Contextual Model for In-patient Stroke Care and Rehabilitation in Malawi

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Abstract

Development of a Contextual Model for In-patient Stroke Care and Rehabilitation in Malawi

Background: Stroke is a known health challenge for the public as it is both incapacitating and fatal to many people world over. Malawi, one of the developing countries has stroke as the fourth leading cause of death, and is fast becoming even more significant due, primarily, to lifestyle changes and nature of healthcare practices. For these reasons, and particularly, the negative impact on quality of life, the management of people with stroke is a critical area of interest. While research activity throughout the world has advanced acute stroke-care interventions, patients in Low to Middle Income Countries (LMICs) benefit less from evidence-based stroke care practices due to less conventional applicability to the setting and continuing medical care and rehabilitation challenges. This doctoral project applied the results of a Diagnostic and Solution Phases to the development of a contextual model for in-patient stroke care and rehabilitation (MoC) in Malawi.

Methodology: The research described in this thesis detailed the processes involved in the ultimate development of the MoC. Based on the well-known Donabedian model as a conceptual framework, this involved detailed investigations into stroke care processes and their challenges in Malawi's four central hospitals across the four political regions (south, east, central and north). Focusing on five key areas, the investigations; 1) explored the process of care of patients with stroke; 2) determined the level of satisfaction with care and rehabilitation services by patients and guardians; 3) determined stroke outcomes at discharge; 4) understood the current evidence on stroke care and rehabilitation services in LMICs; and 5) developed a contextual model for in-patient stroke care and rehabilitation.

This research was conducted after the project initiation phase with ethical clearance from the University of the Western Cape (in South Africa) and the College of Medicine Research Council (COMREC) (in Malawi). The second phase of the project, the assessment phase, involved site visits to each setting to monitor data collection by the stationed research assistants for the descriptive cross-sectional studies and the execution of focus group discussions. Lastly, the design phase of the project was executed by multidisciplinary nominal group technique meetings held at the largest and representative of the four referral hospitals, Queen Elizabeth Central Hospital in the south of the country.

Results: The primary objectives of this research were investigated through series of five scientific papers that have respectively been presented as Chapters 3 to 7. *Paper 1 and Paper 2,* presented as Chapters 3 and 4 respectively, addressed Objective Number 1, which aimed to investigate and understand stroke care processes. *Paper 3,* presented as a subsection of Chapter 4, explored stroke care provision challenges at the largest referral hospital. It complimented Objective 1 by describing the downside of stroke care. *Paper 4,* presented as Chapter 5 addressed Objectives 2 and 3. It determined stroke outcomes and satisfaction among patients with stroke and their guardians. *Paper 5,* presented as Chapter 6, addressed Objective 4, a scoping review, documented evidence of stroke care and service delivery in LMICs, which informed the development of the MoC. Lastly, *Paper 6*, presented as Chapter 7 addressed Objective 5, the actual development of the contextual MoC.

Results by chapters:

1. Chapter 3 quantitatively addressed objective one, which was to investigate and understand stroke care processes among service providers in Malawi's referral hospital.

   Results showed that two thirds of staff who were interviewed (50/80; 62%) rated care they provided to patients as "good". However, nearly half (37; 46%) said no team meetings were routinely held, and there was no inter-professional collaborative work. Evidence of this observation was in the 71 (91%) responses indicating that service providers do not rely on other cadres to provide care. This was similar across the four hospitals, p=0.432. Referrals of patients with stroke to and from the central hospital was most likely done by medical doctors 57/108 (53%) and nurses (20; 19%). Physiotherapists made the third most referrals to the central hospital (18; 17%), but were second when it came to referring patients beyond the acute care setting (35; 29%) Medical doctors and physiotherapists were responsible for most of the neurological assessments (62/136; 46%; 47; 35%,); swallowing screening 44/101 (44%); 26 (26%) and DVT prevention/prophylaxis (46 (43%); 30 (28%). Physiotherapists and nurses were frequently mentioned as responsible for early patient mobilisation by 55/119 (46%) and 31(26%) of respondents respectively.

2. Chapter 4 subsection (a) addressed objective one, to determine and explore the process of care for patients with stroke in Malawi. The chapter aimed to, qualitatively, understand stroke processes of care at a central hospital

   Four key themes emerged with information about: 1) the acute stroke presentation and hospital emergency care, 2) acute stroke diagnosis and assessment services, 3) acute stroke care interventions and services, and 4) discharge planning and referral destinations. The patients presented to the hospital with a wide range of impairments and received emergency and ongoing care. The diagnosis of stroke was made through clinical and laboratory tests, and basic radiologic studies. Physicians, nurses and physiotherapists formed a triple pillar of stroke care; however, physiotherapists were loosely attached care-providers due to weak

multidisciplinary team practices. Of significant note was the glaring absence of care protocols at every level of stroke care management.

3. Chapter 4 subsection (b) highlighted stroke care challenges at the largest referral hospital.

Four key themes emerged: 1) Lack of effective implementation of stroke care approaches due to lack of recognition and priority in critical care medicine, limited interprofessional contacts, communication disarray among providers, and lack of follow-up after discharge, particularly from rehabilitation professionals; 2) Erratic and insufficient physiotherapy treatment due to limited referrals by physicians, limited visibility of physiotherapists in the hospital, and lack of proper service planning by physiotherapists; 3) Patient-mix challenges from intermingling patients with varying conditions, risking both physical harm and the development of nosocomial infections, and; 4) Resource limitations from inadequate qualified service providers, limited medical supplies, unreliable equipment, and lack of warm bedding for patients.

4. Chapter 5 addressed objectives 2 and 3, which were to determine patients with stroke and caregiver satisfaction with care and rehabilitation service delivery in Malawi's central hospitals and; to determine stroke patient outcomes at discharge. The chapter, therefore, aimed to determined stroke outcomes and satisfaction among patients with stroke and their guardians.

With 79% of the original study sample taking part, there was improvement in patients' functional status at discharge compared to on admission with notable improvement in self-care ($p<0.001$), sphincter control ($p<0.001$), locomotion ($p<0.001$), and social cognition ($p<0.001$), but no significant improvement in transfers ($p=1.000$), and communication ($p=0.865$). Satisfaction with care was high, with no significant differences between males and females ($p=0.415$), age in years ($p=0.397$), and distance to the clinic ($p=0.615$). Satisfaction ratings were also high from caregivers' responses and their scores were not associated with age ($p=0.663$) or distance to the hospital ($p=0.872$). Quality of life was poor, most patients were either unable or had severe limitation in functional dimensions of mobility (22(28%), self-care (19(25%) and performance of usual activities (25(33%). Every additional year in age was associated with an average of 0.36 decrease in quality of life score coefficient, -0.36 (95% CI: -0.63; -0.10); $p=0.008$.

5. Chapter 6 addressed objective number 4, which was to determine the current evidence of stroke care and rehabilitation service provision by conducting a scoping review.

Of the 177 references identified, twenty articles, published between 2010 and 2017, were included in the review. Applying the Donebedian Model of quality of care, seven dimensions of stroke-care structure, six dimensions of stroke care processes, and six dimensions of stroke care outcomes were identified. Structure of stroke care (SS) included availability of a stroke unit (SU), an accident and emergency department, a multidisciplinary team, stroke specialists, neuroimaging, medication, and health care policies. Stroke care processes (SP) that emerged were assessment and diagnosis, referrals, intravenous thrombolysis, rehabilitation, and primary and secondary prevention strategies. Stroke-care outcomes (SO) included quality of stroke-care practice, functional independence level, length of hospital stay (LOS), mortality, living at home, and institutionalization.

6. Chapter 7 addressed objective number 5 of the current project, which was to develop a new contextual model for in-patient stroke care and rehabilitation in Malawi.

Using the Nominal Group Technique, the MoC was developed through four thematic areas of MoC principles, stroke care structure, stroke care process and stroke care outcomes. Using pooled data from diagnostic phase, this study generated five guiding principles for the current MoC which are: 1) Interdisciplinary teamwork; 2) Patients journey; 3) Goal-directed intervention; 4) Human-centered care and; 5) Evidence-based care. Stroke care structure comprised of stroke care pathway, which is formed by system of emergency unit, medical ward, and rehabilitation department, and three structural requirements for each of the three sections. These requirements are human resource, equipment and medicine, and information storage and retrieval. Stroke process of care included subjective assessment, objective assessment, data analysis and diagnosis, problem list and implementation of therapeutic approaches. This study showed that outcome measures to use are quality of stroke care practice, functional independence, integration into the community, length of hospital stay (LOS), and discharge home.

Conclusions:

1. Exploring the processes of care, the first project objective, we showed that care was categorized into acute management and investigations, early management, and general management in the country's central hospitals. Physicians, nurses, and physiotherapists formed the triple pillar of stroke care team, although physiotherapists were re loosely attached care providers, due to weak multidisciplinary team practices. Limited multidisciplinary teamwork affected the quality of care for people with stroke. Further challenges were structural. There was limited space for patients and inaccessible structures, which affected appropriate service provision; limited resources, only minimal qualified service providers, inadequate medical supplies, and unreliable medical equipment at best.

2. Determining the functional outcomes and satisfaction with care for patients with stroke in the central hospitals, the second and third project objectives, revealed that patient outcomes improved significantly on discharge compared to admission status. In additional, patients and informal caregivers showed they were highly satisfied with the provision of stroke care. However, high ratings on these outcomes did not translate into high quality of life. For example, they lacked functional independence and had moderate challenges in various domains of everyday life post-hospitalization. There is a need to focus on evidence-based intervention areas of stroke care that can impact the patients' quality of life.

3. From the scoping review, addressing objective four of the project, it was clear that there is lack of uniformity in the way stroke care is advanced in LMICs. This is reflected through the unsatisfactory stroke care structure, processes, and outcomes, a theme that also emerged in the studies done locally. The review further highlighted the need to implement change with stroke-care settings, adopting quality improvement strategies. Further, the health ministry and governments must decisively and deliberately face the increasing stroke burden by setting policies that advance improved care of and outcomes for patients with stroke based on evidence and proven interventions.

4. The Model of Care (MoC) developed to fulfill the last objective of this PhD project, was guided by five principles: utilization of a multidisciplinary team approach to care, importance of the patients' journey, goal-directed interventions, human-centered and, evidence-based care (EBC). It highlighted stroke care structure, processes, and outcomes across the stroke care pathway from Emergency Department (ED), the medical ward, and the Rehabilitation Department. To deliver effectively on processes of care, the MoC recommended that the multidisciplinary team needed clear objectives, protocols, policies, role delineation, and clear channels of communication. The team should run weekly multidisciplinary ward rounds, with regular clinical meetings, morning reports, and in-service training. Executing early care interventions is key to successful outcomes. To measure effectiveness of stroke structure and process, the MoC emphasized the use of quality stroke-care practices, promoting functional independence, integration into the community, minimal length of hospital stay (LOS), and discharge home as primary outcome measures.

5. There is a need for further research into stroke care structure and processes aiming to develop a coordinated protocol-driven stroke section or unit within Malawi's central hospitals, similar what exists in other LMICs, such as South Africa, and in the industrialized world.

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Key words

Stroke

Acute stroke

Stroke care

Process of care

Model of Care

Rehabilitation

Central hospitals

Stroke outcomes

Malawi,

Low and Middle Income Countries**.**

DECLARATION

I hereby declare that "Development of a Contextual Model for In-patient Stroke Care and Rehabilitation in Malawi" is my own work and that it has not been submitted, or part of it, for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

Name: __George Chimatiro__ _____   Date: __12/10/19_____

Signed: ____ _____

Acknowledgements:

Dedication

I dedicate this work to my Uncle, Mr. FB Namwawa, who has been my inspiration and advisory voice for most part of my life; who as I write is incapacitated by the effects of diabetes, amputated and all that, but keeps moving to put his life and that of others in place. You are my hero! To my mother, Mary 'Nangondo' Chimatiro for the "tough love" she gave during my initial 14 years of life, before her passing days towards my 15th birthday. "Your first born could not understand what you wanted of him mama, but you put him in the right footage that stands the test of time; that continue brushing the perched dew for others to pass dry". Because I did not understand, I did not love her, but now standing here, I know, and I love her more! To my wife Meria, it has been a tough going, but she stood by me: trusting, loving and caring! Thank you for the gift of children and the life we have grown. To my intelligent and wise father, Mr Lameck Chimatiro, you are a candle in the darkness. Humble man, a teacher of silent truths. I am positively patient because of you and positively aggressive because of mama. Thank you, papa.

List of publications and conference by candidate from the current project

1) **Chimatiro, G. L.,** & Rhoda, A. J. (2018). Stroke patients' outcomes and satisfaction with care at discharge from four referral hospitals in Malawi: A cross-sectional descriptive study in limited resource. *Malawi Medical Journal*, *30*(3), 152-158.

2) **Chimatiro, G. L.,** & Rhoda, A. J. (2019). The challenge to providing stroke care and rehabilitation in Malawi. *Journal of Global Health Reports*, *3*, e2019049.

3) **Chimatiro, G. L.,** & Rhoda, A. J. (2019). Scoping review of acute stroke care management and rehabilitation in low and middle-income countries. *BMC health services research*, *19*(1), 789.

4) **Chimatiro, G.L.,** & Glickman, L.B. (2020). *Stroke Processes of Care in Malawi: Challenges and Potential Solutions*. Glickman, LB (Ed). Malawi: Its history, culture, environment, education and health **care.** Nova Publications https://novapublishers.com/shop/malawi-its-history-culture-environment-education-and-healthcare/

Conference presentations

Presentation of findings of "Stroke patients' outcomes and satisfaction with care at discharge from central hospitals in Malawi: A cross-sectional descriptive study in limited resource areas" at the 22nd College of Medicine Research Dissemination Conference in November 2018.

Definition of terms

Definition of terms in the thesis

Stroke	Quickly developing clinical signs of central (at times general) unsettling influence of cerebral work, enduring more than 24 hours or driving to death with no clear cause other than that of vascular root (WHO, 1989). Term used regardless of type or side affected.
Rehabilitation	A goal-oriented preparation pointed at empowering an individual with disability to reach an ideal mental, physical, and/or social useful level, hence giving him/her with the apparatuses to progress his/her own life (Langhorne & Legg, 2003). Term used to mean stroke rehabilitation.
Patient with stroke	In this study, a patient with stroke refers to a person affected by stroke (WHO, 1989) who was admitted and treated at one of the central hospitals in Malawi during the period of data collection.
Caregivers	Term used interchangeably with "guardian" to mean a person connected to the stroke client, providing direct care to them on a daily basis (Teel et al, 2001).
Service providers	Term for professionals providing direct health service to patients with stroke at one of the four central hospitals in Malawi (Carr, 2001).
Central Hospital:	Hospital that provides tertiary (and secondary) care services in Malawi. The term is used interchangeably with referral hospital in this project
Quality of Life post stroke:	A multi–dimensional construct that consists of at least three broad domains: physical, mental and social. It focuses on the impact of stroke and/or the treatment including rehabilitation on the patients' perception, of their status of health, and, on subjective wellbeing or satisfaction with life (Opara & Jaracz, 2010).
Satisfaction with care:	Measure of the extent to which the patient is content with the care they receive in hospital setting, in this project at the central hospital.
Monitoring:	It is a process of routine tracking and reporting of priority information about a program or project, its input and intended output, outcomes and impact (UNAIDS, 2009).

Key Abbreviations Used in the Study

MoC: Model of Care

NSWRMC: New South Wales Rehabilitation Model of Care.

HHSSC: Hamilton Health Sciences Stroke Model of Care

MoCA: Montreal Cognitive Assessment

FIM: Functional Independence Measure

EQ-5D-5L: 5 Level Euro Quol 5 Dimension scale

SASC: Patients Satisfaction with Inpatients Stroke Care (Hospital Scale)

C-SASC: Caregivers Satisfaction with Inpatient Stroke Care (Hospital scale)

NHSRC: National Health Sciences Research Committee

COMREC: College of Medicine Research and Ethics Committee

NGT: Nominal Group Technique

CHAM: Christian Association of Malawi

QECH: Queen Elizabeth Central Hospital

KCH: Kamuzu Central Hospital

DVT: Deep Venous Thrombosis

MRI: Magnetic Resonance Imaging

CT Scan: Computed Tomography Scan

QoL: Quality of Life

IQR: Interquartile Range

CI: Confidence Interval

VAS: Visual Analogue Scale

LoS: Length of Hospital Stay

SPO: Structure Process and Outcomes

ED/EU: Emergency Department/Emergency Unit

SU: Stroke Units

MESH: Medical Subject Headings

CINNAHL   Cumulative Index to Nursing and Allied Health Literature

PT   Physiotherapy

mRs   modified Rankin scale

DM   Donabedian Model

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1.0 Chapter 1: Introduction

1.1 Background

Stroke is a known health challenge for the public as it is both incapacitating and fatal to many people world over. Malawi, one of the least developed countries has stroke as the fourth leading cause of death, after HIV/AIDS, upper respiratory tract infections, and malaria . The 1970 World Health Organization's (WHO) definition of stroke, still standing today, is 'rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin' (Aho, 1980; p. 114). Stroke leads to disability or functional loss due to a brain abnormality of an anatomical, physiologic, mental, or emotional nature (Carvalho-Pinto & Faria, 2016; Carmo, Oliveira, & Morelato, 2016). Physically, according to an Australian observational study, sequelae such as spasticity that develop after stroke have been found to cause contractures during the first four months of onset. However, the typical muscular weaknesses that develop afterwards are found to be the main contributor to activity limitation and loss of functional independence. In addition to the physical impairments, cognitive dysfunction is also common after stroke, making a significant impact on attention, executive functions and general functional abilities (Carvalho-Pinto & Faria, 2016; Al-Qazzaz, Ali, Ahmad, Islam, & Mohamad, 2014)). With the myriad challenges to which stroke pathology frequently leads, the goal of management of patients with stroke is to improve functional outcomes and quality of life to reduce stroke burden. Management of patients with stroke is an area of increasing interest in different parts of the world including low- and middle-income countries (LMICs).

1.2 Overview of stroke: Definition, Types, Symptoms, Diagnosis, and treatment

The 1970 World Health Organization (WHO) definition of stroke that still stands today is a 'rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin' (Aho, Harmsen, Hatano, Marquardsen, Smirnov, & Strasser, 1980). The condition which is also known as cerebrovascular accident (CVA) is either caused by blockage (ischemia) or rupture (hemorrhage) of an artery that perfuse the brain, thereby interrupting the cerebral blood flow (Lloyd-Jones, Adams, Carnethon, et al.., 2009).

Ischemic stroke is caused by a reduction in blood flow to the brain. Averagely ischemic stroke is 80-85% worldwide (Adeoye, & Broderick, 2010). The primary aim in early management is to accelerate reperfusion (increasing cerebral blood flow) via thrombolysis (Candelario-Jalil, 2009). Intracerebral hemorrhage, on the other hand, result from raptured blood vessel and is a common problem affecting 10–15% of people worldwide (Adeoye, & Broderick, 2010). This world prevalence is lower than what was found in a Malawian hospital-based study which had shown intracerebral hemorrhage to be 25.8% of participating stroke cases (Heikinheimo, Chimbayo, Kumwenda, Kampondeni, & Allain, 2012). Pathologically, the intracerebral hemorrhage often affects cerebral lobes, the basal ganglia, the thalamus, the brain stem (predominantly the pons), and the cerebellum (Qureshi, Tuhrim, Broderick, Batjer, Hondo, & Hanley, 2001).

As a fourth leading cause of death in Malawi, stroke is a significant cause of disability, as the population over 55 years continues to increase (Mahawish & Heikinheimo, 2010). Stroke lead to myriad of impairments that often affect patients and guardians. These include sudden loss of consciousness, weakness of one side of the body, inability to speak properly, dysphagia, impaired cognition, loss of sensibility, convulsions, and raised blood pressure (Lawrence, Coshall, Dundas, Stewart, & Wolfe, 2001)

Stroke diagnosis require meticulous assessment. 'The ability to safely visualize in vivo the brain and blood vessels and to analyze blood flow has improved physicians' ability to diagnose the causes and mechanisms of their patients' strokes, to more accurately prognosticate, and to more rationally choose treatment' (Caplan, 1991). Assessment for diagnosis includes patient history, physical examination, neurological examination and applying stroke outcome measures and diagnostic tests (Yan, Li, Chen, et.al. 2016). History and physical examination remain key to diagnosing stroke. Commonly the feature of an ischemic stroke is its acute onset. However, most common physical findings of this type of stroke are focal weakness and speech disturbance (Nor, Davis, Sen, et al. 2005). While both ischemic stroke and intracerebral hemorrhage are characterized by acute onset symptoms, patients with intracerebral hemorrhage may report gradual worsening of symptoms after the sudden onset. They may also have a decreased level of consciousness (Suarez, Tarr, & Selman, 2006). Additionally, the National Institute of Health Stroke Scale (NIHSS) is one of the widely used classifications of early stroke severity but generally the combination of signs and symptoms remains key in diagnosing stroke than the use of one instrument findings (Yew, & Cheng, 2009).

Regarding management, as many as 52% of patients with stroke experience Acute Hypertensive Response (AHR) after stroke regardless of the type (Willmot, Leonardi-Bee, & Bath, 2004). AHR is defined as, "systolic BP ≥140 mm Hg or diastolic BP of ≥90 mm Hg demonstrated on 2 recordings taken 5 minutes apart within 24 hours of symptom onset" (Whitworth, 2003). This is often reflected in patients who were

inadequately treated or had undetected chronic hypertension (Arboix, Roig, Rossich et.al. 2004). There is a need for appropriate rehydration before pharmacological intervention to control the condition (Qureshi , 2008).

In particular, Ischemic stroke is treated by using recombinant tissue plasminogen activator (rt-PA) which is associated with improved clinical outcome of stroke (Candelario-Jalil, 2009). Whereas surgical decompression is widely accepted as potentially life-saving (Adeoye, & Broderick, 2010) for patients with intracerebral hemorrhage.

Beside medical and surgical care, patients with stroke require medical rehabilitation. The ultimate aim of rehabilitation during acute stroke is to facilitate skill reacquisition towards independent performance of the activities of daily living and achievement of functional recovery. Early therapy has been found helpful in achieving such aim (Fang, Chen, Li, Lin, Huang, & Zeng, 2003). Studies show that when patients with stroke spend time per day in specific physiotherapy, occupational therapy and speech and language therapy activities progress in functional recovery among patients with stroke across all levels of severity (Bode, Heinemann, Semik, & Mallinson, 2004). Physiotherapists address functional activities of bed mobility, sit to stand, transfers, and gait retraining (Shinohara, & USuda, 2013). Occupational therapists on the other hand assists patients with stroke in order for them to regain their ability to complete activities across manifold life roles that includes include basic activities of daily living, home management, work or school activities, and recreation activities. They do this by modifying tasks and adapting environment in which the tasks are performed; decreasing structural and functional impairments, or by combination of approaches (Richards, Latham, Jette, Rosenberg, Smout, & DeJong, 2005). Whereas speech and language therapists address language problem and dysphagia as they work with patient and educating the informal caregivers on supportive techniques.

Service providers, patients and informal caregivers also work together in limiting stroke recurrence. Primary stroke prevention strategies include blood pressure control, which has been associated with a significant reduction of stroke risk (Xing, Arai, Lo, & Hommel, 2012) and promotion and maintenance of healthy lifestyles (Damasceno, Gomes, Azevedo, et.al. 2010). Secondary prevention of stroke, on the other hand, include regular blood pressure checks and controls, antiplatelet and lipid-lowering therapy, homocysteine-lowering therapy, self-management, and family support (Yan, Li, Chen, et.al. 2016).

Nunes and Queirós, (2017), found that during the hospitalization period, a careful hospital discharge planning and comprehensive care to patients and informal caregivers, in particular the functional and psycho-emotional aspects, tended to have an impact on the quality of life of patients. There is a need to emphasize education regarding stroke as part of discharge planning to informal caregivers and the patients with stroke so that they know the "dos" and "don'ts" after discharge.

1.3   Donabedian Model: The conceptual framework

The World Health Organisation (WHO) stated that stroke burden in LMIC could be lessened by the provision of quality and standardised stroke care. Provision of quality health care, which some authors describe as a human right, also results in satisfaction for the patients as well as the community in general and optimal performance for health care facilities (Janicijevic, Seke, Djokovic, & Filipovic, 2013). The Donabedian Model is known for its comprehensiveness in assessing quality of health care. It is also adequately flexible as it can practically be applied to many situations or locations. The model has three features of health care quality, namely, structure, process, and outcome . Related to health care, Structures are, by definition, the physical and organizational sides. Facilities, equipment, personnel, operational, and financial processes supporting medical care are examples of health care structures. Processes, on the other hand, refer to procedures performed for the patient by practitioners in the course of treatment (Gustafson, 1995). Further, processes relate to every resource and mechanism provided by the structures. Examples include the number and caliber of physicians, nurses, and physiotherapists to carry out patient care activities to achieve positive outcomes (McDonald, Kathryn, Sundaram et al., 2007). Donabedian differentiated two types of outcomes (Donabedian, 1988). On the one hand, he described technical outcomes as encompassing the physical and functional aspects of care, for example, successful management of hypertension in patients, absence of contractures, loss of mobility, and patient quality of life. On the other hand, he described interpersonal outcomes, including dimensions of the "art" of medicine, such as satisfaction with care and the resulting patient's perceived quality of life. Further, Donabedian stated that structure, process, and outcomes are linked. Therefore, good structure should promote good process and good process should promote good outcomes (Donabedian, 1988).

Donabedian's Structure Process and Outcomes framework was applied successfully in the study to assess the quality of care in the Integrated Chronic Disease Management ICDM model used by South Africa's National Department of Health for implementing the ICDM model (Department of Health, Republic of South Africa. Integrated Chronic Disease, 2014). In that model, participants were satisfied with these SPO-related dimensions of patient management: 1) structural constructs such as presence of tools, adequate medicinal supplies, and convenience of

care for long-term illnesses; 2) process constructs, e.g. nurse communications with patients, nurse attention and friendliness to client requirements, ethical behavior of nurses, patients' institutional transfers or referrals, advance-packing of drugs, patient physical evaluations; and nurse-patient contact duration. Outcome constructs on the other hand included coherence of integrated chronic disease care, the nurses' skill, and patients' perceived confidence in the nurse's services delivery (Ameh, Gómez-Olivé, Kahn, Tollman, & Klipstein-Grobusch, 2017).

Figure 1.1 Donabedian model for quality of care

1.4 Stroke Care and Rehabilitation: Applying the Donabedian Model

The Best Practice Guidelines highlighted that when stroke occurred, patients requiring care must be admitted to a stroke unit, or, to generic wards in the absence of SU. The stroke units and/or general wards should be operated by multidisciplinary team with special capability and interest in the care of patients with stroke. Using the Structure Process and Outcomes (SPO) conceptual framework, stroke care and service delivery was highlighted.

1.4.1 The Stroke Care and Rehabilitation Structure

Based on SPO framework in rehabilitation, the structure of care included the facilities and professionals available for rehabilitative care. Donabedian generally clarified that structures are the physical and the organizational facets of the sites. For illustration, the offices, gear, work force, operational, and budgetary forms supporting restorative care comprised wellbeing care structure. Information relating to the qualifications of the health professionals providing the service was also a key stroke-care structural requirement. Based on the scoping review conducted by this researcher, there are seven healthcare structural requirements in LMICs, including accessibility of a stroke unit, emergency unit, a multidisciplinary team, stroke experts, neuroimaging, pharmaceutical, and health care policies. Well-functioning structure could facilitate better processes of stroke care .

Malawi, a low-income country, has limited health care services, both in quantity and quality for 18+ million people. Access to health care is generally in the major cities of a predominantly rural country. The country's total expenditures on healthcare per capita is $93, compared to the international standard of $2014. Malawi's healthcare conveyance framework is four-tiered, comprising of community, essential, auxiliary, and tertiary care.

There is currently no stroke unit in any of the four political regions of the country, the locations of the four-referral hospitals. Patients with a suspected stroke are referred to a secondary (district) or a tertiary (referral) hospital, which are quite general in their stroke service provision. Therefore, components of needed stroke care structures are limited. This includes a lack of stroke care protocols and guidelines, limited stroke care team membership and variety, with the absence of occupational therapy and speech and language therapy (Mahawish & Heikinheimo, 2010; Baatiema, Sav, Mnatzaganian, Chan, & Somerset, 2017). The unavailability of key medical supplies such as r-TPA in most LMICs compounds optimal care provision from the lack of a stroke unit. Furthermore, LIMCs, such as Malawi, frequently endure need of offices for neuroimaging and thrombolysis in numerous tertiary service care centers, as well as lacking emergency vehicle administrations, constrained instructive efforts and awareness, lacking training of crisis care physicians, inaccessibility of mechanical thrombectomy interventions, and few radiologists and MRI innovation . This state could affect accuracy in stroke diagnosis and compromise the administration of appropriate emergency and ongoing care services.

Currently, stroke care in Malawi referral hospitals experience stroke-care-service implementation challenges due to lack of recognition of the importance of stroke in critical care medicine, limited multidisciplinary contacts, patient mix challenges due to lack of dedicated stroke wards, and resource limitations such as limited medical supplies and limited and or unreliable equipment.

1.4.2 The Stroke Care and Rehabilitation Process

As highlighted earlier, process of care refers to procedures and content of care, such as the referral process to and through the system as well as the services that the patient receives as performed by practitioners in the course of treatment. For example, the components included in the process of care for patients with stroke are provision of assistive devices and prostheses, type of exercises given, use of physical agents such as

therapeutic ultrasound as well as frequency and duration of rehabilitation. Bravata et al. (2010) on the other hand, identified seven common forms of stroke care for assessment that include neurological assessment, gulping assessment, deep vein thrombosis (DVT) prophylaxis, early mobilization, blood pressure (BP), fever, and hypoxia management. In addition, the authors found that three of the seven forms of stroke care were autonomously linked with decline in the combined result of gulping assessment, DVT prophylaxis, and treatment of all occurrences of hypoxia with supplemental oxygen.

After admission, patients with stroke are assessed through patient subjective history, physical examination, neurological examination, utilization of stroke scales, and diagnostic tests (Yan et al., 2016) to identify key processes of care needing attention for better outcomes for the individual patient. In Malawi, primary investigations for patients with stroke included Computerized Tomography (CT) scan, the gold standard to identify stroke type, although at times, an Magnetic Resonance Imaging (MRI) was used as well. This was evidenced in a prospective Malawian hospital-based study (Heikinheimo, Kumwenda, Kampondeni & Allain, 2012) at Queen Elizabeth Central Hospital (QECH) in 2012, with 127 of 150 patients having access to brain imaging. One-hundred twenty-four patients had CTs and three had MRI, which is owned by College of Medicine. At the time of implementing this project, however, none of the four referral hospitals in Malawi had a working CT scan after the ones at QECH and Kamuzu Central Hospital got out of order. Reliance on clinical presentation and history of the condition is, therefore, key to stroke diagnosis in the absence of sophisticated diagnostic tools. Swallowing was also assessed, as 50% of patients with stroke present with swallowing problems in the acute phase.

When the final diagnosis of stroke is made, intravenous thrombolysis (rtPA) should be administered as noted in evidence-based treatments for acute ischemic stroke in some settings within LMICs (Yan et al., 2016), based on findings in developed countries (Rahil, Afshin, Anahid & Salvador, 2012). In Malawi, anticoagulants, ACE-inhibitors, and statins are not routinely available in the central hospitals. Patients with ischemic stroke are, therefore, placed on aspirin (75mg, once per day) (Heikinheimo, Kumwenda, Kampondeni & Allain, 2012).

Rehabilitation represents an important aspect of stroke care for most patients although the intervention remains sporadic in most LMICs due mainly to restraint in terms of number and variation of rehabilitation experts (Ossou-Nguiet et al., 2017). In any case, it is obvious that recovery ought to commence as early as conceivable after stroke, in a perfect world, inside 24 to 48 hours after a seen stroke. This international recommendation also highlighted local policies such as the Malawi Standard Treatment Guidelines. The objective of rehabilitation is to have improved results related to stroke impairments, action restrictions, and support restrictions . This includes proper positioning, turning, and early mobilisation to prevent pressure sores and proper feeding positions to prevent aspiration pneumonia; close monitoring to avert therapeutic and neurological complications and achieve best results; education on protective measures such as trauma prevention and optimal positioning for painful shoulder, while giving other restorative functional retraining (Tipping, 2008; Langhammer, 2000). Research showed that physiotherapy interventions led to reduced length of hospital stay, better motor control, and enhanced abilities in ADLs . Another aspect in stroke rehabilitation was occupational therapy that focused on the patient's cognitive impairments and ADL skills during hospital stay. Tipping also stated that speech and language therapists work on language and swallowing problems through direct communication with patients and providing information to informal caregiversand families about the conditions . There is paucity of occupational and speech therapy intervention for patients with stroke in Malawi. This is due to absence of speech and language therapists, and limited number of occupational therapists, whereby those available are concentrated to teaching institution and private sector.

While the processes of stroke care are implemented, preventive strategies are also administered. These include primary strategies such as blood pressure regulation, advancement and preservation of healthy lifestyle (Albertino et al., 2010), and secondary approaches such as blood pressure regulation, self-management, and family support (Yan et al., 2016).

1.4.3 Stroke Care and Rehabilitation Outcomes

Based on Donabedian's Structure Process and Outcomes (SPO) framework on stroke care, outcomes are classified into two: technical outcomes and interpersonal outcomes. Specifically, in LMICs that had way better structure and forms of care, patients were more likely to be alive, have reduced LOS, greater independence, and staying at home a year after witnessed stroke (Yan et al., 2016). Whereas, in those countries with weaker structures and processes of care, there was poor stroke service delivery (Al Khathaami et al., 2011) and poor stroke care practices

(Leonard et al., 2017). In a recent study in Malawi following stroke care at a referral hospital, patients experienced enhancement in functional results on discharge compared to admission and were fulfilled with care arrangement in spite of having a poor quality of life at discharge (Chimatiro, Rhoda & De Wit, 2018).

In line with Donabedian's observation that structure, process, and outcomes are not independent from each other, it is evident that stroke care in Malawi and other countries of similar socioeconomic status have unsatisfactory structures. There are a limited number, variety, and lower stroke-care skills level for the service provided in settings with insufficient neuroimaging and medical supplies. There are, hence, limitations in the processes of care impacted by the evident structural limitation. This state, therefore, leads to unsatisfactory stroke care outcomes such as limited stroke care provision in the LMICs and poor quality life. There is a need for improvement strategies to address structural and process limitations in stroke care for outcomes to ultimately improve in Malawi and other LMICs.

1.5   Model of care inherent principles and characteristics

To facilitate positive outcomes for patients with stroke, there is a growing call for use of models and guidelines that are based on available evidence. Model of care could be a multifaceted concept, which for the most part characterizes the way health services are conveyed (Queensland Health, 2000) in a particular setting and context. Guidelines, on the other hand, for the most part center on clinical practice instead of conveyance of services (Agency for Clinical Innovation, 2013). A model outlines best-practice client care delivery through the application of a set of service standards over recognized clinical streams and patient flow continuums (Waikato Health Board, 2004). Universally, the World Confederation for Physical Treatment (WCPT) has prioritised the improvement and usage of models and clinical guidelines in its policy (Mead, 2006). The advantage of the model of care in rehabilitation is that it makes a difference to broaden the scope of services, upgrade treatment, and encourages the specialist to improve quality while reducing the cost of care given (National Institute for Health and Care Excellence, 2013; Maher, 2008).

To facilitate the understanding of "model of care," three models, including the New South Wales Rehabilitation Model of Care (NSWRMC), the Four-Level Model of Health Care System, and the Hamilton Health Sciences Stroke Model of Care (HHSSMC) were reviewed. Five themes or principles emerged: patient-centeredness, patient journey, multi-professional teams, evidence-based practice, and organisation and leadership.

Patient centeredness is the fifth principle of the New South Wales Rehabilitation Model of Care, and a strong theme in the Four-Level Model of Health Care System. Patients are assessed with their status directing their management. The need for appropriate settings for rehabilitation is emphasised, including where patients should receive rehabilitative care and in the most appropriate setting based on the patient's individual needs.

The patient journey along the continuum of care is clearly stated in the New South Wales Rehabilitation Model of Care (NSWRMC). The model highlighted five components along the patient journey: 1) referrals, 2) access and initial contact, 3) rehabilitation assessment on admission, 4) service delivery, and 5) discharge and follow-up. Effective multidisciplinary teamwork runs across the three models, in evaluating stroke severity, etiology, and functional status. Therefore, according to Hamilton Health Sciences Stroke Model of Care (HHSSC), every band or stroke care station must have dedicated staff, with stroke care experience. This also satisfies the third principle of the (NSWRMC) that states that patients have access to a 'core' multidisciplinary team.

The models of care also highlight the need for strong use of evidence-based practice. This is shown by evident use of outcome measures including the Functional Independence Measure, Montreal Cognitive Assessment (MoCA), the Chedoke McMaster Stroke Assessment Measure, in addition to ascertaining family situation, pre-existing co-morbidity, fall risk and discharge environment. Another aspect highlighted by the models is effective organisation. Specifically, they inform the need for effective leadership, effective communication, and efficient resource mobilisation including human, to meet the increasing demand for stroke care including community visit. The sense of commitment to the principles and the working definition by the organisational leadership would ensure efficient implementation of the stroke care services as stipulated in principle number one of the (NSWRMC).

The three models reviewed were based on western industrialised settings. Their applicability to settings in developing countries could be challenged by different circumstances such as weak structures and processes as reported by studies in LMICs including Malawi (Al Khathaami et al., 2011; Leonard et al., 2017). However, production and/or adaptation of models in the care of stroke in resource-limited areas is a necessity (Joubert, Prentice, Moulin et al. 2008). Joubert et.al. (2008) stated that, informed by best-practice guidelines and recommendations for frameworks of stroke care, versatile models of care (MoC) that are suitable for local needs ought to be concocted for rural and territorial settings.

1.6   Developing a Model of Care

The advancement of a MoC, agreeing to the Agency for Clinical Innovation (2013) includes five stages. To begin with, Project Initiation, where services for review are identified. Based on the gaps, one starts to construct a case for change. The MoC designers get sponsorship to continue with the program of work and set up project management mechanisms. Under this stage, activities incorporate creation of the introductory high level "case for change" by measuring the degree of the problem and the cost of proceeding business as usual. They too create and agree on project points, targets, and scope. Clinicians, supervisors, and partners are recognized and engaged in the venture. Critical is their evaluation on the off chance that this is a project they will value.

Second, Assessment and Diagnostic phase, where the degree of the issue is defined, and the root cause understood to address the genuine issue. Exercises beneath this stage incorporate meeting such as workshops, interviews, and brain storming sessions. Developers also carry out an 'As is' analysis, determining the current stroke-care delivery processes. Data is reviewed including demand investigation, epidemiology, and service usage. Budgetary investigation of the cost of proceeding business "as usual" is also carried out. Literature is reviewed; innovations already in the field are analysed. The case for change is then finalised. Identification and prioritization of issues, points, and objectives are revisited to guarantee the venture is progressing well.

Third, the Solution Design Phase is where solutions are developed and selected. The MoC document is then created. Activities include clearly defining the change, involving changing the focus from how care practices are currently executed, and improvements needed. It requires a high level of creativity to allow innovation and willingness of the team to consider change. Ideas in this phase are based on sound evidence from literature reviews, best practice guidelines, and conceptualizing workshops with representation from clinicians, consumers, operational, data, and administrative staff. MoC designers moreover construct the capability of front-line clinicians and supervisors to change the process/system, create a communication plan and identify dangers to implementation. The Fourth phase is the Implementation Phase, where the project is implemented. The Fifth Phase, the Sustainability Phase, is where use of the MoC is optimised, results monitored, and the impact evaluated.

As highlighted, development of a MoC involves five stages. It is notable that the same framework has been used to develop specific models of care, without necessarily following five steps. For example, the development of the NSWRMC (2015) and the HHSSMC Care used the first three steps of project initiation, assessment or diagnostic phase and design phase, with reporting as the fourth phase.

1.7   Rationale for this study

Contingency theory in health care organisations contends that the "best" approach depends on contingency factors, including the situation relating to the quality of life and resources available and involved. Most MoC are based on Western, high-income settings, with no known applicability to developing LMICs where contingent factors are evidently different. However, the framework for MoC development "could" apply in a modified or adapted version. To the knowledge of this researcher, there is no MoC and there is a lack of optimal care structure and process for persons with stroke in Malawi. This is due to the limited number and quality of human resources for health related to stroke care, limited and often-out-of-order diagnostic and medical equipment, and limited drug and medical supplies as observed during the diagnostic phases of this project. These deficits could be responsible for many of the poor stroke outcomes in the country . Assuming that such a "model" could spur better stroke care service delivery, this doctoral project applied a Diagnostic and Solution Phase to develop a contextual model for in-patient stroke care and rehabilitation in Malawi in order to have favorable stroke outcomes and better post discharge community re-integration experiences for the persons with stroke.

1.8   Problem statement

Currently, discrepancies exist in the way stroke care is applied in LMICs, with consequent poor stroke service delivery (Al Khathaami et al., 2011) in most countries within LMICs. Malawi trails the key requisites, as the country continues to suffer a critical shortage of health care personnel at all levels of the health system. It has a paucity of stroke care specialists, no stroke unit, and limited financial and material resources. Yet the MoC and rehabilitation have been reported to be helpful in widening the scope of services, optimizing treatment, and facilitating the practitioners in improving quality while reducing cost of the care provided (National Institute for Health and Care Excellence, 2013; Maher, 2008). As highlighted, the published MoCs are based on western high-income settings, with no known applicability to developing LMICs. However, the framework for the MoC development could be applied. There is currently no known MoC for patients with stroke in Malawi that could ensure better stroke care, outcomes, and consequently lead to optimum community re-integration experience by patients with stroke.

1.9   Research Question

The research question was, "What is a context-appropriate MoC and rehabilitation for patients with stroke managed in Malawi's central hospitals?"

1.10   Research aim

The overall aim of the current project was to develop a contextual Model of Care and rehabilitation for patients with stroke in Malawi.

1.11   Research objectives

The research question was answered by achieving five objectives in the two categories of diagnostic phase and solution design phase:

a)   Diagnostic phase objectives:

1.   To determine and explore the process of care of stroke patients in Malawi

2.   To determine patients with stroke and caregiver satisfaction with care and rehabilitation service delivery in Malawi's central hospitals

3.   To determine stroke patient outcomes at discharge

4.   To determine through a scoping review the current knowledge related to stroke care and rehabilitation service provision

b)   Solution design phase objective

5.   To develop a new contextual model for in-patient stroke care and rehabilitation in Malawi.

Sub-objectives to solution design phase

I.   To gain consensus on the guiding principles and recommendations as generated from diagnostic phase

II.   To generate a stroke care pathway at a referral hospital

III.   To generate and gain consensus on stroke care structure, process, and outcomes

1.12 Thesis outline

This PhD thesis is comprised of 8 chapters, primarily about stroke care in LMICs, with Malawi as the country of interest. Utilizing a multimethod approach, the thesis outlines the structures, processes, and outcomes as shown in the final product of this project, the contextual model of care and rehabilitation for patients with stroke in Malawi's main referral hospitals.

Chapter 1, presents "The Development of a Contextual Model for In-patient Stroke Care and Rehabilitation in Malawi" provides background on stroke as a world concern but with daunting challenges and a high burden for the people of Malawi. Stroke management have been described according to the Donabedian Model and conceptual framework. Based on the Model, the need for the development of a contextual model of care became clear. The chapter also presents project questions and objectives.

Chapter 2, presents "The Theoretical Methodology for the PhD project" presents the theoretical explanations of methodology used for this PhD project. Overall research methods covering the two phases of the project: diagnostic and solution design phases, setting, approaches and designs, data collection instruments, and ethical concerns have been described in detail.

Chapter 3 presents "Stroke Process of Care in referral hospitals: A Cross-Sectional Study in Malawi's Referral Hospitals". It partially addresses objective one through a quantitative, descriptive cross-sectional study, aimed at investigating and understanding stroke care processes among service providers in Malawi's referral hospitals.

Chapter 4 presents ("State of care and rehabilitation for people with stroke at Queen Elizabeth Central Hospital in Malawi: A qualitative report"). It addresses objective one, a qualitative exploratory study that helped better understand the current state of stroke care from the perspectives of service providers, patients with stroke and their informal caregivers in Malawi, helping to inform a new MoC. Chapter 4 presents The challenge to providing stroke care and rehabilitation in less-resourced country: Lessons learned". It is a qualitative exploratory study that explored stroke-care provision challenges at the largest referral hospital in Malawi, from the perspectives of service providers, patients with stroke, and their informal caregivers.

Chapter 5 presents the "Patients with stroke's outcomes and satisfaction with care at discharge from central hospitals in Malawi: A cross-sectional descriptive study in a limited resource area". This paper was published in Malawi Medical Journal: DOI http://www.mmj.mw/?p=7710). It addresses objectives 2 and 3 through a descriptive cross-sectional study to determine stroke outcomes and satisfaction with care among patients with stroke and their informal caregiversin the country's referral hospitals.

Chapter 6 presents the , "Scoping review of acute stroke care management and rehabilitation in LMICs". It addresses objective 4, through an interpretative scoping literature review, based on Arksey and O'Malley's five-stage-process that aimed to document evidence of stroke care and service delivery in low and middle-income countries to better inform the development of a context-fit stroke model of care. This paper was published in BMC Health Services Research Journal: URL: https://link.springer.com/article/10.1186/s12913-019-4654-4

Chapter 7 presents the design phase of the MoC. Nominal Group technique (NGT) that was adopted to gain consensus on ideas from a group of professionals, "A contextual model of care with rehabilitation for patients with stroke in Malawi: The design phase". It is published as a chapter "Stroke Processes of Care in Malawi: Challenges and Potential Solutions" by Nova Publications in a book entitled "Malawi: its history, culture, environment, education and healthcare" https://novapublishers.com/shop/malawi-its-history-culture-environment-education-and-healthcare/

Chapter 8 is the conclusion chapter, including a summary of the thesis, an overall conclusion based on the aim of the study, and recommendations emanating from the study.

2.0 Chapter 2: Theoretical Methodology for the PhD project

This chapter describes the overall methodological approaches for the entire research project. In particular the methodology was designed to cover two phases of the project: firstly, diagnostic phase, that was covered by four objectives, namely: 1) To determine and explore the process of care of stroke patients in Malawi; 2) To determine patients with stroke and caregiver satisfaction with care and rehabilitation service delivery in Malawi's central hospitals; 3) To determine stroke patient outcomes at discharge and; 4) To determine the current knowledge related to stroke care and rehabilitation service provision by conducting a scoping review. Second was solution design phase that was set to develop a new contextual model for in-patient stroke care and rehabilitation in Malawi. The setting for the research project is described with an overview of the country, Malawi, the health system delivery, the four referral hospitals across the country and their respective medical wards where patients with stroke are admitted. An overview of different data collection methods and instruments, and data analysis is provided. Motivation for the same is highlighted. Ethical considerations have also been explained.

2.0 Overall research approach

A multi-method approach was used to gather relevant data towards development of the MoC. "Multiple methods are used in a research program when a series of projects are interrelated within a broad topic and designed to solve an overall research problem" . Tashakkori and Teddlie noted that the main advantage of a multi-method approach includes triangulation to approve data and results. It combines a range of information sources, strategies, or perceptions and imagination by finding new or dumbfounding variables that fortify further work and extending the scope of the research to take in relevant angles of the circumstance. The multi-method approaches applied in this PhD by publication included qualitative and quantitative strategies, and a scoping review complete the assessment phase. Nominal Group technique has too been highlighted systematically within the design stage for the MoC.

2.0.1 Phase One: Diagnostic Phase

This was achieved by quantitative cross-sectional studies in the four central hospitals; qualitative study at the largest and "representative" referral hospital, Queen Elizabeth Central Hospital. The quantitative and qualitative studies covered the first three objectives of the project, namely: 1) To determine and explore the process of care of stroke patients in Malawi; 2) To determine patients with stroke and caregiver satisfaction with care and rehabilitation service delivery in Malawi's central hospitals; 3) To determine stroke patient outcomes at discharge and; Scoping review on acute stroke care in LMICs was then carried out 4) To determine the current knowledge related to stroke care and rehabilitation service provision. This section describes the approaches in detail and the output studies are highlighted.

2.0.1.1 Quantitative research approach and design

Quantitative research is a type of research into a social phenomenon by testing a theory which is comprised of variables that are measurable by numbers and analysed using statistics, thereby determining if the theory predicts the phenomena of interest. The researcher selects a topic from within a general area of study, sets out to collect data using standardised questionnaires to participants who are recognized through different forms of sampling, ordinarily random sampling (Dudwick, 2006). After factual examination, the quantitative analyst creates hypothesis by looking at examined data and background information on the study issue and the questions being examined and comparing the findings with past research findings to draw out its more extensive implications in a report (Bernard, 2013). The quality of a quantitative study approach rests in its capacity to permit for a broader think-about owing to the more prominent number of study respondents. This manages generalisability of the results and permits more noteworthy objectivity and exactness of the findings (McNabb, 2015). This project covered Malawi's four central hospitals yielding more study participants, sufficient for quantitative study approach. A cross-sectional study design was used.

Cross sectional study design could be a type of research approach where either the whole population or its subset is carefully chosen and from which data is collected to assist in answering research questions of interest (Olsen, 2004). This sort of research is carried out at one time point or over a brief period, ordinarily to appraise the predominance of the outcome of interest for a given population (Levin, 2006). In spite of the fact that, by nature, it is not easy to form causal inference in a study when this design is utilized, it is moderately reasonable and conceivable for public health planning, understanding disease etiology, and for the generation of theories (Levin, 2006). Descriptive cross-sectional study design

in the current project was utilised 1) With 101 healthcare providers *(described in paper #1; chapter3 which partly addresses objective 1)* using a self-developed stroke process of care questionnaire to examine the process of care during service delivery; 2) With 114 adult patients with stroke and their informal caregivers*(described in paper # 4 in chapter 5, addressing objectives 2 and 3)* using the functional independence measure (FIM), 5-level EuroQoL-5 dimension version (EQ-5D-5L), Patients Satisfaction with Inpatients Stroke Care Hospital scale (SASC Hospital scale), and Caregivers Satisfaction with Inpatient Stroke Care Hospital scale (C-SASC Hospital scale) to determine stroke outcomes at discharge. These studies were executed in the country's referral hospitals.

2.0.1.2 Qualitative Research approach and design

Qualitative study is an investigative process where the analyst steadily makes sense out of the "phenomenon" by differentiating, comparing, imitating, cataloguing, and classifying the objects of study (Miles, 1984; Creswel, 2009). Pope and Mays' undertaking of qualitative research led to the development of concepts that helped to understand social phenomena in a characteristic setting with emphasis on experiences, implications, and views of participants (Pope & Mays, 1995), by means of the use of verbal data instead of scaled, calibrated estimations (Thomson, 2007). Qualitative investigation is important in health administrations because it not only allows researchers to get to areas not amenable to quantitative investigation, but it is, additionally, a prerequisite for great quantitative research, especially in regions with exceptionally small past studies (Pope & Mays, 1995). Malawi is one of the LMICs, with a paucity of research activity on this topic and without a stroke model of care as advanced in this project. However, there are challenges associated with qualitative research, such as researcher subjectivity and biases particularly during analysis of data. In addition, the process is time-consuming, costly, and difficult to generalise findings due to the small sample size and differences in settings. Measures to address these limitations were carried out in this researcher's respective papers.

The qualitative exploratory study design was utilised to determine the nature of the problem and understand it without being conclusive about the evidence through use of unstructured interviews. The FDG that were conducted at Queen Elizabeth Central Hospital in the Southern region of the country led to an understanding of the state of stroke care (*paper #2; chapter 4 which partly addresses objective 1 of the project*) and challenges to care provision (*paper # 3; chapter 4*) in the resource-poor country of Malawi. Focus group discussions were utilised to capture data from service providers, patients with stroke, and their informal caregivers.

Focus group discussions have their origins in social science research from the 1930s and 1940s, following frustrations by the limits of survey research. It was then popularised by private marketing firms from 1950 – 1980. Academic revival has since then strengthened the use of focus group discussions as a good way of exploring a topic.

This study utilised focus group discussions to capture attitudes, practice, and opinions about stroke care in Malawi's central hospitals. Morgan described focus group discussion as an intermediate data collection method between two principle means of collecting qualitative data, which are participant observation and open-ended (individualised) in-depth interview. On the one hand, the power of focus group discussion over participant observation is in its ability to observe a large amount of interactions on unobservable attributes such as attitudes and decision-making processes of study participants within a short period. However, according to Morgan , the limitation of focus group discussion when compared to participant observation is that it does not provide a naturalistic environment where true behaviours and the culture of the group is captured as in long-duration participant observation. On the other hand, focus group discussion is also stronger when compared to open-ended (individualised) interview as the researcher can observe participant interaction and learn differences and similarities on opinions and views about the topic of research interest. It is impossible to observe the same in open-ended (individualised) interviews.

As noted, this study aimed to develop an innovative contextual model of stroke patient care and rehabilitation in Malawi. Focus group discussion was used as an adjunct data-collection method to gather qualitative data. The researcher opted for the focus group discussion to capture data from professionals through three different panels; service providers, patients with stroke, and informal caregiversof the patients. The service providers' heterogeneity and the fact that they follow duty roster would make it difficult to observe them in their natural settings at the same time. If it was possible to observe them in their natural settings, participant observation more than focus group discussion would be best suited. Focus group discussion was an attempt to explore participants' attitudes and decision-making process in the care of patients with stroke in central hospitals, which cannot be explored by participant observation . Better than an open-ended (individualised) interview, the focus group discussion was expected to explore stroke care phenomenon in an environment that enabled participant interaction differences and similarities to be observed.

The participants in the group were homogenous, since they all provided care to the patients with stroke (service providers group), or they were patients with stroke (second group), or they were informal caregivers for patients with stroke (third group). However, the service providers were, by researcher design, intrinsically heterogeneous in that they belonged to three different professional categories of health care providers: physicians, rehabilitation personnel that included physiotherapists and rehabilitation technicians, and nurses. In line with Schutt's work "Investigating the Social World", this researcher hoped that the service providers with the common goal of improving the outcomes for patients with stroke would be more willing to share their feelings and experiences. On the other hand, by being heterogeneous in professional background, the service providers' focus group could spark more ideas . The power brought through heterogeneity could be pertinent to the development of the desired innovative model of care.

Complemented by quantitative cross-sectional studies, this design helped to provide triangulated and clear data related to stroke care and rehabilitation in the country, where research data was sparse and gaps were easily noted.

2.0.1.3 Scoping review

A scoping review is a scientific process, also referred to as 'mapping,' "a process of summarising a range of evidence in order to convey the breadth and depth of a field". Extending this explanation, Mays et al. simply stated the aim of a scoping review, "to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as stand-alone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before". Scoping reviews are carried out without emphasis of quality of included articles, a sharp contrast from systematic reviews where authors typically assess the quality of included studies (Rumrill, 2010; Grant, 2009). The widely used scoping review methodology is that which was proposed by Arskey and O'Malley .

This project utilised scoping review framework by Arksey and O'Malley (2005). Accordingly, this framework is a five-stage-process with an extra expert consultation stage. In Stage 1, the researchers identify the research question. Arksey and O'Malley said, research question must be wide so that relevant literature is not missed out; Stage 2 is where relevant studies are identified.
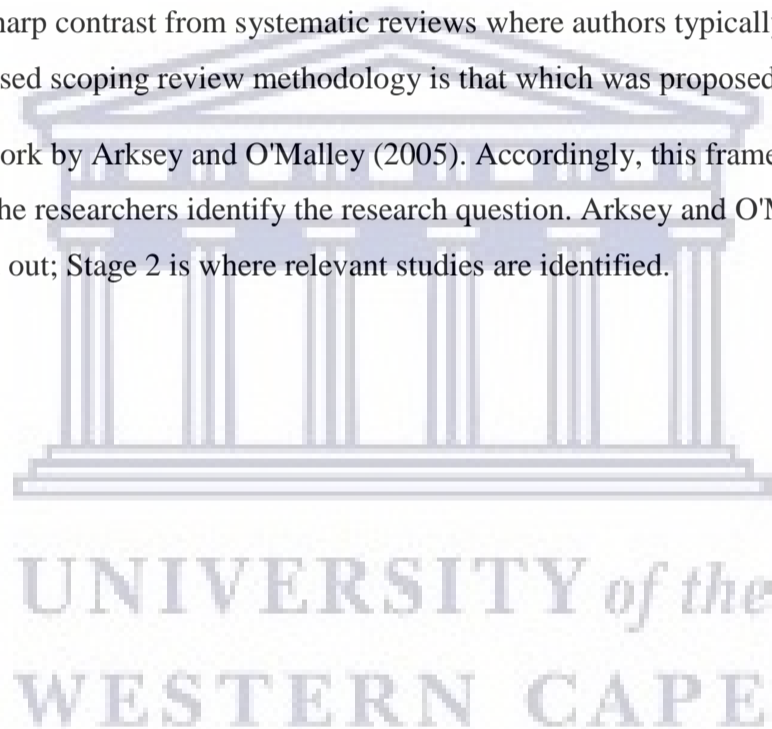
Table 2.1 Arskey and O'Malley Framework, adapted from CQUniversity Library O'Malley's

Arskey and O'Malley Framework Stages		Description
1	Identifying the research question	The first step involves formulating the research question and during the process, researchers should keep in mind the aspects of the research they are hoping to identify such as interventions or patient population. In keeping the research question broad enables researchers to explore the breadth of literature available to assist in answering the question.
2	Identifying relevant studies	The scoping search needs to be as comprehensive as it can be in identifying both published and unpublished studies, therefore it is important for researchers to search various sources such as, electronic databases, reference lists, hand-searching and know professional networks for conference proceedings and newsletters. During this initial stage the feasibility of undertaking a scoping review needs to be considered (time and cost), therefore it is important for researchers to establish time span and language limits to apply to the search strategy. Once the search terms, time span, language and resources selected the search is undertaken.
3	Study selection	The selection of studies to be included in the results list can be determined by applying the ad-hoc inclusion/exclusion criteria formulated from the research question. Two reviewers undertake this process. Researchers can also apply learned knowledge to the inclusion and exclusion of studies. Once the reviewers have completed the initial review of title and abstracts, the process of applying the inclusion/exclusion criteria to the full text of studies identified as best in answering, the research question is undertaken and a final decision on the studies to be included for analysis are decided upon.

4	Charting the data	'Charting the data' is the process of charting key pieces of information from the primary studies included in the final analysis.
		Charting enables the researcher to build a picture of theme's that come through in the literature. According to Spencer, L. and Ritchie, J. (2002) charts are set up with headings and subheadings which can be derived from a thematic framework. They lay out of the charts "will depend on whether analysis is to be thematic (for each theme across all respondents) or by case (for each respondent across all themes) (Spencer & Ritchie, 2002, pp. 182-183).
		Coding Part 2: Thematic Coding by Graham R Gibbs provides a short lecture on how to extract themes from text. (YouTube)
		Software such as NVivo can also assist in charting the data from the studies included for analysis. Researchers can also create a chart for recording data in Excel.
		The data recorded could be a mixture of general information and specific information such as population included in the study, intervention/s and outcome measures.
5	Collating, summarizing and reporting the results	In a scoping review, researchers do not need to synthesize the evidence found when charting the data. The approach taken is on which includes "some analytic framework or thematic construction in order to present a narrative account of existing literature" (Arksey & O'Malley, 2005, p. 27).
		When writing the results a researcher can also include charts or tables of mapped literature as this can shed light on the methods used and an indication of the breadth of literature available related to the research question.
6 (optional)	Consultation exercise	An opportunity for researchers to collaborate with other professionals and consumers. Undertaking this step may provide researchers with further publications that not identified in the undertaking of a scoping review and further insights/personal experiences related to the researched topic.

In Stage 3, researchers select study articles. There is a high likelihood that the scoping review will yield an excessive number of articles in the area of interest due to its lack of inclusion and exclusion criteria at the beginning. However, it is a more inclusive scan of the literature than used in a systematic review.

Stage 4 involves "charting" the data. Ritchie and Spencer said "charting" depicts the procedure for integrating and interpreting qualitative data by filtering, recording and sorting material based on key issues and topics that arise .

Stage 5 includes collating, outlining, and detailing the outcomes. For clarification on Arksey and O'Malley's framework, refer to figure 1 above.

Use of the scoping review was relevant in this project in Malawi, a less-developed country with a paucity of its own research, a limited number of human resources for health generally, and rehabilitation personnel, in particular. The aim of the scoping review in this project was to document evidence of stroke care and service conveyance in LMICs *(paper 5 in chapter 6)* that would way better illuminate advancement of a context-fit stroke MoC for Malawi.

