In terms of mobility, 66% of the patients found it easier to sit without losing balance at all; and only slightly more than one third found it easy to stand without losing their balance. However, almost half of the patients could walk without losing their balance and 44% could move from bed to chair, but one fourth of them could not do it at all. Only 29% of the patients did not find it difficult to walk one block and one third of the patients could not at all walk fast. It was found that 43% and 47% of the patients could not climb at all one flight and several flights of stairs respectively; and 42% of the patients could not get in and out of a car at all.

Regarding activities of daily living (ADL), it was found that more than half of the patients did not have any difficulty to cut their food whereas more than one third could not dress the upper part of their body. However, 42% could not bathe by themselves and more than half were not able to clip their toe nails. Getting to the toilet on time was too difficult a task for 36% of the patients. The study found that 64% and 65% of the patients did not find any difficulty at all to control their bladder and bowels respectively. In total, 42% of the patients could not do any light household task such as dusting, making the bed, take out garbage nor wash the dishes and 46% were not able to go out for shopping. More than half of the patients could not do any heavy household chores such as vacuuming, doing laundry or do yard work.

The memory and thinking domain of Quality of Life (QOL) was accessed by seven items as presented in the Table 4.8.5. The majority of the patients did not find any difficulty to remember things, concentrate and think quickly. The only issue that was identified was regarding their ability to solve their everyday problems. It was found to be not difficult at all among only 22% of the patients.

**Table 4.8.5: The percentage distribution of different items of memory and thinking domain at 6 months after stroke**

In the past week, how difficult was it for the patient to rate his/her	Not difficult at all	A little Difficult	Somewhat difficult	Very difficult	Extremely difficult
1. Remember things that people just told you?	76.0	3.9	6.4	6.0	7.7
2. Remember things that happened the day before?	74.7	3.9	9.9	8.2	3.4
3. Remember to do things (e.g. keep scheduled appointments or take medication)?	81.5	4.7	3.9	8.2	1.7
4. Remember the day of the week?	77.3	6.9	4.3	6.9	4.7
5. Concentrate?	64.8	18.5	6.9	9.4	0.4
6. Think quickly?	60.9	14.2	9.9	12.9	2.1
7. Solve everyday problems?	21.9	24.5	18.9	24.9	9.9

Table 4.8.6 shows the percentage distribution of the nine items of emotion domain at 6 months after stroke. Only 27% of the patients did not feel sad at all at any of the time; 45% of them did not feel at all that there was nobody who is close to them. However, 22% of the patients felt most of the time that they were a burden to others and only three percent of the patients felt that they had nothing to look forward to. One tenth of the patients blamed themselves most of the time for the mistakes they had made. Though, 39% of the patients did not enjoy things as much as ever whereas only 9% felt quite nervous all of the time. Despite having the challenges of stroke sequelae, the

majority (72%) of the patients felt that life is still worthy living and 60% could smile and laugh all of the time.

**Table 4.8.6: The percentage distribution of different items of emotion domain at 6 months after stroke**

In the past week, how often did the patient	None of the time	A little of The time	Some of the time	Most of the time	All of the time
1. Feel sad?	26.6	22.3	26.2	22.3	2.6
2. Feel that there is nobody you are close to?	44.6	21.9	20.2	11.2	2.1
3. Feel that you are a burden to others?	39.1	9.4	22.3	21.5	7.7
4. Feel that you have nothing to look forward to?	47.2	9.9	21.0	18.5	3.4
5. Blame yourself for mistakes that you made?	60.1	14.6	12.0	10.3	3.0
6. Enjoy things as much as ever?	39.1	16.7	25.3	11.2	7.7
7. Feel quite nervous?	49.4	14.6	18.5	9.0	8.6
8. Feel that life is worth living?	3.4	4.3	2.6	17.2	72.5
9. Smile and laugh at least once a day?	3.4	6.4	6.9	23.6	59.7

As shown in Table 4.8.7, most of the patients did not face any difficulty at all regarding the attributes of communication which was assessed by seven items. Only close to one third of the patients found it extremely difficult to call another person on the telephone including dialling and selecting the correct phone number.

**Table 4.8.7: The percentage distribution of different items of communication domain at 6 months after stroke**

In the past week, how difficult was it for the patient to	Not difficult at all	A little Difficult	Somewhat difficult	Very difficult	Extremely difficult
1. Say the name of someone who was in front of him/her?	77.3	7.3	4.7	5.2	5.6
2. Understand what was being said to you in a conversation?	80.7	8.2	5.6	2.1	3.4
3. Reply to questions?	77.7	8.2	6.9	7.3	0.0
4. Correctly name objects?	67.0	8.6	11.2	9.0	4.3
5. Participate in a conversation with a group of people?	68.2	11.2	6.9	9.0	4.7
6. Have a conversation on the telephone?	54.5	14.2	6.9	6.4	18.0
7. Call another person on the telephone, including selecting the correct phone number and dialling?	25.8	21.5	8.2	14.2	30.5

The percentage distribution of the different items of social participation domain of QOL of the patients at 6 months post stroke is shown in Table 4.8.8. Most of the time during the last four weeks, 43% of the patients (n=100) were limited in their work whether it is paid (61% out of the 43%) or voluntary (39% out of the 43%). Slightly more than half of the patients were limited in their social activities and had to pursue of their quite recreation like crafting and reading. It was also found that most of the time, 42% were also limited in the pursuit of their active recreation and 36% reported to have limitation regarding their roles as family members. Religious activities were limited in 37% of the patients and 37% could control their lives as they wish and 39% were able to help others.

**Table 4.8.8: The percentage distribution of different items of participation domain at 6 months after stroke**

During the past 4 weeks, how much of the time has the patient been limited regarding	None of the time	A little of the time	Some of the time	Most of the time	All of The time
1. His/her work (paid, voluntary or other)	11.6	6.0	6.9	43.3	32.2
2. His/her social activities?	6.0	13.7	12.4	51.5	16.3
3. Quiet recreation (crafts, reading)?	9.4	9.9	17.2	53.2	10.3
4. Active recreation (sports, outings, travel)?	7.3	11.2	24.0	41.6	15.9
5. Your role as a family member and/or friend?	10.3	10.8	30.6	36.2	12.1
6. His/her participation in spiritual or religious activities?	17.6	7.7	30.9	36.1	7.7
7. His/her ability to control his/her life as he/she wishes?	12.4	15.0	24.0	36.5	12.0
8. His/her ability to help others?	11.2	9.0	22.3	39.1	18.5

The distribution of dimension specific QOL scores for the 233 respondents at 6-months after stroke is shown in Table 4.8.9. With the exception of memory (Mean 80.5, SD 22.2) and communication (Mean 78.4, SD 24.5) domains, all the dimensions specific QOL were found to be low especially that of hand function (Mean 28.5, SD 25.1).

**Table 4.8.9: Distribution of scores for the different dimensions of QOL of the 233 patients at 6-months after stroke**

SIS 3.0 subscales	Number of items	Mean	SD	95% CI
Strength	4	33.6	21.5	(30.7, 36.4)
Memory & thinking	7	80.5	22.2	(77.7, 83.3)
Emotion	9	57.4	12.3	(55.8, 59.0)
Communication	7	78.4	24.5	(75.4, 81.8)
Hand function	5	28.5	25.1	(25.2, 31.9)
Mobility	9	49.8	30.5	(46.0, 53.8)
ADL/IADL	10	46.4	24.8	(43.4, 49.8)
Participation	8	39.6	23.6	(36.6, 42.9)
Physical domain (1, 5, 6, 7 combined)	31	39.6	21.3	(36.9, 42.4)
Patient's global assessment of recovery	1	57.2	19.9	(54.7, 59.9)

SD, standard deviation; CI, confidence interval

### 4.2.3 Information about 1-year follow-up

#### 4.2.3.1 Incidence proportion of functional status at 1-year after stroke

At 1 year after stroke, the level of disability as measured by the modified Rankin Scale (MRS) reveals that, more than one third of the stroke survivors had the disability at the moderate level and another 29% of the stroke survivors had the disability at the moderately severe level (table 4.8.10). In terms of the Barthel Index (BI) scale, almost half of the patients were moderately dependent and another 37% were, severely dependent for all basic activities of daily livings (ADLs). None of the patients was fully independent. According to the Beck Depression Inventory (BDI) scale, close to half of patients had minimal clinically significant depression, 44% had mild clinically significant depression and none of the patients had severe depression.

**Table 4.8.10: Incidence proportion of functional status at 1-year after stroke**

<b>Functional Measures</b>	<b>Mean</b>	<b>SD</b>	<b>n</b>	<b>%</b>	<b>95% CI</b>
<b>Modified Rankin Scale scores</b>	3.1	1.1			
No symptom			00	00	(0.0, 0.0)
No significant disability			17	7.8	(4.6, 11.5)
Slight disability			37	17.1	(11.5, 22.1)
Moderate disability			82	37.8	(30.9, 44.7)
Moderately severe disability			62	28.6	(22.6, 34.6)
Severe disability			19	8.8	(5.1, 12.4)
Death			00	00	(0.0, 0.0)
<b>Barthel Index scale scores</b>	68.5	18.8			
100 (fully independent)			00	00	(0.0, 0.0)
91-99 (mild dependence)			33	15.2	(10.6, 19.8)
61-90 (moderate dependence)			102	47.0	(40.6, 53.9)
21-60 (severe dependence)			80	36.9	(30.4, 43.8)
<20 (total dependence)			2	0.9	(0.0, 2.3)
<b>Beck Depression Inventory scores</b>	10.3	4.0			
0-9 (minimal depression)			106	48.8	(41.9, 55.3)
10-16 (mild depression)			95	43.8	(37.3, 50.2)
17-29 (moderate depression)			16	7.4	(4.1, 11.1)
30-63 (severe depression)			00	00	(0.0, 0.0)

SD, standard deviation; CI, confidence interval

#### **4.2.3.2 Percentage distribution and means of perceived social support at 1-year after stroke**

Table 4.8.11 shows the percentage distribution of all the twelve items of the Multidimensional Scale of Perceived Social Support (MSPSS). One third of the patients were neutral in agreeing to the presence of special person who is around them when he/she needed as perceived support. The situation is the same regarding the available person around them with whom they could share their joys and sorrows. Almost one third of the patients mildly agreed that their family really tried to help them. In the same context, more than one third of the patients were mildly satisfied with the emotional support that they received from their families. Slightly more than one third of the patients were neutral in agreeing to have a special person as a source of comfort whereas close to one fourth of the overall patients mildly agreed to that point. Meanwhile, one third were also neutral in accepting that their friends tried to help them whereas a slightly more than one fourth of the patients agreed that their friends did try. More than one third of the overall patients were neutral in agreeing that they can count on their friends when things go wrong whereas 20% mildly agreed upon to that point. It was found that one third was neutrally satisfied if they could talk about their problems to their family. Close to one third of the patients neutrally agreed to have friends as a perceived social support with whom they can share their joys and sorrows. Almost one third of the stroke survivors mentioned about the presence of a special person in their lives who care about their feelings. Only slightly more than one fourth of the patients (strongly and very strongly) agreed that their family were willing to help them to make decisions, while 27% mildly agreed and slightly more than one fourth were just neutral in agreeing to that point. More than one third of the patients neutrally agreed that they could talk about their problems with their friends.

**Table 4.8.11: Percentage distribution and means of perceived social support at 1 year after stroke**

<b>Perceived Support from Family, Friends and Significant Others</b>	<b>Very Strongly Agree</b>	<b>Strongly Agree</b>	<b>Mildly Agree</b>	<b>Neutral</b>	<b>Mildly Disagree</b>	<b>Strongly Disagree</b>	<b>Very Strongly Disagree</b>
1. Special person who is around when he/she is in need.	3.2	11.1	31.8	33.6	16.6	3.7	0.0
2. There is a special person whom he/she can share his/her joys and sorrows.	2.3	11.5	30.4	33.6	18.9	3.2	0.0
3. His/her family really tries to help him/her	6.5	20.7	32.3	28.6	11.5	0.5	0.0
4. He/she gets the emotional help and support he/she needs from his/her family	8.3	18.4	35.9	30.4	6.0	0.9	0.0
5. He/she has a special person who is a real source of comfort to him/her	4.1	18.0	22.6	34.1	17.5	3.7	0.0
6. His/her friends really try to help him/her	1.4	9.2	26.7	33.2	17.1	12.4	0.0
7. He/she can count on his/her friends when things go wrong.	2.3	7.4	20.3	37.3	19.4	13.4	0.0
8. He/she can talk about his/her problems with his/her family.	4.1	15.7	29.0	33.2	15.7	2.3	0.0
9. He/she has friends with whom he/she can share his/her joys and sorrows.	1.8	9.7	21.7	31.3	19.8	15.7	0.0
10. There is a special person in his/her life that cares about his/her feelings.	3.2	14.3	24.0	30.4	18.4	9.7	0.0
11. His/her family is willing to help him/her make decisions.	7.4	21.2	26.7	26.3	18.0	0.5	0.0
12. He/she can talk about his/her problems with his/her friends.	0.9	3.7	21.7	36.4	21.7	15.2	0.5

It can be seen from the table 4.8.12 that aside from friends, the majority of the patients individually and collectively agreed to perceive the presence of family and significant others like neighbours and sympathizers around them as a significant supports.



**Table 4.8.12: MSPSS Means, Standard Deviations and Confidence Intervals Estimates (N=217) at 1 year after stroke**

MSPSS Subscales	Number of items	Mean	SD	95%CI
Overall support	12	55.8	13.0	(53.9, 57.5)
Family	4	62.3	14.6	(60.3, 64.2)
Friends	4	49.0	16.4	(46.8, 51.2)
Significant others	4	56.0	15.0	(53.9, 57.9)

SD, standard deviation; CI, confidence interval

#### **4.2.3.3 Incidence proportion of the Quality of Life (QOL) domains at 1 year after stroke**

The percentage distribution of the physical activity impairment by different domains at 1 year after stroke is shown in the Table 4.8.13. The domain is represented by strength, hand function, mobility and activities of daily living. It can be seen that 42% had a little strength and a slightly more than one fourth of the patients had no strength at all at the arm that was affected by the stroke. Regarding the grip strength at the affected hand, 46% had a little strength and 28% some strength. It was also found that 38% had some strength in the leg that was affected by the stroke whereas more than one third had little strength. About 38% also reported to have had a little strength and almost one third had some strength at the foot/ankle that was affected by the stroke.

In terms of hand function, 44% of the patients found it very difficult to carry heavy objects such as carrying a bag of groceries and 21% could not even do it at all. More than one third of the patients found it very difficult to turn a door knob. Meanwhile, 40% of the patients found it very difficult to open a can or a jar where as 31% could not even do it at all. Again, 41% of them found it very difficult to tie a shoe lace and one third of them were not able to perform this simple function while 38% of the patients found it very difficult to pick up a dime.

**Table 4.8.13: Percentage distribution of physical activity domains at 1 year after stroke**

<b>STRENGTH</b>					
<b>In the past week, how would the patient rate the strength of his/her</b>	<b>A lot of strength</b>	<b>Quite a bit of strength</b>	<b>Some strength</b>	<b>A little strength</b>	<b>No strength at all</b>
1. Arm that was most affected by stroke	0.0	8.3	22.6	42.4	26.7
2. Grip of his/her hand that was most affected by stroke	0.5	7.8	26.7	46.5	18.4
3. Leg that was most affected by stroke	1.8	21.2	38.2	35.0	3.7
4. Foot/Ankle that was most affected by stroke	0.9	24.9	32.3	38.2	3.7
<b>HAND FUNCTION</b>					
<b>In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Somewhat difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
1. Carry heavy objects (e.g. bag of groceries)?	7.8	9.7	17.1	44.2	21.2
2. Turn a doorknob?	8.3	4.1	20.7	39.2	27.6
3. Open a can or jar?	5.5	6.9	16.6	40.1	30.9
4. Tie a shoe lace?	4.6	8.8	12.9	41.0	32.7
5. Pick up a dime?	10.6	5.5	17.1	37.8	29.0
<b>MOBILITY</b>					
<b>In the past 2 weeks, how difficult was it to...</b>	<b>Not Difficult at all</b>	<b>A little difficult</b>	<b>Somewhat difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
1. Stay sitting without losing your balance?	59.9	17.1	9.2	10.6	3.2
2. Stay standing without losing your balance?	35.9	19.8	11.1	24.0	9.2
3. Walk without losing your balance?	44.7	16.1	10.6	13.8	14.7
4. Move from a bed to a chair?	43.3	10.6	13.4	18.9	13.8
5. Walk one block?	29.0	16.1	20.3	20.3	14.3
6. Walk fast?	10.6	16.1	20.7	33.2	19.4
7. Climb one flight of stairs?	14.3	14.3	13.8	37.3	20.3
8. Climb several flights of stairs?	6.5	16.1	16.1	37.8	23.5
9. Get in and out of a car?	14.7	14.3	16.6	30.4	24.0
<b>ACTIVITIES OF DAILY LIVING (ADL)</b>					
<b>In the past 2 weeks, how difficult was it to...</b>	<b>Not Difficult at all</b>	<b>A little difficult</b>	<b>Somewhat difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
1. Cut your food with a knife and fork?	53.0	14.7	12.4	14.3	5.5
2. Dress the top part of your body?	18.9	16.1	12.9	35.5	16.6
3. Bathe yourself?	15.2	9.7	14.3	43.3	17.5
4. Clip your toenails?	9.7	6.5	15.2	40.6	28.1
5. Get to the toilet on time?	26.3	11.1	18.4	26.7	17.5
6. Control your bladder (not have an accident)?	57.1	18.0	5.1	12.0	7.8
7. Control your bowels (not have an	61.8	18.9	7.4	8.3	3.7

accident)?					
8. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)?	18.4	13.4	15.7	44.2	8.3
9. Go shopping?	18.0	7.4	13.4	32.3	29.0
10. Do heavy household chores (e.g. vacuum, laundry or yard work)?	8.8	11.1	15.7	40.6	24.0

In relation to mobility, 60% of the patients found it easier to stay without losing their balance and only 36% found it easier to stand without losing their balance. Moreover, 45% of the patients could walk without losing control of their balance and 43% could move from bed to chair. Only less than half of the patients found it a little difficult and not difficult at all to walk one block and one third of the patients found it very difficult to walk fast. It was found that 37% and 38% of the patients found it very difficult to climb one flight and several flights of stairs respectively; and again 30% of the patients could not at all get in and out of a car.

Pertaining to activities of daily living, it was found that more than half of the patients had no difficulty at all to cut their food but, more than one third found it very difficult to dress the upper part of their body while 43% found it very difficult to bathe by themselves. Clipping toe nails was found to be very difficult for 41% of the patients. Only slightly more than one third of the patients found it (a little difficult and not difficult at all) to get to the toilet on time. The study found that 57% and 62% of the patients did not find any difficult to control their bladder and bowels respectively. Generally, 44% of the patients found it very difficult to carry out light household tasks such as dusting, making a bed or taking out garbage and 32% of them also found it very difficult to go shopping. In total, 41% of the patients found it very difficult to perform heavy household chores such as vacuuming, doing laundry or doing yard work.

Table 4.8.14 shows the memory and thinking domain of QOL at 1 year after stroke as assessed by seven items. It can be seen that the majority of the patients did not find any difficulty to remember things, concentrate and quickly think. Solving everyday problems was the only issue that was found to be a little difficult to only 35% and not difficult at all to only 18% of the patients.

**Table 4.8.14: The percentage distribution of different items of memory and thinking domain at 1 year after stroke**

In the past week, how difficult was it for the patient to rate his/her	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
1. Remember things that people just told you?	59.4	18.9	10.6	7.4	3.7
2. Remember things that happened the day before?	66.8	11.5	12.0	8.3	1.4
3. Remember to do things (e.g. keep scheduled appointments or take medication)?	74.2	12.9	3.2	8.8	0.9
4. Remember the day of the week?	72.8	12.0	6.5	6.5	2.3
5. Concentrate?	60.8	22.6	10.6	6.0	0.0
6. Think quickly?	57.6	20.3	9.2	12.9	0.0
7. Solve everyday problems?	18.4	34.6	27.6	18.4	0.9

The emotion domain of Quality of Life (QOL) was assessed by nine items as presented in Table 4.8.15. Only 30% of the patients felt sad some of the times and more than half (a little of the time and none of the time) did not feel sad; 41% of the stroke survivors did not feel at all that there is nobody who is close to them. However, more than one third of the patients did not feel that they were a burden to others and 44% also did not feel at all that they had nothing to look forward to. Only one tenth of the patients most of the time blamed themselves for the mistakes they have made, whereas more than one third of them enjoy things as much as ever all of the time. It was found that only 2% felt quite nervous all of the time. The majority (76%) of the patients felt that life is worthy of living and 73% could smile and laugh all of the time.

**Table 4.8.15: The percentage distribution of different items of emotion domain at 1 year after stroke**

In the past week, how often did the patient	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. Feel sad?	25.8	26.7	30.9	16.6	0.0
2. Feel that there is nobody you are close to?	41.5	26.7	23.0	8.3	0.5
3. Feel that you are a burden to others?	37.3	14.3	28.1	17.5	2.8
4. Feel that you have nothing to look forward to?	44.2	15.2	26.7	12.4	1.4
5. Blame yourself for mistakes that you made?	59.0	18.0	12.9	10.1	0.0
6. Enjoy things as much as ever?	1.4	16.1	24.4	21.7	36.4
7. Feel quite nervous?	48.4	17.5	19.8	12.0	2.3
8. Feel that life is worth living?	5.5	1.4	5.5	12.0	75.6
9. Smile and laugh at least once a day?	1.4	2.3	6.5	16.6	73.3

Although 10% of the patients found it extremely difficult to call another person on the telephone including dialling and selecting a correct number, the majority of the patients did not face any difficulty at all regarding the different aspects of communication which was assessed by seven items as shown in the table 4.8.16.

**Table 4.8.16: The percentage distribution of different items of communication domain at 1 year after stroke**

In the past week, how difficult was it for the patient to	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely Difficult
1. Say the name of someone who was in front of him/her?	70.0	14.3	5.1	6.5	4.1
2. Understand what was being said to you in a conversation?	69.6	19.8	5.1	2.3	3.2
3. Reply to questions?	68.7	18.0	7.4	6.0	0.0
4. Correctly name objects?	65.0	12.4	14.7	6.0	1.8
5. Participate in a conversation with a group of people?	62.2	16.6	11.5	7.4	2.3
6. Have a conversation on the telephone?	53.0	17.1	8.3	17.5	4.1
7. Call another person on the telephone, including selecting the correct phone number and dialling?	25.8	24.9	13.4	25.8	10.1

The percentage distribution of the different items of social participation domain of QOL of the patients at 1 year after stroke is shown in Table 4.8.17. Most of the time during the past four weeks, almost half of the patients were limited in their work whether paid or voluntary. It was found that most of the times, 48% of the patients were limited in the pursuit of their social activities and 39% were engaged in quite recreation such as crafting and reading. Some of the times, more than one third of the stroke patients were limited in the pursuit of their active recreation like outing or travelling. It was observed that 36% reported to have limitations some of the times regarding their roles as a family member whereas one third in most of the times were limited regarding their religious activities. However, in most of the time, 43% of the patients were limited most of the times in controlling their lives as they wish and half of them were limited regarding their ability to help others.

**Table 4.8.17: The percentage distribution of different items of participation domain at 1 year after stroke**

During the past 4 weeks, how much of the time has the patient been limited regarding	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. His/her work (paid, voluntary or other)	11.1	6.9	14.3	47.5	20.3
2. His/her social activities?	6.5	13.4	16.6	47.9	15.7
3. Quiet recreation (crafts, reading)?	9.2	10.6	27.2	39.2	13.8
4. Active recreation (sports, outings, travel)?	6.5	13.4	28.6	39.2	12.4
5. Your role as a family member and/or friend?	8.8	11.5	35.9	32.3	11.5
6. His/her participation in spiritual or religious activities?	13.4	13.4	33.6	36.4	3.2
7. His/her ability to control his/her life as he/she wishes?	8.8	13.8	27.2	43.3	6.9
8. His/her ability to help others?	6.9	8.8	25.8	50.2	8.3

Table 4.8.18 shows the dimension specific QOL scores for the 217 respondents at 1 year after stroke were found to be adequate except for strength, hand function and participation domains. The composite physical domain was also found to be low at 1 year after stroke.

