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Volume 1

Collaborative capacity development to complement stroke rehabilitation in Africa

Edited by
Quinette Louw

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The publisher (AOSIS) endorses the South African 'National Scholarly Book Publishers Forum Best Practice for Peer Review of Scholarly Books'. The manuscript was subjected to rigorous two-step peer review prior to publication, with the identities of the reviewers not revealed to the author(s). The reviewers were independent of the publisher and/or authors in question. The reviewers commented positively on the scholarly merits of the manuscript and recommended that the manuscript be published. Where the reviewers recommended revision and/or improvements to the manuscript, the authors responded adequately to such recommendations.

Research Justification

The purpose of this book series is premised on the growing need to understand and optimise human functioning, often impaired by injury or disease. Estimates from the Global Burden suggest that about 75% of years lived with disability are because of conditions which can be ameliorated by rehabilitation. In Africa, the transitioning in disease burden from communicable disease mortality, to communicable and non-communicable disease morbidity and injury puts the spotlight firmly on the need to increase awareness for the need to enhance human function and develop and implement innovative, evidence-informed strategies to optimise functioning for people living with all levels of disability.

This scholarly book focuses on stroke in Africa. Stroke is a leading cause of disability amongst adults of all ages, contributing significantly to health care costs related to long-term implications, particularly if rehabilitation is sub-optimal. Given the burden of stroke in Africa, there is a need for a book that focuses on the functioning of African stroke survivors and the implications for rehabilitation within the African context. In addition, there is a need to progress with contextualised, person-centred evidence-based guidance for the rehabilitation of people with stroke in Africa, thereby enabling them to lead socially and economically meaningful lives. The research incorporated in the book used a range of primary and secondary methodological approaches (scoping reviews, systematic reviews, meta-analyses, descriptive studies, surveys, health economics and clinical practice guideline methodology) to shed new insights into African-centred issues and strategies to optimise function post-stroke.

A similar e-book series or journal does not exist either in Africa or internationally. The focus on Africa fills an important and unique gap in current offerings. The book series embraces a multidisciplinary approach and meshes technology, health and functioning. The book is intended to be used by scholars including researchers and academics in health sciences. The content of the book includes information generated by postgraduate research candidates (30%), although more than 50% of this content was reworked for inclusion into this book. More than 50% of the book contains original research specifically for inclusion in the book and about 20% of the content is based on substantial reworking of research previously conducted by researchers and academics who authored the book. No material has been reproduced in this book verbatim and if part of any book is used in any form, it has been rephrased or embedded in the discussions in this book, with the due reference provided in each case. Therefore, the book presents content that has not been presented, published or plagiarised from any source(s).

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List of Abbreviations

AAC	Augmentative and Alternative Communication
ABC	Activities-specific Balance Confidence Scale
ABILHAND	Hand Function Ability Stroke Questionnaire
ABILOCO	Locomotion Ability Questionnaire
ACTIVLIM	Activity Limitations Questionnaire
ADLs	Activities of Daily Living
AGREE II	Appraisal of Guidelines Research and Evaluation Version II
AHA	American Heart Association
AIDS	Acquired Immunodeficiency Syndrome
AP	Anteroposterior
ASA	American Society of Anesthesiologists
BBS	Berg Balance Scale
BDI	Beck Depression Inventory
BOS	Base of Support
CBR	Community-based Rehabilitation
CCA	Cross-cultural Adaptation
CCV	Cross-cultural Validation
CES-D	Center for Epidemiologic Studies Depression Scale
CHC	Community Health Centre
CHW	Community Health Worker

CI	Cognitive Impairment
COP	Centre of Pressure
CPD	Continuous Professional Development
CPG	Clinical Practice Guideline
CRT	Cognitive Rehabilitation Therapy
CSIP	Caregiver Support Intervention Programme
CSN	Conceptual System for Nursing
CVA	Cerebrovascular Accident
D&E	Demographic and Environmental
DALYs	Disability-adjusted Life-years
DCPs	Discharge Plannings
ECHO	Extension for Community Healthcare Outcomes
ED	Emergency Department
FES	Falls Efficacy Scale
FRT	Functional Reach Test
FSST	Four Square Step Test
GBD	Global Burden of Disease
GDS	Geriatric Depression Scale
HADS	Hospital Anxiety and Depression Scale
HICs	High-Income Countries
HIV	Human Immunodeficiency Virus
HPT	Hypertension
HREC	Health Research Ethics Committee
HRQoL	Health-related Quality of Life
IADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning, Disability and Health
IPA	Interpretative Phenomenological Analysis
LHS	London Handicap Scale
LMICs	Low- and Middle-income Countries
LPAA	Life Participation Approach to Aphasia
MDC	Minimal Detectable Change

MDT	Multidisciplinary Team
ML	Mediolateral
MRI	Magnetic Resonance Imaging
MSCRIM	Maleka Stroke Community Reintegration Measure
NCDs	Non-communicable Diseases
NDoH	National Department of Health
NGO	Non-governmental Organisation
NGT	Nasogastric Tube
NHI	National Health Insurance
NHMRC	National Health and Medical Research Council
N.R.	Not Reported
OPD	Outpatient Department
OT	Occupational Therapy
PASS	Postural Assessment Scale for Stroke
PET	Psychoeducation Treatment
PHQ-9	Patient Health Questionnaire-9
PRISMA	Preferred Reporting Items for Scoping Review and Meta-Analyses
PROGRESS	Place, Race, Occupation, Gender or Sex, Religion, Education, Socioeconomic Status and Social Capital
PROM	Patient-Reported Outcome Measure
PSD	Post-stroke Depression
PT	Physiotherapy
PWBA	Partial Weight Bearing Asymmetry
QoL	Quality of Life
SA-CPG	South African Clinical Practice Guideline
SA-cSRG	South African Contextualised Stroke Rehabilitation Guideline
SDG	Sustainable Development Goal
SDH	Social Determinants of Health
SF-PASS	Short-form-postural Assessment Scale for Stroke

SIS	Stroke Impact Scale
SLT	Speech and Language Therapist
SoBE	Strength of the Body of Evidence
SSA	Sub-Saharan Africa
SSS	Scandinavian Stroke Scale
SS-QoL	Stroke-Specific Quality of Life Scale
StatsSA	Statistics South Africa
SU	Stellenbosch University
SW	Social Worker
SWOT	Strengths, Weaknesses, Opportunities and Threats
TB	Tuberculosis
TBT	Timed Balance Test
TiDIER	Template for Intervention Description and Replication
TPA	Tissue Plasminogen Activator
TUG	Timed-Up-and-Go Test
UN	United Nations
WCRC	Western Cape Rehabilitation Centre
WHO	World Health Organization
WHOQoL-BREF	World Health Organization Quality of Life BREF

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Preface

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This e-book takes a rehabilitation lens to explore the challenges and facilitators to preventing, diagnosing and managing cerebrovascular accident (CVA or stroke) in Africa. The continent of Africa contains countries with some of the world's poorest economies, as well as some of the world's wealthiest. These extremes are reflected in large differences in population health, resources, climate, geography, lifespan, diet, transport, education, access to healthcare, types of employment, wages and opportunity. The continent of Africa covers 6% of Earth's surface and 20% of its land area. It is the second most-populated continent on Earth, with the United Nations (UN) population estimates on 28 October 2019, of 1 318 453 701 (reflecting approximately 16.7% of the world's population). Africa is also a continent rich in culture, tradition, folk-law and folk-medicine, language, foods and beliefs. There are also unique African health issues that have been well-documented for over two centuries; for instance, maternal and child health concerns, deadly and/or debilitating infectious diseases, birth defects and childhood malnutrition, adolescent health concerns related to traditional ritual practices and trauma (World Health Organization [WHO] African Health Report 2014).

In contrast to steadily decreasing stroke events for adults in Western countries, the prevalence and burden of stroke in Africa is rising (Owolabi et al. 2015). Prevalence estimates vary between African countries, because different diagnostic criteria are applied, there is variable diagnostic accuracy, and very often,

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incomplete reporting mechanisms (Owolabi et al. 2018). From a systematic review of 50 relevant African studies published between 1970 and 2017, these authors estimated age-standardised African prevalence of approximately one stroke for every 10.2 adults. Many reasons are proposed for such high stroke prevalence, including a rise in modifiable risk factors for stroke precursor diseases (hypertension [HPT], diabetes and obesity) such as smoking, harmful use of alcohol, physical inactivity and unhealthy diets. Moreover, there are the ubiquitous African challenges of low health literacy, increasing industrialisation, urbanisation and loss of traditional ways and low numbers of healthcare providers to deal with large numbers of patients, particularly in rural areas (Owolabi et al. 2018; Urimubenshi et al. 2018). Added to these potentially multiplicative causes of stroke are comorbid human immunodeficiency virus (HIV) and tuberculosis (TB), where the diseases themselves, and/or the drugs used for their treatment can increase individual susceptibility to stroke (Benjamin et al. 2012; Pasticci et al. 2013).

Improving capacity across African healthcare settings is essential to ensure best practice public health programmes to increase awareness of stroke and its causes, its early identification and acute management and its rehabilitation (Louw et al. 2018). African clinical practice guidelines (CPGs) for medical diagnosis and management in any setting have been reported as of variable methodological quality (Okwen et al. 2018) and until 2019, there was no CPG for stroke rehabilitation relevant to African settings (Grimmer et al. 2018). The launch of the South African Contextualised Stroke Rehabilitation Guideline (SA-cSRG) in 2019, funded by the WHO and Stellenbosch University (SU), and written in conjunction with the South African Department of Health, marked an increased focus on the importance and quality of stroke rehabilitation. These guidelines were the genesis for the information presented in this e-book.

The chapters in this book address issues of stroke rehabilitation as varied as Africa itself. Readers will find information about and discussion around policy and legislation, health systems, international and local rehabilitation frameworks, the rehabilitation workforce (including professional competencies, integrated care, alternative care providers and care substitution), outcome measures, culturally appropriate assessment and care, patient and family empowerment and healthcare barriers and facilitators. Chapters in this book provide information relevant to many end-users, including policy makers and legislators; clinicians in all rehabilitation disciplines; educators of next generation rehabilitation providers; researchers; and stroke survivors and their families.

There are six themes that thread throughout this book:

1. The first theme is ‘Stroke rehabilitation service delivery perspectives’ and draws on research throughout Africa to present Africa’s unique challenges within the healthcare system, with particular reference to the delivery of rehabilitation services, healthcare system issues related to integrated stroke management and gaps in healthcare in Africa that affect the rehabilitation outcomes for stroke survivors.
2. The second theme ‘Collaborative care and communication needs’ focuses on the communication needs of people with stroke and reports on a series of primary research studies into this important functional capacity. The next chapter in this theme highlights the importance of collaborative capacity as it relates to nurses’ engagement in improving communication and safe swallowing.
3. The third theme is entitled ‘Mental health and well-being’. This theme highlights the challenges of assessing and addressing the mental health needs of people in stroke in Africa. Mental health problems post-stroke are common and significantly influence rehabilitation outcomes. The burden and mental health of caregivers are also affected and the second chapter in this theme addresses this important topic.
4. The fourth theme is about stroke rehabilitation and outcome measures relevant to African settings. The theme entitled

‘Outcome measurement considerations’ deals with objective applying balance assessments of an example of an objective and self-reported outcome measurement. This theme describes profiles of stroke survivors which are unique to Africa, and how these can influence outcomes and person-centred rehabilitation.

5. The fifth theme ‘Illuminating social determinants’ describes how the social determinants of challenges such as geography, transport, finances, health literacy and healthcare worker shortages influence rehabilitation in African settings. This chapter described these crucial aspects within the context of a South African case study.
6. The final theme ‘Care pathways and contextualised evidence rehabilitation’ includes two interlinked chapters. This first chapter deals with the importance of building relevant and applicable evidence around patient pathways which reflect African contexts. This chapter also describes the associated costs of rehabilitation (in different healthcare settings); the importance of not recreating the wheel by using available evidence sources; contextualising rehabilitation recommendations based on research generated in high-income countries (HICs) to enable efficient operationalisation within, and by African health services; and the importance of developing research evidence that is relevant to African stroke rehabilitation questions and needs.

Readers of this book will leave with a greater understanding of the challenges of providing evidence-based stroke rehabilitation in Africa, and also with many solutions to improve rehabilitation practices. This book provides one important step towards addressing the devastating consequences of stroke which affects so many Africans, who are without the knowledge and resources available to many stroke survivors in high-income settings. The chapter authors anticipate that publication of this book will mark an upswing in Africa, and internationally, to the attention given to the rehabilitation provided to African stroke survivors.

THEME 1

Stroke rehabilitation service delivery perspectives

Chapter 1

Stroke rehabilitation services in Africa – Challenges and opportunities: A scoping review of the literature

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■ Abstract

Background: Stroke is increasingly becoming a public health problem in Africa as it causes high rates of disability and mortality. Therefore, there is a need to strengthen rehabilitation services within the African healthcare systems in order to improve patient outcomes.

Aim: To gather the scientific evidence on the current status of rehabilitation service delivery for people with stroke in Africa, in light of contextual challenges and opportunities.

Methods: A five-step methodological framework was used to conduct the review which involves (1) identifying the research question, (2) identifying relevant studies, (3) selecting the studies, (4) charting the data and (5) collating, summarising and reporting the results. The WHO service delivery framework was used to report the results.

Findings: A total of 51 studies were reviewed. Most of the studies stemmed from Southern Africa (43%); 37% from Western Africa and 18% from Eastern Africa. Physiotherapy (PT) (82%) was the most reported rehabilitation service whilst clinical psychology (7%), nutrition (14%) and social work (21%) were the least. Comprehensiveness of rehabilitation services was reported by 55% of the studies.

Common barriers were cost of care, lack of appropriate transport, poor referral processes, lack of resources, geographical distance and uneven terrain, variable skills and attitudes of service providers. Common challenges included low service frequency and duration, incomprehensive and fragmented services, lack of trained personnel and infrastructure limitations.

Conclusion: Stroke rehabilitation services in Africa are generally poor, lacking the required components of an effective healthcare service, hence impacting on social and community reintegration of people with stroke.

Keywords: Stroke; Rehabilitation; Service delivery; Clinical context; Africa; Health systems; Outcomes.

Introduction

Stroke is the second most common cause of death (Lozano et al. 2012), and the third most common cause of disability-adjusted life-years (DALYs) worldwide (Murray et al. 2012). Globally, about 16 million new cases of stroke and 62 million people with stroke were estimated in 2005, with deaths from stroke accounting for

9.7% of all global deaths. In the absence of significant international public health responses, projections based on the current trends, incidence velocity, risk factor prevalence, population-attributable risks and relative risk for risk factors indicate that by 2030, stroke will be the first leading cause of death in middle-income countries and the third in low-income countries, especially in Africa. (Owolabi et al. 2015). In 2010, the absolute number of people affected with first stroke was 16.9 million, with stroke-related deaths accounting for 5.9 million and DALYs lost being 102 million (Feigin et al. 2014).

Within high-income (developed) countries (HICs), adequate health services and strategies for stroke prevention and post-stroke care (such as smoking cessation, control of hypertension [HPT] and acute stroke units) appear to have contributed to a steady decline since 1940 in stroke incidence, mortality, mortality-to-incidence ratios and DALYs lost (Johnston, Mendis & Mathers 2009; Whisnant 1984). Disability-adjusted life-years are calculated as the sum of the years of life lost because of premature mortality in the population from a particular condition, and the years lost because of disability for people living with the health condition or its consequences (WHO 2004). In contrast, there has been a rise in the burden of stroke over recent years in low- and middle-income countries (LMICs) and it is expected to accelerate unless there is concerted intervention (Feigin et al. 2014). Eighty-six per cent of all stroke deaths around the world take place in LMICs (Jonson, Onuma, Owolabi & Sachdev 2016).

Further, LMICs account for over 87% DALYs lost from stroke, which is about seven times the DALYs lost in HICs (Owolabi et al. 2015).

Many African countries are undergoing ‘epidemiological transition’ (Kabudula et al. 2017) driven by socio-demographic and lifestyle changes, related to unchecked industrialisation and a rise in many modifiable, lifestyle-related vascular disease risk factors. These include smoking, harmful use of alcohol, physical inactivity and unhealthy diets resulting in an increased prevalence of obesity and HPT, precursors for heart disease, diabetes and stroke (Owolabi et al. 2014). Consequently, the burden of non-communicable diseases (NCDs) is growing (Owolabi et al. 2014).

Africa as a region has demonstrated concerningly high rates of stroke in the last 30 years. A significant mean increase in age-standardised ischaemic stroke incidence of 14.8% occurred between 1990 and 2010. During this time period (in 2002), the global burden of disease (GBD) estimates showed that three African countries (Angola, Liberia and Sierra Leone) had recorded the highest stroke mortality and DALYs lost, in the world (WHO 2002). Moreover, between 2002 and 2004, 8% of all new stroke cases worldwide occurred in Africa and 5% of all people with stroke were African (WHO 2004). The GBD 2010 data showed an increase in age-standardised haemorrhagic stroke incidence from 1990 to 2010, ranging from 13.0% (Gambia) to 45.7% (Burundi), and an increasing age-standardised ischaemic stroke incidence from 1990 to 2010 ranging from 5.2% (South Africa) to 27.8% (Democratic Republic of Congo) (Krishnamurthi et al. 2013).

The progression in epidemiologic transition together with the high burden of NCDs including stroke has increased the need for rehabilitation services especially in LMICs. In response to this global problem, the WHO launched the ‘Rehabilitation 2030 – call for action’ initiative in order to sensitise rehabilitation stakeholders to initiate coordinated and concerted efforts of strengthening rehabilitation in health systems (Gimigliano & Gegrini 2017). Despite the WHO’s efforts and the increasing stroke burden, the provision of ‘stroke care in Africa’ is below international recommended standards with ‘variations across countries and settings’ (Urimubenshi et al. 2018).

Health systems in many African countries are characterised by geographical and financial inaccessibility, rapid turnover of people in key positions, lack of continuity in policy, lack of resources, poor management of available resources and poor implementation (African Health Monitor 2012).

It is recommended that appropriate systems of stroke care be established in Africa and other LMIC regions to control the increasing death and disability associated with stroke (Feigin et al. 2009; Langhorne, De Villiers & Pandian 2012; Owolabi et al. 2015).

Rehabilitation is a key component of the stroke patient's journey as conceptualised in the World Stroke Organization Stroke Services Framework (Lindsay et al. 2014). Providing rehabilitation for individuals who have suffered a stroke lowers the risk for death and disability. For instance, a Cochrane systematic review (Legg, Drummond & Langhorne 2006) found that occupational therapy (OT) rehabilitation was associated with a reduced risk for death and reduced dependency on others for assistance with personal activities of daily living (ADL). A more recent Cochrane systematic review (Pollock et al. 2014) found that interventions that included intensive, repetitive, task-oriented and task-specific constraint-induced movement therapy, mental practice, virtual reality and interactive video games were associated with significant improvements in arm function. Furthermore, a systematic review of the literature and meta-analysis (Urimubenshi et al. 2017) showed that early mobilisation for people with stroke was associated with lower case fatality, shorter lengths of hospital stay and fewer medical complications.

Despite available evidence of effectiveness of rehabilitation, rehabilitation services in Africa are generally not comprehensive and manifest low compliance with rehabilitation best practice (Urimubenshi et al. 2018). The translation into practice of available best evidence about stroke rehabilitation is often hindered by many complex contextual factors related to patients, caregivers, healthcare facilities and personnel resulting in poor patient outcomes. For example, lack of infrastructure for rehabilitation services; poor communication between patients, family members and healthcare professionals; poor awareness of rehabilitation services; overprotectiveness from healthcare professionals and family members; unstimulating hospital environments; lack of health literacy and inter-related economic, social and cultural issues have been reported to have negative effects on delivery of, and compliance with, rehabilitation (Basri, Naseen & Naz 2017; Holmqvist & Von Koch 2001).

To control the increasing burden of stroke in Africa, the many barriers to stroke rehabilitation need to be identified and addressed prior to rolling out any new stroke care initiative. A recent review of the literature identified environmental barriers to stroke rehabilitation including lack of rehabilitation specialists, financial challenges and geographical inaccessibility of rehabilitation services (Urimubenshi et al. 2018). This review considered the whole stroke-affected patient pathway and included only seven studies that reported on rehabilitation. These studies did not consider contextual factors in stroke rehabilitation. Using Urimubenshi et al.'s (2018) review as a background, and the WHO healthcare service delivery framework (2010) which recommends provision of rehabilitation services by a comprehensive multidisciplinary human resource, access to high-quality and continuous services as well as multi-sectorial coordination and stroke rehabilitation policy and legislation, we conducted a scoping review for literature reporting on stroke rehabilitation services in Africa. We particularly considered unique African contextual factors in this review.

The aim was to use the review findings to inform policy makers and healthcare professionals about challenges associated with healthcare systems and opportunities that need to be considered to facilitate effective and integrated service delivery for people with stroke in Africa.

Methods

Review framework

This scoping review was conducted according to a methodological framework recommended by Levac, Colquhoun and O'Brien (2010), using a five-step framework which involves (1) identifying the research question, (2) identifying relevant studies, (3) selecting the studies, (4) charting the data and (5) collating, summarising and reporting the results. To report the review, Tricco et al.'s (2018) guidelines proposed for scoping reviews were followed.

Step 1: Defining the review objectives

This provided a roadmap for the entire review process in order to clearly define the breadth and depth of the literature scoping process. In line with the purpose of scoping reviews, our approach was broad, with a special emphasis on studies that investigated any aspect of stroke rehabilitation in Africa.

The main review constructs included synthesis of evidence relating to stroke rehabilitation services in Africa, particularly considering context-specific factors affecting the process or outcomes of rehabilitation provided to people with stroke in Africa.

The review objectives were to:

1. summarise and synthesise evidence regarding factors affecting delivery of rehabilitation services for people with stroke in Africa
2. determine the health system-related factors facilitating delivery of rehabilitation services in Africa
3. determine the health system-related factors hindering delivery of rehabilitation services in Africa
4. establish opportunities for achieving integrated and efficient stroke rehabilitation services within African health systems.