2.0.2   The Solution Design Phase

This section present the solution design phase, which adopted Nominal Group technique (NGT) as a method to gain consensus on ideas from a group of professionals. The resulting paper has been published as a chapter in a book entitled, "Malawi: Its History, Culture, Environment, Education and Healthcare", under the title, "*Stroke Processes of Care in Malawi: Challenges and Potential Solutions*".

2.0.2.1 Nominal Group Technique

Nominal Group Technique (NGT) is the research approach that "combines quantitative and qualitative data collection in a group setting, and avoids problems of group dynamics associated with other group methods such as brainstorming, Delphi, and focus groups". The NGT approach was initially depicted in the 1960's as a method that encouraged compelling group decision-making in social psychological research studies (Delbecq, 1971). Since then, the method is broadly perceived and utilized in education, health, social service, industry, government associations, and related areas. The NGT are typically applied in situations that require identification of problems, designing solutions, and launching priorities (Delbecq, 1971; Jones, 1995). Its purpose is, therefore, to generate information as required in the area of interest that can consequently be prioritised through discussion in a group setting of, usually, 5-9 participants or, sometimes, more (Thomas, 1983; Twible, 1992). NGT is characterised by a pre-meeting with identified participants, limiting participant input to a single assembly lasting up to two hours, assignment completion and quick dissemination of outcomes to the group , and with limited researcher-bias as the process is highly structured. NGT involves four steps as seen in the figure below. The analysis and reporting of NGT data follow a mixed method approach, hence inductive content analysis (Patton, 1990) is often used that verifies individual participant comments to those recorded on a flipchart. Quantitative data from scoring and ranking methods are also analysed to identify group priorities.
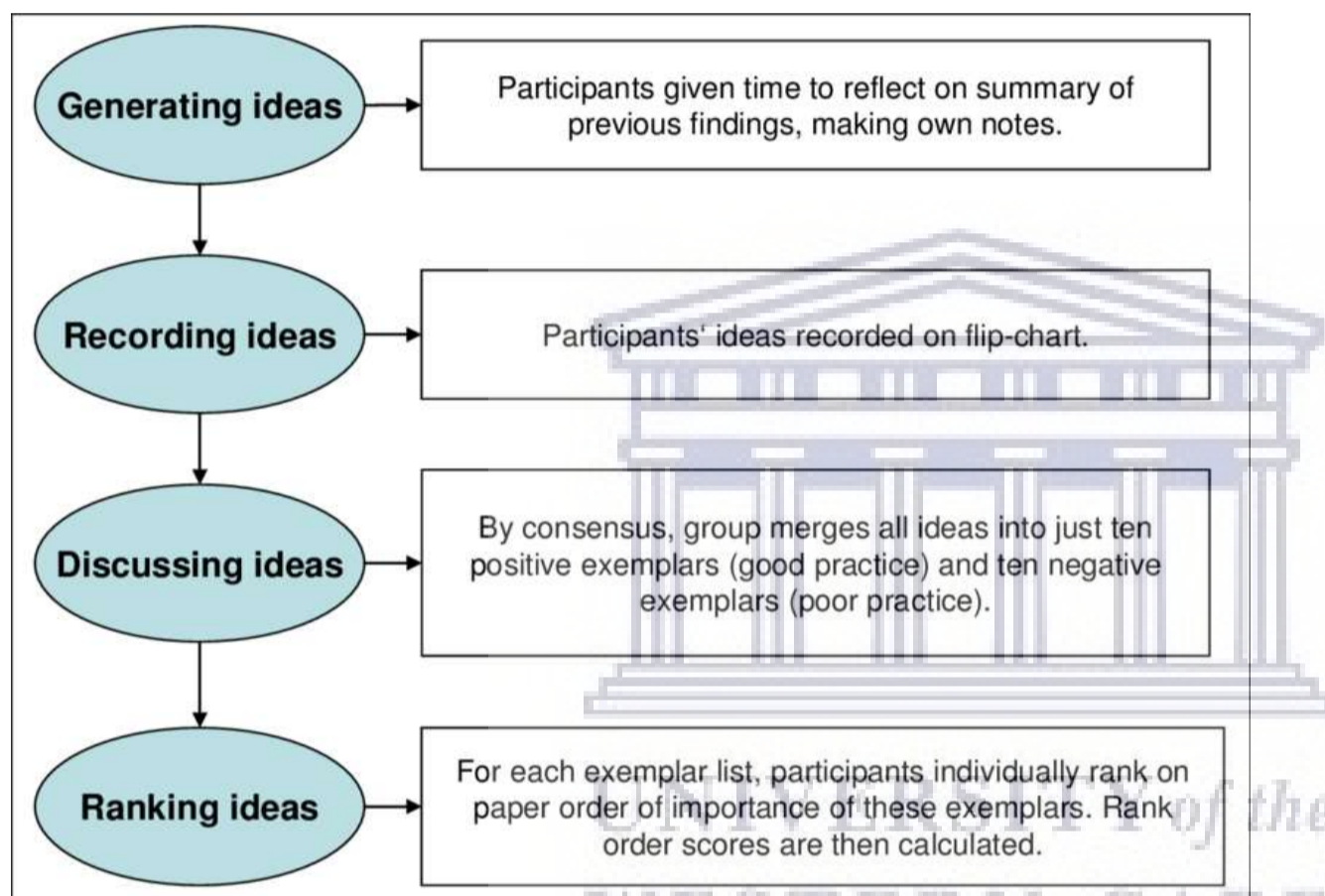
Figure 2.1 Nominal Group Discussion Process

Although NGT requires intense preparation, and minimises discussion that would allow for the complete generation of options from participants, there is less fortifying group process than other procedures (Sample, 1984), it does produce a more noteworthy number of thoughts than conventional group discourses and balances the impact of people by restricting the control of dominant opinion makers (Dunham, 1998; Potter, 2004), as is the case in brainstorming, and focus groups .

In this project, four-step-sessions occurred: individual writeup (generating ideas), round-robin feedback (recording ideas/options), discussion (discussing options), and voting on options (ranking them). Specific information on data collection method for NGT is highlighted in chapter 8.

Table 2.2: Project phases, objectives, methods and key deliverables

Phase	Objectives	Study design/	Key deliverables

		Data collection tools and sample	
Diagnostic phase	1) To determine and explore the process of care for patients with stroke in Malawi	Survey amongst 101 Service providers, (22 rehabilitation personnel [15 physiotherapists and 7 Rehabilitation technicians], 29 physicians and 51 nurses. Using Measure of Processes of Care for Service Providers (MPOC-SP (A) and Stroke Processes of Care Questionnaire FDGs among 10 service providers (5 physiotherapists, 5 nurses), 6 patients with stroke, and 7 Guardians Semi structured interviews among 4 physicians (medical doctors).	**Manuscript 1 as chapter 3** Stroke Process of Care in referral hospitals: A Cross-Sectional Study in Malawi's Referral Hospitals **Manuscript 2 as chapter 4** State of care and rehabilitation for people with stroke at Queen Elizabeth Central Hospital in Malawi: A qualitative report. **Manuscript 3, a section in chapter 4** The challenge to providing stroke care and rehabilitation in less-resourced country: Lessons learned. This paper was published in Journal of Global Health Reports. DOI: 10.29392/joghr.3.e2019049.
	2) To determine patients with stroke and caregivers' satisfaction with care and rehabilitation service delivery in Malawi's central hospitals	Survey among 114 patients with stroke and their respective caregivers, utilizing 1) Stroke patients Satisfaction with Stroke Care (SASC) hospital scale; 2) Care Givers Satisfaction with Stroke Care (C-SASC) hospital scale	**Manuscript 4 as chapter 5** Patients with stroke's outcomes and satisfaction with care at discharge from central hospitals in Malawi: A cross-sectional descriptive study in a limited resource area. Published in Malawi Medical Journal: DOI http://www.mmj.mw/?p=7710).
	3) To determine stroke patient outcomes at discharge	Survey among 114 patients with stroke, utilizing: 1) Functional Independence Measure to determine client abilities on various self-care and activities of daily living tasks at discharge; 2) EuroQol- 5 Dimension (EQ-5D) questionnaire to determine stroke patients perceived quality of life at discharge.	**Manuscript 4 as chapter 5** 1)Patients with stroke's outcomes and satisfaction with care at discharge from central hospitals in Malawi: A cross-sectional descriptive study in a limited resource area. Published in Malawi Medical Journal: DOI http://www.mmj.mw/?p=7710).
	4) To determine the current knowledge related to stroke care and rehabilitation service provision by conducting a scoping review.	Scoping Review Based on framework developed by Arksey, and O'Malley (2005). Literature published/gray between 2010 - 2017	**Manuscript 5 as chapter 6** Scoping review of acute stroke care management and rehabilitation in LMICs Published by BMC Health Services Journal https://doi.org/10.1186/s12913-019-4654-4

Solution design phase	**Main objective:** To develop a new contextual model for in-patient stroke care and rehabilitation in Malawi. **Sub-Objectives** To gain consensus on the guiding principles and recommendations as generated from diagnostic phase To generate a stroke care pathway at a referral hospital To generate and gain consensus on stroke care structure, process, and outcomes	Nominal Group technique among 9 inter-professional participants (one medical registrar, two emergency nursing officers, two nursing officers (medical), two physiotherapists, one radiology technician and one health systems manager)	Manuscript 6 as chapter 7 A contextual model of care and rehabilitation for patients with stroke in Malawi: The design phase. Published as a chapter "Stroke Processes of Care in Malawi: Challenges and Potential Solutions" by Nova Publications in a book entitled "Malawi: its history, culture, environment, education and healthcare" https://novapublishers.com/shop/malawi-its-history-culture-environment-education-and-healthcare/

2.1   Research Setting

This project was carried out in Malawi where the researcher lives and works. The country is located in southeast Africa, bordered by Zambia to the northwest, Tanzania to the northeast, and Mozambique to the east, south and west. Malawi is over 118,000 km2 in estimate, with an evaluated population of 18 million people. This landlocked nation is one of the low income countries in the world. The economy is generally based on farming, which constitutes 90% of trade profit (Malawi Growth and Development Strategy 2006 -2011). Malawi has a low investment in health, estimated at 20 dollars (US) per capita expenditures (WHO, 2008). Be that as it may, the health care conveyance framework comprises of government facilities, Christian Association of Malawi (CHAM), and private service suppliers (WHO, 2008). The health services, complemented by conventional healers, have been reported to be accessed by individuals with inabilities, with 60% of those in need getting the services (Loeb & Eide, 2004). Additionally, until 2010, Malawi only trained rehabilitation technicians. The introduction of a formal physiotherapy program at the College of Medicine (COM) in 2010 has seen a growing number of qualified physiotherapists. However, meeting the rehabilitation needs of a country of 18+ million people remains a tall order for Malawi. Additionally, beyond the inadequacy of rehabilitation personnel at any level, there is the lack of overall recognition for its very critical importance in patient management .

This study, the first of its kind, was conducted in Malawi's four central hospitals; two in the southern region and one in each of the central and northern regions. The country's health service conveyance framework is four-tiered, comprising of community, essential, auxiliary, and tertiary

care levels. According to the African Monitor, at the community level, the health care service is provided by personnel with basic knowledge in health care, called health surveillance assistants. The health care focus at the community level is preventative interventions. Primary care, on the other hand, is delivered through clinics and health centers. Secondary and tertiary care services are provided by district and central (referral) hospitals, respectively. The country has 28 district hospitals and four referral hospitals. As part of the diagnostic phase of MoC development, research was conducted in the eight medical wards of the four central hospitals across the country's southern, eastern, central and northern

** Ministry of Health (2011). Malawi: Health sector strategic plan 2011-2016. Draft III. Lilongwe, Malawi: Government of Malawi.

regions. Although the four are classed referral hospitals, they also operate as district hospitals as there are no distinct district hospitals in those districts where they are located. The choice of the four hospitals border on fluidity of their services delivery, they provide both secondary and tertiary care services. These referral hospitals, however, receive some patients requiring critical care medicine, from health centers of the district of their location, and the district hospitals of the region. The referral hospitals included a 1400, 1000, 500 and 306 bed-capacity-hospital in the south, central, eastern and northern region of Malawi respectively.

Based on the 2011 Hospital report, the 1400-bed-capacity, Queen Elizabeth Central Hospital treated 504,320 outpatients and 91,332 in-patients. It had 1154 personnel and 75 medical personnel were estimated to run stroke care wards/settings at QECH (15 rehabilitation, 55 nurses, 8 medical doctors). Averagely 18 patients with stroke were see per month. The 2014 hospital report (according to hospital registry) for the 1000-bed-capacity Kamuzu Central Hospital in the central region of Malawi treated 180,000 out patients and had 41,000 admissions. It had 530 personnel and 71 of them were in stroke care setting at KCH (17 rehab, 47 nurses, and 7 medical doctors). The report further show the hospital admitted 20 patients with stroke per month. The 306-bed-capacity Mzuzu Central hospital in the northern region of Malawi treated 159,000 people as outpatients and had 77,000 admissions (2014 statistics). It had 276 personnel with 23 personnel in stroke care settings (3 rehab, 11 nurses, and 9 medical doctors). The hospital admitted 16 patents with stroke per month. Zomba Central hospital situated in the eastern region of Malawi is a 500-bed capacity hospital. Number of pts were not seen not immediately available. However based on personal communication at the hospital registry, in 2014 the hospital had 280 personnel. Twenty five (25) of them were in stroke care setting (3 rehab, 15 nurses, 7 medical doctors). The hospital admitted 17 patients with stroke per month. Therefore the project expected to have 71 patients with stroke per month from the four hospitals (18 patients per hospital, average); and 187 medical personnel directly involved in stroke care (40 rehab, 84 nurses, and 63 medical).

At the four settings, patients with stroke come into first contact with the hospital, from nearby Health center, or from district hospital (severe cases) at the Casualty or Emergency Department or Accident and Trauma Center. They are then admitted to medical wards and consequently, referred for physiotherapy, which is the main rehabilitative care available in the central hospitals.

2.2   Data Collection

2.2.1   Data collection Instruments

In this section, six quantitative and a qualitative focus group discussions serve as data collection instruments. The quantitative data collection instruments consist of the Stroke Process of Care Questionnaire, Measures of Processes of Care for Service Providers (MPOC-SP), Functional Independence Measure (FIM), (EQ-5D-5L), Patients Satisfaction with Inpatients Stroke Care (SASC Hospital scale), and Caregivers Satisfaction with Inpatient Stroke Care (C-SASC Hospital scale). In addition, there is focus group discussion detail as another data collection instrument.

2.2.1   Stroke Process of Care Questionnaire

2.2.1.1   Introduction

This 37-item stroke process of care questionnaire (Appendix 12f) was developed by the principal investigator using a Likert scale, and informed by the five-step Radhakrishna questionnaire development process . The four-part questionnaire captured 1) demographics, then participants knowledge, attitude, and behavior regarding: 2) inter-professional stoke care, 3) referral system, and 4) the care process.

2.2.1.2   Development process

2.2.1.2.1   Background

The aim of the study was to develop a contextual model of care and rehabilitation in Malawi. A questionnaire was developed to partly answer the first objective of the study: to determine and explore the process of care of patients with stroke in Malawi. The target audience of this

questionnaire was the services providers grouped in three panels: rehabilitation personnel, physicians, and nurses. In Malawi, the services providers are those who provide care to patients with stroke after receiving a minimum of a three-year diploma course in any of the rehabilitation, nursing or medical fields to as high as PhD. Radhakrishna said, a clear understanding of what the study is answering and knowledge of the target audience of the questionnaire is prerequisite and forms a good basis for a valid questionnaire.

2.2.1.2.2 Questionnaire conceptualisation

The researcher transitioned into the second phase of questionnaire development by recollecting literature about stroke processes of care with questions structured based on the immerging literature . The Researcher grouped the questions into three sections. Section 1: seven questions to seek knowledge, attitudes, and reflections about inter-professionalism in care of patients with stroke and had three questions. Section 2: two questions to seek participants' hospital knowledge about the referral system along the stroke care continuum. Section 3: nine questions to collect participants' views, knowledge, and practice about process of care for patients with stroke.

2.2.1.2.3 Questionnaire format

The researcher then formed a panel of four experts in rehabilitation and medicine in Malawi, South Africa, the United States, and the Netherlands. To ensure improved quality of the survey questionnaire through content-validity-check, the experts were selected through direct contact for their experience in questionnaire development reflected in their articles as lead authors (South African, AR and Dutch expert, LDW), experience or knowledge of the construct being measured as stroke care specialist through snowballing (Malawian expert, MN), language experience through expertise in education curriculum development, English-first-language speaking background and co-authorship in research paper (US expert LG) and above all, whether the experts were willing and available to participate. In this third phase, the experts reworked the draft statements and questions formed initially by the researcher and made some additions. The key domains during the expert validation process were representativeness related to how the items encompassed the construct of interest, clarity or proper wording of the items, and relevance of the item to a specific aspect of the construct. There was also selection of appropriate scales of measurement, questionnaire layout, format and question ordering by the experts. After five rounds of communication and correction based on feedback at each communication level, through track changes via email, a final 31 questions and six sub-questions draft questionnaire was produced. It had four sections as follows:

Section 1: The purpose was to gather participants' demographics such as age, sex, profession and education background, and duration in stroke patient-care setting. It had six questions. Section 2: The purpose was to gather data on inter-professional stroke care. It had eleven questions on opinions about general care of patients with stroke in their hospital, team meetings and frequency of meetings, contacts and collaboration with professionals of other fields in the care of patients with stroke, and any other comments participants had regarding stroke care. It had 11 questions. Section 3: The purpose was to gather information about the referral system, from and to where patients with stroke are referred and by whom. Section 4: The purpose was to collect service providers' views regarding stroke care processes. This section had 11 questions on neurological assessment, swallowing screening, DVT prevention/ prophylaxis, temperature regulation and fever managements, hypoxia management, risk factor management, early mobilisation, activities of daily living, prevention of complications due to immobility, provision of assistive devices, therapy provision and therapy frequency and a comment section.

2.2.1.2.4 Establishing face and content questionnaire validity

The sum of efficient or built-in mistake of the survey questionnaire was established by employing a board of specialists and a field test (Radhakrishna, 2007).The questionnaire was sent to four independent professionals who were not involved in its development (a physiotherapist, occupational therapist, nurse and medical doctor), asking for their opinion on the new questionnaire. They all agreed with the purpose of the questionnaire. The instrument was approved as valid in content, appropriate for target study participants, the service providers, and comprehensive enough for the study objective. It was, however, perceived to be too long for the busy schedules of service providers in low-resourced service areas such as Malawi. Based on the necessity of the items listed, it was difficult to shorten the questionnaire based on the observations of the professionals. However, the researcher would allow for a longer time for questionnaire response by respondents.

2.2.1.2.5 Establishing questionnaire reliability

The random error in estimation (reliability), showing the exactness of the measuring instrument was completed through a pilot study, where the questionnaire was administered by the principal investigator at QECH. Pilot study alludes to a smaller than expected form of a full-scale study (in some cases called 'feasibility' study). It can moreover allude to pre-testing of a specific research instrument such as a questionnaire or interview schedule. The value of pilot study is well captured by Blaxter, et al. when they stated, "You may think that you know well enough what you are doing, but the value of pilot research cannot be overestimated. Things never work quite the way you envisage, even if you have

done them many times before, and they have a nasty habit of turning out very differently than you expected". It is against this background that the researcher had to pilot-test the developed questionnaire in order to prevent waste of resources. Piloting prevent wastage through what Kimberlin and Winterstein highlighted as the value of pretesting or piloting a measuring instrument. It involves identifying the error sources and refining the measuring instrument to minimise measurement error before implementation of data collection using the developed questionnaire. The developed instrument was administered to ten pilot subjects in the same way as it would be administered in the main study. Piloting was done at the biggest referral hospital, Queen Elizabeth Central Hospital. The participants were briefed on the aim of the study. They were also encouraged to give feedback on ambiguities that may be experienced per question answered and to record the time each questionnaire would take for completion at their normal pace. They were also encouraged to state their recommendations on the state and quality of the questionnaire. The questionnaire took an average of 20 minutes to complete. Typographic errors and ambiguities in instructional statements were raised and corrected. It was then ready for use in the main study.

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2.2.2 Measures of Processes of Care for Service Providers (MPOC-SP)

2.2.2.1 Background
The Measures of Processes of Care for Service Providers (MPOC-SP) (appendix 12e) is a 27-item self-administered questionnaire. It has four domains: Showing Interpersonal Sensitivity (10 items); Providing General Information (five items); Communicating Specific Information (three items); Treating People Respectfully(nine items). The questionnaire was used in this study to determine service providers' self-evaluation regarding family-centered care in their management of patients with stroke in the acute phase. Bamm and Rosenbaum highlighted the significance of family-centeredness in care provision that "A family-centered approach provides an important conceptual foundation for a contemporary model of health service delivery, as is evident from numerous studies". The researcher considered that family-centeredness is also the progressive concept in the development of a contextual model of care and rehabilitation of patients with stroke, the main aim of the present study.

2.2.2.2 Validity and reliability
Measures of Processes of Care for Service Providers (MPOC-SP) had been found in a Singaporian study that it is cross-cultural tool. It had also demonstrated validity and reliability both in pediatrics setting and among service providers for adult patients . MPOC-SP has demonstrated good internal consistency (Cronbach's alpha ranging from .76 to .88), test-retest reliability (intraclass correlation coefficients ranging from .79 to .99), and is valid. In addition, paired with the Stroke Process of Care Questionnaire, the MPOC-SP had been piloted with service providers at QECH, with no changes recommended as an outcome.

2.2.3 Functional Independence Measure (FIM)

2.2.3.1 Background

Developed in 1987, the FIM (appendix 12a) is used to objectively measure the functional status of persons with disablement that are admitted to an in-patient rehabilitation facility. Its use enables rehabilitation team members to know progress in the client's level of function following a series of therapeutic modalities. Hence, the use of FIM facilitates quality decision-making about whether or not to change a treatment approach or decisions about discharge planning. In addition, knowing the progress of intensive rehabilitation in quantitative terms is essential for achieving evidence-based care or practice. The Uniform Data System for Medical Rehabilitation , however, highlighted that FIM administration needs a well-trained person for accurate and comparable results.

Structurally, the FIM is an 18-item instrument that defines two statistically and clinically different indicators, motor and cognitive function. Specifically, thirteen items define disability in motor functions while five items define disability in cognitive functions.

2.2.3.2 Validity and Reliability
FIM instruments has been thoroughly tested for validity, reliability, responsiveness to change, feasibility for use, and its meaningfulness in clinical settings when administered by a qualified clinician . It takes 15 to 20 minutes to administer and has also been used in African studies. The instrument was translated into the local Malawi dialect by a qualified and independent translator at the University of Malawi and piloted for face validity at QECH, with good feedback from participants and taking 10 to 15 minutes to complete.

2.2.4 5 Level Euro Quol 5 Dimension scale (EQ-5D-5L)

2.2.4.1 Background

EQ-5D-5L (appendix 12d) is the latest version of EQ-5D-3L version, which was developed in the 1980s by the EuroQol group. It is an instrument used to describe and value health-related quality of life among patients in a clinical setting. Structurally, it has two parts, a simple descriptive profile covering combined functional and psych-affective areas, which are five in number, and a visual analog scale (VAS), which captures an individual's "health today".

2.2.4.2 Validity and reliability

As an instrument, the EQ-5D-5L has been tested in various studies and found to be reliable and valid. It was also tested with good results among acute patients with stroke**.** The instrument was translated into the local dialect by a qualified and independent translator from the University of Malawi and piloted for face validity at QECH, with good feedback from participants, and that it took participants 10 to 15 minutes to complete.

2.2.5 Patients Satisfaction with inpatients stroke care (SASC Hospital scale)

2.2.5.1 Background

The patient Satisfaction with Stroke Care (SASC) (appendix 12b) hospital scale was used to determine levels of satisfaction with stroke care and rehabilitation service delivery among patients with stroke.

2.2.5.2 Validity and Reliability

The SASC questionnaire was also found to be reliable and valid with a Cronbach's alpha of 0.80 and Intraclass Correlation Coefficients of 0.80.

2.2.6 Caregivers Satisfaction with inpatient stroke care (C-SASC Hospital scale)

2.2.6.1 Background

The Caregivers Satisfaction with Stroke Care (C-SASC) (appendix 12c) hospital scale was used to determine levels of satisfaction with stroke care and rehabilitation service delivery among informal caregiversof patients with stroke.

2.2.6.2 Validity and reliability

C-SASC is reported to have a Cronbach's alpha of 0.85, indicating good reliability with strong construct validity. Its authors highlighted that the scale is a promising instrument for measuring informal caregiversof patients with stroke's satisfaction with stroke care.

Together with the SASC Hospital Scale, the instruments were translated into local dialect by a qualified and independent translator from the University of Malawi and piloted for face validity at QECH, with good feedback from participants, and that it took the participants 5 to 10 minutes for completion.

2.2.7 Focus Group Discussion Guide

2.2.7.1 Background

A focus group discussion guide, which is also called a topic guide, is a questionnaire for focus groups but referred to as discussion "guide" and not a questionnaire, because its key aim is just to "guide." Regarding the guide, the moderator may decide to deviate from it, as participants bring up new and pertinent areas of discussion. According to Clark, when developing a questionnaire, the researcher needs to have a thorough thought in six areas:

1) There is a need to estimate duration of the focus group, as this will determine development of a reasonable number of questions that can be answered by the participants, estimating each question to cover 5 to 7 minutes for participants to fully give their responses. The three focus group discussion guides targeting service provider, patients with stroke, and informal caregivers had six questions each for 10 to 15 participants that were approached. Basing on the number of questions, the focus groups were designed to last between 50 to 105 minutes.

2) The FGD guide should have interviewer instructions. These instructions are the ones that tell the moderator when to do what. Development of this project's guides included the instructions by highlighting the information in brackets for example (Consent forms for focus group participants signed and demographic questionnaire filled in advance), (Turn on Tape Recorder), or in italics for example, *Probes for Discussion.*

3) Clarifying the aim and objectives for the FGD. Clark said, it was important to begin by writing out reasons you are doing the research, including specific questions you want answered, and what decisions you will use the research results to help inform. The guides for the current project contained three statements that spelled out the aim and objectives: 1) We are here to discuss as a group about your experiences with stroke care and rehabilitation service delivery in the hospital; 2) It is hoped that the information that we will gathers will assist in producing a new way of caring for patients with stroke in hospitals; 3) We asked you to participate because you are one of the team members providing services (appendix 11)/patient with stroke (appendix 9)/guardian for patients with stroke (appendix 10) at one of the central hospitals in the country. Additionally, the questions that were included were open ended. Six questions to service providers are highlighted as an example as: 1) Let's start by explaining the processes that patients with stroke undergo during their hospital stay (from admission to discharge); 2) Specifically, what do you do when a patient with stroke patient is referred to your section; 3) In your opinion, what works well regarding care/rehabilitation service delivery in your section? 4) In your view, what are the challenges regarding service delivery in your section? 5) From your experience, what should be done to service delivery for improvement in your respective sections and; 5) Any additional information that you would like to provide (a turn for each participant).

4) Consideration of warm-up sections. Clark said, prior to your questions, devote the first few minutes to warming-up the participants, to relax them in a group setting, and get them to start thinking about the subject generally. This is done by giving them very broad questions initially. After calling for introductory statements from each participants, among patients with stroke as an example, "Briefly tell us who you are (no names), where you live, what you do ", a general question was given, " Let's start the discussion by talking about how stroke happens and how you went to the hospital." This question was aimed to explore individual stroke onset experience but also initiate the thought of the day's topic.

Fifth, the main section. This is where all the questions were asked. The author warned against closed-ended and leading questions. "Really you want to see if participants mention it themselves, without being prompted" . The current project's FGD guides had questions that were broad and not specific on expected answers. For example, one of the questions to informal caregivers was, "Explain the processes he/she went through during your hospital stay (from admission to discharge)". From this, based on responses the moderator would use probes to explore answers to more specific questions and obtain deeper meaning to the responses.

Lastly, in the closing section, the investigator may want to spend the last few minutes of the discussion checking the understanding of the participants' responses. This called for shorter list of questions by the investigator. The guides in this project allowed for summary of the discussion and participant feedback on the summary. Additionally, each question ended with rounding up or putting together the information from different participants, making sure the meaning of the responses were as intended by the participants.

2.2.8   Nominal Group Technique data collection process

Nominal Group technique (NGT) was adopted to gain consensus on ideas from a group of professionals at the country's largest referral hospital, the 1400 bed-capacity Queen Elizabeth Central Hospital (QECH). NGT is reportedly effective in problem identification, development of solutions, and establishing priorities (Carney, 1996; Jones, 1995; Justice, 1990). Nine purposefully selected information-rich participants took part during the workshop. The aim of this phase was to develop a contextual model for inpatient stroke care and rehabilitation by following three steps: generating a stroke care pathway at a referral hospital, gaining consensus on the guiding principles and recommendations, generating and gaining consensus on stroke care structure, process, and outcomes.

Principles for a preferred MoC and rehabilitation were drafted based on literature and findings during the diagnostic phase. Wider consultation on the principles with key stakeholders was completed interprofessionally (Agency for Clinical Innovation, 2013).

Four-step-sessions of individual write-up, round-robin feedback, discussion, and voting on ideas was implemented to address the objectives. On the day of the meetings, five documents and a pen were placed on each table in a U-shaped sitting pattern. The room also had a projector for computer images and a free-standing flipchart. The five documents were 1) The Focus Group Discussion Confidentiality (FGDC) form, demographic questionnaire, agenda and schedule, worksheet (appendix 12g), and ideas rating sheet (Appendix 12h). Participants were asked to complete and return the confidentiality form and the demographic questionnaire within the first few minutes.

The researcher started the discussion session by introducing himself, welcoming the participants, and explaining the aim of the meeting and expected outcomes. He then presented the insights from the assessment and diagnostic phases

After the 1ˢᵗ presentation, the moderator read each question, with appropriate pacing for each participant to have sufficient time to answer before moving on. The participants were asked to generate as many ideas as possible without discussing them with others. Based on the level of the study participant's knowledge, the process worked well, producing a sound list of ideas during the round-robin feedback session. Because of time constraints, the participants were instructed that they could add other ideas during the following session.

After every question was individually answered, the moderator called for the round-robin feedback session, where participants were asked to read their ideas aloud. Here, the facilitator also encouraged the participants to add new ideas after listening to other comments during their individual turn and not repeat comments. The moderator recorded the ideas exactly as expressed by the participants on a flipchart. To avoid biasing the participants, the moderator did not take part in the idea generation and presentation although the lead researcher took part as a tenth participant.

The participants were then asked to discuss the generated ideas, making sure each participant understood what the ideas meant or represented for the ranking phase that followed. During this process, ideas that appeared similar were grouped together after participant consensus.

After discussing and clarifying the ideas, the participants were asked to privately vote to prioritise the options and rank them on the rating sheet in order of importance from the best (ranked 1) to the least (ranked 5). The moderator then tallied the options on the flipchart according to participant feedback. Five options were identified which were then subjected to another round-robin ranking to determine the order based on importance.

2.3   Data Collection Instruments Translation

After seeking permission to use the SASC Hospital Scale, C-SASC Hospital scale, FIM, and focus group discussion guides, these were translated into Chichewa, the major Malawian local dialect (by MK from Linguistics department, Chancellor College, University of Malawi), and then back translation to ensure content accuracy. These instruments were translated because they would be used to survey views of patients with stroke and informal caregivers who have varied literacy backgrounds.

2.4   Procedure for overall data collection

2.4.1   Training of research assistants

After obtaining permission to conduct the study from relevant authorities, four research assistants (three intern physiotherapists and one rehabilitation technician) who were purposefully selected were individually trained in two phases. Phase one was orientation to the study aim and objectives. They were also orientated to data collection instruments including the keys of some questionnaires such as Functional Independence Measure, SASC Hospital Scale and C-SASC Hospital Scale. They were also oriented to ethical issues i.e. protection of human subjects in this study, issues of confidentiality; that data collected is private and should be kept as such. Research assistants were taught on data collection procedures, including participant search and recruitment, questionnaire administration and collection, data sorting and storage, and their role in focus group discussion i.e. participant invitation, sitting arrangement, note taking and provision of logistical support. Phase two involved training them at the site of work, practically administered questionnaires, one from each participant groups in their settings.

2.4.2   Meeting with heads of Departments and Service Providers

After training, the researcher and research assistant met the head of department who advised on the day to make a presentation of study synopsis to team of medical doctor. This happened at two major central hospitals Queen Elizabeth and Kamuzu Central Hospital. Later, questionnaires were administered to the physicians who were individually invited to participate. For the nurse participants, the researcher and assistant held meetings with matrons of medical ward and briefed their teams in morning meetings. Then, the matron guided the research team to nurse in-charge of respective wards who would then guide the team to individual nurses. A meeting was held with individual nurse or sometimes group (if they are found in the office). The process happened with rehabilitation personnel in the physiotherapy department. Aim and objectives of the study were discussed and participants were then invited to take part. The research assistants then hand-delivered the questionnaires. An average of five days was allowed for participants to fill out the questionnaire with face to face and phone call reminders in between.

2.4.3   Identification of patients and informal caregivers

Trained research assistants accessed patient records on weekly basis to identify possible stroke patients who could participate in the study and their respective caregivers in the four institutions. The assistant also relied on in-hospital referral system where the medical doctors doing ward rounds in medical ward refers admitted stroke patients to the physiotherapy department. When identified, the research assistant was charting

inclusion/exclusion criteria and if found fit as study participant, the assistant would explain the purpose and the aim of the study using the information sheet (appendix 6 and 7) and invited them to participate in the study. After willingly signing the consent form (appendix 4), the stroke patient would fill out the FIM admission column. They would then be followed up to when discharge decision is arrived at by the physicians. On a day before discharge, the research assistant administered the three questionnaires (FIM discharge, EQ-5D-3L and SASC Hospital Scale) to the patient with stroke and one questionnaire, C-SASC to the respective guardian. This was happening in a room within the ward.   Addresses and phone numbers were collected for those who were willing to be contacted for focus group discussion at a later date.

2.4.4   Participant recruitment for focus group discussion

Communication to recruit study participant to the focus group discussion was initially made during questionnaire administration in the cross-sectional survey on the same study. Those who accepted to be contacted later gave in their phone numbers. For service providers group, this was easier as the participants had interest in stroke care, knew about topic of discussion from information sheet and questionnaire administration and prospective location which is within the central hospital and natural setting for the study participants. Holbrook and Jackson got a good turn out by study participants for the focus group discussion when he went directly to places where potential participants were likely to meet and socialise. Patients with stroke and caregiver group agreed to converge at the central hospital on agreed date and time. To make sure that required number of participants attended the focus group discussion, the participants were overbooked by one participant in each panel of service provider. Letter of invitation, detailing aim of the focus group discussion and the study was sent a week before, followed by Phone call reminders.

2.4.5   Focus group discussion process

After welcoming research participants to a round table focus group discussion, at Queen Elizabeth Central Hospital, the participants were asked to sign a focus group confidentiality binding form (appendix 5) to show that they understood the information given to them regarding the study and that they were willing to participate in the group discussion with a clause "I hereby agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group". Then, they responded to the demographic questionnaire.

The Moderator (researcher) then welcomed the participants by highlighting his background as a PHD student, aim of the study and that participants were asked to participate because they either provided services to patients with stroke admitted to the central hospital where they work (service providers group), or that they were living with stroke after admission to the central hospital (stroke patient group), or that they were primary informal caregiversto the patient with stroke who were once admitted and discharged from one of the central hospitals (informal caregivers group). Note-taker and logistic support assistant were also introduced to the focus group participants.

Issues about what focus groups are, were also highlighted: that the researcher and the two research assistants would be there to learn as they express their views regarding stroke care process; that it was not a meeting to achieve consensus but rather gathering information and; that the discussion would be audio-recorded and note-taken so that no information was missed out. Logistics and ground rules of the focus group discussion were then highlighted. The moderator had focus of the discussion, steering the discussion and noting which questions were sufficiently covered and that it was time to go to the next question. The note-taker, on the other hand, focused on capturing the details of the conversation and nonverbal behaviour. This team member, however, had the ability to make a probe in the course of the conversation so that he had a clear understanding of what an individual participant was putting across. The third assistant provided logistical support, checking-in participants, dealt with administrative issues, and handled latecomers. The roles and significance of the included research team members in the focus group discussion in the current study have been highlighted in literature.

After welcoming the participants, the moderator switched on the recorder, moving from inviting participant to ask any question, if any, regarding the focus group discussion, to the phase of self-introductions, and then to question time and probing. The moderator used a prepared protocol to guide the discussion. The guide had 6 question areas: 1) Let's start by explaining the processes that stroke patient undergo during their hospital stay, from admission to discharge; 2) specifically, what do you do when stroke patient is referred to your section; 3) in your opinion, what works well regarding care/rehabilitation service delivery in your section? 4) In your view, what are the challenges regarding service delivery in your section? 5) From your experience what should be done to service delivery in respective sections? 6) Any additional information? Focus group discussion for patients with stroke also answered six question areas: 1) let's start the discussion by talking about how stroke happened and how you got to the hospital; 2) explain the processes you went through during your hospital stay, from admission to discharge; 3) in your opinion, what worked well? What did you like about your hospital stay and treatment? 4) In your view, what didn't work well? What did you not like regarding the care you received while in hospital? 5) From your experience, what should be done to make hospital stay and care better for the

patients? 6) Any additional information? Similarly, the guardians' groups discussed on six question areas as well, thus 1) let's start the discussion by talking about how stroke happened to your loved one and how he/she got to the hospital; 2) explain the processes he/she went through during your hospital stay, from admission to discharge; 3) In your opinion, what worked well, what did you like about your hospital stay and treatment? 4) In your view, what didn't work well, what did you not like regarding the care you received while in hospital? 5) From your experience, what should be done to make hospital stay and care better for the patients? 6) Any additional information?

Focus group discussion guide for patients with stroke and informal caregivers were translated into local dialect, Chichewa, and checked for correctness.

2.5 Data management

Research data management (or RDM) depicts the organisation, storage, conservation, and sharing of data that's collected and utilized in a research project over the lifetime of a research exercise, including choices related to how data will be protected and shared after the project comes to a conclusion. Researchers, however, face challenges with keeping the data safe and secure due to limited data management skills. For example, research carried out in 2009 at the University of Minnesota found glaring evidence related to challenge with research data management skills because over a quarter of the researchers who participated reported to have lost important data due to the lack of a backup system; 72% used unsecured media, such as CDs, DVDs, and flash drives to back-up data. Such limitation among researchers challenge what Holbrook and Jackson said, that proper data management is the critical aspect of any research. In this project, the research team drew an agreement on data collection, data management, data use, and data storage, and protection before rolling out the data collection aspect of the research. Paper-based questionnaires were used to capture data and later electronically entered into a Microsoft Excel database. Stata v13.0 (Stata Corp, Texas, USA) was used for data cleaning and statistical analysis. The group discussion data were recorded as audio files and text files by the note-taker. Audio data was transcribed verbatim soon after the discussions, removing all participant personal information that could lead to their identification. The data was then carefully documented to enable sharing, if need be, at a later stage. Audio data and text data with potential to violate the principle of anonymity was then destroyed after the research process.

2.6 Data Analysis and Interpretation

Data analysis entails examining, arranging collected data, reducing the large body of data that the researcher has gathered for easy interpretation to unearth true meaning, draw conclusions, and support decision-making to solve pressing research problems (Kothari, 2004; Bryman, 2016). Quantitative analysis use statistics which are autonomous of the analyst deductive thinking, while qualitative investigation is subordinate on the researcher's analytic, integrative abilities and inductive thinking, including individual knowledge of the social setting where the data is collected. A deductive approach deals with "developing a hypothesis (or hypotheses) based on existing theory, and then designing a research strategy to test the hypothesis" through use of either univariate or multivariate analysis. An inductive approach, on the other hand, 1) condenses raw textual data into a brief, summary arrangement; 2) builds up clear links between study goals and the outline of discoveries from the crude data; and 3) helps develop an outline of the underlying structure of stroke care experiences as is the care in the current project, or just processes that are obvious in the raw data. See figure 3 below.
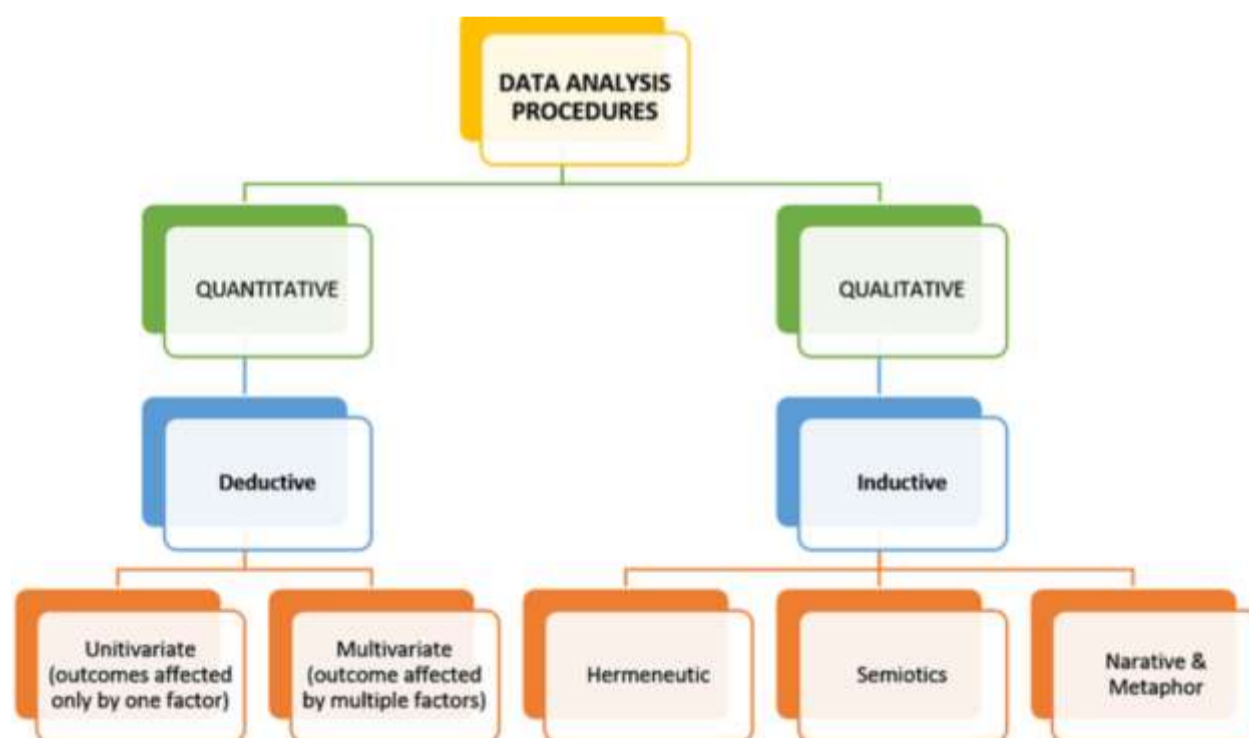
Figure 2.2 flow of quantitative and qualitative data analysis

In particular, after the data collection, the researcher identifies a level of measurement as the first step in quantitative analysis. Data can, therefore, be at four-measurement-level possibility , including 1) nominal data, which is basic classification of data without logical order e.g. male or female; 2) ordinal data, with logical order but without constant differences between values e.g. T-shirt size such as same, medium, and large; 3) interval data with logical order, continuous, and has standardised differences between values though it lacks natural zero e.g. Celsius degrees and; 4) ratio data, which has logical order, continuous, and has standardiszed differences between values, with a natural zero, e.g. height, weight, age, and length. When the level of measurement is determined, specific analysis technique is then chosen, including 1) Data tabulation, e.g. frequency distributions and percent distributions; 2) Data descriptive, e.g. Mean, medium, mode, minimum and maximum values; 3) Data disaggregation, which involves tabulation of data across multiple categories and; 4) Moderate and advanced analytical methods (regression, correlation, variance analysis). For quantitative data in this project, summary statistics were computed as median (interquartile range), having confirmed that continuous variables were not normally distributed. All normally distributed variables were summarised using mean and standard deviation (SD). Univariate associations were assessed using the Kruskal-Wallis Test for categorical variables and the Wilcoxon Rank-Sum Test for continuous variable. Simple bar graphs, pie charts, and scatter plots were plotted to visualise the distribution of variables. One-way tabulation was used to compute proportions for categorical variables. The quantitative data analysis in the current project yielded two descriptive cross-sectional study reports; Chapter 3 *(paper 1)* that examined the process of care during service delivery, and Chapter 6 *(paper 4)* that determined stroke outcomes and satisfaction with care.

Qualitative data analysis, on the other hand, involves identifying patterns and themes in collected data to draw meaning and answer research questions. There are commonly two descriptive approaches to qualitative data analysis, content analysis and thematic analysis. On the one hand, content analysis describes the characteristics of data by exploring who says what, to whom, and with what effect. On the other hand, thematic analysis is mainly described as "a method for identifying, analysing, and reporting patterns (themes) within data". Probably, clear differences exist where it is explained that content analysis can be used to analyse data qualitatively, and at the same time quantify the data. This has been clearly espoused by Leedy and Ormrod who said, content analysis is both qualitative and quantitative whereas thematic analysis simply provides a purely qualitative, detailed, account of data . In this project, thematic analysis was utilised to understand salient points related to stroke care from a purely qualitative view point.

Thematic data analysis for the FGD data was carried out using Braun and Clarke (2014) six-step data analysis framework (see below). Step 1: Familiarising oneself with the data. After the transcription, the researcher reads the text data repeatedly to identify items of potential interest in stroke care; Step 2: generating initial codes that identify important features of the data relevant to answering the research question(s). The researcher applied codes to the dataset. Step 3: searching for themes. The researcher then examined the codes and organised data to identify broader patterns of meaning; Step 4: reviewing themes. The researcher applied the themes to the dataset to determine what story is emerging that answers the research question related to stroke care. At this point, some themes regarded as having similar intent were combined, whereas others of less meaning were discarded altogether; Step 5: defining and naming themes. Each theme was reviewed as to its detail and significance. Step 6: producing a report. The researcher then linked the themes, forming a narrative that was then compared with literature to come up with qualitative exploratory study reports to understand state of stroke care (Chapter 4; *paper 2*) and challenges to care provision (Chapter 5; *paper 3*) in a resource-poor country of Malawi.
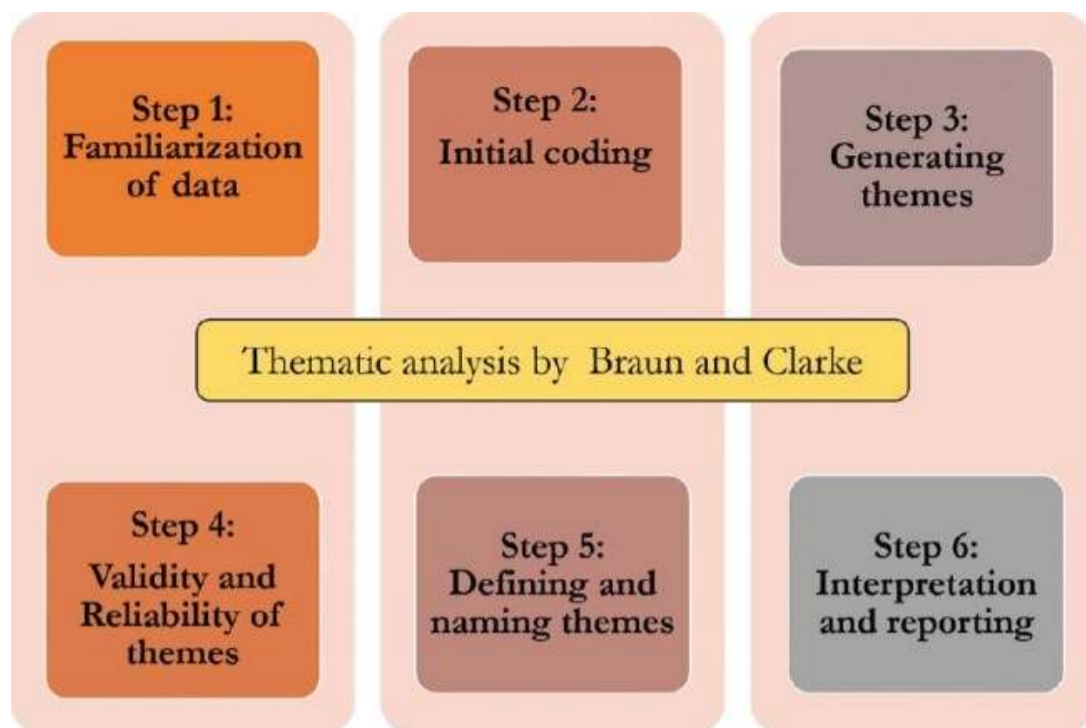
Figure 2.3 Qualitative thematic analysis

Steps in data analysis common to all qualitative investigations incorporate (Yamashita & Espinosa, 2015) 1) Quick preparation and recording of data, which included putting together vital data, including date/time details and perceptions; 2) Commencement of data analysis before long after collection; 3) Reduction of data to significant information; 4) Identification of significant patterns and topics by means of either content analysis, which included coding the information for certain words or content, distinguishing their patterns,; or thematic analysis, which involved grouping data into themes that answer research problem; 5) Display of data, which included organising data in forms of graphics, maps, tables, etc., to draw conclusions and; 6) "Drawing of conclusion and verification". In this project, the qualitative thematic analysis was used to identify, analyse, and report patterns (themes) within data to interpret various aspects of the current research topic (Boyatzis, 1998). The primary data was manually analysed.

2.7 Qualitative study Trustworthiness

Lincoln observed that the area of qualitative research was still emerging (Lincoln, 1995) and, therefore, subject to misunderstanding by many. Nevertheless, Guba (1981) produced four constructs on trustworthiness in qualitative research that has since gained acceptance by many (Shenton, 2004). These were credibility, dependability, confirmability and transferability.

2.7.1 Credibility

Credibility deals with "How congruent are the findings with reality?" (Merriame, 1998). In the current project credibility was achieved In through proper interview techniques using an interview guide. Probing was used for further clarification, making sure that clear and complete view was solicited from the participant(s); after transcription, we checked the quality of transcription in a peer review process. The transcripts were further check by two members from each of the guardians, patients with stroke, and Service providers' panel for verification, fulfilling the principle of member checking by Guba (1981). In addition, we gathered and analyzed data from three different groups; service providers, patients with stroke, and informal caregivers, satisfying triangulation as recommended by Guba (1981).

2.7.2 Dependability

There is tie between credibility and dependability with Lincoln and Guba arguing that "in practice, a demonstration of the former goes some distance in ensuring the latter" (Lincoln & Guba, 1985). However, we achieved dependability by the dense description of qualitative research methods; an independent researcher, physiotherapist, peer-reviewed the data after transcription and translation. Additionally, data was gathered from three different groups of participants, fulfilling triangulation (Lincoln, & Guba 1985)

2.7.3 Confirmability

Polit and Beck (2006) stated that confirmability demonstrates objectivity or neutrality of the data. We achieved this through member checking of the data after transcription where we engage two members per group; and triangulation, whereby data was gathered from three different groups (Lincoln and Guba 1985). Additionally, personal biases were bracketed under the principle of epoche (Moustakes 1994), so that experiences were taken from group participant's perspectives (Mays & Pope, 2000).

2.7.4   Transferability

Krefting (1990) said that it is not always easy to transfer qualitative research findings when areas do not share common characteristics. We, however, have used dense description of qualitative procedures and findings. Instruments used have also been included in the appendix. A complete set of data analysis documents is available upon request. The accessibility of research instruments may give potential researchers the ability to transfer the findings of the inquiry to other areas.

2.8   Ethical considerations

Historical facts about research in Africa are haunting as people lost their lives through unethical experimentation and clinical trials. For example, in the 1990s, Zimbabwe reported a case of arrest of Dr. McGawn for instituting a clinical trial using new drugs and anesthetics, "Nazi-style experiments", on 500, mostly black Africans, and 6 people died due to the trials, without approval of National drug authority and his patients. Other countries such as Nigeria and South Africa have equally had reported cases of unethical and harmful research activity on human subjects. Such a background culminated in African states rising to the challenge by formation and strengthening research ethics committees . However, reported changes to the effort were many and included: poorly developed ethics review committees secondary to erratic meetings and poor leadership; resource limitation such as absence of computers, and office space; limited or outdated legislation; committee members who were overworked, and with limited training and; general lack of training in bioethics and research ethics.

The government of Malawi, through the Ministry of Health research unit, made a requirement that "all researchers wishing to conduct health-related research in Malawi must submit their research proposals and related materials for scientific and ethical review to the National Health Sciences Research Committee (NHSRC) or its subsidiary, The College of Medicine Research and Ethics Committee (COMREC)". In particular, COMREC reviews proposals from the faculty and students of the College of Medicine and Kamuzu College of Nursing. Whereas proposals from all other researchers and institutions are reviewed by the NHSRC.

Just like other International Review Boards, COMREC is strict in its adherence to research ethics principles. It expects all researcher to be clear on what ethical issues need to be addressed, and how are they going to be addressed. For protection of human subjects, researchers submitting to COMREC must follow the Declaration of Helsinki – 1964; if animals are used, researchers must consider the 1985 WHO International Guiding Principles for Biomedical Research Involving Animals and; if using human tissues or other biological materials, researchers must refer to the 1991 WHO Guidelines for the Opportunistic Procurement and Use of Human Tissue and other Biological Materials in Research

This project that focused on collecting data from patients with stroke, their guardians, and service providers (physiotherapists/rehabilitation technicians, nurses and physicians) was guided by the Declaration of Helsinki – 1964. The Declaration was developed by the World Medical Association as a statement of ethical principles to guide physicians and other participants engaged in medical research that engages human subjects . It, in part, highlights that research though necessary should not trample upon the wellbeing of human participants, "*In medical research on human subjects, considerations related to the well-being of the human subject should take precedence over the interests of science and society*". Therefore, "*No national ethical, legal or regulatory requirement should be allowed to reduce or eliminate any of the protections for human subjects set forth in this Declaration*" Declaration of Helsinki – 1964.

This PhD project received ethical approval from the University of the Western Cape in South Africa: registration number 15/6/31 (appendix 2); COMREC, subsidiary of NHSRC in Malawi: approval number P.10/15/1819 (appendix 3). Additionally, permission was sought from relevant authorities in the central hospitals. All participants gave written informed consent for participating in the study. There was limited access (only by study team) to study tools containing participant information through physical security to the study office and all electronic data were stored on a password protected computer to uphold participant privacy and confidentiality.

Potential risks to research participants were mitigated by setting up system, such as having hospital emergence numbers and alerting personnel on existence of data collection task in the department. The system aimed at acting promptly to assist in situation of any discomfort, psychological or otherwise that would be experienced by the research participant. Appropriate referrals would, therefore, be made to a suitable professional for further assistance or intervention, such as counselling. None of the participants, however, experienced any discomfort. Some of the findings of this project have been published in peer-reviewed journals, and presented during conferences. The bound copy of the thesis will be made available to University of the Western Cape, University of Malawi-College of Medicine library, and all central hospitals in Malawi.

Specific information on ethical issues are presented in respective papers and chapters.

3.0 Chapter 3: Stroke Process of Care in referral hospitals: A Cross-Sectional Study in Malawi's Referral Hospitals

This chapter quantitatively addressed objective one, which was to investigate and understand stroke care processes among service providers in Malawi's referral hospitals.

3.0   Background

Stroke is the fourth leading cause of death after HIV/AIDS, upper respiratory tract infections and malaria in Malawi (Center for Disease Control and Prevention, 2016). The World Health Organisation (WHO) highlighted lessening the current stroke burden in Low and Middle Income Countries (LMICs) by the provision of quality and standardised stroke care. This indicated the need to ensure increased uptake of evidence-based stroke-care interventions in LMICs.   The clinical process of care among patients with stroke includes assessment, completed within 48 hours post stroke (Casaubon et al., 2016); early mobilisation to prevent or reduce complications, such as infections, deep vein thromboses (DVT), and falls and promote recovery; avoidance of urinary catheterizstion that frequently leads to complications such as bladder infections (Lauck et al., 2018); treatment of hypoxia, hyperglycaemia and suspected infections; and ongoing rehabilitation activities.

Stroke rehabilitation processes and, particularly, physiotherapy processes are often described by frequency, duration, and content of the treatment sessions. The National Stroke Foundation Stroke Guidelines Expert Working Group stated that for those undergoing active rehabilitation as much physiotherapy and occupational therapy should be provided as possible with a minimum of one hour of active practice per day, at least 5 days a week. However, compliance to this recommendation may vary from place to place. And, not surprisingly, not all patients with stroke receive rehabilitation. A study from Malaysia revealed that 37% of patients with stroke did not receive rehabilitation during their hospital stay. The same trend was seen in an earlier Rwandan four-year document review, where 45% of the patients did not receive rehabilitation. The frequency of rehabilitation is also lower than recommended. For example, in a retrospective study focusing on access, timing and frequency of very early stroke rehabilitation, physiotherapy was 4.9 sessions during the first 7 days of admission, followed by occupational therapy with 4.2, and speech therapy with 4.0 sessions (Reuter et al., 2016). These numbers are even lower in Sab-Saharan African countries (Urimubenshi & Rhoda, 2010; Kambalametore, 2008), with marked lower therapy duration. In Malawi, physiotherapy service, is currently limited to central or referral hospitals. In practice, physiotherapists assess the patient with stroke and their progress to identify rehabilitation goals. As part of the acute care process, the physiotherapists encourage early mobilisation and positioning to prevent pressure sores, and proper feeding positions that encourage function and prevent aspiration pneumonia .

The Best Practice Guidelines highlight that when stroke occurs, patients requiring care should be admitted to a stroke unit or where the units do not exist, should be admitted to generic wards. The stroke units and/or general wards should be staffed by a coordinated inter-professional team with special expertise in stroke care. In Africa, inter-professional stroke care teams are formed largely by nurses, specialist medical doctors (neurologists, emergency physician specialists), non-specialist medical doctors, clinical psychologists, physiotherapists, and a dietitian. This is often in the absence of other important professional members in stroke care such as speech and language therapists and occupational therapists. Further, inter-professional collaborative team work in Africa remains a dream in most stroke care settings. For example, a qualitative study in Ghana revealed that stroke care is driven by physicians without adequate involvement of other staff and that allied health staff, in particular, expressed a sense of marginalisation and disconnectedness, especially in the early stages of care . The collaborative team efforts are, therefore, compromised in most facilities.

The current paper reports on the process of stroke care in Malawian central hospitals. It is a part of a larger investigation that will lead to the development of contextual model of care for patients with stroke in the country.

3.1 Methodology

3.1.1 Research Setting

This study was conducted in the Malawi's four referral hospitals as describe in chapter 2 under overall methodology

3.1.2 Research Design

A cross-sectional descriptive study was conducted.

3.1.3 Study Population and Sampling

The population of the stroke service providers within the four central hospitals in Malawi were 101 in total (22 rehabilitation personnel [15 physiotherapists and 7 Rehabilitation technicians], 29 physicians and 51 nurses), who were providing direct care to patients with stroke from 1st April 2016 to 31st May 2016. Inclusive sampling was used to recruit all of those providers since this is optimal in a cross-sectional study.

3.1.4 Inclusion/exclusion criteria

Criteria included all professionals who had provided service to hospitalised patients with stroke for a minimum of one year, and were willing to take part in the study during the sampling period of 1s April to 31st May, 2016.

3.1.5 Data collection and procedure

Data were collected using a self-developed questionnaire that was created by the study team with guidance from existing literature and international technical experts in the field of stroke care. The questionnaire captured demographics, knowledge, attitude and behaviour regarding stroke care; inter-professional stroke care parameters; referral systems; and the stroke care process. The final questionnaire comprised of 37 items on a Likert scale for measuring the process of stroke care (Appendix 10f). Once finalised, the questionnaire was field piloted through independent critique by other experts not involved in the study as well as completion by pseudo participants. This process ensured that the questionnaire format, questions and logic flow were enhanced, and that face validity and reliability were confirmed. A final revised version following the pilot was developed for use in the study. The questionnaire took an average of 20 minutes to complete. Four research assistants (three physiotherapists interns and one rehabilitation technician) completed data collection following the researcher-administered protocol training. Every effort was made to ensure consistency during the data collection. Procedure for data collection have been explained in detail in chapter two.

3.1.6 Data management and analysis

Data were collected using paper-based questionnaires and were later electronically entered into a Microsoft Excel database. Stata v13.0 (Stata Corp, Texas, USA) was used for data cleaning and statistical analysis. Summary statistics were computed as median (interquartile range), having confirmed that continuous variables were not normally distributed. All normally distributed variables were summarised using mean and standard deviation (SD). Univariate associations were assessed using the Kruskal-Wallis Test for categorical variables and the Wilcoxon Rank-Sum Test for continuous variable due to the small number of participants in the study (N = 89). Simple bar graphs, pie charts, and scatter plots were plotted to visualise the distribution of variables. One-way tabulation was used to compute proportions for categorical variables.