**Table 4.8.18: Distribution of scores for the different dimensions of QOL dimensions of 217 patients at 1-year after stroke**

SIS 3.0 subscales	Number of items	Mean	SD	95% CI
Strength	4	37.6	18.4	(35.1, 40.1)
Memory & thinking	7	80.9	20.0	(78.1, 83.7)
Emotion	9	54.3	12.6	(52.5, 56.1)
Communication	7	79.6	21.8	(76.5, 82.2)
Hand function	5	31.2	25.3	(27.8, 34.6)
Mobility	9	54.1	27.6	(50.2, 57.9)
ADL/IADL	10	52.2	22.7	(49.2, 55.2)
Participation	8	41.0	19.4	(38.1, 44.1)
Physical domain (1, 5, 6, 7 combined)	31	43.8	19.7	(41.1, 46.4)
Patient's global assessment of recovery	1	62.9	15.2	(60.8, 65.0)

SD, standard deviation; CI, confidence interval

#### 4.2.4 Changes in functional status, social support and Quality of Life at 6 months and 1 year after stroke

Table 4.9 shows changes in functional scores over the time period and social support from 6 months to 1 year after stroke. There were changes in all the mean functional scores. Regarding the changes that occurred between 6 months and 1 year, by stroke patients significantly improved in relation to their level of disability as measured by the MRS. There were also significant changes in both the activities of daily living (BI scores) and the level of depression (BDI) scores. Mental health improved significantly. The mean scores of perceived social support from 6 months to 1 year were significantly decreased both in regards to overall social support and individual category of the three domains or subscales.

**Table 4.9 (a): Changes in functional status at 6 months and one year after stroke**

Functional measure	6 months (N=233)		1 Year (N=217)		Mean difference	SD	P-value
	Mean	SD	Mean	SD			
<b>Modified Rankin Scale (MRS)</b>	3.3	1.1	3.1	1.1	-0.2	0.5	<0.001*
<b>Barthel Index (BI)</b>	60.5	25.1	68..5	18.8	8.0	8.7	<0.001*
<b>Beck Depression Inventory (BDI)</b>	12.3	5.0	10.3	4.0	-2.1	1.9	<0.001*

*SD*, standard deviation; \*Statistically significant at  $p < 0.001$ . **MRS** = Modified Rankin Scale grades as: 0 indicating no symptoms; 1 (regardless of symptoms, no significant disability); 2 denoted as slight disability, 3 as moderate disability, 4, moderately severe disability, 5 means severe disability and 6(dead). **BI** = Barthel Index, The mean BI score of (< 20 was classified as total dependence and demanding “institutional care”; 21-60 as severe dependence; 61-90, moderate dependence; 91-99 as mild independence and 100, fully independent). **BDI**= Beck Depression Inventory for level of depression scores: 0-9, minimal; 10-16, mild; 17-29, moderate; and 30-63, severe.



**Table 4.9 (b): Changes in perceived social support at 6 months and one year after stroke**

MSPSS subscale	6 months (N=233)		1 Year (N=217)		Mean difference	SD	P-value
	Mean	SD	Mean	SD			
<b>Overall support</b>	66.4	8.8	55.8	13.0	-10.6	8.7	<0.001*
<b>Family</b>	69.5	11.9	62.3	14.6	-7.2	9.7	<0.001*
<b>Friends</b>	62.1	9.7	49.0	16.4	-13.1	13.0	<0.001*
<b>Significant others</b>	67.5	10.9	56.1	15.0	-11.4	10.6	<0.001*

*SD, standard deviation, MSPSS multidimensional Scale of Perceived Social support; \*statistically significant at p<0.01.*

The changes that occurred between 6 months and 1 year after stroke in relation to QOL, the condition of stroke patients changed significantly in all dimensions as shown in the 4.10. Except for the emotion domain, the scores of the different QOL dimensions were significantly higher at 1 year after stroke. The overall post stroke recovery of survivors substantially becomes better.

**Table 4.10: Changes in Quality of Life (QOL) 6 months and one year after stroke**

SIS subscale	6 months (N=233)		1 Year (N=217)		Change		P-value
	Mean	SD	Mean	SD	Mean	SD	
	Strength	33.6	21.5	37.6	18.4	4.0	
Memory & Thinking	80.3	22.2	80.9	20.0	0.7	4.1	0.019*
Emotion	57.4	12.3	54.3	12.6	-3.1	10.0	<0.001*
Communication	78.4	24.5	79.6	21.8	1.2	4.9	<0.001*
Hand function	28.7	25.1	31.2	25.3	2.5	5.4	<0.001*
Mobility	49.8	30.5	54.1	27.6	3.6	4.7	<0.001*
ADL/IADL	46.4	24.8	52.2	22.7	5.4	5.1	<0.001*
Participation	39.8	23.6	41.0	22.4	1.2	5.8	0.002*
Physical domain (1,5,6,7 combined)	39.9	21.3	43.8	19.7	3.9	3.2	<0.001*
Global recovery	57.2	19.9	62.9	15.2	5.7	7.5	<0.001*

*ADL/IADL, Activities of Daily Living/Instrumental Activities of Daily Living; \*Statistically significant at p<0.001.*

#### 4.2.5 Predictors of stroke specific dimensions of Quality of Life (QOL) domains at 6 months after stroke

The tables below (Tables 4.11 - 4.19) show the results of the stepwise linear regression model which was conducted to examine the relationship between different domains of QOL at 6 months after stroke. In these tables, only significant associations between various predictors and domains were presented.

**Table 4.11: Predictors of strength dimension of QOL at 6-months after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.56)**

<b>Variable</b>	<b>Coefficient (SE)</b>	<b>95%CI</b>	<b>P-value</b>
<b>Age</b>	-0.27 (0.12)	(-5.04, 0.04)	0.023
<b>Occupation before stroke</b> (Self employed )	23.67 (7.07)	(9.74, 37.60)	0.001**
<b>Occupation after stroke</b> (Government)	-15.77 (7.78)	(-31.12, 0.42)	0.044*
<b>Income</b> (Enough and save)	21.12 (8.04)	(5.26, 37.00)	0.009**
<b>Caregiver</b> (Couple)	28.33 (10.22)	(8.17, 48.49)	0.006**
(Children)	19.88 (9.87)	(0.42, 39.34)	0.045*
<b>Effect to work</b> No effect at work	32.35 (8.39)	(15.81, 48.90)	<0.001**
<b>Hospital treatment charges</b> Unable to pay	-9.92 (3.63)	(-17.0, 2.76)	0.007**
<b>Modified Rankin Scores</b> (Degree of disability)	-7.66 (1.72)	(-11.0, 4.28)	<0.001**
<b>Beck Depression Inventory Scores</b> (Severity of depression)	-1.06 (0.25)	(-1.56, 0.56)	<0.001**

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at p<0.05, \*\*\*statistically significant at p<0.01.

Table 4.11 present the results of the forward stepwise linear regression models at 6 months after stroke. The adjusted R<sup>2</sup> of this model is 0.56 which means that 56% of the variation in strength domain of QOL is explained by the linear effects of the predictor variables presented. An increase in age has almost 3 times negative effect on the strength domain of physical health. Negative significant association exists between

working with the government after stroke and the strength dimension of QOL at 6 months after stroke. Having enough income, couple or children as caregivers at 6 months after stroke is positively associated with strength dimension of QOL.

When stroke's consequences have no effect to one's work it is also positively associated with the strength dimension of QOL. The inability of stroke survivors to pay for the hospital treatment charges is negatively associated with strength dimension of QOL at 6 months after stroke. Increased degree of disability and increased depression reduced the strength dimension of QOL at 6 months after stroke.

**Table 4.12: Predictors of hand function dimension of QOL at 6-months after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.45)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Education</b>			
(Primary)	9.82 (4.34)	(1.27, 18.38)	0.025*
<b>Side of stroke</b>			
(Right)	8.15 (3.21)	(1.81, 14.48)	0.012*
<b>Status in the family</b>			
Member	-30.79 (11.05)	(-52.60, 8.99)	0.006**
<b>Caregiver</b>			
(Couple)	28.59 (13.47)	(2.01, 55.16)	0.035*
(Family member)	39.23 (13.33)	(12.94, 65.52)	0.004**
<b>Effect to work</b>			
(No effect to work)	32.73 (11.06)	(10.93, 54.54)	0.003**
<b>Hospital treatment charges</b>			
(Free)	-11.40 (5.00)	(-21.25, 1.54)	0.024*
<b>Barthel Index score</b>			
(Level of independence)	0.38 (0.13)	(0.13, 0.63)	0.003**

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at  $p < 0.05$ , \*\*\*statistically significant at  $p < 0.01$ .

Table 4.12 present the results of the forward stepwise linear regression models at 6 months after stroke. The adjusted R<sup>2</sup> of this model is 0.45 which means that 45% of the variation in hand function domain of QOL is explained by the linear effects of the predictor variables presented. Positive significant associations exist between having at least a primary education, right sided stroke, having couple or family members as

caregivers and the stroke's consequence having no effect to one's work with hand function dimension of QOL at 6 months after stroke. Negative significant association exist between hospital treatment charges when offered free and the hand functions dimension of QOL at 6 months after stroke. But, a change in 1 standard deviation of Barthel Index (level of independency on functional status) has 3 times higher impact on hand function domain of physical health.

**Table 4.13: Predictors of mobility dimension of QOL at 6-months after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.51)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Age</b>	-3.37 (0.18)	(-0.72, 0.025)	0.036*
<b>Education</b>			
Tertiary	16.13 (7.06)	(2.21, 30.05)	0.023*
Secondary	14.65 (6.61)	(1.61, 27.70)	0.028*
Primary	16.45 (4.93)	(6.74, 26.17)	0.001**
<b>Occupation before stroke</b>			
Government	22.36 (9.88)	(2.88, 41.84)	0.025*
Trading	24.36 (7.64)	(9.29, 39.44)	0.002**
<b>Side of stroke</b>			
Right	9.15 (3.65)	(1.95, 16.34)	0.013*
<b>Caregiver</b>			
Couple	61.81 (15.30)	(31.63, 91.99)	<0.001**
Children	46.93 (14.77)	(17.79, 76.07)	0.002**
Family member	50.22 (15.14)	(20.36, 80.07)	0.001**
<b>Barthel Index score</b> (Level of independence)	1.03 (0.94)	(0.85, 1.22)	<0.001**

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at  $p < 0.05$ , \*\*statistically significant at  $p < 0.001$ .

Table 4.13 present the results of the forward stepwise linear regression model at 6 months after stroke. The adjusted R<sup>2</sup> of this model is 0.51 which means that 51% of the variation in mobility domain of QOL is explained by the linear effects of the predictor variables presented. For every one year increase in age, there is more than 3 times negative effect on the mobility dimension of wellbeing. Positive significant association exists between education (primary, secondary and tertiary) and the mobility dimension of physical health at 6 months after stroke. Being employed with the government or engaged in trading before stroke is positively associated with mobility dimension of

QOL. Positive significant association exists between right sided paralysis and improved mobility at 6 months after stroke. Caregiving by couple, children or family members is positively associated with mobility dimension of physical health. A change in 1 standard deviation of Barthel Index Score (level of independence on functional activities) is associated with improved mobility dimension of QOL.

**Table 4.14: Predictors of ADL/IADL dimension of QOL at 6-months after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.64)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Education</b>			
Primary	13.61 (3.87)	(5.97, 21.25)	0.001**
<b>Occupation before stroke</b>			
Government	20.10 (7.77)	(4.78, 35.43)	0.010*
Farming	12.43 (6.16)	(0.27, 24.57)	0.045*
Trading	14.98 (6.01)	(3.12, 26.83)	0.014*
<b>Side of stroke</b>			
Right	8.26 (2.87)	(2.60, 13.92)	0.004**
<b>Caregiver</b>			
Couple	34.60 (12.04)	(10.86, 58.33)	0.004**
Children	26.76 (11.62)	(3.85, 49.68)	0.022*
Family member	39.46 (11.91)	(15.98, 62.94)	0.001**
<b>Effect to work</b>			
No effect at work	21.19 (9.88)	(1.72, 40.67)	0.033*
<b>Hospital treatment charges</b>			
(Social work support)	-15.48 (6.98)	(-29.26, 1.70)	0.028*
<b>Barthel Index score</b>	0.68 (0.09)	(-1.51, 0.85)	<0.001**
(Activities of Daily Living)			
<b>Beck Depression Inventory score</b>	-0.57 (0.27)	(-1.10, 0.044)	0.034*
(Severity of depression)			

CI confidence interval, SE standard error, NOTE only significant factors are shown, \*statistically significant at p<0.05, \*\*\*statistically significant at p<0.01.

Table 4.14 present the results of the forward stepwise linear regression models at 6 months after stroke. The adjusted R<sup>2</sup> of this model is 0.64 which means that 64% of the variation in mobility ADL/IADL domain of QOL is explained by the linear effects of the predictor variables presented. There is a significant positive association between primary education and the ability to carry out the activities of daily living at 6 months after stroke. The ability to carry out the activities of daily living improved in those

engaged in active occupation (government, farming and trading) before their stroke. Positive significant association exists between right sided paralysis and the ADL/IADL domain of QOL. Activities of daily living improved when the caregivers are the spouse, children or family member within 6 months after stroke. Dependence on others to pay for treatment cost negatively affects the ability to carry out the ADL at 6 months after stroke. A change in 1 standard deviation of Barthel Index (level of dependence on functional activities) has almost 7 times higher impact on ADL/IADL. Conversely, an increase in 1 standard deviation of Beck Depression Inventory (level of depression) negatively affects the ADL/IADL dimension of wellbeing at 6 months after stroke.

**Table 4.15: Predictors of physical dimension of QOL at 6-months after stroke on linear regression (Model Adjusted R<sup>2</sup>=0.57)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Education</b>			
(Primary)	11.52 (3.26)	(5.09, 17.95)	0.001**
<b>Occupation before stroke</b>			
(Government)	18.65 (6.54)	(5.76, 31.54)	0.005**
(Self-employed)	10.23 (3.99)	(2.37, 18.10)	0.011*
<b>Side of stroke</b>			
(Right)	7.05 (2.41)	(2.29, 11.81)	0.004**
<b>Caregiver</b>			
(Couple)	38.34 (10.13)	(18.36, 58.30)	0.000**
(Children)	26.96 (9.78)	(7.68, 46.24)	0.006**
<b>Effect to work</b>			
(No effect at work)	26.04 (8.31)	(9.65, 42.43)	0.002**
<b>Barthel Index Score</b>	0.56 (0.70)	(0.42, 0.70)	0.000**
(level of independence)			
<b>Beck Depression Inventory Score</b>	-0.57 (0.22)	(-1.0, 0.14)	0.010*
(Severity of depression)			

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at p<0.05, \*\*\*statistically significant at p<0.01.

Table 4.15 present the results of the forward stepwise linear regression models at 6 months after stroke. The adjusted R<sup>2</sup> of this model is 0.57 which means that 57% of the variation in physical health domain of QOL is explained by the linear effects of the predictor variables presented. Positive significant association exists between primary

education and the physical health at 6 months after stroke. At 6 months after stroke, the physical health improved for those that were engaged in active occupation (government or self employed) prior their stroke. Right sided paralysis was positively associated with improved physical health at 6 months after stroke. Physical health improved significantly when the caregiver is a spouse or children at 6 months after stroke. When the stroke has no impact on occupation, physical health improved 26 times. A change in 1 standard deviation of Barthel Index (level of independency on functional status) has almost 6 times higher impact on physical health. An increase in the level of depression as measured by the Beck Depression Inventory has almost 6 times negative effect on physical health.

**Table 4.16: Predictors of memory/thinking dimension of QOL at 6-months after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.44)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Residency</b> (Urban)	9.92 (3.44)	(3.14, 16.70)	0.004**
<b>Occupation after stroke</b> (Self-employed)	16.21 (6.85)	(2.71, 29.72)	0.019*
<b>Income</b> (Enough and save)	22.52 (9.44)	(3.91, 41.13)	0.018*
<b>Caregiver</b> (Couple)	53.07 (12.00)	(29.40, 76.73)	<0.001**
(Children)	40.66 (11.59)	(17.81, 63.51)	0.001**
<b>Modified Rankin score</b> (Degree of disability)	6.14 (2.37)	(1.47, 10.80)	0.010*
<b>Barthel Index score</b> (level of independence)	0.25 (0.11)	(0.025, 0.47)	0.029*
<b>Beck Depression Inventory score</b> (Severity of depression)	-1.37 (0.35)	(-2.06, 0.68)	<0.001**
<b>Social support</b> (Friends)	-0.34 (0.16)	(0.65, 0.02)	0.038*

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at p<0.05, \*\*statistically significant at p<0.01.

Table 4.16 present the results of the forward stepwise linear regression models at 6 months after stroke. The adjusted R<sup>2</sup> of this model is 0.44 which means that 44% of the

variation in memory and thinking domain of QOL is explained by the linear effects of the predictor variables presented. There is a significant positive association between urban residency and memory and thinking at 6 months after stroke. Thus persons who were self employed before their stroke had improved memory and thinking. Positive significant association exists between having enough income and improved memory and thinking at 6 months after stroke. Memory and thinking improved significantly when the caregiver is a spouse or children. A change in 1 standard deviation of Modified Rankin Score (degree of disability) and the Barthel Index (level of independence on functional status) has 6 times and almost 3 times higher effect on memory and thinking respectively. An increase in the level of depression as measured by the Beck Depression Inventory is negatively associated with memory and thinking at 6 months after stroke. Patients who depend on friends and not spouse or their children for support were 3 times worse in memory and thinking at 6 months after stroke.

**Table 4.17: Predictors of emotion domain of QOL at 6-months after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.41)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Marital status</b>			
(Widow)	-9.03 (3.03)	(-14.1, 3.05)	0.003
<b>Education</b>			
(Secondary)	8.60 (2.95)	(2.78, 14.41)	0.004
<b>Side of stroke</b>			
(Right)	4.73 (1.63)	(1.52, 7.94)	0.004
<b>Hospital treatment charges</b>			
(Able to pay)	6.98 (2.42)	(2.20, 11.76)	0.004
(Friends)	8.37 (3.36)	(1.74, 15.00)	0.014
<b>Beck Depression Inventory Score</b>	-0.95 (0.19)	(-1.33, 0.57)	<0.001**
(Severity of depression)			
<b>Overall perceived social support</b>	0.28 (0.09)	(0.11, 0.46)	0.002

CI confidence interval, SE standard error, NOTE only significant factors are shown, \*statistically significant at p<0.05, \*\*statistically significant at p<0.001.

Table 4.17 present the results of the forward stepwise linear regression models at 6 months after stroke. The adjusted R<sup>2</sup> of this model is 0.41 which means that 41% of the



variation in emotion domain of QOL is explained by the linear effects of the predictor variables presented. Negative significant association exists between level of depression, social disadvantage position such as a status of being a widow and emotion dimension of quality of life at 6 months after stroke. Emotion is improved in patients who can support themselves or dependent on their friends to pay for the treatment cost. Social support has almost 3 times higher effect on the emotion dimension of quality of life at 6 months after stroke.

**Table 4.18: Predictors of communication dimension of QOL at 6-months after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.55)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Residency</b> (Urban)	7.09 (3.40)	(0.38, 13.79)	0.038*
<b>Occupation before stroke</b> (Labourer)	-16.67 (6.54)	(-29.56, 3.78)	0.012*
<b>Side of stroke</b> (Right)	-8.52 (2.83)	(-14.10, 2.94)	0.003**
<b>Status in the family</b> (Member)	-49.64 (9.74)	(-68.84, 30.43)	<0.001**
<b>Hospital treatment charges</b> (Social work support)	-10.03 (4.40)	(-18.70, 1.35)	0.024*
<b>Beck Depression Inventory score</b> (Severity of depression)	-1.89 (0.38)	(-2.65, 1.13)	<0.001**

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at p<0.05, \*\*\*statistically significant at p<0.001.

Table 4.18 present the results of the forward stepwise linear regression models at 6 month after stroke. The adjusted R<sup>2</sup> of this model is 0.55 which means that 55% of the variation in communication domain of QOL is explained by the linear effects of the predictor variables presented. Communication improved about 7 times in patients who are urban resident and deteriorate in thus who are labourers before their stroke. Patients with right sided paralysis are associated with reduced communication at 6 months after stroke. Being a member and not the head of the family is negatively associated with communication at 6 months after stroke. Thus that depend on social work support to pay

the hospital treatment cost are worse in communication. Increased level of depression is associated with reduced communication.

**Table 4.19: Predictors of participation dimension of QOL at 6-months after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.61)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Education</b>			
(Primary)	8.23 (3.44)	(1.44, 15.02)	0.018*
<b>Income</b>			
(Enough and save)	22.55 (8.41)	(5.95, 39.14)	0.008**
<b>Caregiver</b>			
(Couple)	31.51 (10.70)	(10.40, 52.61)	0.004**
(Family member)	32.35 (10.59)	(11.47, 53.23)	0.003**
<b>Effect to work</b>			
(No effect to work)	36.58 (8.78)	(19.26, 53.89)	<0.001**
<b>Hospital treatment charges</b>			
(Government)	-39.69 (18.01)	(-75.20, 4.17)	0.029*
<b>Modified Rankin score</b>			
(Degree of disability)	-4.82 (2.03)	(-8.83, 0.82)	0.019*
<b>Barthel Index score</b>			
(Level of independence)	0.32 (0.10)	(0.13, 0.51)	0.001**
<b>Beck Depression Inventory score</b>			
(Severity of depression)	-0.71 (0.30)	(-1.31, 0.11)	0.020*

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at p<0.05, \*\*statistically significant at p<0.001.

Table 4.19 present the results of the forward stepwise linear regression models at 6 months after stroke. The adjusted R<sup>2</sup> of this model is 0.61 which means that 61% of the variation in participation domain of QOL is explained by the linear effects of the predictor variables presented. Primary education is positively associated with participation at 6 months after stroke. Social participation improved when the caregiver is a spouse or a family member. There is a significant association with level of disability and functional status. A change in 1 standard deviation of the Barthel Index (level of independence on functional status) has 3 times higher effect on social participation. Increased degree of disability as measured by the Modified Rankin Scale reduced social participation. Social participation improved when the consequence of stroke has no effect on the occupation of the patients. Patients who depend on the government to pay

for the treatment cost scored worse in participation. Negative significant association exists between the increased level of depression and social participation at 6 months after stroke.

#### 4.2.6 Predictors of stroke specific dimensions of Quality of Life (QOL) domains at 1 year after stroke

The tables below (table 4.20 - 4.28) show the findings of linear regression model which was conducted to examine the relationship between different domains of QOL at 1 year after stroke. In these tables, only significant associations between various predictors and domains were presented.

**Table 4.20: Predictors of Strength dimension of QOL at 1 year after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.55)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Age</b>	-0.34 (0.10)	(-0.54, 0.14)	0.001**
<b>Occupation before stroke</b>			
(Government)	15.81 (5.86)	(4.24, 27.38)	0.008**
(Farming)	11.45 (4.61)	(2.35, 20.55)	0.014*
<b>Income</b>			
(Enough and save)	21.90 (6.98)	(8.13, 35.67)	0.002**
<b>Caregiver</b>			
(Couple)	26.95 (8.82)	(9.55, 44.36)	0.003**
(Children)	19.30 (8.50)	(2.52, 36.08)	0.024*
(Family member)	19.72 (8.69)	(2.57, 36.86)	0.024*
<b>Effect to work</b>			
(No effect to work)	24.87 (7.52)	(10.03, 39.71)	0.001**
<b>Hospital treatment charges</b>			
(Unable to pay)	-9.30 (3.16)	(-15.54, 3.06)	0.004**
<b>Modified Rankin score</b>			
( Degree of disability)	-5.42 (1.44)	(-8.26, 2.58)	<0.001**
<b>Barthel Index score</b>			
(Level of independence )	0.30-(0.09)	(0.13, 0.48)	0.001**
<b>Beck Depression Inventory score</b>			
(Severity of depression)	-0.68 (0.29)	(-1.25, 0.11)	0.019*
<b>Overall Social support</b>			
(Support by friends)	0.23 (0.69)	(0.09, 0.36)	0.001**
	0.21 (0.10)	(0.12, 0.39)	0.033*

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at p<0.05, \*\*\*statistically significant at p<0.01.

Table 4.20 present the results of the forward stepwise linear regression models at 1 year after stroke. The adjusted  $R^2$  of this model is 0.55 which means that 55% of the variation in strength domain of QOL is explained by the linear effects of the predictor variables presented. A one year increase in age has more than 3 times negative effect on the strength domain of physical health. Stroke survivors that were engaged in active occupation (government and farming) before their stroke are positively associated with improved strength dimension of physical health at 1 year after stroke. Having enough income and supportive spouse, children or family member as caregivers at 1 year after stroke is positively associated with strength dimension of QOL. When stroke's consequences have no effect to one's work it was positively associated with the strength dimension of QOL. Increase in the degree of disability reduced the strength dimension of physical health. Patients who were unable to pay for the hospital treatment cost are worse in strength. Negative significant association exists between increased level of depression and strength dimension of physical health. However, overall social support and especially by friends is associated with increased strength at 1 year after stroke.