Step 2: Identifying relevant studies

Search strategy

A comprehensive electronic search of PubMed, Scopus and Africa Wide Information databases was undertaken between March and May 2019. A key term search strategy was employed using the words ‘stroke’ AND ‘rehabilitation services’ AND ‘Africa’. The search was repeated with ‘Africa’ being replaced by the names of the countries which were known to have people actively involved in rehabilitation research: Benin, Burkina Faso, Egypt, Ghana, Nigeria, Mauritania, Morocco, Rwanda, South Africa, Tanzania, Tunisia and Uganda. The search term ‘rehabilitation services’ was then also replaced with specific types of rehabilitation services and for each new set of terms, the search strategy was re-run: PT, OT, speech and language therapy, nursing, psychotherapy, dietetics, nutrition, care, therapy and therapeutics. The reference lists of systematic reviews and primary studies that met the inclusion criteria were also searched manually to identify potentially eligible studies that had not been identified by the primary search approach.

Eligibility criteria

The decisions to include literature were made in three stages:

1. Literature was initially considered as relevant to the review if it reported English language primary research (qualitative or quantitative studies of any design) conducted within an African setting, and published in peer-reviewed journals between 2008 and 2018.
2. Studies were then interrogated as to whether they addressed at least one WHO service delivery component (2010) including stroke rehabilitation policies, legislation and guidelines for stroke rehabilitation; access to stroke

rehabilitation services; human resources (availability and training) and types of stroke rehabilitation services, quality or challenges facing stroke rehabilitation.

3. The final criteria for including studies in this review were that they reported on people accessing rehabilitation services as inpatients or outpatients and reported outcomes linked to one or more components of rehabilitation (PT, OT, SLT, referral, access or assistive devices).

Step 3: Study selection

There was a two-step process to selecting studies for the review:

1. Two authors independently scrutinised the titles and abstracts of all retrieved publications to assess their potential eligibility.
2. These same authors reviewed independently the full texts of the publications identified as potentially relevant in the previous step to determine if they met the inclusion criteria. In cases of disagreement, a decision was made by discussion and consensus.

Step 4: Data charting

All included studies were first categorised by study design (qualitative or quantitative). Data extraction was then undertaken independently by four reviewers. Before commencing data extraction, the reviewers first discussed the information to be extracted to ensure that they all had clarity about the data extraction process. They also developed a data charting form and piloted it on two studies which were selected randomly.

The form included information on author, year, country, study title, study design and the WHO rehabilitation service components (comprehensiveness, accessibility, quality, continuity, coordination, person-centredness and accountability). To ensure consistency of the data extraction process, the reviewers agreed on the ways in which the eight components of the WHO service delivery framework would be considered, using the definitions given in Table 1.1.

TABLE 1.1: Application of the WHO service delivery framework.

WHO service delivery component	Aspects of information from included studies addressing the component
Comprehensiveness	Different types of rehabilitation services including PT, OT, speech-language therapy, psychotherapy, nursing care, nutrition and dietetics, and assistive devices. Multidisciplinary team approach to care for people with stroke
Accessibility	Factors related to geography (distance, terrain and environment), financial costs for rehabilitation services, transportation (mode and availability), referral pathways
Coverage	Focus of the targeted population or group(s) in the provision of stroke rehabilitation services
Continuity	Stroke rehabilitation services across levels of care (acute care, inpatient and outpatient) and settings (hospital, home, community and workplace)
Quality	Effectiveness (improvement in clinical and socio-economic outcomes), patient centredness (patient satisfaction) and timeliness (frequency and duration of the rehabilitation services)
Person-centredness	Involvement of patients, family and caregivers in planning, goal setting and implementation of rehabilitation services. Rehabilitation outcomes centred around the patient
Coordination	Multi-sectorial (health, social and built environment) and multi-level (patient, family, caregivers and community) involvement in provision of stroke rehabilitation services
Accountability & efficiency	Proper management and governance of the inputs (workforce and financing), process and outputs of rehabilitation services

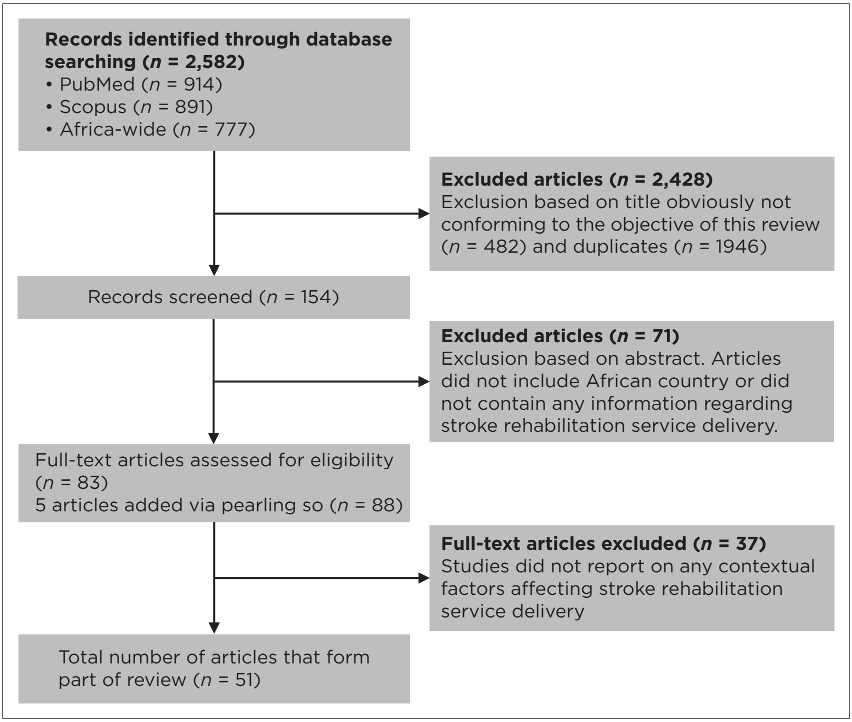
OT, occupational therapy; PT, physiotherapy; WHO, World Health Organization.

Results

On searching the three databases, 2582 articles were identified. Removal of duplicates and screening of the titles and abstracts resulted in 83 potentially relevant articles. After full text retrieval, another 30 articles were excluded, whilst five additional articles were identified from reference lists of the included articles. Finally, 51 studies were included in the review (Figure 1.1).

Included studies

Table 1.2 reports on the study characteristics. Almost half of the studies stemmed from countries in Southern Africa (43%); 37% from Western African countries; 18% from East African countries;



Records identified through database searching (*n* = 2,582)
- PubMed (*n* = 914)
- Scopus (*n* = 891)
- Africa-wide (*n* = 777)

Excluded articles (*n* = 2,428)
Exclusion based on title obviously not conforming to the objective of this review (*n* = 482) and duplicates (*n* = 1946)

Records screened (*n* = 154)

Excluded articles (*n* = 71)
Exclusion based on abstract. Articles did not include African country or did not contain any information regarding stroke rehabilitation service delivery.

Full-text articles assessed for eligibility (*n* = 83)
5 articles added via pearling so (*n* = 88)

Full-text articles excluded (*n* = 37)
Studies did not report on any contextual factors affecting stroke rehabilitation service delivery

Total number of articles that form part of review (*n* = 51)

FIGURE 1.1: Flow chart showing selection of articles for inclusion in scoping review.

and one study originated from Central Africa. Of the 51 studies included, only 28 studies reported on the comprehensiveness component of rehabilitation services.

Table 1.2 shows the different types of services reported on in the respective African countries; however, it does not reflect the quality of service or certainty of the services available. Physiotherapy (82%) was the most reported rehabilitation service whilst clinical psychology (7%), nutrition (14%) and social work (21%) were least reported. In addition to rehabilitation services, studies also reported specialist care, that is, neurologist (Andrews & Pillay 2017; Rhoda et al. 2015); ear, nose and throat specialist (Andrews & Pillay 2017); geriatrician (De Villiers, Kalula & Burch 2009) and physician (Sarfo et al. 2018a).

TABLE 1.2: Characteristics of included studies ($n = 51$).

Author (year) country	**Aim**	**Study design**	**Eligibility criteria**	**Sample characteristics**
Akosile et al. (2016) Nigeria	To determine the level of satisfaction with community reintegration and related factors amongst Nigerian community-dwelling people with stroke	Cross-sectional survey	Factors for community reintegration	71 people with stroke (mean age = 64.14 ± 10.26 years; range: 41–82 years); 36 (50.7%) were women
Amosun, Nyante and Wiredu (2013) Ghana	To assess the perceived and experienced restrictions in participation and autonomy amongst adult people with stroke in Ghana	Mixed methods	Factors affecting patients' participation	200 adult people with stroke (mean age 53.7 ± 7.9 years; range:18–65 years)
Andrews and Pillay (2017) South Africa	To explore the clinical practice activities of SLTs in the clinical evaluation of swallowing in adults with acute stroke	Survey design with exploratory and descriptive designs	Rehabilitation service	38 practitioners who had a speech-language therapy degree in 2014 or earlier were currently working with adults with neurogenic dysphagia post-acute stroke in South Africa
Baatiema et al. (2017a) Ghana	To understand stroke care professionals' views on the barriers which hinder the provision of optimal acute stroke care in Ghanaian hospital settings	Qualitative (thematic and grounded theory)	Barriers to evidence-based acute stroke care	40 participants comprising neurologists, emergency physician specialists, non-specialist medical doctors, nurses, physiotherapists, clinical psychologists and a dietitian

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

Table 1.2 continues on the next page→

TABLE 1.2 (Continues…): Characteristics of included studies (*n* = 51).

Author (year) country	Aim	Study design	Eligibility criteria	Sample characteristics
Baatiema et al. (2017c) Ghana	To identify and evaluate available acute stroke services in Ghana and the extent to which these services align with global best practice	Survey	Rehabilitation services	11 major referral hospitals (regional and tertiary – teaching hospitals) in Ghana
Blackwell and Littlejohns (2010) South Africa	To measure the prevalence, assessment, and review the management strategies of dysphagia in three private rehabilitation clinics in South Africa	Mixed methods	Review of service	90 patients from three private rehabilitation clinics in Gauteng, South Africa (mean age at onset = 62 ± 12.0 years, 50 men and 40 women)
Blixen et al. (2017) Uganda	To assess perceived barriers to stroke recovery and prevention in an urban or suburban Ugandan population	Qualitative	Perceived barriers	48 participants: 9 adult people with stroke (mean age = 63 ± 15.0 years; range: 35–85 years); 8 caregivers (mean age = 47 ± 15.3 years; range = 24–68); 31 community members (mean age = 44.7 ± 16.8 years; range = 21–76 years)
Birabi et al. (2012) Nigeria	To determine the cost burden of a cerebrovascular accident condition (stroke) in Nigeria	Prospective cross-sectional study	Factors influencing outcome	29 stroke patients managed between 2005 and 2011 (mean = 49.66 ± 7.46 years, range = 34–62 years, 65.5% men)

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

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TABLE 1.2 (Continues...): Characteristics of included studies (*n* = 51).

Author (year) country	Aim	Study design	Eligibility criteria	Sample characteristics
Cawood and Visagie (2015) South Africa	To determine environmental barriers and facilitators to participation experienced by a group of people with stroke in the Western Cape province of South Africa	Descriptive, mixed methods	Factors influencing outcome	53 people with stroke
Chimatiro and Rhoda (2014) Malawi	To report on the environmental barriers to reintegration experienced by patients with stroke post-discharge from a rehabilitation centre in Malawi	Qualitative	Factors influencing outcomes	Eight stroke patients (mean age = 54 ± 5.2 years)
Chimatiro, Rhoda and De Wit (2018) Malawi	To determine stroke outcomes and satisfaction with care in the country's central hospitals	Descriptive cross-sectional survey	Patients' outcomes and satisfaction	90 adults with stroke, representing 79% of the initial study population. Overall mean age was 58.6 ± 16.3 years) and 48 (53%) were men
Cockburn et al. (2014) Cameroon	To describe how a group of front-line practitioners collaborated with academics and students to develop best practice guidelines for the management and rehabilitation of stroke in adult patients in Cameroon	Development of clinical guidelines	Stroke guidelines	N/A

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

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TABLE 1.2 (Continues…): Characteristics of included studies (*n* = 51).

Author (year) country	Aim	Study design	Eligibility criteria	Sample characteristics
Damasceno et al. (2010) Mozambique	To determine the incidence, characteristics, and short-term consequences of hospitalisations for stroke in Maputo, Mozambique	Retrospective study (patient records)	Outcomes of rehabilitation services	651 patients with new stroke events (mean age = 59.1 ± 13.2 years and 53% men)
De Villiers et al. (2009) South Africa	To document the outcome of patients admitted to the first multidisciplinary stroke unit opened at a secondary hospital in Cape Town, South Africa	Retrospective study	Outcomes of rehabilitation services	195 stroke patients: mean (SD, 95% CI) age of admitted patients was 58.8 ± 14.5 years, range = 56.7–60.9 years); 60% were women and 46% were black Africans. The remainder were of varied ancestry
De Villiers et al. (2011) South Africa	To determine survival, disability and functional outcomes of stroke patients following their discharge from an acute stroke unit in an urban community with limited rehabilitative resources	Longitudinal	Rehabilitation service	196 stroke patients. Median age was 60 (IQR 51–69) years, 135 (68.9%) were women
Duff et al. (2017) South Africa	To establish the rate of return to work and the factors that influence return to work after stroke	Quantitative cross-sectional study	Factors influencing outcomes	97 adult people with stroke from 8 stroke rehabilitation units in Johannesburg (mean age = 51 ± 10.5 years; range = 18–64 years)

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

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TABLE 1.2 (Continues...): Characteristics of included studies (*n* = 51).

Author (year) country	Aim	Study design	Eligibility criteria	Sample characteristics
Ekechukwu et al. (2017) Nigeria	To investigate the clinical and psychosocial predictors of community reintegration amongst people with stroke 3 months post in-hospital discharge	Prospective exploratory	Factors predicting outcomes of care	55 people with stroke (mean age = 61.21 ± 11.25 years; range = 31–86 years) 26 men, 29 women
Elloker et al. (2018) South Africa	To investigate the factors influencing community participation amongst community-dwelling people with stroke in the Western Cape, South Africa	Quantitative, cross-sectional survey	Factors and outcomes of rehabilitation services	106 community-dwelling people with stroke: men 50%, women 50%
Glickman (2018) Malawi	To compare client community reintegration status following discharge from the Kachere Rehabilitation Centre, Blantyre, Malawi, in 2 consecutive years with client versus guardian perspectives on reintegration status	Descriptive cross-sectional survey	Outcomes of rehabilitation services	36 patients with diagnosis of neurological dysfunction: 19 with stroke, 16 non-stroke diagnosis and 1 unknown (22 male patients, 14 female patients; mean age = 55 years; range = 27–91 years)
Hassan, Visagie and Mji (2011) South Africa	To explore levels of strain experienced by caregivers and the variables that impact on their strain	Mixed methods, descriptive	Factors related to care	57 caregivers of people with stroke (6 men, 51 women)

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

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TABLE 1.2 (Continues…): Characteristics of included studies (n = 51).

Author (year) country	Aim	Study design	Eligibility criteria	Sample characteristics
Hurst et al. (2016) Nigeria	To gather information from physicians, people with stroke, and their caregivers about the challenges of living with stroke disease	Qualitative	Rehabilitation service	Healthcare professionals (3 hospital administrators, 19 healthcare providers, mean age = 43 years); caregivers (*n* = 39, 24 women, 25 men, mean age = 40 years), and adult stroke patients (*n* = 44; 20 women, 24 men, mean age = 59 years)
Ibeneme et al. (2016) Nigeria	To identify people with stroke with symptoms of PSD and the extent of psychiatry needs and care they have received whilst on PT rehabilitation	Multiple case study	Outcomes of rehabilitation services	50 people with stroke (22 women, 28 men) at the outpatient unit of PT Department, University of Nigeria Teaching Hospital, Enugu (mean age = 54.76 ± 8.79 years, range = 26–66 years)
Joseph and Rhoda (2013) South Africa	To determine the activity limitations and factors influencing functional outcome of patients with stroke managed at a specialised rehabilitation centre	Longitudinal, descriptive study	Factors influencing outcomes	67 patients with stroke (mean age = 52.95 ± 12.19 years; range = 23–79 years)

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

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TABLE 1.2 (Continues...): Characteristics of included studies (*n* = 51).

Author (year) country	**Aim**	**Study design**	**Eligibility criteria**	**Sample characteristics**
Joseph et al. (2018) South Africa	To investigate objectively measured physical activity in people with stroke living in low-income areas of Cape Town, South Africa	Cross-sectional design	Rehabilitation service, factors and outcomes of rehabilitation services	45 people with stroke (mean age = 58.4 ± 13.7 years, 51 % men)
Kamwesiga, Tham and Guidetti (2017) Uganda	To explore and describe clinical characteristics and functioning during the acute or sub-acute phase and chronic phase, as well as the impact of stroke on everyday life during the chronic phase in people with stroke in central Uganda	Cross-sectional observational study	Outcomes of rehabilitation services	Acute and sub-acute (*n* = 58; age range 16–74) Chronic (*n* = 62; age range = 19–75)
Kossi et al. (2016) Benin	To examine the functional recovery of stroke patients in the Republic of Benin	Observational cohort study	Outcomes of rehabilitation services	68 people with stroke (mean age = 60 ± 9 years; 52% men)
Kpadonou et al. (2013) Benin	To analyse the occurrence and development of post-stroke verbal communication disorders in Benin	Retrospective, descriptive and analytical study	Outcomes of rehabilitation services	563 post-stroke patients treated in rehabilitation department of the National university hospital of Cotonou from January 2006–December 2010 (mean age was 57.17 ± 12.62 years, sex ratio was 1.75)

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

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TABLE 1.2 (Continues...): Characteristics of included studies (*n* = 51).

Author (year) country	Aim	Study design	Eligibility criteria	Sample characteristics
Legg and Penn (2013) South Africa	To explore understandings of stroke and aphasia in a South African township	Longitudinal observational study	Factors influencing rehabilitation outcomes	Five adults living with aphasia in Khayelitsha (three men, two women, mean age = 55.6 years, range = 35–76 years)
Mlenzana, Eide and Frantz (2018) South Africa	To explore caregivers' perceptions and satisfaction regarding rehabilitation services in the Western Cape, South Africa and to inform clinical practice and policy in this emerging field	Explorative, descriptive and qualitative design	Factors influencing rehabilitation outcomes	Thirteen caregivers (mean age = 47; range = 27–70 years; 5 men)
Natta et al. (2015) Benin	To evaluate the feasibility of a self-rehabilitation protocol in Benin	Feasibility	Rehabilitation service	Chronic stroke patients (mean age = 57.4 ± 13.7 years, range = 30–77 years)
Ntamo, Buso and Longo-Mbenza (2013) South Africa	To determine the extent and the socio-demographic reasons for poor attendance for outpatient PT by stroke patients	Observational descriptive study	Factors influencing rehabilitation outcomes	103 stroke patients who attended PT in Mthatha General Hospital in 2007 (mean age = 46.4 ± 18.8 years; range = 42.4–50.3 years)
Ntsiea et al. (2012) South Africa	To establish current practice in return to work intervention programmes for patients with stroke	Cross-sectional survey	Rehabilitation service	36 stroke rehabilitation facilities within the Gauteng province in South Africa

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

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TABLE 1.2 (Continues…): Characteristics of included studies (*n* = 51).

Author (year) country	Aim	Study design	Eligibility criteria	Sample characteristics
Oduor et al. (2015) Kenya	To describe the stroke types, risk factors, outcomes and stroke quality of care in a large academic medical centre hospital	Retrospective study	Outcomes of rehabilitation services	155 patients had stroke between January 2010 and December 2014 (42% were male patients, the median age was 61 [IQR: 49–72] years)
Olaleye, Hamzat and Owolabi (2014) Nigeria	To investigate the feasibility and clinical effectiveness of stroke rehabilitation at a primary health centre compared with domiciliary rehabilitation with a view to enhance access to PT services in low-income countries	Single blind randomised control trial	Service provision	52 people with stroke (24 men, 28 women) who were recently discharged from two inpatient health facilities in Ibadan, Nigeria
Olaleye and Lawal (2017) Nigeria	To investigate the pattern of referral for and utilisation of PT in the continuum of stroke care at a tertiary hospital in Ibadan, Nigeria	Retrospective survey (document analysis)	Rehabilitation service	306 people with stroke mean age = 59.9 ± 13.0 years (median = 60.0 years)
Olaleye, Hamzat and Akinrinsade (2017) Nigeria	To investigate the satisfaction of people with stroke with outpatient PT care	Comparative cross-sectional survey	Service provision	60 people with stroke (mean ages in the tertiary hospitals, state hospital and private mission hospital groups were 58.7 ± 12.3, 64.6 ± 12.5 and 61.7 ± 9.3 years, respectively). RR = 92.3%

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

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TABLE 1.2 (Continues...): Characteristics of included studies (*n* = 51).

Author (year) country	Aim	Study design	Eligibility criteria	Sample characteristics
Olukolade and Osinowo (2017) Nigeria	To examine efficacy of CRT in the treatment of PSD amongst stroke survivor	Randomised clinical trial using experimental design	Outcomes of rehabilitation services	30 participants with PSD: 13 men (43.3%) and 17 women (56.7%)
Pareck and Rhoda (2013) South Africa	To determine functional outcomes and factors influencing functional outcomes of stroke patients admitted to a South African tertiary hospital	Longitudinal study	Outcomes of rehabilitation services	100 stroke patients (mean age = 59.83 ± 15.71 years with 51% female patients and 49% male patients)
Peters et al. (2013) Nigeria	To explore the frequency and determinants of return to work amongst Nigerian people with stroke	Cross-sectional survey	Rehabilitation service	101 community-dwelling people with stroke (mean age = 47.2 ± 12.3 years, range = 24–90 years, 56.4% men and 43.6% women)
Rhoda, Mpofu and De Weerdt (2011) South Africa	To determine the activity limitations of stroke patients receiving rehabilitation at outpatient Community Health Centres	Longitudinal observational study	Outcomes of rehabilitation service	100 participants: (mean age = 61.0 ± 10.55 years, range = 36–85 years), men 50 (50%) and women 50 (50%) recruited into the study at a median 21 days post-stroke
Rhoda et al. (2014) South Africa	To compare the motor and functional recovery of stroke patients in Germany versus stroke patients receiving rehabilitation in South Africa	Retrospective survey	Outcomes of rehabilitation services	73 South African stroke patients (mean age = 63.4 ± 10.0 years) 73 German stroke patients (mean age = 63.9 ± 9.2 years)

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

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TABLE 1.2 (Continues...): Characteristics of included studies (*n* = 51).