3.1.7 Ethical considerations

Ethics approval was received from the University of the Western Cape: registration number 15/6/31; College of Medicine Research and Ethics Committee (COMREC) of the University of Malawi: approval number P.10/15/1819. Additional permission was sought from relevant

authorities in the central hospitals. All participants gave written informed consent for participating in the study. There was limited access (only by study team) to study tools containing participant information through physical security to the study office and all electronic data were stored on a password protected computer to uphold participant privacy and confidentiality.

3.2   Results

Demographic Characteristics of study participants

Of 101 service providers who were originally sampled after meeting inclusion criteria, 12 (12%) were unable to participate due to work engagement outside their normal work places during data collection. Thus, the study reports on 89 (88%) professionals who completed study questionnaires. The overall median age was 30 years (IQR: 26-35) and the majority were men 50 (63%). Participants' median age did not differ across the four hospitals, (p=0.199), but Mzuzu hospital had more female participants 10/16 (63%) compared to the other three hospitals which had more men than women, (p=0.038) (Table 3.1). The majority had either a first degree (BSc) 34 (43%) or a Diploma 32 (40%) with only 4 (5%) with a Master's Degree, two in QECH and two in Lilongwe Central hospital. Experience dealing with patients with stroke was similar across the four hospitals, (p=0.096) with the majority 48 (60%) serving for ≤5 years. Of note, none of the professionals in Mzuzu Central hospital had served for ≥10 years. There was a dearth of specialists with only three in QECH in the entire country and most of those who participated in the study were nurses 35 (44%).

Table 3.1: Demographic characteristics of professional study participants (N = 80)

Variable	Characteristic	QECH	%	Lilongwe	%	Mzuzu	%	Zomba	%	p-value*
		Hospital of study recruitment								
Age (years)	Median (IQR)	28.5	(25; 38)	31	(27;34)	28	(26;33)	32.5	(30;45.5)	0.199**
Sex	Male	20	76.9	11	52.4	6	37.5	12	75.0	0.038
	Female	6	23.1	10	47.6	10	62.5	4	25.0	
Education	Masters	2	7.7	2	9.5	0	0.0	0	0.0	0.003
	Bachelor's degree	13	50.0	15	71.4	3	17.7	3	18.8	
	Diploma	8	30.8	3	14.3	11	64.7	10	62.5	
	Certificate	1	3.9	0	0.0	2	11.8	2	12.4	
Experience with stroke care	≤ 5 years	18	69.2	12	57.1	12	70.6	6	37.5	0.096
	6-10 years	3	11.6	4	19.1	5	29.4	6	37.5	
	> 10 years	5	19.2	5	23.8	0	0.0	4	25.0	
Cadre	Medical Doctors	4	15.4	10	47.6	1	6.3	2	12.5	0.010
	Nurses	13	50.0	5	23.8	8	50.0	9	56.3	
	Physiotherapists	4	15.4	6	28.6	2	12.5	3	18.8	
	Specialists	3	11.5	0	0.0	0	0.0	0	0.0	
	Other	2	7.7	0	0.0	5	31.3	2	12.5	

IQR: interquartile range

 * Fisher's Exact test unless described otherwise

 ** Kruskal-Wallis test

Multidisciplinary stroke care

Health care professionals rated themselves highly when assessed using the developed Stroke Process of Care Questionnaire for Self-Providers, with no significant differences in self-ratings across the four hospitals, (p=0.105) (Table 3.2). Most participants (50/80, 63%) rated care as Good but 14 (18%) rated care as Poor or Very Poor. Nearly half 37 (46%) of participants said no team meetings were routinely held in their work places with no difference across the four hospitals, (p=0.432). While most participants 71 (91%) said they did not rely on other cadres to provide care, this was slightly different in Zomba Central where 5/16 (9%) differed with that assertion, (p=0.008).

Table 3.2: Inter-professional stroke care

		Hospital of study recruitment								
Variable	Characteristic	QECH	%	Lilongwe	%	Mzuzu	%	Zomba	%	p-value
Perceived quality of stroke care	Excellent	0	0.0	0	0.0	0	0.0	3	18.7	0.105
	Very good	6	23.1	1	29.4	5	29.4	1	6.3	
	Good	15	57.7	14	64.7	11	64.7	10	62.5	
	Poor	3	11.5	5	23.8	1	5.9	1	6.3	
	Very poor	2	7.7	1	4.8	0	0.0	1	6.3	
Conduct of team meetings	No	15	57.7	10	47.6	5	31.3	7	46.7	0.432
	Yes	11	42.3	11	52.4	11	68.8	8	53.3	
Rating of contacts with other cadres	Excellent	1	4.0	0	0.0	0	0.0	1	6.3	0.974
	Very satisfactory	2	8.0	2	11.1	4	23.5	2	12.5	
	Satisfactory	15	60.0	11	61.1	10	58.8	9	56.3	
	Unsatisfactory	6	24.0	5	27.8	3	17.7	4	25.0	
	Very unsatisfactory	1	4.0	0	0.0	0	0.0	0	0.0	
Reliance on other cadres to provide care?	No	1	3.9	0	0.0	1	5.9	5	9.0	0.008
	Yes	25	96.1	19	100.0	16	94.1	11	91.0	

Professionals who collaborate in stroke care

Medical doctors were the most frequently mentioned (29%) professionals that participants were likely to work with in the care of patients with stroke (Fig. 3.1), then nurses (28%) and physiotherapists (23%).
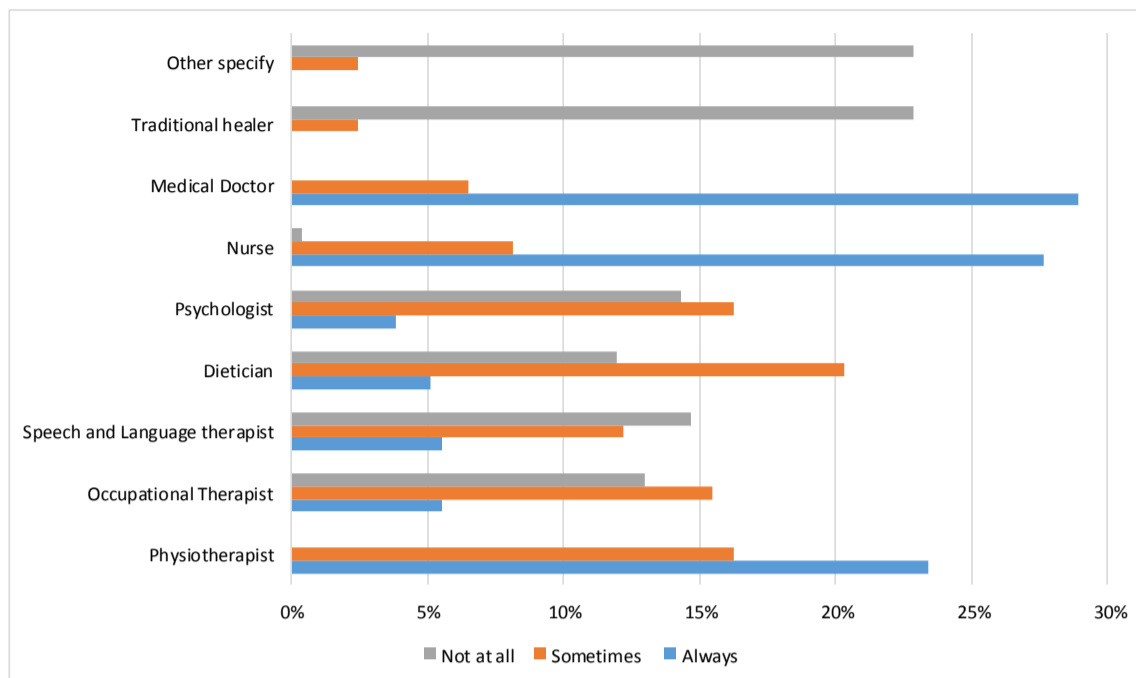
Figure 3.1 Professionals likely working with in the care of patients with stroke

Referrals

Participants were asked to describe the process of referrals in and out of their hospital. Thirty eight (35%) of 110 participant responses said referrals to their hospital were always made from primary health centres (PHCs) or clinics [38/110 (38%)] seconded by referrals from district hospitals [34 (31%) (Table 3.3)]. However, many of the participants [23 (21%)] also mentioned that patients were directly from home (family). On the other hand, most patients were referred to either rehabilitation centres [26 (39%)] or home (family) [20 (30%)] after receiving care in the central hospital (Table 3). Some patients were still referred back to the district hospital (11 or 16%) or public health centres (5 or 7%) from the central hospital.

Medical doctors were the most likely professionals to refer patients to [57/108 (53%)] and from [53 (45%)] the central hospitals (Table 3.4). While nurses were the second most likely to make referrals (20 or 19%), they were the third most likely to refer patients out of the central hospital (14 or 12%). Physiotherapists made the third most referrals to the central hospital (18 or 17%) but were second when it came to referring patients out of the central hospital (35 or 29%).

Table 3.3: Institutional referrals

Referral in							Referral out					
Institution	Always		Sometimes		Not at all		Always		Sometimes		Not at all	
Health centre/clinic	38	35%	38	17%	0	0%	5	7%	30	15%	38	20%
District hospital	34	31%	42	19%	2	2%	11	16%	40	21%	22	12%
Rehabilitation centre	6	5%	46	21%	22	17%	26	39%	48	25%	4	2%
Traditional healers	2	2%	4	2%	67	52%	1	1%	1	1%	68	36%
Family	23	21%	43	20%	9	7%	20	30%	41	21%	13	7%
Community-based organizations	6	5%	45	21%	22	17%	4	6%	34	18%	36	19%
Other	1	1%	1	0%	7	5%	0	0%	0	0%	7	4%

Table 3.4: Referrals by professionals

Referral in by						Referral out by					
Professional	Always		Sometimes		Not at all		Always		Sometimes		Not at all	
Physiotherapist	18	17%	39	23%	13	6%	35	29%	29	24%	8	3%
Occupational Therapist	3	3%	21	13%	44	20%	7	6%	14	12%	46	18%
Speech and Language Therapist	6	6%	16	10%	45	20%	6	5%	10	8%	51	20%
Dietician	1	1%	14	8%	52	23%	1	1%	9	7%	57	23%
Psychologist	1	1%	15	9%	51	23%	3	3%	11	9%	53	21%
Nurse	20	19%	41	25%	12	5%	14	12%	30	25%	26	10%
Medical Doctor	57	53%	20	12%	1	0%	53	45%	18	15%	4	2%
Specialist	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Other specify	2	2%	1	1%	7	3%	0	0%	0	0%	7	3%

Patient assessment and management

Medical doctors [62/136(46%)] and physiotherapists [64/136(47%)] were responsible for most of the neurological assessments (Fig. 3.2). Similarly, swallowing screening (Fig. 3.3) and DVT prevention/prophylaxis (Fig. 3.4) were mostly completed by medical doctors and physiotherapists. A total of 44/101 (44%) and 26 (26%) participants reported that swallowing was always completed by medical doctors and physiotherapists, respectively. Of the 106 responses, 46 (43%) and 30 (28%) said medical doctors and physiotherapists, respectively, were always responsible for DVT prevention/prophylaxis. The regulation of temperature/fever management was mostly handled by nurses [65/135 (48%)] and medical doctors (54, 40%) (Fig. 3.5). Medical doctors (55, 44%) and nurses 51 (40%) were the most frequently responsible for Hypoxia management (Fig. 3.6).
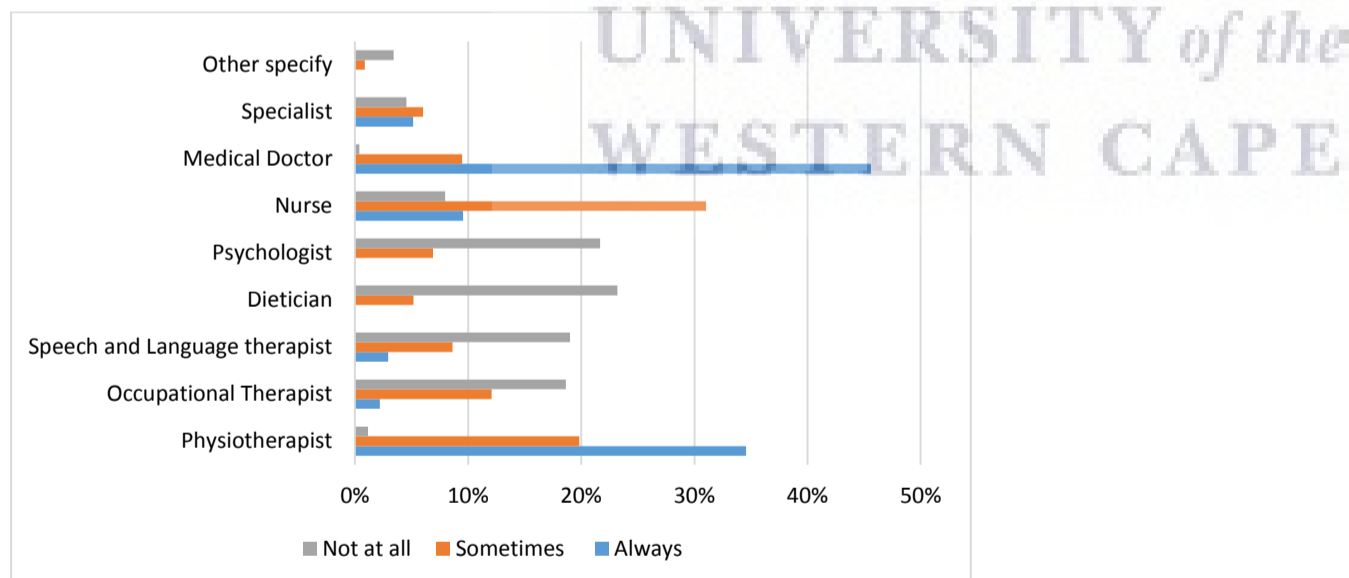
Figure 3.2: Neurological assessment responsibility
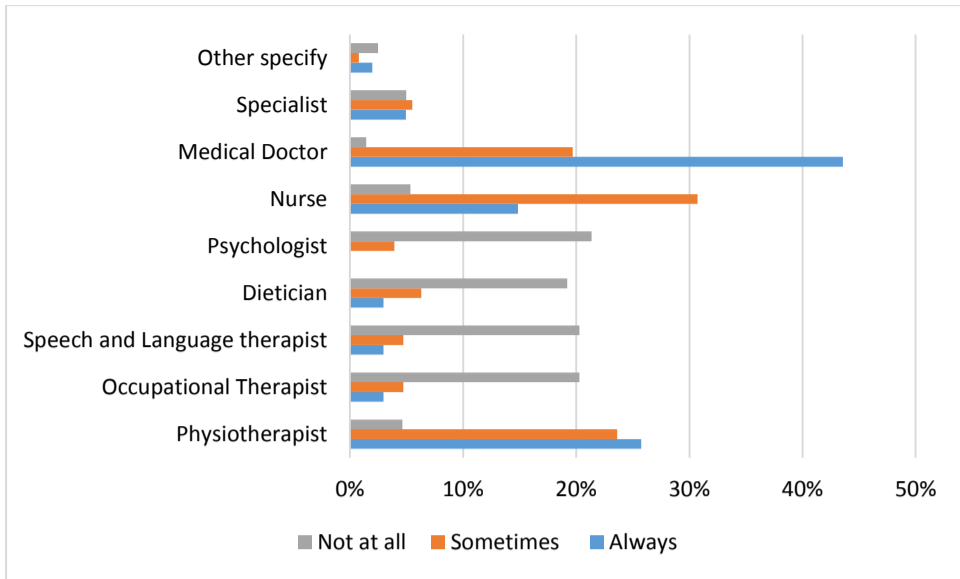
Figure 3.3 Swallowing screening responsibility
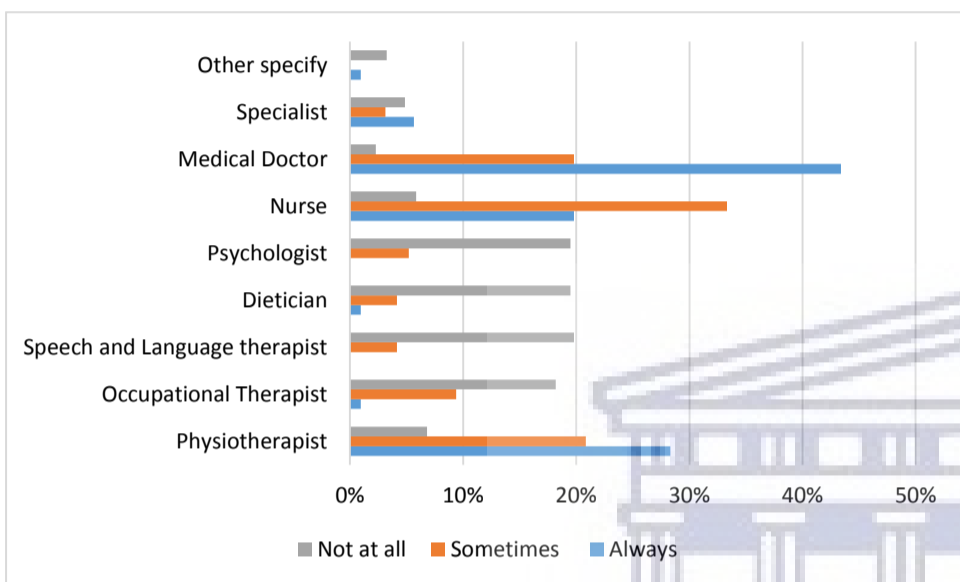
Figure 3.4 DVT prevention responsibility
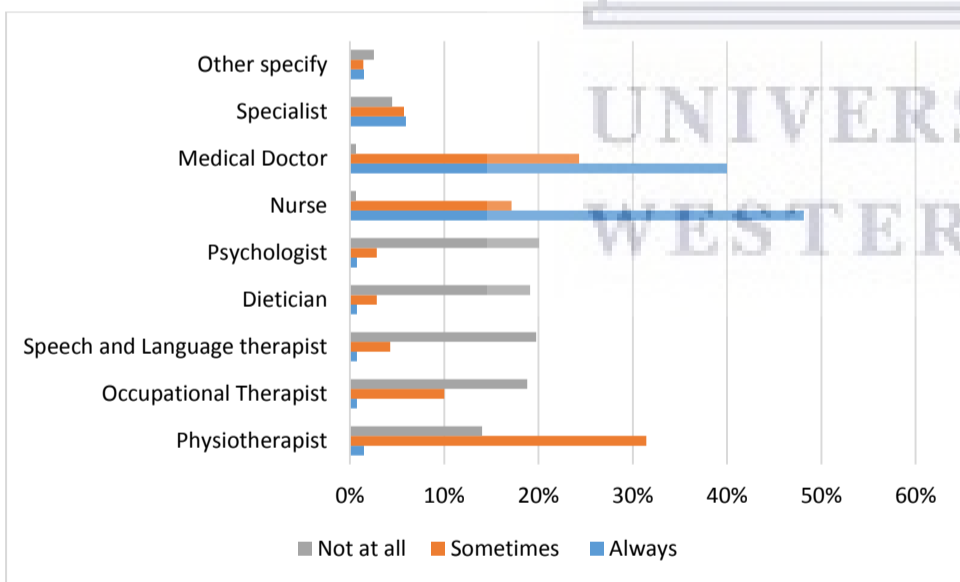
Figure 3.5 Temperature or fever management responsibility
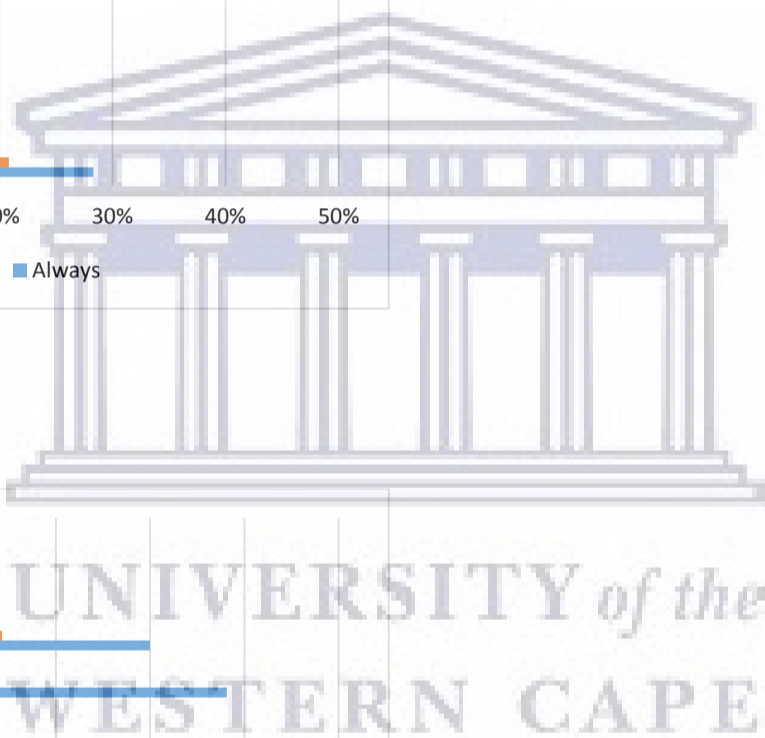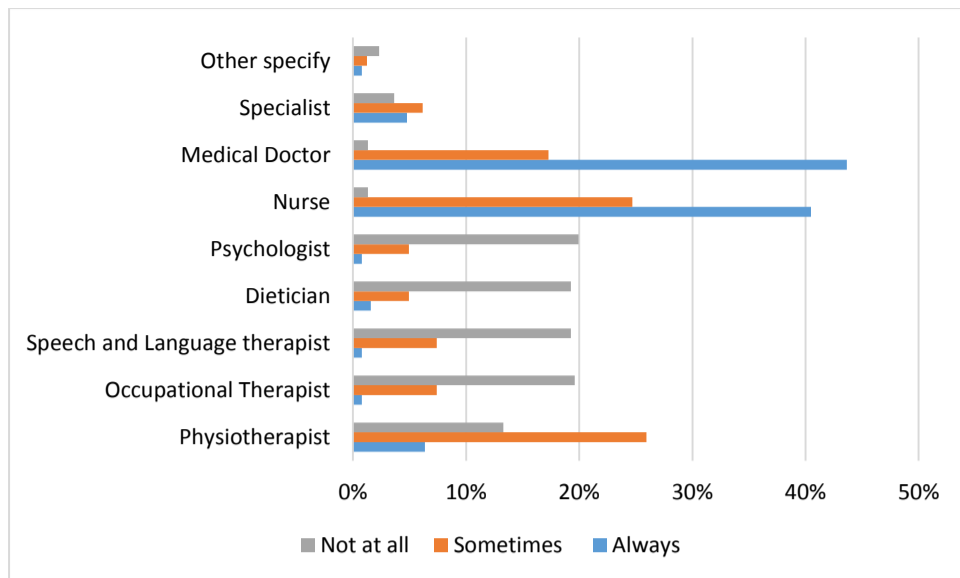
Figure 3.6 Hypoxia management responsibility

For patient management, doctors, nurses and physiotherapists were responsible most frequently. For managing blood pressure, 65 (44%) and 52 (35%) said medical doctors and nurses, respectively, were always responsible. For managing diabetes, 53/128 (41%) and 41 (32%) of participants said medical doctors and nurses were responsible. For managing cholesterol, 45(42%) and 31 (29%) of the participants said medical doctors and nurses, were responsible respectively. Physiotherapists 55/119(46%) were frequently mentioned as responsible for early patient mobilisation, with nurses being the next most frequent 31(26%). Nurses and physiotherapists had similar frequencies for patient daily activities training 26/82(32%) on either category) and prevention of complications due to immobility 36(37%) vs. 38(39%), respectively. The vast majority of participants reported that the provision of assistive devices was the role of physiotherapists (47, 69%).

Frequency of therapy

Among 15 professionals, physiotherapists and rehabilitation technicians who were directly responsible for providing therapy to patients, 9 (60%) said they gave therapy once a week. (Fig 3.7).
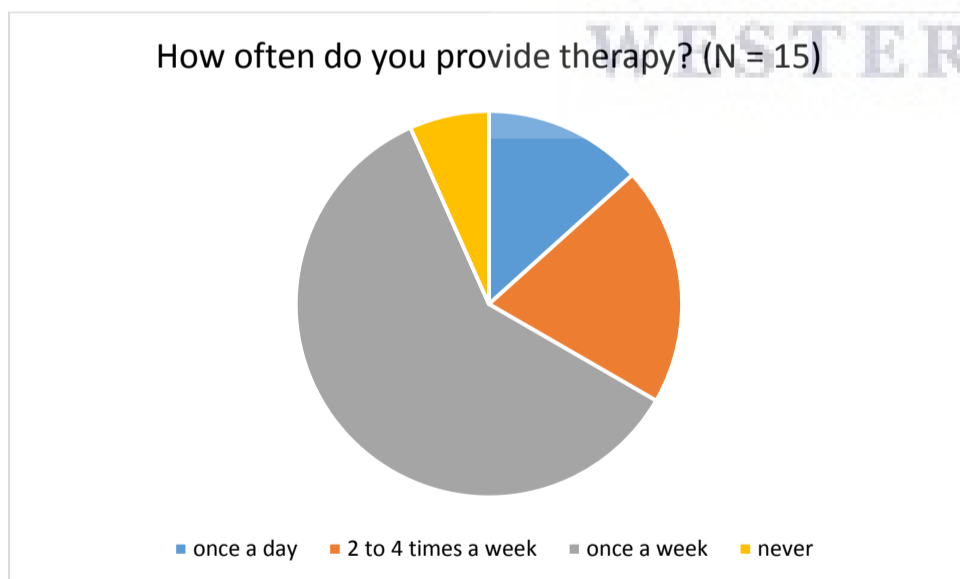
Figure 3.7 Frequency of therapy

3.3   Discussion

In general, the aim of this study was accomplished in determining the process of stroke care in Malawi's central hospitals. Demographically, study participants were generally young, with males in majority. It is not clear why the majority were young, but in recent years, the government of Malawi has retired the aged workforce following the civil service reforms. It could also be that the research assistants, being young, were mostly welcomed by the younger workforce in the stroke care settings. We reason that the young workforce as reflected in this study may afford opportunity for flexibility through adoption of new ideas toward care of patients with stroke in Malawi. It has been reported elsewhere that, although the older workers often possess a stronger work ethic than their younger colleagues, employers view older health workers as being more reluctant to try new ideas and technology than their younger counterparts.

The importance of interprofessional teamwork in health care has been consistently highlighted. Different policy documents recognise that Inter-Professional Collaborative Team Work is encouraged to ensure patients' needs are effectively met (Casaubon et al. 2016; Smith, 2010). However, the current study shows that there was limited inter-professional collaboration across the study sites. This is evidenced by the finding that over forty six percent of participants said there were no inter-professional team meetings held across the four central hospitals. And that over ninety percent of participants said they did not rely on other cadres during care provision. This finding relates well to qualitative study findings in Ghana, where physician-led stroke care is without adequate involvement of staff of different professional backgrounds. This is a typical scenario where inter-professional collaboration is not working. Lack of inter-professional collaboration has been associated with a negative impact on rehabilitation and care delivery as reported in a Swedish study. Improved inter-professional team work in Malawi's central hospitals could improve stroke care delivery system and stroke outcomes. There is a need for the central hospitals to put in place mechanisms that enhance interprofessional team work that can improve stroke care by instituting stroke care protocols and guidelines, and to provide equal opportunities for career advancement, lifelong learning amongst service providers.

This study shows that medical doctors, physiotherapists, and nurses are the main providers of stroke patient care but loosely coordinated and without organised meetings. Medical doctors were the most frequently-mentioned professionals that participants were likely to work with in the care for patients with stroke, seconded by nurses, and then physiotherapists. This is limited when compared to a report that highlights stroke care team in Africa as largely formed by nurses, specialist medical doctors (neurologists, emergency physician specialist), non-specialist medical doctors, clinical psychologists, physiotherapists, and a dietitian. Absence of occupational therapy and speech and language therapy in the current study and other African studies may be linked to a weakened rehabilitation component of stroke care in most African settings, which could be responsible for poorer stroke outcomes at discharge.

Clinically, the content side of the process of stroke care and rehabilitation in the current study is categorised into three areas: 1) Acute Assessment and Investigation, 2) Early Management, and 3) General Management. Acute assessment and investigation processes of care include neurological assessment and swallowing screening as done by physicians, and physiotherapists. This study shows less subcomponents when compared to acute assessment and investigations highlighted in earlier studies regarding the process of care in stroke units. The study which was done by Langhorne and Pollock, in collaboration with The Stroke Unit Trialists' Collaboration, indicated that process of care under the category of acute assessment and investigations included standard clinical history and examination, routine biochemistry and haematology investigations, ECG and CT scanning plus the use of carotid Doppler ultrasound, and nursing and therapy assessment. The glaring differences can be attributed to the limitation in questionnaire design or by the observation that Malawi hospitals possess limited investigation tools. However, under this category, swallowing function, among all other processes of care, has been associated with improved outcomes among patients with ischemic stroke and transient ischemic attacks (Bravata et al., 2010). A swallowing function assessment does not need a sophisticated structure of care.

We postulate that it can be used as a critical component of process of care and addressed across the wide spectrum of hospitals in Malawi when managing acute stroke.

Early management in the current study includes, regulation of temperature or fever; management of hypoxia, hypertension, diabetes cholesterol and DVT prevention or prophylaxis as managed by physicians, nurses and physiotherapists. This is similar to the stroke unit early management process of care component, which includes careful management of food and fluid intake, the use of insulin for hyperglycemia, the selective use of oxygen and cautious reduction of very elevated blood pressure. Additionally, prevention and management of complications are included, such as the use of compression stockings, antibiotics for suspected infection, avoidance of urinary catheters, and treatment of constipation. DVT prophylaxis and treatment of hypoxia, among all other processes of care within early management category, have been associated with improved outcomes among those patients with ischemic stroke and transient ischemic strokes (Bravata et al., 2010). As these do not require a sophisticated structure of care, we again postulate that it can be used as a critical component of process of care and addressed across the wide spectrum of hospitals in Malawi when managing acute stroke.

General management, in the current study, includes early patient mobilisation, training in activities of daily living and prevention of complications due to immobility and provision of assistive devices as done by physiotherapists and nurses. The cadres responsible for the general management in the current study is limited when compared to what is practiced in a stroke unit where it is done by physiotherapists, occupational therapists, speech and language therapist social worker and clinical psychologist (Rhoda, Mpofu & De Weerdt, 2009). Malawi lacks a number and variety of rehabilitation cadres. Embedding the basic knowledge in occupational therapy and speech and language therapy by rehabilitation technicians in the stroke care system in Malawi's central hospitals could be a short-term solution.

Literature on stroke unit shows that there is Discharge Planning as an additional content of care which is not reflected in the current study. Discharge Planning in stroke care is where early contact with patients and caregivers to make appropriate comprehensive assessments for hospital discharge is done (Rhoda, Mpofu & De Weerdt, 2009). Discharge Planning is critical, and physiotherapists need to be part of the planning in order to address anticipated challenges by patients with stroke and their caregivers once they return to their home communities related to barriers to community participation (Chimatiro & Rhoda, 2013; Glickman et al., 2015).

This study also showed that there is limited therapy frequency. Most rehabilitation personnel provide once weekly therapy, which is significantly below the recommendation of a minimum of 1 hour active practice per day, at least 5 days a week (Boddice, Brauer, Gustafsson, Kenardy & Hoffmann, 2010). This finding is also lower when compared to a German study that showed that physiotherapy was being applied most frequently of any other rehabilitation profession with 4.9 sessions per 7days (Reuter et al., 2016) and a Rwandan study that found physiotherapy sessions were 3.7 per 7days. Findings of the current study could be attributed to the limited number and variety of rehabilitation personnel and lack of coordination of the rehabilitation services in the central hospitals.

Limitations of this study include relatively small sample. However, the survey response rate was good at 79%. This is above the approximated 60% response rate, which is a recommended goal for most researchers. This study was limited to central hospitals so there is a sample selection bias as other health care workers in district hospitals have not been included especially the physicians, nurses and physiotherapists.

Conclusion/recommendations

Limited inter-professional team work may affect the quality of care for people with stroke. Medical doctors, nurses and physiotherapists are a limited team in the absence of occupational therapists, speech therapists, counsellors or social workers. The occupational therapy component of

rehabilitation technicians training needs to be strengthened. Government leaders may need to consider instituting occupational therapy and speech and language therapy training at existing medical institutions, as well as employ and retain rehabilitation personnel. Development of stroke physiotherapy protocols in Malawi's central hospitals would help strengthen physiotherapy management of people with acute stroke and ultimately patient outcomes and quality of life for people in Malawi.

4.0 Chapter 4: Stroke care and rehabilitation for people with stroke at Queen Elizabeth Central Hospital in Malawi: A qualitative report

4.0 Introduction

This chapter addressed objective 1, To determine and explore the process of care of stroke patients in Malawi.

4.1 Background

Management of people with stroke is an area of increasing interest in Low- and Middle-Income Countries (LMICs), accepting that stroke impact will be lessened by the provision of quality and standardised stroke care. In LMICs, such as those in Africa, stroke care processes are largely the combined efforts of nurses, specialist medical doctors, non-specialist medical doctors, clinical psychologists, physiotherapists, and dieticians (Baatiema, Sav, Mnatzaganian, Chan & Somerset, 2017). In Malawi, there are no speech therapists, and infrequently, a handful of foreign-trained occupational therapists (Fielder, Mpezeni, Benjamin & Cary, 2013)

Donabedian's Lasting Framework for Health Care Quality describe the "process" of care as the components of care delivered in a given setting. Policies indicate that stroke care must commence within the first 48 hours by assessing and preventing stroke progression, recurrence, and the development of common post-stroke sequelae while ensuring early mobilisation and rehabilitation of the patient (Lindsay, Gubitz, Bayley & Phillips, 2013). In Malawi, primary radiological investigation is CT scan, with MRI use in selected cases. In the absence of sophisticated diagnostic tools, history and physical examination are the strongly-suggested approaches to diagnosing stroke. Specific stroke management processes aimed at addressing stroke risk factors and complications are implemented in the emergency department and then, the general medical ward. These include control of hypertension, supplemental oxygen to maintain body oxygen saturation above 95%, insulin administration to address hyperglycaemia, fever management through administration of paracetamol, intravenous non-glucose fluids for rehydration, the administration of aspirin (75mg/day) as an anticoagulant in ischemic stroke, a swallowing assessment, and referral for physiotherapy when the patient is medically stable.

For the best outcomes post stroke, physiotherapy should commence within 24 to 48 hours of stroke onset, at a minimum of 1-hour per day, 5 days per week (Lindsay, Gubitz, Bayley & Phillips, 2013; The Scottish Intercollegiate Guidelines Network, 2010). However, physiotherapy services for Malawians is not nearly adequate due to the country's general shortage of rehabilitation personnel

The human resource constraints contribute to the lengthy hospital stay and possibly to the poor quality of life at discharge for patients with stroke. To the knowledge of these researchers, there is a paucity of evidence that highlight stroke care practice as it exists in Malawi referral hospitals. Information from patients with stroke, informal caregivers and health care providers is also lacking. Therefore, the purpose of this study was to 1) explore care pathways for patients with stroke in Malawi's main central hospital to 2) help to inform a new model of care. The study analysed data on the management of patients with stroke, collected through focus group discussions with patients, informal caregivers, physiotherapists, and nurses, and four semi-structured interviews with conveniently-selected physicians.

4.2 Methodology

4.2.1 Design, setting and participants

A qualitative exploratory study was used to explore care practice for patients with stroke at Queen Elizabeth Central Hospital (QECH) in Blantyre, located in the southern region of Malawi. It was chosen because of its representativeness of stroke care and convenience. Participants were drawn from a group of stroke care service providers including physicians, rehabilitation personnel, and nurses (Table 1). Due to failed attempts to have physician's participation in the focus group discussions (FGDs), semi-structured open-ended-question interviews were conducted individually to gain their perspectives on stroke care. Two other FGDs were held with the patients with stroke and their caregivers (Table 2). The study was conducted continuously from end of October to early November, 2016.

4.2.2 Sampling, sample size

Participants in the FGDs were purposively sampled with the aim of having between 6-12 participants per FGD. The four FGDs consisted of 5 nurses, 5 physiotherapists/rehabilitation technicians, 6 patients with stroke, and 7 informal caregivers. Four semi-structured interviews were conducted with physicians directly involved in the management of patients with stroke. The composition of the first two FGDs was slightly below the recommendation of Kuzel who said, "six to eight participants are enough for a homogenous sample" in a qualitative study. However, the number of FGDs in this study is in line with recommendations that indicate FDGs per study must be more than one but seldom more than

four. Eligibility for participation for service providers' FGD included: providing care to the patients with stroke; a physician in the medical department, a rehabilitation staff who is a physiotherapist or a rehabilitation technician, or a nurse who had minimum of one year working with patients with stroke. Being diagnosed patients with stroke or being guardian of patient with stroke was the main criteria for their inclusion. All participants were aged ≥18 years and gave appropriate consent for participation per the College of Medicine Research and Ethics Committee (COMREC) requirements.

4.2.3   Data Collection and Procedure

Interview guides in the local language (*Chichewa*) were used for the patients and caregivers, and English for Physiotherapists and nurses. Semi-structured interviews were in English for physicians to capture information about stroke care practice and the pathway at a referral hospital. The key issues that were explored were how the stroke occurred, how the patients were transported to the hospital, and the processes including treatments that the patients underwent during their hospital stay.

The four FGDs lasted an average of two hours; the four semi-structured interviews (SSI) an average of 25 minutes. Data were captured using digital audio recorders as described in chapter two of this thesis

4.2.4   Data analysis

Field summaries developed by the research assistants provided quick impressions of emerging issues and helped researchers to determine information saturation. Recorded data were translated and transcribed verbatim, removing any personal identifiers. Thematic analysis was used to identify, analyse, and report patterns within the data to interpret various aspects of the current research topic. The primary data was manually analysed using an excel spreadsheet by coding themes against corresponding statements from the transcripts.

4.2.5   Ethical considerations

The study was approved by the University of the Western Cape (registration number 15/6/31; COMREC of the University of Malawi: approval number P.10/15/1819). All participants either gave written informed consent in English or the local language, or witnessed consent plus thumb-print depending on their literacy level. An independent witness, usually a person nominated by the participant or a health worker, read and helped the participant understand the study information before consent was given. Participants were identified numerically for the FGDs, semi-structured interviews, and during data analysis, to uphold anonymity.

4.3   Results

To explore stroke care practice in Malawi's main referral hospital, data were captured through four FGDs and four SSI. These reported results are the combined pooled data. Of the eight nurses invited, five participated, three of whom were female, ages ranged from 27-36 years. Five of seven rehabilitation staff participated (three physiotherapists; two rehabilitation technicians). They were all female, aged 24-35 years, with varying amounts of work experience (1-11+ years). Semi-structured interviews were conducted with four of the eight physicians, three of whom were male (Table 4.1). A total of 10 patients and 10 caregivers were contacted and approached; six patients participated, four of whom were female. Seven informal caregivers participated, one male (Table 4.2).

Table 4.1: Socio-demographic Data for service providers.

Profession	Age	Gender	Experience in the current job	Experience in health care
Focus Group Discussion 3 (FGD 3) nursing				
Nurse	27	M	3-5yrs	3-5yrs
Nurse	32	F	6-10yrs	6-10yrs
Nurse	23	F	3-5yrs	3-5yrs
Nurse	36	F	6-10yrs	6-10yrs
Nurse	31	M	3-5yrs	3-5yrs
Focus Group Discussion 4 (FGD 4) rehabilitation				
Physiotherapist	25	F	1-2yrs	3-5yrs
Rehabilitation technician	32	F	6-10yrs	6-10yrs

Rehabilitation technician	35	F	6-10yrs	>11yrs	
Physiotherapist	25	F	1-2yrs	1-2yrs	
Physiotherapist	24	F	1-2yrs	2-5yrs	
Individualized semi-structured interviews (SSI) medical doctors					
MD consultant 1	30	M	6-10yrs	6-10yrs	
MD registrar 2	27	M	6-10yrs	6-10	
MD registrar 3	30	M	3-5yrs	6-10yrs	
MD consultant 4	34	F	6-10yrs	6-10yrs	

Table 4.2: Socio-demographics for patients with stroke and her/his caregiver

Initial	Age	gender	Pre-morbid Occupation	Marital status	
1 (FGD 1) patients					
LB	39	F	Business woman	Married	
LM	64	F	Farmer	Widowed	
JY	62	M	painter	Married	
EL	30	F	Business woman	Married	
MC	45	F	Business woman	Married	
UW	68	M	Security guard	Widowed	
(FGD 2) Caregivers					**Relationship to patient**
MG	61	M	Farmer	Married	Brother
MN	40	F	Business woman	Married	Daughter
GM	42	F	Business woman	Married	Sister
BB	20	F	Business woman	Single	Sister
AE	56	F	Farmer	Married	Spouse
EC	30	F	Business woman	Married	Sister
EL	34	F	Business woman	Married	Sister

Four overall themes emerged from the data. These are 1) acute stroke presentation in hospitals and emergency care, 2) acute stroke diagnosis and assessment services, 3) acute stroke care interventions and services, and 4) discharge planning and referral destinations.

4.3.1 Acute stroke presentation in hospitals and emergency care

Stroke onset is a rapidly occurring event often leaving the individual with multiple impairments. These impairments could affect communication flow between patient and caregivers, or bring confusion and helplessness to informal caregivers about what exactly happened. For example, patients may be unable to speak, *"she stopped talking and we did not communicate to each other until we came here at the hospital"* (caregiver 1); Lose consciousness, *"They told me that I was picked up on Sunday evening while I was unconscious"* (patient 7); become disoriented, *"she was talking but could not recognise people who visited her"* (caregiver 7); Unable to physically use one side of their body, *"When we went to the hospital the arm and the leg was not working"* (caregiver 2) *"The commonest presentation most of the times is weakness of the extremities of the upper or lower limbs"* (MD 1). Or suffer brain assault in form of convulsion, *"...or they are having convulsions or their blood pressure is very high"* (MD 4).

At the first contact with the hospital, patients are trenched, triaged, and assessed while control measures attempt to reverse risk factors.

4.3.1.1 Casualty trenching

At the emergency department, the team receives patients with their referral notes. *"You basically receive the patient from, incase it's a referral. You get the handover from the referring staff and then you take the patient where we call the triage category"* (MD 2). They also make a quick scan of their vital signs for any emergency care, in preparation for triaging, *"check vital signs, check BP, check temperature, respiratory status, GCS (Glasgow Comma Scale) of the patient after that then you assess for hydration status, if this patient is dehydrated you commence some IV right away, after you have done that you write a form and then call for a doctor to review"* (nurse 3).

4.3.1.2 Triaging

Triaging is "sorting the patients and setting priorities for their treatment in urgent care setting, emergency rooms, clinics, hospitals, health maintenance organisation, or in the field". From casualty trenching, the patients with stroke are then assigned to the appropriate team that examines them further. The physicians check vital signs to determine status and decide whether or not the patient needs to be admitted. *"…. there is maybe one, two or three groups that work together. .., it could be medical, it could be surgery, it could be obstetric, it could be gynae or psychiatry so they are the ones who sort of channel or flow of the patients"* (MD 1). *"If there is a need for a medical team to come that is when the medical team will come and review the patient"* (MD 2) *"And this doctor will examine again the patient and check the vitals again and then he will say this patient need admission, then you fill the file and he writes the management and then he instructs the nurses and the medicine department to send the patient to the ward"* (Nurse 5)

The physician assesses for the potential cause of the stroke. They want to better understand the risk factors (hypertension, cardiac condition, HIV infection, neurosyphilis or family history). *"I would say basically in the first assessment we have to tease out what has caused stroke among them as I was saying, the commonest being raised blood pressures, hypertension…cardiac conditions…or other infection HIV or neurosyphilis"* (MD 2)

They also assess the patient with GCS and check for evidence of aspiration pneumonia, *"based on the story, then on observation, mostly we assess GCS …and look for any evidence of aspiration pneumonia"* (MD 4)

Based on the findings, the physician carries out preliminary interventions to control reversible risk factors. For example, hydralazine or amlodipine may be administered with hypertension. *"…for high blood pressures, it depends, if the diastolic is more that 120 (I: mmh) sometimes we can just use hydralazine and just reassess. Or sometimes we give them amlodipine and see otherwise we just watch and observe (I: Mmmh) because we don't want to drop the blood pressures rapidly"* (MD 3)

Glucose is administered in an effort to resuscitate the patient. *"If they are hypoxic right away they will be put on oxygen, so that is what I mean. For example, (I: Mmh) if they are hypoxemic before we do anything, we have noted, maybe we have measured the sugar, the sugars are low, we may consider giving glucose (I: Mmh). So, that is part of resuscitation like to stabilise them"* (MD 2).

To manage pneumonia, ceftriaxone and metronidazole are given in addition to oxygen therapy. *"yeah if its aspiration pneumonia (I: Mmh) we will just transfer them into resuscitation oxygen therapy and also give them antibiotics. Give them ceftriaxone, metronidazole in our setting"* (MD 4)

If the patient with stroke presents with convulsions, the physician administers phenobarbitone. *"If it is convulsions, they will be given convulsants and commonly we use phenobarbitone"* (MD1)

4.3.1.3 Decision to Admit

Hospital admission for patients with stroke is based on physicians' judgement, since there are no admission protocols. *"Ah sometimes we don't, I should say there is no clinical rule to… we say, this patient we should admit or not. It just depends on your clinical judgement"* (MD 3). The clinician's judgement may, however, be informed by the patient's clinical presentation. For example, if the patient has a comorbidity such as pneumonia, raised blood sugar or hypertension, *"based on the clinical presentation; if they have got comorbidity conditions is it hypertension or maybe they have developed ah pneumonia. If they have got ah say raised blood sugars. So if there is anything that we can't treat, we can't reverse, then we usually admit"* (MD 1). Or if the patient is too sick, or has developed severe neurological deficits, *"if they are too sick that the neurological function is so worse such that there is alteration in the Glasgow score, those automatically end up in the ward"* (MD 2). Or if the patient with stroke is young, *"And especially if it's a young stroke patient or even when a patient has very high blood sugars we also admit"* (MD 4)

There is no stroke unit or stroke-dedicated ward in any of the country's hospitals. Patients with stroke are, therefore, admitted to the general wards, where acute supportive care is continued, and a detailed assessment ensues, *"Basically they will be admitted in the general male or female ward. It's just a general ward and ah it's not specifically a neurological ward"* (MD 1). Depending on their medical status, some may be admitted to the High Dependent Unit (HDU) of the general ward, *"If they are men, they are admitted to 3B and if they are females, they go to 4A. Some end up in HDU in the wards depending on the situation"* (MD 2).

Acute stroke diagnosis and assessment services

Assessment and diagnosis of patients with stroke by physicians is by use of subjective assessment, checking for associated end-organ damage, physical examination by evaluating integrity of the nervous system, radiological, and laboratory investigation. Initially, clinical history is captured to understand what could have happened: weakness, loss of consciousness or coma, headache, vomiting, very high blood pressure, or simply history of collapse may indicate hemorrhagic stroke, *"so mostly we rely on clinical history; Weakness or loss of consciousness or by a certain onset of headache or history of vomiting, or the patient has got very high blood pressures and comatose we think mostly that's hemorrhagic"* (MD 3). *"On the history, some of the things said like they say she just collapsed when she was coming from the bathroom, so you can have that also in mind, sometimes they can say she was complaining of headaches before that".* (MD 4).

Physicians then check any damage to end organs from the stroke risk factors. They check the status of such organs as kidneys and the heart and whether they have a cardiac problem. For example. *"We want to see if there is any evidence of any other end organ damage from the hypertension (I: Mmm) so we are checking the kidneys and the heart as I said"* (MD 1). *"you can look for a kidney function. And then you look for other starters of stroke whether they have heart disease"* (MD 4)

Physicians carryout physical examination of all body systems, including the neurological system, to understand the type, severity, and nature of the current stroke. *"Physical examination for all the body system including the neurological system"* (MD 2). *"We also perform separately a neurological examination to have an idea of the nature and type of this stroke"* (MD 4)

In addition to the physical examination, a mental examination determines the patient's level of consciousness, often with the use of the GCS, *"Neurological assessment is also supposed to be there.... we could also see if the patient is at least trying to respond."* (Nurse 5).

Further assessment is enhanced with radiological investigations. An echocardiogram (ECG) is used to rule out a thrombus or any evidence of arrhythmia; *"For cardiac causes what we usually request is echocardiogram ECG as well as cardiac echo to see whether there is thrombus or to see if there is evidence of arrhythmia on ECG"* (MD 1).

The ECG also checks for long-standing hypertension, *"And you can do other studies to confirm that they have had long standing hypertension we do ECG"* (MD 4); a chest x-ray confirms the presence of aspiration pneumonia, *"chest x-ray if we are suspecting aspiration pneumonia (I: Mmh). We may order chest x-ray just to exclude that"* (MD 2). An MRI can be used in selected cases such as in young patients. This is so because MRI is not readily available in the country's hospitals. *"For example we are still suspecting other things for example if they are young (I: Mmh) and they have developed stroke we order MRI"* (MD 3).

Laboratory tests are carried out to further understand the underlying cause of the stroke. For example, the Venereal Disease Research Laboratory test (VDRL) is used to rule out syphilis as a potential cause for the condition, *"For example for syphilis (I: Mmh) it's also another cause of stroke (I: Mmh) ya. They usually have VDRL done"* (MD 2); HIV and blood sugar levels are routinely tested, *"so we routinely do HIV tests and syphilis tests in strokes and also random outlook to see also if they were not diagnosed with diabetes already (I: Mhh) ya, so it's just a basic screen for these factors"* (MD 4),as well as a check for malaria parasites *"malaria parasites are also checked"* (Nurse 2).

Laboratory investigations determine levels of creatinine, urea, and electrolytes. *", they also do lab investigations, by also checking the creatinine levels, urea, electrolytes levels"* (Nurse 3)

Acute stroke care interventions and services

Stroke care in Malawi's referral hospital is mainly the work of medical, nursing, and physiotherapy staff.

4.3.1.4 Medical

After admission, the medical clinicians continue with the care-plan as started at the point of admission, and monitoring to ensure that all other plans are implemented, *"it is the same things that had been requested on admission (I: mmm) because some things get not on time as quick as others"* (MD 1). Once the patient is admitted, physicians monitor the patient for possible deterioration, *"Because some patients you see that they come in, they are better than they are deteriorated in the ward (I: Mmh) so you need to focus on the possible deterioration"* (MD 3). They are, however, maintained on oxygen and glucose, based on their condition, *"Usually ah it's just general management and supportive management. They are ... we give them oxygen (I: mmh) they are hypoglycemic we supplement them with glucose"* (MD 2). Additionally, if unable to swallow and are incontinent of urine, a nasogastric tube and urinary catheter are inserted, respectively *"A lot of the care is done in the ward so like feeding, putting in an NGT, catheterising them if they need that. Eh, and turning them"* (MD 4). They are also turned in bed periodically, as a way of preventing pressure sores, *"Sometimes more importantly we catheterise them because most of them they have urinary incontinence so it may contribute to pressure sores"* (MD1)

4.3.1.5 Nursing

Nurses administer the patient's plan of care. They monitor the condition with BP checks, *"Mostly patients who come with stroke are hypertensive, most of the times they are hypertensive, so we make sure that is maintained as well as monitored in terms of BP checks"* (Nurse 1), compliance with medication, *"we also ensure that patients maintain taking the prescribed medications"* (Nurse 2); insertion of nasogastric tubes and catheters, and general bed care, *"...ah things like ah sometimes gastric tube insertions, putting catheters (I: mmm) and also bed care or whatever they call it"* (Nurse 3). They assist in feeding the patient and assist with bed turning schedule for dependent patients, *"On the nutrition side it's also our responsibility, because there are others who are not able to feed, so assist them on how they can feed to be nutritionally good as a patient"* (Nurse 2); *"Some are scheduled for 2 hourly checks and some are scheduled for 4 hourly checks. Some we make sure that those things are done as indicated in patients files"* (Nurse 5). Nurses also perform basic exercises, such as range of motion, to prevent complications of immobility, *"we also do partly exercise for the patient as part of Physiotherapy and turning of the patient"* (Nurse 1)

4.3.1.6 Physiotherapy

Physiotherapy is not initiated until the acute symptoms have stabilised *"so the target would be to reverse any reversible issues...and to stabilise the patient ...and to start involving physiotherapy"* (MD 1). Physiotherapists screen the patient in the ward. When the patient can tolerate bedside physiotherapy, they are transported to the department for thorough assessment and treatment, *"as a physio or rehabilitation technician you go to the wards, you start by assessing the patient and after assessing then you say this patient is better enough you can take them out of the ward and bring them to the GYM"* (Physiotherapist 1). However, there appears to be a disconnect in knowledge and practice between physiotherapists and physicians as to when physiotherapy interventions should begin post stroke, *"How are we defining stable. From what perspective are we saying this is stable and this is improvement? Maybe that is where there is disjoint"*. (MD3)

In the physiotherapy department, a detailed history and objective assessment is carried out, a treatment plan and goals are set, and implementation begun based on priority areas, *"So, a full history and full objective assessment which is difficult in the ward but we still try and then we decide there what we should do for the patient like your treatment goals and everything but starting with the priorities"* (Physiotherapist 4). After assessment, the rehabilitation team members take time to educate the patient about the nature of her/his stroke and specifically what has happened, and next steps (dependent on cognitive status), *"So it's our role to explain to the patient this is what is happening to you, it's going to take time and I am going to help you to get better but then it will take time and you're your acceptance to what is happening to you"* (Physiotherapist 5). The patient with stroke is counselled on the benefit of physiotherapy and adherence to therapy, even if it may take a relatively long period of time to improve. Caregivers are counselled on stroke to better understand what happened to their loved one. They are informed that it is not deliberate that the patient may behave strangely after their stroke. In this way, the confidence of the caregiver is secured early, as an important starting point in the care for patients with stroke, *"I take time to explain what has happened to the patient, they should understand because some informal caregiversfeel like may be the patient is doing that deliberately they just want to irritate them so I want to get the confidence of the guardian first"* (rehabilitation technician 3). The caregivers are involved in the therapy of the patient, such as engaging them in the basic therapeutic exercises for carry over purposes, *"the guardian should be there I will start treat, demonstrating and teaching the guardian at the same time. I want to do this whether it's a passive range of motion I want you to handle the patient this way I start that on the first day"* (Physiotherapist 2)

Therapists carry out different treatment approaches including range of motion exercises and positioning, *"the first thing that I will go for is the passive range of motion and the positioning"* (Physiotherapist 4). They also engage the patient in motor control retraining in different positions depending on the status of the patient, *"So on the management, apart from passive mobilisation, positioning like in my case I also focus on sitting position depending on how the patient is"* (Physiotherapist 2). The patients with stroke are then engaged in functional retraining, especially in the areas of deficit e.g. walking, *"If I see that the patient has a little bit of movement in the area where they were affected the next step that I take is to take them out of the bed with assistance though with close supervision if that is possible. If I need to use something a walking stick I have to use it"* (Physiotherapist 4)

4.3.1.7 Discharge planning and referral destination

Nurses, physiotherapists, and physicians are actively engaged in preparing the patient for discharge. Here, general education for patient and caregivers is part of discharge planning, *"we also give education which is part of the discharge plan"* (Nurse 1). At this point, the service providers' focus is prevention of stroke reoccurrence hence, highlight the need for medication adherence after discharge, *"On the discharge, the main focus, doctors, us nurses the main focus is prevention of recurrence of another stroke in future adherence to the prescribed medication"* (Nurse 3). The service providers also help to build a support system for the patient in view of the pending discharge. They do this by determining the guardian's knowledge and abilities on how best to support the patient after discharge, *"emphasise on informal caregiverswhat they know and*

exactly what to do with the patient so that is one of the major area we consider" (Physiotherapist 2). This study showed that the patients with stroke appeared to understand the importance of adherence to prescribed medicine and are aware of the consequences of zero adherence, *"The doctors prescribing medication and taking the medication on time without skipping, and if you do not take the medication religiously, you end being in hospital again that is what we were advised"* (Patient 2). Additionally, they understand the risk factors and prevention strategies for stroke recurrence, for example, by stopping beer drinking and limiting salt intake, *"They told me, on the day I was discharged, to stop drinking alcohol"* (Patient 4); *"I was advised to avoid eating food that has too much salt"* (Patient 5)

Physicians help to make decisions on discharge destination for patients with stroke, dependent on the recovery status and nature of the stroke (hemorrhagic versus thrombolytic). With severe stroke, where there is no rehabilitation potential, the patients are discharged home with Tiyanjane, a palliative care group, *"And there will be few other patients who have had a major bleed and there is not much that can be done we discharge them via Tiyanjane"* (MD 3) or with services from the physiotherapy department, *"or via physiotherapy clinic"* (MD 2), yet others are referred to Kachere Rehabilitation Center (KRC) for intensive in-patient rehabilitation, *"So we can discharge them and they can go to KRC"* (MD 4)

As part of discharge arrangement, patients with stroke are scheduled for reviews at hypertension clinic or the general clinic, *"And also these patients we follow them up in hypertension clinic (I: ok) or general Clinic"* (MD 4). The patient may also be scheduled for the physiotherapy department of the central hospital to accelerate recovery, *"may be this patient is discharged after three or four weeks, then that patient can be coming in to the department as an outpatient and then keep on seeing the patient until you feel that this patient is alright and can get discharged"* (Physiotherapist 2). Yet others may be referred to other outpatient facilities close to their homes, *"if maybe they are coming from Kasungu where we know that there is rehab personnel we emphasise that please while you are in Kasungu please attend physiotherapy services at the hospital and meet these people"* (Physiotherapist

4.4 Discussion

The aim of this study was to explore care pathways for patients with stroke at Queen Elizabeth Central Hospital in Malawi to potentially inform a new model of care. Patients with stroke present to the hospital with a myriad of impairments. These included sudden loss of consciousness, weakness of one side of the body, inability to speak properly, loss of memory, disorientation, loss of sensibility, convulsions, and raised blood pressure. The findings on impairments was comparable to other study findings. For example, Lawrence et.al. quantitatively found that weakness is the most prevalent impairment in a multiethnic study: upper limb (77.4%), followed by urinary incontinence (48.2%), impaired consciousness (44.7%), dysphagia (44.7%), and impaired cognition (43.9%). In line with the authors, we agreed that assessment of acute impairments and disability is necessary to determine the appropriate nursing and rehabilitation needs.

Acute stroke care starts in an emergency department, beginning with triaging, assessment and management of reversible risk factors. This is in line with evidence-based recommendations that highlight the need for appropriate triage of patients with stroke, followed by administration of tissue plasminogen activator (tPA) for suitable patients who report to the department within 4.5 hours post onset of stroke, and proactive management of fever, hyperglycemia, and swallowing before prompt transfer to a stroke unit or medical ward (Hacke et al., 2008). It was, however, not a common practice in public hospitals to administer tPA. This was due to absent or unreliable patient history documenting time of onset.

Stroke diagnosis in the current study was made by marked reliance on clinical history and physical examination, in the absence of sophisticated diagnostic testing. Clinical methods have been mostly relied upon in resource-limited areas with success in diagnosing stroke, although Imam and Olorunfemi said it needs proper attention through skills check, and that accurate diagnosis of stroke in terms of site, size and type still requires radiological methods. This study showed that clinical methods are complemented by laboratory investigations, such as HIV test, VDRL, blood sugar test, and Full Blood Count to check creatinine, urea and electrolyte levels; and radiological investigations, primarily chest X-ray, cardiac ECO, ECG and MRI (often available for young patients with stroke). Limitation of radiological equipment to meet the demand led to selective test ordering, particularly with MRI. This implied that most people did not access radiological services, resulting into non-specific intervention to patients with stroke in the country.

The decision to admit a patient with stroke was determined during continuing investigations of stroke and its potential causes. Of note, was the absence of a guiding admission protocol and a reliance on physician judgement. Their basis was the presence of comorbidities, such as hypertension or diabetes mellitus (that cannot be reversed instantly) or development of secondary complications such as aspiration pneumonia, or worsening of the neurological state, noted by a declining GCS, and younger age. Compared to an earlier study curried out in Bristol, England, the current study showed that more stroke complications predicted the decision to admit in Malawi than in Bristol, where most patients would be

admitted on account of living alone and having a more severe stroke. Furthermore, the patients with stroke in Malawi are admitted to a general male or female medical ward against the common trends in other countries, where admission to a stroke unit is recommended even in some developing countries. Malawi does not have a stroke unit.