**Table 4.21: Predictors of hand-function domain of QOL at 1-year after stroke on linear regression analysis (Model Adjusted  $R^2=0.48$ )**

<b>Variable</b>	<b>Coefficient (SE)</b>	<b>95%CI</b>	<b>P-value</b>
<b>Education</b>			
(Primary)	10.17 (4.46)	(1.38, 18.97)	0.024*
<b>Caregiver</b>			
(Couple)	33.46 (13.42)	(6.97, 59.95)	0.014*
(Family member)	42.81 (13.22)	(16.73, 68.90)	0.001**
<b>Effect to work</b>			
(No effect at work)	35.20 (11.44)	(12.61, 57.78)	0.002**
<b>Hospital treatment charges</b>			
(Social work support)	-15.90 (7.79)	(-31.28, 0.52)	0.043*
<b>Barthel Index (BI) score</b>			
(Level of independence)	0.48 (0.16)	(0.17, 0.78)	0.003**
<b>Social support</b>			
(From significant others)	-0.43 (0.19)	(-0.80, 0.06)	0.023*

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at  $p<0.05$ , \*\*\*statistically significant at  $p<0.01$ .

Table 4.21 present the results of the forward stepwise linear regression models at 1 year after stroke. The adjusted  $R^2$  of this model is 0.48 which means that 48% of the variation in hand function domain of QOL is explained by the linear effects of the predictor variables presented. Positive significant associations exist between having at least a primary education and hand function dimension of physical health. Hand function significantly improved when the caregiver is a spouse or a family member. When the consequence of stroke had no effect on the work of the survivors, hand function is improved. Patients who are dependent on social work support to pay the hospital treatment cost are worse in hand function dimension of physical health. There is a significant association between the level of independence on functional status and hand function dimension of physical health. However, patients with poor social support from significant others are associated with decreased hand function dimension of physical health at 1 year after stroke.

**Table 4.22: Predictors of mobility domain of QOL at 1-year after stroke on linear regression analysis (Model Adjusted  $R^2=0.53$ )**

<b>Variable</b>	<b>Coefficient (SE)</b>	<b>95%CI</b>	<b>P-value</b>
<b>Age</b>	-0.43 (0.16)	(0.75, 0.12)	0.008**
<b>Education</b>			
(Primary)	11.98 (4.54)	(3.01, 20.94)	0.009**
<b>Occupation before stroke</b>			
(Government)	20.80 (9.09)	(2.86, 38.74)	0.023*
(Self-employed)	23.15 (5.47)	(12.36, 33.94)	<0.001**
(Trading)	23.24 (6.81)	(9.80, 36.68)	0.001**
<b>Side of stroke</b>			
(Right)	9.30 (3.37)	(2.64, 15.95)	0.006**
<b>Caregiver</b>			
(Couple)	51.88 (13.68)	(24.88, 78.88)	<0.001**
(Children)	41.03 (13.19)	(15.01, 76.05)	0.002**
(Family member)	43.57 (13.47)	(16.98, 70.16)	0.001**
<b>Barthel Index (BI) score</b>	1.08 (0.12)	(0.85, 1.30)	<0.001**
(Level of independence)			

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at  $p<0.05$ , \*\*statistically significant at  $p<0.001$ .

Table 4.22 present the results of the forward stepwise linear regression models at 1 year after stroke. The adjusted  $R^2$  of this model is 0.53 which means that 53% of the variation in mobility domain of QOL is explained by the linear effects of the predictor variables presented. An increase in age has more than 3 times negative effect on the mobility dimension of physical health. Positive significant association exists between primary education and the mobility dimension of wellbeing at 1 year after stroke. Stroke survivors that were engaged in active occupation before their stroke were associated with improved mobility. Positive significant association exists between right sided paralysis and improved mobility function at 1 year after stroke. Caregiving by spouse, children or family members is positively associated with mobility dimension of physical health. A change in 1 standard deviation of Barthel Index Score (level of independence on functional activities) is associated with improved mobility dimension of QOL.

**Table 4.23: Predictors of ADL/IADL domain of QOL at 1-year after stroke on linear regression analysis (Model Adjusted  $R^2=0.58$ )**

Variable	Coefficient (SE)	95%CI	P-value
<b>Education</b>			
(Primary)	13.15 (3.60)	(6.04, 20.27)	<0.001**
<b>Occupation before stroke</b>			
(Government)	18.74 (7.21)	(4.51, 32.98)	0.010*
(Self-employed)	8.94 (4.34)	(0.37, 17.50)	0.041*
(Farming)	14.21 (5.67)	(3.01, 25.40)	0.013*
(Trading)	15.23 (5.40)	(4.56, 25.89)	0.005**
<b>Side of stroke</b>			
(Right)	8.59 (2.68)	(3.31, 13.87)	0.002**
<b>Caregiver</b>			
(Couple)	29.05 (10.86)	(7.63, 50.47)	0.008**
(Children)	22.97 (10.46)	(2.32, 43.62)	0.029*
(Family member)	32.92 (10.69)	(11.83, 54.02)	0.002**
<b>Effect to work</b>			
(No effect at work)	18.67 (9.26)	(0.41, 36.93)	0.045*
<b>Hospital treatment charges</b>			
(Social work support)	-15.44 (6.30)	(-27.87, 3.00)	0.015*
<b>Barthel Index (BI) score</b>	0.74 (0.11)	(0.53, 0.95)	<0.001**
(Level of independence)			

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at  $p<0.05$ , \*\*statistically significant at  $p<0.001$ .

Table 4.23 present the results of the forward stepwise linear regression models at 1 year after stroke. The adjusted  $R^2$  of this model is 0.58 which means that 58% of the variation in ADL/IADL domain of QOL is explained by the linear effects of the predictor variables presented. Positive significant association exists between primary education and the ADL/IADL domain of physical health. Activities of daily living are improved in patients who were engaged in active occupation before their stroke. Right sided paralysis is positively associated with improved ability to execute ADL/IADL at 1 year after stroke. Ability to carry out activities of daily living improved significantly when the caregiver is a spouse, children or family member at 1 year after stroke. Positive significant association exists when the stroke's effects have no impact on the occupation and the ADL/IADL domain of physical health. A change in 1 standard deviation of Barthel Index (level of independency on functional status) has 7 times higher impact on the ability to carry out the ADL/IADL. Patients who depend on social work support to pay the hospital treatment cost are worse in ADL/IADL domain of physical health.

**Table 4.24: Predictors of physical domain of QOL at 1-year after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.60)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Education</b>			
Primary	9.41 (3.04)	(3.42, 15.41)	0.002**
<b>Occupation after stroke</b>			
(Government)	15.71 (6.08)	(3.72, 27.71)	0.011*
(Self-employed)	8.90 (3.66)	(1.68, 16.12)	0.016*
(Farming)	10.24 (4.78)	(0.80, 19.68)	0.034*
<b>Income</b>			
(Enough and save)	15.75 (7.24)	(1.47, 30.03)	0.031*
<b>Side of stroke</b>			
(Right)	6.42 (2.25)	(1.97, 10.87)	0.005**
<b>Caregiver</b>			
(Couple)	35.34 (9.15)	(17.28, 53.39)	<0.001**
(Children)	25.86 (8.82)	(8.46, 43.26)	0.004**
(In-laws)	32.38 (13.74)	(5.27, 59.49)	0.020*
(Family member)	34.76 (9.01)	(16.98, 52.54)	0.000**
<b>Effect to work</b>			
(No effect at work)	23.92 (7.80)	(8.53, 39.32)	0.002**
<b>Modified Rankin Scale (MRS) score</b>	-3.28 (1.36)	(-5.96, 0.60)	0.017*
(Degree of disability)			
<b>Barthel Index (BI) score</b>	0.65 (0.84)	(0.48, 0.81)	<0.001**
(Level of independence)			

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at p<0.05, \*\*\*statistically significant at p<0.001.

Table 4.24 present the results of the forward stepwise linear regression models at 1 year after stroke. The adjusted R<sup>2</sup> of this model is 0.60 which means that 60% of the variation in physical health domain of QOL is explained by the linear effects of the predictor variables presented. Positive significant association exists between primary education and the physical health. Patients engaged in active occupation before their strokes are associated with improved physical health. Right sided paralysis is positively associated with improved physical health at 1 year after stroke. Physical health improved significantly when the caregiver is a spouse, children or family member at 1 year after stroke. Increased level of disability reduced physical health. A change in 1 standard deviation of Barthel Index (level of independency on functional status) has almost 7 times higher impact on physical health.



**Table 4.25: Predictors of memory/thinking domain of QOL at 1-year after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.45)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Residency</b> (Urban)	9.98 (3.25)	(3.58, 16.38)	0.002**
<b>Occupation after stroke</b> (Self employed)	15.28 (6.79)	(1.88, 28.68)	0.026*
<b>Income</b> (Enough and save)	19.08 (8.66)	(2.00, 36.16)	0.029*
<b>Caregiver</b> (Couple)	49.08 (10.94)	(27.48, 70.67)	<0.001**
(Children)	39.18 (10.55)	(18.37, 60.00)	<0.001**
(Family member)	57.17 (10.78)	(35.90, 78.43)	<0.001**
<b>Hospital treatment charges</b> (Able to pay)	8.09 (3.92)	(0.35, 15.84)	0.041*
<b>Barthel Index (BI) score</b> (Level of independence)	0.26 (0.13)	(0.01, 0.52)	0.046*
<b>Beck Depression Inventory (BDI) score</b> (Severity of depression)	-1.31 (0.42)	(-2.14, 0.48)	0.002**

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at p<0.05, \*\*\*statistically significant at p<0.001.

Table 4.25 present the results of the forward stepwise linear regression models at 1 year after stroke. The adjusted R<sup>2</sup> of this model is 0.45 which means that 45% of the variation in memory and thinking domain of QOL is explained by the linear effects of the predictor variables presented. At 1 year after stroke, there is a significant positive association between urban residency and memory and thinking. Self employed before their stroke is associated with improved memory and thinking. Positive significant association exists between having enough income and improved memory and thinking at 1 year after stroke. Memory and thinking improved significantly when the caregiver is a spouse, children or a family member. Patients who are unable to pay for the for the treatment cost are 8 times worse in memory and thinking at 1 year after stroke. Positive significant association exists between increased level of independence on functional status and memory and thinking. An increase in the level of depression as measured by the Beck Depression Inventory is negatively associated with memory and thinking at 1 year after stroke.

**Table 4.26: Predictors of emotion domain of QOL at 1-year after stroke on linear regression (Model Adjusted R<sup>2</sup>=0.38)**

<b>Variable</b>	<b>Coefficient (SE)</b>	<b>95%CI</b>	<b>P-value</b>
<b>Marital status</b> (Widow)	-7.87 (3.40)	(-14.57, 1.16)	0.022*
<b>Income</b> (Just enough)	5.38 (1.89)	(1.65, 9.10)	0.005**
<b>Hospital treatment charges</b> (Able to pay)	8.25 (2.64)	(3.05, 13.45)	0.002**
(Friends)	10.17 (3.78)	(2.73, 17.61)	0.008**
<b>Beck Depression Inventory (BDI) score</b> (Severity of depression)	-1.06 (0.25)	(-1.56, 0.56)	<0.001**
<b>Overall social support</b>	0.23 (0.60)	(0.11, 0.35)	<0.001**

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at p<0.05, \*\*statistically significant at p<0.001.

Table 4.26 present the results of the forward stepwise linear regression models at 1 year after stroke. The adjusted R values (R<sup>2</sup>) of this model is 0.38 which means that 38% of the variation in emotion domain of QOL is explained by the linear effects of the predictor variables presented. Negative significant association exists between increased level of depression, social disadvantage position such as a status of being a widow and emotion dimension of quality of life. Emotion is improved in patients who can support themselves or dependent on their friends to pay for the treatment cost. Overall social support has almost 2 times higher effect on the emotion dimension of quality of life at 1 year after stroke.

**Table 4.27: Predictors of communication domain of QOL at 1-year after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.54)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Residency</b>			
(Urban)	7.51 (3.25)	(1.12, 13.92)	0.022*
<b>Occupation before stroke</b>			
(Labourer)	-14.89 (6.38)	(-27.49, 2.29)	0.021*
<b>Side of stroke</b>			
(Right)	-6.08 (2.70)	(-11.41, 0.70)	0.025*
<b>Hospital treatment charges</b>			
(Social work support)	-13.17 (6.36)	(-25.71, 0.62)	0.040*
(Free)	-8.28 (4.16)	(-16.49, 0.80)	0.048*
<b>Beck Depression Inventory (BDI) score</b>			
(Severity of depression)	-1.40 (0.47)	(-2.32, 0.47)	0.003**

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at p<0.05, \*\*\*statistically significant at p<0.01.

Table 4.27 present the results of the forward stepwise linear regression models at 1 year after stroke. The adjusted R values (R<sup>2</sup>) of this model is 0.54 which means that 54% of the variation in communication domain of QOL is explained by the linear effects of the predictor variables presented. Communication improved about 8 times in patients who are urban residents and deteriorate in those who were labourers before their stroke. Patients with right sided paralysis are associated with reduced communication at 1 year after stroke. Patients that depend on social work support or unable to pay the hospital treatment costs are worse in communication. Increased level of depression is associated with reduced communication at 1 year after stroke.

**Table 4.28: Predictors of participation domain of QOL at 1-year after stroke on linear regression analysis (Model Adjusted R<sup>2</sup>=0.61)**

Variable	Coefficient (SE)	95%CI	P-value
<b>Occupation before stroke</b>			
(Farming)	11.23 (5.40)	(0.58, 21.87)	0.039*
<b>Income</b>			
(Enough and save)	23.36 (8.17)	(7.25, 39.47)	0.005**
<b>Caregiver</b>			
(Couple)	23.98 (10.32)	(3.61, 44.35)	0.021*
(In-laws)	32.73 (15.50)	(2.14, 63.32)	0.036*
(Family member)	26.51 (10.17)	(6.45, 46.57)	0.010*
<b>Effect to work</b>			
(No effect at work)	37.05 (8.80)	(19.69, 54.42)	<0.001**
<b>Modified Rankin Scale (MRS ) score</b>	-6.79 (1.89)	(-10.51, 3.06)	<0.001**
(Degree of disability)			
<b>Barthel Index (BI) score</b>	0.39 (0.12)	(0.16, 0.62)	0.001**
(Level of independence)			
<b>Social support</b>			
(Friends)	2.8 (0.12)	(0.05, 0.51)	0.019*
(Significant others)	-0.33 (0.17)	(-0.66, 0.003)	0.048*

*CI* confidence interval, *SE* standard error, **NOTE** only significant factors are shown, \*statistically significant at p<0.05, \*\*\*statistically significant at p<0.01.

Table 4.28 present the results of the forward stepwise linear regression models at 1 year after stroke. The adjusted R values (R<sup>2</sup>) of this model is 0.61 which means that 61% of the variation in participation domain of QOL is explained by the linear effects of the predictor variables presented. Patients who were farmers before their stroke are associated with improved social participation at 1 year after stroke. There is a significant positive association between having enough income and social participation. Social participation improved when the caregiver is a spouse, in-law or family member. There is increased degree of disability as measured by the Modified Rankin Scale reduced social participation. A change in 1 standard deviation of the Barthel Index (level of independence on functional status) has 3 times higher effect on social participation. Social participation improved when the consequence of stroke has no effect on the occupation of the patients. Overall social support improved social participation but withdrawal of support by significant others e.g. neighbours, reduced social participation at 1 year after stroke.

### 4.2.7 Summary

Stroke patients significantly improved in relation to their level of disability as measured by the MRS. There were also significant changes in both activities of daily living (BI scores) and the level of depression (BDI scores); mainly mental health improved. The mean scores of perceived social support from 6 months to 1 year were decreased both in regards to overall social support and individual category of the three domains or subscales. In relation to QOL, the condition of stroke patients changed significantly in all dimensions. Except for the emotion domain, the scores of the different QOL dimensions were significantly higher at 1 year after stroke.

Linear regression model for the predictors of satisfactory QOL at 6 months after stroke highlighted factors which were re-grouped as: **Stroke related:** side of stroke, degree of disability (Rankin Score); **Support related:** caregiver, and social support; **Job-related:** occupation (before and after stroke), income, effect on work, education; **Function related:** activities of daily living (Barthel Index Score), and residency.

At 1 year after stroke, all these above factors were still predictors of satisfactory QOL after stroke, in addition to, -hospital treatment charges and perceived social support by friends.

The predictors of unsatisfactory QOL after stroke were: older age, occupation after stroke, hospital treatment charges, degree of disability (Rankin Score), level of depression (Beck Inventory Score), and side of stroke. Withdrawal of support by significant others was the sole factor associated ( $p < 0.05$ ) with unsatisfactory QOL at both 6 months and at 1 year after stroke.

### **4.3 PHASE 3- QUALITATIVE PHASE**

In this phase, the researcher presents the findings that explains the underlying reasons why and how individuals retain or lose their sense of wellbeing after stroke. The purpose was to explore the necessary reasons for the observed patterns in the quantitative phase, understand the mechanism by which stroke affects the QOL of the individuals and elucidate the nature of the stroke experience that may not be covered during phase II or concealed in the quantitative findings. The researcher described the backgrounds of the participants who participated in the in-depth interview and then present the findings of the in-depth interview with the subjects in the form of themes that emerged in the analysis. The key findings are illustrated by the quotes from the participants.

#### **4.3.1 Demographic and clinical characteristics of the study participants**

The total number of the study participants was 15 stroke survivors out of which eight were males and the remaining was females. All of the 15 stroke survivors interviewed were diagnosed with stroke within the past one year and their age ranged from thirty-five to seventy-six years. Eleven of the survivors were married and four were widowed and lived with their children or relatives in mostly extended family settings. All the participants were Muslim and belonging to Hausa ethnic group among whom ten are urban and five are rural dwellers. Nine among the fifteen respondents had suffered a left hemispheric stroke.

As shown in Table 4.28, as measured by Modified Rankin Scale, one of the participants had no significant disability, two had slight disability, and five had moderate disability, six with moderately severe disability and only one had severe disability. According to

the Barthel Index (BI) scale, one of the respondents was totally dependent in all the basic ADLs. And another 5 (33%) were severely dependent. More than half (53%) of the respondents were moderately dependent whereas only one of the stroke survivors was fully independent.

**Table 4.29: Demographic and clinical characteristics of the study participants**

Name	Age	Sex	Stroke laterality	Date of stroke	Date of interview	mRS	BI
A.U	55	F	Left	November 18, 2010	February 27, 2012	3	80
A.T.	50	M	Right	January 6, 2011	March 3, 2012	4	58
S.I.	55	M	Left	November 19, 2010	March 7, 2012	3	68
Z.I.	40	F	Right	January 22, 2011	March 9, 2012	4	60
D.B	62	M	Left	December 9, 2010	March 11, 2012	4	75
A.A.	35	F	Right	January 12, 2011	March 13, 2012	2	75
A.M.	76	F	Right	December 15, 2010	March 15, 2012	5	19
B.S.	48	F	Left	November 2, 2010	March 16, 2012	3	85
A.I.	52	F	Right	January 11, 2011	March 17, 2012	3	62
J.A.	61	M	Left	December 13, 2010	March 21, 2012	4	55
S.A.	57	M	Right	January 15, 2011	March 27, 2012	2	82
D.S.	52	M	Right	November 8, 2010	April 3, 2012	4	58
S.B.	70	M	Left	January 2, 2011	April 7, 2012	4	58
N.R.	65	M	Right	December 4, 2010	April 8, 2012	3	88
B.G.	54	F	Right	November 24, 2010	April 15, 2012	1	91

**NOTE:** a. Names are numbered to keep confidentiality.

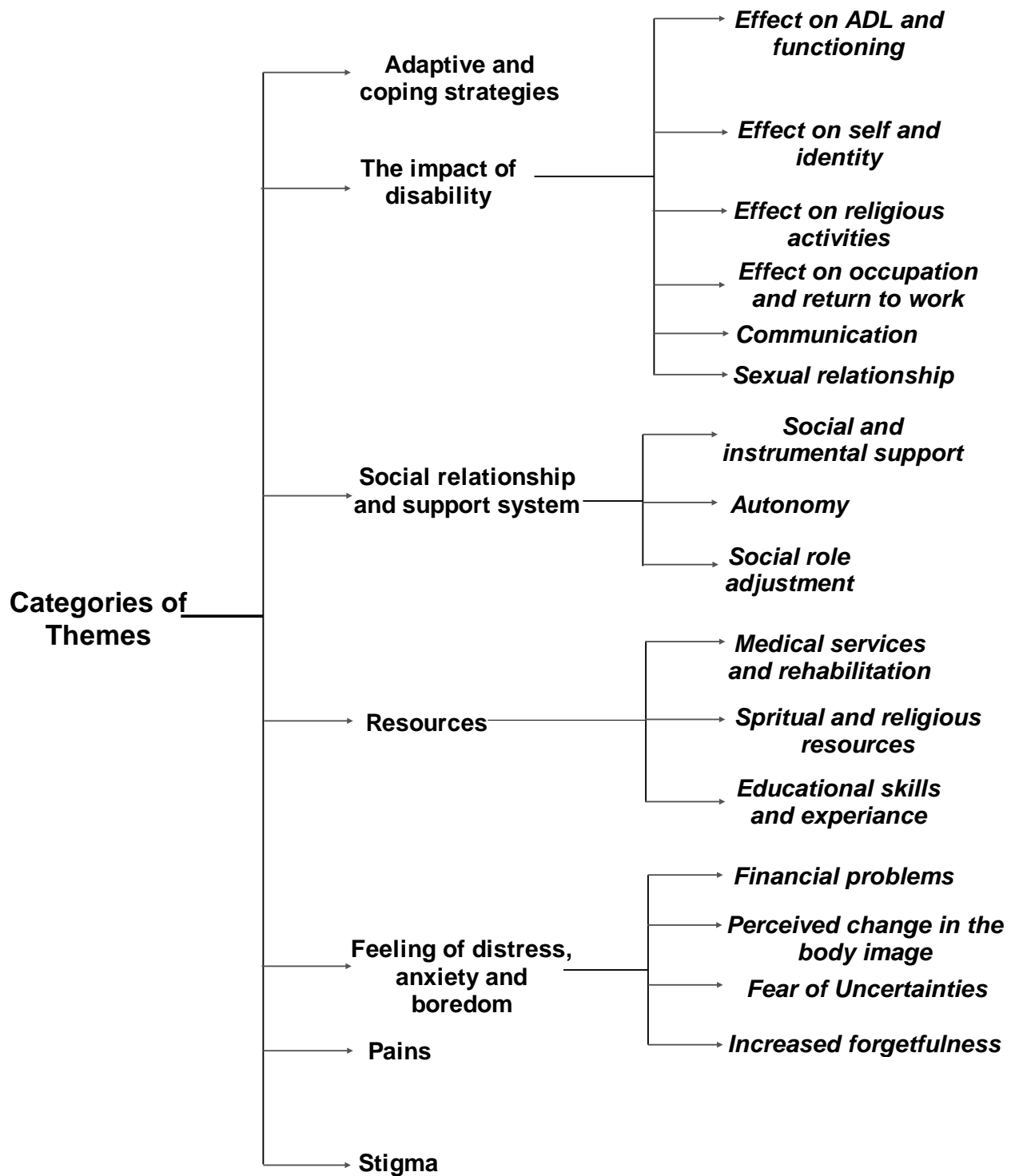
**MRS** = Modified Rankin Scale grades as: 0 indicating no symptoms; 1 (regardless of symptoms, no significant disability); 2 denoted as slight disability, 3 as moderate disability, 4, moderately severe disability, 5 means severe disability and 6(dead).

**BI** = Barthel Index, The mean BI score of (< 20 was classified as total dependence and demanding “institutional care”; 21-60 as severe dependence; 61-90, moderate dependence; 91-99 as mild independence and 100, fully independent).

### **4.3.2 Generated Themes**

The themes that emerged indicate the factors influencing stroke survivor's quality of life as discussed by the respondents. The identified themes are either patient improving or diminishing in their QOL and were classified into categories of factors as shown in Figure 4.5. The 19 sub themes emerged from the in-depth interview. These themes influencing stroke survivor's quality of life were regrouped into 7 themes. Of these, 4 themes have further related issues whilst 3 were independent issues: adaptive and coping strategies, the impact of the extent of disability (effects of activities of daily living on functioning, effect on self and identity, effect on religious activities, effect on occupation, return to work, communication and sexual relationship), social relationship and support system (social and instrumental supports, autonomy, and social role adjustments), resources (medical services and rehabilitation, spiritual and resources, educational skills and experiences), anxiety and distress due to (financial resources, perceived change in body image, fear of uncertainties, increased forgetfulness), pains and stigma.