Author (year) country	Aim	Study design	Eligibility criteria	Sample characteristics
Rhoda et al. (2015) South Africa	To present provision of inpatient stroke rehabilitation. In addition, the challenges experienced by the individuals with participation post-discharge are also presented	Mixed methods: retrospective survey, interviews	Rehabilitation service	South Africa (*n* = 168; mean age 62.6 ± 13.78 years, range = 20–90 years, women = 59%) Tanzania (*n* = 145; mean age = 57.7 ± 18.67 years, range = 19–80, women = 52.3%) Rwanda (*n* = 139; mean age = 56.3 ± 17.4 years, range = 17–92 years, women = 53.2%)
Rouillard et al. (2012) South Africa	To determine activity limitations, participation restrictions, HRQoL and caregiver strain in community-dwelling people with stroke discharged from an intensive inpatient rehabilitation programme at 6 months post-stroke	Longitudinal descriptive study	Outcomes of rehabilitation services	59 patients: mean age = 51.9 ± 14.3 years, range = 21–80 years, 20 men, 26 women
Sarfo et al. (2017a) Ghana	To assess the burden of post-stroke physical deficits, rates of utilisation of PT services and perceptions of telerehabilitation amongst recent Ghanaian people with stroke	Cross-sectional survey	Factors influencing outcomes	100 people with stroke: Mean ± SD age of study participants was 57.2 ± 13.3 years of which 51.0% were men with a mean duration of stroke of 1.3 ± 2.2 years

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

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TABLE 1.2 (Continues...): Characteristics of included studies (*n* = 51).

Author (year) country	Aim	Study design	Eligibility criteria	Sample characteristics
Sarfo et al. (2018a) Ghana	To preliminarily assess the feasibility and outcomes of mobile technology-assisted physical therapy exercises for people with stroke in Ghana	Prospective single-arm, pre–post study	Stroke rehabilitation services	20 people with stroke: mean ± SD age was 54.6 ± 10.2 years, 11 (55%) were men, average time from stroke onset was 6 months
Seedat and Penn (2016) South Africa	To investigate the outcome of an oral care protocol	Quantitative, quasi-experimental parallel group design	Rehabilitation service	139 nurses at a tertiary government hospital in South Africa, 46 patients with oropharyngeal dysphagia with either stroke or traumatic brain injury as the underlying medical pathology
Soeker and Olaoye (2017) Nigeria	Exploring and describing the experiences of rehabilitated people with stroke and perceptions of stakeholders about people with stroke returning to work in South West Nigeria	Qualitative	Factors influencing outcomes	19 participants, comprising nine people with stroke, two key informants, who were rehabilitation specialists, and eight caregivers of the respective people with stroke

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

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TABLE 1.2 (Continues…): Characteristics of included studies (*n* = 51).

Author (year) country	Aim	Study design	Eligibility criteria	Sample characteristics
Stenumgård et al. (2017) Madagascar	To investigate the feasibility of collecting data on stroke patients in a resource-constrained hospital in Madagascar	Retrospective	Rehabilitation service, factors and outcomes	30 stroke patients (median age = 62.5 years [IQR 58–67], 16 men)
Urimubenshi and Rhoda (2010) Rwanda	To describe the process of PT for patients with stroke treated at Ruhengeri Hospital in Rwanda, as documented in patients' folders	Quantitative retrospective design (medical records)	Rehabilitation services	139 stroke patients admitted at Ruhengeri between 2005 and 2008 (mean age = 53.6 years, 53.2% women, 46.8% men)
Urimubenshi (2015) Rwanda	To explore the activity limitations and participation restrictions experienced by people with stroke in Musanze district in Rwanda	Qualitative phenomenological	Factors influencing outcomes	10 persons with stroke living in Musanze (mean age = 56.3 ± 16.9 years, range = 24 and 79 years, 50% women)
Wasserman, De Villiers and Bryer (2009) South Africa	To develop a community-based model of stroke care for patients in a rural African setting	Longitudinal study	Rehabilitation service	30 consecutive stroke patients assessed at discharge and 3 months post-discharge using the Barthel Index and Modified Rankin Scale

CI, cognitive impairment; CRT, cognitive rehabilitation therapy; HRQoL, health-related quality of life; IQR, interquartile range; N/A, not applicable; PSD, post-stroke depression; PT, physiotherapy; SD, standard deviation; SLT, speech-language therapist.

Three studies (Baatiema et al. 2017a; Blackwell & Littlejohns 2010; Cockburn et al. 2014) found that even though the multidisciplinary healthcare practitioners were available, there was poor coordination between the different disciplines, which negatively impacted on patient outcomes.

Information about stroke rehabilitation services

Table 1.3 displays information on the comprehensiveness of stroke rehabilitation in Africa. Not all studies provided information on service provision. Many studies reported a specific need for certain rehabilitation services, but then reported the service to be either absent or inefficient, that is OT/SLT (Baatiema et al. 2017c; Cockburn et al. 2014; Rhoda et al. 2014, 2015); SLT (Kpadonou et al. 2013; Sarfo et al. 2017a); OT (Urimubenshi 2015); clinical psychologist (Urimubenshi 2015); mobility devices (Chimatiro & Rhoda 2014) and specialist stroke units (Legg & Penn 2013). Comprehensive multidisciplinary teams (MDTs) consisting of five or more healthcare professionals were reported in five South African-based studies (Andrews & Pillay 2017; Groenewald & Rhoda 2017; Rhoda et al. 2015; Rouillard et al. 2012; Wasserman et al. 2009).

Barriers to rehabilitation

Common barriers limiting access to rehabilitation services by people with stroke in Africa were:

- Cost of care (Andrews & Pillay 2017; Birabi et al. 2012; Hassan et al. 2011; Hurst et al. 2016; Kamwesiga et al. 2017; Natta et al. 2015; Rhoda et al. 2015; Sarfo et al. 2018a; Soeker & Olaoye 2017).
- Lack of appropriate means of transport (Amosun et al. 2013; Baatiema et al. 2017a; Blixen et al. 2017; Cawood & Visagie 2015; Damasceno et al. 2010; Kamwesiga et al. 2017; Natta et al. 2013; Ntamo et al. 2013; Rhoda et al. 2015; Rouillard et al. 2012; Sarfo et al. 2018a).

TABLE 1.3: Reported information about the comprehensiveness of stroke rehabilitation services in Africa.

Author (year) country	**Rehabilitation services**								
	PT	**OT**	**SLT/P**	**Nurse**	**SW**	**Nutr.**	**Psych**	**MD**	**Devices**
South Africa									
Andrews and Pillay (2017)	✓	✓		✓	✓	✓		✓	
Andrews and Pillay (2017)	✓	✓		✓	✓	✓		✓	
Blackwell and Littlejohns (2010)			✓	✓		✓		✓	
Cawood and Visagie (2015)									✓
De Villiers et al. (2009)	✓			✓	✓			✓	
Elloker et al. (2018)	✓								
Groenewald and Rhoda (2017)	✓	✓	✓		✓			✓	
Legg and Penn (2013)	✓	✓		✓					
Joseph et al. (2018)	✓	✓							
Rhoda et al. (2014)	✓	✓	✓						
Rouillard et al. (2012)	✓	✓	✓	✓	✓				
Wasserman et al. (2009)	✓	✓	✓	✓	✓	✓		✓	
Rhoda and Henry (2006)	✓	✓		✓	✓			✓	
Rhoda et al. (2015)	✓	✓	✓	✓				✓	
Nigeria									
Akosile et al. (2016)									✓
Hurst et al. (2016)	✓		✓	✓			✓		
Ibeneme et al. (2016)	✓								
Peters et al. (2013)	✓			✓				✓	
Ghana									
Amosun et al. (2013)	✓								
Baatiema et al. (2017c)	✓				✓		✓	✓	
Sarfo et al. (2017a)	✓	✓							
Sarfo et al. (2018a)	✓							✓	

MD, medical doctor; Nutr, Nutritionist; OT, occupational therapy; Psych, psychologist; PT, physiotherapy; SLT/P, speech and language therapist or pathologist; SW, social worker.

Table 1.3 continues on the next page→

TABLE 1.3 (Continues...): Reported information about the comprehensiveness of stroke rehabilitation services in Africa.

Author (year) country	Rehabilitation services								
	PT	OT	SLT/P	Nurse	SW	Nutr.	Psych	MD	Devices
Rwanda									
Rhoda et al. (2015)	✓	✓	✓	✓				✓	
Urimubenshi and Rhoda (2011)	✓							✓	
Urimubenshi (2015)	✓								
Malawi									
Chimatiro and Rhoda (2014)	✓	✓	✓	✓					
Chimatiro et al. (2018)	✓								
Cameroon									
Cockburn et al. (2014)	✓								
Kenya									
Oduor (2015)	✓								
Benin									
Kpadonou et al. (2013)			✓						
Tanzania									
Rhoda et al. (2015)	✓	✓	✓	✓				✓	

MD, medical doctor; Nutr, Nutritionist; OT, occupational therapy; Psych, psychologist; PT, physiotherapy; SLT/P, speech and language therapist or pathologist; SW, social worker.

- Poor referral channels and lack of resources (Andrews & Pillay 2017; Baatiema et al. 2017a; Blixen et al. 2010; Cawood & Visagie 2015; Cockburn et al. 2014; Mlenzana 2018; Natta et al. 2013; Soeker & Olaoye 2017).
- Geographical distances and difficult terrain (Andrews & Pillay 2017; Baatiema et al. 2017a; Blixen et al. 2010; Cawood & Visagie 2015; Cockburn et al. 2014; Mlenzana 2018; Natta et al. 2013; Soeker & Olaoye 2017).
- Variable skills and attitudes of rehabilitation service providers (Chimatiro & Rhoda 2014; Natta et al. 2013).

Table 1.4 summarises information on barriers and Figure 1.2 illustrates the frequency of barriers as reported in the included studies (*n* = 51).

TABLE 1.4: Reported barriers to access to rehabilitation services.

Barriers	Reference and country	Barriers to access of rehabilitation services
Cost of care	Andrews and Pillay (2017) South Africa	Insufficient resources and funds to cater for rehabilitation services
	Birabi et al. (2012) Nigeria	Healthcare costs for patients with stroke were mainly spent on PT that was not affordable to most Nigerians
	Hassan et al. (2011) South Africa	Most patients had financial challenges
	Hurst et al. (2016) Nigeria	Stroke patients could not continuously access and adhere to prescribed rehabilitation and medical services because of financial constraints
	Kamwesiga et al. (2017) Uganda	Very few people attended rehabilitation because of lack of financial resources at the family level
	Natta et al. (2015) Benin	Very limited access to rehabilitation services. No social security system and therapy sessions are expensive. Outpatient rehabilitation services were poorly attended because of finances as they cannot afford private transport
	Rhoda et al. (2015) South Africa	Barriers to rehabilitation services included finances
	Sarfo et al. (2018a) Ghana	Inconsistent access to PT services because of lack of finances
	Sarfo et al. (2017a) Ghana	Patients in rural areas had limited access to care because of high cost of travel and services
	Soeker and Olaoye (2017) Nigeria	Cost of treatment was high
Lack of transport	Amosun et al. (2013) Ghana	Lack of transport for patients to access care
	Baatiema et al. (2017a) Ghana	Limited ambulance services to transport patients to hospitals after an acute episode
	Blixen et al. (2010) Uganda	Limited access to care because of poor transport
	Cawood and Visagie (2015) South Africa	Poor modes of patient transportation
	Damasceno et al. (2010) Mozambique	Transport was the major barrier to accessing rehabilitation services in Mozambique
	Kamwesiga et al. (2017) Uganda	Very few patients attended rehabilitation services because of lack of transport
	Natta et al. (2013) Benin	Transport was a major barrier to access rehabilitation services
	Ntamo et al. (2013) South Africa	Outpatient rehabilitation was poorly attended because of an inadequate public transport system because they cannot use taxis

PT, physiotherapy.

Table 1.4 continues on the next page→

TABLE 1.4 (Continues...): Reported barriers to access to rehabilitation services.

Barriers	Reference and country	Barriers to access of rehabilitation services
	Rhoda et al. (2015) South Africa	Lack of transport was a main barrier to rehabilitation services
	Rouillard et al. (2012) South Africa	Transport limited access to participation
	Sarfo et al. (2018a) Ghana	Patients in rural areas had limited access to care because of lack of transport
Geographical location	Rhoda et al. (2015) South Africa	Barriers to rehabilitation services were the physical environment of rural settings
	Sarfo et al. (2018a) Ghana	Patients in rural areas had limited access to care because of poor physical environment
	Soeker and Olaoye (2017) Nigeria	Rehabilitation centres were situated in distant places
	Urimubenshi (2015) Rwanda	Physical barriers to access of rehabilitation services included poor roads
	Wasserman et al. (2009) South Africa	Home-based stroke carers travelled long distances on foot to conduct home-based rehabilitation
Poor referral channels and lack of resources	Andrews and Pillay (2017) South Africa	Inadequate rehabilitation equipment
	Baatiema et al. (2017a) Ghana	Diagnostic services were only available on weekdays until 17:00
	Blixen et al. (2010) Uganda	Appointment difficulties
	Cawood and Visagie (2015) South Africa	Long queues and waiting times for stroke patients
	Cockburn et al. (2014) Cameroon	Delays in initiating post-stroke rehabilitation
	Mlenzana (2018) South Africa	Poor referral channels to rehabilitation centres for stroke patients
	Natta et al. (2013) Benin	The care at community centres was inadequate in terms of resources (equipment and staff)
	Soeker and Olaoye (2017) Nigeria	Difficulty accessing rehabilitation services and inadequate equipment
Poor attitudes of rehabilitation staff	Chimatiro and Rhoda (2014) Malawi	Poor attitude of healthcare services and transport costs were key barriers
	Natta et al. (2013) Benin	Rude rehabilitation staff

PT, physiotherapy.

This review indicated that most stroke patients and their immediate families could not afford the cost of rehabilitation services care (Andrews & Pillay 2017; Birabi et al. 2012; Hassan et al. 2011; Hurst et al. 2016; Kamwesiga et al. 2017; Natta et al. 2013; Rhoda et al. 2015; Sarfo et al. 2018a; Soeker & Olaoye 2017).

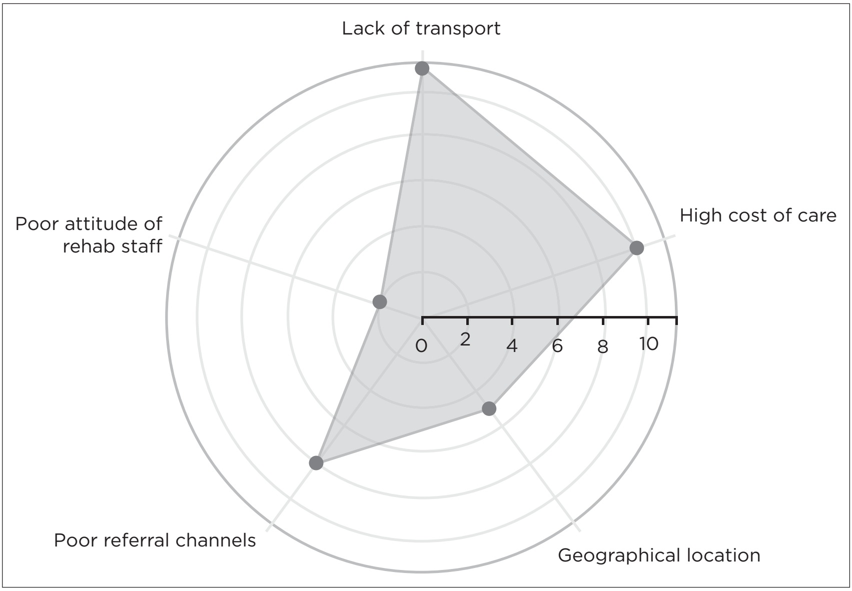


FIGURE 1.2: Barriers for access to rehabilitation services.

This inability to pay for rehabilitation services might be attributed to the high levels of poverty amongst patients and their families, and the lack of social security support from the government.

The lack of funds mostly affected access to outpatient rehabilitation services, especially for people living in rural and remote areas who were required to fund an appropriate means of transportation to and from the clinic. These challenges led to inconsistent or total lack of attendance of rehabilitation services by stroke patients, and ultimately poor rehabilitation outcomes.

Many people with stroke, and/or their caregivers, experienced difficulties accessing care either immediately after an episode of stroke (Baatiema et al. 2017a) or in attending follow-up post-discharge rehabilitation in outpatient clinics (Amosun et al. 2013; Blixen et al. 2010; Damasceno et al. 2010; Kamwesiga et al. 2017; Natta et al. 2013; Ntamo et al. 2013; Rhoda et al. 2015; Rouillard et al. 2012; Sarfo et al. 2018a).

This finding was largely because of the lack of appropriate means of transportation which took account of physical and mobility limitations. It appeared that most people with stroke and their caregivers preferred to travel in an ambulance, personal car or hired taxi; however, these options were not always available (Baatiema et al. 2017a).

The healthcare system-related barriers to access to rehabilitation services included difficulties in securing appointment for outpatient rehabilitation (Baatiema et al. 2017a), and long queues and waiting times for care (Cawood & Visagie 2015).

Large geographical distances and poor physical conditions were reported as major barriers for most stroke patients when accessing both outpatient and home-based care (Rhoda et al. 2015; Sarfo et al. 2018a; Soeker & Olaoye 2017; Urimubenshi 2015; Wasserman et al. 2009).

Similarly, the poor attitudes of rehabilitation staff were noted by some patients and their caregivers (Chimatiro & Rhoda 2014; Natta et al. 2013). Table 1.5 summarises barriers to equitable and accessible rehabilitation services.

As a result of these barriers, universal coverage of rehabilitation services in Africa was reported to be low, with variations within and between countries. Regarding within-country variations, universal coverage in South Africa was reported to be much lower in primary than in secondary and tertiary healthcare facilities (Legg & Penn 2013; Olaleye 2014; Pareck & Rhoda 2013). Regarding between-country differences, an international comparative study (Rhoda et al. 2015) reported that compared to 98% patients with stroke in South Africa, only 40% in Rwanda and 68% in Tanzania received PT rehabilitation services during their acute hospital stay.

Inadequate (non-universal) coverage of rehabilitation services in Africa was attributed to several reasons. Firstly, there was insufficient training (Sarfo et al. 2018a) or employment of the rehabilitation professionals to meet the patient needs (Cockburn et al. 2014; De Villiers et al. 2011; Hurst et al. 2016; Sarfo et al. 2017a; Wasserman

TABLE 1.5: Barriers to universal coverage of rehabilitation services.

Barriers	Reference and country	Coverage of rehabilitation services
Ratios (staff: population/ patients)	Blackwell and Littlejohns (2010) South Africa	Low ratios of speech and language pathologists compared to larger caseloads
	Cockburn et al. (2014) Cameroon	Poor staffing in facilities and high caseloads. There were less than 10 CBR providers in the entire region with only four physiotherapists with experience in stroke rehabilitation
	De Villiers et al. (2011) South Africa	At the time of the study, the facility was staffed by two occupational therapists, two physiotherapists, one speech therapist, two social workers and a dietician
	Hurst et al. (2016) Nigeria	Many patients were daily received at an ambulatory care clinic, but the personnel were not enough
	Ntamo et al. (2013) South Africa	Care at community centres was inadequate in terms of resources (equipment and human resources)
	Rhoda et al. (2015) South Africa	Limited inpatient rehabilitation services
	Sarfo et al. (2017a) Ghana	African countries had very low coverage of PT services because of low ratios of physiotherapists to general population (0.1:100 000). Coverage of PT services in rural settings where most (60%) people in Africa live was even poorer
	Sarfo et al. (2018a) Ghana	Lack of trained rehabilitation personnel, with 2.5 physiotherapists per 100 000 people served
	Soeker and Olaoye (2017) Nigeria	Inadequate coverage of rehabilitation services
	Urimubenshi and Rhoda (2010) Rwanda	Only 40% of patients received PT services during their hospital stay in Rwanda
	Urimubenshi and Rhoda (2011) Rwanda	Insufficient rehabilitation services to cater for the entire district
	Wasserman et al. (2009) South Africa	Medical doctors and other healthcare professionals (nurses, four physiotherapists, one occupational therapist, SLT, one dietician and two social workers) covering an entire municipality with a population of 184 049
Levels of care	Baatiema et al. (2017a) Ghana	Absence of national level or hospital-level community stroke awareness programmes
	Chimatiro et al. (2018) Malawi	Physiotherapy services were restricted to central hospitals only
	Hassan et al. (2011) South Africa	Some stroke patients did not receive rehabilitation services, whilst others only accessed outpatient rehabilitation at the primary care level
	Legg and Penn (2013) South Africa	In-hospital and outpatient rehabilitation services were only available at large provincial hospitals

CBR, community-based rehabilitation; PTs, physiotherapy; SLT, speech and language therapist.

Table 1.5 continues on the next page→

TABLE 1.5 (Continues...): Barriers to universal coverage of rehabilitation services.