This study showed that three professional cadres are directly involved in the care of patients with stroke at the ward level (physicians, nurses, and physiotherapists). This was smaller than a typical stroke team elsewhere in Africa, which included nurses, specialist medical doctors, non-specialist medical doctors, clinical psychologists, physiotherapists, and a dietitian. Malawi is grappling with both number and variety of healthcare workers with state-of-the-art knowledge and skills. However, in practice, the current study indicated that the physicians continued to make follow-up on results of ordered investigations during the initial patient care at the emergency department. They may make new orders based on the patients prevailing status. The known basic management of stroke by primary physicians in the hospital was management of hypertension, diabetes, hyperlipidemia, and other comorbidities associated with patients. They also treated many complications of stroke, including aspiration pneumonia, urinary tract infections, and thromboembolic disease (Cavalcante et al., 2011).

Nurses had different intervention roles for hospitalised patients with stroke. A review by Cavalcante, Moreira, Guedes et.al, revealed that nurses performed four interventions namely, clinical nursing, educational, management, and research interventions. In the current study, nurses implemented orders by the physicians and advocated for change or diverse care processes based on their assessment of the patient's condition. They monitored patient conditions through vital checks, gave medication, inserted a gastric tube when needed, assisted with patient feeding, and catheterised. They engaged in pressure sore prevention, facilitated medication compliance, provided direct support in feeding patients, and training on how to safely, periodically turn in bed, and basic exercises. This finding corresponded to clinical care interventions that are more related to the patients' biological aspects, such as physiological function assessment, drug administration and motor and functional rehabilitation as highlighted in the review. It was beyond the scope of this study to explore research, management, and educational roles of the nurses.

The current study showed an interesting finding regarding stroke physiotherapy and rehabilitation in a hospital setting. Physicians' knowledge about necessity of physiotherapy intervention at as early as first day of stroke was high but this does not, in practice, translate to early referral of these patients to physiotherapy. Physiotherapists knowledge of early intervention also did not translate into practice. Further, there was no agreement on when to refer patients. The common understanding was that patients must be stable first, before referral for physiotherapy. However, the definition of stability confused physicians and consequently affected their decision time for referral. The implication is that most patients with stroke are not referred by the physicians until late, or until the physiotherapist checks in the ward themselves. This finding is in sharp contrast to the utilisation of physiotherapy in the continuum of stroke care at a tertiary hospital in Ibadan, Nigeria where the referral rate for physiotherapy was high (75.8%). This challenged the implementation of evidence-based practice and recommendations that highlighted physiotherapy and rehabilitation of patients with stroke to commence within 24 to 48 hours of stroke onset for best outcomes (Fielder, Mpezeni, Benjamin & Cary, 2013; Ayanian & Markel, 2016). There was a need to establish and promote multidisciplinary team to foster teamwork.

Physiotherapists conducted full subjective and objective assessments that guided the direction of treatment. This study showed that physiotherapists performed educational and clinical interventions. In particular, physiotherapists educated patients and caregivers about stroke condition and expected course of recovery. They also clinically intervened to restore physical functioning through positioning, passive range of motion exercises, sit to stand exercises, and gait training. Physiotherapy was critical to patient outcomes, including ADL independence and mobility. Bernhardt et al identified physiotherapists as important drivers of mobility in the acute phase of stroke care. Additionally, physiotherapists' early mobilisation and functional training have been considered the most important aspect of acute treatment in a Stroke Unit (Indredavik, Bakke, Slørdahl, Rokseth & Haheim, 1999).

As part of discharge planning, service providers take time to highlight important topics with informal caregiverson what to do while at home including a home exercise and activity program. They emphasised that education is part of discharge planning to caregivers and patients to know what they must and must not do. The patients are likely to be discharged via Tiyanjane or through the physiotherapy department. Others are referred to KRC or sent directly home. Depending on their condition at discharge, patients were given follow-up appointments at the general or hypertensive clinic. Nunes and Queirós found that during the hospitalisation period, a careful hospital discharge planning and comprehensive care to patients and caregivers, in particular the functional and psycho-emotional aspects, tended to have an impact on the quality of life of patients. There is a need for further study on discharge planning in Malawi's central hospital as this study showed there was no protocol, with inconsistency in discharge planning.

Limitations

This study was conducted at one of the four referral hospitals in the country, which may have differing priorities in practice and context. However, as the largest referral hospital in the country, there may be higher likelihood of representativeness on stroke care in Malawi. Stroke care in other active centers such as district hospitals was omitted. However, those hospitals are closer in proximity to the people, therefore, care

in such setting may exhibit different contextual issues regarding challenges and facilitators to patient care from those in this study's referral hospital.

Conclusion/recommendations

This study presented current care practices for patients with stroke in Malawi's referral hospitals. Physicians, nurses, and physiotherapists form a triple pillar of stroke care although physiotherapists are loosely attached care providers due to weak multidisciplinary team practices. Alarmingly, there was a glaring absence of stroke care protocols at every level. Clearly, further research on care structures would guide development of stroke sections/units within Malawi central hospitals with the strong implication that quality of care and outcomes for patients with stroke could improve.

The challenge to providing stroke care and rehabilitation in less-resourced country: Lessons learned

4.5   Introduction

Under this subsection, the researcher presents further qualitative findings regarding challenges to providing stroke care in Malawi as published in Journal of Global Health Reports.

4.6   Background

There is a large burden and mortality of stroke all over the world, with the 2013 Global Burden Disease report showing a significant increase in stroke burden over the last two and half decades, especially in developing countries (Feigin, Forouzan & Krishnamurthi, 2014) (Feigin V. , Lawes, Bennett, Barker-Collo & Parag, 2009). In Malawi, stroke is the fourth leading cause of death after HIV/AIDS, upper respiratory tract infections, and malaria

Management of stroke is, therefore, an area of increasing interest even in low to middle income countries. This is in line with the WHO observation that the stroke burden in the LMICs can be lessened by the provision of quality and standardised stroke care . However, stroke care, particularly in LMICs, is hampered significantly by structural and resource challenges. For example, Best Practice Guidelines emphasise that patients with suspected stroke should be admitted to a stroke unit or to generic ward that is specifically staffed by a coordinated inter-professional team with special expertise in stroke care. In practice, interprofessional care in Africa remains quite limited. Teams exist often in the absence of professional members, such as speech and language therapists and occupational therapists, which are poorly managed (Baatiema, Sav, Mnatzaganian, Chan & Somerset, 2017).

Resource constraint is another challenge that impedes robust stroke care in LMICs. For example, while some Malawian hospitals run radiological investigations, particularly CT scan and X-ray, this is often in absence of sophisticated diagnostic tools. Therefore, history and physical examination are the strongly-used approaches to diagnosing stroke, often not specific in differentiating ischemic from hemorrhagic stroke. Additionally, it is known that for the best outcome post stroke, physiotherapy should commence within 24 to 48 hours of stroke onset and continue throughout admission period to discharge and community living depending on need (Lindsay, Gubitz, Bayley, & Phillips, 2013; The Scottish Intercollegiate Guidelines Network, 2010). However, physiotherapy services to the Malawian population is not currently adequate due to the general shortage of rehabilitation personnel in the country and lack of recognition of its critical importance in patient management (Fielder, Mpezeni, Benjamin & Cary, 2013). Rehabilitation staff shortage is widespread challenge in LMICs, preventing most patients from receiving rehabilitation during their hospital stay (Nordin, Aziz, Alkaff, Sulong & Aljunid, 2012; Urimubenshi & Rhoda, 2010), or receiving inadequate rehabilitative care in quality, number of sessions (Reuter et al., 2016), and therapy duration (Jette et al., 2005).

Contextually, stroke care is also challenged by the absence of direct health policy support from the state or national level (Leonard et al., 2017). This is further evident by health priorities, resources focusing on confronting infectious diseases such as HIV, malaria, and tuberculosis (Bonita, Mendis, Truelsen et.al., 2004); poverty and populations too large to manage (Feigin V. , Lawes, Bennett, Barker-Collo & Parag, 2009); and lack of awareness and understanding of non-communicable diseases in general and stroke in particular by the general population, healthcare providers, and governments (Checkley, Ghannem, Irazola & et.al., 2014).

To the knowledge of the researchers, there is paucity of research that has explored the challenges to stroke care in Malawi. However, it is clear patients with stroke have poor outcomes at discharge (Chimatiro, Rhoda & DeWit, 2018), and they experience significant barriers to community reintegration after discharge (Glickman et al., 2015; Chimatiro & Rhoda, 2013) . Understanding all of these challenges could potentially inform a new model of care for future consideration.

4.7 Methodology

4.7.1 Design, setting and participants

A qualitative exploratory approach was used to better understand care practice for patients with stroke at a major referral hospital in Malawi. The importance of qualitative research to successfully translate best scientific evidence into clinical practice is well known (Greenhalgh, Howick & Maskrey, 2014). Malawian health service delivery system is four-tiered consisting of community, primary, secondary and tertiary care levels. According to the African Monitor (issue number four) as authored by Greenhalgh et al. (2014), at the community level, the health care service is provided through personnel with basic knowledge in health care called "health surveillance assistants." Health care focus at the community level is preventive interventions. Primary care is delivered through clinics and health centers. Secondary and tertiary care services are provided by district and central (referral) hospitals respectively. The country has 28 district and four referral hospitals across the country. Those four referral hospitals also operate as district hospitals since there are no distinct districts hospitals in the areas of their location.

This research was conducted at Queen Elizabeth Central hospital (QECH) in Blantyre, situated in the southern region of Malawi. QECH, with-1400 bed-capacity is the largest referral hospital in Malawi, and was chosen for its representation, size and convenience. Participants were drawn from a group of stroke care service providers that included physicians, rehabilitation personnel, and nurses (Table 1). Due to failed attempts to have physicians in a focus group discussion (FGD) setting, semi-structured open-ended-question interviews were conducted in offices at their workplace to gain their perspectives on stroke care. This approach afforded some flexibility with which the participants could be reached. Two other FGDs were held with patients with stroke and their caregivers (Table 2). The study was conducted from October through November, 2016.

4.7.2 Sampling and sample size

Participants in the FGDs were purposively sampled, aiming to have between 6 and 12 participants per FGD. The four FGDs comprised of 5 nurses, 5 physiotherapists/rehabilitation technicians, 6 patients with stroke, and 7 informal caregivers. Four semi structured interviews were conducted with stroke care physicians. The composition of the first two FGDs were slightly below recommendation by Kuzel, who said, "six to eight participants are enough for a homogenous sample" in a qualitative study. However, the number of FGDs in this study is in line with recommendations that indicate FDGs per study must be more than one but seldom more than four . Eligibility for participation for the service providers' FGD included: providing care to the patients with stroke; serving as a physician in medical department, a rehabilitation member of staff who is a physiotherapist or a rehabilitation technician, or a nurse with a minimum of one year-working with patients with stroke. Patients with stroke or serving as their caregiver was the main criteria for their inclusion in the FGDs. All participants were ≥18 years and gave appropriate consent for participation per the College of Medicine Research and Ethics Committee (COMREC) requirements.

4.7.3 Data collection and procedure

Interview guide in the local language (*Chichewa*) was used to guide the FGDs of patients and caregivers, and English version among the professionals. The key issues were the challenges in service delivery and solutions for improving it.

4.7.4 Data analysis

The four FGDs lasted for an average of two hours each and the four semi-structured interviews with physicians lasted an average of 25 minutes each. Data were captured using digital audio recorders. Field summaries developed by the research assistants provided quick impressions of emerging issues and helped researchers to determine information saturation. Recorded data were translated and transcribed verbatim, removing any personal identifiers. Thematic analysis was used to identify, analyse, and report patterns (themes) within data to interpret various aspects of the current research topic . The primary data was manually analysed.

4.7.5 Ethical considerations

The study was approved by the University of the Western Cape (registration number 15/6/31; COMREC of the University of Malawi: approval number P.10/15/1819). All participants either gave written informed consent in English or the local language or witnessed consent plus thumb-print if illiterate before participation depending on their literacy level. An independent witness, usually a person nominated by the participant or a health worker, read and helped the participants understand the study information before giving approval. Participants were identified with a number during the FGDs, semi-structured interviews, and data analysis to uphold anonymity.

4.8 Results

The aim of the current study was to explore the challenges related to stroke care practice at a large Malawian referral hospital. Data was captured through four FGDs and four semi structured interviews. These reported results are the combined pooled data. Refer to participant demographics (Tables 1 & 2 above)

Four overall themes emerged from the data. These were 1) Lack of effective implementation of stroke care approaches 2) Erratic physiotherapy treatment 3) Patient-mix challenges and 4) Resource limitations. They are presented next.

4.8.1 Lack of effective implementation of stroke care approaches

Under this theme, four sub-themes emerged: lack of stroke-care recognition in critical care medicine, limited interprofessional contacts, communication disarray, and lack of follow-up after discharge.

4.8.1.1 Stroke care lacks recognition in critical care medicine

Physicians in this study observed that stroke care at the QECH is faced with a clear challenge of recognition in critical care medicine, which in practice places priority on patients with reversible conditions, such as post-surgery complications. This observation is evident in the quote by a respondent physician 2, *"...and the other thing may be our intensive critical care medicine, it doesn't allow for, sort of patients who have a lot of comorbidities. Priority is placed on people who have got reversible conditions, who are mostly surgical patients. Ah so it's quite difficult to get a stroke patient to ICU. So, in terms of intensive care support, imaging and that kind of stuff we have got several limitations"*. In addition, there is no dedicated stroke unit and team that is specific to stroke care. This was highlighted by physician 3, *"We don't have a dedicated unit for stroke; that is also another challenge"*.

4.8.1.2 Limited inter-professional contacts

In this study, the service providers, particularly physicians and physiotherapists, highlighted their wanting inter-professional contact in the central hospital. They said that apart from sectional handover meetings, professionals of different background do not meet to discuss patient care, as indicated by physician 1: *"most people will attend department specific meetings ...so as clinicians we do have meetings but they do not involve nurses, radiologists or physiotherapists"*. This is supported by what was said by physician 3, *"The meetings that we have are mostly the handover meeting. But there is no I should say there is no special meeting for stroke patients"*. Attempts made in conducting meetings by several professionals before have not been appreciated by others who felt left out of the deliberations. For example, physiotherapists think the meeting if chaired by medical department then it will all be medicine, no incorporation of other professions as said by physiotherapist 3: *"but then when you go to the morning meetings you find that everything that's being discussed is medicine related and no physiotherapy, it will just be like the patient will require physiotherapy and that it will be as though they don't regard that there is a physiotherapist present so I think over time you get demoralised and stop attending the meetings"*. This limited inter-professional contact at the hospital level led to difficulty coordinating stroke care services resulting in poor stroke care at hospital level, as hinted by physician 4: *"The care is generally very poor. Ah, especially trying to coordinate to get everyone involved, to get physiotherapy involved. Ah to get good nursing care for the stroke patients I think that's a problem"*.

4.8.1.3 Communication disarray

This study revealed that there is inadequate patient advice and education on her/his health condition; limited access to information by caregivers; limited communication of information about diagnosis to the patient and guardian; and lack of privacy related to patient information.

Caregivers described inadequate patient advice and education. Physicians do not take time to explain the patient's condition to the caregivers and what to expect, except through informal channels. For example, Caregiver 3 said she only got the information through the patient's file which she, by default, held, *"For me to realise that this is stroke, it was the patients file, as we were waiting to go to the ward, I read the patient file that is when I read that they have written that the patient has stroke, they did not explain to us the problem with the patient"*. Whereas Caregivers 2 and 4 simply said, *"For us they did not tell us that it is stroke"* and *"when we came to the hospital they did not tell us that this is stroke"*, respectively. The caregivers also said this continues to time of discharge. Particularly, they did not feel they were taught enough about what they can do after discharge, as evident in what caregiver 7 said, *"They did not teach us what to do to the patient at home"*.

Caregivers also observed that physicians are often ready to give out information about HIV status and nothing more, *"What the doctors are open to say is the blood drawn for HIV test that they tell the guardian, but the other information you have to search for yourself to find out what is going on"*. Although they are not satisfied with the way such sensitive information is handled. *"There is this lady ... who draws blood for HIV test, when she comes with the results she will just say you are ok, but you or you, let's meet outside and what kind of a picture is she giving to the other guardian who are there?"* In support of this observation, Caregiver 3 simply said, patients are often disappointed with this, *"So many patients are disappointed with the way this information is given to them"*.

Physicians agree with the caregiver observations, but they explained that sometimes it is difficult to pass information about diagnosis because of caregiver expectations. This is evident in what physician 1 said, *"Most of the time, people want the situation to reverse, which might not happen"*.

4.8.1.4 Lack of follow-up arrangements post discharge

Nurses observed that there is no proper follow up to see how patients are doing after discharge as highlighted by nurse 3, *"When they are discharged straight home, I think there is no proper medical personnel to follow them to their home and see how they are doing except if they are given the days to come for checkup"*. This probably amounts to many unanswered questions by patients after discharge, as hinted by Patient 1, *"The numbness affects the other side where it was not paralysed that is the only problem that is remaining and because of my ignorance I just assume it's the medication I am taking. Sometimes is the headache, so this might be another problem"*.

Respondents alluded to the necessity of follow-up arrangements in checking and correcting carry- over programs. Cooperation between patient and caregiver becomes a challenge as patients feel their guardian is "torturing" them, as observed by physiotherapist 5: *"Because sometimes the patient would be cooperative to us as rehab or health worker that they have to listen to them, but if they go home, let's do this they say you are torturing me leave me alone"*. This is supported by physiotherapists who said follow-up would even help in correcting how caregivers carry out physiotherapy home programs: *"Sometimes, it's not the patient who is always complaining; some informal caregiversare really aggressive. Sometimes you just tell the guardian: can you demonstrate….. How you do things at home, just looking at how the guardian has handled the patient's hand or leg, you even scream yourself, please stop!"(*Physiotherapist 2).

4.8.1.5 Erratic physiotherapy treatment

This study emphasised limitation in physiotherapy service delivery for patients with stroke at the referral hospitals through the three sub-themes: 1. Limited referrals by the physicians to the physiotherapists; 2) Limited visibility of physiotherapists in the hospital; and 3) Lack of adequate service plans by physiotherapists.

4.8.1.5.1 Limited referrals by physicians

Patients with stroke and rehabilitation personnel observed that there are limited referrals to physiotherapy. For example, Patient 3 said she was not advised to have physiotherapy. This is evident in the quote, *"They should have told us that? (about) our conditions and advised us that we need to go for physio. They did not inform us"*. This sentiment was supported by patient 4 who said, *"It's true, they just discharged us without informing us that we have to go for physio"*. However, some patients experienced that they were treated by a physiotherapist, although it was erratic. While others were seen by the physiotherapist four times per week as evident in this quote from Patient 2, *"We were going to the physio department for exercises on the leg and arm for four days"*, others were seen twice as per Patient 3, *"They were coming twice per week. They were stretching me"*, yet others received no physiotherapy treatment as per Patient 4, *"We didn't do the physios, and they never came"*.

While recognising efforts by some physicians to refer patients with stroke, rehabilitation personnel observed that only a handful are referred. This is evident in the quote by respondent physiotherapist 2*, "but in case where nobody has gone to check, we tend to have a couple of referrals but then when you compare with the patients that are discharged and those that come for rehabilitation the numbers are different. Those who come for rehabilitation are few and those who go home are many"*. But some rehabilitation personnel reason that physicians weigh who is most affected and so can benefit from physiotherapy and others observed that doctor's workload is huge and they miss out on the need to refer the patient for physiotherapy. According to the rehabilitation personnel, those who are less affected by stroke are likely to be discharged without referral to physiotherapy compared to those who are severely affected as evident in the quote by rehabilitation technician respondent 4, *"I think the doctors will try to weigh to say we have let's say 12 stroke patients on the ward for example they will see I think the ones who are very affected by the stroke and weigh them against the ones who have been affected less so I think they will refer the ones who have been affected more to Physiotherapy and they feel better to discharge the ones who have minor complications"*. But respondent physiotherapist 1 reasons on issues of workload, *"They know that there is physiotherapy and they know that this patient needs physiotherapy but when they are writing at the discharge form may be they have a lot of workload they may miss out to say the patient should go through physiotherapy"*.

4.8.1.5.2 Limited physiotherapist ward visibility

Although patients with stroke and rehabilitation personnel think there is deficit in referral by physicians, the physicians and nurses think otherwise. The physicians observed that it is the physiotherapist who decide to come late even after referral arguing that the patient is not stable enough to be seen by a physiotherapists as evident in this quote by physician 1, *"So we have seen cases whereby you are giving a consultation and people* (physiotherapists) *come and say they are not stable ah contact us when they are stable. Nothing has been done. So it's that kind of situation"*. On the other hand, the nurses observed that physiotherapists had limited communication with other professionals. This was noted in what Nurse 3 said: *"We the nurses and the physiotherapist most of the times the physiotherapist guy just comes and tell us that I have come for*

this patient and then they go to the patient and they do whatever they will do after that they will just go, like in my experience”. And supported by Nurse 2 who said, there is a need for behavioural change, *“but there are others as she has already said they just come and do whatever they wanted to do and off they go, so if there can be a behaviour change on that, I think it could be better for our patients”*

4.8.1.5.3 Almost non-existent physiotherapy plans of care

Physicians observed that patients with stroke received a "raw deal" from the physiotherapy department, as the need for physiotherapy is not matched by availability. It appeared to them that there is no good planning for the service. This is evident in what respondent physician 4 said, *“They need a lot of rehabilitation but most of the times there is no good plan or good service for that”*. As a result, there is a lot of stroke complications such as pressure sores and aspiration pneumonia, evident in this quote by Physician 3: *“So, in general like in the ward they get a lot of complications like pressure sores and aspiration pneumonia because they don’t get turned enough and there is no adequate care for them (I: mmh), ya”*.

4.8.1.6 Patient-mix challenge

This study showed that the patients and caregivers observed the mixing of patients with different conditions as causing risk to those with stroke: dangers of physical harm from the confused and infections from those with contagious conditions. This is highlighted by Patient 1: *“I have seen that our condition is very serious, that we don’t move around and they would mix us with mental patients, I was slapped by a mental patient while I was in the hospital”*. This is supported by caregivers, *“I just want to comment, we were at ward 4A and some patients come there with mental problems, if possible, can they be given their own side because at times they disturb other patients like they would want to beat a patient or a guardian or even the nurses”* (caregiver 5). Nurses and physicians also supported the patient and caregiver observations. The nurse attributed this to lack of space, as noted by Nurse 1: *“the space is not enough we end up mixing them with others who have infectious diseases”*. On the other hand, Physician 3 simply said, *“They are mixed with other patients”*.

4.8.1.7 Hospital facilities not “disability-friendly”
This study found that caregivers encountered challenges when trying to complete caregiving roles in the hospital. Hospital structures and facilities are not accessible to patients with stroke: do not have supportive features in the toilets and bathrooms, hampering their use. From Caregiver 6: *“the issue of the toilets and bathrooms. There is no chair for stroke patients so if you let them sit on the floor how would you help the patient to get up”*. This was supported by Caregiver 1 *“It is really difficult to make the stroke patient kneel or sit down at the same time to carry them to the wheelchair so the toilet and the bathroom are not user friendly for stroke patients”*. The challenge with accessibility is not just limited to bathroom and toilet. Caregivers observed that some facilities necessary for stroke care are also difficult to use. In the X-ray department, it is not easy to position the patient for radiological investigations. Caregiver 7 said, *“One, at the x-ray department they have the same bed like this and a step, for a stroke patient it is very difficult to carry the patient from the wheelchair, to the steps and on the bed. The step was meant for the patient who is able to walk and step without any help. It’s very difficult to put the patient on the x-ray bed”*.

4.8.1.8 Resource limitation

Resource limitation has come through strongly in this study in four sub-themes: 1) limited number of qualified service providers; 2) inadequate medical supplies; 3) unreliable equipment: and 4) lack of warm bedding.

4.8.1.8.1 Limited number of qualified service providers
The service providers and caregivers observed that among other challenges to patient care are limits in numbers of qualified service providers to meet the special needs of patients with stroke. For example, physicians highlight that staffing has always been a challenge in all the disciplines that directly provide care to patients with stroke. This is evident from Physician 2: *“staffing is always a problem. Not only on the physiotherapy aspect but also on the clinical side. There is usually few people anyway to attend to large number of patients that’s number one”*. And supported by Physician 3, stating that the ratio of patients to nurses is "unbelievable," *“When the students are not around, it turns to be difficult because (ward) 3B most of the times has more than 70 patients and there are a few nurses”*. There were similar observations by rehabilitation personnel and caregivers. For instance, Physiotherapist 2 said there are limited numbers of rehabilitation personnel in the Physiotherapy Department, therefore, they must be allocated wisely, *“we don’t have enough people in the department to be able to do that, so they would rather place those few people in the wards, where it is really important”*. Caregivers on the other hand observed that sometimes it is the students who seem to increase the number of personnel, but they leave huge gaps when they go. Along this line, caregiver 1 said, *“Sometimes the nurses might look as*

if there are so many but most of them are just trainees. At the end, it's just only one nurse who is on duty, especially on weekends. The nurse might be serving a lot of patients at once and it is very overwhelming on one person".

4.8.1.8.2   Inadequate medical supplies

This study showed that stroke care settings are riddled with widespread shortages of basic medical supplies such as medication, catheters, nasogastric tubes (NGT), BP machines, bedding and pillows. Shortage of medications are also felt by caregivers who have been told to go and buy them as highlighted by Caregiver 7: *"But here they just told us that you have been discharged and gave us one tablet and they told us that the other medication is not available, when we asked where can we get the medication for BP, they told us that you have to buy it"*. Physicians shared the same observation on shortage of medications and diagnostic tests that both hamper care. Physician 4 noted that *"It's also lack of medication and may be not having access to all the tests that you want to do for them, ya"*. Limitation of some medical supplies explains stroke complications at ward level such as onset of aspiration pneumonia due to lack of NG tubes to support the dependent patients, highlighted by Physician 3: *"sometimes a patient can be out of stroke but has aspiration pneumonia can be quite challenging. And sometimes we don't have NGT for feeding so informal caregivershave to go and buy it"*. In addition, blood pressure machines are in limited supply, thereby, affecting effective monitoring of patients with stroke, highlighted by Nurse 2: *"sometimes you might have one BP cuff so that patient needs to be checked BP every two hours and you might happen that you have got five patients with that condition, so sometimes it's kind of difficult to monitor them"*. Rehabilitation personnel see limitation of beddings and pillows as affecting treatment techniques, such as positioning as highlighted by Physiotherapist 3: *"The positioning has been tricky because we don't have pillows in the ward and some patients will come with basically one cloth and some patients come with a blanket so we can use that before trying to help with the positioning of the patient but lack of pillows on the ward has also been a challenge"*. But the shortage of medical supplies is explained by the fact that it is a referral hospital as reasoned by Physician 2, *"resources are scarce because ah Queens is a big hospital, it's a referral hospital so most of the hospitals refer their patients here and the demand is just too high (I: yes). So there are other situations where you may find out that catheters are not even there sometimes in HDU"*.

4.8.1.8.3   Unreliable equipment
The current study found that the other challenge is unreliable equipment mechanically. Diagnostic equipment is often out of working order. Physician 1 said equipment, such as echo-cardiographs are often not able to process, *"radiologically yes we just do an echocardiogram because most of the times we are not able to process. We do not have a working CT scan (I: ok), so we can't get an MRI in good time"*. This was supported by Physician 2, who gave an example of CT scanner not working: *"CT scan not at Queens at the moment it was broken down so there is an external arrangement (I: ya) at Adventist. (I: ok, so) A process, anyway, which is not automatic but eventually it works"*. Frequent breakdown of equipment was also felt by the patients, evident in what Patient 3 said: *"they took my book and read it and we went to his office, and he told me that the computer is not working"*.

4.8.1.8.4   Lack of warm bedding
Caregivers in this study were concerned that the hospital could not provide warm bedding for the patients, noted by Caregiver 1: *"Nowadays, you only have a chitenje (*a "wrap*"), and you use that to put on the bed and as well as to cover the patient, before they used to give blankets to the patients even when your patient is cold they would bring you extra blankets"*. This is supported by what caregiver 2 observed as "pathetic,*" "You are sleeping on plastic mattress, you are covering the patient with a plastic like bed sheet and on top there is a fan, oh it's really pathetic"*.

4.9   Discussion

The aim of the current study was to explore the challenges to stroke care at a major referral hospital in a low-resource setting. It showed many challenges related to the implementation of stroke care, with little recognition of critical care medicine, limited interprofessional contacts, communication disarray, unavailable or nonoperational equipment, and lack of follow-up after discharge. The finding on lack of recognition of stroke care medicine is interesting but not surprising because in most cases, emergency departments are overcrowded, a direct result of limited ICU beds in most hospitals. There is a need to power the emergency department through training of relevant health care workers in critical medicine so that most of such critical stroke care is available when the patient arrives at the hospital. This recommendation is in line with what one of the founders of critical care, Dr. Ake Grenvik, wrote in the preface to the *Textbook of Critical Care* (4th edition) that, many critically ill

patients no longer need admission to the hospital if the diagnostic work-up and treatment may be completed in an emergency department (Grenvik, Ayres, Holbrook & Shoemaker, 2000). In a related qualitative study in Ghana among health professionals, the authors also found that multidisciplinary stroke team, which in most cases is physician-driven was inadequate, not inclusive, and an obstacle to effective patient care (Baatiema et al., 2017). Additionally, although patients live geographically far away from a hospital, it should put into its programming follow-up plans specific to patients with stroke. Liaison with district hospitals and health centers can also be critical as patients with stroke as well as their caregivers have a need for long-term care (Visser-Meily, van den Bos & Kappelle, 2009).

This study unearthed limitation in physiotherapy service delivery for patients with stroke at the referral hospitals through three themes: 1) limited referral by the physicians to the physiotherapists; 2) limited visibility of physiotherapists in the hospital: and 3) lack of proper service plans by physiotherapists. In line with a Ghanaian study finding, general nurses believed that the absence of a specific protocol or clinical guideline for acute stroke care was a key barrier (Baatiema et al., 2017). We reasoned that the protocols set in place would enforce general understanding that different professionals are needed for holistic care for patients with stroke. Additionally, as utilisation of physiotherapy during hospital admission has been associated with reduced length of hospital stay among patients with stroke, there is a need for hospital physicians to recognise and engage physiotherapists as early as possible along stroke care continuum.

The current study further showed that patients with stroke and caregivers observed the mixing of patients with different conditions as increasing the risks of communicable diseases for those with stroke. They observed that the tendency of mixing patients with stroke with those having other conditions, such as the confused and those with infectious diseases, brings with it a danger of physical harm and infection. This is against common trends in other countries, where admission to a stroke unit is recommended, even in developing countries (Baatiema et al., 2017). In addition to this seemingly structural challenge, this study found that the caregivers observed that hospital structures and facilities are not accessible to patients with stroke. There is a need to institute stroke units with all facilities in place and accessible. Provision of adequate infrastructure has been associated with the increased level of job satisfaction among health workers and a potential factor for prevention of nosocomial infections .

Resource limitation is another challenge (qualified service providers, inadequate medical supplies, unreliable equipment, and lack of warm bedding). This study echoed the findings in Ghana where limited staff especially stroke specialists, shortage of medical equipment, such as blood pressure (BP) monitoring apparatus, cardio monitors, suction machines, adjustable hospital beds and inadequate space to facilitate patient care, were key barriers across the study sites (Baatiema et al., 2017). There was a need for hospitals to be competitive through provision of equal opportunities for career advancement, lifelong learning, and flexible work schedules as well as to develop policies that promote loyalty and retention (Marchal, Brouwere & Kegels, 2005) of the few who are already in the system.

Limitations

This study was conducted at only one of the four referral hospitals in Malawi, which may have differing presentations in practice and context. However, as the largest referral hospital in the country, there may be higher likelihood of "representativeness" regarding challenges to stroke care in similar-level hospitals.

Conclusion/recommendations

This study presented the challenges in stroke care provision from a pooled data of focus group discussion and semi-structured interviews. The challenges are structural, where space and inaccessible structures affects service provision, practice, where there is limited multidisciplinary teamwork and; resource, where there is a handful of qualified service providers, inadequate medical supplies, and unreliable equipment. There is a need to put care protocols in place and reinforce them to facilitate holistic care for patients with stroke. Provision of adequate infrastructure including setting up stroke-specific units is an imperative. And individual hospitals with government support must work to create equal opportunities for provider career advancement and develop policies that promote skills, loyalty and retention of the existing workforce.

5.0 Chapter 5: Patients with stroke's outcomes and satisfaction with care at discharge from central hospitals in Malawi: A cross-sectional descriptive study in a resource limited area

5.0   Introduction

This chapter addresses objectives 2 and 3 which are: to determine patients with stroke and caregiver satisfaction with care and rehabilitation service delivery in Malawi's central hospitals and; to determine stroke patient outcomes at discharge.

5.1   Background

Stroke outcomes are an indicator of quality of stroke services provided (Myint et al., 2016). There is a dearth of literature reporting on stroke outcomes in most sub-Saharan African countries including Malawi. A prospective study that investigated stroke outcomes among patients with HIV one year after stroke found that 53.4% of patients had poor outcomes including severe disability and death (Heikinheimo, Kumwenda, Kampondeni & Allain, 2012). This study showed that poor stroke outcomes were independent of HIV infection.

Quality of life (QoL) post stroke is an appraisal of general wellbeing of individuals affected by stroke. Acute stroke is known to lower the QoL for its survivors through the disability it brings and associated emotional distress that could lead to depression. For example, in a Tanzanian study, 68% of all aged patients with stroke gave up their work permanently, and experienced marked disability through failure to walk independently, to perform self-care and usual activities and exhibition of psych-affective disorders such as depression, and anxiety (Howitt et al., 2011). In Malawi, an interview-based study by Heikinheimo and Chimbayo was conducted where 81 patients with stroke, who were followed up six months after stroke, revealed that "good" functional outcomes in the domains of activities of daily living (ADLs) and communication was positively associated with better QoL. Women scored worse in the fatigue and cognition domains. Older age was also associated with lower QoL in the ADLs domain.

Besides functional health outcomes and QoL, patients' satisfaction is an important indicator of the quality of care in a given setting (Cramm, Strating & Nieboer, 2012). This may explain the degree to which patients comply with their treatment, whereby the high satisfaction ratings may attract high level of adherence to treatment. Factors related to satisfaction include patients' socio-demographic characteristics, physical and psychological state, attitudes, and expectations of health care, as well as structure, process, and outcome of care (Sahin, Yilmaz & Lee, 2007).

In this study, we described functional outcomes among patients with stroke, their satisfaction with care and QoL after completing treatment in four referral hospitals in Malawi.

5.2 Methodology

5.2.1 Research setting

This study was conducted in eight medical wards across the four central hospitals in Malawi, which admit and manage patients with stroke. The hospitals are Kamuzu Central Hospital (KCH [Central region, Lilongwe]) with 1000 beds, Queen Elizabeth Central Hospital (QECH [Southern region, Blantyre]) with 1400 beds, Mzuzu Central Hospital (MCH [Northern region, Mzuzu]) with 306 beds, and Zomba Central Hospital (ZCH [Eastern region, Zomba]) with 500 beds. In all of these hospitals, patients with stroke come into first contact with the hospital at the casualty, or emergency department, or accident and trauma Center, as it is called in different settings. In Malawi, there is basic physiotherapy service, currently restricted to central hospitals. In practice, physiotherapists assess patients with stroke and their progress to identify physiotherapy goals. Technically, during the acute phase, besides counselling patients with stroke and their caregivers, physiotherapists work on prevention of early stroke complications such as aspiration pneumonia and deep venous thromboses (DVT). As part of acute care, physiotherapists encourage early mobilisation and positioning to prevent pressure sores, and proper feeding positioning to encourage function and prevent aspiration pneumonia during admission (Baatiema et al., 2017).

5.2.2 Research design

A descriptive cross-sectional study design was used. Patients and informal caregivers completed paper questionnaires, Functional Independence Measure (FIM), 5 Level Euro Quol 5 Dimension scale (EQ-5D-5L), Patients Satisfaction with Inpatients Stroke Care (Hospital Scale) (SASC) and Caregivers Satisfaction with Inpatient Stroke Care (Hospital scale) (C-SASC), which were electronically processed using a Microsoft Excel database. In this paper, we report quantitative data.

5.2.3 Study population and sampling

In this hospital-based study, the entire population of patients with stroke available during the time of study was included as this is an optimal situation in a cross-sectional study. The study population included 114 patients with stroke and their informal caregivers, admitted to the hospitals in the research setting during the months of April and May in 2016, and their informal caregivers. Inclusive sampling was used to recruit participants.

5.2.4 Inclusion and exclusion criteria

Patients' inclusion criteria were: (1) clinically diagnosed stroke by a qualified physician through history and physical examination (both parameters have been used in community studies with 92% sensitivity for diagnosing stroke and transient ischemic attack), (2) 18 years of age or older, (3) cognitively sound, able to speak and be understood, and (4) admitted to one of the four central hospitals. Informal caregivers were those persons who provided direct support and other caregiving roles to the person with stroke without compensation. Patients who were hemiplegic due to head injury were excluded.

5.2.5 Sampling and recruitment

Three intern physiotherapists and one rehabilitation technician assisted with data collection after undergoing study protocol training. Each research assistant abstracted data from patients' records on a weekly basis to identify potential study participants. The assistant also relied on the hospital referral system, where the rounding doctors referred admitted patients with stroke to the Physiotherapy Department. The eligibility screen was then applied to all those who were eligible to participate in the study. Data were then collected from eligible and consented patients, first on admission using the Functional Independence Measure (FIM). On discharge, the FIM was re-administered and other data collection instruments were equally administered as per study protocol.

5.2.6 Outcomes and measurement

The researchers used pre-validated tools to assess study outcomes. Patient outcomes were measured through items contained in the FIM, which is a valid and reliable tool for evaluating patients with stroke on admission and at discharge to determine their functional status, their follow up, and disease progression (Rayegani et al., 2016). The FIM scale contains 18 items: 13 in the physical or motor domains, and 5 items in the cognition domain. Motor items measure self-care, sphincter control, locomotion, and transfer abilities. Cognitive ones evaluate communication and social cognition skills. For levels of independence, as measured by the FIM, each item is scored from 1 to 7, where 1 indicates total dependence and 7 indicates total independence. Possible scores range from 18 to 126. The higher the score, the greater the degree of independence in ADLs. Quality of life and self-rated health were assessed using the EQ-5D-5L, which has both a descriptive system and EQ Visual analogue scale. The descriptive system comprised 5 dimensions (mobility, self-care, usual activities, pain/discomfort, and

anxiety/depression) with 5 levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. The respondent is asked to indicate his/her health state by ticking (or placing a cross) in the box against the most appropriate statement in each of the 5 dimensions. The EQ visual analogue scale records the respondent's self-rated health on a 20-cm vertical line. The scale has endpoints labelled 'the best health you can imagine' and 'the worst health you can imagine'. This information is used as a quantitative measure of health as judged by the individual respondents. The EQ-5D-5L is a well-established tool for measuring quality of life (Chen et al., 2016). Its descriptive system as a generic health outcome measure has been reported to be valid among patients with acute stroke, demonstrating some psychometric advantages in comparison with the earlier version, EQ-5D-3L (Golicki et al., 2015). Patients' and care givers' satisfaction with stroke care were measured using the Patient Satisfaction-With-Stroke-Care (SASC) hospital scale and Care Giver Satisfaction-With-Stroke-Care (C-SASC) Hospital Scale. All instruments were translated into the local language (Chichewa) by qualified and independent translators at the University of Malawi and piloted for face validity at Queen Elizabeth Central Hospital, with positive feedback from participants.

5.2.7 Data Collection Procedure

As described in chapter 3

5.2.8 Data analysis and interpretation

Stata v13.0 (Stata Corp, Texas, USA) was used for data management and statistical analysis. Summary statistics were computed as median (interquartile range), having confirmed graphically using histograms and by applying the Shapiro-Wilk normality test that continuous variables were not normally distributed. All normally distributed variables were summarised using means with standard deviations (SD). Univariate associations were assessed using the Kruskal-Wallis Test for categorical variables and the Wilcoxon Rank Sum Test for continuous variables due to the small number of participants in the study (N = 90). The correlation between two continuous variables was assessed using the Pearson product moment correlation coefficient (r). Simple bar graphs, pie charts, and scatter plots visualise the distribution of appropriate variables. One-way tabulation was used to compute proportions for categorical variables. Simple linear regression was used to investigate associations between two continuous variables.

5.2.9 Ethical considerations

Ethical approval was received from the University of the Western Cape (registration number 15/6/31) and the College of Medicine Research and Ethics Committee (COMREC), University of Malawi (approval number P.10/15/1819). All participants gave a written or thumb print-witnessed informed consent before participating in the study. Heads of each central hospital gave permission for the study to recruit within their hospital. Access to the data collected was limited only to study staff to uphold confidentiality and privacy of study participants through protection, known only to the investigator.

5.3 Results

Out of 114-person study sample, 9 died before discharge, 11 were excluded due to speech problems, and 4 were lost to unexpected discharge. This study, therefore, had complete data from 90 participants, representing 79% of the initial study population.

Overall mean age was 58.6 years (SD=16.3) and 48 (53%) were male. The majority of the patients were recruited from Queen Elizabeth Central Hospital (QECH) (28; 31%) and Kamuzu Central Hospital (KHC) (27; 30%), while 19 (21%) and 16 (17%) were from Mzuzu and Zomba central hospitals (MCH and ZCH) respectively (Table 5.1). Comparable age (p=0.109) distribution across the four hospitals was observed, but there were significantly more male patients at KCH (17 [63%]) and MCH (14 [73%]), while QECH had more female patients (18 [64%]); p=0.041. Patients in QECH and MCH spent a significantly longer time in the hospital with median (interquartile range [IQR]) length of hospital stay (LOS) of 10.5 days (IQR: 5-18) and 12 days (IQR: 7-14) respectively, per the patient's satisfaction with in-patient Stroke Care (SASC) scale. This was significantly different from the median LOS of 6.5 days (IQR: 5-7.5) and 5 days (IQR: 4-10) for KCH and Zomba Central Hospitals (ZCH) (p=0.008) respectively.

Table 5.1: Demographic characteristics of patients (N = 90)

Variable		QECH		Lilongwe		Mzuzu		Zomba		p-value*
Hospital of study recruitment										
Number recruited (n, %)		28	31	27	30	19	21	16	17	
Age (years) (median (IQR)		59	(41; 72)	60	(53; 68)	70	(58; 77)	53	(35; 66)	0.109**
Sex: male (n, %)		10	35	17	63	14	73	7	43	0.041
Female (n, %)		18	64	10	37	5	26	9	56	
Length of hospital stay (LOS)	Median (IQR)	10.5	(5; 18)	6.5	(5; 7)	12	(7; 14)	5	(4; 10)	0.008

IQR: interquartile range

* Fisher's Exact test unless described otherwise

** Kruskal-Wallis test

Functional Independence Measure (FIM)

Overall, FIM-scores increased significantly between admission (median=51.5 IQR: 39-62) and discharge (median=70, IQR: 52-95) (p<0.001). Significant improvements between admission and discharge existed in the following FIM components: self-care, sphincter control, locomotion and social cognition (p≤0.003) (Table 5.2). Score for self-care increased from a median of 11 (IQR: 7-18) on admission to 20.5 (IQR: 12-31) on discharge. Similarly, sphincter control and locomotion improved from a median of 4 (IQR: 2-12) and 2 (IQR: 2-6) to 10 (IQR: 5-14) and 6 (IQR: 2-11) respectively. However, there was no significant improvement in transfers and communication (p-values≥0.865), which was the same across the four sites.

Table 5.2: Functional Independence Measure (FIM) (N=90)

	Admission		**Discharge**		
	Median	**IQR**	**Median**	**IQR**	**p-value***
Self-care	11	7; 18	20.5	12; 31	<0.001
A eating	3	2; 6	6	4; 7	<0.001
B grooming	1	1; 3	4	2; 6	<0.001
C bathing	1	1; 2	3	1; 5	<0.001
D dressing - upper body	1	1; 2	3	1; 5	<0.001
E dressing - lower body	1	1; 2	3	2; 6	<0.001
F toileting	1	1; 3	4	2; 6	<0.001

Sphincter control	4	2;12	10	5;14	<0.001
G Bladder management	2	1;6	6	3;7	<0.001
H Bowel management	2	1;6	6	3;7	<0.001
Transfers	3	3; 8	3	3; 8	1.000
I bed, chair, wheelchair	1	1; 3	1	1; 3	1.000
J toilet	1	1; 4	1	1; 4	1.000
K tub, shower	1	1; 3	1	1; 3	1.000
Locomotion	2	2; 6	6	2; 11	<0.001
L walk/wheelchair	1	1; 3.5	3	1; 6	<0.001
M stairs	1	1; 3	3	1; 5	<0.001
Communication	14	12; 14	14	13; 14	0.865
N comprehension	7	7; 7	7	7; 7	0.975
O expression	7	6; 7	7	7; 7	0.975
Social cognition	12	6; 14	14	10; 14	<0.001
P social interaction	6	3; 7	7	5; 7	<0.001
Q problem solving	5	3; 7	7	5; 7	<0.001
R memory	4	2; 6	6	3; 6	0.003
Total FIM Score	51.5	39; 62	70	52; 95	<0.001

* Wilcoxon Signed Rank Test

Satisfaction with care: Patients' and caregivers' perspective

Patients' satisfaction with care was high, with a median score of 19.5 out of a maximum score of 28 (IQR: 15-23). There was no significant difference between male (20 [IQR: 14-25]) and female (19 [IQR: 15.5-22.5]) patients, p=0.415. Similarly, satisfaction scores did not differ by age (years), with a coefficient of -0.04 (95% CI: (-0.14; 0.06); p=0.397. Satisfaction ratings were also high from caregivers' responses, with a median score of 24 (IQR: 21-27). However, the ratings of female caregivers (25 [IQR: 21-29]) and that of their male counterparts: 23 [IQR: 20.5-26]), were not statistically significantly different, (p=0.058). Again, caregivers' satisfaction scores were not associated with age: 0.02 (95% CI: -0.07; 0.1), p=0.663. There was a positive linear relationship between patient and caregivers' satisfaction scores with Pearson correlation coefficient (r) = 0.66; (p=0.001) (Figure 5.1).
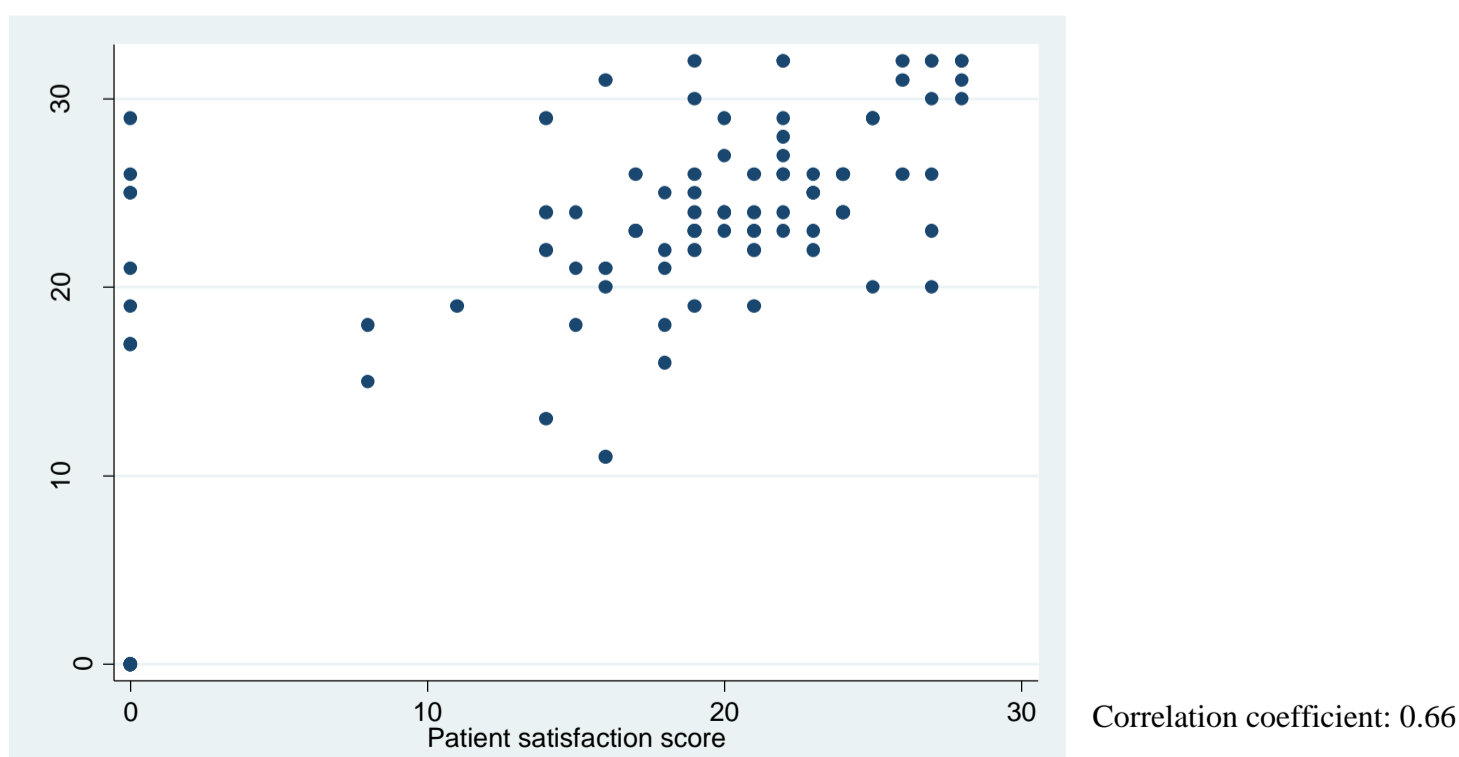

Correlation coefficient: 0.66

Figure 5.1 Correlation between patients' and caregivers' satisfaction scores

Quality of life (QoL)

QoL of patients with stroke in this study is generally poor evidenced by higher level scores of the ED 5D functional dimensions of mobility, self-care and performance of usual activities (Table 5.3). On mobility, most patients were either unable to walk (22 [29%]) or had severe problems with walking (18 [24%]). Most patients (19[25%]), had severe problems with self-care, seconded by 10 (13%) who were unable to perform self-care activities. Most patients were also unable to do their "usual" activities. Most others experienced severe problems (25 [33%]) in doing the same. Patients, however, did not show increased levels of psych-affective disorders. Most of them scored low on pain or discomfort (19 [25%]), or moderate pain or discomfort (20 [27%]), and the majority did not feel anxious or depressed (19 [25%]), or were just moderately anxious or depressed (18[24%]). On the Visual Analogue Scale (VAS), the participant's experience of "health today" was average, with a median VAS score of 50 out of 100 (IQR: 45-75). QoL was similar between male (median score 52.5 [IQR: 45-75]) and female patients (50 [IQR: 45-70]), p=0.307. Using a simple linear regression model, every additional year in age was associated with an average of 0.36 decrease in quality of life score coefficient; -0.36 (95% CI: -0.63; -0.10); p=0.008.

Table 5.3: Quality of life (QoL) items

ED-5D Dimension & levels		Description of perceived problems	Number	Percentage
Mobility	Leve 1	I have no problems in walking about	5	6.58
	Level 2	I have slight problems in walking about	19	25.00
	Level 3		12	15.79
	Level 4	I have moderate problems in walking about	18	23.68
	Level 5		22	28.95
		I have severe problems in walking about		
		I am unable to walk about		
Self-care	Leve 1	I have no problems washing or dressing myself	2	2.63
	Level 2		10	13.16
	Level 3	I have slight problems washing or dressing myself	18	23.68
	Level 4		19	25.00
	Level 5	I have moderate problems washing or dressing myself	10	13.16
		I have severe problems washing or dressing myself		
		I am unable to wash or dress myself		
Usual activities Level 3	Leve 1	I have no problems doing my usual activities	2	2.63
	Level 2		9	11.84
		I have slight problems doing my usual activities	8	10.53
	Level 4		25	32.89
	Level 5	I have moderate problems doing my usual activities	32	42.11
		I have severe problems doing my usual activities		
		I am unable to do my usual activities		
Pain/discomfort Level 3	Leve 1	I have no pain or discomfort	19	25.33
	Level 2	I have slight pain or discomfort	19	25.33
		I have moderate pain or discomfort	20	26.67
		I have severe pain or discomfort	12	16.00
	Level 4	I have extreme pain or discomfort	5	6.67
	Level 5			
	Leve 1	I am not anxious or depressed	19	25.33

	Level 2	I am slightly anxious or depressed	16	21.33
Anxiety/depression Level 3		I am moderately anxious or depressed	18	24
		I am severely anxious or depressed	7	9.33
	Level 4	I am extremely anxious or depressed	15	20.00
	Level 5			

5.4   Discussion

The main findings from this study were improved functional outcomes among patients with stroke at discharge from four central hospitals; high satisfaction ratings with stroke care by patients and care givers although quality of life after the stroke episode was generally poor; and patients with stroke spent relatively fewer days in the hospital compared to other African countries. Stroke functional outcomes, perceived quality of life, and satisfaction with care are used in rehabilitation to determine quality of stroke services (Myint et al., 2016). Therefore, understanding those domains was a step towards identifying areas for improvement in stroke service provision.

Despite resource constraints, patients with stroke had functional outcomes that significantly improved on discharge from the four central hospitals in Malawi. The improvement in patients' functional status on discharge compared to on admission in most FIM components is both positive and interesting given that Malawi is one the poorest countries, with very limited health care resources in general, and for managing stroke in particular (Gadama et al., 2017). In fact, there is no stroke unit and there are very limited qualified stroke specialists, with only one medical resonance imaging (MRI) facility as a vital diagnostic equipment throughout the country. We believe that the general improvement in functional status of the patients is natural recovery although the impact of therapy may not be completely ruled out. However, the positive findings in stroke functional outcomes based on FIM ratings in the current study are comparable to findings in other similarly low-resource settings. For example, a study of hospitalised patients with stroke in a low resource setting in Singapore showed that regardless of the stroke subtype or subgroup, all patients made clinically significant functional gains on completion of inpatient care (Ng et al., 2013).

We further note that despite notable improvement in self-care and locomotion FIM components, our patients still needed moderate assistance on discharge in those areas. Additionally, while there was significant progress in sphincter control from failure on admission to nearly full control at discharge, there was no significant improvement in all items related to transfers and communication. In transfers, patients were still dependent at discharge. These findings imply that additional well-focused care including effective inter-professional collaboration that ensure timely engagement of physiotherapy service may be needed to gain further improvement of patients with stroke (Ng et al., 2013; Scottish Intercollegiate Guidelines Network, 2010).

Patients' satisfaction with care is another critical indicator of the quality of care in a given setting (Cramm, Strating & Nieboer, 2012). In this study, patients and caregivers expressed high satisfaction with care with no differences among men and women or by age. However, female caregivers had significantly higher satisfaction ratings compared to male caregivers. Caregiving is generally performed by women in the Malawian culture, perhaps explaining the difference in caregivers' satisfaction ratings. Female caregivers tended to be more resilient in caregiving roles, based on observation. We also postulated that the general increase in satisfaction ratings could be connected to lack of knowledge of "what is" and what "ought to be".

Despite improvement in functional outcomes and high satisfaction scores, patients with stroke in this study had poor quality of life, as measured by EQ-5D-5L and its associated Visual Analogue Scale (VAS) (Golicki et al., 2015). Most patients were either unable or had severe problems with walking, doing their self-care, and usual activities. This is similar to a Tanzanian study where 68% of patients with stroke of varying ages gave up their work permanently. They also experienced marked disability, depression, and anxiety (Howitt et al., 2011). Poor QoL in this study is also similar to the findings of earlier studies (Scottish Intercollegiate Guidelines Network, 2010; Ministry of Health., 2009). We also found that as patients got older, they were more likely to have poorer QoL than younger patients. Similar observations were made by Dayapoglu et. al who found that patients aged 61 to 71 years had the lowest scores on functional status, well-being, and general health perception and the lowest mean QoL score. Therefore, there is a need to focus on functional abilities when managing patients with stroke with the aim of improving their health-related quality of life.

The current study also showed that patients with stroke across the four central hospitals spent an average of 8.5 days in the hospital although those at Queen Elizabeth and Mzuzu Central Hospitals spent significantly longer when compared to LoS for patients with stroke at Kamuzu and Zomba central hospitals respectively. The average LoS was generally lower when compared to that reported by Heikinheimo and Chimbayo who showed that the average hospital stay at Queen Elizabeth Central Hospital was 15.7 days, and that of a retrospective analysis of health records of patients with stroke admitted into the medical wards of the University College Hospital, Ibadan, which found 13.7 ± 8.9 as an average LoS

(Somotun, Osungbade, Akinyemi, Obembe & Adeniji, 2017). However, a similar finding was recorded by Nakibuuka et al in Uganda at Mulago National Referral and Teaching Hospital, where patients with stroke had an average length of hospital stay of 8.9 days. On the one hand, the reduction in hospital stay in the country's central hospitals could be a good development considering cost-related implications of acute stroke care. On the other hand, though, the poor QoL at discharge means that people with stroke are not being helped to achieve their highest possible potential post stroke. Saposnik et. a1 stated that length of stay is the major determinant of cost-determining factors during acute stroke hospitalisation, an important consideration for limited resource areas such as Malawi.

Limitations in this study included the small sample size and selection bias, with only those who were able to understand and speak the spoken language were included. This left out some people with probably severe stroke disability. Therefore, this study may have been underrepresented in this group. Other patients with mild stroke and not admitted to one of our sample hospitals are not represented in the current study. The quality of life findings may be spurious as there were no comparison measurements. Finally, the comorbidities that potentially impact patient function and QOL have not been captured in the current study. The current study was carried out at central hospitals, leaving out district hospitals that may be more active in managing and discharging patients with stroke.

Conclusion

The functional outcomes of patients with stroke in this cross-sectional study improved significantly on discharge compared to admission status. Patients and caregivers showed that they were highly satisfied with the way care was provided despite having poor quality of life post-stroke treatment. There is a need to focus on proven interventions on areas of stroke care, such as introduction of stroke units, that can impact the patients' quality of life in resource limited settings such as Malawi. Malawi could consider the introduction of specialised stroke care units, which have been found to improve outcomes even LMICs.

6.0   Introduction

This chapter addresses objective number 4 which is to determine the current evidence of stroke care and rehabilitation service provision by conducting a scoping review.

6.1   Background

Stroke is a major public health concern, both debilitating and deadly to millions of people worldwide each year. Stroke frequently leads to loss of functional independence from physical and cognitive dysfunction. While stroke is stressful, efforts toward better outcomes such as limiting the disability, more effective means of coping with loss, adaptation to change, and temporal ordering of coping processes could help patients recover to their highest possible functional level. To achieve these outcomes, high quality care is needed. The quality of patient care can be conceptualised using a model such as the one developed by Donebedian.

Donabedian Model (DM): The Conceptual framework

Known as the most comprehensive model for assessing quality of health care as presented in 1966, the model has three distinct aspects to health care quality: structures, processes, and outcomes (SPO) . Accordingly, *Structures* of health care are defined as the physical and organisational aspects of care settings, for example, facilities, equipment, personnel, operational, and financial processes supporting medical care. *Processes* in patient care include resources, mechanisms provided by the health care structures to carry out patient-care activities that promote recovery, functional restoration, survival, and patient satisfaction (the *Outcomes*).

In addition to developing the methodology for measuring structures, processes, and outcomes, Donabedian made an equally important contribution by prioritising governance and management. When supported by measurement methods, they could be the determining causes of the effectiveness and efficiency of health services. Related to quality of care, Donabedian said "systems… are enabling mechanisms only. It is the ethical dimension of individuals that is essential to a system's success" . This is in sharp contrast to the ideologies of other researchers who advocated universal coverage or claimed that physicians' clinical and financial autonomy was a precondition for the quality of care.

The relationships between structures, processes, and outcomes were effectively presented in a South African study which assessed quality of integrated chronic disease among patients and operational managers. The study found that structure-related construct was the availability of equipment, supply of critical medicines, and accessibility of chronic disease care. Those related to process were communication between the nurses and patients, attendance of the nurses to patients' health needs, professional conduct of the nurses, nurses' friendliness with patients, hospital referrals for patients, pre-packaging of medicines, physical examination of patients; and the time nurses spent with patients during consultation. Outcome-related construct included coherence of integrated chronic disease care, competence of nurses, and patients' confidence in nurses (Ameh S. , Gómez-Olivé, Kahn, Tollman & Klipstein-Grobusch, 2017).