**Figure 4.5: Thematic classification of the factors influencing stroke survivor's QOL**

### 4.3.2.1 Adaptive and coping strategies

Coping is defined as the constantly changing cognitive and behavioural efforts to manage the specific external and internal demands that are evaluated as stressful or exceeding the resources of the person (Donellan et al., 2006). Coping strategies refers to the specific efforts, both behavioural and cognitive, that the person use to master, tolerate, reduce or minimize the consequence of stroke (Donellan et al., 2006). Adaptive strategies are those physical and environmental adaptations, those aspects of culture that serves to minimise the stressful events of stroke (Donellan et al., 2006). One of the main issues raised by the respondents was the adoption of adaptive strategy. Findings suggest that in order to curtail the effect of their functional constraints on their QOL after stroke, eight respondents raised issues related to measures of adaptive approach. Discovering ways to favourably adapt to their disabilities was identified as one of the critical factor influencing the survivor's wellbeing. Employing adaptive strategies even for simpler day-to-day activities that were central to a person's identity was identified as important for a survivor's quality of life. Although with little difficulty, Mr. A.T., improvise ways to adapt to his disabilities in order to live independently as he stated,

- .... *One has to learn to live with it. At the moment I try to do a lot of things. You see like..... Regarding toileting.... I am getting used to.... When I defecate I then use my walking frame and dispose it in a toilet... at the pit latrine. I told my family to leave that for me because I started getting better....and this actually made me feel good.*

Coping strategies appeared to be very important to the respondents. Narrating how fortunate they were, survivors who discovered measures to adapt to their disabilities generally made positive accounts about their situations. Mrs. A.I. reveals that despite her residual disabilities, she is "happy" that she can walk for an appreciable distance even though she stops and rest in between, she said,

- .... *I still can walk from here to there.... Like from here to Bus Stop I can go, but I will rest like twice.... or only once.... If I walk and feel like I will have difficulty breathing, I then sit. Even if the walk is twice as this one I can still do but I will be resting in between.*

#### **4.3.2.2 The impact of the extent of disability**

All respondents except one with no significant disability were experiencing some residual impairment from their stroke. With physical impairments, many shared that they used mobility assistive devices such as the walkers, wheelchairs and canes; one of the respondents was bedridden and required constant care. Some of the respondents although with normal cognitive functions, reported memory problems and reduced speed of information processing. Respondents revealed the personal narratives of their lives to imply how their lives had changed after their stroke were no longer engaged in the activities they used to do before their stroke. Not all of the respondents manifested with a reduced sense of wellbeing following the changes stroke brought about to their lives, but appeared to rely upon the magnitude to which the disabilities that resulted from their stroke affected their sense of self, religious activities, flexibility, identity and their livelihood/occupation after stroke.

##### **4.3.2.2.1 Effects on ADL and functioning**

Seven of the respondents reported how they were restricted from carrying out their normal activities of daily living (ADL), that they could no longer engage in activities such as such as cleaning, washing, bathing and toileting. Three of the respondents reported that they were not able to drive now, which they could previously. Four of the respondents, reported that they were restricted in carrying out even the less physically vigorous adventures such as reading. For instance a 70 year old man who is a devout Muslim and an Islamic scholar who had engaged in teaching his pupils and regularly reading the holy Quran before his stroke, reports that:

- *.... I use to go to Islamic school to teach before (my stroke)... but I cannot go now because things are difficult and complicated for me now. You see this is a Quran and I can sit down and read it a lot before but now sooner did I start reading the Quran.... then my voice diminishes and I must have to stop. You see I am very limited in this regard. My inability to recite Quran worries me. I am completely devastated. (Mr. S.B.).*

One of the participants lamented that her stroke limited her ability to carry out her normal activities of daily living as she recounts:

- *You see I cannot do anything: .... Sweeping, washing I cannot do now. I was even thinking that I can sweep a little but I can't although I tried to take bath independently. This hand is the one that does all the work and is completely gone. (Mrs. Z.I.).*

A 55-year-old driver who had enjoyed taking a walk after coming back home when he closes at work and had engaged in a very active life before his stroke reports that *“Before I use to go out for a walk as leisure.... I can walk a reasonable distance by foot, walk around and come and sleep. I can walk for more than 3 kilometres every day, but couldn't do now. So you see one must be disturbed”* (Mr. S.I.). But he interestingly further reveals that he is occasionally simply relieved by seeing other peoples more affected than him: *“.... Good quality of life is when you are healthy but once you are not healthy you are disturbed. And I see that others are more affected than I am and so this actually relieves me.”* Moreover, respondents whose extent of disabilities resulting from their stroke does not have much impact on the pursuit of their activities of daily living reported higher subjective wellbeing. For example, Mrs. B.G. reported that apart from cutting her right nails, there is nothing that someone does for her:

- *You see I am happy that my stroke doesn't limited me like the many survivors I have seen.... I was not affected to the extent that I cannot do anything. I can do a lot of things without asking anyone to do for me. There is nothing that someone does for me at all apart from cutting my nails.... because this right hand is the dominant hand and is the one affected (Mrs. B.G.).*

#### **4.3.2.2.2 The impact of the disability on self and identity**

Although not all the respondents demonstrated a reduced sense of wellbeing, but they all narrated that their lives had changed since they had their stroke and narrated stories of how their lives changed after their stroke; because they no longer engage in the activities they used to do or the person they used to be prior to their stroke. The wellbeing of the survivors seemed to substantially decrease when a person is restricted from involving in activities that constituted a salient aspect of his/her identity owing to

the residual disabilities after his/her stroke. Moreover, the respondents' wellbeing appeared to rely upon the extent to which their disabilities influence their sense of self and identity. For example, as a mother of a 16-month-old child, one 35-year-old woman narrated her frustrations at simply not being able to satisfactorily take care of her son as she recounts:

- *My son.... since I had this stroke I couldn't bathe him.... except for others to do that for me... you see! Others only take him for me and I only watch..... I swear this is very worrying to me....As a mother it hurts me that I couldn't cuddle my son.... Too bad! (Mrs. A.A.).*

Because of the cardinal importance of the type of clothing worn for his identity, one of the respondents who described himself as an elder statesman and a successful businessman narrated that his inability to wear the clothing of his choice and identity resulted in a decreased sense of wellbeing:

- *.... I put my big clothes before and I enjoy that...But this illness made me keep them and only put light clothing so where is the happiness.... For people to see you as a complete and respectable man is more preferred. I feel worried because the clothes are kept and I just look at them. When I wear them I feel heavy and uncomfortable.... devastated. (Mr. N.R.).*

Mrs. A.I. who is a housewife and local trader described herself as a reference person in her family before her stroke due to her active engagement in all her family matters and events remarks, “.... it worries and devastate me that I don't carry out such things (pause)...” (Mrs. A.I.). She struggles with her sense of self and identity in agreement with her pre-stroke identity due to the loss incurred by her stroke as she reveals:

- *I was the reference person in our family before.... Because we are many and I am the one that take care of all such events but not now see what I became. Even the youth in our family house are saying that they lost a heroine. This seriously worries me.... I feel so devastated and unimportant. My main worry is that I don't carry out such things. (Mrs. A.I.).*

Despite the fact that his children runs the business for him, Mr. S.A. who is a 57-year-old businessman (cloth seller) still goes to the market that he referred to be not too far

from his house. He was advised to continue to take part in his business in order to maintain his aspect of self, identity and wellbeing. He said:

- *I sell yards in the market and so you see there is no problem.... You see is my children runs that for me but people just want me to be there so this is why I go even if it means to chat with people.... They take me on motorcycle to the market but I come back on foot so that I exercise.... While coming back I cautiously follow the side of the road opposite to the moving cars so that I see them. (Mr. S.A.).*

For some respondents, the residual impairments and disabilities following their stroke were a source of worry leading them to report a reduced sense of wellbeing. For those of them whose physical, social and financial independence were essential for their abilities to carry out self defining activities, their quality of lives were notably affected.

Mr. A.T., a 50-year-old politician and businessman who described himself as a “man of the people as and a generous person” before his stroke reports that:

- *My main problem is not being able to visit my relatives and friends because I was known for that and so this actually worries me! And when you are said to be a ‘giving person’ and suddenly becomes trapped by an illness like stroke.... So you see all these are issues that are giving me worries. I pity myself.... (Sigh).*

Another woman states that:

- *You see I am always known to be a sociable and busy woman but now, look at what I became. I am now in one place and quite restricted that I have to be brought everything.... Even last week when my brother’s wife delivered and I was taken there for 11 days, I still couldn’t be my real self.... I actually don’t do many things including associating freely. Even if I go to where people are, I would go to the side and sit alone. (Mrs. B.S.).*

#### **4.3.2.2.3 Effects on religious activities**

The effect of stroke on religious activities is one of the common themes identified by the respondents. Respondents revealed frustrations at simply not being able to perform their prayer in congregation as enjoined by their religion (Islam). Some of the respondents revealed that:

- *Well, like religious activities I experience problems in that regard.... Because going to the mosque to pray in congregation is better than praying alone. Because if you pray alone you get just one reward but if you pray in congregation you get 27 rewards.... and so this worries me that I cannot go and pray in congregation. (Mr. S.B.).*
- *I feel as if these prayers that I performed, have I really performed it well? Even when I got much better it took about three weeks doubting what I was doing while praying,*

*sometimes I even repeat a prayer with hope that it may remedy the one at fault.*(Mrs. B.G.).

#### **4.3.2.2.4 Effect on occupation and return to work**

To gain a better understanding of the effects of having a stroke on the lives of the respondents, they were asked to comment on the effect it has on their source of livelihood and or occupation. Respondents emphasized the various ways that their lives had changed since their stroke. The effect of residual impairment was consistently reported as the main concerns, due to the constraints placed on their occupations. Survivors provided many examples how their occupations discontinued or how they were severely restricted and often stressing that there had been a loss of a previously active lifestyle. For Mrs. Z.I., who used to be a tailor, stated that, she was just too restricted by her stroke to return to her tailoring job.

- *I am a tailor and so how do I work now? .... You see because this hand is giving me problem.... I can't manipulate and do other things with it.... It's the right hand that is affected and you know it's everything in life and now it's no more.... My leg and hand are all gone.... And my voice is still shaky and so how do I talk to my customers... I cannot do.... and even to swing the tailoring machine needs a sound leg.... Look!! I am so devastated!*

Similarly, another 61 year old man who had worked as a bricklayer throughout his life was distressed at being unable to return to his work following his stroke because of his residual physical disabilities.

- *Bricklaying was my source of livelihood and I cannot do that now.... (Pause), because one needs hand to take something, right? So my hand cannot take anything and I cannot withstand prolonged standing.... So you see is not possible.... I use to earn a lot of money before.... But everything stops now and you see this affected my quality of life.... The hand and the leg must be strong before one works.... the leg cannot stand and the hand cannot hold so how do one work? You see is not possible and this is the reason.... This is a handiwork and so if you are healthy you do it and if you are not, you just look and see others doing.... (Sigh). (Mr. J.A.).*

The following participants also narrated their frustrations and how distressed they were at being unable to return to their work.

- *.... I am limited a great deal.... This disease prevented me from selling my Soya beans cake. You see I can't squeeze and cook it... I cannot do. You see I have to first sieve, put it on fire, put it down and sieve again, if it solidifies I then cut and fry. I cannot do these*

*now because it's the hand that helps.... One hand cannot do the work.... I am really worried. (Mrs. A.I.).*

- *You see I sell firewood and now if I ask them to supply me and get disarranged after being supplied, I think of how to rearrange it and tie it using rope. (Mrs. A.U.).*
- *I sell starch and tying it is the problem for me now. When you cannot do something to earn a living, you completely become devastated as I am. (Mrs. B.S.).*
- *My occupation is handiwork and I cannot do it now because my hand is not moving. I do welding and as I sit now my hand cannot move....I cannot walk and so I am idle. (Mr. D.S.).*

For Mr. D.B., who became a trader after his retirement stated that anxiety that resulted following his stroke was the cause of his discomfort and hence his inability to return to work.

- *.... My quality of life is affected.... for example related to running my business and associating with people is low because if you are in a gathering of a lot of people you feel.... You feel as if something is 'shocking you' or.... you just feel disturbed. And if you stay in one place you also feel disturbed. This is very worrying and difficult to explain. (Mr. D.B.).*

While the effect of the residual impairment and anxiety were consistently mentioned as the limiting or restricting factor, other common concerns were financial. For example, Mrs. A.A., a 35 year old who described herself as very versatile and entrepreneur minded stated that financial problem is the only limiting factor that prevented her from engaging in something as she recounts:

- *I can do different kinds of things as I was used to before my stroke.... I am entrepreneur minded. Now there is no money....we used up all the money in buying medications and managing this expensive disease.... I swear its only lack of money that prevented me from buying and selling ....I can even go to the market and buy by myself or give it to children to buy for me. (Mrs. A.A.).*

#### **4.3.2.2.5 Communication problems**

Perhaps due to the direct effect of speech problem on social relationship, respondents revealed frustrations and emotional reactions owing to communication difficulties resulting from their inability to effectively communicate. Mrs. A.M. reports, *"It hurts when you are asked to repeat what you just said, I find this irritating!"* Frustrations with



speech also seemed to be associated with the difficulty some survivors experience in associating with others and thereby affecting their self esteem. The following participant recounts,

- *You see but if I talk my sound become confused.... my voice shiver and my mouth twist and so I am also worried in this regard.... And you see if I talk for sometimes, my voice diminishes and I find it difficult to freely associate with my friends all the time. (Mr. D.S.).*

#### **4.3.2.2.6 Problems with sexual relationship**

Six of the respondents recounted the ways upon which the degree to which their sexual functions and relationship was affected following their stroke and demonstrated a decreased sense of wellbeing. For instance, Mr. D.B. reported how he was devastated due to the complaints by his two wives over the loss of sexual functions he sustained following his stroke:

- *....You can't relate with your family (wives) the way you are used to it before your stroke. Because you can do it at any time before, but you now lost the urge and you sometimes cannot even sustain your erection because the nerves are weak.... And your family (wives) always are worried that you don't pay your sexual obligations so this must disturbs one.... I feel worried and devastated.... (Pause) too bad!*

Similarly, Mr. J.A., a 61-year-old former bricklayer expressed his frustrations when he lamented over how he was prevented from maintaining a sustained erection following his stroke and the effects it had on his relationship, he stated,

- *You see now I spend 3 months without having sex with my wife because my penis cannot be erect, even if I try and try its not possible and I am still unable to regain its full function....This is worrying me a lot, quite a lot and my wife is showing her serious worries. (Mr. J.A.).*

Mr. S.I. attributed his decreased sexual functions to be associated to the medications prescribed to him at the hospital which he claimed to have reduced his libido and recounts how seriously the medications affected his sexual relationship with his wife of more than 25 years:

- *Actually these medications seriously reduce one's libido.... because sometimes a person will feel as if he completely doesn't have a penis and this causes worry.... This really affected my quality of life to a large extent since there is nothing like libido and so there is nothing like having sex except that you.... even my wife is more worried because she always wants to see me strong and happy.*

The degree to which the stroke influenced the survivor's quality of life also appeared to rely on the extent to which their physical disabilities affected their sexual relationships. For instance, Mrs. Z.I., a 40-year-old former tailor remarks, "*The hand is the problem and so you are very limited in that regard, because the hand cannot do anything*". Similarly, Mr. S.A. stated that:

- .... *You see the hand is weak and is making it difficult for me to have sex with my wife. The strength of my erection has also reduced.... But the hand is more **problematic** in that regard.*

#### **4.3.2.3 Social relationship and support system**

Themes emphasizing social relationship and support system include social support and instrumental support, feelings of dependency, and social roles limitation.

##### **4.3.2.3.1 The benefits of social and instrumental support**

The majority of the support systems explained by the respondents were emphasized by the social and instrumental support themes. Coherent with the quantitative findings, respondents disclosed that they benefited from the help of different social supports provided by their friends, spouses, and families and significant others. Social support themes consisted of narratives regarding how families, spouses, friends and significant others supported or did not support the respondents by rendering them emotional, financial and instrumental supports that were essential to them after their stroke. Mr. A.T., a 50-year-old politician and businessman regarded the support he received from his brother, family and people around him as what helped him significantly improved as he stated:

- *I am happy with the support I am getting from my brother who is also my close ally, because he is seriously taking care of me with all his knowledge, his wealth and his health.... He all gave them for me.... And I thank God, my relatives and the people around because everyone is trying his best for me with all his wealth, prayer and ....coming here to chat with me so as to help me get rid of my sorrows, they all do these things for me.(Mr. A.T.).*

He also described his stroke as a “lesson or a testimony” that God showed to him to see how he is regarded by the people due to the immense level of support he received from them as he remarks, *“If not because of this stroke, if I am told this is how I am to the people I can doubt it.... I can sincerely doubt it.”* Mrs. A.U., who is a 55-year-old widow, narrated how she has improved owing to the emotional and financial supports she received from her children and the people that regularly visited when she recounts:

- *There are people that come to visit me and we sit and discuss.... Some that are willing would even give me money and I would pray for God to bless them. I feel happy.... Everybody feels happy when financially aided and will feel strong since you are helped with what you can use to buy kerosene and other things.... one actually feels happy. (Mrs. A.U.).*

Respondents also identified family members as rendering them with instrumental supports that were essential to them following their stroke. For Mrs. A.A., she found her daughters enormously supportive, remarks,

- *I have a well grown up girls that help me do almost all the home chores. They clean the house.... Sweep the house, wash my plates and wash.... toilets, and also put water in the bucket and take it to bath room and even help me wash parts of my body that I cannot do by myself.... They are very supportive.... (Laugh).*

Mr. A.T., who walks using a walking frame, describes it as “everything”, when he comments:

- *You see if not because you told me that you were coming, by now I would have gone out to walk around. I use this walking frame to walk. It’s everything for me.... I always pray for a person that invented it. He actually tried a lot.... it helps us a lot. I enjoy it since the day I started using it up till today.... I now use it just as a pilot fly an aeroplane. This is how I walk with this walking frame (laugh).*

In turn, withdrawal of support and not being included in decision making could equally have a detrimental consequence on the survivor’s subjective wellbeing. Withdrawal of support was characterized by reduced frequency of contacts with friends and family, especially friends. Respondents disclosed to have been abandoned by their friends and families and this experience of social isolation was the cause of distress in these respondents, due to feeling of loss as reported by the following participants:

- *You see to make the story short, at the moment.... People even consider me dead. They consider me completely dead. I am not even important now. To me, people look at me as completely unimportant and as a burden.... (Sigh) (Mrs. A.A.).*

- .... I must be worried.... I must feel worried because, this room would have been full by early morning of everyday but not now. They do not come now because they are tired of me. By Allah people are now tired of me.... (Sigh). Before, I do whatever for them even before the time and now they see me disabled, neglected and not being cared for.... (Crying)(Mrs. A.M.).

#### **4.3.2.3.2 Autonomy**

Although appreciative of the supports they received from the family, friends, spouses and significant others, some of the respondents felt very uncomfortable with their dependence on others. Perception of being a burden on others was associated with anxiety and a reduced quality of life. One of the participants was simply worried in part as a result of her perception to being a ‘burden’ to her only child and grandchildren when she stated:

- .... Even a while ago I cried and cried.... (Sigh)... I cannot do anything. There is nothing I can do rather than to sit down..... And then lie down.... I do nothing. This is only what I do. I do nothing....by Allah I do nothing. But I am tired about this.... (Crying).... you are only to keep sitting....becoming a burden on your children I keep burdening them every now and then.... You see I am a burden to them, for we are always on the road to the hospital.... He has not benefited himself and neither do I. that’s how we are.... (Pause). (Mrs. A.M.).

#### **4.3.2.3.3 Social roles limitation**

When asked to describe how they were limited in their social activities and how these affected their quality of lives, launching into biographical accounts of their lives, respondents recounts the challenges they face with respect to their social interaction with people. It was revealing from participant’s discussions that social role limitation challenged relationships that are further distressed by their level of restrictions. Survivors no longer engage in their habitual activities and often become bored or depressed. Mrs. A.I. who reported that she used to be a very socially active person before her stroke, but she could no longer involve in social events:

- I am very limited regarding my social interaction with people. You see I cannot now go to people and associate freely especially during social events like wedding ceremony....You see I cannot talk for long time, share food for the people and all those

*things. Associating with my close friend and family becomes difficult.... I cannot roam about, I cannot do it and this worries me a lot.... (Pause).*

For Mrs. A.M., her inability to regularly visit her friends and family which is part of her cultural roles is the source of her frustration as she narrates,

- *When a social event arises I cannot associate with people. I don't even go except to delegate one of my children or grandchildren to represent me. I don't have a sound leg and is it not what one uses to walk? .... And so without a sound leg where do you go? You cannot go to people or visit. By Allah (she swears) you cannot visit and this is simply disgusting!*

#### **4.3.2.4 Resources**

The different resources that were described by the respondents as essential in helping them adapt to their stroke and thereby enhancing their quality of life include: spiritual & religious resources, life course educational skills and experiences, cognitive, personal and logical reasoning skills.

##### **4.3.2.4.1 Medical services and rehabilitation**

Some of the participants in the study reported receiving treatment for their stroke. Treatment included medication in conjunction with rehabilitation to improve their functional outcome. While social and instrumental supports were described as essential factors associated with subjective wellbeing by the respondents, medical services and rehabilitation, most notably, by physiotherapists was also acknowledged by the participants as influential. All participants reported taking part in rehabilitation process and valued the role physiotherapy played in increasing their strength and mobility. One of the respondents describes physiotherapy services he receives in a hospital as effective in helping him regain his functional mobility and as a source of his joy and encouragement:

- *I cannot do anything before but when I was first taken for Physiotherapy, I told them that I cannot walk and one of the Physiotherapists supported my legs and hands and told me to stand up and I did.... He also instructed me to sit down which I also did and we did for sometimes. Since that time I had an improved courage. Today I can crawl, change on my knees.... I am also lucky that I can stand and sit independently (Mr. A.T.).*

Mrs. B.G., who is a 54-year-old widow and a former food seller reveals, “*Although I almost regained my whole body functions, I still go for Physiotherapy, I enjoy it.... They discharged me, but I still go*”. Similarly, despite her residual functional limitations, Mrs.

A.A. also recounts:

- *.... But I am happy with Physiotherapy.... I thank God this is not how I was after my stroke. I have dramatically improved.... With the help of Physiotherapists, I can kneel in the toilet, bend and do whatever I want to do.*

Medical counselling by the Doctors and on consultation days were reported by some participants as a motivating factor for their successful process of adaptation to their disabilities thereby enabling them to demonstrate an increased sense of wellbeing. For instance, Mr. S.A. stated that:

- *The reason why I am not worried is because Doctors in the hospital warned us to be reducing our worry, which is why I am not much bothered by my limitations.... I still feel a little worried about my condition but I don't give it a deep thought.*

#### **4.3.2.4.2 Spiritual and religious resources**

Some of the respondents identified religious and spiritual resources as essential in helping them to manage the worry and distress associated with their post-stroke lives in order to maintain their sense of subjective wellbeing. For instance, Mrs. A.A. remarks that:

- *It hurts to see that I cannot do what I was used to doing before my stroke.... (Pause) it hurts. And I was advised not to be getting worried.... So If I realize I am getting worried, I just take my Quran or any Hausa book and read. I especially enjoy reading the Quran.... If I finish reading it, I just feel relieved and then continue with my usual affairs.*

When asked how he copes with his residual disabilities, Mr. A.T. claimed that the spiritual and religious essence he developed following his stroke is what was responsible for his ability to manage the worry and distress associated with his post-stroke life:

- *I believe this is God's blessing because I don't think of it at all.... and because I believe it's my destiny. Anything that you know if not prayer and reading Quran, there is*

*nothing that interests me or that I think of... And I never allowed this sickness worry me because I know is either of two; either I recover or if it's my time I die... (Laugh)... I only pray that what I suffered is rewarded by God.*

Similarly, another 40 year old woman recounted that, “... you see I am a devout Muslim.... I am always relieved by the faith.... My faith is awakened after this stroke.... If I started feeling worried I just remember that is God that intended to see me like this and if He wants to heal me, I will recover” (Mrs Z.I.). The following respondents sought for help from spiritual faith for strength especially because of their diminished material, social and health status. Despite her functional limitations, Mrs. A.I. recounted that as a Muslim, she believes whatever transpire in her life is from God, “*I am not worried because I know is God that afflicted me with It.*”, Mrs. A.U., who is a housewife displayed a similar level of spirituality as she elaborates:

- *... To be frank with you, I am never worried by this illness because I put off all worries.... I told you that I completely surrendered to God. He is the only one that heals and I have given Him my life to decide.*

For these stroke survivors, spiritual connection transform them, made them resilient and helped them maintain balance and achieve peace. The spiritual foundations developed also helped these respondents to develop healthy behaviours and attitudes, which convinced them to have a significant effect on their subjective wellbeing.