Barriers	Reference and country	Coverage of rehabilitation services
	Olaleye (2014) Nigeria	Physiotherapy services were available at secondary and tertiary care centres
	Pareck and Rhoda (2013) South Africa	Better access to rehabilitation was available at tertiary care and not primary care. The mean length of stay was 10 days in hospital
Health insurance	Birabi et al. (2012) Nigeria	It was recommended that the government should put in place a strengthened medical insurance programme that can assist stroke sufferers' access to medical care especially PT care at affordable or highly subsidised rates that can enable sufferers to recover from this condition without disabilities. Increased funding of acute stroke medical care and rehabilitation services in hospitals was also advocated for
	Olaleye and Lawal (2017) Nigeria	There was under-utilisation of outpatient PT services because most patients had no health insurance coverage and were expected to pay for rehabilitation services out of their pocket

CBR, community-based rehabilitation; PT, physiotherapy; SLT, speech and language therapist.

et al. 2009). This situation was worse for occupational therapists and SLTs (Blackwell & Littlejohns 2010; Wasserman et al. 2009). Secondly, there were inadequate infrastructure and equipment (Ntamo et al. 2013). Thirdly, the lack of, or limited, health insurance was highlighted, which meant many people relied on the public health system (Birabi et al. 2012; Olaleye & Lawal 2017).

Quality of rehabilitation services

Information on quality of rehabilitation services in the included studies comprised elements related to effectiveness, patient centredness and timeliness as conceptualised in the WHO service delivery framework (2010). In a study from Nigeria (Olaleye et al. 2017), the majority (98%) of patients perceived that PT services contributed to their clinical conditions' improvement. This was supported by the results from another Nigerian study (Olaleye & Lawal 2017) which reported that the utilisation of inpatient PT was significantly associated with reduced length of hospital stay. However, the services provided by untrained personnel were reported to be ineffective (Soeker & Olaoye 2017).

Regarding patient centredness, patients with stroke in different African settings were satisfied with the rehabilitation services they received (Groenewald & Rhoda 2017; Olaleye et al. 2017; Sarfo et al. 2018a). However, the high cost of these services, lack of continuity of care (Olaleye & Lawal 2017) and specialised vocational rehabilitation (Duff et al. 2017) as well as insufficient service frequency and duration (Olaleye et al. 2017) were sources of dissatisfaction. Insufficient frequency and duration for the rehabilitation services could be linked to staff shortages (Blackwell & Littlejohns 2010), which could have resulted in long waiting times to access rehabilitation (Mlenzana 2018). Table 1.6 summarises information on the quality of rehabilitation services.

TABLE 1.6: Quality of rehabilitation services.

Element of service	Reference and country	Quality of rehabilitation services
Effectiveness	Olaleye et al. (2017) Nigeria	Nearly all the participants (98.3%) indicated one of good, very good and excellent improvement in their clinical conditions with PT
	Olaleye and Lawal (2017) Nigeria	Utilisation of inpatient PT was significantly associated with reduced length of hospital stay
	Soeker and Olaoye (2017) Nigeria	Hospital-based rehabilitation was replaced by unsupervised home-based rehabilitation which was ineffective
Patient centredness	Akosile et al. (2016) Nigeria	All patients were not fully satisfied with their community reintegration
	Duff et al. (2017) South Africa	Unsatisfactory rehabilitation services. Insufficient vocational rehabilitation services
	Groenewald and Rhoda (2017) South Africa	Most (81%) of participants had an excellent perceived satisfaction level towards their rehabilitation at discharge
	Olaleye et al. (2017) Nigeria	Majority expressed satisfaction with their PT care and the modal response being very good (59.3%). However, lack of continuity (being treated by different physiotherapists) and cost of care were sources of dissatisfaction
	Mlenzana (2018) South Africa	Rehabilitation services were meeting the needs of the patients although the needs of the caregivers also should be addressed in rehabilitation. Rehab service quality was poor: long waiting times and disorganisation, poor patient and caregiver satisfaction

CBR, community-based rehabilitation; OT, occupational therapy; PT, physiotherapy.

Table 1.6 continues on the next page→

TABLE 1.6 (Continues...): Quality of rehabilitation services.

Element of service	Reference and country	Quality of rehabilitation services
	Sarfo et al. (2018a) Ghana	60% of participants reported 'excellent' satisfaction with the telehealth system, 30% reported 'very good', 5% reported 'good' and 5% reported a fair experience with the post-stroke rehabilitation intervention. All subjects reported they would use the telerehabilitation intervention in the future
Timeliness	De Villiers et al. (2011) South Africa	Patients at the facility received less than 2 h of individual rehabilitation therapy per week
	Rhoda et al. (2011) South Africa	Decreased intensity of treatment received by the participants
	Amosun et al. (2013) Ghana	Physiotherapy and OT were offered at least 6 days a week, and each treatment session lasted 30 to 45 min
	Rhoda et al. (2014) South Africa	Patients received outpatient therapy once per week
	Rhoda et al. (2015). Rwanda, South Africa, Tanzania	A proportion of 40%, 68% and 98% of stroke patients in Rwanda, Tanzania and South Africa, respectively, received PT rehabilitation during acute hospital stay. The mean total number of PT rehabilitation sessions was two in both Rwanda and Tanzania and three in South Africa
	Olaleye et al. (2017) Nigeria	Patients felt the PT services they were receiving were not adequate as it was characterised by few sessions of short duration
	Olaleye and Lawal (2017) Nigeria	Frequency of PT services was inadequate (once every 3 weeks); patients found PT useful. Patients were generally satisfied with outpatient PT care. All the participants appreciated their relationship with the physiotherapists. The participants felt the physiotherapists attending to them at the clinic are being changed too often. They claim this limits the extent to which they can bond with their physiotherapist. Although they expressed that they had a good relationship with the physiotherapists, they felt the changes introduce too much variability into the treatment and treatment time is used by the new physiotherapist to get acquainted with them
	Mlenzana (2018) South Africa	Rehabilitation service quality was poor because of long waiting times and disorganisation
	Whitehead and Baalbergen (2019) South Africa	Frequency of PT services was inadequate in the outpatient's settings. CBR must be improved

CBR, community-based rehabilitation; OT, occupational therapy; PT, physiotherapy.

Continuity of care

Involvement of family members and caregivers

Family members and caregivers of people with stroke were reported to be generally confronted by many contextual challenges, including lack of transport, lack of income and having to manage complex life roles (employment, home duties and caring for the stroke sufferer).

This could contribute to lack of the stroke sufferer's engagement with community-based healthcare after hospital discharge (Blixen et al. 2010; Hassan et al. 2011). The literature also suggested that caregivers may not receive adequate support from rehabilitation professionals after their family members have been discharged from in-hospital rehabilitation (Hassan et al. 2011; Rouillard et al. 2012; Sarfo et al. 2017a; Whitehead & Baalbergen 2019). These challenges can hinder continuity of care and the stroke survivor's smooth transition from hospital to community. It can also threaten the patient's safety especially for those who are discharged with significant neuro-motor deficits which require ongoing assistance with activities of daily living (ADLs).

In attempts to improve continuity of care and engage patients, families and caregivers better, some studies recommended that patients and their families or caregivers be viewed as members of the interdisciplinary rehabilitation team right from the beginning of the patient's rehabilitation journey (Mlenzana 2018; Rouillard et al. 2012; Sarfo et al. 2017a; Whitehead & Baalbergen 2019). Moreover, the literature recommends that families or caregivers should be better supported regarding education on causes and consequences of stroke, recovery from stroke, and their role in this. Similarly, caregivers of stroke patients undergoing rehabilitation are in a prime position to give feedback to rehabilitation providers on the patient's needs and challenges.

Family members and caregivers of people with stroke can play a valuable role as therapy 'extenders' as they can assist patients daily with aspects of rehabilitation (e.g. reinforcing balance, mobility, wheelchair activities, joint mobilisation and self-care) services. Their engagement with care provided in-hospital, and in outpatient settings, can assist in relieving workload stresses on rehabilitation professionals caused by low staff numbers and high patient caseloads (De Villiers et al. 2009; Glickman & Chimatiro 2018).

☐ Post-discharge outpatient services

Most rehabilitation after discharge from hospital care occurs at outpatient rehabilitation clinics. There is sound evidence that continuing rehabilitation after the acute stroke phase improves function, and enhances the likelihood of return to work and community reintegration (Joseph & Rhoda 2013; Peters et al. 2013; Sarfo et al. 2017a).

However, for most people, regularly attending follow-up rehabilitation at outpatient clinics can be challenging because of lack of finances, variable local outpatient rehabilitation services, difficulties with transport and having to travel a long distance to healthcare facilities on poor roads, over difficult geographical terrain (Joseph & Rhoda 2013; Sarfo et al. 2017a). Because of these challenges, many patients miss out on scheduled appointments and consequently develop avoidable complications that may compromise quality of life (QoL), employability ßand family circumstances. Dealing with avoidable complications can put further strain on the already under-resourced healthcare system in many African countries and can make the rehabilitation process more difficult for patients, caregivers and healthcare providers (Peters et al. 2013).

☐ Community and home-based care

The cost of in-hospital rehabilitation is high and unaffordable for most patients (Olaleye 2014) making community-based care the preferred rehabilitation option. Community-based care is meant to be readily accessible and affordable (Urimubenshi 2015;

Wasserman et al. 2009). However, for many patients, there are no community-based rehabilitation (CBR) centres nearby which impedes continuity of care post-hospital discharge.

Patients who cannot afford community-based care or supervised home-based care resort to unsupervised exercises that can be ineffective and a threat to their safety (Soeker & Olaoye 2017) or may be lost to follow-up (Urimubenshi & Rhoda 2011; Wasserman et al. 2009). To ensure continuity of care for people with stroke in African countries, one of the studies (Natta et al. 2013) recommended a mobile phone-supported telerehabilitation programme. This intervention was feasible in most resource-poor African countries, as patients preferred it, and found it to be simple, robust, user friendly and easy to operate.

An overview of African rehabilitation found that in the East African countries of Tanzania and Rwanda, there was no post-discharge follow-up rehabilitation services for stroke patients, whilst in South Africa, follow-up services were available, but were either not comprehensive or were received by only a few stroke patients after discharge (Rhoda et al. 2015). Early in-hospital discharge with no follow-up care has been reported in Rwanda (Urimubenshi & Rhoda 2011) and in Malawi (Chimatiro & Rhoda 2014).

In Ghana, patients who were discharged with residual mild to moderate deficits were often lost to follow-up and often acted on advice by hospital physiotherapists that they did not necessarily require follow-up care, seemingly because of low staff ratio and high caseloads (Sarfo et al. 2017a). However, this differs from Kenya (Oduor 2015) where stroke patients are followed up and receive outpatient and later on home-based care after hospital discharge. Table 1.7 outlines research findings on continuity of care.

Person-centredness approach in stroke rehabilitation

There was a small amount of research on patients' acceptability of rehabilitation services. Patients generally perceived that the physiotherapists were caring, encouraging and friendly to them,

TABLE 1.7: Continuity of rehabilitation services.

Category	Reference and country	Continuity of rehabilitation services
Family members and caregivers	Blixen et al. (2010) Uganda	Non-adherence to mainstream care because of behavioural barriers like burden on caregivers. Limited follow-up because of transport
	Cawood and Visagie (2015) South Africa	Most patients received support from their immediate family
	De Villiers et al. (2009) South Africa	Families also assisted with in-hospital rehabilitation in order to reduce burden on healthcare staff. Implementation of multidisciplinary stroke care using minimal additional resources in an urban secondary hospital in South Africa
	Glickman and Chimatiro (2018) Malawi	Stroke patients' guardians in Malawi were mainly women and they offered multiple physical and psychological support on a day-to-day basis both in and out of hospital. Guardians were observed to function as therapy extenders who reinforced balance and mobility training, wheelchair activities, muscle strengthening, joint mobilisation and self-care
	Hassan et al. (2011) South Africa	Most caregivers did not get adequate support after discharge hence there was no smooth transition from hospital to community
	Mlenzana (2018) South Africa	Rehabilitation professionals involved caregivers in extending care to the home after patient discharge. Caregivers also gave feedback on patient's needs and challenges
	Rouillard et al. (2012) South Africa	Support of patients and caregivers over the transition after discharge was lacking
	Sarfo et al. (2017a) Ghana	For subjects with severe deficits, the involvement of family member as caregivers with guidance by PT or nurse assistants remotely would be essential to ensuring safety of implementation of the intervention
	Wasserman et al. (2009) South Africa	All patients discharged into family care
	Whitehead and Baalbergen (2019) South Africa	Patients and their families or caregivers should be part of the interdisciplinary team from the start. They must receive education on the causes and consequences of stroke and recovery from strokes

ADLs, activities of daily living; CBR, community-based rehabilitation; PT. physiotherapy.

Table 1.7 continues on the next page→

TABLE 1.7 (Continues...): Continuity of rehabilitation services.

Category	Reference and country	Continuity of rehabilitation services
Outpatient clinics	Amosun et al. (2013) Ghana	Patients' attendance of outpatient rehabilitation was limited because of socio-cultural beliefs and practices
	De Villiers et al. (2011) South Africa	Patients who were not severely disabled received outpatient rehabilitation services
	Joseph and Rhoda (2013) South Africa	Only 20% of the patients received follow-up medical or rehabilitation services
	Ntamo et al. (2013) South Africa	Most patients did not honour their outpatient PT appointments. Most of these patients who defaulted returned with other medical conditions. Rehabilitation became difficult for the patient and therapists after defaulting and outcomes were poor. This problem put further strain on the already under-resourced healthcare system
	Peters et al. (2013) Nigeria	Outpatient PT is essential for stroke patients after discharge from hospital
	Sarfo et al. (2017a) Ghana	Non-attendance of outpatient PT services was because of lack of money for transportation
Community or home-based rehabilitation	Chimatiro and Rhoda (2014) Malawi	No home-based care service
	De Villiers et al. (2011) South Africa	Patients received home-based rehabilitation after hospital discharge
	Hassan et al. (2011) South Africa	There were no appropriate follow-up rehabilitation services within patients' vicinity and no transport was available for patients to access services in neighbouring communities
	Hurst et al. (2016) Nigeria	Patients tried to exercise in their home with the aid of a caregiver, physiotherapist or in some cases on their own
	Natta et al. (2013) Benin	Self-rehabilitation programme post-discharge is feasible in developing countries in Africa
	Olaleye (2014) Nigeria	Increasing cost of in-hospital rehabilitation makes home-based rehabilitation more attractive. Many patients cannot afford outpatient PT and therefore end up lost in the community with no care. Primary healthcare centres are community-based and are accessible and affordable to most patients
	Rouillard et al. (2012) South Africa	Post-discharge support for patients and caregivers should be provided. Many patients required assistance with ADLs
	Sarfo et al. (2017a) Ghana	Stroke patients preferred follow-up sessions through mobile phone telerehabilitation. The telerehabilitation services should be simple, robust, user friendly and easy to operate

ADLs, activities of daily living; CBR, community-based rehabilitation; PT. physiotherapy.

Table 1.7 continues on the next page→

TABLE 1.7 (Continues...): Continuity of rehabilitation services.

Category	Reference and country	Continuity of rehabilitation services
	Soeker and Olaoye (2017) Nigeria	Hospital-based treatments for survivors were replaced by home programmes carried out by survivors without the supervision of therapists, which rendered rehabilitation ineffective
	Urimubenshi (2015) Rwanda	No CBR services were provided to stroke patients
	Urimubenshi and Rhoda (2011) Rwanda	No CBR services, patients only get hospital-based rehabilitation, and the study suggests physiotherapist should visit the stroke patients' homes to assess physical barriers
	Wasserman et al. (2009) South Africa	No rehabilitation in the communities
Lost to follow-up	Chimatiro and Rhoda (2014) Malawi	No follow-up rehabilitation services provided to the discharged patients
	Oduor (2015) Kenya	There was continuity of care after discharge from hospital
	Rhoda et al. (2015) South Africa	No follow-up rehabilitation services were available to patients, in Tanzania and Rwanda. Limited outpatient referral for South African participants
	Rouillard et al. (2012) South Africa	Many participants did not have any substantial follow-up after discharge. Follow-up after discharge was reported in few participants
	Sarfo et al. (2017a) Ghana	Patients with mild to moderate deficits were not continued on therapy because the physiotherapists advised that there was no need for continuation because of high caseloads and under-staffing
	Urimubenshi and Rhoda (2011) Rwanda	No post-discharge follow-up
	Urimubenshi (2015) Rwanda	Patients are discharged early and there is no follow-up rehabilitation post-discharge

ADLs, activities of daily living; CBR, community-based rehabilitation; PT, physiotherapy.

that they were helpful and boosted patients' confidence in the recovery process. In addition, patients appreciated the fact that they were, in most cases, able to receive answers at any time from physiotherapists to their questions (Olaleye et al. 2017).

Other evidence that speaks to the importance of a person-centred approach in rehabilitation was a report on the implementation of a mobile phone-based telemedicine programme which was personalised and goal-oriented to address the needs of individual patients (Sarfo et al. 2018a). 'Excellent' satisfaction with the programme was reported by 60% of study participants (Sarfo et al. 2018a).

For rehabilitation services to be considered person-centred, rehabilitation professionals should focus on patients' personal perceptions, expectations, experiences and values (Amosun et al. 2013; Chimatiro & Rhoda 2014; Elloker et al. 2018). The aim of rehabilitation should not necessarily be to improve neurological and motor impairments but to address environmental barriers and improve individual activity and participation capacity in order to facilitate return to work and community reintegration (Rhoda et al. 2011; Soeker & Olaoye 2017).

Coordination of rehabilitation services

Reintegration of people with stroke back to work and into the community is the ultimate aim of the care and rehabilitation process and for it to be achieved, there is a need for proper coordination of various multi-sectorial stakeholders. However, reintegration of people with stroke is a challenge in many African countries because the built environment and infrastructure in many African cities and towns are mostly not conducive to this (Blixen et al. 2010).

Moreover, the community members in society and workplaces have poor attitudes; there is stigmatisation of people with stroke as well as the general lack of patient information services regarding prevention of stroke, causes of stroke and best practice health-promotion interventions (Cawood & Visagie 2015; Rhoda et al. 2015). These challenges could be well-addressed if there was effective inter-sectorial coordination and linkages between the different stakeholder organisations, government agencies and associations.

Accountability on management and governance of rehabilitation services

Stroke rehabilitation services in Africa do not have adequate support from governments in the form of development and implementation of national stroke policy frameworks (Baatiema et al. 2017c). In the few cases where policy frameworks or practice guidelines are available (Ntsiea et al. 2012), there are few government incentives to facilitate implementation processes (Cockburn et al. 2014).

Likewise, facilitation of the development of evidence-based clinical practice guidelines (CPGs) and endorsement or implementation of guidelines by the government is rather wanting, consequently hampering provision of best practice care for people with stroke (Baatiema et al. 2017c; Kamwesiga et al. 2017). Similarly, some people with stroke in some African countries do not receive disability funding from the government social welfare agencies (Duff et al. 2017).

Stroke rehabilitation service delivery processes in some hospitals in Africa are generally ineffective because the processes are characterised by several systemic challenges such as difficulties in accessing patients' files, obtaining appointments as well as physically getting to a rehabilitation department from patients' point of entry to the hospital (Mlenzana 2018). These problems require administrative interventions by both the hospital management and the government. Moreover, there is still a dire need for government support and commitment towards increasing the workforce of rehabilitation professionals by improving the training and employment rates in order to mitigate staff shortage (Glickman 2018).

Strength, weakness, opportunity and threat analysis

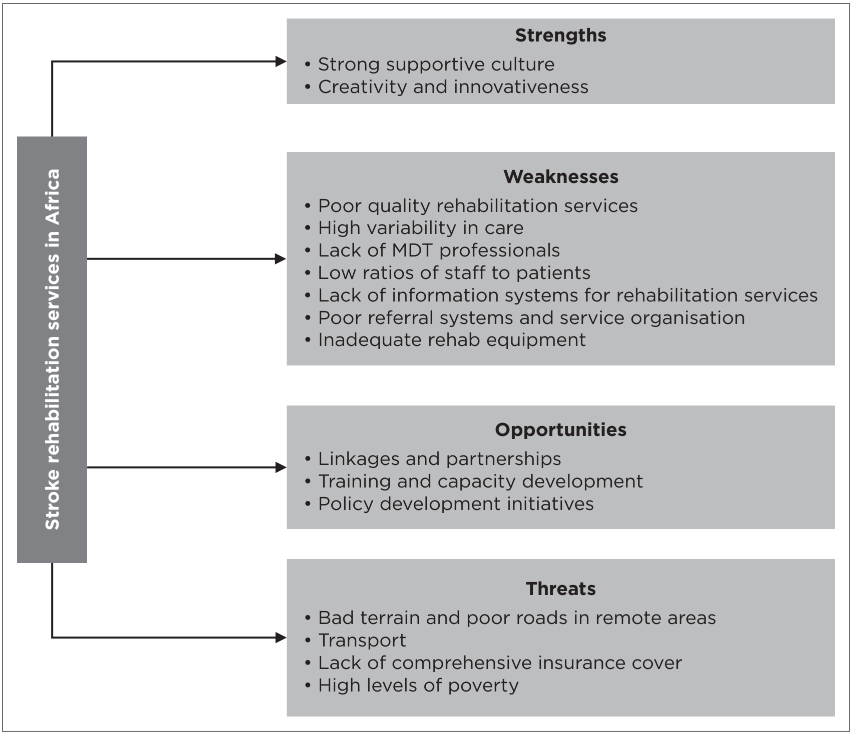
A strength, weakness, opportunity and threat (SWOT) analysis was conducted on the key findings from the reviewed studies (*n* = 51). This was undertaken to establish the weaknesses and threats which need to be minimised or eliminated, as well as strengths and opportunities that should be optimised, in order to improve the quality of stroke rehabilitation services in Africa. To undertake a SWOT analysis, the reviewers defined the SWOT items in terms of the WHO service delivery components. Table 1.8 and Figure 1.3 outline this approach.

Discussion

Stroke is an increasing concern in Africa, and particularly so in sub-Sahara Africa (Owolabi et al. 2015). In Africa, most people with stroke live in remote and rural settings, characterised by high levels of poverty and lack of good built environment and infrastructure. Rehabilitation for people with stroke is strongly recommended as it optimises function, participation, QoL, return to work and community reintegration. The WHO provides a standard framework that gives guidance on how healthcare (including rehabilitation services) can be structured and implemented. This is intended to maximise benefits and outcomes for people with stroke and minimise burdens and healthcare costs.