Effective stroke care included assessment (completed within 48 hours post stroke), (Casaubon et al., 2016) early mobiliation to prevent or reduce complications such as infections, deep vein thromboses (DVT), and falls, and promote recovery, avoidance of urinary catheterisation leading to bladder infections, treatment of hypoxia, hyperglycemia, and suspected infections, and ongoing rehabilitation activities. Internationally, four acute-care intervention processes have been recommended by most stroke experts as the most effective front-line interventions. Those included care in a specialised stroke unit (SU), thrombolytic therapy through tissue plasminogen activator (t-PA) for acute ischemic stroke (within 4.5 hours of initial onset) (Wardlaw, Murray, Berge & Del Zoppo, 2009; Hacke et al., 2008), aspirin therapy for acute ischaemic stroke (within 48 hours) (Sandercock, Counsell, Tseng & Cecconi, 2014), and decompressive surgery (within 48 hours) (Vahedi et al., 2007) to reduce stroke-related mortality and morbidity (Donnan et al., 2011).

As highlighted, the most effective stroke-care service requires an organised setting such as SU care. However, where units do not exist, patients with stroke should be admitted to generic wards staffed by a coordinated multidisciplinary team with special expertise in stroke care. In some settings in LMICs, such as those in Africa, multidisciplinary stroke-care teams are formed with non-specialist service providers and in the absence of other equally important professionals, such as speech therapists (Baatiema et al., 2017). There is also a need for readily available

radiological equipment to make the most accurate stroke diagnosis. Clinical methods predominate in resource-limited settings, (Morgenstern et al., 2004) although Imam and Olorunfemi said such methods still need proper attention through a skills check. Accurate diagnosis of stroke related to site, size, and type still requires radiological methods.

It was recommended that appropriate systems of stroke care be established in LMICs to control the increasing death and disability associated with stroke (Feigin, Lawes, Bennett & Parag, 2009; Langhorne, de Villiers & Pandian, 2012). However, implementation of those systems is challenged by the absence of direct health policy support from the state or national level for stroke care (Baatiema et al., 2017).

Applying Arskey and O'Malley's scoping review methodology, the purpose of this review was to systematically document the evidence of stroke care and rehabilitation service provision in LMICs that could inform the development of a more-effective contextual model of care for Malawians and ultimately an improvement in their quality of life.

The following broad question was used to ensure that all relevant literature was included ,

"What are the components of acute stroke care and rehabilitation services by health personnel across the hospital stroke care continuum in LMIC?" This question was delineated to have "stroke care" AND "profession and setting" search terms.

6.2   Methods

6.2.1   Identifying relevant studies

According to Joanna Briggs Institute, in searching for articles to be included in a scoping review, the researcher undertakes a limited search of relevant databases, followed by analysis of text words from titles, abstracts, and index words. Therefore, this researcher performed an electronic database search that included Cochrane Library, Credo Reference, Health Source: Nursing/Academic Edition, Science Direct, BioMed Central, CINNAHL with full text, Academic Search Complete, and Google Scholar in January 2018. Search tools such as medical subject headings (MESH) and truncation to narrow or expand searches were utilised. Single and combined search terms included acute stroke, stroke care, stroke rehabilitation, developing countries, and LMIC. This study included empirical English articles on stroke care published between 2010 and 2017. Excluded studies were those from high-income countries using the World Bank definition not within the defined range of publication time and those covering participants under 18 years of age, per the United Nations Conventions of the Rights of the Child.

6.2.2   Selection of articles for inclusion

The researchers used a two-stage selection criterion by Halas, Schultz, Rothney, Goertzen, Wener, and Katz . Initially, the researcher and team (GC, SM, FM HZ, and JA) screened the titles and reviewed them for relevance to acute stroke hospital and rehabilitation care from LMICs. Secondly, they screened the chosen articles' abstracts with key sections of the introduction for answers to the research question and objectives, methods that included the article design, setting or context, key findings, and conclusions.

6.2.3   Data charting and collation

If the article met the inclusion criteria, the information relating to aim of the study was extracted and captured on a data charting form. The data charting table/form as displayed in Table 1 included the citation (author and year), country, recruitment context, study design, sample, outcomes based on objectives, and key findings. The table/form was peer-reviewed, with ambiguity removed in the process. The authors and research assistants (GC, HZ, JA, SM) initially extracted data independently then met to determine if the data extractions were consistent with the aim of the study and the research questions (Ref. appendix 1).

6.2.4   Collating, Summarising and reporting findings

To evaluate the evidence of stroke care in LMICs, the researchers summarised and categorized the data in line with the SPO model as the conceptual framework.

6.3   Results

The search identified 177 articles. Duplicates (n=27) were manually removed. Title and abstract searches revealed 58 articles not within the context of the research question. Seventy-two articles did not meet the inclusion criteria for various reasons, leaving 20 articles for the scoping review (Figure 6.1 below).
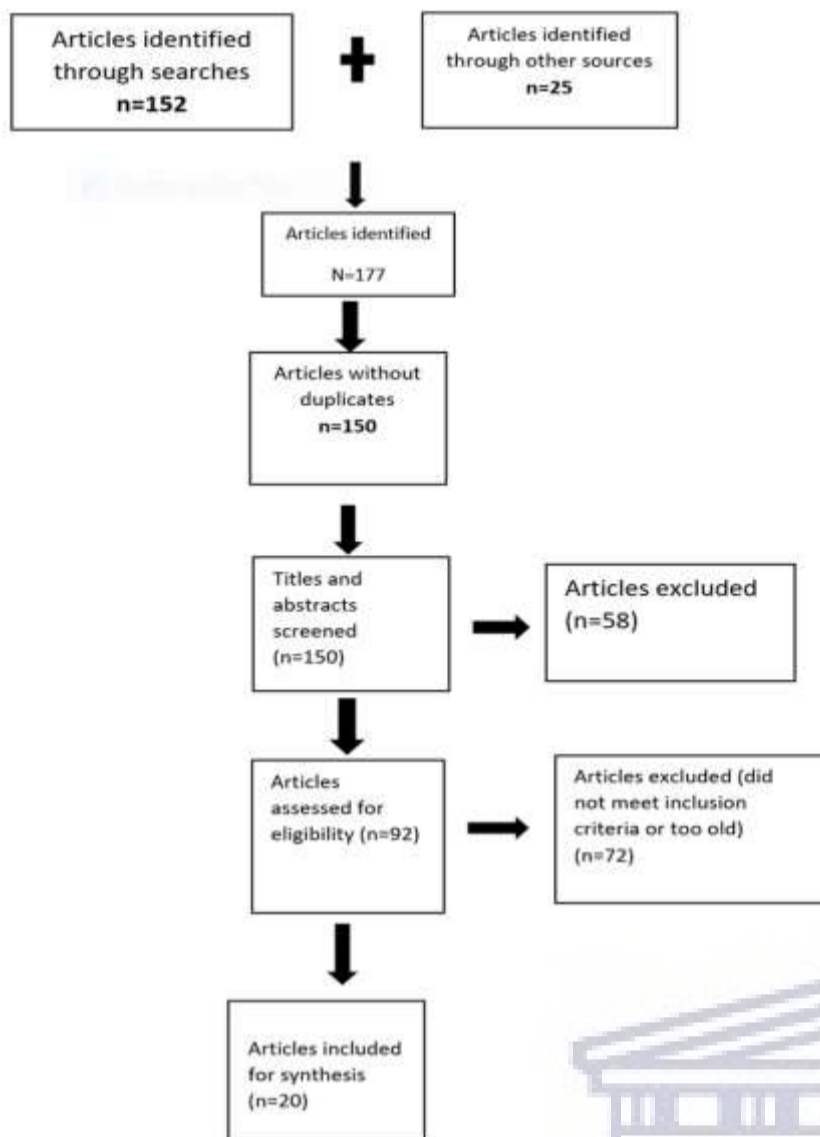
Figure 6.1 Scoping review process

Evaluating the evidence on stroke care in the LMICs was facilitated by synthesising findings of studies describing hospital acute stroke care and rehabilitation. The findings have been displayed with their general characteristics such as the settings and locations (Table 6.1). Various stroke care practices and service limitations have been noted based on conclusions and recommendation towards better practice by the authors. The Donabedian Model identified three primary themes of stroke care which are stroke care structure, process, and outcomes.

Table 6.1: Scoping review articles (key details)

Author reference & recruitment context	Study design	Sample	Content of interest	Key findings
Acute stroke presentation in hospitals				
1. Albertino, Joana, Ana, et,al. nd Urban Hospitals. (Central hospitals, public hospitals, military hospitals & private clinics)	Retrospective & prospective August 1, 2005 - July 31, 2006	651 cases	Incidence, characteristics & short-term consequences of hospitalizations for stroke in Maputo and Mozambique	-531 pts (81.6%) with first stroke -601 cases (92.3%) confirmed by CT scan (83.4%) or necropsy (8.9%) -351 (58.4%) ischemic, 242 (40.3%) hemorrhagic, & 8 (1.3%) subarachnoid hemorrhage -Ischemic events increased continuously with age (higher in men 45 to 64 yrs) -Incidence of haemorrhagic stroke rose up to 74 years (yrs) of age; declining thereafter -15% of stroke events occurred in subjects aged 45 yrs. (??and higher/lower/exactly) -60% of pts. arrived at hospital

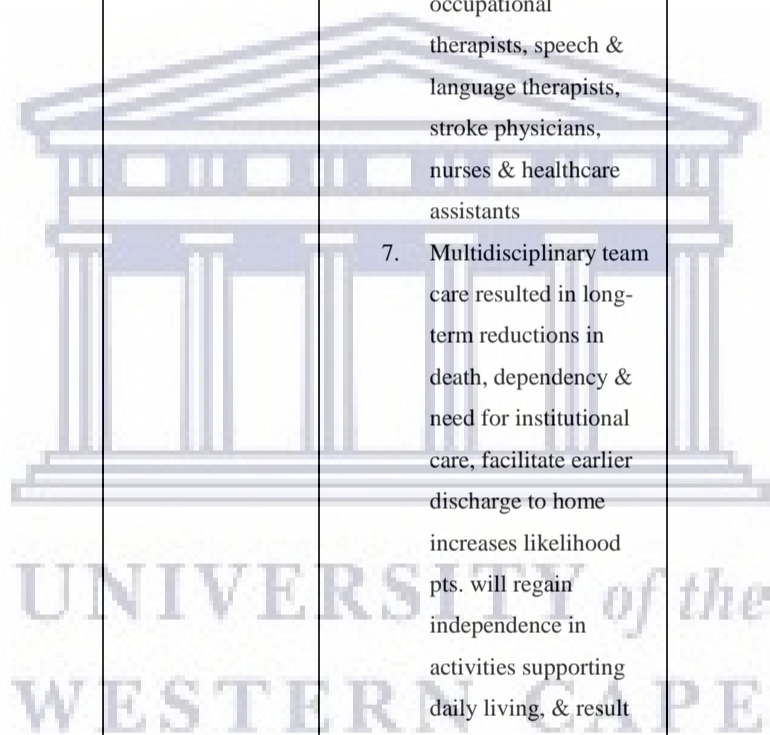|				on same day as symptom onset
				-Most prevalent risk factor was hypertension (86.6% to 96.0%)
				-254 pts. (101 ischemic & 133 hemorrhagic stroke events) died during 28-day follow-up period
2. Lijing, Chaoyun, Jie et.al. 2016	Review 2015	17 included systematic reviews, observational cohort studies, meta-analyses, & case reports	-Risk factors for stroke -Primary prevention of stroke -Treatment of stroke during the acute stage -Secondary prevention -Stroke rehabilitation	- History of hypertension, current smoking, diabetes mellitis, diet risk score, physical inactivity, alcohol intake, psychosocial stress & depression, & cardiac causes -Guidelines for stroke diagnosis: patient history, physical examination, neurological examination & stroke scales, & diagnostic tests - Primary preventive approaches: blood pressure control & promotion & maintenance of healthy lifestyle: not starting to smoke, & smoking cessation for smokers, no binge drinking, being physically active, & a healthy diet with adequate fruit & vegetable intake, reduced dietary trans-fat intake, & reduced sodium intake -Intravenous thrombolysis approved as evidence-based treatment for acute ischemic stroke -Mechanical thrombectomy in combination with pharmacological thrombolysis improved functional outcomes - Pts. who received organized inpatient care in a SU were more likely to be alive, independent, & living at home 1 yr after stroke -Secondary prevention of stroke: blood pressure control, antiplatelet & lipid-lowering therapy, homocysteine-lowering therapy, self-management, & family support -Stroke rehabilitation: inpatient, home, & community-based programs, including physical, occupational, speech, & recreation therapies - Availability of & access to rehabilitation services low in LMICs -Factors for limited accessibility: poor physician knowledge of the role of rehabilitation; lack of rehabilitation components in the standard of care; long intervals from stroke onset to admission to rehabilitation; infrequent, unskilled, & short-lived provision of rehabilitation care; & inadequate public insurance or financial support for

				rehabilitation care
3. El Sayed, El Zahran & Tamim, 2014 Urban hospital	Retrospective chart review	87 pts.	Pt characteristics & outcomes	Mean age of 71.9 yrs; most pts. arrived by private transport (85.1%): weakness & loss of speech most common presenting signs (56.3%); 37.9% of pts. presented within 4.5 hours of symptom onset Nine pts. (10.3%) received rt-PA2 groups (rt-PA versus non rt-PA)with similar outcomes (mortality, symptomatic intracerebral hemorrhage, mRs scores, & residual deficit at hospital discharge) rt-PA utilization was higher than expected
			Barriers to rt-PA utilization	Delayed presentation barrier to rt-PA administration
4. Ashraf, Maneesh, Praveenkumar, et.al. 2015 Urban Hospital. India	Cross-sectional prospective study (Jan- Dec 2012	264 pts.	Factors contributing to delay in hospital arrival	Median delay = 12 hours. Distance from hospital, history of coronary artery disease, & presence of hemiplegia
5. Tirschwell, TGN, Ly, Van Ngo et.al. 2012 Urban Hospital (n=1) Vietnam	Prospective cohort study	754 pts.	Patient characteristics	328 (43.5%) ischemic, 356 (48.5%) hemorrhagic Risk factors: for ischemic stroke: atrial fibrillation, lower prevalence of hypertension, & previous history of stroke Pts. with ischemic stroke less likely to have disturbed consciousness & speech disturbances, likely to have observed weakness, lower mean systolic & diastolic blood pressures, & higher mean total cholesterol levels
			Clinical predictors of 28-day mortality for admitted pts.	28-day crude mortality was 20.3 % for pts. with ischemic stroke & 51.0%???; overall 37% 28-day predictor of poor outcome: hemorrhagic stroke type, worse pre-stroke Modified Rankin Scale (mRS), disturbed consciousness, absence of observed weakness at presentation, higher diastolic blood pressure, higher glucose levels, current tobacco smoking, & history of hypercholesterolemia Strongest predictor: limited access to evidence-based standards of care due to limited local resources, & local evidence.
6. Robert & Zamzami, 2014	Literature review		Incidence, prevalence type, risk factors of	Low incidence & prevalence of stroke compared to Western

| Saudi Arabia | | | stroke; influence of age, gender differences, neuropsychiatric manifestations, health-related quality of life (QOL), LOS (LOS), medical care, & rehabilitation. | countries

Ischaemic stroke predominated; Sub-Arachnoid Haemorrhage very rare

Important risk factors: hypertension, diabetes mellitus, coronary diseases, & smoking

Men at higher risk than women

Depression not frequent

Low QOL in pts. from Saudi Arabia compared with other countries

Age & functional status influenced HRQOL

Stroke severity, nature & other medical complications: predictors of LOS

Ministry of Health offers rehabilitation services; have one active stroke center

Research on stroke, establish SUs, increase public awareness, train health care providers, & increase the rehabilitation centers |
|---|---|---|---|---|
| 7. Nor, Noor, Sharifa, et.al. 2012 Urban Hospital. (n=1) | Retrospective study from June to October 2010 for pts. 2006–2009 | 557 pts. | Individuals receiving rehabilitation services, their functional status on discharge | 1. Ischemic stroke highest stroke subtype (66.4%) 2. No research on causes of ischemic stroke in Malaysians 3. 62.7% received rehabilitation during hospitalization: daily physiotherapy & occupational therapy 4. 3.0 days mean time from diagnosis of stroke to initiation of rehabilitation 5. Mean disability level at discharge = 3.5 6. Highest level of function at discharge: walking, then standing from sitting, followed by bed mobility & sitting up from supine (47%, 25%, 15%, 12%) 7. > 50% of pts. had mRS score > 3 on discharge 8. Inadequate rehabilitation services for acute & sub-acute stroke survivors |
| 8. Badachi, Mathew, Prabhu et.al. nd | | 100 consecutive acute ischaemic events | Failure of pts. to recognize stroke symptoms, | 1. Poor recognition of stroke symptoms by pts., relatives, & |

			awareness of thrombolysis as a treatment modality, failure of patient's relative to recognize stroke, failure of primary care physician to recognize stroke, transport delay, lack of neuroimaging & thrombolysis facility in 1st hospital of arrival, & non-affordability	primary health care physicians; hence prehospital delay; attributed to lack of knowledge of stroke symptoms & hesitation to initiate treatment 2. No facilities for neuroimaging & thrombolysis for most tertiary hospital 3. Low utilization of thrombolytic therapy due to high cost 4. Inadequate ambulance services, especially in rural areas 5. Education efforts & awareness 6. Training of emergency physicians 7. Improve infrastructure in district hospitals 8. r-TPA should be available at subsidized rates 9. Neuroimaging facilities should be improved & made affordable 10. Uses of dedicated ambulance services 11. Stroke prevention programs on thrombosis needed
Tertiary care center, South India				

stroke care structure

9. Ossou-Nguiet, Sossoumihen, Matali et.al. 2017 Urban Hospital (n=1)	Case report	1	Inadequate availability of IV thrombolysis & mechanical thrombectomy interventions in SU.	1. Pt received IV thrombolysis only & died 24-hrs after admission 2. The unavailability of mechanical thrombectomy interventions 3. Few radiologists & MRI in sub-Saharan Africa 4. Need for enough medical personnel & appropriate equipment in SUs
10. Linda, Sebastiana, & Vanessa, 2009 Urban Hospital. (n=1)	Retrospective study	195 pts. (94 admitted before initiating SU, 101 thereafter)	Outcome of multidisciplinary stroke care in limited-resource settings	1. Inpatient mortality dropped from 33% (n=31) to 16% (n=16) 2. Referral to inpatient rehabilitation increased from 5% (n=53) to 19% (n=513) at discharge 3. Standardized investigation and evaluation of stroke admissions was better 4. Initiation of secondary prevention strategies was achieved 5. Prevention & treatment of complications of

				stroke was also achieved
				6. Evaluation by multidisciplinary rehabilitation team was better achieved in SUs than in general ward
				7. Staff education in stroke care & standardized discharge & rehabilitation planning was also better achieved in SU, compared to general wards
				8. Involvement of relatives in SU was better achieved than in general wards
11. Gould, Asare, Akpalu et.al. nd Ghana			Review of local services for stroke care, assist with service plans, provide multidisciplinary education & training, & practical case-based problem solving	1. Need for frontline staff to improve delivery of stroke care 2. Establishment of Ghana's first SU
12. Ahmed, Nourelsabah, Nada et.al. 2016 Urban Hospital. Egypt	Case report (Oct, 2016)	1	Administration of rTPA, dose, recommended administration time & availability of 2 in hospitals	Partial improvement during 3-month period after rTPA administration
Stroke Care Process				
13. Leonard, Michael, George et.al. 2017 Urban hospitals. (n=11) A non-probabilistic purposive sampling technique used for recruitment	descriptive study: Nov 2015 - Apr 2016	11 participants (neurologists & physician specialists) & medical officers (general physicians).	evaluating available acute stroke services	1. Availability of designated accident & emergency departments 2. Limited functional diagnostic & assessment services 3. Specific stroke clinical guidelines in all study hospitals 4. Few SUs available 5. No functional & standardised multidisciplinary team was evident 6. No provision of thrombolysis using tPA reported 7. Surgical procedures not conducted in any study hospital 8. Fewer/absence of stroke specialist 9. No direct health policy support from the state

				or national level for stroke care
14. David, nd	Review of stroke evidence	I reviewer	Effect of multidisciplinary stroke care & possible future direction	1. Pre-hospital & acute services improved recognition of stroke, established rapid specialist assessment resulting in more accurate diagnose & quality care 2. Thrombolysis can be safely administered up to six hours after witnessed stroke onset 3. Rehabilitation is key to stroke care 4. Rehabilitation interventions remain limited in some areas 5. Rehabilitation should commence as early as possible after stroke 6. SU team includes physiotherapists, occupational therapists, speech & language therapists, stroke physicians, nurses & healthcare assistants 7. Multidisciplinary team care resulted in long-term reductions in death, dependency & need for institutional care, facilitate earlier discharge to home increases likelihood pts. will regain independence in activities supporting daily living, & result in fewer pts. requiring long-term institutional care 8. Multidisciplinary team approach most effective way of providing high-quality stroke services 9. Need for early referral to clinical psychologists or psychiatrists to provide interventions when need arises 10. Co-ordinated multidisciplinary teamwork made improvements in quality of care in pts with stroke
15. Al Khathaami, Algahtani, Alwabel, Alosherey, Kojan, &	Situation analysis study. Phone interviews.	83 Neurologist.	Views & beliefs about current stroke care in the country, system deficiencies,	1. 71% of neurologists rated the care provided to stroke pts. at 6 or below on a scale between 1 (very poor) & 10 (best care)

Aljumah et.al. 2011 Urban hospital, Saudi Arabia			attitude towards t-PA use, logistics required to provide optimal stroke care, & the priorities needed for improvement	2. Deficiencies in stroke care starting from prevention & education at the community level to post-stroke rehabilitation 3. Lack of thrombolysis program to the existing shortage of resources 4. Need for improvement
16. Ogungbo, Ushewokunze, Mendelow et.al. 2005. Nigeria	Situation analysis	Not specified	How to improve management of stroke	1. Population strategy by implementing Public awareness programs, Life style modification strategies 2. Introduction of stroke study groups & development of local guidelines among physicians
17. Rahil, Afshin, Anahid et.al. 2012	Letter to the Editor. Iran		Cost-effectiveness of rTPA in developing countries	1. No studies on cost-effectiveness of rTPA in developing countries 2. Studies done revealed rTPA as cost-effective in developed countries 3. Few rehabilitation centres in developing countries
Stroke care outcomes				
18. Baatiema, Chan, Sav et.al. 2017. Hospitals across Africa	Systematic review using PRISMA	4 non experimental studies with 330 study participants between 2009 & 2016	Clinical efficacy of SUs Thrombolytic therapy	2. Less deaths (16%) Vs 33% prior SU 3. LOS 6.8days compared to 5.1 days i general wards 4. Stroke referrals to inpatient rehab was higher than to general ward, (19% vs 5%) 5. Though not significant, patient access to CT brain scan was higher, 16%, in SU compared to 13% in the general medical ward 6. Improved pt outcomes with use of thrombolytic therapy 7. Thrombolytic therapy can generate optimal patient outcomes in Africa 8. Imperative for policymakers to increase efforts to increase the use of thrombolytic therapy in hospital settings to reduce the current disproportionately high stroke burden in Africa
19. Rhoda A, Cunningham N, Azaria, 2015 Hospitals (n=3) R, South Africa & TZ	Retrospective	452 pts.	-Time from stroke onset to admission -in-patient physio & rehabilitation	Time interval stroke onset to admission 6.8, 0.3, & 1.2 days LOS stay; 8.2, 7.38, & 12.19 for R, SA, & TZ respectively 40%,68%, & 98% of pts. with stroke in R, TZ, & SA respectively, received physio-rehabilitation, 2 sessions/week in R & TZ, & 3 in SA
20. Olaleye & Lawal, 2017 (Urban hospital	Retrospective	783 pts.	Inpatient physio rehabilitation	1. Mean LOS=16.2 days 2. Referral rate for PT high (75.8%) 3. Mean time from

Nigeria)				admission to referral for PT = 3 days
				4. Majority (63.4%) of pts. referred utilized PT ; mean number of PT sessions during in-patient care = 8.7
				5. Utilization of in-patient PT significantly associated with reduced LOS

6.4 Descriptive presentation of results

The overall aim of this study was to determine the current evidence of stroke care and rehabilitation in LMICs. To achieve this aim, we first needed to understand current stroke care services in the countries that share similar evidence of stroke burden and economic characteristics. Studies from LMICs per the World Bank classification from 2009 and 2017 were included. In addition to noting the number of articles, we recorded general characteristics such as study settings. The findings were further illustrated in three key thematic areas based on the Donabedian model. The results are highlighted by the combination of texts, tables, and figures.

6.5 General characteristics of included articles

There was a total of 20 articles published between 2009 and 2017. They were from different LMICs, with half (10) of the articles from Africa and the other half (10) from Asia. The design for most of the articles was a retrospective chart review (n=8). Others were systematic reviews (n=3), case report, situational analysis, and descriptive studies (n=2), and one each for cross-sectional prospective study, literature review, descriptive studies, prospective follow-up. The focci of the articles was hospital care and rehabilitation services. The topics were categorised into SPO.

6.6 Stroke Care Structures

This scoping review had 19 dimensions of stroke care, thematically established from 11 articles (Albertino et al., 2010; Yan et al., 2016; Robert & Zamzami, 2014; Badachi, Mathew, Prabhu, Nadig & Sarma, 2015; Ossou-Nguiet et al., 2017; Linda, Sebastiana, & Vanessa, 2009; Leonard et al., 2017; Clarke, 2013; Al Khathaami et al., 2011; Ogungbo et al., 2005; Baatiema, Chan, Sav & Somerset, 2017).
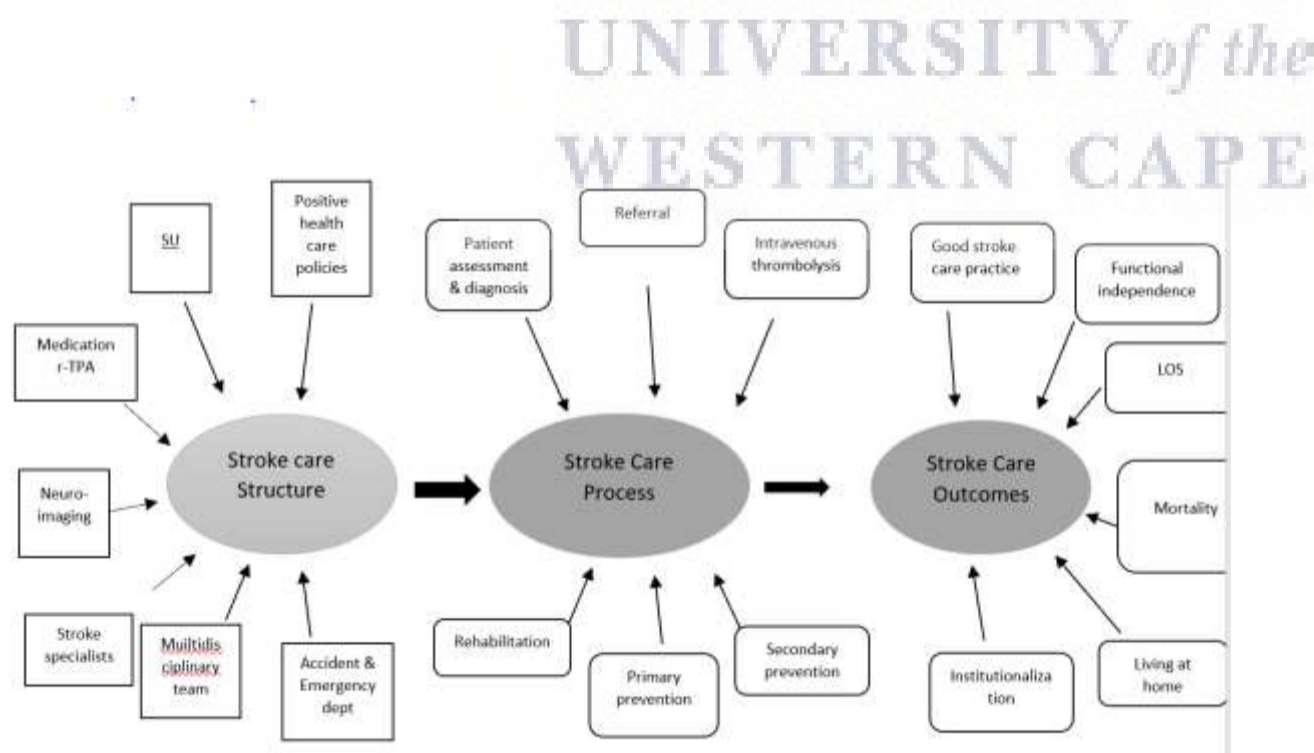
Figure 6.2 dimensions of care

Seven of them constituted the stroke care structure (Fig 6.2). They were SU, accident and emergency department, multidisciplinary team, stroke specialists, neuroimaging, medication, and health care policies. There were few or no SUs in any of the settings within the LMICs (Al Khathaami et al., 2011). The availability of designated accident and emergency departments that triage patients in LMICs, with specific clinical guidelines and functional and standardized multidisciplinary teams was associated with optimal stroke-care practice (Leonard et al., 2017). There are, however, few specialist health care workforces for acute stroke care both in number and variety (Leonard et al., 2017) to constitute

multidisciplinary teams. This type of teamwork was reported as the most effective way of providing high-quality stroke services, even in less-resourced LMICs.

There were no facilities for neuroimaging and thrombolysis for many tertiary hospitals, inadequate ambulance services especially in rural areas, limited educational efforts and awareness, inadequate training of emergency care physicians (Badachi, Mathew, Prabhu, Nadig & Sarma, 2015), unavailability of mechanical thrombectomy interventions, and few radiologists and MRI technology in sub -Saharan Africa (Ossou-Nguiet et al., 2017). In those countries that had key radiological devices, such Computed Tomography (CT) scanners, there were effective diagnostic workups on patients with stroke. For example, 601 cases (92.3%) were confirmed either by CT scan (83.4%) or necropsy (8.9%) as ischemic or hemorrhagic stroke, or subarachnoid hemorrhages (Albertino et al., 2010). Of note was that standardised investigation and evaluation of stroke assessment and admissions was much better after initiating multidisciplinary Stroke-Unit care as established in some countries such as Ghana, as a new development in the stroke care structure (Leonard et al., 2017).

There was also limitation in availability of key medical supplies, such as rtPA in most LMICs. Additionally, there was poor physician knowledge of the role of rehabilitation; lack of rehabilitation components in the standard of care; a long interval from stroke onset to admission to rehabilitation; infrequent, unskilled, and short-lived provision of rehabilitation care; and inadequate public insurance or financial support for rehabilitation care (Yan et al., 2016).

In a related matter, countries such as Ghana had no direct health policy support from the state or national level for stroke care (Leonard et al., 2017). Studies recommended that policymakers could facilitate the utilisation of thrombolytic therapy in hospital settings to reduce the current disproportionately high stroke burden in Africa (Albertino et al., 2010); rtPA could, therefore, be made available at subsidised rates; neuroimaging facilities could be improved and made affordable in addition to use of dedicated ambulance services, and stroke prevention programs on thrombosis should be initiated (Ogungbo et al., 2005). Population strategy could focus on implementing public awareness programs, life-style modification strategies, the introduction of stroke study groups, development of local guidelines among physicians (Ogungbo et al., 2005), upscaling rehabilitation services by training health care providers and increasing the number of rehabilitation centers.

Some studies recommended a need for ministries of health and governments in LMICs to adopt and implement SUs for their reported impact on stroke outcomes (Ossou-Nguiet et al., 2017) (Baatiema, Chan, Sav & Somerset, 2017). For instance, the multidisciplinary teams afforded by SUs had been reported to have led to a drop in inpatient mortality, and increased referral to inpatient rehabilitation (Linda, Sebastiana & Vanessa, 2009). Additionally, standardised investigation and evaluation of stroke admissions was much better after initiating multidisciplinary SU care; initiation of secondary prevention strategies, prevention and treatment of complications of stroke, evaluation by a multidisciplinary rehabilitation team, staff education in stroke care and standardised discharge and rehabilitation planning and involvement of relatives were more easily achieved in SUs than in general wards (Linda, Sebastiana & Vanessa, 2009; Baatiema, Chan, Sav & Somerset, 2017). Introduction of SUs was also associated with reduced LOS (Baatiema, Chan, Sav & Somerset, 2017).

6.7   Stroke Care Process

The process of stroke was illustrated by 12 articles (Albertino et al., 2010; Yan et al., 2016; Badachi, Mathew, Prabhu, Nadig & Sarma, 2015; Ossou-Nguiet et al., 2017; Linda, Sebastiana & Vanessa, 2009; Clarke, 2013; Al Khathaami et al., 2011; Baatiema, Chan, Sav & Somerset, 2017; El Sayed, El Zahran & Tamim, 2014; Rahil, Afshin, Anahid & Salvador, 2012; Rhoda, Cunningham, Azaria & Urimubenshi, 2015; Olaleye & Lawal, 2017; Ashraf, Maneesh, Praveenkumar & Saifundheen, 2015). Six stroke care processes, illustrated in Figure 2 consist of assessment and diagnosis, referral, intravenous thrombolysis, rehabilitation, and primary and secondary prevention strategies. Stroke assessment and diagnosis in LMICs was challenged by lack of proper stroke care structure (Badachi, Mathew, Prabhu, Nadig & Sarma, 2015; Ossou-Nguiet et al., 2017). Stroke assessment for diagnosis included patient history, physical examination, neurological examination and stroke scales, and diagnostic tests (Yan et al., 2016). However, recognition of stroke had improved following the introduction of pre-hospital and acute services (Ashraf, Maneesh, Praveenkumar & Saifundheen, 2015).

Five studies highlighted the management of ischemic stroke using rtPA. Intravenous thrombolysis was approved as an evidence-based treatment for acute ischemic stroke in some settings within the LMICs (Yan et al., 2016). Although there were no studies on the cost-effectiveness of rtPA in developing countries, studies in developed countries revealed that rtPA was cost-effective (Rahil, Afshin, Anahid & Salvador, 2012) in treating ischemic stroke. Improved patient outcomes with the use of thrombolytic therapy could generate optimal patient outcomes in Africa as lack of thrombolysis program was said to add to the existing shortage of resources (Al Khathaami et al., 2011). Thrombolysis could be safely administered up to six hours after witnessed stroke onset. However, delayed presentation to the hospital was the main barrier to rt-PA administration in Lebanon.

Rehabilitation services for patients with stroke was highlighted in seven articles. Of importance was the common finding that rehabilitation represented a key part of stroke care for the majority of patients. However, despite much research revealing the necessity of rehabilitation, the intervention remained limited in most LMICs. Recommendations were for rehabilitation to commence as early as possible after a witnessed stroke. SU team or just stroke team (in absence of SU) included physiotherapists, occupational therapists, speech and language therapists, stroke physicians, nurses and healthcare assistants. Referral to in-patient rehabilitation varied depending on the approaches to stroke care, as introduction of SUs and multidisciplinary team in some LMICs was associated with a huge increase in referrals. The mean time from admission to referral for physiotherapy was 3 days (Linda, Sebastiana & Vanessa, 2009). The majority of patients referred utilised physiotherapy and the mean number of physiotherapy sessions received during in-patient care in the sampled urban hospitals varied. For example, physiotherapy was utilised 2 sessions per week in Nigeria, 2 sessions per week in Rwanda and Tanzania respectively, and 3 in South Africa (Rhoda, Cunningham, Azaria & Urimubenshi, 2015).

Two reports highlighted stroke prevention strategies, with approaches including blood pressure control, promotion and maintenance of healthy lifestyles (i.e., not smoking or smoking cessation for smokers, no binge drinking, being physically active, and a healthy diet with adequate fruit and vegetable intake, reduced dietary trans-fats, and reduced sodium (Albertino et al., 2010). Secondary prevention of stroke, on the other hand, included blood pressure control, antiplatelet and lipid-lowering therapy, homocysteine-lowering therapy, and self-management and family support (Yan et al., 2016).

6.8   Stroke Care Outcomes

Regarding stroke care outcomes, 7 studies (Yan et al., 2016; Robert & Zamzami, 2014; Leonard et al., 2017; Clarke, 2013; Al Khathaami et al., 2011; Olaleye & Lawal, 2017; Mohd Nordin, Aziz, Alkaff, Sulong & Aljunid, 2012) reported a total of six dimension of stroke-care outcomes illustrated on the right side of Figure 1. They were quality of stroke care practice, functional independence, length of hospital stay (LOS), mortality, living at home, and institutionalisation. Of note were LMICs with better structure and processes of care such as availability of SU, patients were more likely to be alive, independent, and living at home one year after stroke (Yan et al., 2016). On the other end, LMICs with no requisites had unsatisfactory or poor stroke service delivery (Al Khathaami et al., 2011) and poor stroke care practice (Leonard et al., 2017). Thrombolysis (Leonard et al., 2017), mechanical thrombectomy in combination with pharmacological thrombolysis when indicated improved functional outcomes (Yan et al., 2016). Utilisation of in-patient physiotherapy (PT) was significantly associated with reduced LOS, and reduced mortality. Absence of rehabilitation on the other hand was associated with reduced level of function, evidenced by increased modified Rankin scale (mRs) score (Mohd Nordin, Aziz, Alkaff, Sulong & Aljunid, 2012). Studies had further shown that a structural dimension such as multidisciplinary stroke care teams resulted in long-term reductions in death, dependency and the need for institutional care, facilitated earlier discharge to the home, increased the likelihood that patients would regain independence in activities that support daily living, and resulted in fewer patients requiring long-term institutional care in some settings within LMIC.

6.9   Discussion

In this paper, we extracted data from twenty articles that highlighted stroke care in LMICs with the guide of the DM on quality of care as a conceptual framework. Nineteen dimensions of stroke care emerged, covering stroke-care SPO. Seven of the 19 dimensions that emerged were structural. They included a SU, accident and emergency department, multidisciplinary team, stroke specialists, neuroimaging, medication, and health care policies (Albertino et al., 2010; Yan et al., 2016; Robert & Zamzami, 2014; Badachi, Mathew, Prabhu, Nadig & Sarma, 2015; Ossou-Nguiet et al., 2017; Linda, Sebastiana & Vanessa, 2009; Leonard et al., 2017; Clarke, 2013; Al Khathaami et al., 2011; Ogungbo et al., 2005; Baatiema, Chan, Sav & Somerset, 2017). Structurally, this review showed that there were few or no SUs in various settings within LMICs. As a result, stroke service delivery in those areas was unsatisfactory or poor (Al Khathaami et al., 2011). The development and running of SUs were a key recommendation in most countries including the developing ones (Baatiema et al., 2017). In LMICs, fast-tracking was needed for the establishment of SUs to revolutionise stroke care provision with the great possibility of improving stroke outcomes (Feigin, Forouzan & Krishnamurthi, 2014). Availability of designated accident and emergency departments with specific stroke clinical guidelines and functional and standardised multidisciplinary teams for acute stroke care were associated with good stroke care practice (Leonard et al., 2017). But the LMICs are grappling with the number and variety of stroke specialists, for example, very few neurologists and almost no speech therapists to form and run efficient teams (Leonard et al., 2017). There is a need for those countries to develop a competitive edge through provision of equal opportunities for career advancement, lifelong learning, and to develop policies that promote loyalty and retention (Marchal, Brouwere & Kegels, 2005). Further, this study highlighted that most LMICs had inadequate facilities for neuroimaging and thrombolysis, inadequate ambulance services especially in rural areas, limited education efforts and awareness about stroke, inadequate training of emergency physicians (Badachi, Mathew, Prabhu, Nadig & Sarma, 2015), and inadequate public insurance or financial support for rehabilitation care (Yan et al.,

2016). There is a pressing need for health care providers to lobby and secure direct health policy support from the state or national level for stroke care (Leonard et al., 2017) to minimise these challenges.

Six dimensions of stroke care processes that emerged in this review were assessment and diagnosis, referral, intravenous thrombolysis, rehabilitation, and primary and secondary prevention strategies (Albertino et al., 2010; Yan et al., 2016; Badachi, Mathew, Prabhu, Nadig & Sarma, 2015; Ossou-Nguiet et al., 2017 Linda, Sebastiana & Vanessa, 2009; Clarke, 2013; Al Khathaami et al., 2011; Baatiema, Chan, Sav & Somerset, 2017; El Sayed, El Zahran & Tamim, 2014; Rahil, Afshin, Anahid & Salvador, 2012; Rhoda, Cunningham, Azaria & Urimubenshi, 2015; Olaleye & Lawal, 2017). Undoubtedly, the structural limitations in LMICs has a bearing on stroke care processes. This review showed that stroke assessment and diagnosis is challenged by inadequate availability of neuroimaging (Badachi, Mathew, Prabhu, Nadig & Sarma, 2015; Ossou-Nguiet et al., 2017). The role for intravenous thrombolysis as evidence-based treatment for acute ischemic stroke is known. It is cost-effective even in LMICs (Rahil, Afshin, Anahid & Salvador, 2012) via its generation of optimal patient outcomes in Africa (Baatiema, Chan, Sav & Somerset, 2017), and lack of the same, adds to the existing shortage of resources (Al Khathaami et al., 2011). We, therefore, share the observation that there is a great need for ministries of health and governments to embrace "the trends", strengthen radiology departments and adopt thrombolysis therapy in stroke care protocols. What was also agreeable in this review was the common finding that rehabilitation represents a key part of stroke care although, clearly, the interventions remain extremely limited in most LMICs. Research recommends that rehabilitation should commence as early as possible after stroke, within 24 to 48 hours. However, access to rehabilitation services remains low in LMICs mostly, due to structural roadblocks such as limitation in number and variety of rehabilitation professionals (Badachi, Mathew, Prabhu, Nadig & Sarma, 2015; Ossou-Nguiet et al., 2017). This review highlighted the need for a two-tier stroke-prevention strategy: primary preventive approaches for stroke, which included blood pressure control and promotion and maintenance of healthy lifestyle (Albertino et al., 2010), and secondary prevention strategies such as blood pressure control, antiplatelet and lipid-lowering therapy, homocysteine-lowering therapy, self-management, and family support (Yan et al., 2016). Primary preventive strategies remained key to the prevention of stroke and must be embraced in all efforts aimed at improving stroke care.

The last six dimensions that emerged were stroke care outcomes that included quality of stroke care practice, functional independence, LOS, mortality, living at home, and institutionalization. Of note was that in the LMICs with better structure and processes of care such as the availability of a SU, patients were more likely to be alive, independent, and living at home one year after stroke (Yan et al., 2016). Comparatively, countries with no requisites had consequent poor stroke service delivery (Al Khathaami et al., 2011). In the LMICs where thrombolysis was administered in combination with mechanical thrombectomy, there was significant improvement in functional outcome (Yan et al., 2016; Leonard et al., 2017). Further, rehabilitative therapy was associated with reduced LOS and reduced mortality. On the other hand, reduced level of function was reported in the situations of absent rehabilitative treatment (Mohd Nordin, Aziz, Alkaff, Sulong & Aljunid, 2012). Additionally, where multidisciplinary teams were implemented, long-term reductions in death, dependency, and early-discharge was reported. There is, therefore, a compelling need for improved structure, allocation of resources, appropriately trained personnel, and recognition of the importance of an integrated team approach to the delivery of stroke care in LMICs. This will ultimately lead to the improved delivery of stroke care (Ossou-Nguiet et al., 2017). and significantly improved outcomes. Many lives could be saved and the quality of life improved for the current and future generations.

This scoping review focused on a broad research field of stroke care. And 2010 to 2017 is reasonably a wide range of publication year, having only 20 articles as meeting inclusion criteria sounds spurious. However, the included articles were very specific to the study question and so could be reflective of stroke care in LMICs. Lack of strict adherence to methodological quality that goes with scoping review might affect the quality of this review. Constant checks with research team members added rigor to the study process. Additionally, the study precluded addressing issues related to personnel availability, program funding, and training institutions across the LMICs to train stroke care specialists.

Conclusions

Inconsistencies exist in the way stroke care is advanced in LMICs. This is reflected in unsatisfactory stroke care structure, processes and outcomes in some settings of study area. There is a need for stroke care settings to adopt stroke care quality improvement strategies. Health ministry and governments need to decisively face stroke burden by setting policies that advance improved care of patients with stroke (Leonard et al., 2017). SUs and rtPA administration could be considered as both a structural and process necessity. They are, clearly, imperative in LMICs such as Malawi for the care of patients with acute stroke whose numbers are increasing exponentially.

7.0 Chapter 7: **A contextual model of care with rehabilitation for patients with stroke in Malawi**

7.0   Introduction

This chapter addresses objective 5 of the current project, which was to develop a new contextual model for in-patient stroke care and rehabilitation in Malawi.

7.1   Background

Stroke is a major cause of morbidity needing specialised care to facilitate positive outcomes . To facilitate those outcomes, there is a growing call for the use of models of care and guidelines that are based on available evidence. A model of care (MoC) is a multifaceted concept, which generally defines the way health services are delivered in a given setting and context. Guidelines, on the other hand, mainly focus on clinical practice rather than delivery of services. A MoC outlines best practices for client care delivery through the application of a set of service principles across identified clinical streams and patient flow continuums. The benefit of the MoC in rehabilitation is that it helps to widen the scope of services, optimise treatment, and facilitate the practitioner's efforts to improve quality while reducing the cost of the care they provide (National Institute for Health and Care Excellence, 2013; Maher, 2008).

Reviewing three models of care, the New South Wales Rehabilitation Model of Care (NSWRMC), the Four-Level Model of Health Care System and, the Hamilton Health Sciences Stroke Model of Care (HHSSMC), five themes or principles emerged as optimal models of care. These were patient-centeredness, patient journey, multi-professional teams, evidence-based practice, organisation and leadership, and consensus opinion. However, the three models reviewed were based on western industrialised settings. Their applicability to settings in developing countries could be challenged by different circumstances, such as resource limitation and the skills level of the workforce. There is a need for the development and implementation of appropriate stroke care in rural settings based on available best-practice recommendations, with "MoC" adapted to local conditions .

The development of a MoC, according to the Agency for Clinical Innovation, involves five stages. First is **Project Initiation,** where services are identified. Based on and analysis of the gaps, one begins to build a case for change. The MoC developers obtain sponsorship to proceed with the program of work and set up project management mechanisms. Under this phase, activities include creation of the initial high level "case for change" by quantifying the extent of the problem and the cost of continuing business as usual. They also develop and agree on project aims, objectives, and scope. Clinicians, managers, and stakeholders are identified and engaged in the project. Important is their evaluation of project value.

Second is **the Assessment and Diagnostic phase,** where the extent of the problem is defined, the root cause understood that addresses the real problem. Activities under this phase include consultation such as workshops, interviews, and brain storming sessions. Developers also carry out an 'As is' analysis, determining current stroke-care delivery processes. Data is reviewed including demand analysis, epidemiology, and service utilisation. Financial analysis of the cost of continuing business as usual must occur. Literature is reviewed, innovations already in the field analysed, finalising the case for change. Identification and prioritisation of issues, aims, and objectives are revisited to ensure the project is progressing well.

The third phase is **the Solution Design**, where solutions are developed and selected. The MoC document is created. Activities include clearly defining the change, which involves changing the focus from how care practices are currently executed and the resulting improvements needed. This requires a high level of creativity to allow innovation. Ideas in this phase are based on sound evidence from literature reviews, best practice guidelines, and brainstorming workshops with representation from clinicians, consumers, operational, data and managerial staff. MoC developers also build the capability of front-line clinicians and manager to change the process/system, develop a communication plan and identify risks to implementation.

Fourth is **Implementation phase**, which is aimed at changing current practice to the desired practices as presented in the new MoC (third phase). There must be a link between what needs to change in the healthcare system and the behavioural changes required to effectively implement the change. This is the most resource-intensive phase of all. Activities under this phase include defining and creating the change clearly, a gap analysis related to the new MoC to assist the implementers in having a clear understanding of their current practice and the gaps to performing according to the new MoC. Service checkpoints are designed against each of the principles in the MoC for easy self-assessment

development of a case for obtaining endorsements from sponsors and stakeholders, presenting to frontline workers, developing communications, and implementation planning.

The fifth phase is **Sustainability**, where use of the MoC is optimised, results monitored, and the impact evaluated. Knowledge management for the activities of the MoC is also critical.

The framework for a MoC has been used to develop specific models of care although not all five steps are necessarily followed. For example, the development of the NSWRMC and the HHSSMC Care used the first three steps of project initiation, assessment or diagnostic phase, and design phase, and then reporting as the fourth phase. This project used the first three phases; initiation, diagnostic and design phases. The diagnostic phase of the project used a multimethod approach where studies helped to first understand care processes, outcomes, and potential challenges in the four Malawian central hospitals. Secondly, a scoping review was conducted to document evidence of stroke care and service delivery to determine its application to a Malawian MoC. In the design phase, the aim was to develop a contextual model for inpatient stroke care and rehabilitation. The steps included generating a stroke care pathway at a referral hospital, gaining consensus on the guiding principles and recommendations as generated from the diagnostic phase then, generating and gaining consensus on stroke care structure, process, and outcomes.

7.3   Methodology

7.3.1   Design, setting, and participants

Nominal Group technique (NGT) was adopted to gain consensus on ideas from a group of professionals at the country's largest referral hospital, the 1400 bed-capacity Queen Elizabeth Central Hospital (QECH) located in Blantyre, a large southern city in Malawi and home to several medical institutions. NGT is reportedly effective in problem identification, development of solutions, and establishing priorities (Carney, 1996; Jones, 1995; Justice, 1990).

Purposeful sampling identified nine participants who took part during the workshop conducted on 18/06/19 and 25/06/19. This sampling technique consisted of identification and selection of information-rich participants, knowledgeable about and experienced in the care of patients with stroke at a referral hospital, available and willing to take part, and able to communicate their experiences and opinion in an objective and reflective manner. The nine participants recruited in this study were within the parameter of five to nine participants recommended for NGT although other researchers have used more than nine (Lloyd-Jones, 1999). The participants included one medical registrar, two emergency nursing officers, two nursing officers (medical), two physiotherapists, one radiology technician and one health systems manager. Due to the limited number of rehabilitation personnel among the nine participants, the team decided to have the scoring and ranking at the rehabilitation department level. The ranking was, therefore, executed in QECH physiotherapy department where eight rehabilitation personnel (6, physiotherapists and 2 rehabilitation technicians) were purposefully recruited.

7.3.2   Data Collection procedure

The development process for the MoC was steered by a team of four professionals who became the reference group for the MoC development in this study. The group included the researcher (GC), moderator (CM) (Dean of Students, Malawi College of Health Sciences), secretary, (JA) (staff physiotherapist at Physiotherapy Health and Fitness Services), and (MN) (general duties assistant and IT technician). The team met three times and the process for the model development was discussed, understood, and agreed upon. As a reference group for the MoC, the researchers summarised key findings from the diagnostic phase, partly captured in the principles of the MoC. Principles for a preferred MoC and rehabilitation were drafted based on literature and findings during the diagnostic phase. Wider consultation on the principles with key stakeholders was completed interprofessionally (Agency for Clinical Innovation, 2013). The reference group also reviewed the documents for use (as highlighted below), making changes where necessary, discussed the budget, and sent invitations to participants. Roles were shared from IT-technician to workshop moderator in readiness for the workshop.

Four-step-sessions of individual writeup, round-robin feedback, discussion, and voting on ideas was implemented to address the objectives. On the day of the meetings, five documents and a pen were placed on each table in a U-shaped sitting pattern. The room also had a projector for computer images and a free-standing flipchart. The five documents were 1) The Focus Group Discussion Confidentiality (FGDC) form, demographic questionnaire, agenda and schedule, worksheet (appendix 12g), and ideas rating sheet (Appendix 12h). Participants were asked to complete and return the confidentiality form and the demographic questionnaire within the first few minutes.

Welcoming remarks

The researcher started the discussion session by introducing himself, welcoming the participants, and explaining the aim of the meeting and expected outcomes. He then presented the insights from the assessment and diagnostic phases (Figure 7.1).

Individual write-up/ Silent generation

After the 1st presentation, the moderator read each question, with appropriate pacing for each participant to have sufficient time to answer before moving on. The participants were asked to generate as many ideas as possible without discussing them with others. Based on the level of the study participant's knowledge, the process worked well, producing a sound list of ideas during the round-robin feedback session. Because of time constraints, the participants were instructed that they could add other ideas during the following session.

Figure 7.1 Principle Investigator presenting MoC diagnostic phase findings with permission from participants

Round Robin Feedback

After every question was individually answered, the moderator called for the round-robin feedback session, where participants were asked to read their ideas aloud. Here, the facilitator also encouraged the participants to add new ideas after listening to other comments during their individual turn and not repeat comments. The moderator recorded the ideas exactly as expressed by the participants on a flipchart. To avoid biasing the participants, the moderator did not take part in the idea generation and presentation although the lead researcher took part as a tenth participant.

Discussion and Clarification

The participants were then asked to discuss the generated ideas, making sure each participant understood what the ideas meant or represented for the ranking phase that followed. During this process, ideas that appeared similar were grouped together after participant consensus.

After discussing and clarifying the ideas, the participants were asked to privately vote to prioritise the options and rank them on the rating sheet in order of importance from the best (ranked 1) to the least (ranked 5). The moderator then tallied the options on the flipchart according to participant feedback. Five options were identified which were then subjected to another round-robin ranking to determine the order based on importance. The options beyond five were maintained as "other(s)" on the list of ideas. However, on some questions, especially those that asked participants to rate "equipment and medication", there was a sixth option, "medication" category. The question that asked for illustration of the stroke care pathway was completed by a nurse, medical registrar, and physiotherapist. Consensus was used to modify one of them by consolidating ideas from the three illustrations (Fig 7.7).

7.3.3 Data Management

One research assistant, one physiotherapist, and one IT-versed individual copied data from the flipchart, displaying it on an overhead projector. The assistant recorded the ranked priorities for each question which made it apparent whether or not an individual idea belonged in the top five of the listed items. This facilitated timely feedback of results to study participants.

Figure 7.2 moderator engaging the participants with permission from participants

7.3.4 Data analysis

The data were analysed both quantitatively and qualitatively. Quantitatively, the data that mostly depicted the principles, interprofessional teams, structure, process and outcomes of stroke care were organised by the relative importance of an idea as reflected in participant placement of that option on the score sheet from 1 to 5 and the frequency of votes by the participants (Tables 1-4). The ideas were ranked from the best (ranked #1) to the least important (ranked #5), with higher scores on particular rankings considered and placed appropriately (Table 2). To find the percentage, the tally number was divided by the maximum possible number of tallies. Of note is the lower tally figure in some sections. This was because other panelists did not feel confident scoring some 'highly medical' options whose significance in service delivery may not be known by rehabilitation personnel, for example. However, the lower number of scores did not necessarily mean less relative importance of sectional options.

Qualitative analysis was used on certain aspects of data that were generated, where the options were agreements from the team members after heated discussions. At this point, the second moderator recorded the resolutions and displayed them with the overhead projector. This made the process mostly transparent, with discrepancies quickly corrected by group consensus. Qualitative data were then analysed around five predetermined themes, which were drawn from chapter four of this project, the diagnostic phase of the MoC development process. The themes were multidisciplinary team, acute assessment and investigation, early management, general management, and discharge planning.

7.3.5 Ethical considerations

Ethics approval for this research was received from the University of the Western Cape: registration number 15/6/31 and the College of Medicine Research and Ethics Committee (COMREC) of the University of Malawi: approval number P.10/15/1819. All participants gave written informed consent for participating in this study.

7.4 Results

Nine participants took part in the discussions (1 physician, 4 nurses, 1 physiotherapist, 1 occupational therapist and 1 radiologist. Five were females, ages ranging from 25 to 38. They had moderate (less than 5 years) to profound (5 to less than 10 years' experience with stroke care (Table 7.1).

Table 7.1: Participant demographics

Profession	age	gender	Experience health care	Experience stroke care
Radiographers	29	M	<5yrs	Moderate
Health systems Manager/ Rehabilitation technician	38	F	5<10yrs	profound
Nurse	31	F	5<10yrs	Profound
Nurse	29	M	<5yrs	Moderate
Nurse	26	F	<5yrs	Moderate
Nurse	25	M	<5yrs	Moderate
Physician	34	M	5<10yrs	Profound
Occupation therapist	26	F	<5yrs	Moderate
Physiotherapist	29	F	<5yrs	Moderate

7.3.1 Principles and recommendations for the MoC

The principles and recommendations were pre-generated by the researcher from lessons drawn from the assessment and diagnostic phase on the current project. They were first discussed by the team, voted, then tallied in the following order of importance: 1) Multidisciplinary team-work 8(80%; 2) Patients journey, 6(60%); 3) Goal-directed intervention 7(70%); 4) Human-centered 5(50%) and; 5) Evidence-based care 6(60%). Other options were stroke service integration, continuation of care, and doing more with fewer resources (Table 7.2).

Table 7.2: Principles guiding MoC

Option	1	2	3	4	5
Principles		score (n=10)			
1) Multidisciplinary teamwork	8 (80%)	1 (10%)	0	1 (10%)	0
2) Patients journey	3 (30%)	6 (60%)	0	0	1 (10%)
3) Goal-directed intervention	0	0	7 (70%)	2 (20%)	1 (10%)
4) Human-centered care	1 (10%)	0	2 (20%)	5 (50%)	2 (20%)
5) Evidence-based care	0	1 (10%)	0	3 (30%)	6 (60%)
Others:					
6) Stroke service integration &. continuum of care					
7) Doing more with less resources					

7.4.1   Multidisciplinary team

Participants in the Nominal Group Technique (NGT) generated and rated the professionals that should comprise the overall multidisciplinary team, how the team should be run, and how such a team should strive to deliver effective and efficient care, where there are limited stroke specialists. The top five professionals were nurses (6 - 60%), physicians (6 - 60%), rehabilitation personnel (5 -50%), radiologists (6 - 60%), and psychologists/councilors (7 - 70%). They also added laboratory personnel (Table 3). It is important to note that the tallied score and its percentage does not necessarily show the descending importance of the options . This is because the tally score was position-dependent whereby the frequency of position number of the option was the one that was dominant when that option was being tallied by the participants.

Related to how the multidisciplinary teams should be run, the participants generated 8 ideas in the following order: 1) Having clear objective protocols, policies, roles, and communications related to referrals (7 - 86%); 2) Running two multidisciplinary ward rounds per week (5 – 71%); 3) Running clinical meetings, sharing notes, using technology as discussion forum and morning reports (4 - 57%); 4) In-service training (4 - 57%); and 5) Early interventions (4 - 57). Others were rotating team leadership, a stroke specialist leading the team, and rotating meeting rooms.

Finally, under the multidisciplinary team, the participants generated and voted on ideas on how the multidisciplinary team should strive to deliver effective and efficient care with limited stroke specialists. Topping the list is the absence of stroke units in the country's central hospitals, each hospital should have a specialty ward for patients with stroke (5 - 71%). Second was effective Communication (4 - 57%) then teamwork spirit (5 - 71%), continuous professional development or training (5 - 71%), and commitment (5 - 71%). Other ideas included goal-orientation, sense of growth and recognition, running journal clubs, and sense of responsibility by individual team members (Table 7.3).