#### **4.3.2.4.3 Educational skills and experiences**

Some of the respondents identified educational skills and experiences that they utilized as helping them adapt with their stroke-induced disabilities by learning and employing self-care efficacy and coping strategies. Education was found to be profitable to the survivors for the flexible coping skills it offers them to in order for them to confront the challenges of living with their disabilities. For instance, Mr. N.R. who is a 65 year old graduate of Mass Communication and a businessman described himself as ‘very lucky’

owing to the self-care efficacy and coping skills his education accorded him following his stroke as he narrates,

- *I can say I am very lucky....Very lucky because my being educated allowed me to deal with my worries and also engage in physiotherapy and abide by all the rules and regulations by my doctor. I follow every instruction given to me in the hospital....I also do my home programs. This is helpful to me a great deal and I learnt this is what some of my fellow survivors do not do. (Mr. N.R.).*

Survivors spoke about how education helped them regain autonomy and control of their everyday life related to personal care, social and religious functioning as well as everyday participation and responsibilities. For instance, Mr. S.B., who is an Islamic scholar referred to his understanding of the teaching of his religion (Islam) and the dynamics of his educational relationship as instrumental in helping him adapt to his disabilities and to engage in rehabilitation programs:

- *Being an Islamic scholar who had been engaged in preaches and studying all his life....You see **Quran** and **Sunnah** of our beloved prophet enjoined and taught us to strive for cure whenever we got afflicted by a disease....learn to live with it and be thankful to God at all times. This is what we sometimes preach.... and so I follow all the instructions and I am actually confident my condition will keep improving. The religious teachings also taught me how to do away with my distress and grief which I once had.... (Mr. S.B.).*

The self efficacy and locus of control are central to how education helps the survivors adapt to their stroke-induced disabilities thereby enabling them to achieve increased QOL after stroke

#### **4.3.2.5 Feelings of distress, anxiety and boredom**

Themes emphasizing these constructs include financial problems, increased forgetfulness and change in body image and fear and uncertainties. The experience of frustration and distress were strongly linked to functional limitations and giving up of valued activities and seemed to be associated with reduced sense of physical and mental wellbeing.



#### **4.3.2.5.1 Due to financial problems**

Some of the participants attributed their reduced sense of wellbeing to be associated to the financial difficulties that ensued after their stroke:

- *I am seriously limited financially and I feel worried. If I don't have money I feel continues anger. A little thing you find it difficult.... Like if you want to buy something and cannot afford sometimes worries me. And sometimes when I feel worried over this financial difficulty I have this bad headache that devastates me. (Mrs. A.I.).*
- *Financial difficulty is the most worrying thing to me and has seriously affected my quality of life a great deal because I cannot do anything.... You only wait till God help you or to be given charity by those who pity your situation. Sometimes if I want to buy my medication I tell people to buy for me and if could not get it, I have to wait till I get the money to buy the medicines. So you see all these things must worry me a lot.... You are worried because you cannot afford what ordinarily was not more than your ability. And there are no any association or government agencies that help us because you need to be connected before you are aided and if you don't have anybody you just pray. (Mrs. B.S.).*

#### **4.3.2.5.2 Due to perceived change in body image**

Some of the respondents were concerned about how their disabilities changed their body image and thereby limiting their QOL.

- *You also see that your mouth is deviated to one side and shaking.... so someone that has never seen you before may ask what this is. You see you can't feel at ease and this is among the reasons why we find it difficult to relate with people. People know you to be clean person before but they now see your mouth drooping saliva and so you see you can't always be in their midst. Thus that do not know this disease may say that 'this person is very clumsy'. (Mr. D.B.).*
- *It changes my look; it changes because you are told that you are not even symmetrical from one side of your body.... I was told this that I look out of shape and I am devastated, God has changed your entire look. (Mrs. A.A.).*

#### **4.3.2.5.3 Fear of uncertainties**

Physical restrictions resulting from stroke had a serious impact on the wellbeing of a number of the stroke survivors who were interviewed. Survivors recounted the numerous ways how the feeling of fear following their stroke had affected their ability to participate in roles or activities that are important aspects of their identity and also on the successful process of adaptation to their disabilities. The frustration expressed by the following respondents at not being able to regularly visit his family and friends due to the fear of being crushed by moving vehicles was a great source of discomfort:

- *I am afraid to even cross a road and so I find it impossible to board a commercial bus.... I may end up being crushed by a moving car. I am so worried by this! I want to go out for a visit but I am afraid! (Mrs. A.A.).*

The following stroke survivor who described himself as a very socially active person before his stroke spoke on how the challenges of living with fear had affected his ability to participate in roles or activities that are important aspects of his life as he recounts,

- *I am afraid of thus reckless boys that ride on motor cycles because they are not sane.... You can just be walking and a boy can just come and crush you. I don't go anywhere, I only go to that corner and come back home and this is the longest walk I can perform. A person that is used to going out and come back and suddenly find himself unable to go out.... You see a person must be worried and this is the actually my worry. (Mr. J.A.).*

For some of the respondents, the feeling of uncertainty about the course of their stroke was often associated with distress and reduced quality of life. For instance, Mr. D.B. revealed frustration pertaining to the uncertainty regarding his functional abilities and recovery. He explains:

- *If I think about it I realize that this is not how I was and this is how God made me now. How can I get well, will I or will never get well? Or this is how my life will end? So these kinds of thoughts must actually affect my quality of life? .... So this must affect my happiness. (Mr. D.B.).*

#### **4.3.2.5.4 Increased forgetfulness**

One of the issues most frequently raised by the respondents was the frustrations and discomfort felt as a result of increased forgetfulness following their stroke. Some of the respondents although with normal cognitive functions, reported memory problems and reduced speed to process information. The extent to which a stroke affected the survivor's QOL appeared to depend on the degree to which their disability affected their memory and their speed to process information. When the residual disability following a stroke prevented a person from remembering or processing information that is integral for his identity, successful process of adaptation and necessary activities of daily living, the wellbeing of survivors was substantially reduced. For example, although fully independent, the inability of a 54-year old woman to instantly process information so as

to engage in the successful adaptation following her stroke resulted in a reduced sense of wellbeing. She states,

- *I easily forget. What I can easily tell before, I now have to take a long time before I remember it.... Like now for me to say something instantly.... sometimes I open the mouth to say it but suddenly forget. But after sometimes.... if I remember and then I tell them....This is.... (Pause) very worrying. (Mrs. B.G.).*

Some of the participants also narrate:

- *I can talk with you now but if you ask me after a while I may not tell you back what I have said. Forgetful.... I cannot remember and so you see I am seriously affected in this regard..... I completely forget and would ask you 'what issue?' Because my brain was seriously affected....This has affected my quality of life....to a large extent indeed.... quite a lot. (Mr. J.A.).*
- *.... The problem is that something that I know very well.... like Moringa leaves.... or a certain soup suddenly escapes me. I can see the thing I need but calling its name escapes me.... Everything.... and this worries me a lot. A lot of times the things I really know but to call its name became impossible, you see this frustrating.... I cannot get it at the time I need. (Mr. N.R.).*

#### **4.3.2.6 Pains**

Issues related to pain were one of the common themes identified by some of the respondents as a great source of distress. Respondents whose pain is so severe e.g. shoulder pain and restricting their activities revealed to have had adverse effect on their lives, leading them to report a reduced quality of life as discussed by the following respondents:

- *For more than two months now I am not myself.... The pain in my shoulder is just unbearable and disabling.... My leg is also paining me and yesterday when I went to the hospital they measured my blood pressure and told me that it was high.... This pain is gradually killing me.... (Crying). (Mr. S.I.).*
- *You see I have pains all over....when I walk my leg, my knee pains me.... my neck pains me and often becomes tightened and caused my voice to become low and awkward. (Mrs. B.S.).*
- *.... My shoulder, my back is all paining once I try standing. Sometimes if I cough I feel pain on my chest. The nature of the disease.... sometimes I chock up with either my saliva or if I talk. I can walk and roam around the neighbourhood but not now....The pain is just too much, to sleep sometimes is just impossible.... too disturbing. (Mrs. A.I.).*

#### 4.3.2.7 The effect of stigma

Interestingly, two out of the four rural and one out of the ten urban dwellers among the respondents mentioned occasions of being stigmatized by the people due to the disabilities that resulted from their stroke. Mrs. A.M., who is bedridden and incontinent, explained how she felt stigmatized by the people following her stroke. She narrates, “... *If a person intends to come, he then stops. I realize they run away from me... because of my urine odour.... Urine odour! If not destiny how could a person like me wet at night? .... It’s very annoying indeed. It hurts me a lot... how can a mature person wets her wrapper*”. Mrs. B.S., who is a widow, also reports that, “It hurts when some people became afraid of you. They thought that this is caused by evil spirit... it hurts”. In the same vein, Mr. D.S. uttered frustration and felt devastated over the instances he was stigmatized following his stroke, he recounts,

- *Some people run away from me and don’t want me to be in their midst, so you see I must be worried.... People show that it’s infectious; one can get infected when I know that it’s not like that but I disengage from them. If I call a nail cutter to cut my nails, he then tells me that he will not do it.... The barber also tells me that he will not cut my hair.... The barber will not come because he was told that he can get infected, this is why I am very devastated. Even if I sent someone to buy me food, people are afraid of my food container because they feel that the disease may be infectious and I am really worried in this regard.... I can move around before but I cannot go to the midst of the people or their gathering but I follow where there are no people. (Mr. D.S.).*

He also stated that:

- *If I go out and women see me they run away as if they see a mad man because you know our village people.... So they use to run away and you wonder what they are afraid of.... If I see people running away from me I feel very worried.*

#### 4.3.3 Summary

The in-depth interview suggests that stroke has a significant impact on the quality of life of survivors. Stroke has a sudden onset leaving the individual and the family ill-prepared to deal with its residual impairment of physical, psychological, and social functions. Following their stroke, respondents often revealed that they no longer used to be the person they used to be. When asked to describe how their QOL was affected after

their stroke, much of the discussions with the patients consisted of narratives indicating the significance of the impact of stroke on quality of life of survivors.

One of the main issues raised by the respondents was the adoption of adaptive strategy. Findings suggest that in order to curtail the effect of their functional constraints on their QOL after stroke, eight respondents were employing adaptive measures. Discovering ways to favourably adapt to their disabilities was identified as one of the critical factors influencing a stroke survivor's wellbeing. Employing adaptive strategies even for simple day-to-day activities that were central to person's identity was identified as important for a survivor's quality of life. Although all respondents indicated that their life had changed after stroke, not all survivors reported a reduced QOL. The main pathway through which stroke affects QOL is the extent to which a disability restricts a person's self of sense, as it contributes to his/her disability. The finding of this study is consistent with the previous research findings verifying the effect of stroke on wellbeing (Clarke, 2009; Clarke & Black, 2005; Curry et al., 2009; Sale et al., 2002). The findings also revealed that physical and cognitive disability are particularly challenging for survivor's QOL if they hinder an individual's ability to return to the activities that are essential to that person's identity. It was also revealing during discussions with participants that social role limitation challenged relationships that are further distressed by their level of restrictions. Our findings revealed that the dynamics of recovery comprises processes involving both the individual and the surrounding social world and must be collectively considered (Clarke, 2009; Clarke & Black, 2005).

The qualitative narratives from the perspectives of the stroke survivors in this study suggest the importance of social relationship and support systems as an essential aspect of long-term stroke-related quality of life. Following their stroke, survivors intimated

how stroke altered social relationships with families, spouses, friends and significant others and how they could no longer be the persons they used to be. When asked to narrate how stroke affected their QOL, the majority of the narratives that emerged from the in-depth interviews were associated to the changes in social relationship and support system. The themes identified by the patients included social and instrumental supports, communication, autonomy, social role adjustments, sexual relationship and stigma.

The finding of this study is consistent with the pre-existing researches verifying the importance of social relationship and support systems after stroke (Clarke, 2009; Clarke & Black, 2005; Curry et al., 2009; Sale et al., 2002) and so it is not surprising that social relationship and support system appeared as main determinant of QOL for stroke patients. One of the major effects of stroke is role limitation. Launching into biographical accounts of their lives, respondents recount the challenges they face with respect to their social interaction with people. It was revealing from participants' discussions that social role limitation challenged relationships that are further distressed by their level of restrictions. Our findings revealed that the dynamics of recovery comprises processes involving both the individual and the surrounding social world and must be collectively considered (Clarke, 2009; Clarke & Black, 2005). Social relationship and support system as reported by Lynch (2008), Levasseur & Noreau (2004) are essential to the survival of the patients after stroke and therefore of significant importance to QOL after stroke. Measures of health-related QOL should include assessment of social relationship and support system. Otherwise, it may be lacking in one of the most essential dimensions of QOL for patients after stroke.

Social relationship and support are important in helping stroke survivors engage in adaptive strategies and return to work thereby reporting an improved QOL. Our study

suggests that social factors have a buffering or moderating effect in stroke survivors, helping to reduce the adverse effect of the consequent disability on wellbeing. Conversely, withdrawal of support could equally have a detrimental consequence on the survivor's QOL. Some of the narratives illustrated how the detrimental effects of disability following stroke are more obvious in survivors with negative social supports, largely due to reduced ability to adapt to disabilities. On certain occasions, some of the respondents uttered frustration and felt devastated over the instances they were stigmatized following their stroke.

The emerging concept of self-care management such as the use of educational skills and experiences, spiritual and religious resources were identified by most of the respondents as essential in helping them confront the challenges of living with stroke. Spiritual and religious resources transform them and made them resilient in maintaining balance and achieve peace. Educational skills and experiences help them adapt to their stroke-induced disabilities by learning and employing self-care efficacy and coping strategies.

## CHAPTER FIVE: DISCUSSION

The purpose of this chapter is to provide an in-depth discussion of the research findings of this mixed-method study. The chapter will begin with an overview of the instruments validation, changes in functional status, social support and quality of life among the stroke survivors, followed by the integrated findings of the quantitative and the qualitative findings of the study. This chapter will also address the limitations and the strength of this mixed-method study.

### 5.1 Instruments validation

There were no tools developed in Hausa language for the evaluation of QOL and perceived social support among stroke survivors. Since MSPSS and SIS 3.0 were developed in the English Language, it was necessary to carry out linguistic validations of the MSPSS and SIS 3.0 in Hausa language and further evaluate their psychometric properties so that they can be used in clinical research and practice in Nigeria. The principal results from the investigation of the MSPSS and SIS 3.0 with stroke survivors in Kano, Nigeria suggest that the MSPSS and SIS 3.0 were suitable measures for assessing perceived social support and quality of life among stroke survivors. The MSPSS and SIS 3.0 validations were conducted in close collaboration between the translation committee comprising of multiprofessional experts from University of Malaya, Bayero University Kano, Nigeria and professional translators from the Freedom Radio Nigeria *muryar jama'a 99.5FM* (an independent radio) and the copyright owners/developers of the questionnaires.

During translations and where required, expressions used in the items were subjected to more culturally acceptable linguistic equivalents similar to concept and meaning to the original items. During pilot studies, the respondents did not encounter problems with



understanding the contents of the Hausa version of the MSPSS and SIS 3.0, but raised concerns on some of the terms used in the items. They provided some suggestions and a consensus was reached and the items were retained by providing supplementary explanatory sentences. The instruments were found to be easily understood, simple, clear and appropriate for the assessment of perceived social support and QOL among the group of stroke survivors.

For the reliability analysis of the SIS 3.0, the Cronbach's alpha values for the items in the respective 8 domains were above 0.55. This indicates that the Hausa-SIS 3.0 index items are well correlated with one another in a decisive way and are suitable to constitute an index. In the CFA, the initial tested model did not fit well [Chi-square/df > 3, TLI and CFI < 0.9 and RMSEA > 0.08]. After correcting for lack of discriminant validity, the 8 domains were maintained, but reduced to two items each. The model fit in the final model was good [Chi-square/df < 3, TLI and CFI > 0.9 and RMSEA < 0.08].

Regarding the MSPSS, the reliability analysis, the Cronbach's alpha for the 12 items was 0.781. All items correlated well with total score and the scale overall. In test-retest reliability analysis, the minimum kappa value was 0.67. This also indicates that the index had been proven to be reliable in yielding rational scores and was highly reliable to be used in the Nigerian setting. In confirmatory factor analysis (CFA), a problem of multicollinearity between the items of the two constructs (family and significant others) was detected. In the region where the study was conducted, significant others and family are culturally regarded as family and so the items of the two constructs were combined into one and the name of the construct was maintained as family. After

dropping one item, a two factor model with just 11 items was found to be acceptable [Chi-square/df < 3, TLI, CFI > 0.9, RMSEA < 0.08].

This study is the first of its kind conducted in Nigeria that involved translating and testing the psychometric properties of the Hausa version of the MSPSS and SIS 3.0. In accordance with the proposal by Clark and Watson (1995) the number of items in an instrument determines the sample size to be used in the psychometric testing. For an instrument with 20 items or less, a sample size between 100 and 200 subjects is deemed to be adequate (Clark & Watson, 1995; Yusof & Jaafar, 2012). Hence, in this study the sample size of 140 is considered to be adequate for testing the psychometric properties of the Hausa versions of the MSPSS and SIS 3.0 indices.

## **5.2 Changes in functional status, social support and QOL**

Assessing stroke recovery at the impairment, activity, and participation levels allows for the determination of the impact of changes in impairments on changes in activity and perceived QOL (Barak & Duncan, 2006; Suenkeler et al., 2002). Sufficient capturing of the physical and psychological wellbeing of the stroke survivors is necessary in determining the efficacy of the therapeutic programs for stroke (Mayo et al., 2002). In this study, BI, MRS AND BDI were used to assess the outcomes or functional status or the stroke outcomes of the stroke survivors at 6 months and 1 year after stroke. Meanwhile, MSPSS and SIS 3.0 questionnaires were used to measure the perceived social support and specific dimensions of QOL of the stroke survivors at 6 months and 1 year after stroke in the Department of Medicine and Physiotherapy of Aminu Kano teaching hospital and two specialist hospitals (Murtala Muhammad Specialist Hospital and Muhammad Abdullahi Wase Specialist Hospital) of Kano state of Nigeria.

There were changes in all the mean functional scores. The patients significantly improved in relation to their MRS, BI and BDI scores. This means that the patients improved in relation to their level of disability, ADL, and depression as measured by MRS, BI and BDI respectively. The increase in MRS, BI and BDI scores corresponded with the significant increase in QOL scores in all dimensions except for the emotion domain which was slightly lower at 1 year than at 6 months after stroke. This result concurs with the findings of the previous studies conducted by Carod-Artal et al., 2000; Kwok et al., 2006; Suenkeler et al., 2002.

However, the mean scores of perceived social support from 6 months to 1 year were significantly decreased both in regard to the overall social support and individual category of the three sub domains or subscales. This implies that the bulk of the stroke survivors in this study are not satisfied or are not constantly receiving social support from their families, friends and significant others from 6 months to 1 year after stroke. The decreased perceived social support was not in tandem with significantly increased QOL scores in all domains except for the emotion domain.

The results also suggested that the associations with functional status as measured by MRS, BI and BDI and social support, measured by MSPSS fluctuates over time after stroke. The result is similar to what was obtained by Kwok et al., 2006; Patel et al., 2006 that the associations with physical and psychosocial measures vary with time.

Regarding the changes in QOL that occurred between 6 months and 1 year after stroke, the condition of stroke patients changed significantly in all dimensions of QOL. Except for the emotion domain, the scores were significantly higher at 1 year after stroke. The possible explanation was that at 1 year after stroke, there were improvements in motor

disability and depressive symptoms. This result confirmed the finding of previous studies by Carod-Artal et al., 2000; Clarke et al., 2000; Robinson-Smith et al., 2000. Despite the fact that social support was decreased at 1 year after stroke, the QOL of the stroke survivors were significantly increased except for the emotion domain which was significantly decreased. The decrease in the emotion domain of QOL from 6 months to 1 year after stroke may be explained by the link between low levels of social support and poor mental health outcomes. This result is similar to the previous findings by Lyncha et al., 1999; Tsouna-Hadjis et al., 2000.

### **5.3 Integration of major findings**

This is the first study on the Health-Related Quality of Life among stroke survivors in Nigeria using a mixed-method approach. By utilizing both quantitative and qualitative methods to examine the determinants of QOL following stroke, this study was able to elicit a thorough insight of the stroke experience. Even though the corroboration of associations in quantitative studies fails to illuminate why and how individuals retain or lose their sense of wellbeing after stroke the qualitative study supplemented the gap.

The quantitative data indicate that increasing age was repeatedly associated with decrease in strength domain of QOL at 6 months and 1 year after stroke. This confirmed the findings of Gosman-Hedström et al., 2008; Gurcay et al., 2009; Nichols-Larsen et al., 2005a; Owolabi, 2008. It was also obvious from the qualitative accounts that aged stroke survivors lamented more bitterly on the more profound effects of stroke on their already compromised ADLs and functioning. This was due to the fact that, (1) Older stroke survivors might have poor health than the younger ones and, (2) Older stroke survivors may be lacking appropriate caregiver because their spouses may be dead and their children may be already married or engaged with active occupation.

In general, functional status i.e. the level of disability and the ability to carry out ADL as measured by MRS and BI respectively were found to be an important determinant of QOL among stroke survivors both at 6 months and at 1 year after stroke. Functional limitations was generally associated with reduced QOL at 6 months and 1 year after stroke, which is consistent with findings by other researchers Altindag et al., 2008; Carod-Artal et al., 2009; Carod-Artal et al., 2000; Kwok et al., 2007; Mayo et al., 2002. The qualitative findings reinforced the effect of impaired functional recovery on QOL. The experience of frustration and distress were strongly linked to functional limitations and giving up of valued activities and seemed to be associated with reduced sense of physical and mental wellbeing. Perception of being a burden to others due to impaired functional recovery was associated with anxiety and a reduced quality of life. The effect of stroke on religious activities is one of the common themes identified by the respondents.

The quantitative findings stressed the importance of depression for the QOL of stroke survivors and the qualitative accounts further explained the effect of depression and distress on the wellbeing of the stroke survivors. Although the level of depression was significantly reduced from 6 months to 1 year after stroke, depression was generally associated with reduced quality of life at 6 months and 1 year after stroke. This is consistent with findings of Altindag et al., 2008; Carod-Artal et al., 2009; Carod-Artal et al., 2000; Kwok et al., 2007. In terms of explaining the negative effect of depression on QOL, the qualitative accounts suggested that the experience of frustration and distress were strongly linked to functional limitations and giving up of valued activities and seemed to be associated with reduced sense of physical and mental wellbeing. For those stroke survivors whose physical, social and financial independence were essential

for their abilities to carry out self defining activities, their quality of lives were notably affected. The wellbeing of the survivors seemed substantially decreased when a person is restricted from involving in activities that constituted a salient aspect of his/her identity owing to the residual disabilities sustained after his/her stroke. Moreover, the respondents' wellbeing appeared to rely upon the extent to which their disabilities influence their sense of self and identity. Issues related to pain were one of the common themes identified by some of the respondents as a great source of distress. Respondents whose pain was so severe thereby restricting their activities revealed that the pain had adverse effect on their lives, leading them to report a reduced QOL.

In the quantitative phase of the research, the type of occupation stroke survivors were engaged before and after stroke was repeatedly found to be associated with most domains of QOL at 6 months and 1 year after stroke, and the qualitative accounts clearly exemplified the importance of occupation and return to work for a positive sense of wellbeing. Stroke survivors who were not able to return to work reported a negative sense of wellbeing. This was consistent with the findings by Mayo et al., 2002; Vestling et al., 2003. The qualitative findings help to explain the necessary ways by which occupation is associated with positive or negative sense of wellbeing after stroke, particularly because, (1) The effect of residual impairment was consistently reported as the main concern, due to the constraints placed on their occupations. Survivors provided many examples how they had to discontinue working or how they were severely restricted and often stressing that there had been a loss of a previously active lifestyle, (2) The wellbeing of the survivors seemed to substantially decrease when a person is restricted from involving in activities that constituted a salient aspect of his/her identity owing to the residual disabilities after his/her stroke. Moreover, the respondents'

wellbeing appeared to rely upon the extent to which their disabilities influence their sense of self and identity.