TABLE 1.8: Application of the strength, weakness, opportunity and threat analysis items in this review.

Item	Original definition	Translation into operational definition for this review
Strength	Internal properties of the system or organisation under study that represent a competitive advantage for that system or its own development	Aspects of rehabilitation services identified as potential or actual success or inspiration in the African context
Weakness	Limitation internal to the system or organisation under study that may hamper its progress	Barriers inherent to healthcare systems, environment and culture which hinder progress, growth and development of stroke rehabilitation service delivery in Africa
Opportunity	Any external environmental factor that may act as a facilitator to the progress of the system or organisation under study	Relevant Africa contextual factors that may be applied to improve the delivery of stroke rehabilitation services
Threat	Any external environmental factor that may act as a barrier to the system or organisation under study	External environmental or socio-cultural factors that may hinder the progress, growth and development of stroke rehabilitation services in Africa



MDT, multidisciplinary team.

FIGURE 1.3: Strength, weakness, opportunity and threat components relevant to the findings of the review.

It is therefore imperative that African healthcare systems are strengthened in order to be able to deliver effective rehabilitation services for the many people who suffer from stroke. This requires a broad understanding of the state of stroke rehabilitation services within different African countries, contexts and healthcare systems, in order to optimise strengths and opportunities and address weaknesses and threats. It is only when a complete picture of stroke rehabilitation in Africa is obtained that services can be improved for better patient outcomes.

Based on the WHO framework on health service delivery, the findings of this review demonstrate that stroke rehabilitation services in Africa are generally poor. They are characterised by lack of comprehensiveness, poor quality, low coverage, disorganisation and inconsistency and lack of adequate government support in terms of investment in policy, human resource, infrastructure and equipment. These factors potentially contribute to poor rehabilitation outcomes, the high levels of disability and low rates of community reintegration and return to work for most people with stroke, which increases societal economic burden and hinders national growth and development.

Multidisciplinary rehabilitation professionals in Africa

Best practice models on stroke rehabilitation recommend an MDT management approach where physiotherapists, occupational therapists, speech-language therapists or pathologists, social workers, nutritionists, clinical psychologists, as well as stroke nurses and neurologists or neuro-surgeons or physicians (Jesus et al. 2019), provide comprehensive and coordinated care for people with stroke.

Multidisciplinary team management should be in place from the acute phase up until community reintegration or return to work (Urimubenshi et al. 2018). This approach has been applied in most HICs and is believed to lead to better health and cost outcomes, and to minimise residual functional disability. By contrast, this review of African literature indicated that in Africa, there was generally a lack of recommended rehabilitation services. Physiotherapy services were the most reported form of rehabilitation (82%) whilst clinical psychology (7%), nutrition (14%) and social work (21%) were least reported (Baatiema et al. 2017a; Hurst et al. 2016). This confirms the widespread limited focus on comprehensive rehabilitation for people with stroke, in African healthcare systems.

The focus is on neuro-motor dysfunction and thus the provision of PT is seen as appropriate care, as this primarily addresses physical function and participation.

Even in instances where an MDT was involved (Baatiema et al. 2017a; Blackwell & Littlejohns 2010; Cockburn et al. 2014), rehabilitation services were not offered in a coordinated fashion because of lack of structured standard practice guidance. This ultimately impacted negatively on patients' outcomes.

There is an urgent need for other allied health services such as OT, speech and language therapy, clinical psychology and medical social work as well as for assistive devices (gait aids, wheelchairs and communication devices) to improve the comprehensiveness of stroke rehabilitation services in Africa. Similarly, most people with acute stroke in Africa are managed in general medical wards and therefore there is a need for healthcare systems in Africa to adopt the stroke unit model of care, which has been proven to be effective in South Africa (Pareck & Rhoda 2013). Establishing a stroke unit model of care does not necessarily require substantial additional investment in terms of human resources or equipment.

Access to rehabilitation services for people with stroke in African countries is also limited as a result of contextual and system-related challenges. These range from high levels of poverty and high cost of care (13 studies) to lack of appropriate means of transport (9 studies), as there are few ambulances whilst patients and caregivers cannot afford to hire private transport.

Coverage of rehabilitation services in Africa

The WHO health service delivery framework recommends that services are designed so that all individuals who would benefit from a particular service are reached, in relevant social and economic groups. Coverage of in-hospital rehabilitation services in Africa is mainly in the form of PT. Not only is this coverage low compared to HICs but there are variations between (Rhoda et al. 2015) and within (Olaleye 2014) African countries. The level of coverage for other well-acknowledged rehabilitation services such as OT or speech and language therapy is even worse than for PT because of low staff: high patient ratios and inadequate staff training in rehabilitation (Blackwell & Littlejohns 2010; Wasserman et al. 2009).

Quality of rehabilitation services in Africa

The quality of rehabilitation services is determined by the level of knowledge, skills and professional competencies of rehabilitation staff, the engagement of patients, caregivers and family in determining appropriate care and the extent to which service providers adhere to standard norms and practices. This review found that patients and their caregivers were satisfied with the rehabilitation services they received; however, they were dissatisfied with the low frequency and duration of rehabilitation sessions, especially during outpatient follow-up care (Groenewald & Rhoda 2017; Olaleye & Lawal 2017).

Continuity of rehabilitation services in Africa

The aim of stroke rehabilitation is to facilitate return to work and community reintegration. Therefore, seamless transition through in-hospital care to outpatient or CBR is critical, as it optimises patient outcomes. This review showed that the transition was not always smooth for most of the patients and their caregivers, as they did not receive adequate support from rehabilitation professionals once patients were discharged from in-hospital rehabilitation care (Chimatiro & Rhoda 2014; Hassan et al. 2011; Urimubenshi 2015; Wasserman et al. 2009).

The main hindrances were inadequate staffing levels at outpatient clinics (Sarfo et al. 2017a), lack of availability of CBR centres (Chimatiro & Rhoda 2014; Urimubenshi 2015; Wasserman et al. 2009) and difficulty in accessing services because of constraints on travel (Hassan et al. 2011; Hurst et al. 2016; Kamwesiga et al. 2017; Natta et al. 2013; Sarfo et al. 2018a;

Urimubenshi & Rhoda 2011). As a result, most people with stroke were lost to follow-up care.

Commitment of African governments towards rehabilitation services

Rehabilitation services for people with stroke is an essential component of a health system especially in Africa where the burden of stroke is increasing rapidly. Therefore, to ensure fulfilment of health equity, human rights and social justice to all, it is imperative for African governments, through their health systems, to ensure that service delivery for people with stroke is enhanced through evidence-informed best practice policy frameworks and facilitation of development and implementation of evidence-based CPGs for stroke rehabilitation. This would consequently improve patients' outcomes and reduce stroke-related disability and mortality.

Conclusion

Africa is facing a significant epidemiological transition as the burden of disease is shifting from communicable to NCDs. Stroke is one of the common NCDs and is increasingly becoming common in Africa, seemingly as a result of the change in socio-economic determinants of health. Most importantly, stroke in Africa affects many persons within their productive working life, and thus poses a serious threat to socio-economic growth and development.

This underscores the need for effective rehabilitation services for people with stroke in Africa in order to optimise the health of people who can contribute to the country.

The WHO has provided recommendations to strengthen health systems, which could be applied to rehabilitation services as a framework to support healthcare policy decision makers in structuring and planning rehabilitation services that meet population needs. In addition, the WHO rehabilitation 2030 call for action sensitises all stakeholders in rehabilitation to advocate for and strengthen rehabilitation across board.

This review presents evidence only from literature published in the English language and predominantly includes studies from Southern and Western African countries and findings cannot necessarily be generalised to other unrepresented languages and geographical areas. In spite of the available evidence on the need for rehabilitation services and guidance on the best strategies to support healthcare systems in delivering rehabilitation services, the main findings of this review show that the rehabilitation services for people with stroke in Africa is generally poor.

They lack the requisite components of an effective healthcare service which include, but are not limited to, comprehensiveness, accessibility, quality, accountability, continuity as well as coordination.

The poor state of rehabilitation services for people with stroke in Africa is attributable to a range of contextual factors: social, economic, geographical and system-related. These factors could only be addressed through customised intervention strategies because of the uniqueness of the African context such as physical terrain, culture and traditions, socio-economic status amongst others. Nevertheless, the uniqueness of the African context such as the deeply entrenched family values and ties that were reported in the reviewed studies also present a unique opportunity for development and implementation of innovative and culturally acceptable solutions to support the delivery of rehabilitation services at the family or community level, in line with the principles of continuity of care.

Further, results of this review underline the need for integration of rehabilitation services into health systems at all levels of care. Multidisciplinary team care should be provided wherever possible. Both in-hospital and out-of-hospital rehabilitation services should be available to all people with stroke to enhance continuity of care and improve rehabilitation outcomes. Hospitals should have specialised rehabilitation units for people with complex problems. This entails establishing stroke units instead of managing people with stroke in general medical wards. Governments should be more accountable for rehabilitation services in terms of financial resource allocation and health insurance coverage.

THEME 2

Collaborative care and communication needs

Chapter 2

A review of the communication needs of persons with stroke within the African context for application within the clinical setting

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■ Abstract

Background: Communication skills are often affected by stroke; however, the communication needs of persons with stroke in the African context are not well understood.

Aim: To identify and summarise the extent and type of research that has been published on the communication needs of persons with stroke. The chapter also aimed to describe the influence of the African context on the communication needs and possible clinical application thereof to promote evidence-based practice.

Methods: The scoping review included 11 peer-reviewed articles and used the Arksey and O'Malley (2005) framework. The country of origin for most of the studies was South Africa with representation of other African countries (i.e. Ghana, Rwanda and Uganda).

Findings: Themes of direct and implied communication needs were identified in the included studies and centred around: health knowledge, social considerations, topics, means of communication, accessing resources, vocational communication and culture and spirituality. These, largely personal factors, were considered in relation to environmental factors within the African context, including poverty, unemployment, healthcare access and informal caregivers. All these factors could contribute to the social participation and integration of persons with stroke.

Conclusion: The African context directly affects the multiple factors influencing communication needs. Improved understanding of these factors will result in the practice of evidence-based healthcare, which could ultimately contribute to communication outcomes for persons with stroke.

Keywords: Communication needs; Persons with stroke; African context; Clinical setting; Resources.

Background

The increase in stroke events in Africa can be attributed to multiple and complex risk factors such as population growth, unchecked industrialisation and an increased consumption of Western diets (Adeloye 2014). Whilst the aetiology of stroke occurring in older persons is more likely related to age-related atherosclerotic risk factors (Smajlović 2015), the causes of stroke in young people are more varied and complex. In the context of a developing region, risk factors for strokes occurring in young people could include neurological complications of infectious diseases (Abdallah et al. 2018), lifestyle diseases such as HPT (Adeloye 2014), dyslipidaemia and diabetes mellitus, smoking and drug abuse, poor nutritional status and environmental stressors (Sarfo et al. 2018b). Genetic risk factors, non-modifiable risk factors such as genetics and pregnancy (Cotoi et al. 2018; Feske 2007) and the use of oral contraceptives for women have also been identified as known contributors to the causes of stroke in young people (Marini, Russo & Felzani 2011).

Regardless of age, cultural or spiritual background, many persons with stroke experience a multitude of sequelae, including physical, emotional, cognitive and communication difficulties (McGrath 2004). Persons with stroke and their families often need to adapt to new roles (or positions) in their households, which can contribute to decreased self-esteem and an increased burden of care on spouses and other caretakers (Bernath 2005; Magwood, White & Ellis 2017; Singhal et al. 2013).

Communication-related difficulties may manifest as cognitive, language and/or speech impairments. Language impairments, such as aphasia, occur in an estimated 30% of persons affected with stroke (Flowers et al. 2013). This condition affects people's ability to understand and/or use language for communicative purposes. Speech impairments, which can manifest as poor speech intelligibility, often include dysarthria, occurring in approximately 42% of stroke cases (Flowers et al. 2013). Moreover, oral and/or verbal apraxia can commonly occur alongside dysarthria and aphasia (Duffy 2013). Communication difficulties usually impact on the person affected with stroke's participation in daily activities and social engagement, and if this is compromised, it can contribute to a decreased QoL.

Although similar rehabilitation is often provided to both young and older persons affected with stroke, younger persons with stroke may present with unique communication needs because of their age and life stage (Teasell, McRae & Finestone 2000). Recent studies have explored the unique concerns that young persons affected with stroke face, although the emphasis has largely been on returning to work (Musser et al. 2014), with concerns focused on the loss of productive working years (Cabral et al. 2017; Lawrence 2010; Magwood et al. 2017; Singhal et al. 2013). Morris (2011) reported that the most unmet needs of stroke-affected young persons included information about the stroke, assistance with finances, intellectual fulfilment and social contacts.

Speech-language therapists aim to manage communication impairments suffered by persons with stroke. In doing this, they fulfil an important role in not only identifying and treating specific communication disorders but also in encouraging participation in daily activities. For the purpose of this chapter, the Life Participation Approach to Aphasia (LPAA) (Chapey et al. 2008) was chosen to explore the extent to which participation in daily activities is affected by communication difficulties. The LPAA deals with body functions and structures, activities, personal contexts and environmental factors, which are essential features of human functioning (WHO 2001).

The LPAA proposes that enhancement of participation involves a consumer-driven, service delivery approach, and it encourages SLTs to consider persons with stroke with communication impairments within their everyday contexts (Chapey et al. 2008). Persons with stroke should be involved in choosing their own therapy goals, which aim to improve participation in their individual contexts. As the LPAA advocates for social reintegration of persons with stroke, personal and environmental factors need to be considered during communication intervention (Shadden & Hagstrom 2007). Environmental factors in African contexts include issues such as unemployment, poverty, health infrastructure, costs and access.

According to the International Labour Organization (2016), unemployment rates in Southern Africa ranged from 32.7% in South Africa, to 93.5% in Uganda, whilst Northern Africa had the highest unemployment rate in the whole African region. In a context in which employment is already scarce, young African persons with stroke may therefore be additionally disadvantaged by long-term, post-stroke sequelae, with up to 80%–90% of young persons with stroke experiencing unemployment after the stroke (Morris 2011). Persons with stroke who experience communication difficulties, as well as their partners, indicated they experienced strained household circumstances, increased financial pressure on families and an increased burden of care on families because of the loss of income (Bernath 2005; Lawrence 2010; Legg 2010). The pensions of older persons with stroke are often directed towards supplying basic needs for their families, because of high unemployment rates amongst working-age adults (Hlati 2017).

Widespread poverty influences access to support infrastructure and has been linked to multimorbidity, affecting individual opportunities for participation for persons with stroke (Penn & Armstrong 2017). According to the Lancet Healthcare Access and Quality Index (Barber et al. 2017), South Africa ranked 119th amongst 195 countries. The ranking was influenced by high mortality rates, constrained healthcare access across populations, as well as the high cost of healthcare and health interventions. However, South Africa was ranked higher than most African countries (for instance Gabon and Botswana), but it ranked below Namibia, which highlights the differences in resources, healthcare priorities and contextual issues across Africa.

Deficits in healthcare infrastructure are largely responsible for the poorer health outcomes for young persons with stroke, compared to patients in HICs (Abdallah et al. 2018; Penn & Armstrong 2017). The lack of appropriate skills, high patient to low healthcare professional ratios, limited healthcare facilities (including rehabilitation services), cultural and linguistic barriers and difficulties in translating knowledge and policies into practice, have been reported as challenges prevalent in the South African public healthcare sector (Khoza-Shangase & Mophosho 2018). Late diagnosis of stroke because of limited awareness of signs and symptoms of stroke, and limited access to healthcare, is common in many African contexts (Sarfo et al. 2018b). Late diagnosis can result in inadequate stroke management and rehabilitation that would have been possible with an early diagnosis. Urbanisation may result in improved access to health services, yet it can be accompanied by strained and crowded living conditions, increased exposure to crime and exploitation and decreased family support for the person affected with stroke, leading to support being sought from the church, neighbours and support centres (Legg 2010). Many persons with stroke opt to return to rural areas, where they may be able to access increased familial support, but where health infrastructure may be even further fragmented and where treatment-seeking pathways often include traditional medicine and community resources (Penn & Armstrong 2017). In Africa, the caring and support of persons with stroke often becomes the responsibility of family members. Because of the increasing incidence of stroke, there is a greater burden on informal caregivers; however, informal caregivers are often ill-prepared to take on this role and to assist persons with stroke within their home environment (Cotoi et al. 2018).

An important environmental factor relating to healthcare infrastructure is that rehabilitation services for people with communication difficulties continue to be underdeveloped in sub-Saharan Africa (SSA) (Wylie et al. 2016). A major concern is the lack of availability of SLTs. A workforce density of between 0 and 6 SLTs per million population is believed to exist in SSA (Wylie et al. 2016). In South Africa, where the SLT profession is better established than in other SSA countries, the SLT-to-total population ratio is estimated as 1:48 000 (Kathard & Pillay 2013). However, even when SLT services are available, concerns such as a lack of contextually relevant resources and materials, as well as language barriers between SLTs and persons with stroke, can complicate communication rehabilitation (Khoza-Shangase & Mophosho 2018).

A challenge in the African context is the range of lived experiences and expectations of persons with stroke, including their understanding and experiences of disability (Penn & Armstrong 2017). The role of culture in shaping understanding and perceptions of health should be central to inform approaches to management, as issues of personal and social identities are based on culture and could affect participation in communication intervention (Legg 2010). For example, it has been increasingly recognised that research related to traditional and spiritual beliefs about causes and treatment of stroke is required, in order to inform culturally relevant stroke management. Considerations should include the complex socio-cultural rules across ages and generations (Legg 2010) and the central role of language and communication in culture (Penn & Armstrong 2017). These issues may influence the social communication needs of a person affected with stroke, as well as their interaction with health professionals who may not share their linguistic and cultural background (Penn & Armstrong 2017).

Despite research conducted to date, there is limited clarity on the communication needs of persons with stroke, especially how these relate to their social needs, experiences and identities. Given the unique contexts of Africa, it is essential that client-based and needs-specific communication intervention are offered to all persons with stroke, with the goal of improving their social reintegration and participation in daily activities. This chapter describes current evidence of the communication needs of persons with stroke in Africa.

This chapter reports on a systematic scoping review of relevant literature, which investigated best practice in addressing communication needs of persons with stroke within African contexts.

Methods

Research question

What are the communication needs of persons with stroke within African contexts?

Research framework

A scoping review of the literature was chosen to interrogate the suspected limited body of evidence of relevant research on the communication needs of persons with stroke in Africa. The methodological framework suggested by Arksey and O'Malley (2005), and further refined by Levac, Colquhoun and O'Brien (2010), was employed. The scoping review for this chapter followed the first five steps of this methodological framework.

Step 1: Defining the review objectives

The review objectives were to:

1. identify and summarise available literature on the communication needs of persons with stroke in Africa
2. determine the extent and type of research that has been published in this area
3. describe how African contexts influence the communication needs of persons with stroke
4. discuss the findings in terms of clinical application in African contexts
5. promote the uptake of evidence-based SLT practice.

Step 2: Identifying relevant studies

Search strategy

Studies were identified by searching electronic databases most relevant to the review question, and comprising MEDLINE (PubMed), EBSCOhost (CINAHL, Africa Wide and Academic Search Premier), Web of Science, Scopus, GoogleScholar and Sabinet. The search was conducted in conjunction with a librarian at Stellenbosch University (SU). Relevant grey literature and higher degree dissertations were also sought by searching SUNScholar, Sabinet, Nexus, DATAD and IR Space. Conference proceedings were searched using the All Academic research site.

The search terms were: (Stroke [Mesh] OR CVA OR cerebrovascular accident OR aphasia OR dysarthria OR apraxia) AND (communication needs OR communication preferences) AND (Africa).

Data management: The literature identified by the search was managed by Mendeley software to increase efficiency of the review process. This software saved the identified articles, removed duplicates, allowed for efficient screening of titles, abstracts and full texts and organised articles (Peters 2017).

Eligibility criteria

Literature published between 2000 and 2018 was sought. This timeframe reflected an increase in the use of technology, as well as in survival rates from strokes, which could have influenced research into the communication needs of persons with stroke. Further motivation for limiting the search to literature published after 2000 includes an increase in strokes affecting younger individuals alongside the quadruple burden of disease in under-resourced countries, an increase in urbanisation and the changing landscape of communication needs in relation to rapidly developing technology. All relevant peer-reviewed research designs were included, although only English-language articles were included. The inclusion criteria filter applied throughout the screening process was that literature should address a diagnosis of 'CVA' or 'Stroke', make reference to direct or implied communication needs and report research conducted in Africa. Two books and one special edition journal could not be accessed because of financial constraints.

Step 3: Study selection

Title screening was conducted by three researchers, using the eligibility criteria. Where it appeared that articles were appropriate from the title, two researchers screened the abstracts against the inclusion criteria and then potentially relevant full-text articles were screened by pairs of researchers. They were retained if they met the inclusion or exclusion criteria and answered the research question. The references of the retained articles were then reviewed for relevance to the review objectives.

Step 4: Extracting and charting the data

Arksey and O'Malley's (2005) suggestions were followed regarding a standard data extraction form. The form developed for this review included details of author, year of publication, study location, study population, methodology, communication needs and any other important findings.