Table 7.3: Overall multidisciplinary team and how it should operate

Option	1	2	3	4	5
a) Professionals comprising interprofessional team Score (n=10)					
1. Nurses	6 (60%)	3 (30%)	1 (10%)	0	0
2. Physicians	3 (30%)	6 (60%	1 (10%)	0	0
3. Rehabilitation personnel	1 (10%)	1 (10%)	5 (50%)	2 (20%)	1 (10%)
4. Radiologists	0	0	1 (10%)	6 (60%)	3 (30%)
5. Counselors	0	0	1 (10%)	2 (20%)	7 (70%)
Others:					
6. Lab staff					
b) How interprofessional team should run Score (n=7)					
1. Clear objectives/ protocols, triaging /policies/roles clearly defined/referrals	6 (86%)	1 (14%)	0	0	0
2. Two multidisciplinary ward rounds per week	0	5 (71%)	1 (14%)	1 (14%)	0
3. Clinical meetings/sharing notes/discussion forum/morning reports	0	1 (14%)	4 (57%)	1 (14%)	1 (14%)
4. Training inservices	0	0	1 (14%)	4 (57%)	2 (28%)
5. Early intervention	0	0	2 (28%)	1 (14%)	4 (57%)
Other ways to manage the team: 6. Rotate leadership					
7. Team led by stroke specialists					

		Score (n=7)				
c)	How the interprofessional team should strive to deliver effective and efficient care in situations with limited stroke specialists					
1.	Having special wards for patients with stroke	5 (71%)	2 (28%)	0	0	0
2.	Effective communications	1 (14%)	4 (57%)	1 (14%)	1 (14%)	0
3.	Teamwork spirit	0	1 (14%)	5 (71%)	1 (14%)	0
4.	Continuous professional development/training	0	0	1 (14%)	5 (71%)	1 (14%)
5.	Professional commitment by team members	0	0	1 (14%)	1 (14%)	5 (71%)
Other impacts on effective team operation:						
6.	Goal orientation					
7.	Sense of growth and recognition					
	Literature reviews/Journal clubs					

7.4.2 Structure process and outcomes of stroke care

7.3.3.1 Structure of stroke care

Participants in the NGT first agreed that the sections within the central hospital where a patient with stroke is managed is the Emergency Department (ED), the patient's initial contact point with the hospital. From the ED, patients are admitted to the medical ward for the implementation of various processes of care with follow up. Some patients are managed outside of the ward, in the Rehabilitation Department, during the period of hospitalisation. Figure 7.3 shows the Stroke Care Pathway.
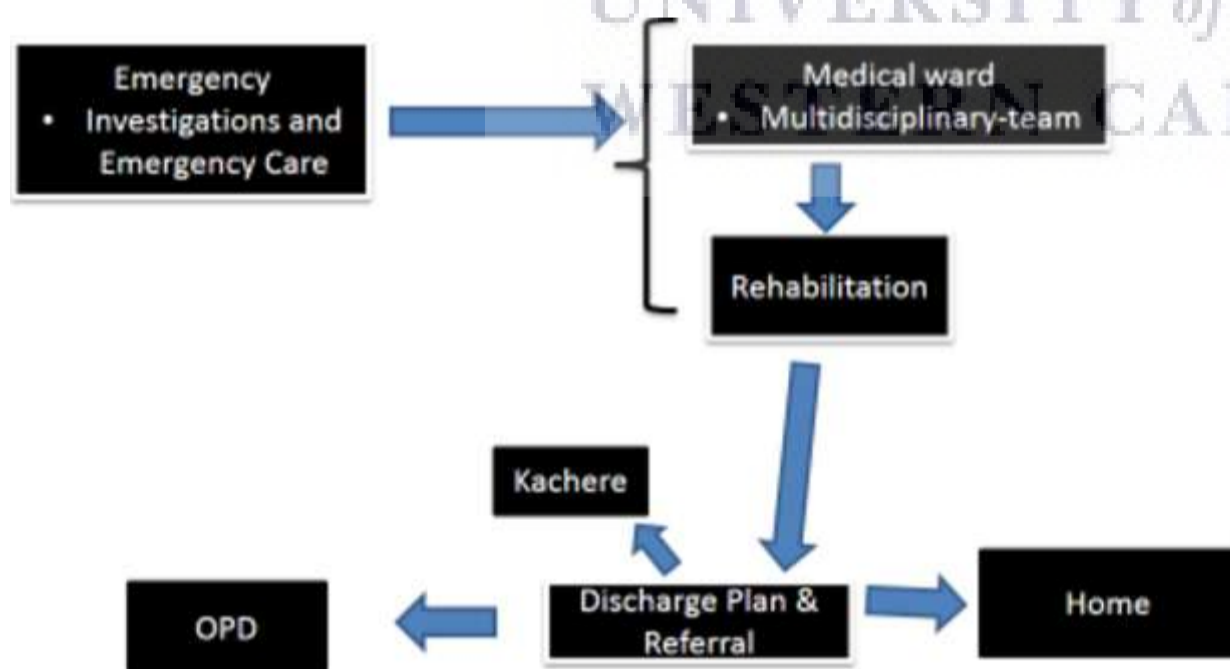

Figure 7.3 Stroke care pathway

The structure of stroke care has three points of care within the hospital: The emergency unit, the ward, and the rehabilitation department. Within each unit of care, three structural areas of need have been displayed: human resource requirements, equipment and medicine and information storage and retrieval (Table 4). Accordingly, in the emergency unit, the ten participants generated and ranked the structural areas in the top five groups, in order of importance: 1. Nurses (7 - 70%), 2. Physicians (7 - 70%), 3. Radiographers/radiologists (7 - 70%), 4. Laboratory staff/ Counselors (6 - 60%), and 5. Supporting staff e.g. clerks (6 - 60%). Others that were mentioned beyond the five options were physiotherapists, neurological staff, and psychologists. Ranking the importance of equipment and medicine, seven participants voted accordingly: 1. Vital signs

monitors e.g. sphygmomanometers (5 - 71%), 2. Airway /oxygen equipment (5 - 71%), 3. Suction machines (5 - 71%), 4. Trolley/wheelchairs (5 - 71%), and 5. X-ray machines (5 - 71%). Medications such as antihypertensive, antiplatelets anticoagulant, antithrombotics, antiepileptics, antibiotics, antidiabetics, and analgesics were next in order of importance. Others mentioned were resuscitation bed, safety materials and equipment (gloves, defibrillator, infusion pump, MRI equipment, and urinary catheters.

Ten participants generated and ranked options on information storage and retrieval requirements as follows: 1. Computers 9 (90%), 2. Files 8 (80%), 3. Data collection forms 6 (60%), 4. Registers 5 (50%), and Discs 7 (70%).

In the medical ward, the human resource requirements were developed, discussed and ranked in the following order: 1. Nurses (7 - 70%), 2. Physicians (6 - 60%), 3. Physiotherapists/ rehabilitation personnel (6 - 60%), 4. Supporting staff, e.g. clerks (7 - 70%), and 5. Radiographers/Radiologists (9 - 90%). Others were neurological staff and psychologist. Equipment and medication requirements were generated and ranked by 7 participants in the following order: 1. Airway /oxygen equipment (5 -71%), 2. Beds with side rails (4 - 57%), 3. Monitors for vital signs, e.g. sphygmomanometers (4 - 57%), 4. Mobility aids (3 - 43%), 5. Urinary catheters and nasogastric tubes (5 - 71%), and Medications such as antihypertensive, antiplatelets anticoagulant, antithrombotics, antiepileptics, antibiotics, antidiabetics, and analgesics. Others mentioned were adaptive equipment and suction machines. Finally, the information storage and retrieval requirement were generated and ranked similarly to the emergency unit.

In the rehabilitation department, the human resource requirements were developed, discussed, and ranked in the following order: 1. Physiotherapist (7 - 88%), 2. Rehabilitation technician (4 - 50%), 3. Occupational therapist/technician (4 - 50%), 4. Speech and language therapist (6 - 75%), and 5. Support Staff (7 - 88%). Equipment requirements for stroke rehabilitation were ranked in the following order: 1. Neuro beds (8 - 100%), 2. Parallel bars (6 - 75%), 3. Wall (stall) bars (4 - 50%), 4. Weights (5 - 63%) and 5. Adapted equipment for ADLS (6 - 75%). The information storage and retrieval requirement were similarly rated as those in the Emergency Department.

Table 7.4: Structure of stroke care

Score (n=10)

Option	1	2	3	4	5
Stroke care settings					
1) Emergency unit					
a) Human resource					
1. Nurses	7(70%)	3 (30%	0	0	0
2. Physicians	3 (30%)	7 (70%)	0	0	0
3. Radiographers/Radiologists	0	0	7 (70%)	2 (20%)	1 (10%)
4. Lab staff/Counsellors	0	0	2 (20%)	6 (60%)	2 (20%)
5. Supporting staff e.g. Clerks	0	0	2 (20%)	2 (20%)	6 (60)
Others					
6. Physiotherapist					
7. Neurological staff					
8. Psychologist					
Equipment and medicine **Score (n=7)**					
1. Monitors for Vital signs e.g. sphygmomanometers	5 (71%)	2 (29%)	0	0	0
2. Airway /oxygen equipment	2 (29%)	5 (71%)	0	0	0
3. Suction machine	0	0	5 (71%)	1 (14%)	1 (14%)
4. Trolley/wheelchair	0	0	2 (29%)	5 (71%)	0
5. X-ray equipment	0	0	1 (14%)	1 (14%)	5 (71%)

6.	Medications: antihypertensives, antiplatelets/anticoagulant/antithrombotics, antiepileptics, antibiotics, antidiabetics, and analgesics					
	Others					
7.	Resuscitation bed					
8.	Safety materials e.g. gloves					
9.	Defibrillator					
10.	Infusion pump					
11.	Stethoscope					
12.	MRI					
13.	Urinary catheters					
14.	Airway equipment					
b) Information storage and retrieval	**Score (n=10)**					
1.	Computers	9 (90%)	1 (10%)	0	0	0
2.	Files	0	8 (80%)	2 (20%)	0	0
3.	Data collection forms	0	1 (10%)	6 (60%)	3 (30%)	0
4.	Register books	0	0	3 (30%)	5 (50%)	2 (20%)
5.	Storage discs	0	0	1 (10%)	2 (20%)	7 (70%)
2) Ward						
a. Human resources	**Score (n=10)**					
1.	Nurses	7 (70%)	3 (30%)	0	0	0
2.	Physicians	3 (30%)	6 (60%)	1 (10%)	0	0
3.	Rehabilitation personnel	0	1 (10%)	6 (60%)	2 (20%)	1 (10%)
4.	Supporting staff e.g. Clerks	0	0	2 (20%)	7 (70%)	1 (10%)
5.	Radiographers/radiologists	0	0	0	1 (10%)	9 (90%)
	Others					
6.	Neurological staff					
7.	Psychologists? how many?					
b. **Equipment and Medicine**	**Score (n=7)**					
1.	Airway/oxygen equipment	5 (71%)	2 (29%)	0	0	0
2.	Beds with side rails	2 (29%)	4 (57%)	1 (14%)	0	0
3.	Monitors for vital signs (e.g. sphygmomanometers)	0	1 (14%)	4 (57%)	2 (29%)	0
4.	Mobility aids	0	0	2 (29%)	3 (43%)	2 (29%)
5.	Urinary catheters and nasogastric tubes	0	0	1 (14)	1 (14%)	5 (71%)
6.	Medications: antihypertensives, antiplatelets/anticoagulant/antithrombolytics,antiepileptics, antibiotics, antidiabetics					
others						
7.	Adaptive equipment for ADL training					
8.	Suction machines					

c. Information storage and retrieval	Score (n=10)				
6. Computers	9 (90%)	1 (10%)	0	0	0
7. Files	0	8 (80%)	2 (20%)	0	0
8. Data collection forms	0	1 (10%)	6 (60%)	3 (30%)	0
9. Register books	0	0	3 (30%)	5 (50%)	2 (20%)
1. Storage discs	0	0	1 (10%)	2 (20%)	7 (70%)
3. **Rehabilitation department**					
a) **Human resource**	Score (n=8)				
1. Physiotherapists	7 (88%)	0	1 (13%)	0	0
2. Rehabilitation technicians	1 (13%)	4 (50%)	2 (25%)	1 (13%)	0
3. Occupational therapists	0	0	4 (50%)	4 (50%)	0
4. Speech therapists	0	0	1 (13%)	6 (75%)	1
5. Support staff	0	0	0	1 (13%)	7 (88%)
b) **Equipment and medicine**					
1. Neuro beds	8 (100%)	0	0	0	0
2. Parallel bars	0	6 (75%)	1 (13%)	1 (13%)	0
3. Wall (stall) bars	0	2 (25%)	4 (50%)	1 (13%)	1 (13%)
4. Weights	0	0	2 (25%)	5 (63%)	1 (13%)
5. Adaptive equipment for ADLS	0	0	1 (13%)	1 (13%)	6 (75%)
6. Stationary bikes					
7. Treadmills					
Information storage and retrieval	Score (n=10)				
10. Computers	9 (90%)	1 (10%)	0	0	0
11. Files	0	8 (80%)	2 (20%)	0	0
12. Data collection forms	0	1 (10%)	6 (60%)	3 (30%)	0
13. Register books	0	0	3 (30%)	5 (50%)	2 (20%)
1. Storage discs	0	0	1 (10%)	2 (20%)	7 (70%)

7.3.3.2 Process of stroke care

Participants in the NGT developed, discussed, and agreed on the general assessment process (Figure 7.4) involving subjective assessment capturing patient history, including demographics, medical and social data, and objective assessment, including physical evaluations, laboratory investigations, and radiological investigations (X-ray, CT scan and magnetic resonance imaging (MRI)). Cognitive and functional status is also assessed using outcome measures such as the Glasgow Comma Scale (GCS), Functional Independence Measure (FIM), and the Montreal

Cognitive Assessment (MoCA). After this process, the collected data is analysed to determine the diagnosis and associated problems, in preparation for developing an informed treatment plan.

After the critical investigations and care in the emergency unit by the emergency team, patients with stroke are managed in the ward and the rehabilitation department by nurses, physicians, and rehabilitation personnel. Participants in the NGT discussed and agreed on the care options and frequency. As explained in the "methodology" of NGT, only the care options were rated and tallied, the frequency of monitoring and care was by group consensus. Seven participants discussed and ranked clinical processes as follows 1. Close monitoring (5 - 71%); 2. Prescribing and administering medication (4 - 57%); 3. Assisting patients with ADLs (5 - 71%); 4. Promoting peaceful death to those who inevitably face it (4 - 57%); and 5. Discharge planning (4 - 57%). The other process that emerged was implementation of stroke prevention strategies. According to the participant's agreement, nurses make close monitoring of the patients every 15 minutes during the acute stage and the critically ill state. However, after stabilisation, they monitor every hour.

Rehabilitative care options were developed, discussed and ranked by eight participants as follows 1. focus on functional independence 6 (75%); 2. guardian involvement and clear communication to guardian and patient 4 (50%); 3. identification for need of referral 5 (63%); 4. considering patient's home environment 6 (75%) and 5. discharge planning 5 (63%). The other process seen by participants as equally important is a stroke prevention strategies. Physiotherapists and other team members treat patients with stroke depending on the patient's medical condition but usually once a day. Table 7.5 shows the Process of Care for patients with stroke by nurses, physicians, physiotherapists, and other rehabilitation personnel that is also represented in figure 7.4.
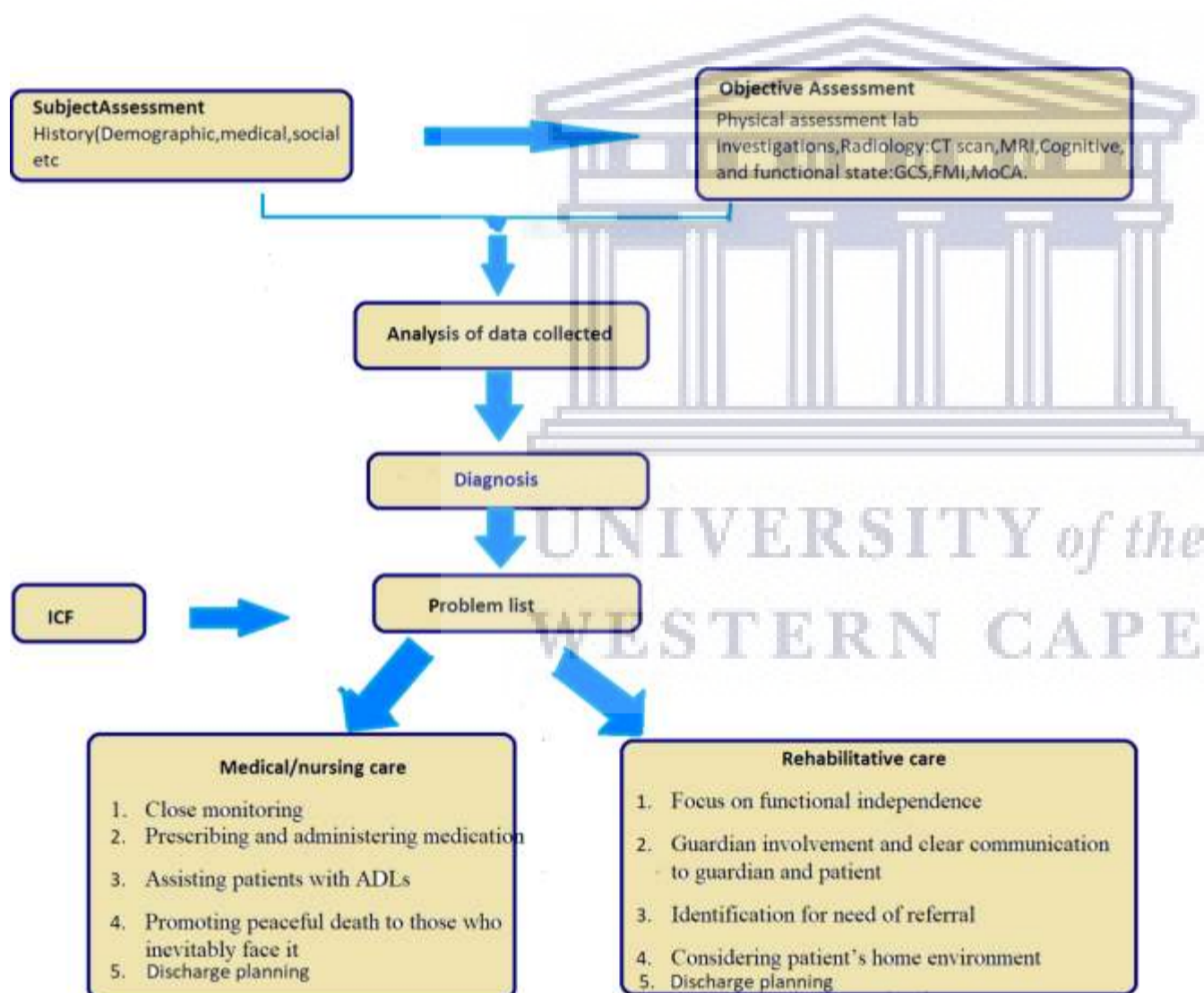

Figure 7.4 Process of care for patients with stroke

Table 7.5: Process of stroke Care

Option	1	2	3	4	5
Nursing/medical care					
Clinical processes score (n=7)					
1. Close monitoring	5 (71%)	1 (14%)	0	1 (14%)	0
2. Administering medication	2 (29%)	4 (57%)	0	0	1 (14%)
3. Providing health education/teaching guardians	0	0	5 (71%)	2 (29%)	0
4. Assisting patient in ADLs	0	0	2 (29%)	4 (57%)	1 (14%)
5. Promoting peaceful death	0	1 (14%)	0	2 (29%)	4 (57%)
Others processes					
6. Discharge plan					
7. Stroke prevention strategies					
Rehabilitative care Score (n=8)					
1. Focus on function/independence	6 (75%)	1 (13%)	1 (13%)	0	0
2. Guardian involvement/clear communication to care giver and patient					
3. Identification for referral needs	2 (25%)	4 (50%)	2 (25%)	0	0
4. Consider home environment/home visits					
5. Discharge planning					
Other processes	0	0	5 (63%)	3 (38%)	0
6. Stroke prevention strategies	0				
		0	1 (13%)	6 (75%)	1 (13%)
	0				
		0	1 (13%)	2 (25%)	5 (63%)

7.3.3.3 Stroke care outcomes

To measure effectiveness of stroke structure and processes, this study showed that outcome measures to be used are quality of stroke care practice (6 - 86%), functional independence (6 - 86%), integration into the community (5 - 71%), length of hospital stay (LOS) (5 - 71%), and discharge home (4 - 57%). Other measures were mortality and institutionalisation rates. See Table 7.6.

Table 7.6: Stroke care outcomes

Option	1	2	3	4	5
Outcomes to measure effectiveness of stroke structure and process score (n=7)					
1. Quality of stroke care practice	6 (86%)	1 (14%)	0	0	0
2. Functional independence	1 (14%)	6 (86%)	0	0	0
3. Integration into the community	0	0	5 (71%)	1 (14%)	1 (14%)
4. Length of hospital stay (LOS)	0	0	1 (14%)	5 (71%)	1 (14%)
5. Discharge home	0	0	1 (14%)	2 (29%)	4 (57%)
Other outcomes					
6. Mortality					
7. Institutionalization					

7.5   Discussion

This project aimed to develop a MoC after carrying out the diagnostic phase. Cross-section studies were conducted in the country's four referral hospital to determine the process and outcomes of stroke care. A complementary qualitative exploratory study among service providers, patients with stroke, and their informal caregiverswas also conducted to help better understand the process of care and potential challenges. We further carried out an interpretative scoping literature review to document evidence of stroke care and service delivery in LMICs. The current study, through the use of NGT with the multidisciplinary team, gained consensus on the MoC principles, multidisciplinary team, stroke care structure, processes, and outcomes.

7.5.1   Principles of the current model of care

The five principles, in the order of importance, were utilisation of a multidisciplinary team approach to care, patients' journey, goal directed intervention, human-centered and, evidence-based care (EBC). Regarding multidisciplinary team, the diagnostic phase of this project revealed that physicians, nurses, and physiotherapists form a triple pillar of stroke care although physiotherapists are loosely attached care-providers due to weakly coordinated multidisciplinary team practices. This finding echoed that of a Ghanaian study that found that multidisciplinary care suffered coordination challenges (Baatiema et al., 2017). This could affect the outcome of stroke care. This study recommended improving patient outcomes by the implementation of well-run multidisciplinary teams with enhanced stroke-care skills and using an evidence-based approach to care. This study further showed for proper running of a stroke multidisciplinary team, there is a need for clear objectives, protocols, policies, roles, and channels of communication. Lack of specific protocols or guidelines has been associated with coordination challenges by the general nurses in a Ghanaian study (Baatiema et al., 2017).

On the second principle, the patient journey, the study recommended the need for aggressive emergency and continuing care and rehabilitation in the stroke-care wards with optimum levels of multidisciplinary teamwork. Acute stroke care begins in an emergency department, first with a triaging, assessment, and management of reversible risk factors based on qualitative study into state of stroke care during the assessment phase of the current project (*chapter 4*). While some approaches are similar to what happens in other countries, key management approach for ischemic stroke, administration of recombinant tissue plasminogen activator (rtPA), is not administered locally as is the care in some LMICs (Hacke et al., 2008). Absence of rtPA adds to the existing challenges of general stroke care in Malawi.

This researcher also found that the decision to admit a patient with stroke was determined amid continuing investigations of the stroke and its potential causes. There was absence of a guiding admission protocol and there was reliance on physician judgement. The role of specific protocols or guidelines on stroke care is known (Baatiema et al., 2017). In the absence of protocols, physicians use clinical indicators such as presence of comorbidities such as hypertension or diabetes mellitus (not quickly reversible) or potential for the development of secondary complications, such as aspiration pneumonia, or worsening of the neurological state, noted by a declining Glasgow Comma Scale (GCS), or a younger age range to influence decision to admit as found during the assessment phase.

Clinically, this researcher had shown that the content side of the process of stroke care and rehabilitation is categorised into three areas: 1) Acute assessment and investigation, 2) Early management, and 3) General management.

For the third principle, utilising goal-directed interventions that promote independence, this study recommends to establish evidence-based goals when managing patients with stroke, with treatment strategies that bring meaningful changes into the lives of patients with stroke, targeting promotion of independent activities, community participation, and reintegration. Stroke care and rehabilitation efforts are implemented to enable patients with stroke achieve the highest possible functional level through reduction of disability and promotion of activity and participation. This is accomplished with the timely diagnosis and treatment of stroke; reducing impairments and preventing/treating complications (Stucki, Reinhardt & Grimby, 2007). The treatment should, therefore, lead to meaningful changes in the lives of patients with stroke, targeting promotion of activity, and community participation.

On the fourth principle, which states the model should have person-centered care ideals, the current study recommended the type of care that ensures person-centered care across the stroke care continuum, with consideration for patient values, preferences, family and social circumstances, and lifestyles. This is in contrast to background reports that stroke care and rehabilitation lacked a whole-person or patient-centered approach (Cott, Wills & Devitt, 2007). Gill et al. noted that the key components of person-centered care included compassion, dignity, and respect, which are exhibited through shared decision-making, supportive self-management, and proactive communications between service providers, patients, and caregivers. Patients with stroke are cared for and rehabilitated in a country that is predominantly rural, with very limited

health care resources but with very strong family ties. Decision-making education and communication, therefore, needs to include the immediate family members and caregivers.

Lastly, for the fifth principle, evidence-based care, this study recommended the establishment of a specialised stroke unit, or at a minimum, have stroke-specific wards in all the Malawi referral hospitals in contrast with the current mixed-patient hospital arena. The study further highlighted the need for the unit or stroke care ward to be staffed by professionals with interests in and specialised stroke-care skills and experience. This recommendation is in line with the literature that supports the quality and standardised care of patients with stroke requiring an organised setting such as in a specialty or Stroke Unit (SU). In those units, the patients access multidisciplinary teams, early clinical processes of care, access to intravenous thrombolysis, and early intensive rehabilitation (Yan et al., 2016; Trialists'Collaboration SU, 2013) (National Stroke Foundation, 2010), Stroke units have been associated with improved patient outcomes even in LMICs (Baatiema et al., 2017).

7.5.2   Stroke Care Structure

Structures of health care are the physical and organizational aspects of care settings, for example, facilities, equipment, personnel, operational, and financial processes supporting medical care (McDonald et al., 2007). There are no formal stroke units in any of the four political regions where we have designated referral hospitals in Malawi, although efforts toward establishment of one at QECH in the southern region of the country is at an advanced developmental stage. This researcher suggested that MoC be designed for stroke wards established within the individual referral hospital. Drawing findings from this study's diagnostic phase, the stroke-care settings should be spacious with facilities accessible to patients with stroke, well-resourced with stroke-special-interest multidisciplinary teams, and adequate medical and radiological supplies. Structurally, the stroke care pathway is established based on an effective multidisciplinary team, satisfied equipment and medication requirements, with information storage and retrieval in designated stroke care settings of the emergency unit, stroke ward, and rehabilitation department.

7.5.2.1   Emergency unit

The government of Malawi, through Health Sector Strategic Plan II (2017-2022), acknowledged that the emergency medical services (EMS) are weak in the country of 18+ million people due to limited resources and logistics for referral of emergencies. There is also lack of capacity to handle any pre-hospital care due to limited paramedics and ambulances, and non-existent dedicated emergency responders. This study highlighted the composition of emergency multidisciplinary team, equipment and medical supplies, and information storage and retrieval requirements. As expected, the emergency unit was responsible for emergency investigations and care. The current study showed that the emergency unit must be powered by a trained multidisciplinary team in stroke care. The team should include emergency nurses, emergency physicians, radiographers/radiologists, lab staff/counsellors, and supporting staff, e.g. clerks. Other team members are physiotherapists, neurologists, and psychologists

For emergency equipment and medical supplies, the study recommended that the emergency unit have adequate equipment and supplies. The equipment must include monitors for vital signs, oxygen equipment, suction machines, trolleys/wheelchairs for moving materials and patient in the hospital, resuscitation or recovery beds, x-ray machines, safety materials (e.g. gloves and masks), a defibrillator, stethoscope, MRI equipment, urinary catheters, infusion pumps, antihypertensive drugs, and analgesics.

The National Community Health Strategy (NCHS) highlighted that "Communication and information management is critical in assessing health outcomes and health coverage, managing the workforce, tracking the quality of care delivered, and ensuring effective integration of service." Generating quality information and making it accessible to all intended users for evidence-based decision-making through standardised and harmonised tools across all programs is, therefore, key . Through the consensus process, this study showed that the emergency unit must have an effective storage and retrieval system, and the following must be available: computers, files, data collection forms, register books, and storage discs.

7.5.2.2   Stroke ward

The diagnostic phase of this project has described a ward where patients with stroke are admitted but marred by patient mix challenges due to lack of a specific dedicated place for stroke care. Facilities are also not accessible for use by patients with stroke as there is a lack of supportive and adaptive features in the toilets and bathrooms, hampering their use for those individuals with motor impairments. Further, this phase showed that nurses, physicians, and physiotherapists are the main team members in stroke care. The study recommended that the ward where patients with stroke are admitted for continued care and rehabilitation must have a dedicated multidisciplinary team that includes nurses, physicians, physiotherapist/rehab personnel, supporting staff, e.g. clerks, and radiographers/radiologists. Neurologists and neurosurgeons (when available) must also form part of the team.

The ward must also be equipped with airway /oxygen equipment, beds with side rails, monitors for vital signs, e.g. sphygmomanometer, mobility aids, urinary catheters, and medical supplies that must include antihypertensive, antiplatelet/ anticoagulant/ antithrombotic, antiepileptic, antibiotics, anti-diabetics. Other equipment needed is adaptive equipment, compression stockings suction machines, intravenous fluids, antiseptics, and nasaogastric tubes. The dedicated stroke ward must also have an effective storage and retrieval system. Therefore, computers, files, data collection forms, registers, and discs must be available.

7.5.2.3 Rehabilitation department

The rehabilitation department has been reported to have limited numbers of rehabilitation personnel and suffer resource limitation like any other section of the referral hospitals, as reported during the diagnostic phase. The current study, however, recommended that the department should have a dedicated rehabilitation team, equipment, and a functioning information storage and retrieval system. In particular, it recommended that the rehabilitation department must have physiotherapists, rehabilitation technicians, occupational therapists, speech and language therapists, and support staff.

This study also showed that the rehabilitation equipment that must be available are neuro beds, mats, parallel bars, wall bars, weights, and adaptive equipment for activities of daily living (ADLs). Other equipment is for cognition, perception, fine motor, sensory skills, and BP machines. The dedicated stroke rehabilitation department must also have an effective storage and retrieval system. Therefore, computers, files, data collection forms, registers, and discs must be available, in sufficient number and in working order.

7.5.3 Stroke care processes and outcomes

Processes in patient care include resources, mechanisms provided by the health care structures to carry out patient-care activities that promote recovery, functional restoration, survival, and patient satisfaction (McDonald et al., 2007). Multidisciplinary teamwork has been credited with improving clinical outcomes, health care processes, and satisfaction in different disease processes (Kilgore, 2009; Rock, 2003). To deliver effectively on processes of care, the multidisciplinary team should work effectively as recommended in the emergency unit, and stroke ward levels.

At the emergency unit level, this study supported by the diagnostic phase findings showed that patients with stroke must be promptly triaged, assessed, and have reversible risk factors managed. Triaging may be followed by administration of tissue plasminogen activator (tPA) for suitable patients who report to the department within 4.5 hours post onset of stroke (Hacke et al., 2008). Additionally, fever, hyperglycemia, and swallowing problems must be proactively managed before prompt transfer to a stroke unit or ward as found during the diagnostic phase and backed by literature (Hacke et al., 2008).

According to this study, after admission, the clinical processes must include close monitoring, drug administration, patient and guardian education, patient ADL support, and promoting peaceful death to those facing it. Overall, however, clinical processes themes are acute assessment and investigation, early management, and general management.

7.5.3.1 Acute assessment and investigation

This study, backed by findings in the diagnostic phase, recommended that acute assessment and investigation processes of care should commence as soon as the patient is admitted. Generally, it should include subjective assessment where history about the patient and condition is taken including demographic features, medical, and social history; objective examination which should include 1) Physical examination such as neurological assessment and swallowing screening, which should be completed by physicians and physiotherapists; 2) Routine biochemistry and

hematology investigations should be performed. In particular, laboratory investigations such as HIV test, VDRL, blood sugar test, and a full blood count to check creatinine, urea and electrolyte levels should be carried out; 3) Radiological investigations with chest X-ray, ECG, CT scan and MRI can be run based on need and; 4) Cognitive and functional evaluations should also be done by physiotherapist and occupational therapist.

After running the assessment processes, the data should be analysed to determine diagnosis and type of stroke and severity. The GCS, FIM, and Montreal Cognitive Assessment should be administered to measure stroke severity, and the International Classification of Functioning, Disability and Health (ICF) should be used to conceptualise stroke disability and functioning.

The WHO ICF model has been used because, by its constructs, it acknowledges that recovery after stroke is a multifaceted process that encompasses the interplay of (1) the pathophysiological processes directly related to the stroke and its associated comorbidities, (2) the impact this condition has on the individual, and (3) contextual variables such as each patient's personal and environmental resources. The ICF, therefore, has been utilised to effectively integrate the principle of patient-centeredness in this MoC by helping to assess and address the functional and societal impact that the condition has at the individual patient with stroke level as well as the effect on informal caregiversand family members.

This study further recommended that the hyper-acute phase, nursing follow-up assessments should be completed, initially, every 15 minutes, then every hour when the patient is stable.

Further, on acute assessment and investigation, this study recommended that physiotherapy and rehabilitation assessment should be completed within 24 hours of referral and reassessment done each time a patient is seen by physiotherapist with support of rehabilitation technicians. The same process should be executed by occupational therapists and speech and language therapists with their counterparts.

After assessment is completed, emergency medical care is administered with the support of nurses and when the patient is stable, responsible physicians should make appropriate referrals to the physiotherapists and the rehabilitation team. The physician should specifically document in the patient's health passport book or file, then refer to appropriate providers by completing a consultation form or making a verbal referral in person or via phone. Nurses should also make timely referral to physicians and physiotherapists after stability of the condition is achieved, or in situation of critical condition such as when the patient's condition is rapidly declining. They should appropriately document and refer verbally or by filling out a consultation form.

Physiotherapists and rehabilitation personnel should also make referrals when necessary to physicians and nurses in situations of a critical condition or when functionally the patient has achieved the optimum level of function. Physiotherapist or other rehabilitation personnel should precisely document in the patient's health passport book or file, then refer by filling a consultation form or making a verbal referral in person or via phone.

7.5.3.2   Early management

This study recommended that as part of care, intravenous thrombolysis should be administered to diagnosed patients with ischemic stroke who presents to the hospital within 4.5 hours of stroke onset. Otherwise, implement ASA (75mg), once a day as an anticoagulant (Heikinheimo, Chimbayo, Kumwenda, Kampondeni & Allain, 2012). The role for intravenous thrombolysis as evidence-based treatment for acute ischemic stroke is known (Yan et al., 2016). It is cost-effective even in LMICs (Rahil, Afshin, Anahid & Salvador, 2012) via its generation of optimal patient outcomes (Baatiema, Chan, Sav & Somerset, 2017), Additionally, regulation of temperature or fever, management of hypoxia, hypertension, diabetes, cholesterol, and DVT prevention or prophylaxis should be observed and done by combined efforts of physicians, nurses, and physiotherapists.

Nurses should implement orders by the physicians and advocate for change or review of care processes based on their monitoring assessment of the patient's condition; provide education to the patient and guardian regarding stroke and train the informal caregiverson patient care skills including patient feeding, bathing and handling; assist dependent patients with ADLs such as hourly bed turning, bathing, dressing, and toileting; promoting peaceful death for those facing it.

7.5.3.3 General management

The current study recommended that rehabilitation should commence within 28 to 48 hours. Rehabilitation should focus on 1) Functional independence. The diagnostic phase highlighted the need for early patient mobilisation, training in ADLs, prevention of complications due to immobility, and provision of assistive devices to promote functional independence as implemented by physiotherapists and nurses. 2) Care giver involvement, with clear communication to care giver and patient; 3) Early identification for need of referral; 4) Considering home environment, where possible, by conducting home visit and; 5) Plan discharge.

Regarding discharge planning, this study, supported by the diagnostic phase findings, recommended that during the admission period, service providers should take time to highlight important topics with informal caregiveron what to do while at home, including a home exercise and activity program. Patient and guardian education and training should be a part of discharge planning to caregivers and patients so that they know what they must and must not do. Involve Tiyanjane (palliative department) earlier to prepare the patient psychologically. Additionally, for those who can access hospitals after discharge, appropriate referrals should be made for outpatient physiotherapy service and general medical review services after discharge. However, based on the severity of the stroke, some patients should be referred to a rehabilitation center such as KRC for intensive rehabilitation. The benefit of proper discharge planning has been reported. Nunes and Queirós found that during the hospitalisation period, a careful hospital discharge planning and comprehensive care to patients and caregiverstended to have an impact on the quality of life of patients , in particular, the functional and psycho-emotional aspects,.

General management also includes stroke prevention. This study highlighted both primary and secondary prevention strategies. Primary prevention strategies include advice on diet, stress management, physical fitness, and routine check-ups. This can be done by conducting awareness campaigns through print and electron media, megaphones, and drama. The primary prevention strategies must also be mainstreamed in school curriculum and government department.

This study also highlighted secondary stroke prevention strategies such as adhering to routine check-ups at hypertension and stroke clinics; treatment compliance by patients through routine check-ups clinics in wards and OPD through Direct Observation Therapy (DOT) by nurses and physicians; home visits, performing special tests and functional reassessment by rehabilitation personnel and; dietary checks by nurses, physicians and rehabilitation personnel and; motivating and counselling caregivers and patients through health talks by rehabilitation personnel, nurses, and physicians

To measure effectiveness of stroke structure and process, this study recommended the use of quality of stroke care practice, functional independence, integration into the community, length of hospital stays (los) and discharge home as primary outcome measures. Others are mortality and institutionalisation.

Limitations

This study was conducted at one of the four referral hospitals in the country. While they are all referral hospitals there might be some differing views regarding stroke care based on contextual experience. However, as the largest referral hospital in the country, representativeness of the findings on stroke care in Malawi may be assured. Without intention of the research, the NGT was done two days. This was because the materials to cover were too much for the employees who only managed to secure 3hours from their work sites. As a result, there was change in the participants on day two as two of the participants, a physiotherapist and physician replaced themselves with their colleagues who were available for the task. This might have affected the flow of discussion as the new participants had to be briefed on the process and the work done earlier. However, the new participants were at the same level of education and experience as the former ones.

Conclusion/recommendations

This study presented MoC for patients with stroke applicable to Malawi's referral hospitals. It is guided by five principles which are utilisation of a multidisciplinary team approach to care, patients' journey, goal directed intervention, human-centered and, evidence-based care (EBC). It highlights stroke care structure, processes, and outcomes across the stroke care pathway from Emergency Department (ED), the medical ward and the Rehabilitation Department. There is a need for development of protocols and guidelines for each of the care setting in order to facilitate coordinated stroke care in the referral hospitals (Baatiema et al., 2017).

8.0 Chapter 8: Conclusions, Limitations and Recommendations

8.0   Introduction

This chapter presents the overall project conclusion, limitation and recommendations of the PhD project

8.1   Background

The aim of this PhD project was to develop a contextual model of care (MoC) and a rehabilitation template in a country with serious health service and human resource gaps. In Chapter 1, the researcher first introduced stroke as a major public health concern in Malawi and world over, related to the resulting mortality and disability. He also introduced the Donabedian Model as the project's conceptual framework with three distinct aspects of health care quality: structure, process, and outcome. Following the template for the MoC, the researcher introduced the Agency for Clinical Innovation's (ACI) framework for a model of care (MoC). The framework is a five-stage-development process: 1) Project Initiation - services for review are identified; 2) Assessment and Diagnostic - the extent of the problem is defined, and the root cause understood to address the real problem; 3) Solution Design Phase - solutions are developed and selected; 4) Implementation Phase - project is implemented and; 5) Sustainability Phase - use of the MoC is optimized, results monitored, and the impact evaluated.

 With lack of optimal care structures and processes for persons with stroke in Malawi due to contextual factors affecting health care delivery in the country, the need for the project was highlighted observing that most MoC are based on Western high-income settings. The gap pointed to the need to achieve five objectives in the diagnostic and solution design phases: 1) determine and explore the process of care of stroke patients in Malawi 2) determine patients with stroke and caregiver satisfaction with care and rehabilitation service delivery in Malawi's central hospitals; 3) determine stroke patient outcomes at discharge and; 4) determine the current evidence of stroke care and rehabilitation service provision by conducting a scoping review. The aim of the first three objectives was to establish a baseline information on stroke care in Malawi while the fourth objective would provide comparative information on stroke care from areas that have some similarities with Malawi, related to health care systems and in particular, stroke care provision. The fifth objective was achieved by crystalizing the information from the diagnostic phase through the use of Nominal Group Technique (NGT) to develop the contextual model of care. This is represented by Figure 8.1.
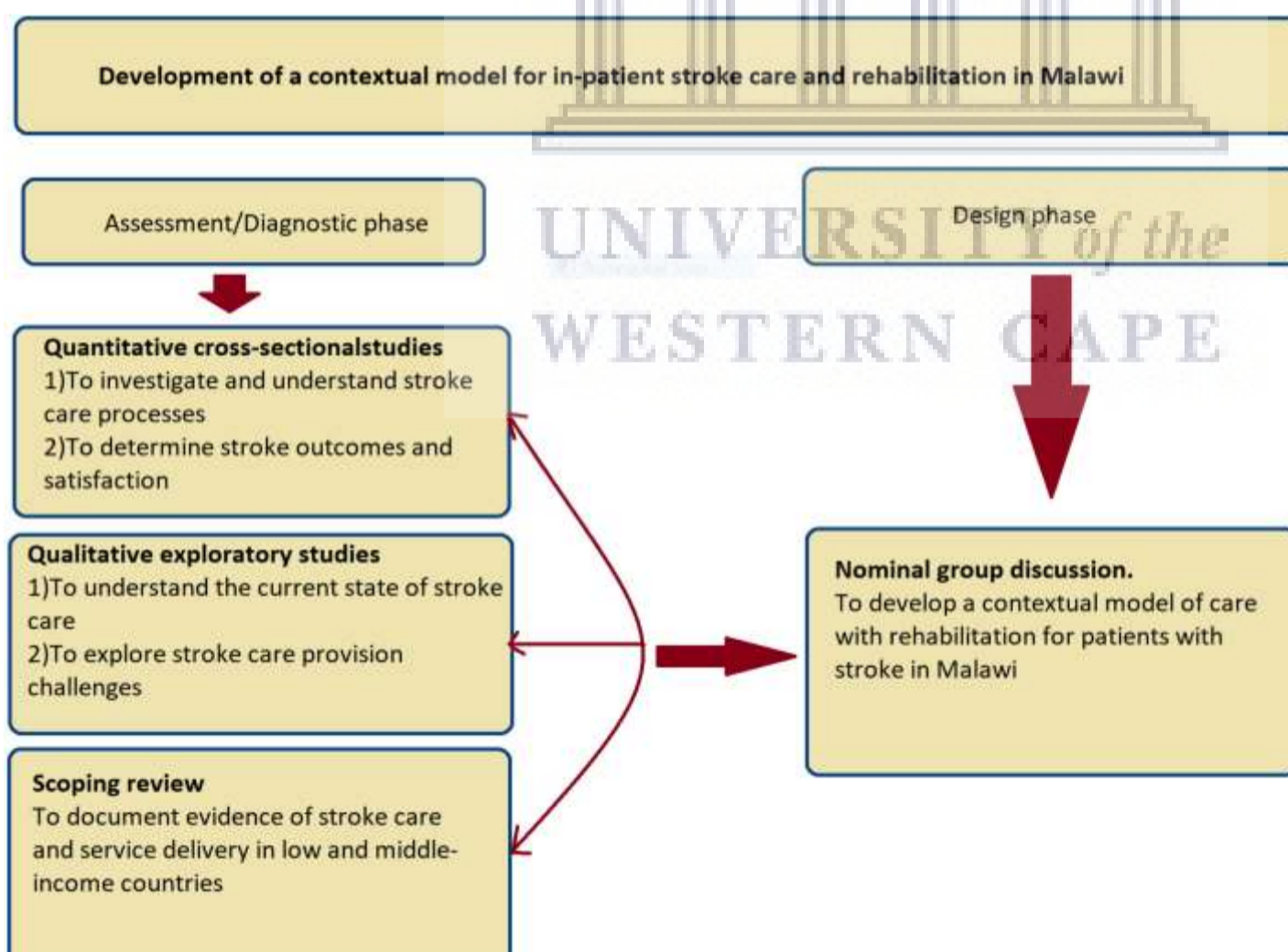

Figure 8.1 PhD Research process

Chapter 2, the researcher described the multi-method approach that was used to gather relevant data towards development of the MoC. This included qualitative and quantitative studies, and a scoping review (diagnostic phase). The Nominal Group technique (NGT) was highlighted for the design phase of the MoC. The quantitative research approach provided an ability to capture data from Malawi's four regional hospitals, yielding more participants whose view could not be effectively captured by qualitative methods. Two quantitative descriptive cross-sectional studies were developed (Chapters 3 and 6). On the other hand, qualitative research allowed deeper understanding of the processes of care for patients with stroke and related challenges in Malawi's central hospitals. This was particularly important since Malawi is one of the least developed countries in the world, with a paucity of research activity on stroke care and without a MoC, as advanced in this project. Two qualitative descriptive research papers (*Chapters 4 and 5*) were developed. The researcher also introduced a five-stage-process, based on Arksey and O'Malley's scoping review framework, to document evidence of stroke care and service delivery in low and middle-income countries (Chapter 7*)*. The researcher's scoping review study has since been published in the BMC Health Services Research Journal.

As represented in figure 1, studies during the diagnostic phase produced valuable information that was used in the design phase using NGT. Six data collecting instruments were described according to history, constructs, validity and reliability. They included 1) Stroke Process of Care Questionnaire, 2) Measures of Processes of Care for Service Providers (MPOC-SP), 3) Functional Independence Measure (FIM), 4) The 5 Level Euro Quol 5 Dimension scale (EQ-5D-5L), 5) Patients Satisfaction with Inpatients Stroke Care (SASC Hospital scale), and 6) Caregivers Satisfaction with Inpatient Stroke Care (C-SASC Hospital scale). Methods of data management, analysis, and interpretation were also described along with research ethics.

Care processes and the type of service delivery are critical elements in stroke care and rehabilitation services. Noting from the literature, that amid acute health care resource constraints in Africa, the process of stroke care differs from setting to setting. The researcher highlighted processes of care in the local research setting. His research was aimed to investigate and understand stroke care processes in Malawi's referral hospitals. The ensuing descriptive cross-sectional study recruited 101 healthcare providers and utilised a Self-Developed Stroke Process of Care (POC) Questionnaire to examine the care process during service delivery. The Kruskal-Wallis test was used to determine univariate associations for the categorical variables and the Wilcoxon Rank-Sum Test for continuous variables. The study demonstrated interesting results, as 62% of those interviewed rated the care provided to patients as "good", when nearly half of them said there were no routine team meetings and no inter-professional collaborative work. Service providers did not rely on other cadres in care provision. This finding was similar across the four hospitals. Referrals of patients with stroke to and from the central hospital were most likely made by physicians and nurses. Although physiotherapists made the third most referrals to the central hospital, they were second when it came to referring patients beyond the acute care setting. Physicians and physiotherapists were responsible for most of the neurological assessments, swallowing screening evaluations, and DVT prevention/prophylaxis. Early patient mobilisation was carried out by physiotherapists and nurses. Stroke PoC are, therefore, categorised into acute management and investigations, early management, and general management. Limited inter-professional teamwork appeared to affect the quality of care in the acute care settings.

To better understand the current state of stroke care in Malawi and to potentially inform a new MoC for the future, the researcher executed a qualitative exploratory study. He utilised purposefully-selected participants in focus group discussions at Queen Elizabeth Central Hospital (QECH). Service providers (nurses and physiotherapists/rehabilitation technicians), patients with stroke (and their caregivers), and physicians were interviewed. Thematic analysis was used to understand the data. According to the research as presented in *chapter 4*, four key themes emerged: 1) The acute stroke presentation and hospital emergency care, 2) Acute stroke diagnosis and assessment services, 3) Acute stroke care interventions and services, and 4) Discharge planning and referral destinations. The patients presented to the hospital with a wide range of impairments and received emergency and ongoing care. The diagnosis of stroke, according to the qualitative study, was primarily made through clinical and laboratory tests, and basic radiologic studies. Physicians, nurses and physiotherapists formed a triple pillar of stroke care. However, physiotherapists were loosely attached care-providers due to weak multidisciplinary team practices. At the least, there was a need to bolster multidisciplinary teamwork due to the glaring absence of care protocols at every level of stroke care.

As research activity throughout the world has advanced related to acute stroke care interventions, patients in Low to Middle Income Countries (LMICs) benefit less from stroke care practices due to continuing challenges. In *Chapter 4*, the researcher systematically explored stroke care provision challenges at the largest referral hospital in Malawi, from the perspectives of service providers, patients with stroke, and their caregivers. A qualitative exploratory study with purposefully-selected participants explored challenges to stroke care from the service providers, patients with stroke, and caregivers perspectives utilising focus-group discussions. Semi structured interviews were also conducted with

physicians for patients with stroke. Thematic analysis was used to categorise that data. The four key themes that emerged as a result included: 1) Lack of effective implementation of stroke care approaches due to poor recognition and priority in critical care medicine, limited interprofessional contacts, communication disarray among providers, and lack of follow-up after discharge, particularly from rehabilitation professionals; 2) Erratic and insufficient physiotherapy treatment due to limited referrals by physicians, limited visibility of physiotherapists in the hospital, and lack of proper service planning by physiotherapists; 3) Patient-mix challenges from intermingling patients with varying conditions, risking both physical harm and the development of nosocomial infections, and; 4) Resource limitations from inadequate qualified service providers, limited medical supplies, unreliable equipment, and lack of warm bedding for patients. This study presented the challenges to stroke care provision, from structural, practice, and resource perspectives.

In addition to understanding the processes during stroke care and rehabilitation and the associated challenges in the four central hospitals, the researcher aimed to better understand the impact on stroke outcomes on the patients. This was with the background of a paucity of studies reporting acute stroke functional outcomes, quality of life and satisfaction with care among patients with stroke in the country. *Chapter 5*, therefore, aimed to determine stroke outcomes and satisfaction with care in the country's central hospitals. A descriptive cross-sectional study, recruiting 114 adult patients with stroke and their caregivers, was completed. Testing using the FIM, EQ-5D-5L, SASC and C-SASC were the basis for data collection. Univariate associations were assessed using the Kruskal-Wallis Test for categorical variables and the Wilcoxon Rank Sum Test for continuous variables. With 79% of the original study sample taking part, there was improvement in patients' functional status at discharge compared to admission. There was notable improvement in self-care, sphincter control, locomotion, and social cognition but no significant improvement in transfers and communication. Satisfaction with care was high, with no significant differences between males and females, age in years and distance to the clinic. Satisfaction ratings were also high from caregivers' responses and their scores were not associated with age or distance to the hospital. Interestingly, although satisfaction ratings were high, the quality of life was poor as most patients were either unable or had severe limitation in functional dimensions of mobility, self-care and performance of usual activities. And every additional year in age was associated with decrease in quality of life. From this study, patients with stroke experienced improvement in functional outcomes on discharge compared to on-admission status. Patients and caregivers were satisfied with care provision in spite of having poor quality of life post stroke treatment.

After understanding the local perspective of stroke care, the researcher carried out a scoping review with the aim to document evidence of stroke care and service delivery in LMIC to better inform development of a context-fit stroke MoC. This interpretative scoping literature review (*Chapter 6*) was based on Arksey and O'Malley's five-stage process.

The following databases were the basis for the literature search, with publications between 2010 and 2017: Cochrane Library, Credo Reference, Health Source: Nursing/Academic Edition, Science Direct, BioMed Central, CINAHL, Academic Search Complete, and Google Scholar. Single combined search terms included acute stroke, stroke care, stroke rehabilitation, developing countries, LMIC. From the process, a total of 177 references were identified. Twenty of them, published between 2010 and 2017, were included in the review. Applying the Donebedian Model of quality of care, seven dimensions of stroke-care structure, six dimensions of stroke care processes, and six dimensions of stroke care outcomes were identified. Structure of stroke care (SS) included availability of a stroke unit (SU), an accident and emergency department, a multidisciplinary team, stroke specialists, neuroimaging, medication, and health care policies. Stroke care processes (SP) that emerged were assessment and diagnosis, referrals, intravenous thrombolysis, rehabilitation, and primary and secondary prevention strategies. Stroke-care outcomes (SO) included quality of stroke-care practice, functional independence level, Length of hospital Stay (LOS), mortality, living at home, and institutionalization. There was a lack of uniformity in the way stroke care was advanced in LMICs. This was reflected in the unsatisfactory stroke care structure, processes, and outcomes.

Following implementation of the four objectives in the diagnostic phase, NGT was used to develop a contextual model of care for patients with stroke in central hospitals in Malawi. Using NGT, consensus was gained on ideas from a group of nine purposefully-selected professionals (physicians, nurses, physiotherapists, occupational therapist, radiologist, and health services manager) at the Malawi's largest referral hospital (QECH). Further, using pooled data from the diagnostic phase, the NGT study generated five guiding principles for the current MoC: 1) Multidisciplinary-team-work; 2) Patients journey; 3) Goal-directed intervention; 4) Human-centered care and; 5) Evidence-based care (refer Table 1). Stroke care structure, on the other hand, comprised of a stroke care pathway formed by system of emergency unit, medical ward, and rehabilitation department, with three structural requirements for each of the three sections. These requirements were human resource, equipment and medicine, and information storage and retrieval (Table 1). Stroke care process included subjective assessment, objective assessment, data analysis and diagnosis, problem list and implementation of therapeutic approaches (Table 8.1). The MoC also showed that outcome measures could be used to understand the quality of stroke care: quality of stroke care practice, functional independence, integration into the community, length of hospital stay (LOS), and discharge home.

Table 8.1: Model of Stroke care and Rehabilitation

Principle Number	Principle	Description
1	Utilisation of a multidisciplinary team approach to care,	Recommended to improve patient outcomes by the implementation of well-run multidisciplinary teams with enhanced stroke-care skills and using an evidence-based approach to care.
2	Patient journey	Recommended the need for aggressive emergency and continuing care and rehabilitation with optimum levels of multidisciplinary teamwork from the emergency unit, stroke ward and rehabilitation department.
3	Utilising goal-directed interventions that promote independence,	Recommended when managing patients with stroke, there is a need to establish evidence-based goals with treatment strategies that bring meaningful changes into the lives of patients with stroke, targeting promotion of independent activities, community participation, and reintegration.
4	Person-centered care	Recommended the type of care that ensures person-centered care across the stroke care continuum, with consideration for patient values, preferences, family and social circumstances, and lifestyles.
5	Evidence-based care,	Recommended the establishment of a specialised stroke unit, or at a minimum, have stroke-specific wards in all the Malawi referral hospitals, in contrast with the current mixed-patient hospital arena, with patients accessing multidisciplinary teams, early clinical processes of care, access to early intensive rehabilitation

Stroke Care Structure Emergency unit, stroke ward, and rehabilitation department with optimum multidisciplinary teamwork, satisfactory equipment and medical supplies, and with efficient information storage and retrieval system.		
Setting	**Description**	**Recommendation**
1) **Emergency unit**	Emergency unit is responsible for emergency investigations and care.	➢ Dedicated emergency team should include emergency nurses, emergency physicians, radiographers/radiologists, lab staff/counsellors, and supporting staff ➢ The equipment must include monitors for vital signs, oxygen equipment, suction machines, trolleys/wheelchairs for moving

		materials and patient in the hospital, resuscitation beds etc. ➤ EU must have an effective storage and retrieval system: computers, files, data collection forms, register books, and storage discs.
2) **Stroke ward**	Must be spacious, facilities accessible to patients with stroke, well-resourced with stroke-special-interest multidisciplinary teams, and adequate medical and radiological supplies.	➤ Dedicated multidisciplinary team should include nurses, physicians, physiotherapist/rehab personnel, supporting staff, e.g. clerks, and radiographers/radiologists ➤ The ward must also be equipped with airway /oxygen equipment, beds with side rails, monitors for vital signs, e.g. sphygmomanometer, mobility aids, urinary catheters, and medical supplies ➤ The dedicated stroke ward must also have an effective storage and retrieval system: computers, files, data collection forms, registers, and discs.
3) **Rehabilitation department**	The department must have a dedicated rehabilitation team, equipment, and a functioning information storage and retrieval system	➤ Must have dedicated team physiotherapists, rehabilitation technicians, occupational therapists, speech and language therapists, and support staff. ➤ Must have neuro beds, mats, parallel bars, wall bars, weights, and adaptive equipment for activities of daily living (ADLs). ➤ Must also have an effective storage and retrieval system: computers, files, data collection forms, registers, and discs must be available, in sufficient number and in working order.
Stroke care processes		
1) **Emergency unit**	➤ Patients with stroke must be promptly triaged, assessed, and have reversible risk factors managed. ➤ Triaging may be followed by administration of tissue plasminogen activator (rtPA) for suitable patients who report to the ED within 4.5 hours post onset of stroke ➤ Proactively manage fever, hyperglycemia, and swallowing problems	

	➢ Promptly transfer to a stroke unit or ward when the danger of complications is minimised
2) Stroke ward	➢ Recommended that acute assessment and investigation PoC should commence as soon as the patient is admitted ➢ After admission, implement clinical processes including close monitoring, drug administration, patient and guardian education, patient ADL support, and promoting peaceful death for those facing it. ➢ During the hyper acute phase, nursing follow-up assessments should be completed, initially, every 15 minutes, then every hour when the patient is stable. ➢ Rehabilitation assessment should be completed within 24 hours of referral and reassessment documented each time the patient is seen

	Assessment
	➢ Subjective assessment, where history about the patient and condition is taken including demographic features, medical, and social history;
	➢ Objective examination which should include
	    1) Physical examination: neurological assessment and swallowing screening, which should be completed by physicians and physiotherapists;
	    2) Routine biochemistry and hematology investigations should be performed. In particular, laboratory investigations, such as HIV test, VDRL, blood sugar test, and a full blood count to check creatinine, urea and electrolyte levels
	    3) Radiological investigations with chest X-ray, ECG, CT scan, and MRI can be run based on need and;
	    4) Cognitive and functional evaluations should also be completed by physiotherapists and occupational therapists.
	➢ Administer GCS, FIM, and Montreal Cognitive Assessment (MCA) should be administered to measure stroke severity; the ICF to conceptualise stroke disability and functioning.

	After assessment ➢ Medical care is administered with the support of nurses and when the patient is stable, ➢ Physicians should make appropriate referrals to the physiotherapists by completing a consultation form or making a verbal referral, with documentation in the patient file. ➢ Nurses should make timely referral to physiotherapists or physicians when patients achieve stability or in are situation of critical condition respectively; document and refer by filling out a consultation form or verbally. ➢ Physiotherapists should also make referrals when
2) Stroke ward	

necessary to physicians and nurses in situations of a critical condition or when, functionally, the patient has achieved the optimum level of function; document in the patient's health passport book or file, then refer by completing a consultation form or making a verbal referral in person or via phone.

Early Management

➢ Administer intravenous thrombolysis to those diagnosed with ischemic stroke and who present to the hospital within 4.5 hours of stroke onset. Otherwise, implement ASA (75mg) once a day as an anticoagulant .

➢ Physicians, nurses, and physiotherapist should work together in regulating fever; management of hypoxia, hypertension, diabetes, cholesterol, and DVT prevention or prophylaxis

➢ Nurses should implement orders by the physicians; advocate for change or review of care processes; provide education to the patient and guardian; assist dependent patients with ADLs; and promote peaceful death for those facing it.

General Management

➢ Rehabilitation should commence within 28 to 48 hours and should focus on:

➢ Functional independence: early patient mobilisation, training in ADLs, prevention of complications due to immobility, and provision of assistive devices to promote functional independence as implemented by physiotherapists and nurses.

➢ Caregiver (guardian) involvement, with clear communication to care giver and patient

➢ Early identification of need for referral

➢ Evaluate the home environment by conducting a home visit (where feasible); and

➢ Plan discharge.

8.2   Project Conclusions

Exploring the processes of care, the first project objective, we showed that care was categorized into acute management and investigations, early management, and general management in the country's central hospitals. Physicians, nurses, and physiotherapists formed the triple pillar of stroke care team, although physiotherapists were re loosely attached care providers, due to weak multidisciplinary team practices. Limited multidisciplinary teamwork affected the quality of care for people with stroke. Further challenges were structural. There was limited space for patients and inaccessible structures, which affected appropriate service provision; limited resources, only minimal qualified service providers, inadequate medical supplies, and unreliable medical equipment at best.

Determining the functional outcomes and satisfaction with care for patients with stroke in the central hospitals, the second and third project objectives, revealed that patient outcomes improved significantly on discharge compared to admission status. In additional, patients and informal caregivers showed they were highly satisfied with the provision of stroke care. However, high ratings on these outcomes did not translate into high quality of life. For example, they lacked functional independence and had moderate challenges in various domains of everyday life post-hospitalization. There is a need to focus on evidence-based intervention areas of stroke care that can impact the patients' quality of life.

From the scoping review, addressing objective four of the project, it was clear that there is lack of uniformity in the way stroke care is advanced in LMICs. This is reflected through the unsatisfactory stroke care structure, processes, and outcomes, a theme that also emerged in the studies done locally. The review further highlighted the need to implement change with stroke-care settings, adopting quality improvement strategies. Further, the health ministry and governments must decisively and deliberately face the increasing stroke burden by setting policies that advance improved care of and outcomes for patients with stroke based on evidence and proven interventions.