Income and having adequate resources were repeatedly associated with various domains of QOL at 6 months and 1 year after stroke in the statistical model. The qualitative accounts further elucidate the extent to which financial problem restrict a person's sense of wellbeing after stroke. The quantitative findings revealed that stroke survivors with sufficient income were generally associated with increased physical and memory domain of QOL at 6 months after stroke and with physical, memory, emotional and participation domain of QOL at 1 year after stroke, which is consistent with findings of other researchers (Clarke & Black, 2005; Gurcay et al., 2009; Kwok et al., 2006; Lynch et al., 2008; White et al., 2008). The qualitative accounts implied that the feeling of worry and anger due to financial difficulties is associated with reduced sense of wellbeing. If financial and occupational reintegration is not ensured, boredom may lead to depression and worsen function thereby reducing the wellbeing of the survivors.

The quantitative data indicate that effect on work was repeatedly associated with QOL on the various domains of QOL. This was consistent with the findings of Lee et al., 2009; Mayo et al., 2002 that poor QOL may be due largely to the negative effect of cognitive and self-care deficits on QOL at 6 months and 1 year after stroke. The qualitative account suggested the pathways by which stroke-induced disabilities affect the work and hence poor QOL among the stroke survivors that (1) the effect of residual impairment was consistently reported as the main concerns, due to the constraints placed on their occupations. Survivors provided many examples how they had to discontinue their occupations or how they were severely restricted and often stressing that there had been a loss of a previously active lifestyle, (2) Survivors were also

distressed and frustrated at being unable to return to their work following their stroke because of residual physical disabilities leading them to have a reduced QOL. (3) The wellbeing of the survivors seemed to be substantially decreased when a person is restricted from involving in activities that constituted a salient aspect of his/her identity owing to the residual disabilities after his/her stroke. Moreover, the respondents' wellbeing appeared to rely upon the extent to which their disabilities influence their sense of self and identity.

Consistent with prior reports of decreased QOL and especially of communication domain of QOL among stroke survivors with left hemispheric lesion (right sided hemiplegia) (Barker-Collo, 2007; Carod-Artal et al., 2009; Kamel et al., 2010 ; Moon et al., 2004; Nichols-Larsen et al., 2005b) due to the damage of left hemisphere with unilateral speech presentation, quantitative findings revealed that although left hemispheric (right sided hemiplegia) was associated with increased physical domain but decreased communication domain of QOL at 6 months and 1 year after stroke. The qualitative account further confirmed the findings and the possible explanations were due to the direct effect of speech problem on social relationship. Respondents revealed frustrations and emotional reactions owing to communication difficulties resulting from their inability to effectively communicate. Frustrations with speech also seemed to be associated with the difficulty some survivors experience in associating with others and thereby affecting their self esteem.

Nevertheless, social support and responsible care giving were found to be the key determinants of QOL among stroke survivors at 6 months and 1 year after stroke in the quantitative findings which is consistent with findings of other research (Brenda et al., 2002; Bruwer et al., 2008; Katherine et al., 2010; Lyncha et al., 1999; Tsouna-Hadjis et



al., 2000). The qualitative accounts also help to explain the underlying mechanism by which social support and care giving are associated with increased or decreased QOL among stroke survivors. Coherent with the quantitative findings, survivors disclosed that they benefited from the help of different social supports provided by their friends, spouses, and families and significant others. Social support themes consisted of narratives regarding how families, spouses, friends and significant others supported or did not support the respondents by rendering them emotional, financial and instrumental supports that were essential to them after their stroke.

Consistent with prior reports, social and instrumental support were also found to have a moderating or buffering effect in stroke survivors (Clarke et al., 2002; Kolella & King, 2004; Salter et al., 2010; Tsouna-Hadjis et al., 2000), thereby reducing the adverse effect of the disability on the QOL. This moderating mechanism was explained by the qualitative findings. Some of the accounts by the survivors elucidated the catastrophic effect of the stroke-induced disability on the QOL of the survivors which are enunciated in survivors with negative social support, largely due to the fact that denial or withdrawal of support affect the strategies to which survivors adapt with their disabilities. Withdrawal of support and not being included in decision making could equally have a detrimental consequence on the survivor's subjective wellbeing. Withdrawal of support was characterized by reduced frequency of contacts with friends and family, especially friends. Respondents who disclosed to have been abandoned by their friends and families reported that this experience of social isolation was the cause of their distress, due to feeling of loss. Negative supports were also associated with reduced QOL because survivors were often stigmatized by the people due to the disabilities that resulted from their stroke thereby leading them to report a reduced QOL.

The quantitative findings indicated that education was found to be associated with almost all the domains of QOL at 6 months and 1 year after stroke. This is consistent with the findings of other researchers (Aprile et al., 2006; Clarke et al., 2002; Jeong et al., 2012; Mayo et al., 2002). The qualitative findings further emphasized the importance of education for the wellbeing of stroke survivors in helping them confront the challenges and adapt to their disabilities after stroke through learning and employing self-care efficacy and coping strategies. Education was also found to be beneficial to the survivors for the flexible coping skills it offers them to in order for them to confront the challenges of living with their disabilities, regain autonomy and control of their everyday life related to personal care, social and religious functioning as well as everyday participation and responsibilities.

#### **5.4 Limitations of the study**

Interpretation of the findings of this study should be considered because of several limitations as follows:

1. The quantitative component of this study was conducted in the stroke referral hospitals in Kano, Nigeria. Stroke survivors can be located in areas other than hospitals and so the socio-demographic characteristics of the participants can have a major influence on the result because patients with mild stroke and those who cannot afford hospital treatment costs may not have been included in the study, as such, QOL may actually be worse than described herein.
2. The study followed the stroke survivors for a period of 12 months (1 year). Different stages of stroke might have different consequence on stroke survivors' experience with stroke. Therefore, different result may be found if the study was carried out at different stages of stroke from acute to several years after stroke.

3. Although the participants from different educational and socioeconomic backgrounds were consecutively recruited in the study, this study was conducted on participants mainly from the urban area. As such the findings of this study cannot claim generalizability to all stroke survivors in Kano, Nigeria.
4. The qualitative interviews were limited to 1 in-depth interview per participant and so may not capture any change over time. If the interviews were to be conducted at different times, the participants may have provided different answers/narratives to similar questions.

### **5.5 Strengths of the study**

In spite of the limitations, there are numerous strengths to this study which are as follows:

1. One of the major strengths of the study was the use of mixed-method design to identify the factors influencing the QOL among stroke survivors. This is the first study on the determinants QOL among stroke survivors in Nigeria using a mixed-method approach. The use of a mixed-method approach allow for a more extensive understanding of the stroke experience.
2. The linguistic validation of instruments for the measurements of QOL and social support and the subsequent assessment of their psychometric properties for use in stroke rehabilitation research and practice in Nigeria. The use of a Stroke Impact Scale (SIS) 3.0 which is a stroke specific, more detailed and more sensitive scale and the assessment of the participants at the same time interval after stroke add value to the study.
3. The low dropout rate and a wide range of age, occupation, income and different degrees of functional level among the cohorts. The dropout rate was further minimized by interviewing patients in their homes if necessary.

4. The use of proxy-raters prevented the exclusion of patients with aphasia and this limit sampling bias.
5. The qualitative component of this study allow for better explanation of the viewpoints of the patients on the impact of stroke on their lives and what improves the QOL post stroke thereby further reiterating on some of the issues that are personally important and salient to stroke patients.

## CHAPTER SIX: CONCLUSION

### 6.1 Conclusion

Results from both quantitative and qualitative data allowed for a considerable understanding of the factors influencing the HRQOL of stroke survivors. The findings revealed that although stroke is a challenging life event, with the benefit of various social resources, individuals can adapt to the disability and regenerate meaning in their lives. The strength of this study is that a combined methods approach allows for the extensive understanding of the stroke experience and the factors influencing stroke survivor's QOL. Phase I involved the validation of the primary tools for the measurement of QOL and social support. Phase II (quantitative phase) is a longitudinal survey to identify the patterns and predictors of QOL at 6 months and 1 year after stroke. The final phase (Phase III) using qualitative methods allowed the researcher to explore in-depth the reasons for the observed patterns obtained from phase II plus to better understand the mechanisms by which stroke affects the QOL of the individuals. It also helps to elucidate the nature of the survivors' experiences that may not be surveyed or revealed in the quantitative findings. Correlations and stepwise linear regression model were used to determine the predictors of QOL, whilst thematic analysis using constant comparative methods and aided by NVivo software were used for the qualitative phase. Of the 233 stroke patients that participated in this study, 51% were males and the remaining was females. Their ages ranged from 19 to 82 years with a mean age of 58.76 (SD 13.24) years indicating that greater incidence of stroke prevailed in the middle aged persons.

Psychometrically the 16-item Hausa (language) version of the Stroke Impact Scale (Hausa-SIS) 3.0's 8 domains (strength, memory, emotion, communication, hand function, mobility, and ADL, participation and physical domains) has good coverage of

Quality Of Life (QOL) construct. In the final analysis, a parsimonious model was obtained with two items per construct for the 8 constructs. The 11-item Hausa version of the Multidimensional Scale of Perceived Social Support (Hausa-MSPSS) is valid for the assessment of perceived social support among stroke survivors in Nigeria. A two-factor model with Family and Friends as the two domains was found to be acceptable. The eight dimensions of QOL, excluding the emotional domain, showed significant improvement at 1 year after stroke. Social support was significantly decreased from 6 months to 1 year after stroke ( $p < 0.005$ ).

Regarding the changes that occurred between 6 months and 1 year, stroke patients demonstrated significant improvement in relation to their level of disability as measured by the MRS. There were also significant changes in both activities of daily living (BI scores) and the level of depression (BDI scores); mainly mental health improved. The mean scores of perceived social support from 6 months to 1 year were dramatically decreased both in regards to overall social support and individual category of the three domains or subscales. In relation to QOL, the condition of stroke patients changed significantly in all dimensions. Except for the emotion domain, the scores of the different QOL dimensions were significantly higher at 1 year after stroke.

Linear regression model for the predictors of satisfactory QOL at 6 months after stroke highlighted: occupation before stroke, occupation after stroke, income, caregiver, effect to work, education, side of stroke, activities of daily living (Barthel Index Score), residency, degree of disability (Rankin Score), and social support. In addition to the predictors of satisfactory QOL at 6 months after stroke, hospital treatment charges and perceived social support by friends were found to be additional predictors of satisfactory QOL at 1 year after stroke. The predictors of unsatisfactory QOL after stroke were:

older age, occupation after stroke, hospital treatment charges, degree of disability (Rankin Score), level of depression (Beck Inventory Score), and side of stroke. Withdrawal of support by significant others was the sole factor associated ( $p < 0.05$ ) with unsatisfactory QOL at both 6 month and at 1 year after stroke.

The qualitative findings underscore the individual's viewpoint of their stroke experience and discovered that stroke survivors describe their losses and improvement according to their subjective interpretation of crucial or important activities in life instead of the standard definition of disability. The social components of QOL after stroke may be better captured as such, and may be independent of physical and psychological domains of QOL. The results emphasized that even in a modified or reduced way; some of the survivors utilized various ways to return to self defining activities so as to restore their sense of identity. This is consistent with Atchley's theory of continuity (Atchley, 1989; Clarke & Black, 2005) which suggests that when faced with disabling conditions in later life, individuals are resilient in finding ways to maintain valued life activities in order to enable them report a high degree of subjective wellbeing. Thus, the qualitative study underscored the fact that although stroke is a challenging life event, survivors can adapt to the disability and regenerate meaning in their lives.

## **6.2 Recommendations**

This study launches the future direction that public health and rehabilitation professionals should consider towards improving the QOL of the stroke survivors in Kano, Nigeria. Recommendations based on the findings of the study are presented in the areas of public health practice and rehabilitation research.

1. The findings of this study revealed that stroke affects every aspect of life. This calls for greater attention for health care providers and rehabilitation professionals to

be actively aware of the patient experiences and perception after stroke and how this influences their recovery, priorities and goals so as to promote practical strategies. This will ensure a focused care relevant to the patients. The understanding of the real need, rather than assumed need is essential as every person's QOL needs are unique. The knowledge of the factors that determine QOL after stroke helps inform the planning of rehabilitation programs and for judicious use of the available resources aimed at improving a QOL after stroke is warranted.

2. Early identification and management of functional disability as well as the assessment of depression, and social support may promote a better understanding of QOL. Thus rehabilitation services involving patients and their goals for leisure, occupation, physical functioning and social activities, should start early.
3. A well planned discharge and rehabilitation programs such as occupational and leisure therapy, home and environmental modifications should be considered and organized by the hospitals that provide for the stroke management.
4. Due to lack of the diagnostic facilities and presence of incomplete data, stroke was categorized as indeterminate in 53% cases. Given the importance of accurate diagnosis prior to the commencement of emergency management and since history and clinical examination alone cannot reliably do so, diagnostic tools should be provided in all hospitals. Accurate diagnosis may facilitate a better understanding of individual needs and thereby planning for programming during recovery.
5. About 74% of the stroke survivors were urban residents which made them convenient to have easy access to rehabilitation services in the study area if the facilities are located close to their residences. The government should help to decentralize facilities that provide for rehabilitation after stroke and also make it affordable because only 3% of the study participants had enough income. The



- importance of having adequate resources such as, for rehabilitation, is strongly associated with community integration and indices of QOL.
6. The 16-item HAUSA-SIS (Appendix J) seems to measure adequately the QOL outcomes in the 8 domains. As such, researchers investigating quality of life in stroke survivors can use this instrument for studies with the hope that it will prove valuable in providing information and strategies to be utilized by health care providers and professionals in their attempt to improve the QOL of stroke patients.
  7. The 11-item Hausa-MSPSS (Appendix K) index is valid for the assessment of perceived social support among stroke survivors in Nigeria. As such, researchers investigating perceived social support from family, friends and significant others in stroke survivors can use this measure for studies with the hope to understand and improve the accessible social support that can be an essential plan in mitigating psychiatric distress and averting post stroke depression.
  8. The incidental findings of this study showed that 23% of the stroke patients captured in the time frame of this study were less than 50 years of age and this confirms that stroke should be regarded as an upcoming serious public health issue in Nigeria. This finding shows that there is a need for more public health education by the primary, secondary and tertiary healthcare providers in Kano, Nigeria to bring about behavioural changes that will curtail the risk of stroke particularly among the young.
  9. Considering the importance and the moderating effect of the support system for the QOL of the stroke survivors that emerged from the findings of this study, development of appropriate programs that enhance social support and social networks of the stroke survivors such as: a stroke club to allow for sharing of feelings, coping experiences and mental support; planning of an effective welfare assistance; ensuring an affordable and appropriate healthcare; provision of disability allowance as well as

income generating programs, will not only prove vital for the wellbeing of the survivors but will also reduce further strain on the health care system. Different approaches such as the formal training of care givers should also be considered to address the psychosocial problems of the stroke survivors. The support of the family and healthcare providers is depicted as a source of motivation. The family promotes the feeling of optimism on the part of the participants. Improvement of accessible social support could be an essential plan in mitigating psychiatric distress and averting post stroke depression.

10. It was found that more than two thirds of the subjects became unemployed after stroke. The lack of meaningful employment post stroke is a factor that needs to be looked into. Provision of disability allowance, effective social welfare assistance, and affordable health care for the stroke survivors could help to curb the associated depression, frustration and the feeling of anxiety leading to poor QOL.
11. Also 50.6% of the stroke survivors cannot return to work after their stroke and therefore lacked important and meaningful activities to occupy the day. Stroke survivors must therefore be encouraged to return to work and the process enabled. If social and occupational reintegration is not ensured, boredom may lead to depression and worsen function thereby reducing the wellbeing of the survivors.
12. Given the emerging concepts of self management of medical tasks, emotional tasks and role task through the use of educational skills and mastery experiences, in helping them confront the challenges of living with stroke, there is need for researchers to work together with other stakeholders to develop and test interventions that can support self-management skills to make continued progress after stroke. This could reduce some of the negative consequences of stroke e.g. reduced quality of life and social isolation.

### **6.3 Recommendations for further study**

This study support the need for a more extensive prospective study with longer period of follow up with a view to further explore the dynamics of socio-demographic and clinical characteristics and changes in physical and psychosocial changes over time.

It is also seen that determinants of Quality of Life (QOL) in stroke survivors vary with time. Longitudinal studies are important in the understanding of stroke, where the changes in adaptation and adjustment are likely to influence survivors' QOL dynamically over the post stroke period. Therefore studies should be conducted to link qualitative findings over time to longitudinal changes in quantitative data

Another study recommended would be to study the impact of stroke as it can be devastating for both the individual and the family. Not only the patients but also their caregivers need professional attention and support in order to maintain their physical and mental and social wellbeing. Further prospective studies should be conducted to assess the determinants of QOL in family members and caregivers of the stroke survivors in Kano, Nigeria.

In addition, effective education of the stroke survivors, their caregivers and health care providers with regards to the factors affecting the QOL of the survivors is important. Future research should address the development of an intervention to take care of such. Evidence-based survivors' education strategies need to be implemented and subsequently evaluated.



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No. Rujukan: PPUM/MDU/300/04/03

10 Februari 2011

**Dr. Ashiru Hamza Mohammad**  
Jabatan Perubatan Kemasyarakatan & Pencegahan  
Pusat Perubatan Universiti Malaya

Puan,

**SURAT PEMAKLUMAN KEPUTUSAN PERMOHONAN MENJALANKAN PROJEK PENYELIDIKAN**  
A mixed-method research on the impact and determinants of health-related quality of life among stroke survivors in Nigeria

**Protocol No : -**

**MEC Ref. No : 830.7**

Dengan hormatnya saya merujuk kepada perkara di atas.

Bersama-sama ini dilampirkan surat pemakluman keputusan Jawatankuasa Etika Perubatan yang bermesyuarat pada 26 Januari 2011 untuk makluman dan tindakan puan selanjutnya.

2. Sila maklumkan kepada Jawatankuasa Etika Perubatan mengenai butiran kajian samada telah tamat atau diteruskan mengikut jangka masa kajian tersebut.

Sekian, terima kasih.

**“BERKHIDMAT UNTUK NEGARA”**

Saya yang menurut perintah,



Norashikin Mahmood  
Setiausaha  
Jawatankuasa Etika Perubatan  
Pusat Perubatan Universiti Malaya

s.k Ketua  
Jabatan Perubatan Kemasyarakatan & Pencegahan



# AMINU KANO TEACHING HOSPITAL

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FWACS, FICS, MRCOG.

**Director of Administration**  
**ALH. MUHD. SULAIMAN, AT**  
B. Ed, CHPM

NHREC/21/08/2008a/AKTH/EC/788

AKTH/MAC/SUB/12<sup>A</sup>/P3/IV/801

6<sup>TH</sup> April, 2011

Ashiru Hamza Muhammad  
c/o Physiotherapy Department  
AKTH, Kano

ufs:

The Head of Department,  
Department of Physiotherapy  
AKTH, Kano

## **RE; ETHICAL APPROVAL**

### **THE IMPACT OF DETERMINANTS OF QUALITY OF LIFE AMONG STROKE SURVIVORS IN NIGERIA – A MIXED METHOD RESEARCH**

Further to your response in respect of the above research proposal, the Committee has considered your proposal and noted same as a prospective study.

In view of this, Ethical approval is hereby granted to conduct the research.

However, the approval is subject to periodic reporting of the progress of the study and its completion to the Ethical Committee.

Best regards.

**BARA'ATU KABIR (Mrs)**  
**SECRETARY**  
**FOR: CHAIRMAN, ETHICAL COMMITTEE**



**KANO STATE**  
**HOSPITALS MANAGEMENT BOARD**  
**BOARD HEADQUARTERS**  
P.M.B 3540, Post Office Road, Kano

HMB/GEN/488/II/

13/05/2011 (13/06/1432AH)

**Ashiru Hamza Mohammad**

Department of Social and preventive Medicine,  
Faculty of Medicine,  
University of Malaya, Malaysia,

**PROVISIONAL ETHICAL CLEARANCE**

Sequel to your application for ethical clearance to conduct a research titled "A MIXED METHOD RESEARCH ON THE IMPACT AND DETERMINANTS OF QUALITY OF LIFE AMONG STROKE SURVIVORS IN NIGERIA" and your appearance before the Hospitals Management Board Ethical Committee on 10<sup>th</sup> May, 2011, I am directed to inform you that Ethical clearance has been granted to conduct your research on the aforementioned topic based on the following conditions.:-

1. That consent of all participants must be obtained by filling and signing in formed consent form.
2. That you are to submit a copy of your final result for final approval.

Best regards,

**AISHA ABDULLAHI**  
AS I / TRAI.  
**FOR: DIRECTOR GENERAL**



## Appendix B: Consent form

### CONSENT BY PATIENT FOR CLINICAL RESEARCH

I, ..... Identity Card No.....  
*(Name of Patient)*

of  
.....  
*(Address)*

hereby agree to take part in the clinical research (clinical study/questionnaire study/drug trial) specified below:

**Title of Study: HEALTH-RELATED QUALITY OF LIFE AMONG STROKE SURVIVORS IN KANO, NIGERIA: A MIXED-METHOD STUDY**

the nature and purpose of which has been explained to me by  
Mr/Dr. .... *(Name & Designation of Doctor)* and interpreted  
by ..... *(Name & Designation of Interpreter)*. to the best of his/her  
ability in ..... language/dialect.

I have been told about the nature of the clinical research in terms of methodology, possible adverse effects and complications (as per patient information sheet). After knowing and understanding all the possible advantages and disadvantages of this clinical research, I voluntarily consent of my own free will to participate in the clinical research specified above.

I understand that I can withdraw from this clinical research at any time without assigning any reason whatsoever and in such a situation shall not be denied the benefits of usual treatment by the attending doctors.

Date: ..... Signature or Thumbprint  
..... *(Patient)*

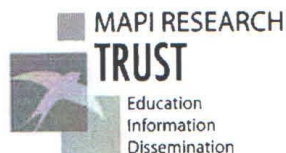
#### IN THE PRESENCE OF

Name ..... )  
Identity Card No. .... ) Signature  
..... ) *(Witness for Signature of*  
*Patient)*  
Designation ..... )

I confirm that I have explained to the patient the nature and purpose of the above-mentioned clinical research.

Date ..... Signature  
..... *(Attending Doctor/Therapist)*

## Appendix C: Mapi Trust, translation certificate



Ashiru Hamza Mohammad  
Center for Population Health  
Department of Social & Preventive Medicine  
Faculty of Medicine  
University of Malaya  
Malaysia

Lyon, July 3rd, 2012

To the attention of Ashiru Hamza Mohammad

Subject : Acknowledgment for the Hausa translation of the SIS 3.0

Dear Ashiru Hamza,

With this letter, I hereby acknowledge receipt of the translation of the SIS 3.0 (Stroke Impact Scale) from the English to Hausa.

Kind regards,



Vanessa

Vanessa MARTEL  
Project Assistant – PRO Information Support  
Mapi Research Trust  
27 rue de la Villette  
69003 Lyon  
FRANCE  
Tel: +33 (0)4 72 13 65 75  
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0843004402 - TVA ; FR 44 453 979 346

**Legal Notice**

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## **Appendix D: Questionnaire**

### **HEALTH-RELATED QUALITY OF LIFE AMONG STROKE SURVIVORS IN KANO, NIGERIA: A MIXED-METHOD STUDY**

#### **INSTRUCTIONS**

1. This Questionnaire is divided in to 3 parts as follows
  - A. Sociodemographic characteristics and health profile
  - B. Assessment of social support Assessment using MSPSS
  - C. Quality of Life assessment using Stroke Impact Scale (SIS 3.0)
  
2. All information provided will be treated with utmost confidentiality. You are therefore required to give true answers to all the questions and according to your perception.





### PART III:

#### D3: Stroke Impact Scale 3.0 (patient version)

The purpose of this questionnaire is to evaluate how stroke has impacted your health and life. We want to know from YOUR POINT OF VIEW how stroke has affected you. We will ask you questions about impairments and disabilities caused by your stroke, as well as how stroke has affected your quality of life. Finally, we will ask you to rate how much you think you have recovered from your stroke. These questions are about the

physical problems which may have occurred as a result of your stroke.

<b>1. In the past week, how would you rate the strength of your...</b>	<b>A lot of strength</b>	<b>Quite a bit of strength</b>	<b>Some strength</b>	<b>A little strength</b>	<b>No strength at all</b>
a. Arm that was most affected by your stroke?	5	4	3	2	1
b. Grip of your hand that was most affected by your stroke?	5	4	3	2	1
c. Leg that was most affected by your stroke?	5	4	3	2	1
d. Foot/ankle that was most affected by your stroke?	5	4	3	2	1

These questions are about your memory and thinking.