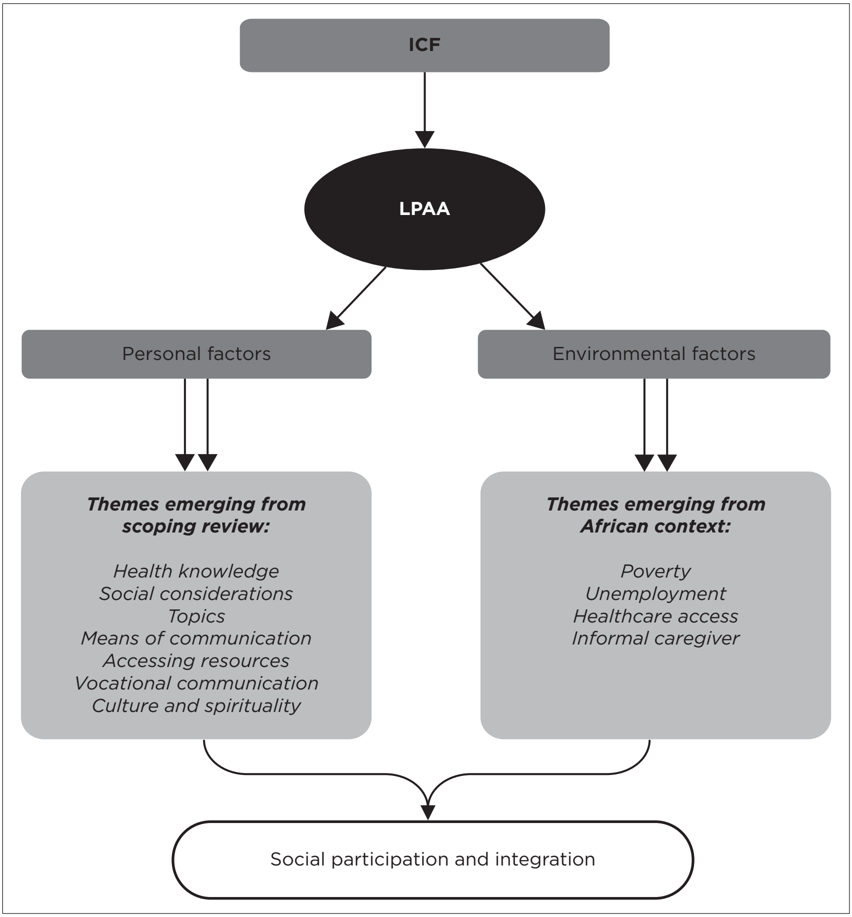
Step 5: Collating, summarising and reporting results

Arksey and O'Malley (2005) suggest that the collected data be analysed numerically, as well as thematically. Numerical analysis allows for the emphasis of the most frequently researched communication needs, the research designs and geographic location of studies, and assists in identifying the gaps in research evidence. Thematic analysis was used to compress large amounts of data to discover and describe content-related categories. As thematic analysis of the dataset includes different methodological designs, both descriptive statistics and narrative analysis were used. Content analysis was undertaken via a structured framework that allowed classification and analysis of the data into codes (Rose, Spinks & Canhoto 2015). The included articles were analysed according to direct and implied communication needs, as well as other important findings.

The LPAA framework was then employed (Figure 2.1) to conceptualise the emerging communication needs from the dataset into themes (personal factors) within the African context (environmental factors). The personal factors that emerged from the dataset included: health knowledge, social considerations, topics, different means of communication, accessing resources, vocational communication needs and culture relevance and spiritual needs. Environmental factors were drawn from contextual information related to the African context from previous research and included: poverty, unemployment, healthcare access and the informal caregiver.

Results

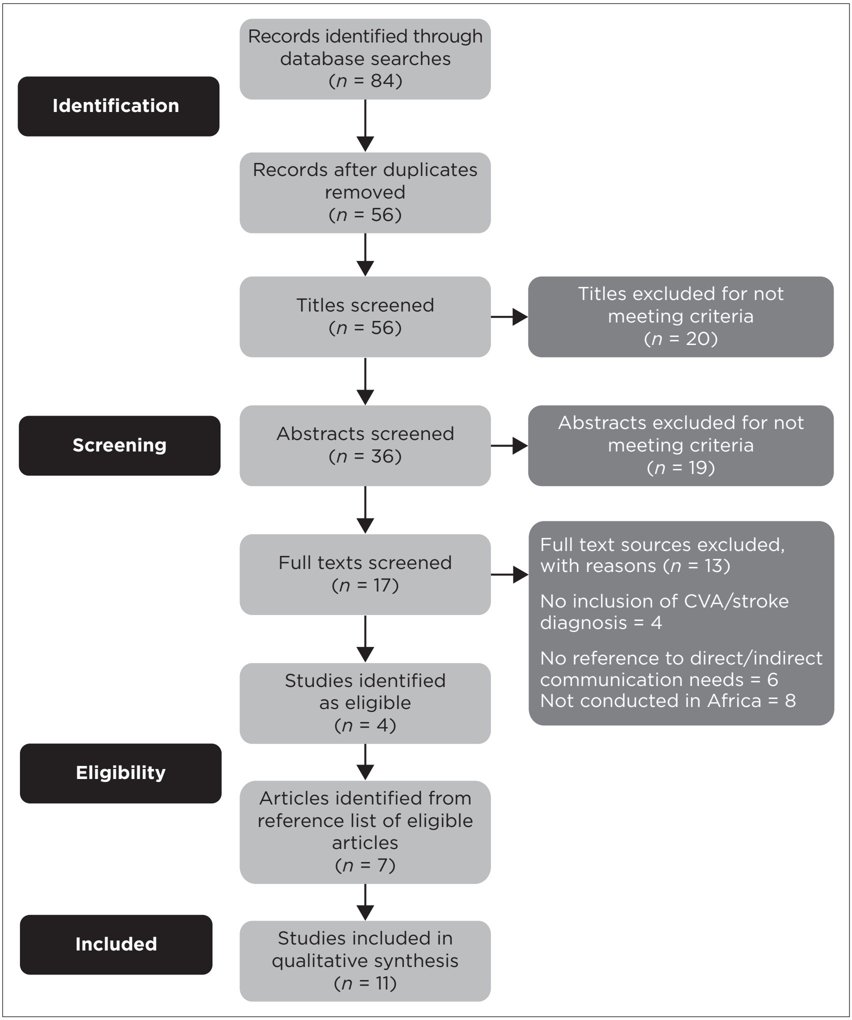
The search yielded a total of 56 articles, of which 20 were excluded following first-level screening (Figure 2.2). After screening abstracts, 21 articles were excluded, and 17 articles proceeded to full-text screening. After this level of screening, only three articles and one unpublished thesis were considered



ICF, International Classification of Functioning, Disability and Health; LPAA, Life Participation Approach to Aphasia.

FIGURE 2.1: Framework of analysis with emerging themes.

relevant to the review. The reference lists of the included studies were then searched manually, and a further five articles and two unpublished theses were included. Thus, the final dataset consisted of seven articles and four theses.



CVA, cerebrovascular accident.

FIGURE 2.2: Preferred reporting items for scoping review and meta-analyses – Scoping review flow diagram.

Study description

Table 2.1 provides an overview of the included studies.

TABLE 2.1: Characteristics of included studies in chronological order (*n* = 11).

Author (year)	Country	Study design	Sample characteristics	Aim	Reference to communication needs (direct and implied)
Bernath (2005)	South Africa	Mixed methods, cross-sectional, parallel case studies	Four persons with stroke with communication difficulties who receive speech therapy	To investigate the social participation of adults with aphasia using patient-centred measures and encompassing the views of the families, particularly the spouses, of those with aphasia	(1) Building and maintaining social relationships to prevent loss of contact with friends and family; (2) spiritual communication needs; (3) use of technology: phone; (4) literacy needs; and (5) changing social roles: decreased self-esteem, need to adapt to new roles in the family
Bham and Ross (2005)	South Africa	Qualitative, descriptive case study, semi-structured interviews	10 caregivers of persons with stroke and 10 traditional healers	To investigate the beliefs of caregivers and traditional healers within the South African Indian Muslim community regarding cause and treatment of stroke and the persons likely to be consulted in this regard	(1) Spirituality: prayer, access, relevance, perceptions of traditional healers; (2) changing social roles: self-confidence; (3) communication of basic needs; (4) health-seeking behaviour; and (5) cultural relevance

AAC, augmentative and alternative communication.

Table 2.1 continues on the next page→

TABLE 2.1 (Continues…): Characteristics of included studies in chronological order (n = 11).

Author (year)	Country	Study design	Sample characteristics	Aim	Reference to communication needs (direct and implied)
Legg (2010)	South Africa	Qualitative, longitudinal, ethnographic	Five persons with aphasia followed longitudinally (6 months – 3 years); interviews and focus groups with stakeholders, families, other persons with aphasia	To explore the experience of aphasia in Khayelitsha, a township on the outskirts of Cape Town characterised by poverty, violence, limited resources and a culture and language that differs from the setting of most speech and language services in South Africa	(1) Vocational communication; (2) building and maintaining social relationships; (3) spirituality; (4) changing social roles: need to discuss family social and financial circumstances; (5) access to AAC; (6) access and ability to communicate healthcare needs; and (7) literacy needs
Amosun, Nyante and Wiredu (2013)	Ghana	Mixed methods, descriptive	200 persons with stroke, > 3 months post-stroke, aged 18–65, reasonable comprehension needed to complete the survey and interviews	To assess the perceived and experienced restrictions in participation and autonomy amongst persons with stroke in Ghana	(1) Spirituality: worship; (2) need to discuss changing social roles; (3) topics: finances; and (4) maintaining and developing social relationships: family gatherings

AAC, augmentative and alternative communication.

Table 2.1 continues on the next page→

TABLE 2.1 (Continues...): Characteristics of included studies in chronological order (*n* = 11).

Author (year)	Country	Study design	Sample characteristics	Aim	Reference to communication needs (direct and implied)
Beringer, Tönsing and Bornman (2013)	South Africa	Quantitative, descriptive	10 persons with stroke with moderate to severe aphasia and adequate comprehension, and their caregivers	To determine the topic preferences of adults with aphasia by providing them with the opportunity to pre-select their preferred topics of conversation. To compare the self-selected and partner-predicted topic preferences	Preferred topics
Urimubenshi (2015)	Rwanda	Qualitative, phenomenological approach	10 persons with stroke needing assistance with at least one activity post-stroke; severe communication difficulties excluded	To explore the activity limitations and participation restrictions experienced by persons with stroke in Musanze district in Rwanda	(1) Vocational communication: return to work; (2) building and maintaining social relationships: social interactions; and (3) spirituality: participating in religious activities

AAC, augmentative and alternative communication.

Table 2.1 continues on the next page→

TABLE 2.1 (Continues…): Characteristics of included studies in chronological order (n = 11).

Author (year)	**Country**	**Study design**	**Sample characteristics**	**Aim**	**Reference to communication needs (direct and implied)**
Cawood and Visagie (2015)	South Africa	Mixed methods, descriptive	Quantitative: 53 persons with stroke; qualitative: 5 persons with stroke	To determine environmental barriers and facilitators to participation experienced by a group of persons with stroke in the Western Cape province of South Africa	(1) Literacy needs; (2) communicating transport needs: (3) need for AAC; (4) use of technology; (5) cultural relevance of materials; and (6) changing social roles: support of family and attitudes
Opoku (2016)	Ghana	Qualitative, descriptive	10 young persons with stroke, one-year post-stroke	To explore the experiences of young adults (18–45 years) living with stroke in Ghana	(1) Spirituality: need to participate; (2) health knowledge: stroke linked to illness of the old, witchcraft when affecting younger persons; (3) vocational communication; (4) health-seeking behaviour: about stroke and prognosis; and (5) building and maintaining social relationships

AAC, augmentative and alternative communication.

Table 2.1 continues on the next page→

TABLE 2.1 (Continues…): Characteristics of included studies in chronological order (*n* = 11).

Author (year)	Country	Study design	Sample characteristics	Aim	Reference to communication needs (direct and implied)
Kamwesiga, Tham and Guidetti (2017)	Uganda	Qualitative, semi-structured interviews	11 persons with stroke, 2 months post-stroke who owned a phone before and after stroke; 9 caregivers	To describe the experiences and meaning of using mobile phones in everyday life after stroke, amongst persons with stroke and their family members in Uganda	(1) Need to use technology: phone; (2) technology promoting sense of belonging; and (3) building and maintaining social relationships: staying connected
Penn and Armstrong (2017)	South Africa (and Australia)	Reflective review, drawn from several qualitative studies	Several qualitative studies included that focused on persons with aphasia in Indigenous populations	To explore the role of culture in aphasia in Indigenous populations, drawing from a body of emerging research, highlight relevant dimensions of understanding and practice for the aphasia clinician	(1) Use of technology: phone; (2) building and maintaining social relationships; (3) changing social roles: identity; (4) accessing healthcare and health promotion; and (5) cultural relevance of resources and information
De Grass-Clementson (2018)	South Africa	Quantitative, descriptive	22 young persons with stroke (aged <45 years); 40 older persons with stroke (aged >45 years)	To describe the communication needs of younger and older persons with stroke in the Western Cape, South Africa	(1) Difficult communication situations; (2) challenging communication and literacy skills; (3) preferred topics; and (4) preferred partner strategies

AAC, augmentative and alternative communication.

Country of origin

Seven of the 11 included studies were conducted in South Africa (64%), with the remaining four studies originating from three other African countries: Ghana (18.2%), Rwanda (9.1%) and Uganda (9.1%). It is important to note the Gross Dometic Product (GDP) for these countries to provide the country context. As of December 2018, the GDP rankings in Africa were as follows: South Africa ranked second with a GDP of 366.30, followed by Ghana at the ninth place with a GDP of 65.56 and then Uganda in the 18th position with a GDP of 27.48 and Rwanda in the 35th position with a GDP of 9.51 (Trading Economics 2019).

Participants

All studies included participants who had sustained strokes; however, not all studies specified the severity of the communication difficulties. Limited studies included persons with stroke with moderate to severe communication difficulties.

Study designs

Four methodological designs were reported (Table 2.1). The majority were qualitative studies (5), followed by cross-sectional quantitative designs (3), mixed methods (2) and one qualitative reflective review.

Timeframe of reporting

The included studies were conducted between 2005 and 2017. Eight of the 11 included studies had been conducted since 2010.

Communication needs

Forty-four direct and implied references were made to communication needs in the included studies. These references were grouped into the following categories during the thematic

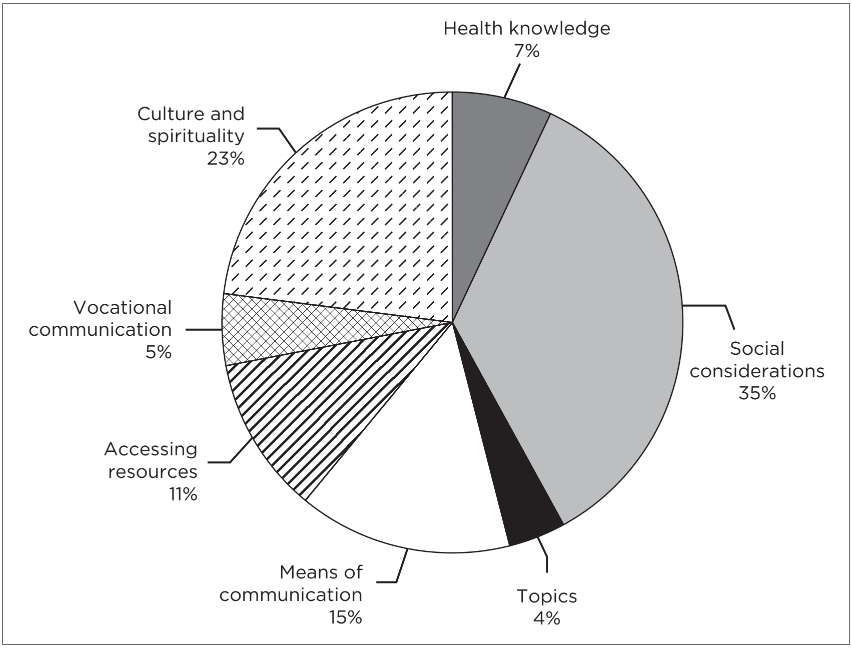


FIGURE 2.3: Representation of the themes that emerged in the included studies.

analysis (Figure 2.3): health knowledge (3), social considerations (15), topics (2), means of communication (7), accessing resources (5), vocational communication (2) and culture and spirituality (10).

■ Health knowledge

Lack of information regarding healthcare and healthcare options has been identified as a major barrier to intervention, especially in the younger stroke-affected population (Opoku 2016). Poor access to healthcare, as well as limited knowledge about available healthcare options, was reported to negatively influence the rehabilitation process of persons with stroke, and also result in poor support for caregivers. In an earlier study exploring cultural views of stroke, Bham and Ross (2005) indicated a lack of community awareness regarding the role of the SLT in post-stroke rehabilitation, which can result in persons with stroke making uninformed decisions regarding their rehabilitation and potentially contributing to poorer functional outcomes. Persons with stroke indicated that the lack of knowledge about stroke in combination with communication difficulties often resulted in their inability to ask questions and gain information regarding their health options. Medical personnel were also reported to be poorly educated regarding the facilitation of healthcare questions in persons with communication difficulties, leaving a common communication gap between parties. The need therefore exists for persons with stroke to participate in health-promotion activities, as well as to be facilitated to ask questions about the availability and appropriateness of healthcare options (Penn & Armstrong 2017).

Social considerations

Changing social roles

After a stroke, many persons with stroke are unable to pursue their former social roles, and thus need to come to terms with, and adjust to, new social roles. This could include reduced involvement in managing household finances or undertaking regular household activities where communication is paramount (Opoku 2016). Adjusting to these new roles can result in decreased self-esteem (Bernath 2005; Opoku 2016), loss of self-confidence (Bham & Ross 2005) and can be a source of stress (Opoku 2016), as many persons with stroke experience a sense of abandonment, loss of contact with partners and poor support provided by family members. Penn and Armstrong (2017) also identified feelings of uncertainty, vulnerability and isolation in persons with stroke who have communication difficulties. Family members can also be affected by the changing social roles, for example, child rearing may be neglected to focus on caring for the person with stroke, which can further contribute to strained circumstances in the home. Exclusion of the person with stroke from family discussions has also been reported (Legg 2010).

Managing finances is a complex higher-order task for any individual, and much more so for persons with a stroke, especially if they had the role of managing finances in the household prior to the stroke. Legg (2010) explored the challenges that are faced by persons with stroke when it came to addressing concerns regarding finances within the home environment, especially where family dependence on monthly disability grants and pensions were at the centre. This study highlights the need to also talk about the current household financial status, considering that many young persons with stroke might not be able to adequately fulfil their role as breadwinners or contributors to the household as they did previously (Cabral et al. 2017).

The need exists for persons with stroke to discuss their changing social roles, and the subsequent effect this has on their households and the wider community (Amosun et al. 2013). This may include consideration of familial, social and financial circumstances (Cawood & Visagie 2015).

Building and maintaining social relationships

Persons with stroke might have difficulties re-establishing social interactions, which include building and maintaining social relationships (Opoku 2016; Urimubenshi 2015). According to Amosun et al. (2013), most restrictions in participating in social and family events are self-imposed. In this study, 19% of persons with stroke reported experiencing difficulties with participation in social activities and relationships. The three most difficult communication skills identified by young persons with stroke were being part of a conversation (73%), explaining their communication difficulties (73%) and following commands (64%) (De Grass-Clementson 2018). Older persons with stroke identified sharing stories (60%) as a difficult communication skill. Reduced engagement in social activities such as attending church or family gatherings could contribute to feelings of social isolation (Legg 2010). Being avoided, feeling excluded and/or experiencing emotional abuse by family members (Amosun et al. 2013; Legg 2010) could further exacerbate these experiences, based on poor social relationships and a lack of effective communication. Young persons with stroke reported finding talking about personal issues and money-related enquiries (55%) difficult, whilst for the older persons with stroke, the second most difficult situations were speaking to people in general contexts (55%) (De Grass-Clementson 2018). Bernath (2005) reported significant changes in the social participation of persons with stroke, which was felt by spouses as well. Communication needs for engaging in social activities as a means of building and maintaining social relationships are evident from these studies.

Preferred strategies of social partners

The preference of persons with stroke regarding the communication strategies used by caregivers and conversational partners has an influence on communication effectiveness and the empowerment of the person with stroke. Most young persons with stroke preferred that communication partners indicated what they understood when a communication breakdown occurred (77%). They also preferred that communication partners guess or complete words (73%), and that they identify the semantic category of intended words (68%). The older persons with stroke identified that fixing communication breakdowns was the third most difficult communication skill. The older persons with stroke preferred communication strategies that focused on not being interrupted (78%), providing affirmation on what was understood (75%) and being asked questions to create more opportunities to explain the message they wanted to impart. The least-preferred communication strategies for both young and older persons with stroke included the multi-modal approach where gesturing, drawing or writing could be incorporated to ensure successful communication (De Grass-Clementson 2018).

Topics

Beringer et al. (2013) focused on the active involvement of persons with stroke in pre-selecting conversational topics, especially in the use of augmentative and alternative communication (AAC). Although the caregivers are often the primary informants of conversational topics, their chosen topics may not always be compatible with those that the person themselves would have chosen. This study showed an average accuracy of 65% obtained between topics selected by the caregiver and those indicated by the person with stroke.

Topics of importance identified by persons with stroke included health and/or rehabilitation-related issues specifically regarding speech therapy, OT and rehabilitation progress; topics related to people, especially children, family and friends; as well as topics regarding the persons with stroke themselves, such as hobbies, job opportunities and transport (Beringer et al. 2013). De Grass-Clementson (2018) found that preferred topics were dependent on age, as 82% of the young persons with stroke preferred to talk about their house, things to fix, their medical diagnosis and associated difficulties, and 77% preferred hobbies, family history and favourite meals or restaurants as preferred topics. The older persons with stroke, however, preferred topics that included the weather (80%), the house and things to fix (78%) and family history or sport (70%). Bham and Ross (2005) reiterated the importance of encouraging persons with stroke to participate in personally relevant activities or tasks, through the provision of appropriate vocabulary for conversational topics regarding basic needs, religion and culture.

Means of communication

Use of technology and social connectedness

A lack of access to telephone services and an inability to communicate via the telephone can result not only in difficulty in maintaining relationships with friends and family but can also leave the person with stroke with the inability to contact emergency and healthcare services when needed (Cawood & Visagie 2015). Talking on the telephone was indicated as the most difficult communication situation for all aged persons with stroke, reported by 59% young and 60% older persons with stroke, respectively (De Grass-Clementson 2018). In Bernath's (2005) study, no participant was willing to answer the telephone at home, and only two were willing to communicate with family members using the telephone.