The Model of Care (MoC) developed to fulfill the last objective of this PhD project, was guided by five principles: utilization of a multidisciplinary team approach to care, importance of the patients' journey, goal-directed interventions, human-centered and, evidence-based care (EBC). It highlighted stroke care structure, processes, and outcomes across the stroke care pathway from Emergency Department (ED), the medical ward, and the Rehabilitation Department. To deliver effectively on processes of care, the MoC recommended that the multidisciplinary team needed clear objectives, protocols, policies, role delineation, and clear channels of communication. The team should run weekly multidisciplinary ward rounds, with regular clinical meetings, morning reports, and in-service training. Executing early care interventions is key to successful outcomes. To measure effectiveness of stroke structure and process, the MoC emphasized the use of quality stroke-care practices, promoting functional independence, integration into the community, minimal length of hospital stay (LOS), and discharge home as primary outcome measures.

There is a need for further research into stroke care structure and processes aiming to develop a coordinated protocol-driven stroke section or unit within Malawi's central hospitals, similar what exists in other LMICs, such as South Africa, and in the industrialized world.

8.3   Project Limitations

1. This project had limitations that need to be considered. At the outset, the cross-sectional studies forming part of the project had relatively small samples. However, the survey response rate was good at 79%. This is above the approximate 60% response rate, a recommended goal for most researchers. It was also limited to central hospitals, with potential sample selection bias as other health care workers in district hospitals were not included, especially the physicians, nurses, and physiotherapists. Sample bias could also be noted in the research where only those who were able to understand and speak the spoken language were included. This left out some people with probably severe stroke disability. Other patients with mild stroke and not admitted to one of our sample hospitals are not represented in the current study.

2. In the stroke outcomes research, the comorbidities that potentially impact patient function and QOL were not captured. And the research left out district hospitals that might be more active in managing and discharging patients with stroke.

3. The qualitative research and NGT were conducted at only one of the four referral hospitals in the country, QECH, which may have differing priorities in practice and context. However, as the largest referral hospital in the country, there may be a higher likelihood of representativeness on stroke care in Malawi.

4. The scoping review focused on a broad research field of stroke care. However, 2010 to 2017 is a reasonably wide range of publication years. On the other hand, having only 20 studies meeting the inclusion criteria may sound spurious. However, the included articles were very specific to the study question and reflective of stroke care. Lack of strict adherence to methodological quality that accompanies a scoping review might have affected the quality of the scoping review that formed part of this PhD project. Constant checks with research team members, however, added rigor to the study processes.

5. Without the intention of the researcher, the NGT was completed in two days. This was because the covered materials were too extensive for the employees who only managed to secure 3 hours from their work sites. As a result, there was change in the participants on day two when two of the participants, a physiotherapist and physician, replaced themselves with their colleagues who were available for the task. This might have affected the flow of discussion since the new participants had to be briefed on the process and the work done earlier. However, the new participants were at the same level of education and experience as the former ones.

8.4 Recommendations for practice

1. The project unearthed lack of uniformity in the way stroke care is advanced in LMICs as reflected in unsatisfactory stroke care structure, processes, and outcomes. There is a need to implement change. Stroke-care settings need to adopt quality improvement strategies. Health ministry and governments must decisively and deliberately face the increasing stroke burden by setting policies that advance improved care of and outcomes for patients with stroke.

2. Structurally, the stroke care settings should be spacious with accessible facilities to patients with stroke; well-resourced with stroke-special-interest multidisciplinary team work and adequate medical and radiological supplies.

3. To deliver effective processes of care, the multidisciplinary team needs to have clear objectives, protocols, policies, roles, and channels of communication. The team should run a minimum of two multidisciplinary ward rounds per week, run clinical meetings, and morning reports; conduct in-service trainings and; execute early care interventions.

4. By curtailing the sense of marginalisation and disconnectedness experienced by physiotherapy professionals in the early stages of stroke care, the patient with stroke could be managed holistically.

5. To measure effectiveness of stroke structure and process, the MoC recommended the use of quality of stroke care practice, functional independence, integration into the community, length of hospital stays (los), and discharge home as primary outcome measure.

6. Development of protocols and guidelines for each of the care setting could facilitate coordinated stroke care in the referral hospitals.

7. There is a need for further research into stroke care structure that could guide the development of a coordinated protocol-driven stroke section or unit within the central hospitals in Malawi, similar to the development in other LMICs, such as South Africa and the industrialised world.

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10.0 Appendices

Appendix 1: Certificate of Ethics approval, COMREC

CERTIFICATE OF ETHICS APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

P.10/15/1819 – Development of contextual model for In-patient stroke care and rehabilitation in Malawi by George Chimatiro

On 4 December 2015

As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC as indicated on the next page

Dr. C. Dzamalala- Chairperson (COMREC)   Date 16/12/2015

Appendix 2: Certificate of Ethics approval, UWC

OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

UNIVERSITY *of the*
WESTERN CAPE

08 September 2015

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by: Mr GL Chimatiro (Physiotherapy)

Research Project: Development of contextual model for in-patient stroke care and rehabilitation in Malawi.

Registration no: 15/6/31

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

A place of quality,
a place to grow, from hope
to action through knowledge

UNIVERSITY *of the*
WESTERN CAPE

Appendix 3a: Consent Form, English

7.0 Appendex 4

i.   **CONSENT FORM**

Title of Research Project:

Development of Contextual Model for In-patient Stroke Care and Rehabilitation in Malawi

Principle Investigator:

George Chimatiro, PT, MSc, University of the Western Cape, South Africa. Email: chimatirogeorge@hotmail.com Mobile: 0888267713

Supervisors:

Anthea J. Rhoda, PT, PHD, Professor at the University of the Western Cape, Deputy Dean Teaching and Learning, Department of Physiotherapy, Faculty of Community and Health Sciences, South Africa

Liesbet De Wit, PT, PHD, Professor at the Vrije Universiteit Brussel, Department of Public Health, Belgium

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name...........................

Participant's signature..................................

Date...........................

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Appendix 3b: Consent form, Chichewa

ii. **FOLOMU YA CHILOLEZO**

MUTU WA KAFUKUFUKU: Kukhonza Ndondomeko ya momwe chithandizo chamankhwala ndi choonjezela kuthekelanso kogwilira ntchito za siku ndi siku pakati pa anthu omwe adwala matenda opuwalisa ziwalo (stroke) zingamapelekedwele mzipatala zikuzikulu m'Malawi

Wochita Kafukufuku:

George Chimatiro, PT, MSc, University of the Western Cape, South Africa. Email: chimatirogeorge@hotmail.com Mobile: 0888267713

Woyang'anila:

Anthea J. Rhoda, PT, PHD, Professor at the University of the Western Cape, Deputy Dean Teaching and Learning, Department of Physiotherapy, Faculty of Community and Health Sciences, South Africa

Liesbet De Wit, PT, PHD, Professor at the Vrije Universiteit Brussel, Department of Public Health, Belgium

Ndondomeko ya kafukufukuyu ndauzidwa mchiyankhulo chomveka ndipo ndamvetsa, mwakufuna kwanga ndavomela kuchita nawo. Mafunso anga onse pa nkhani imeneyi ayankhidwa. Ndikuziwanso kuti nkhani zokhuza ine zidzasungidwa mwachinsisi, ndipo kuti nditha kusiya kuchita nawo kafukufuku ameneyu popanda kupeleka chifukwa chilichonse. Komanso ndikatelo sindilandila mkwiyo uliwonse.

Dzina la ochitanawo kafukufuku:...

Chidindo chaochitanawo kafukufuku:...

Tsiku:...

Version 2: 19/11/2015

Appendix 4a: Focus Group Confidentiality Binding Form, English

8.0 Appendex 5

i. **FOCUS GROUP CONFIDENTIALITY BINDING FORM**

Title of Research Project:

Development of Contextual Model for In-patient Stroke Care and Rehabilitation in Malawi

Principle Investigator:

George Chimatiro, PT, MSc, University of the Western Cape, South Africa. Email: chimatirogeorge@hotmail.com Mobile: 0888267713

Supervisors:

Anthea J. Rhoda, PT, PHD, Professor at the University of the Western Cape, Deputy Dean Teaching and Learning, Department of Physiotherapy, Faculty of Community and Health Sciences, South Africa

Liesbet De Wit, PT, PHD, Professor at the Vrije Universiteit Brussel, Department of Public Health, Belgium
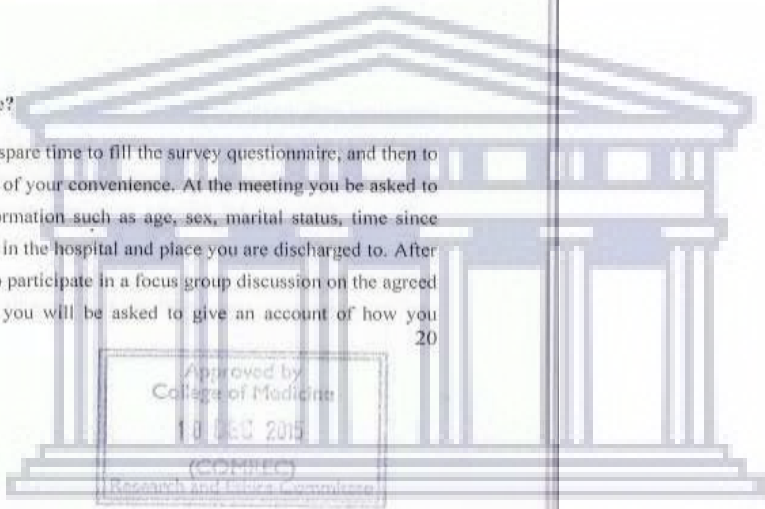
The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone by the researchers. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I understand that confidentiality is dependent on participants' in the Focus Group maintaining confidentiality. I also know that this research project involves making audiotapes of you.

I hereby agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

Participant's name...

Participant's signature..

Date...........................

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Appendix 4b: Focus Group Confidentiality Binding Form, Chichewa

ii.   Folomu Yotsindika Chinsisi pa Zokabirana za pa gulu

(FOCUS GROUP CONFIDENTIALITY BINDING FORM)

MUTU WA KAFUKUFUKU: Kukhonza Ndondomeko ya momwe chithandizo chamankhwala ndi choonjezela kuthekelanso kogwilira ntchito za siku ndi siku pakati pa anthu omwe adwala matenda opuwalisa ziwalo (stroke) zingamapelekedwele mzipatala zikuzikulu m'Malawi

Wochita kafukufuku:

George Chimatiro, PT, MSc, University of the Western Cape, South Africa. Email: chimatirogeorge@hotmail.com Mobile: 0888267713

Woyang'anila:

Anthea J. Rhoda, PT, PHD, Professor at the University of the Western Cape, Deputy Dean Teaching and Learning, Department of Physiotherapy, Faculty of Community and Health Sciences, South Africa

Liesbet De Wit, PT, PHD, Professor at the Vrije Universiteit Brussel, Department of Public Health, Belgium

Ndondomeko ya kafukufukuyu ndauzidwa mchiyankhulo chomveka ndipo ndamvetsa, mwakufuna kwanga ndavomela kuchita nawo. Mafunso anga onse pa nkhani imeneyi ayankhidwa. Ndikuziwanso kuti nkhani zokhuza ine zidzasungidwa mwachinsisi, ndipo kuti nditha kusiya kuchita nawo kafukufuku ameneyu popanda kupeleka chifukwa chilichonse. Komanso ndikatelo sindilandila mkwiyo uliwonse. Ngoziwanso kuti makina osungila mawu agwiritsidwa ntchito pa kafukufuku ameneyu

Ine ndikulonjeza kusunga chinsisi cha zokambirana za paguluzi, posaulula maina kapena zinthu zomwe anthu ena anena pa nthawi ya dzokambirana zimenezi, kwa anthu ena amene padalibe ndipo sizikuwakhudza.

Dzina la ochitanawo kafukufuku:..

Chidindo chaochitanawo kafukufuku:...

Tsiku:...

Version 2: 19/11/2015

9.0 Appendex 6

i.   **INFORMATION SHEET: Stroke patients**

Project Title:

Development of Contextual Model for In-patient Stroke Care and Rehabilitation in Malawi

Principle Investigator:

George Chimatiro, PT, MSc, University of the Western Cape, South Africa. Email: chimatirogeorge@hotmail.com Mobile: 0888267713

Supervisors:

Anthea J. Rhoda, PT, PHD, Professor at the University of the Western Cape, Deputy Dean Teaching and Learning, Department of Physiotherapy, Faculty of Community and Health Sciences, South Africa

Liesbet De Wit, PT, PHD, Professor at the Vrije Universiteit Brussel, Department of Public Health, Belgium

What is this study about?

This is a research project being conducted by George Chimatiro, PHD student at the University of the Western Cape. We are inviting you to participate in this research project because you suffered stroke, got admitted and treated at one of the central hospitals in the country. The purpose of this research project is to develop a new way of caring for patient with stroke (Model of stroke management) in Malawian hospitals.

What will I be asked to do if I agree to participate?

After signing the consent form you will be asked to spare time to fill the survey questionnaire, and then to meet those carrying out research at a place and time of your convenience. At the meeting you be asked to fill a form that seeks your socio-demographic information such as age, sex, marital status, time since onset of stroke, side of body affected, length of stay in the hospital and place you are discharged to. After responding to the questionnaire you may be asked to participate in a focus group discussion on the agreed date, time and place. At the meeting, as a group you will be asked to give an account of how you

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developed stroke, how you were managed, what you like about the care and how you would like the care to be improved. The researcher and/or research assistant will be available and ready to answer your questions should you have some, in a meeting that may last about 1 hour.

Would my participation in this study be kept confidential?

The researchers will undertake to protect your identity and the nature of your contribution. To help protect your confidentiality and retain your anonymity, we will not ask for or write your name on all papers related to this research. Instead identification codes using numbers will be used on survey and other data forms to ensure anonymity, and the researcher will personally collect all data collection forms and will ensure their storage in a locked and secure place. When we will finally write a report about this study your identity will remain protected and not displayed at any point. This study will use focus groups therefore if you happen to be a participant in the focus group discussion the extent to which your identity will remain confidential is dependent on participants' in the Focus Group maintaining confidentiality.

What are the risks of this research?

There may be some risks from participating in this research study. All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention, such as counselling.

What are the benefits of this research?

This research may not be personally helpful to you, but the results may help the investigator learn more about the experiences of stroke patients regarding hospital care and rehabilitation. We hope that, in the future, other people might benefit from this study through improved care and rehabilitation service delivery for people affected by stroke.

Do I have to be in this research and may I stop participating at any time?

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Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by George Chimatiro, PHD student under physiotherapy department of University of the Western Cape. If you have any questions about the research study itself, please contact George Chimatiro at: University of the Western Cape, physiotherapy department on telephone number: +27219592542, or mobile number: +265888267713, or email: 3077278@uwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

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Prof José Frantz

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

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The COMREC Secretariat

University of Malawi - College of Medicine Research & Ethics Committee

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This research has been approved by the University of the Western Cape's Senate Research Committee in South Africa and College of Medicine Research & Ethics Committee in Malawi .

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Appendix 5b: Information sheet: stroke patients, Chichewa

ii.   Ndondomeko ya kafukufuku: Kwa anthu odwala matenda opuwalitsa ziwalo (stroke).

Mutu wa kafukufuku

Kukhonza Ndondomeko ya momwe chithandizo chamankhwala ndi choonjezela kuthekelanso kogwilira ntchito za siku ndi siku pakati pa anthu omwe adwala matenda opuwalisa ziwalo (stroke) zingamapelekedwele mzipatala zikuzikulu m'Malawi

Wochita kafukufuku:

> George Chimatiro, PT, MSc, University of the Western Cape, South Africa. Email: chimatirogeorge@hotmail.com Mobile: 0888267713

Woyang'anila:

> Anthea J. Rhoda, PT, PHD, Professor at the University of the Western Cape, Deputy Dean Teaching and Learning, Department of Physiotherapy, Faculty of Community and Health Sciences, South Africa

> Liesbet De Wit, PT, PHD, Professor at the Vrije Universiteit Brussel, Department of Public Health, Belgium

Kodi kafufukuyu ndiokhuza chiani?

Akuchita kafukufukuyu ndi a George Chimatiro, omwe akuchita ma phunziro a pamwamba (PHD) ku South Africa pa sukulu ya ukachenjede ya University of the Western Cape. Mukupemphedwa kuchita nawo kafukufuku ameneyu inu mudadwalapo matenda opuwalisa ziwalo ndipo mudagonekedwapo ndi kulandira chithandizo mu china mwa zipatala zikuluzikulu mdziko muno. Cholinga cha kafukufukuyu ndicho kukhonza Ndondomeko ya momwe chithandizo chamankhwala ndi choonjezela kuthekelanso kogwilira ntchito za siku ndi siku pakati pa anthu omwe adwala matenda opuwalisa ziwalo (stroke) zingamapelekedwele mzipatala zikuzikulu mziko lino.

Kodi ndidzafunsidwa chiani ngati ndidzafune kuchita nao?

Mukabvomera ndi kusaina mapepala osonyedza kuti mwavomela, ochita kafukufukuyu azakumana nanu pa malo ndi nthawi yomwe inu mungagwirizane nayo. Panthawiyo muzapemphedwa kuti mulembe kapena kunena zinthu zina zokhuza inu monga; zaka zanu zakubadwa, kaya ndiinu amayi kapena

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abambo, wokwatiwa/wokwatila, nthawi yomwe munadwala matenda opuwalisa ziwalo, komanso mbali ya thupi lanu yomwe inakhuzidwa ndimatendawa, nthawi yomwe mwakhala m'chipatala, ndi komwe mukupita mukatuluka mchipatala. Kenaka muzayankha mafunso omwe ali pa folomu ya kafukufuyu pa tsiku loti mawa mukutulutsidwe. Mwina muzapemphedwanso kuzakhalanawo pa mkomano ndi odwala ena pofuna kukambilana, kuziwa zomwe mwakumananazo kumbali ya zinthu monga momwe stroke inayambila, chithandizo chomwe mwalandila, ngati mwakhutitsidwa nacho kapena ayi, ndinso maganizo anu pa zomwe ziyenela kuchitika pofuna kupititsa mtsogolo mapelekedwa a chithandizo kwa anthu omwe adwala matenda opuwalisa ziwalowa. Ochita kafukufukuyu adzakhala okonzeka kuyankha mafunso aliwonse omwe mongakhale nawo okhuza kafukufuku ameneyu. Kukumanaku kudzatenga mphindi zosaposela ola limozi.

Koma chinsisi pa kuchita nawo kufukufuku ameneyu chizasungidwa?

Tidzayesesa kwambiri kusunga chinsisi chanu. Mwachitsanzo simudzafunsidwa kupereka kapena kulemba dzina lanu pa mapepala okhuza kafukufukuyu. Mmalo mwake nambala yoimila dzina lanu (code) idzagwilisidwa ntchito, ndipo wochita kafukufukuyu adzaonesetsa kuti mapepala onse agwiritsidwa ntchito popeza zofunikira za kafukufuku ameneyu atenga ndipo asungidwa pa malo obisika. Pakutha pa kafuku ameneyu dzina kapena chilichonse chokhuzana ndinu sichizaonetsedwa kwa aliyense kapena paliponse. Ngati mupemphedwe kuchita nao zokambilana zapagulu zokhuza kafukufuku ameneyu chitengela ndi masungidwe a chinsisi cha gulu lonse.

ndizoopsa ziti zomwe ndingakumane nazo pa kafukufuku ameneyu?

Mwina mutha kukumana ndizovuta zina panthawi yakafukufuku ameneyu. Pamene anthu akumana nkumanena zokhuza za moyo wawo kapena waena pamatha kukhala zokhumudwisa zina. Koma ngati mutapeza mavuto aliwonse mkati mwa kafukufuku ameneyu kaya mthupi kapena mmaganizo mwanu, tidzakhala okonzeka kukutumizani ku malo komwe mungalandire chithandizo choyenelera choyenelela.

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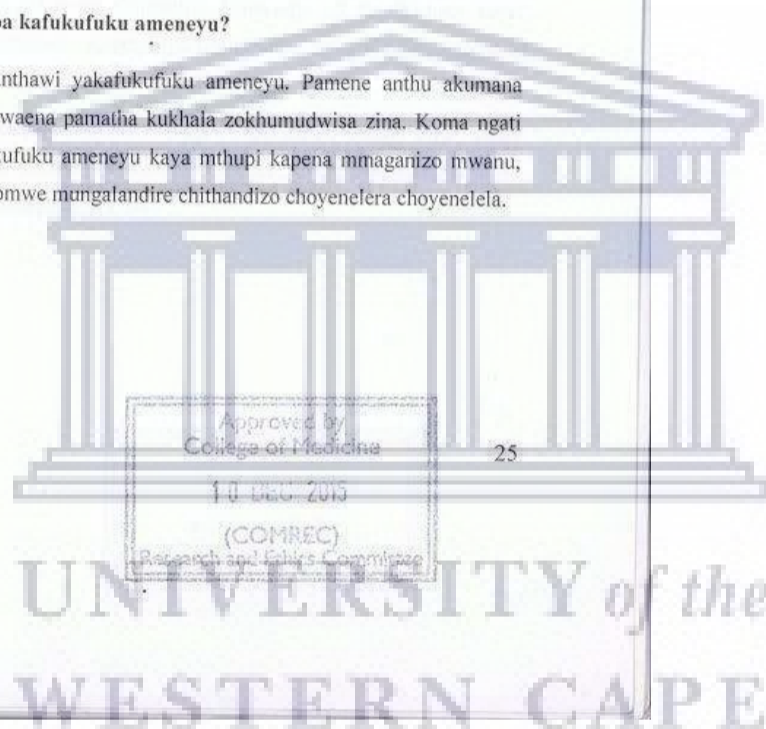
Pali phindu lanji pa kafukufuku ameneyu?

Mwina kafukufuku ameneyu sangakhale wothandiza chilichonse kwa inu monga munthu, koma zotsatila zake zingazathandize wochita kafukufuku ameneyu kudziwa bwino zovuta zomwe odwala matenda opuwalitsa ziwalo amakomana nazo ndizomwe akuganiza zokhuzana ndikukweza chisamaliro cha odwala matenda amenewa. Tili ndi chikulupiliro kuti mtsogolo muno anthu ena osiyanasiyana adzapindula kuzela mu nzelu zatsopano zimene zidzapezeke chifukwa cha kafukufuku ameneyu, komanso ma dotolo ogwira ntchito ya zolimbisa ziwalo adzapindulanso. Pakutelo odwala matenda opuwalitsa ziwalo azathandizidwa mwaukadaulo.

Kodi n̄kofunika kupanganaye kafukufukufukuyu? Nanga ndili mkati mochita naye kafukufukuyu ndingathe kusiya kapena kuchoka nthawi iliyonse?

Kafukufuku ameneyu mutha kuchita nawo mwakufuna kwanu. Muthanso kukana. Ngati musankha kuchita nawo mudziwe kuti muthanso kuchoka nthawi iliyonse ngati mwafuna kutelo. Ngati simukufuna kuchita nawo, kapena mwaganiza zosiya kutenga nawo mbali pa kafukufuku ameneyu, simudzalandila chilango kapena mkwiyo uliwonse kuchokera kwa omwe akuchititsa kufukufukuyu.

Kodi nanga ntakhala ndi mafunso?

Akuchita kafukufukuyu ndi a George Chimatiro, omwe akuchita ma phunziro a pamwamba (PHD) ku South Africa pa sukulu ya ukachenjede ya University of the Western Cape, ku depatimenti yophunzitsa anthu oyang'anila anthu odwala matenda opuwalitsa ziwalo. Ngati muli ndi mafunso okhuza kafukufukuyu (musachedwe), lankhulani ndi a George Chimatiro, University of the Western Cape, Physiotherapy department. Telefoni: 0027219592542. Kapena tumizani kalata pa: 3077278@uwc.ac.za Kapena: MAP, P.O. Box 256, Blantyre, Malawi. Telefoni: +265888267713.

Mukakhala ndimafunso okhudzana ndi kafukufukuyu komanso ufulu wanu ngati mmozi mwa ochita nawo kafukufuku ameneyu, kapena mukufuna kunena za mavuto aliwonse amene mwakumana nawo pankhani imeneyi (musazengereze) tumizani nkhawa zanu kwa:

Dr Nondwe Mlenzana

Head of Department

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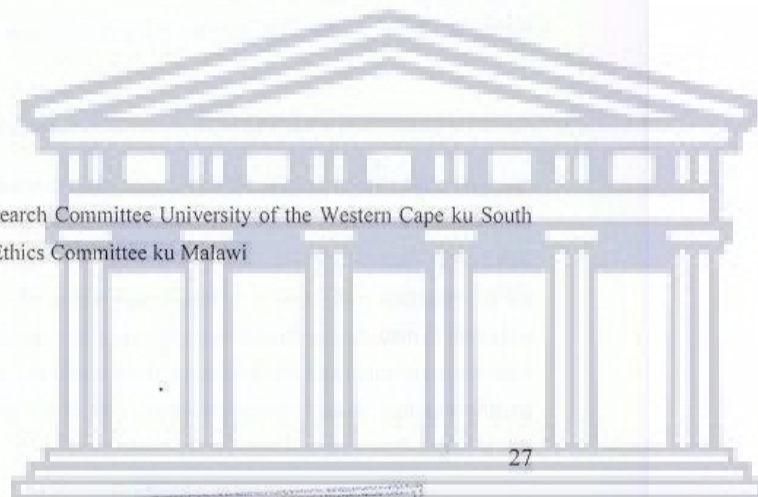
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Appendix 6a: Information Sheet: Guardians, English

10.0   Appendex 7

i.   **INFORMATION SHEET: Caregivers**

Project Title:

Development of Contextual Model for In-patient Stroke Care and Rehabilitation in Malawi

Principle Investigator:

George Chimatiro, PT, MSc, University of the Western Cape, South Africa. Email: chimatirogeorge@hotmail.com Mobile: 0888267713

Supervisors:

Anthea J. Rhoda, PT, PHD, Professor at the University of the Western Cape, Deputy Dean Teaching and Learning, Department of Physiotherapy, Faculty of Community and Health Sciences, South Africa

Liesbet De Wit, PT, PHD, Professor at the Vrije Universiteit Brussel, Department of Public Health, Belgium

What is this study about?

This is a research project being conducted by George Chimatiro, PHD student at the University of the Western Cape. We are inviting you to participate in this research project because you are a caregiver of a stroke patient who got admitted and treated at one of the central hospitals in the country. The purpose of this research project is to develop a new way of caring for patient with stroke (Model of stroke management) in Malawian hospitals.

What will I be asked to do if I agree to participate?

After signing the consent form you will be asked to spare time to fill the survey questionnaire on a day before discharge and then to meet those carrying out research at a place and time of your convenience. At the meeting you be asked to fill a form that seeks your socio-demographic information such as age, sex. After responding to the questionnaire you may be asked to participate in a focus group discussion on the agreed date, time and place. At the meeting, as a group, you will be asked to give an account of how your patient developed stroke, how managed, what you like about the care and rehabilitation service delivery, and how you would like the care to be improved. The researcher and/or research assistant will be

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available and ready to answer your questions should you have some, in a meeting that may last about 1hour.

Would my participation in this study be kept confidential?

The researchers will undertake to protect your identity and the nature of your contribution. To help protect your confidentiality and retain your anonymity, we will not ask for or write your name on all papers related to this research. Instead identification codes using numbers will be used on survey and other data forms to ensure anonymity, and the researcher will personally collect all data collection forms and will ensure their storage in a locked and secure place. When we will finally write a report about this study your identity will remain protected and not displayed at any point. This study will use focus groups therefore if you happen to be a participant in the focus group discussion the extent to which your identity will remain confidential is dependent on participants' in the Focus Group maintaining confidentiality.

What are the risks of this research?

There may be some risks from participating in this research study. All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention, such as counselling.

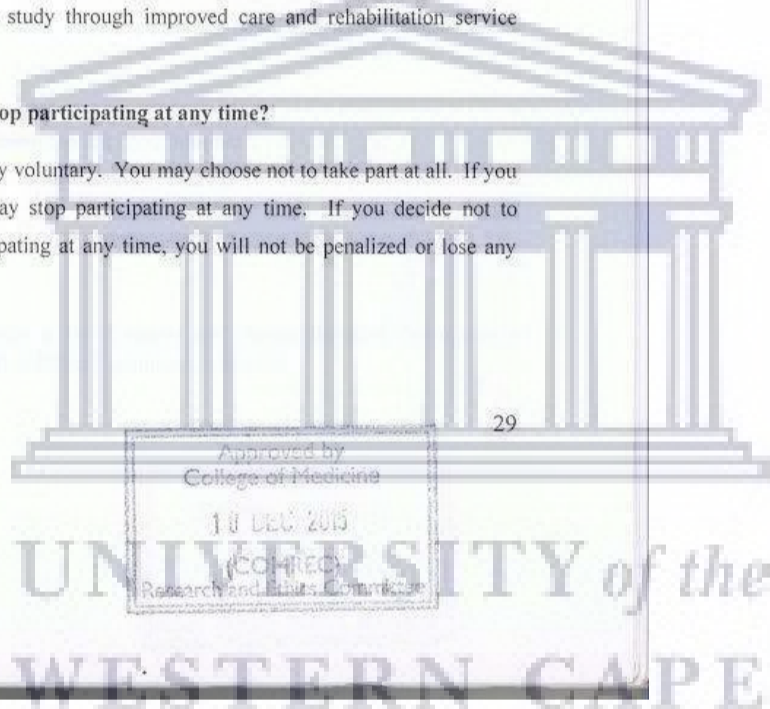**What are the benefits of this research?**

This research may not be personally helpful to you, but the results may help the investigator learn more about the experiences of stroke patients regarding hospital care and rehabilitation. We hope that, in the future, other people might benefit from this study through improved care and rehabilitation service delivery for people affected by stroke.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

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Appendix 6b: Information Sheet: Guardians, Chichewa

ii. Ndondomeko ya kafukufuku: Kwa anthu osamalira odwala matenda opuwalitsa ziwalo (stroke).

Mutu wa kafukufuku

Kukhonza Ndondomeko ya momwe chithandizo chamankhwala ndi choonjezela kuthekelanso kogwilira ntchito za siku ndi siku pakati pa anthu omwe adwala matenda opuwalisa ziwalo (stroke) zingamapelekedwele mzipatala zikuzikulu m'Malawi

Wochita kafukufuku:

George Chimatiro, PT, MSc, University of the Western Cape, South Africa. Email: chimatirogeorge@hotmail.com Mobile: 0888267713

Woyang'anila:

Anthea J. Rhoda, PT, PHD, Professor at the University of the Western Cape, Deputy Dean Teaching and Learning, Department of Physiotherapy, Faculty of Community and Health Sciences, South Africa

Liesbet De Wit, PT, PHD, Professor at the Vrije Universiteit Brussel, Department of Public Health, Belgium

Kodi kafufukuyu ndiokhuza chiani?

Akuchita kafukufukuyu ndi a George Chimatiro, omwe akuchita ma phunziro a pamwamba (PHD) ku South Africa pa sukulu ya ukachenjede ya University of the Western Cape. Mukupemphedwa kuchita nawo kafukufuku ameneyu inu mukusamalira ndikupeleka chithandizo kwa munthu yemwe wadwala matenda opuwalisa ziwalo ndipo wagonekedwapo ndi kulandira chithandizo mu china mwa zipatala zikuluzikulu mdziko muno. Cholinga cha kafukufukuyu ndicho kukhonza Ndondomeko ya momwe chithandizo chamankhwala ndi choonjezela kuthekelanso kogwilira ntchito za siku ndi siku pakati pa anthu omwe adwala matenda opuwalisa ziwalo (stroke) zingamapelekedwele mzipatala zikuzikulu mziko lino.

Kodi ndidzafunsidwa chiani ngati ndidzafune kuchita nao?

Mukabvomera ndi kusaina mapepala osonyedza kuti mwavomela, ochita kafukufukuyu azakumana nanu pa malo ndi nthawi yomwe inu mungagwirizane nayo. Panthawiyo muzapemphedwa kuti mulembe

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Kodi nkofunika kupanganaye kafukufukufukuyu? Nanga ndili mkati mochita naye kafukufukuyu ndingathe kusiya kapena kuchoka nthawi iliyonse?

Kafukufuku ameneyu mutha kuchita nawo mwakufuna kwanu. Muthanso kukana. Ngati musankha kuchita nawo mudziwe kuti muthanso kuchoka nthawi iliyonse ngati mwafuna kutelo. Ngati simukufuna kuchita nawo, kapena mwaganiza zosiya kutenga nawo mbali pa kafukufuku ameneyu, simudzalandila chilango kapena mkwiyo uliwonse kuchokera kwa omwe akuchititsa kufukufukuyu.

Kodi nanga ntakhala ndi mafunso?

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Mukakhala ndimafunso okhudzana ndi kafukufukuyu komanso ufulu wanu ngati mmozi mwa ochita nawo kafukufuku ameneyu, kapena mukufuna kunena za mavuto aliwonse amene mwakumana nawo pankhani imeneyi (musazengereze) tumizani nkhawa zanu kwa:

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Kapena:

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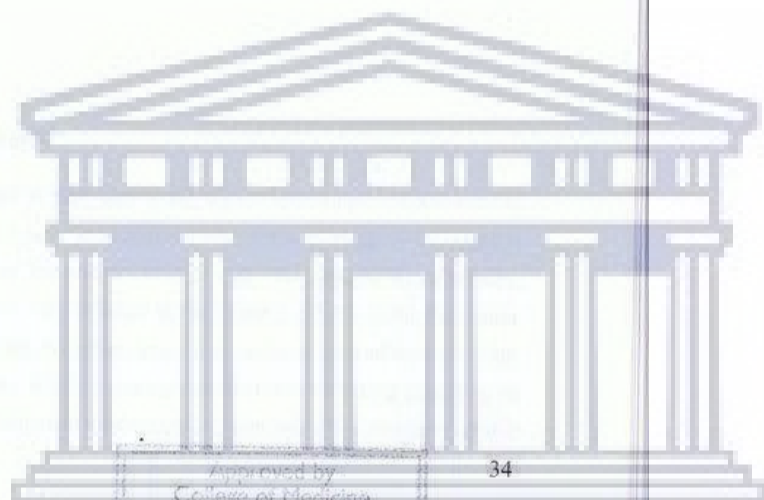
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Appendix 7: Information Sheet: Service Providers

i.   **INFORMATION SHEET: Service Providers**

Project Title:

Development of Contextual Model for In-patient Stroke Care and Rehabilitation in Malawi

Principle Investigator:

George Chimatiro, PT, MSc, University of the Western Cape, South Africa. Email: chimatirogeorge@hotmail.com Mobile: 0888267713
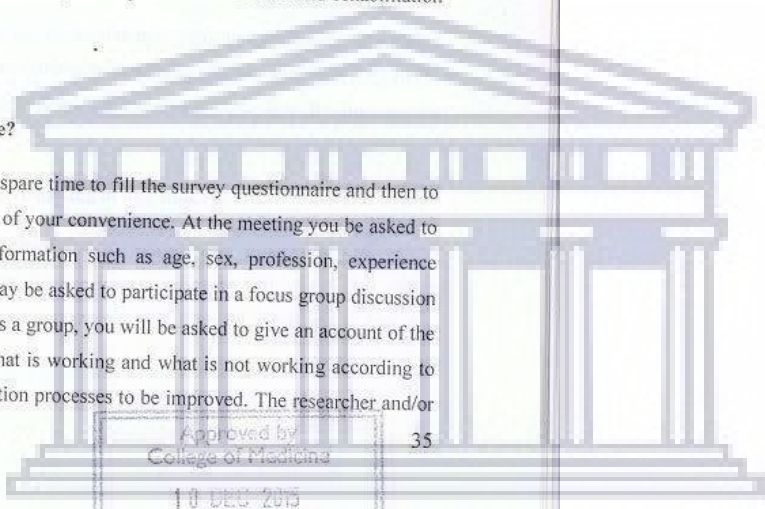
Supervisors:

Anthea J. Rhoda, PT, PHD, Professor at the University of the Western Cape, Deputy Dean Teaching and Learning, Department of Physiotherapy, Faculty of Community and Health Sciences, South Africa

Liesbet De Wit, PT, PHD, Professor at the Vrije Universiteit Brussel, Department of Public Health, Belgium

What is this study about?

This is a research project being conducted by George Chimatiro, PHD student at the University of the Western Cape. We are inviting you to participate in this research project because you provide either medical or nursing or rehabilitation services to stroke patients at one of the central hospitals in the country. The purpose of this research project is to develop a hospital model of care and rehabilitation service delivery for stroke patients.

What will I be asked to do if I agree to participate?

After signing the consent form you will be asked to spare time to fill the survey questionnaire and then to meet those carrying out research at a place and time of your convenience. At the meeting you be asked to fill a form that seeks your socio-demographic information such as age, sex, profession, experience (years). After responding to the questionnaire you may be asked to participate in a focus group discussion on the agreed date, time and place. At the meeting, as a group, you will be asked to give an account of the processes involved in the care of stroke patients, what is working and what is not working according to you, and how you would like the care and rehabilitation processes to be improved. The researcher and/or

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research assistant will be available and ready to answer your questions should you have some, i
meeting that may last about 1hour.

Would my participation in this study be kept confidential?

The researchers will undertake to protect your identity and the nature of your contribution. To h
protect your confidentiality and retain your anonymity, we will not ask for or write your name on
papers related to this research. Instead identification codes using numbers will be used on survey a
other data forms to ensure anonymity, and the researcher will personally collect all data collection for
and will ensure their storage in a locked and secure place. When we will finally write a report about th
study your identity will remain protected and not displayed at any point. This study will use focus grou
therefore if you happen to be a participant in the focus group discussion the extent to which your identi
will remain confidential is dependent on participants' in the Focus Group maintaining confidentiality.

What are the risks of this research?

There may be some risks from participating in this research study. All human interactions and talkin
about self or others carry some amount of risks. We will nevertheless minimise such risks and ac
promptly to assist you if you experience any discomfort, psychological or otherwise during the process o
your participation in this study. Where necessary, an appropriate referral will be made to a suitabl
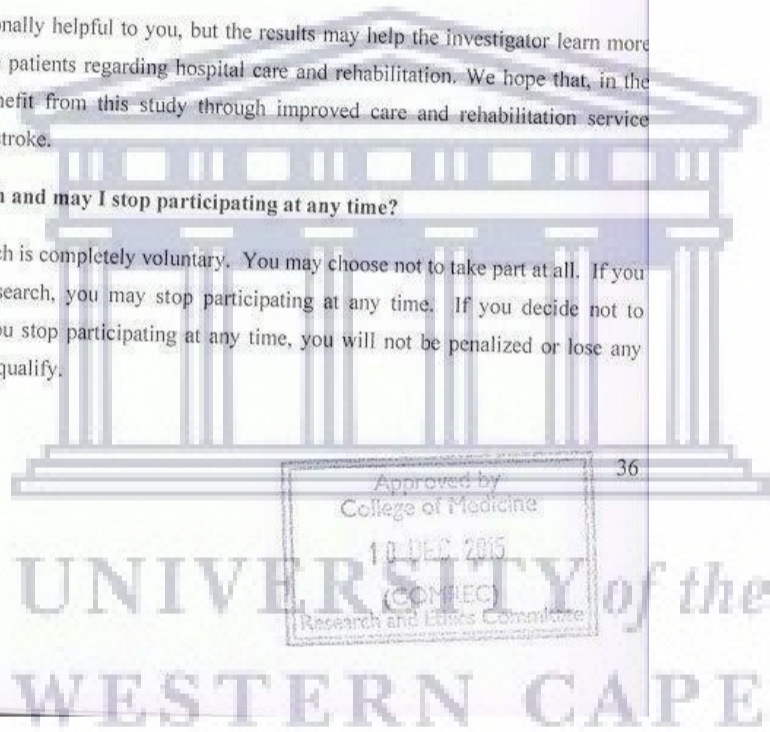professional for further assistance or intervention, such as counselling.

What are the benefits of this research?

This research may not be personally helpful to you, but the results may help the investigator learn more
about the experiences of stroke patients regarding hospital care and rehabilitation. We hope that, in the
future, other people might benefit from this study through improved care and rehabilitation service
delivery for people affected by stroke.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you
decide to participate in this research, you may stop participating at any time. If you decide not to
participate in this study or if you stop participating at any time, you will not be penalized or lose any
benefits to which you otherwise qualify.

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What if I have questions?

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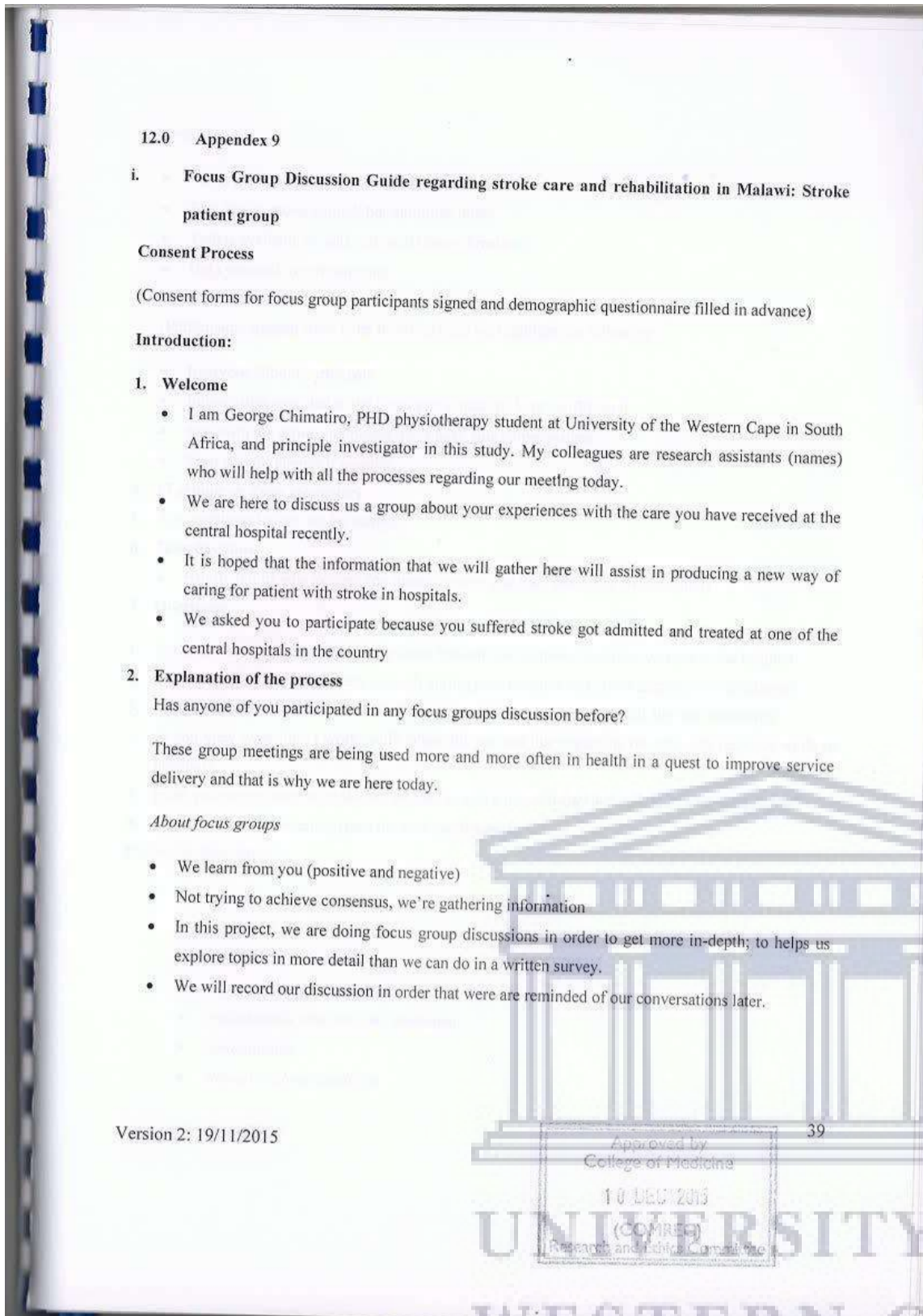Chichiri

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Appendix 8a: Focus Group Discussion Guide: stroke patients, English

12.0   Appendex 9

i.   **Focus Group Discussion Guide regarding stroke care and rehabilitation in Malawi: Stroke patient group**

Consent Process

(Consent forms for focus group participants signed and demographic questionnaire filled in advance)

Introduction:

1. Welcome

   - I am George Chimatiro, PHD physiotherapy student at University of the Western Cape in South Africa, and principle investigator in this study. My colleagues are research assistants (names) who will help with all the processes regarding our meeting today.
   - We are here to discuss us a group about your experiences with the care you have received at the central hospital recently.
   - It is hoped that the information that we will gather here will assist in producing a new way of caring for patient with stroke in hospitals.
   - We asked you to participate because you suffered stroke got admitted and treated at one of the central hospitals in the country

2. **Explanation of the process**

   Has anyone of you participated in any focus groups discussion before?

   These group meetings are being used more and more often in health in a quest to improve service delivery and that is why we are here today.

   About focus groups

   - We learn from you (positive and negative)
   - Not trying to achieve consensus, we're gathering information
   - In this project, we are doing focus group discussions in order to get more in-depth; to helps us explore topics in more detail than we can do in a written survey.
   - We will record our discussion in order that were are reminded of our conversations later.

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Logistics

- Focus group will last about one hour
- Feel free to move around, but minimize noise
- Toilets available should you need (show direction)
- Help yourself to refreshments

3. Ground Rules

(Participants suggest rules to be followed) and we highlight the following:

- Everyone should participate.
- Information provided in the focus group must be kept confidential
- Stay with the group and please don't have side conversations
- Turn off cell phones if possible

4. **(Turning on Tape Recorder)**

5. Any questions before we get started?

6. **Introductions**

- Briefly tell us who you are (no names) where you live, what you do (go round)

7 **Questions:**

1. Let's start the discussion by talking about how stroke happened and how you got to the hospital
2. Explain the processes you went through during your hospital stay (from admission to discharge)
3. In your opinion what worked well? What did you like about your hospital stay and treament?
4. In you view what didn't work well? What did you not like regarding the care you received while in hospital?
5. From your experience what should be done to make hospital stay and care better for the patients?
6. Any additional information (turn for each participant)?

Probes for Discussion:

- *referral*
- *casualty department*
- *investigations done*
- *initial and ongoing treatment*
- *professionals who provided treatment*
- *rehabilitation*
- *education about condition*

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- *discharge planning*

That concludes our focus group. Thank you so much for coming and sharing your thoughts and opinions with us.

Materials and supplies for focus groups

- Consent forms
- Focus Group Discussion Guide for Facilitator
- 1 recording device
- Notebook for note-taking
- Refreshments

Appendix 8b: Focus Group Discussion Guide: stroke patients, Chichewa
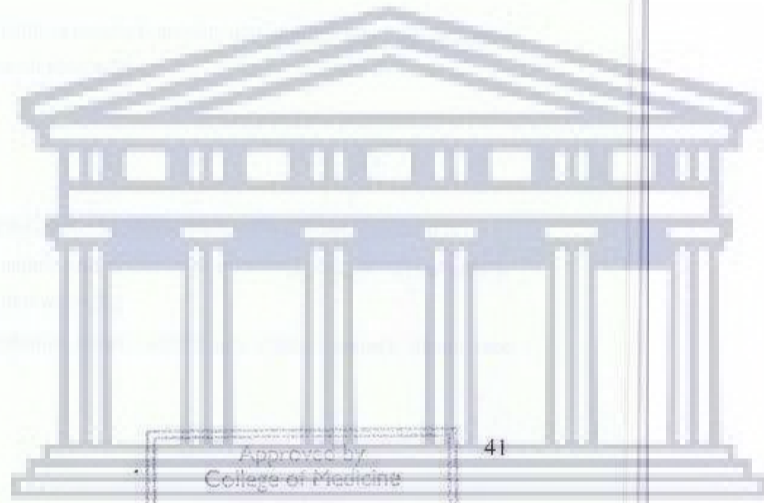
ii. **Mlozo wa Zokambirana za Pagulu Zokhudza chithandizo cham'chipatala kwa anthu omwe adwala matenda opuwalisa ziwalo (stroke): Gulu la anthu odwala**

Ndondomeko ya Chilolezo

(Makalata ovomereza kuchita nawo zokambirani asainidwe ndipo mafolomu okhuza mbili ya ochitanao zokabilana ayankhidwe)

Mau Otsogolera:

1. **Malonje**
   - Dzina langa ndine George Chimatiro, Ophunzira ukachenjede wothandiza anthu odwala matenda akufa kwa ziwalo pa sukulu ya ukachenjede ya Western Cape ku South Africa. Ineyo ndi amene ndili wankulu wa kafukufukuyu. Palinso anzanga ena omwe akuthandizira mu kafufukuyu ndipo azithandiza keyendetsa msonkhano wanthu lero.
   - Lero tikambirana zomwe mukudziwa kapena zomwe mudazionapo zokhudza chisamaliro chomwe munalandirapo ku chipatala chachikulu.
   - Tikuyembekezera kuti zomwe tipeze pano zithandiza kukhazikitsa njira zabwino zothandizira odwala matenda akufa kwa ziwalo mzipatala.
   - Takusankhani kuti muchte nawo zokambiranazi chifukwa inu mudadwalapo matenda akufa kwa ziwalo ndipo mudagonekedwapo ndi kulandira chithandizo mu china mwa zipatala zikuluzikulu mdziko muno.

2. **Dongosolo la Ndondomekoyi**
   Alipo wainu amene adachitapo zokambirana pagulu?

   Zokambirana ngati izi zikugwiritsidwa ntchito kwambiri masiku ano pofuna kupititsa patsogolo ntchito zothandiza wanthu, nchifukwa chake tili pano lero.

   Zokhudza magulu osankhidwa

   - Tiphunzira kuchokera kwa inu
   - Sikuti tikufuna kuti tonse tikambe mogwirizana, chofunika ndi kupeza zomwe zimachitika
   - Muntchitoyi, tikuchita zokambirana mmagulu kuti tipeze zenizeni komanso tione nfundo zomwe sizingatheke kugwiritsa ntchito kafukufuku wolemba.
   - Zokambiranazi tizijambula ndi chojambulira mawu ndicholinga chakuti zomwe tikambirane tizisunge.

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Zofunika

- Zokambirana zikhala za ola limodzi
- Ndinu omasuka kumasuntha mwakachetechete
- Malo odzithandizira alipo (alozedwa)
- Zakumwa zoziritsa kukhosi zilipo

3. Malamulo

(Okambirana akonze malamulo okha) Kuphatikizapo izi:

- Aliyense atenge nawo mbali pazokambirana
- Zokambidwa pano zikhale zachinsinsi
- Musachoke kapena kumakamba nkhani zina zokambirana zili mkati
- Matelefoni ammanja azimitsidwe ngati ndikotheka kutero.

4. **(Kuyatsa chojambulira mau)**

5. Alipo ali ndi funso tisadayambe?

6. **Kudziwana**

Mwachidule tiuzeni kuti ndinu ndani (osati dzina lanu) Komwe mumakhala, zomwe mumachita (aliyense afotokoze yekha)

7. **Mafunso**

1. Tiyambe ndikufotokoza momwe matenda akufa kwa ziwalo (stroke) aanakuyambirani ndi mmene mudakafikira kuchipatala
2. Fotokozani mmene zinayendera mutafika kuchipatala (Mutangofika, atakugonekani mpaka kukutulutsani)
3. Mmene munaonera, nchani chidayenda bwino? Ndithandizo lanji lomwe mudakhutira nalo mmene munali mchipatala?
4. Mmene munaonera ndi chani chomwe sichidayende bwino chokhudzana ndi thandizo limene mudalandira muli mchipatala?
5. Momwe munaonera mukuganiza kuti zoyenera kuchitika ndi chani kuti odwala azikhutira ndi thandizo lomwe amalandira kuchipatala?
6. Pali zowonjezera? (munthu aliyense apatsidwe mpata)

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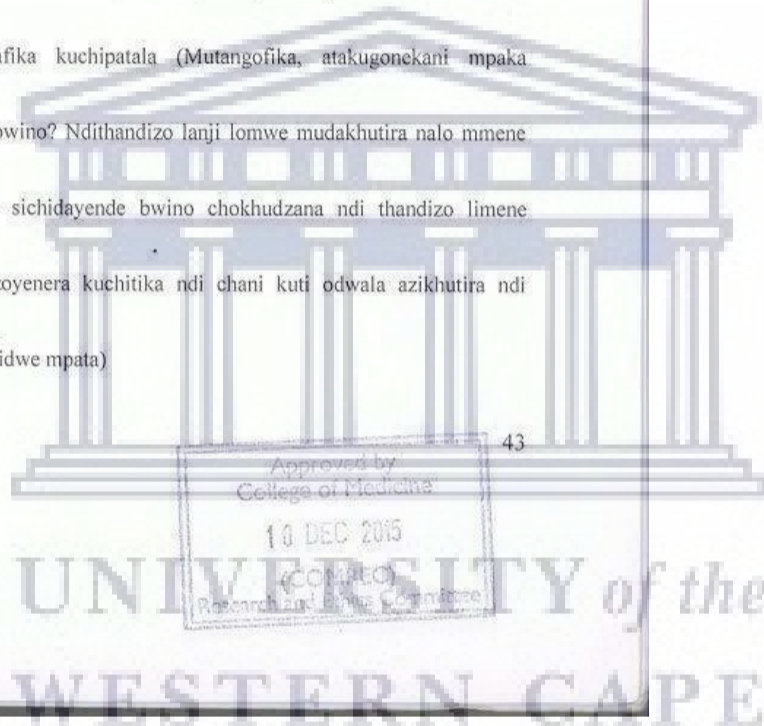
Mavuto omwe akambidwe pa zokambiranazi

- *Kutumizidwa kuchipatala chachikulu*
- *Kungozi*
- *Kufufuza za matenda*
- *Thandizo loyambilira ndi lopitiliza*
- *Achipatala omwe adawathandiza*
- *Kuthandiza kuti abwerele mwakale*
- *Maphunziro okhudza matendawa*
- *Ndondomeko yokatsata akatulutsidwa mchipatala*

Apa nde pamapeto pa zokambirana zathu. Zikomo kwambiri chifukwa chakubwera kwanu, komanso kutiuza maganizo anu.

Zimene zinagwitsidwa ntchito pa Zokambiranazi:

- makalata yovomereza kuchita nawo zokambirana
- Ndondomeko yoyendetsera zokambira ya mtsogoleri wazokambirana
- Chipangizo chojambulira mawu
- Makope
- Zakumwa zozilitsa kukhosi

iii.   Focus Group Discussion Guide regarding stroke care and rehabilitation in Malawi: Caregivers group

1. **Consent Process**

(Consent forms for focus group participants signed and demographic questionnaire filled in advance)

Introduction:

2. **Welcome**

- I am George Chimatiro, PHD physiotherapy student at University of the Western Cape in South Africa, and principle investigator in this study. My colleagues are research assistants (names) who will help with all the processes regarding our meeting today.
- We are here to discuss us a group about your experiences with the care that the patient you are taking care of received at the central hospital recently.
- It is hoped that the information that we will gather here will assist in producing a new way of caring for patient with stroke in hospitals.
- We asked you to participate because you are a caregiver of a stroke patient who got admitted and treated at one of the central hospitals in the country

3. **Explanation of the process**

Has anyone of you participated in any focus groups discussion before?

These group meetings are being used more and more often in health in a quest to improve service delivery and that is why we are here today.

4. *About focus groups*

- We learn from you (positive and negative)
- Not trying to achieve consensus, we're gathering information
- In this project, we are doing focus group discussions in order to get more in-depth; to helps us explore topics in more detail than we can do in a written survey.
- We will record our discussion in order that were are reminded of our conversations later.

5. *Logistics*

- Focus group will last about one hour

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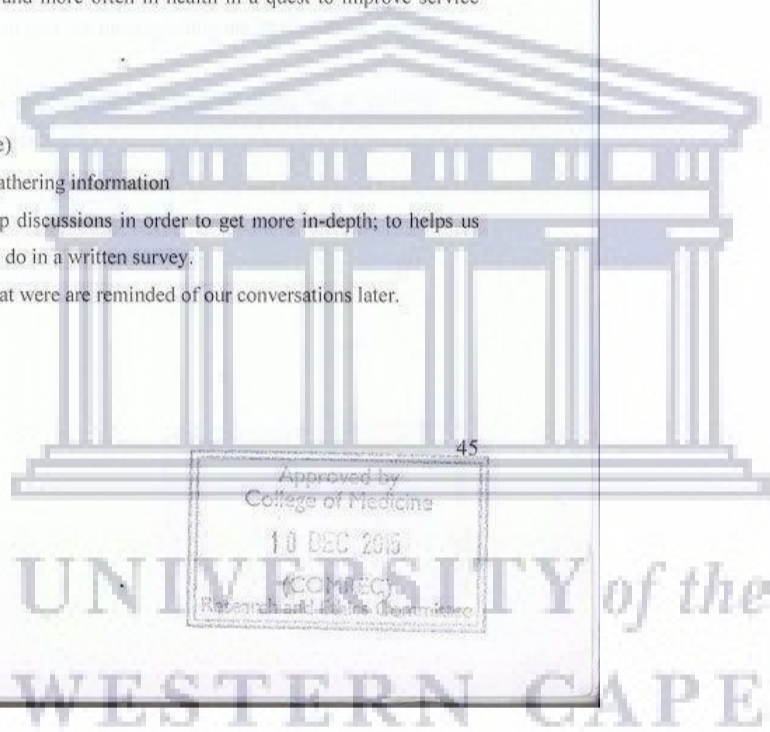
45

- Feel free to move around, but minimize noise
- Toilets available should you need (show direction)
- Help yourself to refreshments
6. Ground Rules

(Participants suggest rules to be followed) and we highlight the following:

- Everyone should participate.
- Information provided in the focus group must be kept confidential
- Stay with the group and please don't have side conversations
- Turn off cell phones if possible
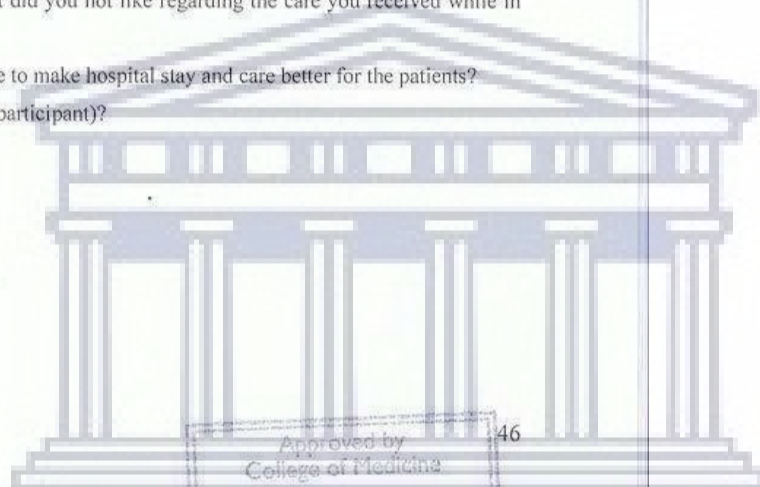

7. **(Turning on Tape Recorder)**
8. Any questions before we get started?
9. **Introductions**
- Briefly tell us who you are (no names) where you live, what you do (go round)

7. **Questions:**

1. Let's start the discussion by talking about how stroke happened to your loved one and how he/she got to the hospital
2. Explain the processes he/she went through during your hospital stay (from admission to discharge)
3. In your opinion what worked well? What did you like about your hospital stay and treatment?
4. In you view what didn't work well? What did you not like regarding the care you received while in hospital?
5. From your experience what should be done to make hospital stay and care better for the patients?
6. Any additional information (turn for each participant)?

Probes for Discussion:

- *referral*
- *casualty department*
- *investigations done*
- *initial and ongoing treatment*
- *professionals who provided treatment*
- *rehabilitation*
- *education about condition*
- *discharge planning*

That concludes our focus group. Thank you so much for coming and sharing your thoughts and opinions with us.