<b>2. In the past week, how difficult was it for you to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Somewhat difficult</b>	<b>Very difficult</b>	<b>Extremely difficult</b>
a. Remember things that people just told you?	5	4	3	2	1
b. Remember things that happened the day before?	5	4	3	2	1
c. Remember to do things (e.g. keep scheduled appointments or take medication)?	5	4	3	2	1
d. Remember the day of the week?	5	4	3	2	1
e. Concentrate?	5	4	3	2	1
f. Think quickly?	5	4	3	2	1
g. Solve everyday problems?	5	4	3	2	1

These questions are about how you feel, about changes in your mood and about your ability to control your emotions since your stroke.

<b>3. In the past week, how often did you...</b>	<b>None of the time</b>	<b>A little of the time</b>	<b>Some of the time</b>	<b>Most of the time</b>	<b>All of the time</b>
a. Feel sad?	5	4	3	2	1
b. Feel that there is nobody you are close to?	5	4	3	2	1
c. Feel that you are a burden to others?	5	4	3	2	1
d. Feel that you have nothing to look forward to?	5	4	3	2	1
e. Blame yourself for mistakes that you	5	4	3	2	1

made?					
f. Enjoy things as much as ever?	5	4	3	2	1
g. Feel quite nervous?	5	4	3	2	1
h. Feel that life is worth living?	5	4	3	2	1
i. Smile and laugh at least once a day?	5	4	3	2	1

The following questions are about your ability to communicate with other people, as well as your ability to understand what you read and what you hear in a conversation.

<b>4. In the past week, how difficult was it to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Somewh at difficult</b>	<b>Very difficult</b>	<b>Extremely difficult</b>
a. Say the name of someone who was in front of you?	5	4	3	2	1
b. Understand what was being said to you in a conversation?	5	4	3	2	1
c. Reply to questions?	5	4	3	2	1
d. Correctly name objects?	5	4	3	2	1
e. Participate in a conversation with a group of people?	5	4	3	2	1
f. Have a conversation on the telephone?	5	4	3	2	1
g. Call another person on the telephone, including selecting the correct phone number and dialling?	5	4	3	2	1

The following questions ask about activities you might do during a typical day.

<b>5. In the past 2 weeks, how difficult was it to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Somewh at difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
a. Cut your food with a knife and fork?	5	4	3	2	1
b. Dress the top part of your body?	5	4	3	2	1
c. Bathe yourself?	5	4	3	2	1
d. Clip your toenails?	5	4	3	2	1
e. Get to the toilet on time?	5	4	3	2	1
f. Control your bladder (not have an accident)?	5	4	3	2	1
g. Control your bowels (not have an accident)?	5	4	3	2	1
h. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)?	5	4	3	2	1
i. Go shopping?	5	4	3	2	1
j. Do heavy household chores (e.g. vacuum, laundry or yard work)?	5	4	3	2	1

The following questions are about your ability to be mobile, at home and in the community.

<b>6. In the past 2 weeks, how difficult was it to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Somewh at difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
a. Stay sitting without losing your balance?	5	4	3	2	1
b. Stay standing without losing your balance?	5	4	3	2	1
c. Walk without losing your balance?	5	4	3	2	1
d. Move from a bed to a chair?	5	4	3	2	1

e. Walk one block?	5	4	3	2	1
f. Walk fast?	5	4	3	2	1
g. Climb one flight of stairs?	5	4	3	2	1
h. Climb several flights of stairs?	5	4	3	2	1
i. Get in and out of a car?	5	4	3	2	1

The following questions are about your ability to use your hand that was MOST AFFECTED by your stroke.

<b>7. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Somewh at difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
a. Carry heavy objects (e.g. bag of groceries)?	5	4	3	2	1
b. Turn a doorknob?	5	4	3	2	1
c. Open a can or jar?	5	4	3	2	1
d. Tie a shoe lace?	5	4	3	2	1
e. Pick up a dime?	5	4	3	2	1

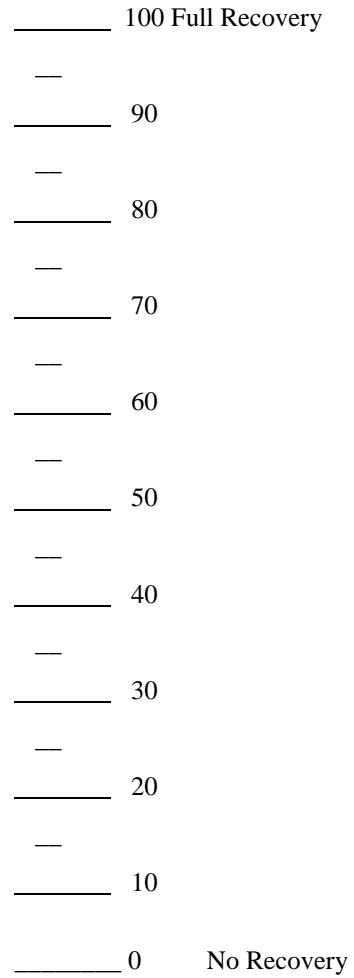
The following questions are about how stroke has affected your ability to participate in the activities that you usually do, things that are meaningful to you and help you to find purpose in life.

<b>8. During the past 4 weeks, how much of the time have you been limited in...</b>	<b>None of the time</b>	<b>A little of the time</b>	<b>Some of the time</b>	<b>Most of the time</b>	<b>All of the time</b>
a. Your work (paid, voluntary or other)	5	4	3	2	1
b. Your social activities?	5	4	3	2	1
c. Quiet recreation (crafts, reading)?	5	4	3	2	1
d. Active recreation (sports, outings, travel)?	5	4	3	2	1
e. Your role as a family member and/or friend?	5	4	3	2	1
f. Your participation in spiritual or religious activities?	5	4	3	2	1
g. Your ability to control your life as you wishes?	5	4	3	2	1
h. Your ability to help others?	5	4	3	2	1



**9. Stroke Recovery**

On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you Recovered from your stroke?



## D4: Stroke Impact Scale 3.0 (proxy version)

The purpose of this questionnaire is to evaluate how stroke has impacted the health and life of \_\_\_\_\_ (patient name). We want to know from YOUR POINT OF VIEW how stroke has affected him/her. We will ask you questions about impairments and disabilities caused by his/her stroke, as well as how stroke has affected his/her quality of life. Finally, we will ask you to rate how much you think s/he has recovered from the stroke.

---

These questions are about the physical problems which may have occurred as a result of the stroke.

1. In the past week, how would you rate the strength of his/her...	A lot of strength	Quite a bit of strength	Some strength	A little strength	No strength at all
a. Arm that was most affected by his/her stroke?	5	4	3	2	1
b. Grip of your hand that was most affected by his/her stroke?	5	4	3	2	1
c. Leg that was most affected by his/her stroke?	5	4	3	2	1
d. Foot/ankle that was most affected by his/her stroke?	5	4	3	2	1

These questions are about his/her memory and thinking.

2. In the past week, how difficult was it for him/her to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Remember things that people just told him/her?	5	4	3	2	1
b. Remember things that happened the day before?	5	4	3	2	1
c. Remember to do things (e.g. keep scheduled appointments or take medication)?	5	4	3	2	1
d. Remember the day of the week?	5	4	3	2	1
e. Concentrate?	5	4	3	2	1
f. Think quickly?	5	4	3	2	1
g. Solve everyday problems?	5	4	3	2	1

These questions are about feelings, about changes in his/her mood and about his/her ability to control emotions since the stroke.

<b>3. In the past week, how often did he/she ...</b>	<b>None of the time</b>	<b>A little of the time</b>	<b>Some of the time</b>	<b>Most of the time</b>	<b>All of the time</b>
a. Feel sad?	5	4	3	2	1
b. Feel that there is nobody he/she is close to?	5	4	3	2	1
c. Feel that he/she is a burden to others?	5	4	3	2	1
d. Feel that he/she have nothing to look forward to?	5	4	3	2	1
e. Blame himself/herself for mistakes that he/she made?	5	4	3	2	1
f. Enjoy things as much as ever?	5	4	3	2	1
g. Feel quite nervous?	5	4	3	2	1
h. Feel that life is worth living?	5	4	3	2	1
i. Smile and laugh at least once a day?	5	4	3	2	1

The following questions are about his/her ability to communicate with other people, as well as his/her ability to understand what she/he reads and hears in a conversation.

<b>4. In the past week, how difficult was it for him/her to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Somewh at difficult</b>	<b>Very difficult</b>	<b>Extremely difficult</b>
a. Say the name of someone who was in front of him/her?	5	4	3	2	1
b. Understand what was being said to him/her in a conversation?	5	4	3	2	1
c. Reply to questions?	5	4	3	2	1
d. Correctly name objects?	5	4	3	2	1
e. Participate in a conversation with a group of people?	5	4	3	2	1
f. Have a conversation on the telephone?	5	4	3	2	1
g. Call another person on the telephone, including selecting the correct phone number and dialling?	5	4	3	2	1

The following questions ask about activities she/he might do during a typical day.

<b>5. In the past 2 weeks, how difficult was it for him/her to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Somewh at difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
a. Cut his/her food with a knife and fork?	5	4	3	2	1
b. Dress the top part of his/her body?	5	4	3	2	1
c. Bathe him/her?	5	4	3	2	1
d. Clip his/her toenails?	5	4	3	2	1
e. Get to the toilet on time?	5	4	3	2	1
f. Control his/her bladder (not have an accident)?	5	4	3	2	1
g. Control his/her bowels (not have an accident)?	5	4	3	2	1
h. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)?	5	4	3	2	1
i. Go shopping?	5	4	3	2	1
j. Do heavy household chores (e.g. vacuum, laundry or yard work)?	5	4	3	2	1

The following questions are about his/her ability to be mobile, at home and in the community.

<b>6. In the past 2 weeks, how difficult was it for him/her to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Somewh at difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
a. Stay sitting without losing his/her balance?	5	4	3	2	1
b. Stay standing without losing his/her balance?	5	4	3	2	1
c. Walk without losing his/her balance?	5	4	3	2	1
d. Move from a bed to a chair?	5	4	3	2	1
e. Walk one block?	5	4	3	2	1
f. Walk fast?	5	4	3	2	1
g. Climb one flight of stairs?	5	4	3	2	1
h. Climb several flights of stairs?	5	4	3	2	1
i. Get in and out of a car?	5	4	3	2	1

The following questions are about his/her ability to use the hand that was MOST AFFECTED by the stroke.

<b>7. In the past 2 weeks, how difficult was it for him/her to use your hand that was most affected by his/her stroke to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Somewh at difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
a. Carry heavy objects (e.g. bag of groceries)?	5	4	3	2	1
b. Turn a doorknob?	5	4	3	2	1
c. Open a can or jar?	5	4	3	2	1
d. Tie a shoe lace?	5	4	3	2	1
e. Pick up a dime?	5	4	3	2	1

The following questions are about how stroke has affected \_\_\_\_\_(name) ability to participate in the activities that she/he would usually do, things that are meaningful to him/her and help him/her to find purpose in life.

<b>8. During the past 4 weeks, how much of the time have he/she been limited in...</b>	<b>None of the time</b>	<b>A little of the time</b>	<b>Some of the time</b>	<b>Most of the time</b>	<b>All of the time</b>
a. His/her work (paid, voluntary or other)	5	4	3	2	1
b. His/her social activities?	5	4	3	2	1
c. Quiet recreation (crafts, reading)?	5	4	3	2	1
d. Active recreation (sports, outings, travel)?	5	4	3	2	1
e. His/her role as a family member and/or friend?	5	4	3	2	1
f. His/her participation in spiritual or religious activities?	5	4	3	2	1
g. His/her ability to control your life as you wishes?	5	4	3	2	1
h. His/her ability to help others?	5	4	3	2	1

**9. Stroke Recovery**

**On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much do you feel \_\_\_\_\_ (name) has recovered from stroke?**

\_\_\_\_\_ 100 Full Recovery

—

\_\_\_\_\_ 90

—

\_\_\_\_\_ 80

—

\_\_\_\_\_ 70

—

\_\_\_\_\_ 60

—

\_\_\_\_\_ 50

—

\_\_\_\_\_ 40

—

\_\_\_\_\_ 30

—

\_\_\_\_\_ 20

—

\_\_\_\_\_ 10

\_\_\_\_\_ 0 No Recovery

## Appendix E: Clinical Assessment Tools

### E1: BARTHEL INDEX

Choose the scoring point for the statement that most closely corresponds to the patient's current level of ability for each of the following items

Item	Unable to perform task	Substantial help required	Moderate help provided	Minimal help required	Fully independent
Personal hygiene	0	1	3	4	5
Bathing self	0	1	3	4	5
Feeding	0	2	5	8	10
Toilet use	0	2	5	8	10
Stair climbing	0	2	5	8	10
Dressing	0	2	5	8	10
Bowel control	0	2	5	8	10
Bladder control	0	2	5	8	10
Ambulation	0	3	8	12	15
or Wheelchair*	0	1	3	4	5
Chair/Bed transfer	0	3	8	12	15

### E2: MODIFIED RANKIN SCALE

Functional independence/Disability with regards to ability to carry out activities	Grade
a. No symptoms at all	0
b. No significant disability: despite symptoms, able to carry out all usual duties and activities	1
c. Slight disability: unable to perform all previous activities but able to look after own affairs without assistance	2
d. Moderate disability: requiring some help but able to walk without assistance	3
e. Moderately severe disability: unable to walk without assistance and unable to attend to own bodily needs without assistance	4
f. Severe disability: bedridden, incontinent and requiring constant nursing care and attention	5
g. Death*	6

### E3: BECK DEPRESSION INVENTORY

Item	Score	Response
1. Sadness		
	0	I do not feel sad.
	1	I feel sad
	2	I am sad all the time and I can't snap out of it.
2. Pessimism	3	I am so sad and unhappy that I can't stand it.
	0	I am not particularly discouraged about the future.
	1	I feel discouraged about the future.
3. Past Failure	2	I feel I have nothing to look forward to.
	3	I feel the future is hopeless and that things cannot improve.
	0	I do not feel like a failure.
4. Loss of pleasure	1	I feel I have failed more than the average person.
	2	As I look back on my life, all I can see is a lot of failures.
	3	I feel I am a complete failure as a person.
5. Guilty feelings	0	I get as much satisfaction out of things as I used to.
	1	I don't enjoy things the way I used to.
	2	I don't get real satisfaction out of anything anymore.
	3	I am dissatisfied or bored with everything
6. Punishment 7. feelings		
	0	I don't feel particularly guilty
	1	I feel guilty a good part of the time.
	2	I feel quite guilty most of the time.
8. Self-dislike	3	I feel guilty all of the time.
	0	I don't feel I am being punished.
	1	I feel I may be punished.
9. Self-critical ness	2	I expect to be punished.
	3	I feel I am being punished.
	0	I don't feel disappointed in myself.
10. Suicidal thoughts	1	I am disappointed in myself.
	2	I am disgusted with myself.
	3	I hate myself.
11. Crying	0	I don't feel I am any worse than anybody else.
	1	I am critical of myself for my weaknesses or mistakes.
	2	I blame myself all the time for my faults.
	3	I blame myself for everything bad that happens.
12. Agitation		
	0	I don't have any thoughts of killing myself.
	1	I have thoughts of killing myself, but I would not carry them out.
	2	I would like to kill myself.
13. Irritability	3	I would kill myself if I had the chance.
	0	I don't cry any more than usual.
	1	I cry more now than I used to.
14. Anhedonia	2	I cry all the time now.
	3	I used to be able to cry, but now I can't cry even though I want to.
	0	I am no more irritated by things than I ever was.
15. Anhedonia	1	I am slightly more irritated now than usual.
	2	I am quite annoyed or irritated a good deal of the time.

	3	I feel irritated all the time.
13. Loss of interest		
	0	I have not lost interest in other people.
	1	I am less interested in other people than I used to be.
	2	I have lost most of my interest in other people.
	3	I have lost all of my interest in other people.
14. Indecisiveness		
	0	I make decisions about as well as I ever could.
	1	I put off making decisions more than I used to.
	2	I have greater difficulty in making decisions more than I used to.
	3	I can't make decisions at all anymore.
15. Worthlessness		
	0	I don't feel that I look any worse than I used to.
	1	I am worried that I am looking old or unattractive.
	2	I feel there are permanent changes in my appearance that make me look unattractive
	3	I believe that I look ugly.
16. Loss of energy		
	0	I can work about as well as before.
	1	It takes an extra effort to get started at doing something.
	2	I have to push myself very hard to do anything.
	3	I can't do any work at all.
17. Changes in sleep pattern		
	0	I can sleep as well as usual.
	1	I don't sleep as well as I used to.
	2	I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
	3	I wake up several hours earlier than I used to and cannot get back to sleep.
18. Irritability		
	0	I don't get more tired than usual.
	1	I get tired more easily than I used to.
	2	I get tired from doing almost anything.
	3	I am too tired to do anything.
19. Changes in appetite		
	0	My appetite is no worse than usual.
	1	My appetite is not as good as it used to be.
	2	My appetite is much worse now.
	3	I have no appetite at all anymore.
20. Concentration difficulty		
	0	I haven't lost much weight, if any, lately.
	1	I have lost more than five pounds.
	2	I have lost more than ten pounds.
	3	I have lost more than fifteen pounds.
21. Tiredness or fatigue		
	0	I am no more worried about my health than usual.
	1	I am worried about physical problems like aches, pains, upset stomach, or constipation.
	2	I am very worried about physical problems and it's hard to think of much else.
	3	I am so worried about my physical problems that I cannot think of anything else.
22. Loss of interest in sex		
	0	I have not noticed any recent change in my interest in sex.
	1	Less I am interested in sex than I used to be.
	2	I have almost no interest in sex.
	3	I have lost interest in sex completely.
Total out of 63		



## Appendix F: Interview guide

### **F1: Demographic and Health profile data**

Name.....

Age.....

Sex.....

Stroke laterality.....

Date of stroke.....

Date of interview.....

### **F2: Interview Guide**

#### **Interview Guide with probes to used for in-depth interview with stroke survivors**

I would like to ask you some questions about yourself. Can you tell me about how has this stroke affected your quality of life?

1. How are you limited in your day-to-day activities and this affect your quality of life?

(Probes: Your ability to sit, stand and walk from one place to another? Activities such as dressing yourself and taking bath? Do household chores? Go shopping and carry things?)

2. How are you limited in your intellectual or cognitive pursuits (e.g. residual memory problems) and how this affects your quality of life?

(Probes: Remember things that people just told you? Solve everyday problems? Remember to do things (e.g. keep scheduled appointments or take medication)? What about perceived change in body image?)

3. How are you limited in your social and recreational activities and how this affects your quality of life?

(Probes: Understand what was being said to you in a conversation? Has your role as a family member and/or friend being affected? Your ability to control your life as you wishes e.g. participating in all ceremonies invited? What kind of social activities and recreation you find relevant? What kind of social and instrumental support do you consider? What about issues related to stigma? What about relationship with husband/wife, does this disease affect that?)

4. How are you limited financially and how this affects your quality of life?

(Probes: Financial hardship either related to income or cost of care and hospital treatment charges? What about personal loss of income or that of a supportive family member?)

5. How are limited in your religious activities and how this affects your quality of life?

(Probes: Your participation in spiritual or religious activities? What about your ability to help others? Praying alone and in congregation? How do physical restrictions and limitations affecting religious activities? What about spiritual and religious resources if applicable?)

6. How are you limited in your career and vocational pursuits and how this affects your quality of life?

(Probes: Your work (paid, voluntary or other)? What about your occupation or source of livelihood? How the feeling of dependency and or loss of job do affected your quality of life? What about the issues of return to work and vocational/job flexibility?)

7. What are the other issues that limit you and how do they that affect your quality of life?

## Appendix G: Hausa version of SIS 3.0 (Patient version)

### SIKELIN AWON TASIRIN BUGUN JINI NAU'I NA 3

Manufar wadannan jerin tambayoyi ita ce domin tantance tasirin bugun jini ga lafiya da rayuwarka. Muna son mu san **YADDA KA KE GANIN** wannan matsala ta yi tasiri a rayuwarka.

Zamu yi maka tambayoyi a kan tawayar da wannan matsala ta haifar maka da kuma yadda ta shafi yadda kake tafiyar da rayuwarka. Daga karshe zamu so mu ji wane irin sauki ka ke jin ka samu daga wannan cuta.

Wadannan tambayoyi sun danganci matsalolin da ake iya gani wadanda an same su ne sakamakon larurar bugun jini

1.A 'yan kwanankin nan yaya ake jin karfin.....	Karfi sosai	Akwai karfi	Akwai dan karfi	Akwai karfi kadan	Babu karfi ko kadan
a. Kafadar da lalurar <u>tafi shafa</u>	5	4	3	2	1
b. Hannun da lalurara <u>tafi shafa</u>	5	4	3	2	1
c. Kafar da lalurara <u>tafi shafa</u>	5	4	3	2	1
d. Tafin kafa da agara da lalurar <u>tafi shafa</u>	5	4	3	2	1

Wadannan tambayoyi sun shafi tunani da kwakwalwa

2. A yan makwannin nan ya kake jin wahala wajen yin.....	Babu wahala	Akwai dan wahala	Da dama	Akwai wahala	Akwai wahala sosai
a. Tuna abin da mutane suka fada bad a jimawa ba?	5	4	3	2	1
b. Tuna abin daya faru a jiya?	5	4	3	2	1
c. Tuna yin abubuwa (kamar ganawa da wani ko lokutan shan magani)?	5	4	3	2	1
d. Tuna ranakun mako?	5	4	3	2	1
e. mayar da hankali kann abubuwa?	5	4	3	2	1
f. saurin tuna abu?	5	4	3	2	1
g. warware matsaloli na yau da kullum?	5	4	3	2	1

Wadannan tambayoyi sun shafi yadda kake/kike ji dangane da sauyin da ka/ki ka samu na yanayin walwala da kuma yadda kake/kike iya shawo kan damuwarka/ki bayan samun mutuwar barin jiki

<b>3. A 'yan kwanakin nan sau nawa kake jin.....</b>	<b>Babu</b>	<b>A lokuta kadan</b>	<b>A wasu lokutan</b>	<b>A yawancin lokuta</b>	<b>Ko da yaushe</b>
a. Jin bacin rai?	5	4	3	2	1
b. Jin babu wani da kake da kusanci da shi?	5	4	3	2	1
c. Jin ka zama wani babban nauyi a kann mutane?	5	4	3	2	1
d. Jin babu wani abu a rayuwa da ka sanya gaba?	5	4	3	2	1
e. Dorawa kai laifi a kann kurakuran da ka aikata?	5	4	3	2	1
f. Jin dadin abubuwa kamar da?	5	4	3	2	1
g. Jin tsoro?	5	4	3	2	1
h. Jin in dai da rai akwai rabon za a iya samun lafiya?	5	4	3	2	1
i. Murmushi da dariya ko da sau daya a rana?	5	4	3	2	1

Wadannan tambayoyi sun shafi yadda kake/kike iya magana da mutane da kuma yadda kake/kike iya fahimtar abin da ka/ki ka karanta da kuma abin da ka/ki ji daga hirar da akeyi

<b>4. A ,yan makwannin nan ya kake shan wahala wajen.....</b>	<b>Babu wahala ko kadan</b>	<b>Da dan wahala kadan</b>	<b>Yakan zamo da wahala</b>	<b>Da wahala</b>	<b>Da wahala sosai</b>
a. Fadin sunan mutumin da ka gani a gabanka?	5	4	3	2	1
b. Fahimtara abin da aka fada maka a cikin hira?	5	4	3	2	1
c. Amsa tambaya?	5	4	3	2	1
d. fadin sunayen abubuwa dai dai?	5	4	3	2	1
e. Shiga cikin hira da sauran jama'a?	5	4	3	2	1
f. Iya hira a wayar Tarho?	5	4	3	2	1
g. Kiran wani a waya da kuma iya zaben lambar waya da kiranta?	5	4	3	2	1

Tambayoyi na gaba sun shafi ayyukan da ake yi a kowace rana

<b>5. A makwanni biyu da suka wuce ya kake shan wahala wajen.....</b>	<b>Babu wahala ko kadan</b>	<b>Da dan wahala kadan</b>	<b>Yakan zamo da wahala</b>	<b>Da wahala</b>	<b>Da wahala sosai</b>
a. Yanka abinci da wuka da cokali mai yatsu?	5	4	3	2	1
b. Sanya sutura a saman jiki?	5	4	3	2	1
c. Yin waka da kan ka?	5	4	3	2	1
d. Yanke farcen kafa?	5	4	3	2	1
e. zuwa bandaki a kan lokaci?	5	4	3	2	1
f. Iya rike fitsari ba tare d kuskure ba?	5	4	3	2	1
g. Iya rike bayan gida ba tare da kuskure ba?	5	4	3	2	1
h. Yin ayyukan gida marasa wahala kamar shara, gyaran gado, zubar da shara da wanke- wanke?	5	4	3	2	1
i. Zuwa cefane?	5	4	3	2	1
j. Yin manyan ayyukan gida kamar wanki ko sharar filin gida?	5	4	3	2	1