Kamwesiga, Tham and Guidetti (2017) reported that persons with stroke felt that a mobile telephone could be a necessary 'lifeline' in complex everyday situations. This study advocates for the need to effectively use a mobile telephone for benefits such as communicating and building connections with other people; structuring routine daily activities; facilitating social and economic well-being; promoting belonging and participation in social relationships; facilitating reintegration in communities and enabling the persons with stroke to feel safe and secure.

Literacy

Many persons with stroke indicated enjoying reading as a recreational activity (Cawood & Visagie 2015). However, reading and writing difficulties may occur after suffering a stroke. In a study by Bernath (2005), all four of the participants reported experiencing some reading and writing difficulties, which can restrict access to, as well as influence the efficiency of, using written communication means (such as emailing). Three of the four participants also indicated difficulty with tasks such as reading newspapers and compensated for this by watching television instead. Older persons with stroke (68%) identified spelling as the most difficult communication skill. Reading difficulties were also reported to be a concern related to participation in religious activities, as many religions make use of texts and other written resources during activities. De Grass-Clementson (2018) indicated that both young and older persons with stroke indicated similar literacy needs which include: reading of religious material, 95% and 85%, respectively, as well as reading of newspapers and magazines. Needs pertaining to writing for all aged persons with stroke included the ability to write lists of things to buy, make note of appointments and be able to write letters and cards.

In the included studies, the ability to read and write on instant messaging via mobile telephones was regarded as the most important skill by young persons with stroke. Literacy impairments in young persons with stroke could also influence work-related activities, and also result in difficulty with administrative tasks such as completing forms (Legg 2010). Thus, the need for client-specific, contextually relevant literacy support was indicated, with the goal of promoting participation in home, community and workplace settings; as well as independence in accessing information.

Alternative and augmentative communication

Cawood and Visagie (2005) noted that even though there is less need for specialised communication devices amongst persons with stroke (compared with other types of assistive devices), a basic pictographic communication board can make a significant difference in communication and increase participation in daily activities. Legg (2010) explored other communication means, such as gesture and facial expressions to supplement the limited verbal output or making use of neighbours and family members to deliver messages. The need for appropriate augmentative and/or AAC options for persons with stroke with communication impairments is highlighted by these studies.

Accessing resources

Medical purposes or accessing healthcare

Perceptions of healthcare professionals' levels of sympathy can influence access to healthcare facilities for persons with stroke (Legg 2010). They reported not being helped often because of their limited ability to communicate their health needs; and thus, they faced challenges when negotiating follow-up appointments and medications with healthcare professionals. This resulted in persons with stroke being willing to travel to facilities further away, where they experienced more sympathetic support from healthcare professionals. Legg (2010) also identified infrequent referrals made to follow-up SLT services on discharge from healthcare facilities, which can limit the access to support for persons with stroke with communication difficulties.

According to Amosun et al. (2013), 23% of persons with stroke perceived restrictions in participation and autonomy in managing their finances. The difficulties that persons with stroke experience with numeracy post-stroke may exclude them from independently completing financial transactions or even activities such as shopping (Bernath 2005). Financial strain can also lead to poor healthcare appointment attendance, over which persons with stroke often have no control. Applications for disability grants are also difficult to secure because of procedural barriers, and they may often not be approved for persons with stroke because of perceptions of cognitive and communicative difficulties not being sufficiently severe to qualify as a disability (Cabral et al. 2017; Penn & Armstrong 2017).

Accessing transport

In poorer areas of Africa, many persons with stroke are limited to using minibus taxis as transport, as their physical disabilities often prevent them from using other forms of transport such as trains and buses. De Grass-Clementson (2018) found that older persons with stroke (50%) indicated that accessing transport was one of the most difficult communication situations they encountered. Not only are minibus taxis generally more expensive than other forms of public transport, but the drivers are often pressed for time, which puts additional pressure on the person with stroke to respond quickly and effectively in hurried and noisy environments. The ability of persons with stroke to ask for, or physically navigate, transport has been reported as a major barrier for regular contact with family and friends who live further away. This can negatively influence the availability of social and emotional support for persons with stroke (Cawood & Visagie 2015). Communication needs surrounding accessing transport would thus include requesting transport and indicating direction or addresses.

Consideration of communication needs related to environmental factors within the African context

Although there are many differences between African countries, there are common environmental factors that need to be considered when discussing the communication needs of young and older persons with stroke. The main emerging environmental factors for the African context included unemployment, poverty, healthcare access and the informal caregiver.

Communication needs related to vocational concerns was a main theme emerging from the scoping review, specifically in younger persons with stroke. Considering the high unemployment rates in Africa and the related financial implications, vocational and financial factors need to be considered during rehabilitation planning for persons with stroke. In South Africa, most persons with stroke receive a disability grant if they are incapable of returning to work. Regrettably, this grant barely finances basic individual needs, which becomes a problem when many persons with stroke are also supporting other family members. Persons with stroke therefore often need to supplement their monthly disability grant, especially if they were supporting their households financially before the stroke.

Considering the backdrop of unemployment in Africa, the need for vocational rehabilitation is particularly important to afford the person with stroke the opportunity to contribute to household finances. High-functioning young persons with stroke who do not have complex rehabilitation needs might return to their previous place of employment. However, most persons with stroke may need to find alternative work opportunities, as they are often unable to fulfil their previous responsibilities or to work the required number of hours because of fatigue (Morris 2011). Young persons with stroke may therefore require guidance regarding possible employment options in view of their changed communication skills.

In a context where unemployment rates are already high, employment opportunities for disabled individuals are even more scarce. Vocational rehabilitation services for young persons with stroke may also be limited by traditional rehabilitation services that have focused on older persons with stroke, who are generally not of working age (Teasell et al. 2000). Vocational communication needs are therefore a priority during communication intervention. In the case of young persons with stroke, SLTs are not only responsible for rehabilitation aimed at returning to work but they should also advocate for the reintegration of persons with stroke into the workplace.

With high poverty rates and financial constraints in many households, attending rehabilitation services might not be considered a priority by persons with stroke or their caregivers, as basic needs often need to be accounted for first. Access to communication rehabilitation might also be affected by transport difficulties, as using public transport is often expensive and exacerbates existing financial constraints. This can negatively affect the rehabilitation attendance and functional outcomes of persons with stroke. These factors emphasise the importance of providing accessible rehabilitation services in communities.

Furthermore, poverty can negatively influence the availability, and use, of technology to access healthcare services and/or to use cell phones as part of rehabilitation. Not all persons with stroke have access to cell phones and cell phones are often shared between family members. Data charges are also often expensive and may limit the use of phones. Computers, laptops and tablets are even more scarce, and Internet access is not readily available in many deep rural areas. Thus, healthcare practitioners should be aware of the technology that is readily available to persons with stroke and consider how this can be used in a cost-effective manner to promote rehabilitation.

The results of this scoping review highlight the importance of understanding the unique communication needs of each person with stroke. According to Greig et al. (2008), possible solutions to address unmet communication needs of persons with stroke could include sessions where information is gained from families, the development of appropriate information packages and establishing stroke support groups. These suggestions may not be sustainable in developing regions because of a lack of available SLTs. For example, in South Africa, the estimated SLT-to-population ratio is 1:25 000 (Kathard & Pillay 2013). Family information sessions are often not conducted because of time constraints and limited resources. The development of appropriate information packages could be hindered by multilingualism, and the diverse cultural and economic backgrounds of persons with stroke, which prevents the development and use of generic information packages. Thus, the need exists to develop culturally appropriate information packages. Establishing stroke support groups within the current South African context could potentially be hindered by factors such as multilingualism, time constraints and limited resources to facilitate support groups. Whilst SLTs often attempt to address the specific communication needs of persons with stroke within groups, the effectiveness of intervention can be negatively affected if personal communication needs are not considered. This scoping review highlights the importance of identifying the barriers and facilitators of the person with stroke on a personal, interpersonal and contextual level to ensure that rehabilitation focuses on social participation and increased QoL.

As noted, informal caregivers often take on the management of the person with stroke. In South Africa, most informal caregivers are provided with verbal and written information to help guide the caregiver regarding communication in the residential setting. This information is often not presented in the home language of the person with stroke or their caregiver, which can influence their compliance with recommendations and increase the chances of misinterpretation. Multilingualism is further complicated in Africa by the limited literacy skills of many informal caregivers. According to the United Nations Educational, Scientific and Cultural Organization (2017), 38% of people living in Africa are illiterate, of which two-thirds are women. Traditionally, in the African context, women usually take on the role of informal caregivers of persons with stroke. Most of the information on stroke and healthcare is distributed in written format, which for someone with limited literacy skills may result in the inadequate transfer of knowledge and negatively influence rehabilitation outcomes for persons with stroke. Furthermore, the lack of infrastructure in most African countries prevents the use of alternative means of distributing information, such as email or social media. Therefore, SLTs need to find innovative means of distributing recommendations regarding communication rehabilitation to informal caregivers. Information and education tasks need to focus on strategies to prevent and repair communication breakdowns, as well as to identify preferred topics about which persons with stroke wish to communicate. In order to provide integrated, contextually relevant, evidence-based care, SLTs should consider the possible interaction between personal and environmental factors described within the LPAA (Figure 2.4).

Drawing from the discussion and clinical considerations in this chapter, both personal considerations as well as environmental factors need to be considered, as advocated by the LPAA. The African context is a unique and challenging setting in which persons with stroke need to be assessed with the goal of determining the relevant individual communication needs. The adequate identification of communication needs for each person with stroke is therefore imperative to provide shorter, cost-effective rehabilitation stays, to increase positive communication outcomes, to afford the person with stroke skills and opportunities for optimal social participation.

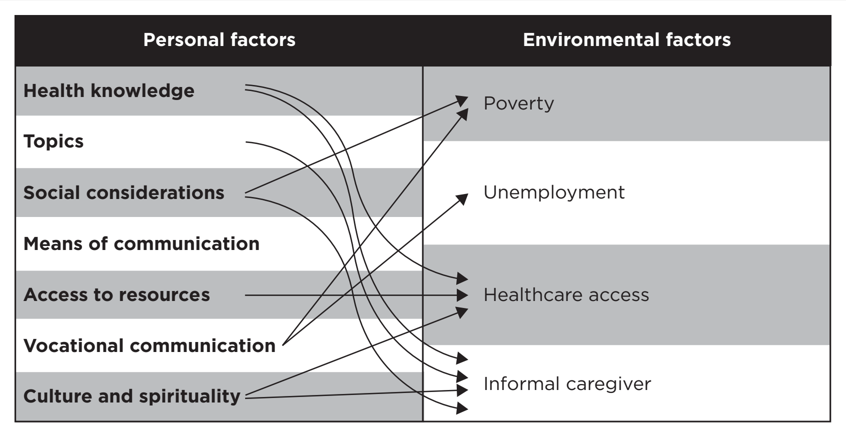


FIGURE 2.4: Possible interaction between personal and environmental factors when considering the communication needs of a person with stroke within the African context.

Vocational communication

Quality of life, well-being and life-satisfaction, especially for young persons with stroke, are directly influenced by their ability to work. Returning to work is of great importance to young persons with stroke, often related to heavy family responsibilities, which requires a stable flow of income into the family to meet financial obligations (Legg 2010; Opoku 2016). Many persons with stroke indicated that they could not resume the work they did prior to the stroke (Opoku 2016). Thus, many persons with stroke are forced to find alternative employment which may be less demanding and which in many cases may result in reduced income. An inability to return to a previous occupation frequently leads to emotional and financial hardships for persons with stroke and their families (Urimubenshi 2015), and as such, vocational communication needs should be considered during rehabilitation planning. This could address concerns such as family stress, returning to previous occupations and planning for future needs (Urimubenshi 2015).

Culture and spirituality

In order to address the individual needs of persons with stroke, resources and materials used within SLT contexts need to be practical, meaningful and culturally appropriate (Bham & Ross 2005; Cawood & Visagie 2015). To avoid communication breakdowns and provide optimal therapy, SLTs thus need to structure information in a manner that is appropriate within the social context of the person with stroke (Penn & Armstrong 2017).

Engaging in religious activities is a source of emotional and social support for many people. It also provides an opportunity for joint participation in activities important to both the person with stroke and their caregiver. According to Bernath (2005), religious activities were one of the activities in which persons with stroke continued to participate, even to a lesser degree, compared to many other activities which they often ceased completely. Reasons for inability to continue with religious activities, however, could indicate difficulties in physically accessing the building in which worship takes place, which may affect the way in which persons with stroke would like to worship (Amosun et al. 2013; Urimubenshi 2015). Participation in additional spiritual activities such as prayer, sharing religious beliefs, reading religious material and listening to sermons on the radio were frequently described as greatly contributing to QoL (Legg 2010; Opoku 2016; Urimubenshi 2015). A participant in Legg's study (2010) described the loss of the ability to preach as an impairment that significantly limited his spiritual identity. Communication needs related to spiritual activities may therefore include participating in spiritual group activities, performing prayers, listening to sermons and reading religious texts.

Discussion and clinical implications

This scoping review provides a comprehensive summary of the last 15 years' literature on the communication needs of young and older persons with stroke in African contexts. The review found only a small number of articles (*N* = 11), which highlights the paucity of research in Africa in this important area. In most of the included articles, the communication needs were implied and not directly stated, except in the works of Beringer et al. (2013) and De Grass-Clementson (2018), which focused specifically on the preferred topics of conversation and communication needs irrespectively, as suggested by persons with stroke.

The scoping review highlighted important themes that should be explored in further research. Using the framework of the LPAA as a way of interrogating the literature ensured that the emergent themes reflected the gamut of personal and environmental considerations in everyday situations. Taking these considerations into account in SLT interventions will empower persons with stroke to participate in decision-making during the rehabilitation process, which can lead to positive rehabilitation outcomes and allows for more effective reintegration to an active life. The evidence-base produced from this review encourages SLTs to focus on relevant and meaningful goals and to support daily participation in activities of choice.

Limitations

The limitations of this study are mainly related to possible concerns regarding the methodological process used in the scoping review. Scoping reviews do not consider the quality of research included and therefore all available methodologies and grey literature were included. Access to all research items that fit the inclusion criteria was not always readily available or costly and as such, some items were therefore not considered in the screening process. Generalisation to the African context of the findings is limited, as the included studies were predominantly from South Africa with some representation of other countries, including Ghana, Rwanda and Uganda.

The number of articles identified in the review was limited by the search strategy, as it focused specifically on the communication needs of persons with stroke. Few studies included participants with stroke with moderate to severe communication difficulties. Thus, the sample of persons with stroke included in this review was skewed to those with less severe strokes. The results need to be interpreted accordingly, as the observed communication needs may not be reflective of, or generalisable to, persons with stroke with more challenging communication difficulties.

The communication needs were not directly stated but implied in most of the articles. This required common themes to be identified during the review process. The implied nature of the information challenged the review process in terms of the thematic analysis but was addressed by making use of triangulation of reviewers. This involved at least two reviewers, discussing and agreeing upon the proposed categorising of information. This aimed to enhance the credibility of the process.

Consideration of communication needs related to personal factors

The health literacy of persons with stroke is an important consideration to ensure their comprehensive engagement in rehabilitation. Their knowledge about stroke can influence the timing of diagnosis and initiation of rehabilitation. Opoku (2016) recognises the fact that persons with stroke often do not receive immediate medical care because of a lack of knowledge regarding signs and symptoms of stroke. This is especially true for the young persons with stroke, as strokes are mostly associated with the older population. The need therefore exists for persons with stroke and their families to be able to ask questions regarding strokes, how to prevent secondary strokes, the available rehabilitation options, as well as rehabilitation prognosis and outcomes.

Adequate health knowledge can ensure that persons with stroke have optimum access to rehabilitation and support services, especially in Africa where communities are not necessarily well-informed about available healthcare services and what these have to offer. The capacity to obtain information from healthcare providers can empower persons with stroke to make informed decisions and convey information to family, and the broader community regarding the rehabilitation process and their specific support needs. Cultural and spiritual beliefs can significantly influence the rehabilitation process, and thus there is a need for persons with stroke to communicate their choices to others, regarding rehabilitation and healthcare. Increased health knowledge might also promote a problem-solving approach to specific rehabilitation options, as well as AAC options. The role of the healthcare provider therefore includes sharing information about the stroke itself, its causes and prevention, and diagnosis; making appropriate referrals and teaching rehabilitation techniques and/or AAC methods to allow persons with stroke to communicate about their healthcare needs.

The findings of the scoping review not only indicated that persons with stroke have specific concerns and issues of interest, but that these should be identified by the persons with stroke themselves. Similar findings were identified across the included studies, irrespective of design or country of location, which strengthens the importance of the review findings. Issues identified in the review included: health, people (i.e. family and friends) and personal aspects such as work, hobbies, household circumstances, finances and religion. These reflect the need for optimal communication and functioning in everyday activities. General topics that were deemed as 'small talk' (such as weather and sport) were not indicated as priority topics. Often these general topics are targeted first in communication rehabilitation, as these topics are often easy to facilitate and require less rapport, especially at the start of the relationship between the SLT and the person with stroke.

The main aim of rehabilitation is to increase participation in everyday situations and as such, topics that are functional and relevant for the person with stroke should be included from the onset of the rehabilitation process. Beringer et al. (2013) highlighted the potential for differences in concerns indicated by caregivers versus those identified by the person with stroke. Thus, SLTs are encouraged to obtain information about concerns and areas of interest from the persons with stroke themselves, even if it requires AAC methods.

Social participation of the person with stroke can be greatly influenced by the long-term sequelae of the stroke. The inability to discuss social needs and changing social roles in relationships can often contribute to increased emotional distress and possible depression. Restricted access to healthcare and transport can further exacerbate social isolation. Moreover, younger persons with stroke may have the additional pressures of needing to return to vocational activities, which may be restricted by communication difficulties. Speech-language therapists should therefore provide persons with stroke with specific techniques to promote effective communication about their changing social roles and relationships. Specific strategies might be needed to facilitate communication between the person with stroke and their caregiver and/or a significant other, including collaboration between healthcare practitioners.

Speech-language therapists should also take responsibility for training the caregiver and/or significant other of the person with stroke in the use of specific and preferred communications strategies, as indicated by the person with stroke, to prevent communication breakdowns. De Grass-Clementson (2018) indicates that most persons with stroke prefer clarification strategies above strategies requiring yes or no responses, as this facilitates increased social participation for the person with stroke. Caregivers and/or significant others often need to be counselled on the importance of social participation for persons with stroke, even if social roles and relationships have changed. Social participation can also include the ability to engage in activities along with family and/or friends, such as attending spiritual activities or going to a restaurant. Speech-language therapists should be aware of the needs of the person with stroke to participate in preferred social activities (this being specifically indicated as a priority for rehabilitation by young persons with stroke).

Over recent years, the advancement of technology has influenced the way in which persons with stroke can be assisted to communicate. Cell phones are often used by healthcare practitioners to communicate with persons with stroke regarding appointments and test results. This review identified a clear need for persons with stroke to be able to interpret and respond to messages such as these and the ability to use a phone to seek help in the case of an emergency is also of utmost importance for them. The ability to use cell phones for instant messaging and social media was indicated as a priority for young persons with stroke. Instant messaging and social media have in recent years become an acceptable manner of building, facilitating and maintaining relationships in the younger population. Social media can also offer an instant support network. However, the need for functional literacy skills in young and older persons with stroke differs. The literacy needs of young persons with stroke tend to focus on the use of technology, specifically for instant messaging and social media, whilst older persons with stroke focus on more traditional literacy goals such as making lists and reading newspapers and books. The necessity is therefore for persons with stroke to not only access cell phone technology but also to effectively convey personal messages and information, which requires a certain level of literacy. The need to access technology and for appropriate literacy skills will therefore influence therapy activities and materials.

Speech-language therapists should also consider providing augmentative and/or AAC options to persons with stroke who are unable to effectively communicate verbally. Speech-language therapists should determine with which topics, and in which situations, the person with stroke needs assistance to promote effective communication. However, the need for, and use of, AAC systems should be discussed with caregivers and/or significant others as well, as cultural and spiritual convictions may influence the use of augmentative or AAC systems.

Future research

The scoping review highlighted the need for research to be conducted related to the communication needs of persons with stroke by both clinicians and researchers from developing countries. Future research could specifically focus on the communication needs of young persons with stroke within the African context to provide a clearer information about preferred methods of SLT rehabilitation, considering resource-constrained environments. Future research could also focus on the applicability and practicality of suggested clinical considerations within local contexts.

The search string employed in future scoping reviews should include 'general needs' of persons with stroke, as most communication needs were mostly implied rather than directly stated within the context of each of the included articles. A further suggestion would be to replace the search term of 'Africa' with specific countries in Africa which is known to have speech therapy services for persons with stroke.

Conclusion

This scoping review reflected emerging research regarding the communication needs of young and older persons with stroke. Gaps were identified in the current evidence base which can now be targeted in future research. The LPAA served as an appropriate framework to describe the personal and environmental factors that influence the communication needs of young and older persons with stroke within the African context. The personal factors emerged directly from the scoping review, whilst the environmental factors were inherent to the African context. A better understanding of the communication needs of persons with stroke within the African context will allow healthcare practitioners to facilitate social participation and community integration more appropriately, which will allow persons with stroke to be included and integrated into everyday situations and improve their QoL.

Chapter 3

Nurses' perceptions of barriers to collaborative care of communication difficulties and dysphagia in persons with stroke

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■ Abstract

Background: An MDT is needed to provide optimal care for persons with stroke. Speech-language therapists are responsible for the initial management of communication difficulties and dysphagia following stroke, whilst nurses are involved in implementing and reinforcing the management guidelines provided by SLTs. It is therefore crucial to identify barriers that may affect nurses' compliance with the SLT's recommendations.

Aim: Describing barriers to collaborative care and adherence to the SLT's guidelines perceived by South African nurses. Specific aims included describing the perceived barriers in terms of personal, interpersonal and social systems.