Materials and supplies for focus groups

- Consent forms
- Focus Group Discussion Guide for Facilitator
- 1 recording device
- Notebook for note-taking
- Refreshments

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Appendix 9b: Focus Group Discussion Guide: Guardians, Chichewa

iv.   Mlozo wa Zokambirana za Pagulu Zokhudza chithandizo cham'chipatala kwa anthu omwe
       adwala matenda opuwalisa ziwalo (stroke): Gulu la othangatila odwala

Ndondomeko ya Chilolezo

(Makalata ovomereza kuchita nawo zokambirani asainidwe ndipo mafolomu okhuza mbili ya ochitanao
zokabilana ayankhidwe)

Mau Otsogolera:

1.   Malonje
•   Dzina langa ndine George Chimatiro, Ophunzira ukachenjede wothandiza anthu odwala matenda
     akufa kwa ziwalo pa sukulu ya ukachenjede ya Western Cape ku South Africa. Ineyo ndi amene
     ndili wankulu wa kafukufukuyu. Palinso anzanga ena omwe akuthandizira mu kafufukuyu ndipo
     azithandiza keyendetsa msonkhano wanthu lero.
•   Lero tikambirana zomwe mukudziwa kapena zomwe mudazionapo zokhudza chisamaliro
     chomwe munalandirapo ku chipatala chachikulu.
•   Tikuyembekezera kuti zomwe tipeze pano zithandiza kukhazikitsa njira zabwino zothandizira
     odwala matenda akufa kwa ziwalo mzipatala.
•   Takusankhani kuti muchte nawo zokambiranazi chifukwa inu mumathangatila munthu yemwe
     wadwalapo matenda akufa kwa ziwalo ndipo adagonekedwapo ndi kulandira chithandizo mu
     china mwa zipatala zikuluzikulu mdziko muno.

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2. Dongosolo la Ndondomekoyi

Alipo wainu amene adachitapo zokambirana pagulu?

Zokambirana ngati izi zikugwiritsidwa ntchito kwambiri masiku ano pofuna kupititsa patsogolo ntchito zothandiza wanthu, nchifukwa chake tili pano lero.

Zokhudza magulu osankhidwa

* Tiphunzira kuchokera kwa inu
* Sikuti tikufuna kuti tonse tikambe mogwirizana, chofunika ndi kupeza zomwe zimachitika
* Muntchitoyi, tikuchita zokambirana mmagulu kuti tipeze zenizeni komanso tione nfundo zomwe sizingatheke kugwiritsa ntchito kafukufuku wolemba.
* Zokambiranazi tizijambula ndi chojambulira mawu ndicholinga chakuti zomwe tikambirane tizisunge.

Zofunika

* Zokambirana zikhala za ola limodzi
* Ndinu omasuka kumasuntha mwakachetechete
* Malo odzithandizira alipo (alozedwa)
* Zakumwa zoziritsa kukhosi zilipo

3. Malamulo

(Okambirana akonze malamulo okha) Kuphatikizapo izi:

* Aliyense atenge nawo mbali pazokambirana
* Zokambidwa pano zikhale zachinsinsi
* Musachoke kapena kumakamba nkhani zina zokambirana zili mkati
* Matelefoni ammanja azimitsidwe ngati ndikotheka kutero.

4. (Kuyatsa chojambulira mau)
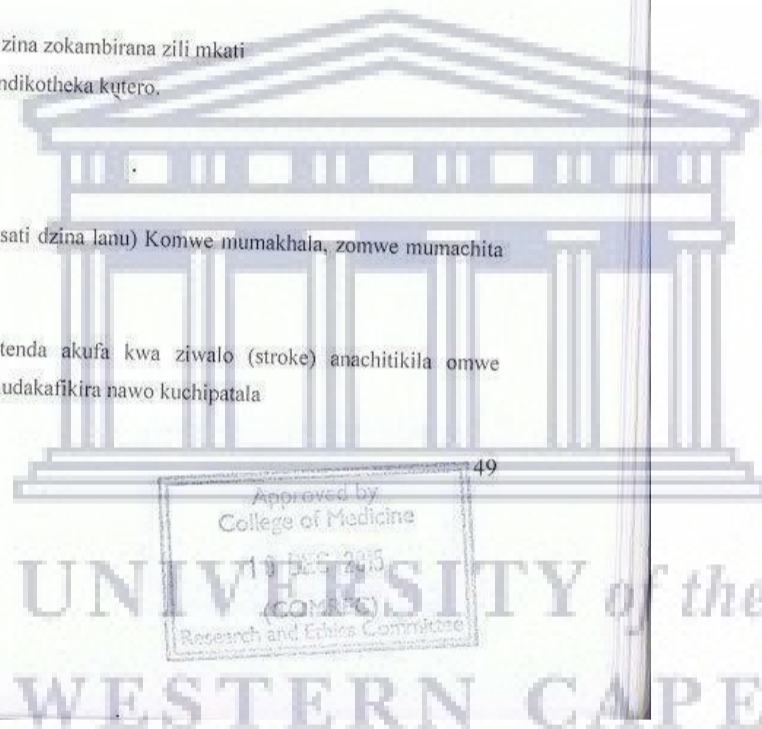
5. Alipo ali ndi funso tisadayambe?

6. Kudziwana

Mwachidule tiuzeni kuti ndinu ndani (osati dzina lanu) Komwe mumakhala, zomwe mumachita (aliyense afotokoze yekha)

7. Mafunso

1. Tiyambe ndikufotokoza momwe matenda akufa kwa ziwalo (stroke) anachitikila omwe mukuwathangatila panowo ndi mmene mudakafikira nawo kuchipatala

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2. Fotokozani mmene zinayendera mutafika kuchipatala (Mutangofika, atawagonekani mpaka kuwatulusa)

3. Mmene munaonera, nchani chidayenda bwino? Ndithandizo lanji lomwe mudakhutira nalo mmene munali mchipatala?

4. Mmene munaonera ndi chani chomwe sichidayende bwino chokhudzana ndi thandizo limene mudalandira muli mchipatala?

5. Momwe munaonera mukuganiza kuti zoyenera kuchitika ndi chani kuti odwala ndi owathangatila azikhutira ndi thandizo lomwe amalandira kuchipatala?

6. Pali zowonjezera? (munthu aliyense apatsidwe mpata)

Nthambi/zikumbuso za zokambiranazi

- *Kutumizidwa kuchipatala chachikulu*
- *Kungozi*
- *Kufufuza za matenda*
- *Thandizo loyambilira ndi lopitiliza*
- *Achipatala omwe adawathandiza*
- *Kuthandiza kuti abwerele mwakale*
- *Maphunziro okhudza matendawa*
- *Ndondomeko yokatsata akatulutsidwa mchipatala*

Apa nde pamapeto pa zokambirana zathu. Zikomo kwambiri chifukwa chakubwera kwanu, komanso kutiuza maganizo anu.

Zimene zinagwitsidwa ntchito pa Zokambiranazi:

- makalata yovomereza kuchita nawo zokambirana
- Ndondomeko yoyendetsera zokambira ya mtsogoleri wazokambirana
- Chipangizo chojambulira mawu
- Makope
- Zakumwa zozilitsa kukhosi

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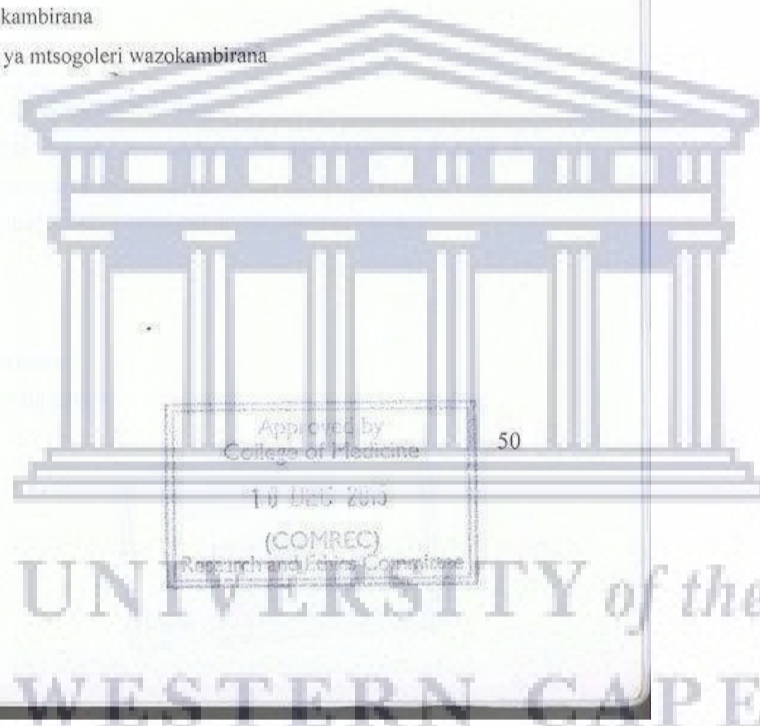
v.   **Focus Group Discussion Guide regarding stroke care and rehabilitation in Malawi: Service Providers**

Consent Process

(Consent forms for focus group participants signed and demographic questionnaire filled in advance)

Introduction:

1.   **Welcome**

- I am George Chimatiro, PHD physiotherapy student at University of the Western Cape in South Africa, and principle investigator in this study. My colleagues are research assistants (names) who will help with all the processes regarding our meeting today.
- We are here to discuss us a group about your experiences with stoke care and rehabilitation service delivery in the hospital
- It is hoped that the information that we will gather here will assist in producing a new way of caring for patient with stroke in hospitals.
- We asked you to participate because you are one of the team members providing either medical, nursing rehabilitation services to stroke patients at one of the central hospitals in the country

2.   **Explanation of the process**

Has anyone of you participated in any focus groups discussion before?

These group meetings are being used more and more often in health in a quest to improve service delivery and that is why we are here today.

About focus groups

- We learn from you (positive and negative)
- Not trying to achieve consensus, we're gathering information
- In this project, we are doing focus group discussions in order to get more in-depth; to helps us explore topics in more detail than we can do in a written survey.
- We will record our discussion in order that were are reminded of our conversations later.

Logistics

- Focus group will last about one hour
- Feel free to move around, but minimize noise
- Toilets available should you need (show direction)

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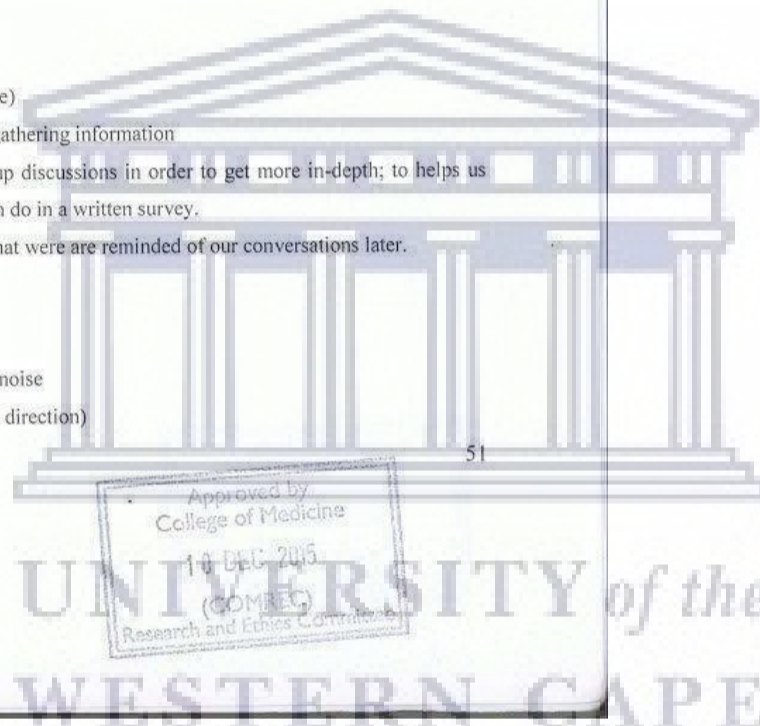
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- Help yourself to refreshments
3. Ground Rules

(Participants suggest rules to be followed) and we highlight the following:

- Everyone should participate.
- Information provided in the focus group must be kept confidential
- Stay with the group and please don't have side conversations
- Turn off cell phones if possible
4. **(Turning on Tape Recorder)**
5. Any questions before we get started?
6. **Introductions**
- Briefly tell us who you are professionally and which department of section of the hospital you work in (go round)

7 **Questions:**

1. Lets start by explaining the processes that stroke patient undergo during their hospital stay (from admission to discharge)
2. Specifically what do you do when stroke patient is referred to you section
3. In your opinion what works well regarding care/rehabilitation service delivery in your section?
4. In you view what are the challenges regarding service delivers in your section?
5. From your experience what should be done to service delivery in respective sections
6. Any additional information (turn for each participant)?

Probes for Discussion:

- *Referral*
- *casualty department*
- *short stay*
- *investigations done*
- *medical wards*
- *initial and ongoing treatment*
- *inter-professional team*
- *education about condition*
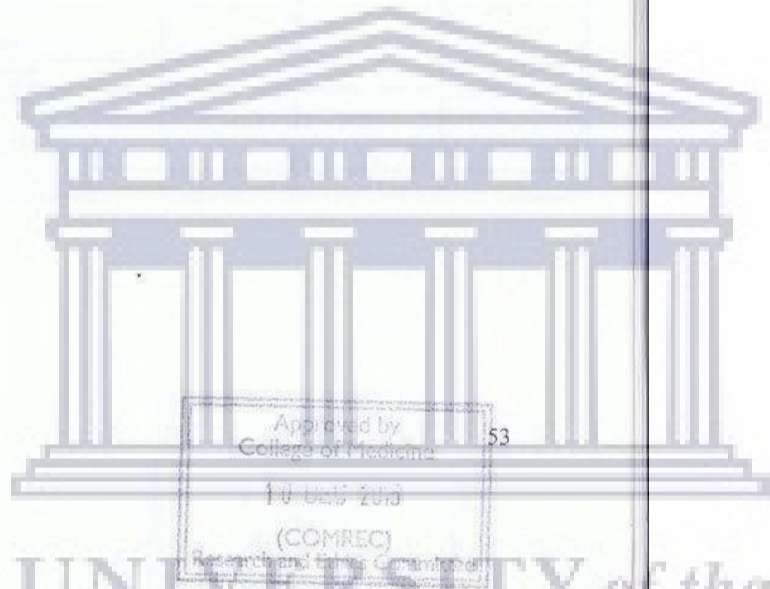- *discharge planning*

Version 2: 19/11/2015

That concludes our focus group. Thank you so much for coming and sharing your thoughts and opinions with us.

Materials and supplies for focus groups

- Consent forms
- Focus Group Discussion Guide for Facilitator
- 1 recording device
- Notebook for note-taking
- Refreshments

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Appendix 11: Data collection Instruments

   a)   Functional independence Measure

13.0   Appendex 10

Data collection instruments

i.   Functional Independence Measure-English

APPENDIX D
Functional Independence Measure (FIM) Instrument

	ADMISSION	DISCHARGE	FOLLOW-UP
Self-Care			
A. Eating			
B. Grooming			
C. Bathing			
D. Dressing - Upper Body			
E. Dressing - Lower Body			
F. Toileting			
Sphincter Control			
G. Bladder Management			
H. Bowel Management			
Transfers			
I. Bed, Chair, Wheelchair			
J. Toilet			
K. Tub, Shower			
Locomotion			
L. Walk/Wheelchair			
M. Stairs			
Motor Subtotal Score			
Communication			
N. Comprehension			
O. Expression			
Social Cognition			
P. Social Interaction			
Q. Problem Solving			
R. Memory			
Cognitive Subtotal Score			
TOTAL FIM Score			

Version 2: 19/11/2015

Approved by
College of Medicine
1 0 DEC 2015
(COMREC)
Research and Ethics Committee

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Functional Independence Measure (FIM) Instrument: Chichewa

	ADMISSION	DISCHARGE	FOLLOW-UP
Self-care			
A. Kudya			
B. Kudzola mafuta			
C. Kusamba			
D. Kuvala malaya			
E. Kuvala kabudula			
F. Kuzithandiza kuchimbudzi			
Sphicnter control		.	
G. Kusadziwonongera ndi mikozo			
H. Kusadziwongera ndi chimbudzi			
Transfers			
I. kama/bedi/ mpando, mpando woyenda ndi matayala			
J. Chimbudzi			
K. Beseni losambira, shawa yosambira			
Locomotion			
L. kuyenda, kuyenda ndi mpando wamateyala			
M. Masitepe			
MOTOR SUBTOTAL SCORE			
Communication			
N. kumva			
O. Kuyankhula momveka ndi momasulira bwino			
Social Cognition			
P. Kuyankhula ndi anthu			
R. Kukumbukira zinthu			
COGNITIVE SUBTOTAL SCORE			
TOTAL FIM Score			

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	Independent	NO
	7. Kuzidalira (Timely, Safely)	**HELPER**
	6. Kuzidalira pogwiritsa zinthu zina (Device)	
L		
E	**Modified Dependence**	
V	5. Kuyang'anira (Subject = 100%+)	
E	4. Kulandira chithandizo chochepa kwambiri (Subject = 75% +)	**HELPER**
L	3. Kukandira chithandizo chapang'ono (Subject =50% +)	
S	**Complete independence**	
	2. kulandira chithandizo chachikulu (Subject = 25% +)	
	1. Kulandira chithandizo chachikulu kwambiri (Subject less than 25%)	
	Note: Leave no blanks. Enter 1 if patient is not testable due to risk	

FIM instrument copyright @ 1997 Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, inc. Reprinted with the permission of UMSDR, University at Buffalo. 232 parker Hall, 3435 Main St, Buffalo, NY 14214

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b) SASC Hospital scale

ii.   Patients' satisfaction with inpatient stroke care (SASC hospital scale): English

Demographics:

Patient: gender: M/F   Age: Date of onset of stroke: DOA:

DOD: discharged to:

Instruction: From the statements below please indicate your level of agreement or disagreement (refer to key at the bottom of this form)	0	1	2	3	4
1. I have been treated with kindness and respect by the staff at the hospital.					
2. The staff attended well to my personal needs while I was in hospital (for example, I was able to get to the toilet whenever I needed).					
3. I was able to talk to the staff about any problems I might have had.					
4. I have received all the information I want about the causes and nature of my illness.					
5. The doctors have done everything they can to make me well again.					
6. I am happy with the amount of recovery I have made.					
7. I am satisfied with the type of treatment the therapists have given me (e.g., physiotherapy, speech therapy, occupational therapy).					
8. I have had enough therapy (e.g., physiotherapy, speech therapy, occupational therapy).					

Key: 0 = strongly disagree; 1= disagree; 2= undecided; 3= agree; 4= strongly agree strongly agree)

  ➤ higher total scores indicate greater satisfaction

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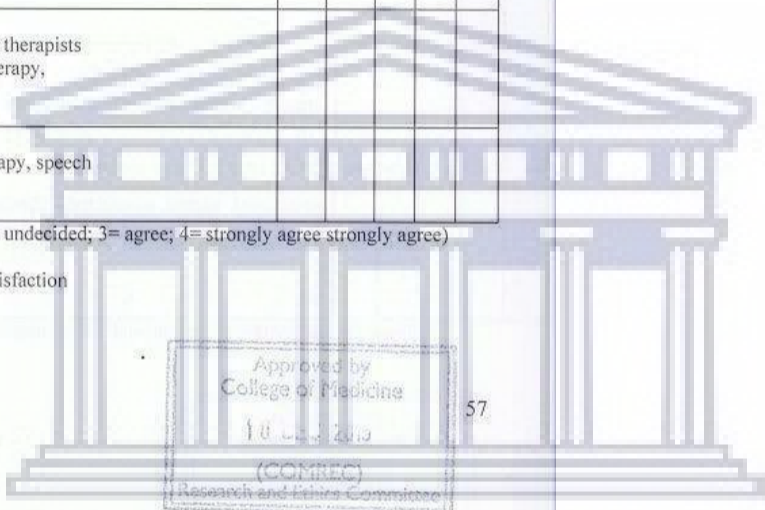
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Patients' satisfaction with inpatient stroke care (SASC hospital scale)-Chichewa

Demographics:

Patient: gender: M/F   Age: date of onset of stroke: DOA:

DOD: discharged to:

Zoyenela kuchita: wonesani ngati mukuvomereza kapena ayi pa ziganizo zotsatirazi, pogwiritsa ntchito mlozo womwe pansi pa folomu iyi	0	1	2	3	4
1.Anthu ogwira ntchito kuchipatala anandithandiza bwino mwaulemu.					
2. Ogwira ntchito kuchipatala anandithandiza pa zovuta zina ndi zina monga kundithandiza kupita kuchimbudzi.					
3. Ndimatha kulankhula ndi ogwira nchito pa zovuta zanga zimene ndinali nazo.					
4. Ndinauzidwa zonse zofunikira zokhudzana ndi matenda anga mpaka chimene chinayambitsa matendawa.					
5. Madokotala anayesetsa kundithandiza kuti ndipeze bwino.					
6. Ndiri okhutitsidwa ndi chithandizo chamachilitso amene ndalandira.					
7. ndiri okhutitsidwa ndi chithandizo cha othandiza odwala chimene anandipatsa monga mafizo (kuphunzira kugwiritsa ntchito ziwalo zanga), kundithandiza kuphunziranso kulankhula ndi zina zotero.					
8. Ndalandira chithandizo cha kuchiza matenda chokwanira monga kuphunzira kulankhura, kuphunzira kugwiritsa ntchito ziwalo zanga monga manja, miyendo ndi zina zotero.					

Mlozo: **0** = kukanisitsa; **1** = kukana; **2** = sindinaganize; **3** = kuvomereza; **4** = kuvomereza kwambiri

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c) C-SASC Hospital Scale

iii.   Caregivers' satisfaction with inpatient stroke care (C-SASC hospital scale): English

Caregiver: age: Gender: M/F

Relationship to patient:

Instruction: From the statements below please indicate your level of agreement or disagreement (refer to key at the bottom of this form)	0	1	2	3	4
1. I have been treated with kindness and respect by the staff at the hospital.					
2. The staff attended to my personal needs while I was in hospital and tried to support me as much as possible.					
3. I was able to talk to the staff about any problems I might have had.					
4. I received all the information I wanted about the causes and nature of the illness of the patient I take care of.					
5. The doctors did everything they could to make the patient I take care of well again.					
6. I am happy with the amount of recovery the patient I take care of has made.					
7. I am satisfied with the type of treatment the therapists have given the patient I take care of (e.g., physiotherapy, speech therapy, occupational therapy).					
8. The patient I take care of has had sufficient therapy (e.g., physiotherapy, speech therapy, occupational therapy).					
9. The patient I take care of has been treated with kindness and respect by the staff at the hospital.					
10. The hospitalization process went smoothly.					
11. I received all the information I wanted to about recovery and rehabilitation after a stroke.					

Key: 0 = strongly disagree; 1= disagree; 2= undecided; 3= agree; 4= strongly agree strongly agree

➤ higher total scores indicate greater satisfaction

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Caregivers' satisfaction with inpatient stroke care (C-SASC hospital scale)-Chichewa

Caregiver: Age: Gender: M/F

Relationship to patient:

Zoyenela kuchita: wonesani ngati mukuvomereza kapena ayi pa ziganizo zotsatirazi, pogwiritsa ntchito mlozo womwe pansi pa folomu iyi	0	1	2	3	4
1. Ndinasamalidwa mokoma mtima ndi mwaulemu ndi ogwira ntchito ku chipatala.					
2. Ogwira ntchito kuchipatala anandithandiza pa zovuta zina ndi zina ndimakumana nazo.					
3. Ndimatha kulankhula ndi ogwira ntchito pa zovuta zanga zimene ndinali nazo.					
4. Ndinauzidwa zonse zofunikira zokhuzana ndi matenda mpaka chimene chinayambitsa matendawa pa wodwala amene ndimamuyang'anira.					
5. Madokotala anayesetsa kuthandiza odwala amene ndimamuwayang'anira kuti apeze bwino.					
6. Ndiri okhutitsidwa ndi kupezako bwino kwa odwala amene ndimawayang'anira.					
7. Ndiri okhutitsidwa ndi chithandizo cha othandiza odwala chimene chaperekedwa kwa wodwala amene ndimamuyang'anira monga mafizo (kuphunzira kugwiritsa ntchito ziwalo zanga), kundithandiza kuphunziranso kulankhula ndi zina zotero.					
8. Wodwala amene ndimamuyang'anira analandira chithandizo chokwanira.					
9. Wodwala amene ndimamuyang'anira analandira ndiponso anathandizidwa mwaulemu ndi mwachikondi ndi ogwira ntchito kuchipatala.					
10. Kugonekedwa kao kuchipatala kunayenda bwino.					
11. Ndinalandira malangizo onse ofunikira pa machiritso ndi kasamalidwe ka munthu amene anadwala matenda ofa ziwalo.					

Mlozo: 0 = kukanisitsa; 1 = kukana; 2 = sindinaganize; 3 = kuvomera; 4 = kuvomera kwambiri

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d) EQ-5D-5L

iv.   Health Questionnaire

English version for South Africa

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

I have no problems in walking about ☐

I have slight problems in walking about ☐

I have moderate problems in walking about ☐

I have severe problems in walking about ☐

I am unable to walk about ☐

SELF-CARE

I have no problems washing or dressing myself ☐

I have slight problems washing or dressing myself ☐

I have moderate problems washing or dressing myself ☐

I have severe problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐

I have slight problems doing my usual activities ☐

I have moderate problems doing my usual activities ☐

I have severe problems doing my usual activities ☐

I am unable to do my usual activities ☐

PAIN / DISCOMFORT

I have no pain or discomfort ☐

I have slight pain or discomfort ☐

I have moderate pain or discomfort ☐

I have severe pain or discomfort ☐

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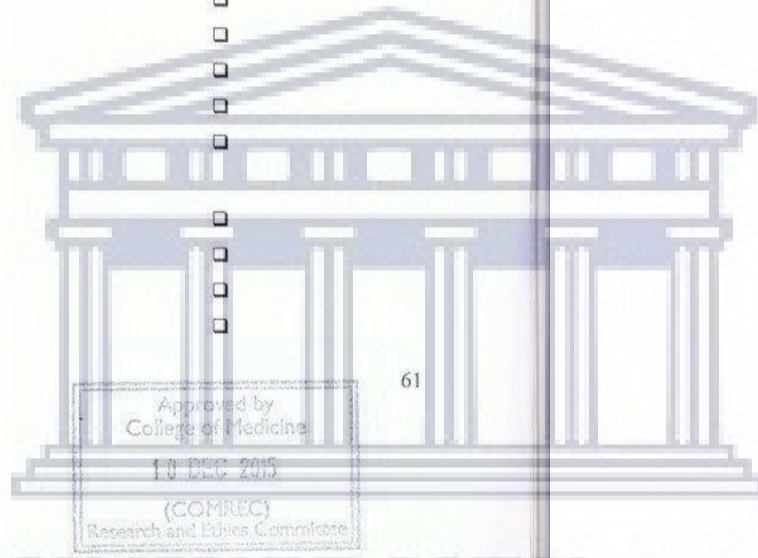
I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION
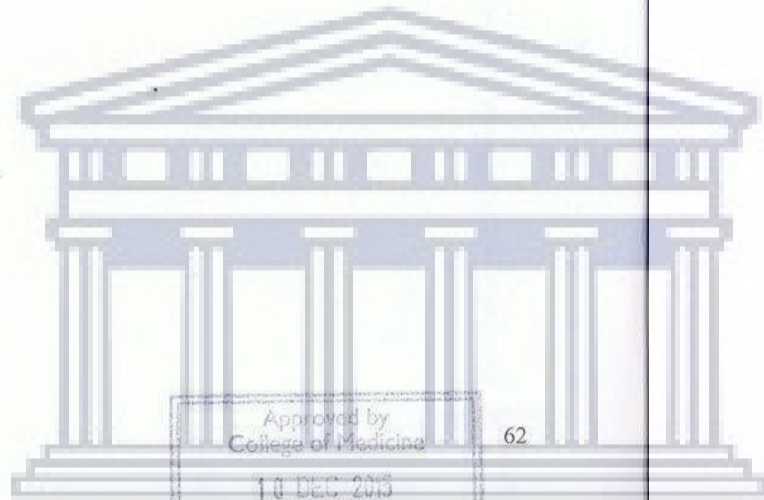
I am not anxious or depressed ☐

I am slightly anxious or depressed ☐

I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

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- We would like to know how good or bad your health is TODAY.

- This scale is numbered from 0 to 100.

- 100 means the <u>best</u> health you can imagine.
  0 means the <u>worst</u> health you can imagine.

- Mark an X on the scale to indicate how your health is TODAY.

- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health
you can imagine

100
95
90
85
80
75
70
65
60
55
50
45
40
35
30
25
20
15
10
5
0
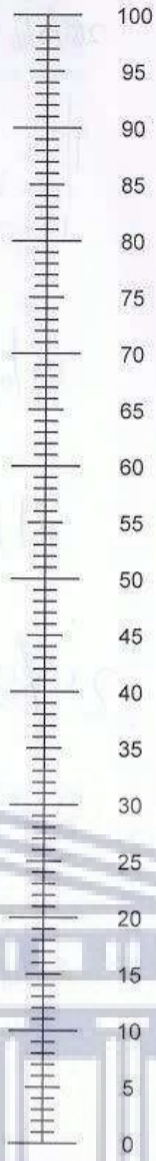
The worst health
you can imagine

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EQ-5D-5L

Pa mutu wina uli wonse, chonde chongani bokosi limodzi lokha lomwe likufotokoza za momwe umoyo wanu ulili LERO.

KUYENDA/KAYENDEDWE

Sindimavutika kuyenda ☐

Ndimavutika pang'ono kuyenda ☐

Ndimavutika ndithu kuyenda ☐

Ndimavutika kwambiri kuyenda ☐

Sindimatha kuyenda ☐

KUZITSAMALIRA

Sindimavutika kusamba kapena kuvala ndekha ☐

Ndimavutika pang'ono kuti ndi sambe kapena ndi vale ndekha · ☐

Ndimavutika ndithu kuti ndi sambe kapena ndi vale ndekha ☐

Ndimavuka kwambiri kuti ndi sambe kapena ndi vale ndekha ☐

Sindimatha kusamba kapena kuvala ndekha ☐

NTCHITO/ZOCHITA ZINA ZA TSIKU NDI TSIKU (e.g. kugwira ntchito, kuwerenga, ntchito zapakhomo, zochitika zokhuza banja kapena zanthawi yongokhala)

Sindimavutika kugwira ntchito kapena kuchita zinthu zina za tsiku ndi tsiku ☐

Ndimavutika pang'ono kugwira ntchito kapena kuchita zinthu zina za tsiku ndi tsiku ☐

Ndimavutika ndithu kugwira ntchito kapena kuchita zinthu zina za tsiku ndi tsiku ☐

Ndimavutika kwambiri kugwira ntchito kapena kuchita zinthu zina za tsiku ndi tsiku ☐

Sindimatha kugwira ntchito kapena kuchita zinthu zina za tsiku ndi tsiku ☐

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ULULU/KUSOWA MTENDERE

|	
Sindimamva ululu/kuwawa kapena kusowa mtendere	☐
Ndimamva ululu/kuwawa kapena kusowa mtendere pang'ono	☐
Ndimamva ululu/kuwawa kapena kusowa mtendere ndithu	☐
Ndimamva ululu/kuwawa kapena kusowa mtendere kwambiri	☐
Ndimamva ululu/kuwawa kapena kusowa mtendere kwambiri zedi	☐

MANTHA/KUDANDAULA/NKHAWA/KUKHUMUDWA

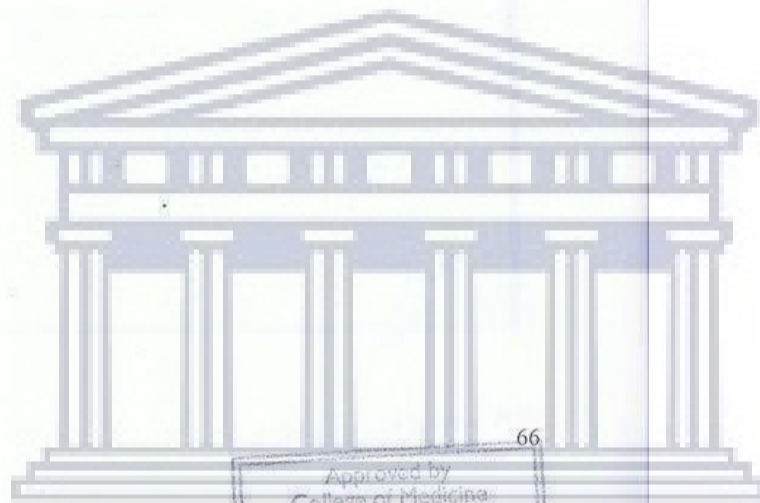|	
Ndilibe mantha/nkhawa kapena sindikudandaula kapena sindinakhumudwe	☐
Ndili ndi mantha/nkhawa kapena ndikudandaula kapenda ndakhumudwa pang'ono	☐
Ndili ndi mantha/nkhawa kapena ndikudandaula kapenda ndakhumudwa ndithu	☐
Ndili ndi mantha/nkhawa kapena ndikudandaula kapenda ndakhumudwa kwambiri	☐
Ndili ndi mantha/nkhawa kapena ndikudandaula kapenda ndakhumudwa kwambiri zedi	☐

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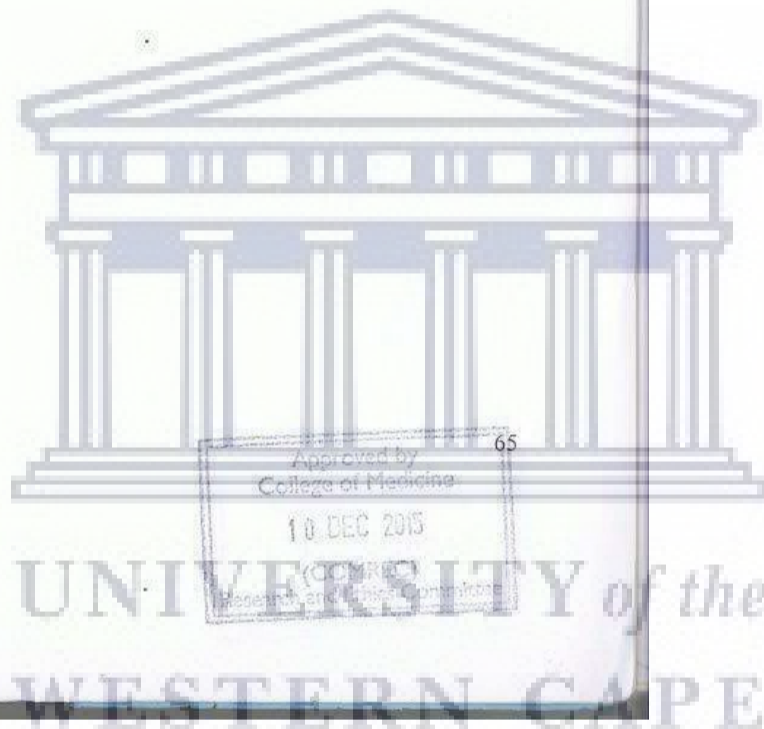
- Tikufuna kuziwa kuti umoyo wanu uli bwino kapena wayipa motani LERO.
- Sikelo iyi yalembedwa 0 mpaka 100.
- 100 akutanthauza umoyo wabwino kwambiri womwe mungawuganizire.
  0 akutanthauza umoyo woyipitsitsa (wodwaladwala) kwambiri womwe mungawuganizire.
- Lembani X pa sikelo kuwonetsa momwe umoyo wanu wulili LERO.
- Tsopano lembani nambala yomwe mwalembapo X pasikelo mu bokosi lomwe lili munsili.
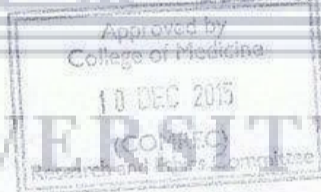
UMOYO WANU LERO =

For the top of the scale = Umoyo wabwino kwambiri womwe mungawuganizire

For the bottom of the scale = Umoyo woyipitsitsa (wodwaladwala) kwambiri womwe mungawuganizire

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e) MPOC-A

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Stroke Process of Care Questionnaire for Service Providers

Instructions

1. This questionnaire has four sections: the first captures demographic data; the second one has questions about inter-professional stroke care; the third part centers on referral system while the fourth part is on the process of care followed when managing patients with stroke.

2. We would like you to describe your 'actual' practice, rather than what you feel would be 'ideal' service. Please be assured that your confidential responses will not be viewed as a judgment of you or how you provide services.

3. Please recognize that just because the practice or behavior is addressed by this measure it DOES NOT mean that it is necessarily an important action or behavior for all professions or to all professionals. Thus, do not feel that selecting a low number is equivalent to giving yourself a poor evaluation.

4. We would like you to think about your experiences as a medical, nursing, or rehab practitioner (e.g. physiotherapist, occupational therapist, rehabilitation technician) for patients with stroke in the hospital setting, or a service provider over the past year. As we are interested in your personal thoughts and practice; we would appreciate your completing this questionnaire on your own without discussing it with anyone else.
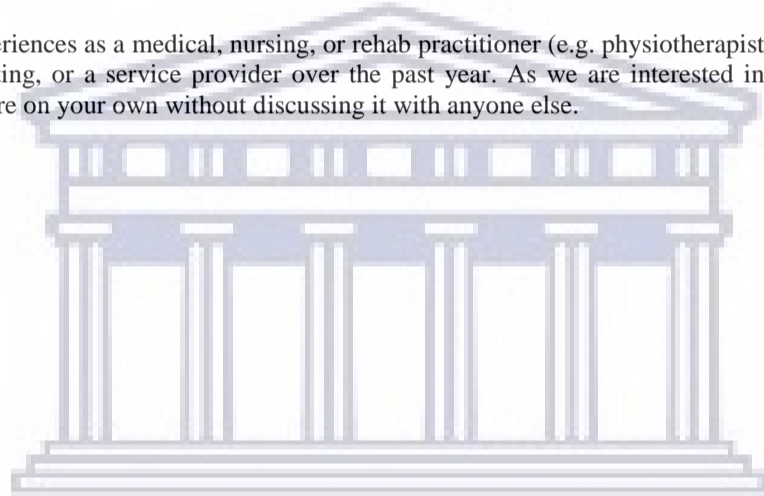
11.0   Section 1: Demographics

11.1 What is your age? ………………………years

11.2 What is your sex?   (circle or tick appropriate answer

1. Male	2. Female	3. Prefer not to state	4. Other

11.3 What is the highest level of education you have attained?

1.certificate	1. diploma	2. Bachelor's degree	3. Master's degree	4. Doctoral degree	5. Other Specify:………………

11.4 How long have you provided care to patients with stroke?

1. ≤ 1 year	2. 1-5 years	3. 5-10 years	4. 10-15years	5. 15-20 years	6. > 20 years

11.5 Circle the professional description that best describes your role in stroke patient care at the moment:

1. Physiotherapist	2. Occupational therapist	3. Speech and language therapist	4. Dietician	5. Psychologist
6. Nurse	7. Medical doctor	8. Specialist Specify………….	9. Other Specify…………..	

12.0   Section 2: Inter-professional Stroke Care

12.0 How would you describe the general care of patients with stroke in the hospital?

1 Excellent	2 Very good	3 Good	4 Poor	5 Very poor

2.2 Do you have meetings to discuss the care of patients with stroke?

1. Yes (if yes, answer next question)	2. No (if no please skip questions 2.3, 2.4, 2.5 and 2.6)

.2.3 What form of team interaction do you have? (You can choose more than one option)

1. Ward rounds	2. Team meetings	3. Case conferences	4. Family meetings	5. Other:(Specify)…………… 6. ……

2.4 What type of team interactions do you have?

1. Multidisciplinary (where persons from several disciplines are involved in the delivery of services, each working within their branch of knowledge).	2. Interdisciplinary (whereby not only are individuals from several disciplines, but the team members have the additional responsibility of the group effort i.e. relating to more than one branch of knowledge)	3. Trans-disciplinary (whereby individuals integrate and move beyond discipline-specific approaches to address a common problem.	4. Other (specify):

.2.5 How often do you have these team meetings?

1. Once a week	2. More than once a week	3. At least once a month	4. Approximately once a year

2.6 Are the meetings regular or as needed?

1. Regular	2. A) As needed B) Who initiates the meeting when needed? ………………………………………..

2. 7 How would you rate your contacts with professionals of other fields regarding stroke care?

1. Excellent	2. Very satisfactory	3. Satisfactory	4. Unsatisfactory	5. Very unsatisfactory

2.8 Would you be able to rely on colleagues of other professional background within the medical field to partner with you in the care of patients with stroke?

1. Yes	2. No

13.0 (From question number 1.2.09 to 1.3.10 you can indicate several options that are in the first column by writing 1 for "always", 2 for "sometimes" and 3 for "not at all" for chosen option in the second column)

13.0 Who would you professionally work with in the care of patients with stroke? (Indicate healthcare providers as available in this hospital):

Professional	Always (1) sometimes (2), not at all (3)
Physiotherapist	
Occupational Therapist	
Speech and Language therapist	
Dietician	
Psychologist	
Nurse	
Medical Doctor	
Traditional healer	
Other specify	

(From questions under referral, you can indicate several options that are in the first column by writing 1 for "always", 2 for "sometimes" and 3 for "not at all" for chosen option)
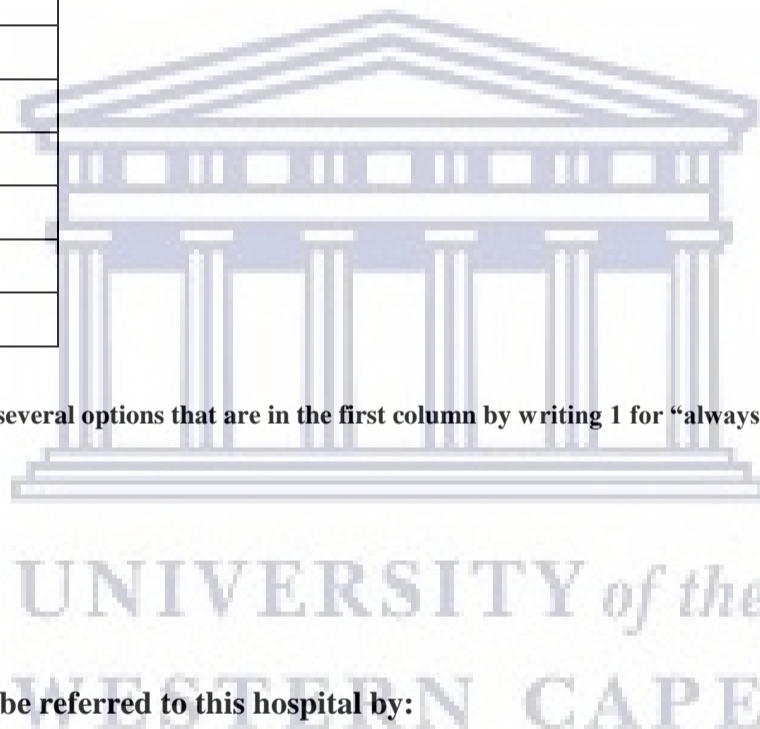
13.1 Referral

13.1.1 Referral Institution

13.1.1.1 Patients with stroke are likely to be referred to this hospital by:

Institution	Frequency: Always (1) sometimes (2), not at all (3)
Health centre/clinic	
District hospital	
Rehabilitation center	
Traditional healers	
Family	
Community-based organizations	
Other specify:	

13.1.1.2 Patients with stroke are likely to be referred from this hospital to:

Institution	Always (1) sometimes (2), not at all (3)
Health centre/clinic	
District hospital	
Rehabilitation center	
Traditional healers	

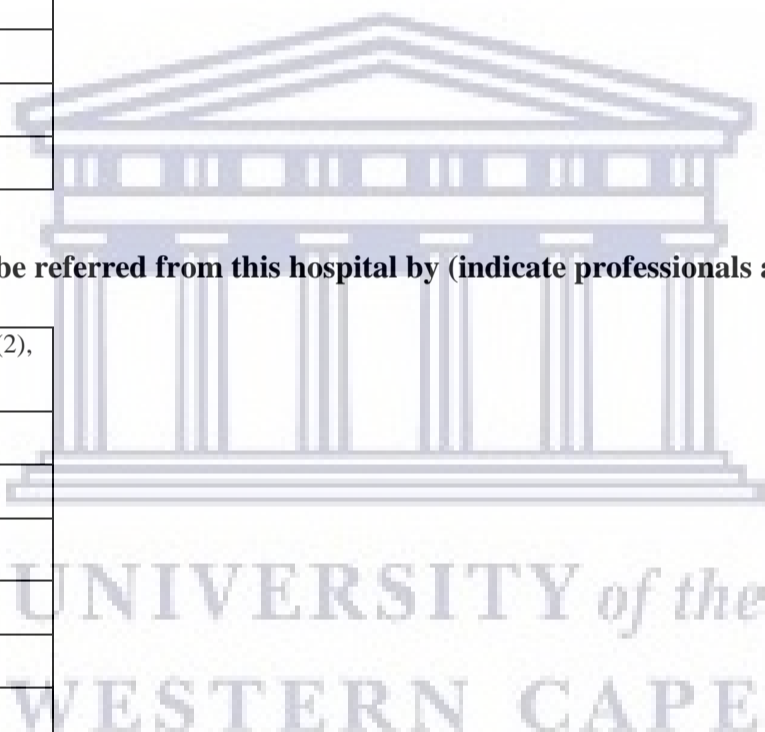| Home/Family of patient	
Community-based organizations	
Other specify	

13.1.2 Referring Healthcare Provider

13.1.2.1 Patients with stroke are likely to be referred to this hospital by (indicate healthcare providers as available in this hospital):

Healthcare Provider	Frequency: Always (1) sometimes (2), not at all (3)
Physiotherapist	
Occupational Therapist	
Speech and Language therapist	
Dietician	
Psychologist	
Nurse	
Medical Doctor	
Specialist Specify:	
Other specify	

13.1.2.2 Patients with stroke are likely to be referred from this hospital by (indicate professionals as available in this hospital):

Healthcare Provider	Always (1) sometimes (2), not at all (3)
Physiotherapist	
Occupational Therapist	
Speech and Language therapist	
Dietician	
Psychologist	
Nurse	
Medical Doctor	
Specialist Specify:	
Other specify	

14.0   Care Process

NOTE: From questions under care process, if you indicate your options using (1) for "always" and (2) for "sometimes" in column 2, please proceed to third column and indicate your option using representative numbers in brackets. If you answer (3) for "not at all" in column 2, please skip third column

14.0 Neurological assessment done by: (indicate healthcare providers as available in this hospital):

Healthcare provider	Frequency Always (1) sometimes (2), not at all (3)	Place where neurological assessment is done: Emergency department & Short stay (1), Medical ward (2), Physiotherapy department (3). Occupational therapy department (4)
Physiotherapist		

Occupational Therapist		
Speech and Language therapist		
Dietician		
Psychologist		
Nurse		
Medical Doctor		
Specialist Specify:		
Other specify		

14.1 Swallowing screening/evaluation done by: (indicate healthcare providers as available in this hospital):

Healthcare provider	Frequency: Always (1) sometimes (2), not at all (3)	Place where Swallowing screening/evaluation is done: Emergency department & Short stay (1), Medical ward (2), Physiotherapy department (3), Occupational therapy department (4)
Physiotherapist		
Occupational Therapist		
Speech and Language therapist		
Dietician		
Psychologist		
Nurse		
Medical Doctor		
Specialist Specify:		
Other specify		

14.2 DVT Prevention/prophylaxis done by: (indicate healthcare providers as available in this hospital):

Healthcare provider	Frequency: Always (1) sometimes (2), not at all (3)	Place of care process where DVT prevention/prophylaxis is done: Emergency department & Short stay (1), Medical ward (2), Physiotherapy department (3), Occupational therapy department (4)
Physiotherapist		
Occupational Therapist		
Speech and Language therapist		
Dietician		
Psychologist		
Nurse		
Medical Doctor		
Specialist Specify:		
Other specify		

14.3 Regulation of temperature/fever management done by: (indicate healthcare providers as available in this hospital):

Healthcare Provider	Frequency: Always (1) sometimes (2), not at all (3)	Place where regulation of temperature/fever management is done: Emergency department & Short stay (1), Medical ward (2), Physiotherapy department (3), Occupational therapy department (4)
Physiotherapist		

Occupational Therapist		
Speech and Language therapist		
Dietician		
Psychologist		
Nurse		
Medical Doctor		
Specialist Specify:		
Other specify		

14.4 Hypoxia Management done by: (indicate healthcare providers as available in this hospital):

Healthcare Provider	Frequency: Always (1) sometimes (2), not at all (3)	Place where Hypoxia Management is done: Emergency department & Short stay (1), Medical ward (2), Physiotherapy department (3), Occupational therapy department (4)
Physiotherapist		
Occupational Therapist		
Speech and Language therapist		
Dietician		
Psychologist		
Nurse		
Medical Doctor		
Specialist Specify:		
Other specify		

14.5 Management of stroke risk factors

14.5.1 Blood Pressure managed by: (indicate healthcare providers as available in this hospital):

Healthcare Provider	Frequency Always (1) sometimes (2), not at all (3)	Place where management of high blood pressure is done: Emergency department & Short stay (1), Medical ward (2), Physiotherapy department (3), Occupational therapy department (4)
Physiotherapist		
Occupational Therapist		
Speech and Language therapist		
Dietician		
Psychologist		
Nurse		
Medical Doctor		
Specialist Specify:		
Other specify		

14.5.2 Diabetes managed by: (indicate healthcare providers as available in this hospital):

Healthcare Provider	Frequency Always (1) sometimes (2), not at all (3)	Place where diabetes management is done: Emergency department & Short stay (1), Medical ward (2), Physiotherapy department (3), Occupational therapy department (4)
Physiotherapist		
Occupational Therapist		
Speech and Language therapist		
Dietician		
Psychologist		
Nurse		
Medical Doctor		
Specialist Specify:		
Other specify		

14.5.3 Cholesterol managed by: (indicate healthcare providers as available in this hospital):

Healthcare Provider	Frequency Always (1) sometimes (2), not at all (3)	Place where Cholesterol management is done: Emergency department & Short stay (1), Medical ward (2), Physiotherapy department (3), Occupational therapy department (4)
Physiotherapist		
Occupational Therapist		
Speech and Language therapist		
Dietician		
Psychologist		
Nurse		
Medical Doctor		
Specialist Specify:		
Other specify		

14.6 Early mobilization (e.g. sitting, transfers, walking) done by: (indicate healthcare providers as available in this hospital):

Healthcare Provider	Frequency: Always (1) sometimes (2), not at all (3)	Place where early mobilization is done: Emergency department & Short stay (1), Medical ward (2), Physiotherapy department (3), Occupational therapy department (4)
Physiotherapist		
Occupational Therapist		
Speech and Language therapist		
Dietician		
Psychologist		
Nurse		
Medical Doctor		
Specialist Specify:		
Other specify		

14.7 Activities of daily living training (e.g. feeding, dressing, bathing, grooming, toileting) done by: (indicate healthcare providers as available

in this hospital):

Healthcare Provider	Frequency: Always (1) sometimes (2),	Place where activities of daily living training is done: Emergency department & Short stay (1),

Healthcare Provider		Frequency: Always (1) sometimes (2), not at all (3)	Place where [...]: Emergency department & Short stay (1), Medical ward (2), Physiotherapy department (3), Occupational therapy department (4)
		not at all (3)	Medical ward (2), Physiotherapy department (3), Occupational therapy department (4)
Physiotherapist			
Occupational Therapist			
Speech and Language therapist			
Dietician			
Psychologist			
Nurse			
Medical Doctor			
Specialist Specify:			
Other specify			

14.8 Prevention of complications due to immobility (e.g. pressure sores, contractures, urinary tract infection) done by: (indicate healthcare providers as available in this hospital):

Healthcare Provider	Frequency: Always (1) sometimes (2), not at all (3)	Place where prevention of complications due to immobility among stroke patients is done: Emergency department & Short stay (1), Medical ward (2), Physiotherapy department (3), Occupational therapy department (4)
Physiotherapist		
Occupational Therapist		
Speech and Language therapist		
Dietician		
Psychologist		
Nurse		
Medical Doctor		
Specialist Specify:		
Other specify		

14.9 Provision of assistive devices (e.g. hand splints, ankle foot orthotics, and elbow crutches) done by: (indicate healthcare providers as available in this hospital):

Healthcare Provider	Frequency: Always (1) sometimes (2), not at all (3)	Place where provision of assistive devices to patient with stroke is done: Emergency department & Short stay (1) Medical ward (2) Physiotherapy department (3) Occupational therapy department (4)
Physiotherapist		
Occupational Therapist		
Speech and Language therapist		
Dietician		
Psychologist		
Nurse		
Medical Doctor		
Specialist Specify:		
Other specify		

15.0   Are you physiotherapist or occupational therapist or rehabilitation technician?

1. Yes (if yes, answer next question)	2. No (if no skip the next question)

15.0 Therapy provision:

Therapy component	Frequency: Always (1) sometimes (2), not at all (3)	Therapists commonly practicing: Physiotherapist (1), occupational therapist (2), rehabilitation technicians (3) **(you can indicate more than one therapist per therapy component)**	Place where provision of assistive devices to patient with stroke is done: Emergency department & Short stay (1) Medical ward (2) Physiotherapy department (3) Occupational therapy department (4)
Gait re-education			
Transfers			
Exercise: stretching/ strengthening of upper/ lower limbs and trunk			
Balance training			
Activities of daily living			
Sensory, perceptual, and cognitive training			
Positioning			

15.1 On average, how often do you provide therapy to individual patient with stroke?

1. 2 to 4 times a day	2. Once a day	3. 2 to 4 times a week	4. Once a week	5. Never
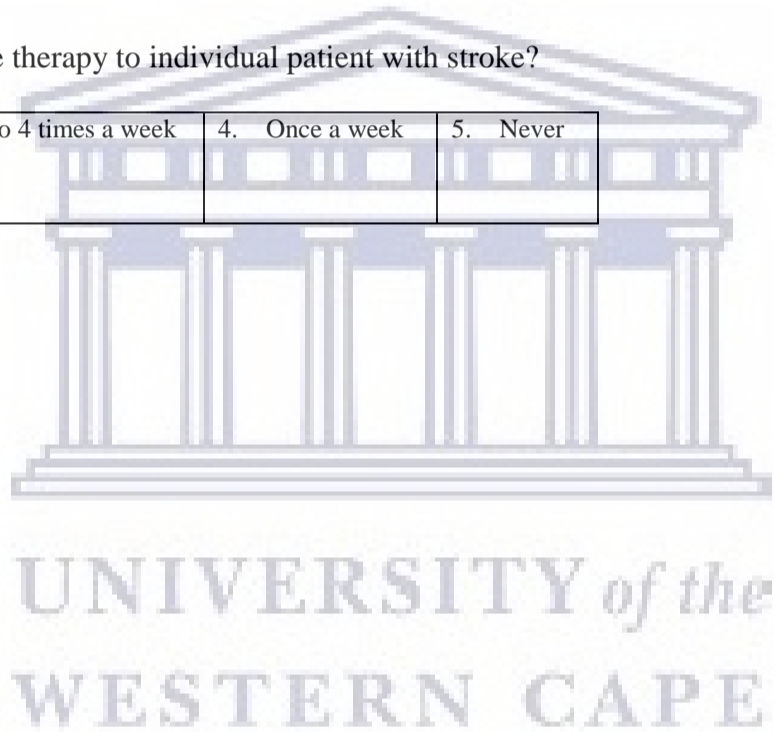
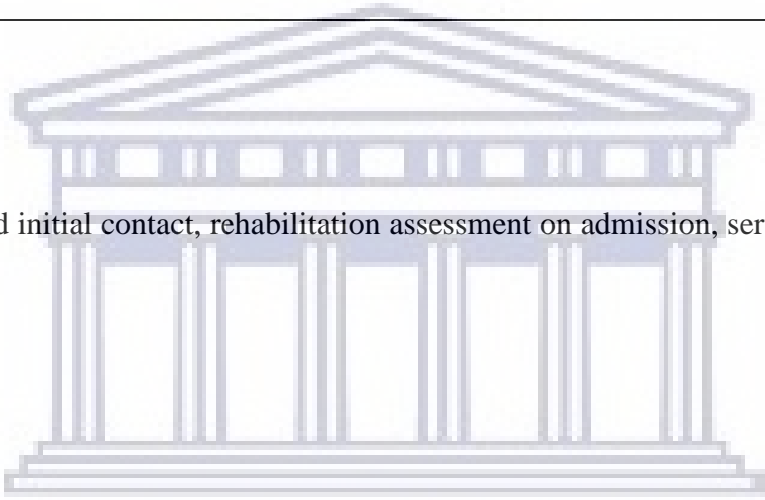**g) Workshop questions sheet for Nominal Group Technique**

Discipline:

Department/ward:

Purpose: To develop a model of care that is engaging to interprofessional team, sensitive to ideals of patient-centered care and with potential to deliver optimal stroke care and rehabilitation outcomes.

Instructions:

1. This is both an individual and group-work meeting.
2. Everyone should participate.
3. With a creative process, please allow every thought to come out, without pre-judging the information.
4. Write freely.
5. Follow the moderator instructions.
6. Stay focused; no side conversations please!
7. Turn off phones and pagers (except for emergencies).

Principles

1. Human centered

2. Empathy for end-users

3. Patients journey (referrals, access and initial contact, rehabilitation assessment on admission, service delivery, and discharge and follow-up)

4. Doing more with fewer resources

5. Multidisciplinary team-work

6. Goal directed intervention

7. Stroke service integration & continuity of care

Recommendations

Stroke care structure

I. Illustrate the ideal stroke care pathway, from emergency care to acute care admission and discharge.

a) How should the care settings for suspected new stroke be "organized" to enhance stroke-specific care and rehabilitation, as to human resources, equipment and medications, information storage and retrieval, services, etc.

b) Emergency unit

i. Human resource:

ii. equipment and medicine

iii. information storage and retrieval

iv. services

c) Ward

i. Human resource:

ii. equipment and medicine

iii.   information storage and retrieval

iv.   services

   d) Physiotherapy department

i.   Human resource:

ii.   equipment and medicine

iii.   information storage and retrieval

iv.   services

II.   What professionals must comprise the multidisciplinary stroke team? How should it run?


III.	In situations of limited stroke specialists in central hospitals, how must the multidisciplinary team be made able to provide effective and efficient stroke-specific care?
IV.	Ideally, what neuroimaging options must be available for stroke care? If not available, what should happen?
V.	What assessment and diagnostic tools should be made available based on your professional background? Why?
VI.	What medications should be available for stroke care within the setting?
VII.	What health care policies facilitate effective stroke care?
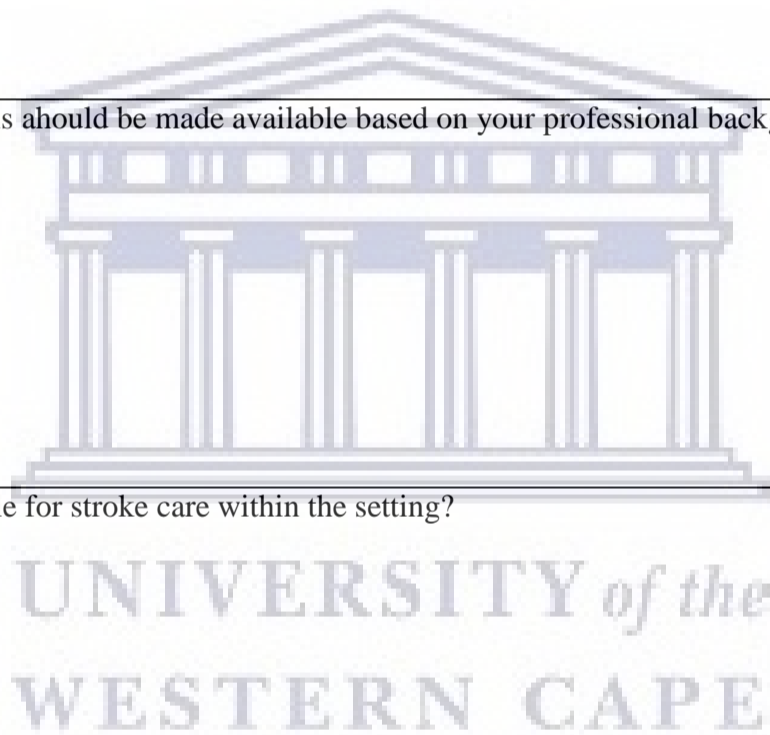
Stroke care process

I. How should I assess and diagnose, based on my professional background, scope of practice, and skills?

II. When must I assess?   How often must I assess?

III. Referral: To whom must I refer and when?   How must I refer?

IV. Intravenous thrombolysis, • What must be an option?   • When administered?   • How much (dosage)

V. Rehabilitation care:

How should I provide it?

How much is needed?

VI.   What are the key prevention strategies, how should they be implemented, and by whom?

Primary

Secondary

Outcomes

VII.   Which of the following outcomes must be used to measure the effectiveness of stroke structure and process? Rate your choices from best to least).

- Quality of stroke care practice
- Functional independence
- Length of Hospital Stay (LOS)
- Mortality
- Discharge home
- Integration into the community
- Institutionalization

Thank you for your input! If you have more ideas, questions, or concerns, please state them at the end of this form or schedule a time to discuss with researcher.

h) NGT Rate sheet

Stroke model of Care: Rate sheet

1)	2)
3)	4)
5)	6)