Wadannan tambayoyi na gaba sun shafi yadda kake/kike iya yin zirga-zirga a cikin gida ko a cikin gari

<b>6. A makwanni biyu da suka wuce ya kake wahala wajen...</b>	<b>Babu wahala ko kadan</b>	<b>Da dan wahala kadan</b>	<b>Yakan zamo da wahala</b>	<b>Da wahala</b>	<b>Da wahala sosai</b>
a. Iya zama daram ba tare da jirkicewa ba?	5	4	3	2	1
39. Iya tsayuwa kyam, ba tare da karkacewa ba?	5	4	3	2	1
b. Tafiya ba tare da faduwa ba?	5	4	3	2	1
c. Tashi daga gado zuwa kujera?	5	4	3	2	1
d. Tattaki?	5	4	3	2	1
e. Tafiya da sauri?	5	4	3	2	1
f. Hawa matakalal bene daya?	5	4	3	2	1
g. Hawa matakalalbene da dama?	5	4	3	2	1
h. Shiga mota da fita?	5	4	3	2	1

Wadannan tambayoyi sun shafi yadda kake/kike iya sarrafa hannun da larurar tafi shafa

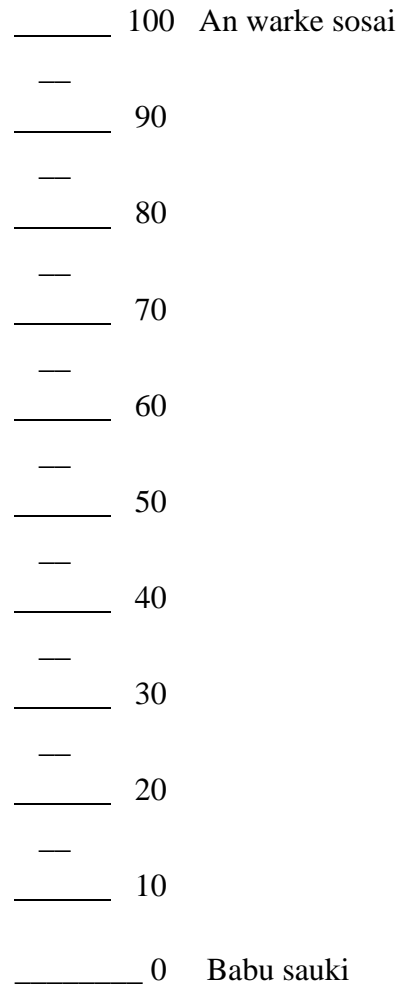
<b>7. A makwanni biyu da suka wuce ya kake wahala wajen amfani da hannun da mutuwar barin jikin ta fi shafa.....</b>	<b>Babu wahala ko kadan</b>	<b>Da dan wahala kadan</b>	<b>Ya kan zamo da wahala</b>	<b>Da wahala</b>	<b>Da wahala sosai</b>
a. Daukar kaya masu nauyi kamar jaka ko cefane?	5	4	3	2	1
b. Murda marikin kofa?	5	4	3	2	1
c. Bude gwangwani?	5	4	3	2	1
d. Daura madaurin takalmi?	5	4	3	2	1
e. Daukar kudi?	5	4	3	2	1

Wadannan tambayoyi sun danganci yadda larurar ta shafi yadda kake/kike tafiyar da ayyukan da ka/ki ka saba yi a da, ma'ana abubuwa masu mahimmanci a rayuwarka

<b>8. A makwanni hudu da suka wuce lokacinka nawa ne ya ragu na...</b>	<b>Babu wahala ko kadan</b>	<b>Da dan wahala kadan</b>	<b>Ya kan zamo da wahala</b>	<b>Da wahala</b>	<b>Da wahala sosai</b>
a. Aiki wanda ake biyanka da na sa kai?	5	4	3	2	1
b. Ayyukan yau da kullum?	5	4	3	2	1
c. Ayyukan nishadantarwa masu sauki, (kamar karatu da yar karamar sana'ar hannu)?	5	4	3	2	1
d. Ayyuka Nishadantarwa masu bukatar kuzari (kamar wasannin motsa jiki da tafiya mai nisa)?	5	4	3	2	1
e. Rawar da kake takawa a matsayinka na wani aIyali ko kuma a cikin abokai?	5	4	3	2	1
f. Yadda kake tafiyar da Ibadarka?	5	4	3	2	1
g. Yaddakake iya tafiyar da rayukar bisa son ranka?	5	4	3	2	1
h. Yadda kake iya taimakon sauran jama'a?	5	4	3	2	1

9.YADDA AKE SAMUN SAUKI DAGA MATSALAR TA MUTUWAR BARIN JIKI

A Wannan jadawali daya fara daga 0 zuwa 100, na a matsayin an samu sauki sosai, sai kuma 0 dake a matsayin babu sauki, sannan kuma wane irin sauki ake samu daga larurar?



## Appendix H: Hausa version of SIS 3.0 (Proxy version)

### SIKELIN AWON TASIRIN BUGUN JINI NAU'I NA 3

Manufar wadannan jerin tambayoyi ita ce domin tantance tasirin bugun jini ga lafiya da rayuwar marar lafiya. Muna son mu san **YADDA YAKE/TAKE GANIN** wannan matsala ta yi tasiri a rayuwar sa/ta.

Zamu yi maka/miki tambayoyi a kan tawayar da wannan matsala ta haifar maka da kuma yadda ta shafi yadda yake/take tafiyar da rayuwar sa/ta. Daga karshe zamu so mu ji wane irin sauki kake/kike jin ya/ta samu daga wannan cuta.

**Wadannan tambayoyi an yi sune kan wasu matsaloli da suka shafi sassan jiki wadanda ka iya faruwa sakamakon cutar mutuwar barin jiki**

1.A makon day gabata yaya zaka/ki iya kwatanta karfin motsa.....	Akwai Karfi sosai	Akwai karfi	Akwai dan karfi	Akwai karfi kadan	Babu karfi ko kadan
a. Hannun shi/ta da lalurar tafi shafa	5	4	3	2	1
b. Rike abu da hannun sa/ta da lalurarar tafi shafa	5	4	3	2	1
c. Kafar sa/ta da lalurara tafi shafa	5	4	3	2	1
d. Tafin kafar sa/ta da अगर sa/ta da lalurar tafi shafa	5	4	3	2	1

**Wadannan tambayoyi sun shafi tunaninta/sa**

2. A yan makwannin da suka wuce yaya take/yake shan wahala wajen yin .....	Babu wahala	Akwai dan wahala	Da dama dama	Akwai wahala	Akwai wahala sosai
a. Tuna abin da mutane suka fada masa/mata bada jimawa ba?	5	4	3	2	1
b Tuna abin daya faru a jiya?	5	4	3	2	1
c. Tuna yin abubuwa (kamar ganawa da wani ko lokutan shan magani)?	5	4	3	2	1
d. Tuna ranakun mako?	5	4	3	2	1
e. mayar da hankali kann abubuwa?	5	4	3	2	1
f. saurin tuna abu?	5	4	3	2	1
g. warware matsaloli na yau da kullum?	5	4	3	2	1



**Wadannan tambayoyi sun shafi yadda mai larurar ke ji dangane da sauyin da ta/ya samu a yanayin walwalar ta/sa da kuma yadda yake/take iya shawo kan damuwarsa/ta tun bayan samun mutuwar barin jiki**

<b>3.A 'yan makwannin da suka wuce sau nawa yake/take .....</b>	<b>Babu</b>	<b>A lokuta kadan</b>	<b>A wasu lokutan</b>	<b>A yawancin lokuta</b>	<b>Ko da yausha</b>
a. Jin bacin rai?	5	4	3	2	1
b. Jin babu wani mutum da yake da kake da ita/shi?	5	4	3	2	1
c. Jin ta/ya zama wani babban nauyi a kann mutane?	5	4	3	2	1
d. Jin bata/shi da wani buri a rayuwa?	5	4	3	2	1
e. Dorawa kansa/kanta laifi a kann kurakuran da ta/ya aikata?	5	4	3	2	1
f. Jin dadin abubuwa kamar da?	5	4	3	2	1
g. Jin tsoro?	5	4	3	2	1
h. Jin in dai da rai akwai rabon za a iya samun lafiya?	5	4	3	2	1
i. Murmushi da dariya ko da sau daya a rana?	5	4	3	2	1

**Wadannan tambayoyi sun shafi yadda take/yake magana da jama'a da yadda yake/take iya fahimtar abin da ta/ya karanta ko ta/ya ji a cikin hira**

<b>4. A ,yan makwannin nan ya yake/take shan wahala wajen.....</b>	<b>Babu wahala ko kadan</b>	<b>Da dan wahala kadan</b>	<b>Yakan zamo da wahala</b>	<b>Da wahala</b>	<b>Da wahala sosai</b>
a. Fadin sunan mutumin da ya/ta gani a gabansa/ta?	5	4	3	2	1
b. Fahimtara abin da aka fada maka a cikin hira?	5	4	3	2	1
c. Amsa tambaya?	5	4	3	2	1
d. fadin sunayen abubuwa dai dai?	5	4	3	2	1
e. Shiga cikin hira da sauran jama'a?	5	4	3	2	1
f. Iya hira a wayar Tarho?	5	4	3	2	1
g. Kiran wani a waya da kuma iya zaben lambar waya da kiranta?	5	4	3	2	1

**Wadannan tambayoyi sun shafi yadda yake/take tafiyar da ayyukansa/ta na kowace rana**

<b>5. A makwanni biyu da suka wuce ya yake/take shan wahala wajen.....</b>	<b>Babu wahala ko kadan</b>	<b>Da dan wahala kadan</b>	<b>Yakan zamo da wahala</b>	<b>Da wahala</b>	<b>Da wahala sosai</b>
a. Yanka abinci da wuka da cokali mai yatsu?	5	4	3	2	1
b. Sanya sutura a saman jiki?	5	4	3	2	1
c. Yin wanka da kansa/ta?	5	4	3	2	1
d. Yanke farcen kafa?	5	4	3	2	1
e. zuwa bandaki a kan lokaci?	5	4	3	2	1
f. Iya riƙe fitsari ba tare da kuskure ba?	5	4	3	2	1
g. Iya riƙe bayan gida ba tare da kuskure ba?	5	4	3	2	1
h. Yin ayyukan gida marasa wahala kamar shara, gyaran gado, zubar da shara da wanke- wanke?	5	4	3	2	1
i. Zuwa cefane?	5	4	3	2	1
j. Yin manyan ayyukan gida kamar wanki ko sharar filin gida?	5	4	3	2	1

**Wadannan tambayoyi sun shafi yadda yake/take iya tafiya a gida ko a cikin jama'a**

<b>6. A makwanni biyu da suka wuce ya yake/take shan wahala wajen...</b>	<b>Babu wahala ko kadan</b>	<b>Da dan wahala kadan</b>	<b>Yakan zamo da wahala</b>	<b>Da wahala</b>	<b>Da wahala sosai</b>
a. Iya zama daram ba tare da jirkicewa ba?	5	4	3	2	1
b. Iya tsayuwa kyam, ba tare da karkacewa ba?	5	4	3	2	1
c. Tafiya ba tare da faduwa ba?	5	4	3	2	1
d. Tashi daga gado zuwa kujera?	5	4	3	2	1
e. Tattaki?	5	4	3	2	1
f. Tafiya da sauri?	5	4	3	2	1
g. Hawa matakalal bene daya?	5	4	3	2	1
h. Hawa matakalal bene da dama?	5	4	3	2	1
i. Shiga mota da fita?	5	4	3	2	1

**Wadannan tambayoyi sun shafi yadda yake/take iya amfani da hannun da tafi shafa**

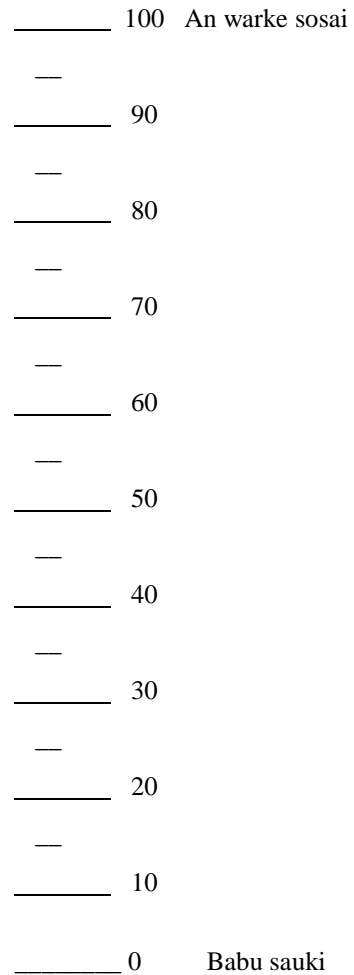
<b>7. A makwanni biyu da suka wuce ya yake/take wahala wajen amfani da hannun da mutuwar barin jikin ta fi shafa.....</b>	<b>Babu wahala ko kadan</b>	<b>Da dan wahala kadan</b>	<b>Ya kan zamo da wahala</b>	<b>Da wahala</b>	<b>Da wahala sosai</b>
a. Daukar kaya masu nauyi kamar jaka ko cefane?	5	4	3	2	1
b. Murda marikin kofa?	5	4	3	2	1
c. Bude gwangwani?	5	4	3	2	1
d. Daura madaurin takalmi?	5	4	3	2	1
e. Daukar kudi?	5	4	3	2	1

**Wadannan tambayoyi sun danganci yadda larurar da..... (SUNA) ya/ta samu ya shafi yadda yake/take tafiyar da ayyukan da ya/ta saba yi, ma'ana ayyuka masu mahimmanci a rayuwarsa/ta**

<b>8. A makwanni hudu da suka wuce lokacinka nawa ne ya ragu na...</b>	<b>Babu wahala ko kadan</b>	<b>Da dan wahala kadan</b>	<b>Ya kan zamo da wahala</b>	<b>Da wahala</b>	<b>Da wahala sosai</b>
a. Aiki wanda ake biyansa/ta da na sa kai?	5	4	3	2	1
b. Ayyukan yau da kullum?	5	4	3	2	1
c. Ayyukan nishadantarwa masu sauki, (kamar karatu da yar karamar sana'ar hannu)?	5	4	3	2	1
d. Ayyuka Nishadantarwa masu bukatar kuzari (kamar wasannin motsa jiki da tafiya mai nisa)?	5	4	3	2	1
e. Rawar da yake/take takawa a matsayinsa/ta na wani a cikin Iyali ko kuma a cikin abokai?	5	4	3	2	1
f. Yadda yake/take tafiyar da Ibadarsa/ta?	5	4	3	2	1
g. Yadda yake/take iya tafiyar da rayukarsa/ta bisa son ransa/ta?	5	4	3	2	1
h. Yadda yake/take iya taimakon sauran jama'a?	5	4	3	2	1

**9. YADDA AKE SAMUN SAUKI DAGA MATSALAR TA MUTUWAR BARIN JIKI**

A wannan jadawali daya fara daga 0 zuwa 100, na a matsayin an samu sauki sosai, sai kuma 0 dake a matsayin babu sauki, sannan kuma yaya kake/kike jin..... (SUNA) yake/take samun sauki daga larurar?



## Appendix I: Hausa version of the MSPSS

### HANYOYI DABAN DABAN NA GWAJIN GANO TALLAFIN DA AKE JIN A NA SAMU

Umarni: Muna so ne mu san yadda ka/ki ka amince dangane da wadannan bayanai. Karanta kowane bayani sannan ka/ki nuna yadda ka/kika amince dangane da kowane bayanin.

Kewaye “1” idan **Sam baka amince ba**

Kewaye “2” idan **Baka/ki amince ba**

Kewaye “3” idan **Da Dama dama**

Kewaye “4” idan **Tsaka tsaki**

Kewaye “5” idan **Ba laifi**

Kewaye “6” idan **Ka amince**

Kewaye “7” idan **Ka amince sosai**

<b>Irin tallafin da ake samu daga ‘yan uwa ko abokai ko sauran jama’a</b>	<b>Na amince sosai</b>	<b>Na amince</b>	<b>Ba laifi</b>	<b>Tsaka tsaki</b>	<b>Da Dama dama</b>	<b>Ban amince ba</b>	<b>Sam ban amince ba</b>
1. Akwai mutum na musamman dake kula da bukату na	7	6	5	4	3	2	1
2. Akwai mutumin da ya nake iya fadawa damuwata da farin ciki na	7	6	5	4	3	2	1
3. Iyali na na kokari matuka a wajen taimakamin	7	6	5	4	3	2	1
4. Iyali na nuna tausayawarsu a gare ni tare da bani duk wani tallafi da nake bukata	7	6	5	4	3	2	1
5. Ina da mutum na musamman wanda ya kasance yana farantami sosai	7	6	5	4	3	2	1
6. Abokaina na kokari sosai wajen taimakamin	7	6	5	4	3	2	1
7. Na amince abokai na zasu tsaya min a duk lokacin da wata matsala ta taso	7	6	5	4	3	2	1
8. Ina iya tattauna matsalata da iyalaina	7	6	5	4	3	2	1
9. Ina da abokai da nake fadawa damuwata da farin ciki na	7	6	5	4	3	2	1
10. Akwai mutum na musamnan a rayuwata da ya damu da bukatuna	7	6	5	4	3	2	1
11. Iyali na a shirye suke su taimaka min a kann duk wata shawara da nake son yankewa	7	6	5	4	3	2	1
12. zan iya tattauna matsalolina da abokaina	7	6	5	4	3	2	1

## Appendix J: 16 item Hausa-Short version of the SIS 3.0

### SIKELIN AWON TASIRIN BUGUN JINI NAU'I NA 3

Manufar wadannan jerin tambayoyi ita ce domin tantance tasirin bugun jini ga lafiya da rayuwarka. Muna son mu san **YADDA KA KE GANIN** wannan matsala ta yi tasiri a rayuwarka.

Zamu yi maka tambayoyi a kan tawayar da wannan matsala ta haifar maka da kuma yadda ta shafi yadda kake tafiyar da rayuwarka. Daga karshe zamu so mu ji wane irin sauki ka ke jin ka samu daga wannan cuta.

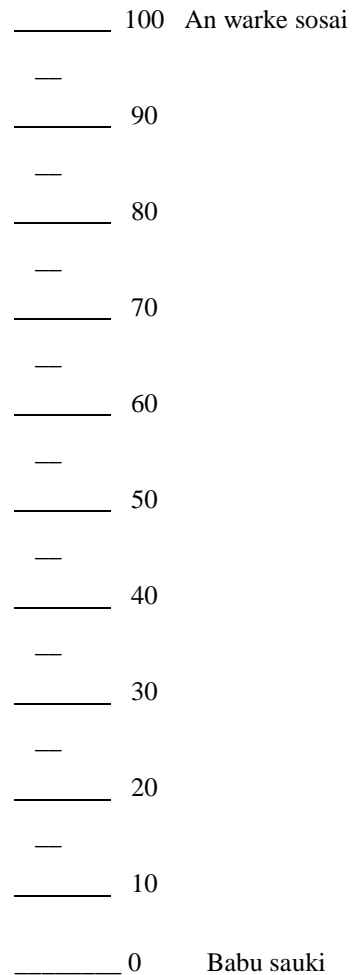
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Wadannan tambayoyi sun danganci matsalolin da ake iya gani wadanda an same su ne sakamakon larurar bugun jini

1.A 'yan kwanankin nan yaya kake/kike shan wahala wajen....	Karfi sosai	Akwai karfi	Akwai dan karfi	Akwai karfi kadan	Babu karfi ko kadan
1. Kafadar da lalurar <u>tafi shafa</u>	5	4	3	2	1
2. Hannun da lalurara <u>tafi shafa</u>	5	4	3	2	1
3. Tuna yin abubuwa (kamar ganawa da wani ko lokutan shan magani)?	5	4	3	2	1
4. Tuna ranakun mako?	5	4	3	2	1
5. Jin bacin rai?	5	4	3	2	1
6. Jin babu wani da kake da kusanci da shi?	5	4	3	2	1
7. fadin sunayen abubuwa dai dai?	5	4	3	2	1
8. Shiga cikin hira da sauran jama'a?	5	4	3	2	1
9. Sanya sutura a saman jiki?	5	4	3	2	1
10. Yin waka da kan ka?	5	4	3	2	1
11. Tashi daga gado zuwa kujera?	5	4	3	2	1
12. Tattaki?	5	4	3	2	1
13. Daura madaurin takalmi?	5	4	3	2	1
14. Daukar kudi?	5	4	3	2	1
15 Aiki wanda ake biyanka da na sa kai?	5	4	3	2	1
16 Ayyukan nishadantarwa masu sauki, (kamar karatu da yar karamar sana'ar hannu)?	5	4	3	2	1

**YADDA AKE SAMUN SAUKI DAGA MATSALAR TA MUTUWAR BARIN JIKI**

A Wannan jadawali daya fara daga 0 zuwa 100, na a matsayin an samu sauki sosai, sai kuma 0 dake a matsayin babu sauki, sannan kuma wane irin sauki ake samu daga larurar?



## Appendix K: 11 item Hausa-Short version of the MSPSS

Hanyoyi Daban-Daban na Gwajin Gano Tallafin da a ke jin a na samu

**Umarni:** Muna so ne mu san yadda ka/ki ka amince dangane da wadannan bayanai.

Karanta kowane bayani sannan ka/ki nuna yadda ka/kika amince dangane da kowane bayanin.

Kewaye “1” idan **Sam baka amince ba**  
 Kewaye “2” idan **Baka/ki amince ba**  
 Kewaye “3” idan **Da Dama dama**  
 Kewaye “4” idan **Tsaka tsaki**  
 Kewaye “5” idan **Ba laifi**  
 Kewaye “6” idan **Ka amince**  
 Kewaye “7” idan **Ka amince sosai**

**Irin Tallafin da a ke ji ana samu daga iyali, abokai da kuma sauran jama’a**

1. Akwai mutum na musamman dake kula da bukatu na	7	6	5	4	3	2	1
2. Akwai mutumin da ya nake iya fadawa damuwata da farin ciki na	7	6	5	4	3	2	1
3. Iyali na na kokari matuka a wajen taimakamin	7	6	5	4	3	2	1
4. Ina da mutum na musamman wanda ya kasance yana farantami sosai	7	6	5	4	3	2	1
5. Abokaina na kokari sosai wajen taimakamin	7	6	5	4	3	2	1
6. Na amince abokai na zasu tsaya min a duk lokacin da wata matsala ta taso	7	6	5	4	3	2	1
7. Ina iya tattauna matsalata da iyalaina	7	6	5	4	3	2	1
8. Ina da abokai da nake fadawa damuwata da farin ciki na	7	6	5	4	3	2	1
9. Akwai mutum na musamnan a rayuwata da ya damu da bukatuna	7	6	5	4	3	2	1
10. Iyali na a shirye suke su taimaka min a kann duk wata shawara da nake son yankewa	7	6	5	4	3	2	1
11. zan iya tattauna matsalolona da abokaina	7	6	5	4	3	2	1



## **Appendix L: Curriculum Vitae**

Ashiru Hamza Mohammad was born on January 10<sup>th</sup>, 1982 in Kano, Nigeria. He is from Turabu village, Kirikasama local government, Jigawa State, Nigeria. He obtained his Bachelor of Science degree in Physiotherapy from Bayero University Kano, Nigeria in 2006. He did his 1 year mandatory Internship training at Jos University Teaching Hospital (JUTH), Plateau State. Once he completed his internship, he proceeded to Cross River State again for his 1 year mandatory National Youth Service (NYSC). He started serving with the Nigerian Navy Hospital, Calabar and completed it at Federal Medical Centre Birnin Kudu, Jigawa State. After the completion of his national youth service in March 2009, he was posted to Gunduma Health System Board to work with the Jigawa State Tuberculosis and Leprosy Control Programme as a state Physiotherapist/Rehabilitation officer. He obtained his Master of Medical Science degree in Public Health from University of Malaya, Kuala Lumpur in June 2010. From July 2010 till April 2014, he worked for his PhD thesis with supervision from Assoc. Prof. Nabilla Al-Sadat of the Centre for Population Health (CePH) and Dr Loh Siew Yim of the Department of Rehabilitation Medicine. Since 2010, he has been working with the Jigawa State, Nigeria Tuberculosis and Leprosy Control Programme as monitoring and valuation officer, as TB/HIV focal person and community-based rehabilitation (CBR) coordinator. He is married to Ramla Ibrahim Karaye and is blessed with a daughter (Halima).