Methods: Data collected via self-administered questionnaires from three interlinked studies in acute care settings in tertiary hospitals and an inpatient rehabilitation centre were analysed to identify barriers to compliance experienced by nurses.

Findings: The studies identified barriers within the personal, interpersonal and social systems which could affect nurses' compliance with recommendations made by SLTs. Personal system barriers to care included nurses' lack of knowledge and training regarding communication and dysphagia management of persons with stroke. Interpersonal system barriers included poor communication between nurses and SLTs and patient-related barriers between nurses and persons with stroke. Social system barriers included staff shortages, heavy workloads and lack of time to perform nursing duties.

Conclusion: Barriers in all three systems need to be addressed to provide optimal care for patients with communication difficulties and dysphagia, with the focus on improved in-service training of nurses and better inter-professional communication between all members of the collaborative care team.

Keywords: Communication difficulties; Dysphagia; Nurses' perceptions; Barriers; Collaborative care.

■ Background

Management for persons with stroke by an MDT is needed to provide the most effective care (Baatiema et al. 2017b; Langhorne, De Villiers & Pandian 2012). Multidisciplinary team management has been evidenced to result in a reduction in mortality when provided within the first 4 weeks post-incident (Miller et al. 2010) and has demonstrated a decreased incidence of aspiration pneumonia in persons with acute stroke who experience swallowing difficulties (i.e. dysphagia) (Aoki et al. 2016). The MDT ideally comprises medical officers, nurses, physiotherapists, occupational therapists, SLTs and social workers who coordinate care and collaborate in assessment and formulation of holistic management plans for persons with stroke (Dziewas et al. 2017). Establishment of effective working relationships within the MDT through communication and collaboration is, therefore, paramount in providing optimal and effective care for persons with stroke (McGinnis et al. 2019).

In South Africa, about 50% of persons with stroke present with communication impairments, such as difficulty in understanding, speaking and literacy (Bryan et al. 2002) and as many as 56% of people with communication impairments experience dysphagia (Blackwell & Littlejohns 2010). Within the MDT, the management of communication difficulties and dysphagia falls within the scope of the SLT, with a key feature of care involving early systematic identification and management of dysphagia to prevent aspiration pneumonia (Langhorne et al. 2012; McGinnis et al. 2019). The implementation of dysphagia management recommendations, however, largely becomes the responsibility of the nurses, as they are involved with the immediate care of persons with stroke and have the most direct contact with them and their caregivers (Baatiema et al. 2017b; Poslawsky et al. 2010). Nurses can also provide valuable assistance in implementing communication recommendations by SLTs, as well as in facilitating participation in ADLs (Clarke & Holt 2015).

The first Stroke Recovery and Rehabilitation Roundtable developed a framework for critical timepoints post-stroke to allow more adequate defining of terms commonly used with reference to stroke recovery (Bernhardt et al. 2017). The phases included: hyper-acute (0–24 h), acute (1–7 days), early sub-acute (7 days–3 months), late sub-acute (3–6 months) and chronic (>6 months). Nurses are well-positioned to create a supportive context to optimise rehabilitation by carrying out and reinforcing the input of other healthcare providers (Booth et al. 2005). Their familiarity with patients, and their relatives, equips them to provide valuable information about persons with stroke's general progress and circumstances to the other MDT members. Their observations, documentation and knowledge of the patient are therefore critical to the success of the rehabilitative process. Collaboration, teamwork, communication and appropriate knowledge and skills of nurses have been identified as crucial factors that influence the quality of rehabilitation provided by members of the MDT (Mhango 2018).

In Africa, the provision of stroke care is below international recommended standards (Urimubenshi et al. 2018). Successful implementation of care for persons with stroke is often compromised by a range of complex and inter-related factors, including economic constraints on the types of services that can be offered. This means that many persons with stroke have limited access to rehabilitation services, despite a growing international focus on the inclusion and rights of persons with disabilities (World Bank & WHO 2011).

Sub-Saharan Africa comprises 24% of the world's health burden, yet has only 3% of global healthcare workers and the lowest density of health workers globally (Anyangwe & Mtonga 2007). Many SSA countries have fewer than 0.5 allied healthcare professionals per 10 000 of the population (Gupta, Castillo-Laborde & Landry 2011). The shortage of SLTs in Africa is underpinned by a lack of training programmes, with only three of the 55 African countries having established SLT programmes. These are in South Africa, Algeria and Egypt. Recently, programmes have been established in Ghana, Togo, Kenya, Mozambique and Uganda (Wylie et al. 2018). Compared to the rest of Africa, the SLT profession in South Africa is the most established, with seven SLT university training programmes. However, even with the increasing number of training programmes, there is an undersupply of SLT graduates to fulfil population needs. These barriers may thus limit efficient and cost-effective collaboration between SLTs and nurses when caring for persons with stroke.

Nurses, particularly in less well-developed geographical regions, are expected to have a wide range of skills and be equipped to deal with a multitude of conditions. Therefore, it often happens that they have limited knowledge about the diagnosis and referral process of dysphagia, the management of dysphagia in acute care settings and the terminology used by SLTs (Dziewas et al. 2017; McGinnis et al. 2019; Rhoda & Pickle-Voigt 2015; Smith et al. 2015). It is thus crucial to identify barriers that may affect nurses' compliance with implementing recommendations made by an SLT.

To address this shortfall, alternative models and new approaches to communication and care are needed. It is likely that rehabilitation for persons with communication difficulties and dysphagia is already provided in some manner by a range of professionals, such as other healthcare workers, teachers, CBR workers, traditional medicine practitioners and family members (Wylie et al. 2018). Speech-language therapists in Africa can play an important professional role in using their specialised training and expertise in communication and dysphagia rehabilitation to empower, train, develop and support these other professionals.

Nurses are strategically positioned to assist in the shared management of persons with stroke (Miller & Kantos 2012). However, to ensure that they are fully able to engage within the MDT, the scope and nature of nursing practice needs to be revisited, in terms of nurses' perceptions of roles, barriers to care and need for additional training. Mhango (2018) recommended that rehabilitation should form part of nursing training programmes to improve nurses' knowledge about rehabilitation of persons with stroke and to equip newly trained nurses with the skills to actively participate in the rehabilitation process. Continuous professional development (CPD) and training within the MDT have been identified as important, not only for facilitating inter-professional collaboration (Braithwaite et al. 2013) but also to ensure evidence-based healthcare (Dziewas et al. 2017; McGinnis et al. 2019).

Healthcare facilities should ideally provide CPD opportunities for the health professionals employed there, to improve their rehabilitation skills (Seedat 2013). Considering shared management of persons with stroke, training for nurses should be aimed at addressing their specific needs and knowledge gaps through collaborative discussions about patient management and demonstrations with the aim of equipping them with the knowledge and skills to assist in providing best practice care for persons with stroke. However, in developing and scheduling these training programmes, organisational challenges such as time constraints, exacerbated by staff shortages, high workloads, shift changes and transport costs, should be considered. Moreover, engaging nurses with content provided in online learning settings could also be challenging because of the lack of Internet access in some parts of South Africa.

The Conceptual System for Nursing (CSN) developed by King (1971, 1981 as cited in Gunther 2014) offers a useful lens through which to explore and interpret nursing practice, and barriers to care for persons with stroke. The CSN proposes an interdependent system of factors that affect patient care within personal, interpersonal and social domains. Personal systems could include knowledge, perceptions and experiences of individuals, whilst interactions between individuals fall within the interpersonal systems, and social systems include systemic aspects that impact on the delivery of services.

Personal systems

Research has identified a lack of nurses' knowledge regarding best practices for the rehabilitation of persons with stroke, as well as lack of knowledge regarding SLT diagnoses and terminology. This is supported by international research (Albini et al. 2013; Diendéré et al. 2016; Dziewas et al. 2017; Wang, Lu & Chang 2014) and African research (Rhoda & Pickel-Voigt 2015). Furthermore, issues of nurses disagreeing with SLT recommendations (Hadely, Power & O-Halloran 2014) and their feelings of inadequacy when working with patients with communication or dysphagia diagnoses (McGinnis et al. 2019; Smith et al. 2015) have been identified.

Interpersonal systems

Poor communication between nurses and patients (Smith et al. 2015) and lack of teamwork and respect between staff members (Parmelee, Lazlo & Taylor 2009) have been described. This can lead to nurses experiencing a lack of recognition and respect by other healthcare professionals for the role they play in the rehabilitation of persons with stroke. Whilst nurses are responsible for delivering general and basic care needs, they may perceive their role as undervalued by the therapists of the MDT team, who focus on specific aspects of the rehabilitation process, for example mobility or swallowing, during scheduled appointments with the patients (Dreyer et al. 2016). Nurses might also perceive that they assume sole responsibility for care when therapists leave and that other team members underestimate their contribution to the success of the patient's rehabilitation (Dreyer et al. 2016). Poor understanding of the concept of an MDT and lack of clarity regarding each team member's role have been reported (Dziewas et al. 2017; Smith et al. 2015). This can negatively affect effective functioning in interpersonal systems.

Social systems

Available resources within the healthcare setting can impact on nurses' engagement with rehabilitation for persons with stroke. Resources can include the number of staff, heavy caseloads and time constraints (Eygelaar & Stellenberg 2012; Ross et al. 2011). Staff shortages are of particular concern in SSA countries, as the ratio of SLTs across four countries was reported as 1 per 2–4 million people, compared to 1 per 2500–4700 people for the US, UK, Australia and Canada (Wylie et al. 2013). According to an African Institute for Health and Leadership Development report in 2017, there is one nurse or midwife eligible to practice, for every 140 South Africans, whilst the SLT-to-total population ratio is estimated as 1:48 000 (Kathard & Pillay 2013). A recent South African study identified the shortage of specialised stroke units along with excessive workload and time constraints, as the primary barriers faced by nurses when caring for persons with stroke in private hospitals (Mhango 2018).

There are complex interactions between personal, interpersonal and social systems. Ineffective functioning in personal and interpersonal systems can be exacerbated by social system barriers such as staff shortages (Eygelaar & Stellenberg 2012). This can contribute to poor use of time, constraints on care and unmanageable workloads (Ross et al. 2011). Inadequate referral systems (Hadely et al. 2014) and lack of resources (Eygelaar & Stellenberg 2012; Ostrofsky & Seedat 2016) can further contribute to perceived barriers to compliance with SLT guidelines and recommendations. Seedat (2013) warned that collaboration between SLTs and nurses, which could be viewed as a means of addressing interpersonal system functioning, may result in shifting the responsibility for managing a patient's dysphagia to the nurses, but without providing nurses with the necessary training, support or acknowledgement. This could further exacerbate personal and social system barriers, by merely adding to nurses' already heavy workloads, potentially resulting in poor compliance with SLT recommendations and affecting patient care.

The research question

This chapter addresses the question 'What are the perceived barriers to care by South African nurses, in the management of communication difficulties and dysphagia in persons with stroke?'

Aim

The overarching aim of this chapter is to describe the barriers in complying with SLT management suggestions as experienced by nurses, related to communication difficulties and dysphagia suffered by persons with stroke.

Source of data

The barriers were identified from three interlinked studies (Coetzee et al. 2016; Du Toit & Senekal 2018; Robbertse 2018). Studies One and Two were final year undergraduate projects that largely informed objectives one to three (see below). These studies used the same questionnaire and category of nurses but in different clinical settings (Coetzee et al. 2016; Du Toit & Senekal 2018). Study Three was conducted by a master's student and focused on barriers to dysphagia care (Robbertse 2018). The qualitative data obtained from the semi-structured interviews from this study were included in this chapter, as it also relates to objectives 1 to 3. The quantitative data from this third study informed objective 4.

Objectives

The first three objectives deal with describing nurses' perceptions of:

1. Personal system barriers: Aspects relating to knowledge, skills and attitudes that have an impact on their adherence to SLT suggestions.
2. Interpersonal system barriers: Aspects relating to the interaction between nurses, SLTs and persons with stroke.
3. Social system barriers: Aspects relating to the healthcare setting that may influence compliance to recommendations made by the SLT.
4. Describe nurses' information delivery preferences and implications for training.

The findings for the first three objectives are described in terms of the CSN framework developed by King (1971, 1981 as cited in Gunther 2014).

Chapter organisation

The chapter is organised to provide a complete description of each of the studies with key points from the results taken through to the discussion. Key methodological elements are summarised in Table 3.1.

Study One

Methodology

Study design

Study One employed a descriptive, cross-sectional design by making use of a self-administered questionnaire (see Appendix A) which yielded quantitative data. A descriptive research design was deemed appropriate as it aimed to obtain information regarding preferences, practices, interests and concerns of a particular group (Creswell 2007). The cross-sectional nature of the study was both time and cost-effective (Grimes & Schulz 2002).

TABLE 3.1: Summary of included studies.

Date	Study One 2016	Study Two 2018	Study Three 2018
Purpose	Barriers to compliance to SLT recommendations regarding communication and dysphagia	Barriers to compliance to SLT recommendations regarding communication and dysphagia	Barriers to care for persons with dysphagia and their information delivery preferences regarding dysphagia care
Researchers	Undergraduate study (Coetzee et al. 2016)	Undergraduate study (Du Toit & Senekal 2018)	Master's study (Robbertse 2018)
Study design	Quantitative, descriptive, cross-sectional	Quantitative, descriptive, cross-sectional	Mixed method, cross-sectional
Setting	Tertiary hospital Neurology wards Western Cape, South Africa	Inpatient rehabilitation centre Neurology wards Western Cape, South Africa	Two tertiary hospitals Neurology and internal medicine wards Western Cape, Free State, South Africa
Participants	Enrolled auxiliary nurses with work experience with persons with stroke	Enrolled auxiliary nurses with work experience with persons with stroke	Nurses experienced in working with persons with stroke
Recruitment	Purposive sampling	Purposive sampling	Purposive sampling
Data collection	Self-administered questionnaire	Self-administered questionnaire	Questionnaire (only Section E), semi-structured interviews
Data analysis	Descriptive statistics	Descriptive statistics	Descriptive statistics, interpretive phenomenological analysis

SLT, speech and language therapist.

☐ Setting

Data were collected in two acute neurology wards at a tertiary hospital in the Western Cape. This hospital setting was selected as it offers specialist medical services that included a stroke unit.

☐ Participants

Sampling: Purposive sampling was applied as it allowed the researchers to select participants according to specific qualities (Tongco 2007).

The researchers ensured that all possible participants working both the day and night shifts, during the 2-month data collection period (i.e. May–June 2016), had an equal chance of being included. This was achieved by setting up data collection times to allow the researchers to approach all the potential participants.

Eligibility criteria: Participants had to have an Enrolled Nursing Auxiliary (ENA) qualification, with at least 6 months' experience working with persons with stroke in the respective neurology wards. The head nurse of the respective wards deemed 6 months as an adequate period of time to afford the ENAs exposure to the format of the clinical notes and the terminology used by the SLTs.

☐ Measurement

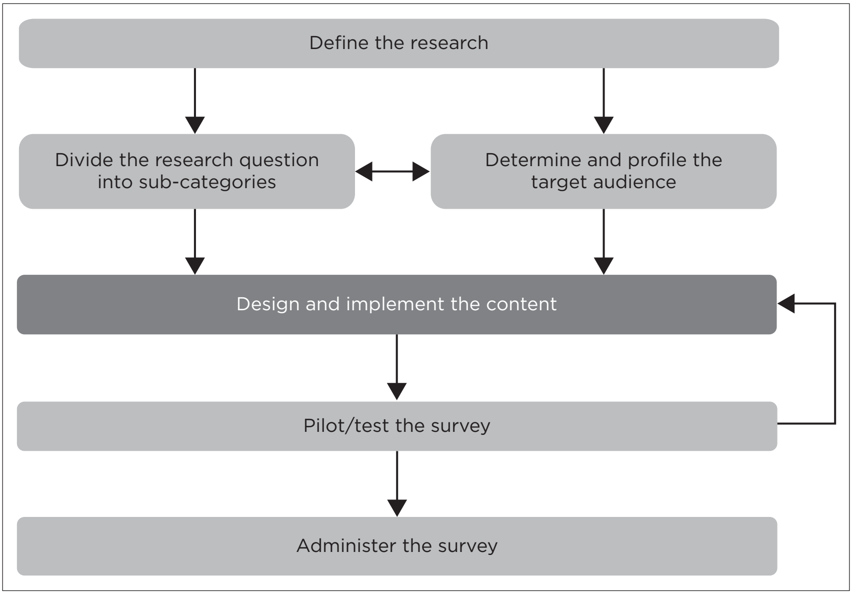
A new questionnaire was developed for this study, as there was no available tool to address barriers to compliance of SLT recommendations which incorporated both neurogenic communication difficulties and dysphagia.

The questionnaire design and validation processes were based on the steps described by Bakla, Çekiç and Kösksal (2013:8) and are outlined in Figure 3.1.

Questionnaire design and content: The research question and study objectives informed the content of the questionnaire.

Literature that provided the most updated and relevant information relating to neurogenic communication disorders and dysphagia was reviewed to inform the aspects included in the development of the content of the questionnaire. The questionnaire consisted of five sections with a total of 42 questions. Thirty-eight of which were closed-ended (multiple choice questions, true or false questions and a Likert scale) and four were open-ended.

The first three sections of the questionnaire focused on objective one (personal system barriers) of the chapter. It focused on the knowledge of diagnoses and signs and symptoms of diagnoses managed by the SLT in persons with stroke.



Source: Bakla, Çekiç and Kösksal (2013).

FIGURE 3.1: Questionnaire design process.

The content of these questions was determined by, and adapted from, information from the Mayo Clinic (Mayo Clinic Staff 2015) and the American Speech-Language-Hearing Association (American Speech-Language-Hearing Association n.d.).

Section A focused on the knowledge of terminology used by the SLT which related to communication difficulties and dysphagia in persons with stroke. It is recognised that sufficient knowledge of relevant terminology is required in healthcare (Hardiker, Hoy & Casey 2000) to ensure optimal communication between nurses and SLTs. This section consisted of 11 multiple choice questions and an open-ended question.

Section B and Section C focused on the signs and symptoms of communication difficulties and dysphagia. This knowledge is considered crucial to aid in the early identification of these disorders (Blackwell & Littlejohns 2010; Poslawsky et al. 2010).

Both sections consisted of four closed-ended questions and an open-ended question.

Section D related to objectives two and three of this chapter (interpersonal and social system barriers). It incorporated challenges identified in existing research by Colodny (2001), McCullough et al. (2007) and Pelletier (2004) and aimed to identify potential barriers to compliance with recommendations made by the SLT. This section consisted of 13 Likert-scale items. The responses on the four-point included: 'Strongly disagree', 'Moderately disagree', 'Moderately agree' and 'Strongly agree'. The concluding question was open-ended and asked for suggestions for improving nurses' compliance with SLT recommendations.

Questionnaire reliability and validity: A pilot study was conducted to determine face and content validity. It allowed the researchers to check study constructs against the feedback provided by end-users (Bless et al. 2013). The pilot study was conducted 2 weeks before the collection of the study data. This allowed sufficient time to address possible feedback provided. It included two registered nurses in the study wards who suggested minor editorial changes to simplify the grammar in the instructions and response options provided to the closed-ended questions. Reliability was addressed by repeating the content of questions in the questionnaire to ensure a true reflection of the responses (Bless et al. 2013).

☐ Data analysis

Descriptive statistics were calculated and reported as frequency counts and percentages. The open-ended questions at the end of Section D yielded short phrases and often single words relating to the need for training and these responses were converted into percentages.

■ Results

A total of 26 out of a potential sample of 35 participants were included in this study (response rate of 74%). No specific reasons were provided by the nine potential participants who declined to participate.

Participants' knowledge regarding terminology for both dysphagia and communication disorders was not optimal. They demonstrated good knowledge of terminology of a more medical nature, related to dysphagia, such as 'nasogastric tube' (96%) and 'aspiration' (92%) than the diagnosis of 'dysphagia' (62%).

As seen in Figure 3.2, the participants had better knowledge of dysphagia than of the communication disorders. With reference to the communication disorders, they had better knowledge about speech-motor disorders (i.e. apraxia and dysarthria) than language disorders. Whilst only 19% had knowledge of aphasia, 50% and 46% had knowledge of apraxia and dysarthria, respectively.

It is important that nurses are aware of the signs and symptoms associated with dysphagia and communication disorders. These were

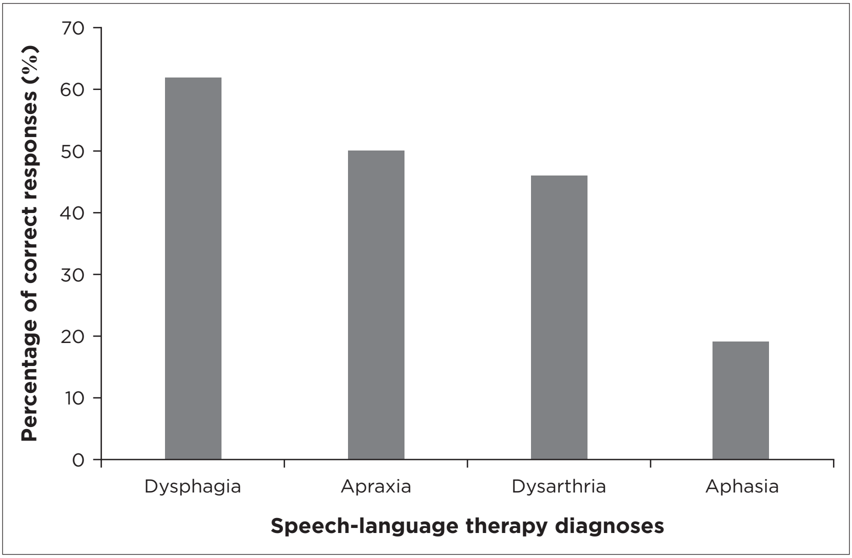


FIGURE 3.2: Knowledge of speech-language therapy diagnoses in two acute neurology wards at a tertiary hospital in the Western Cape (Study One).

identified accurately by 58% of the participants, whilst 42% and 46% respectively could identify signs and symptoms associated with aphasia and apraxia. Only 27% could identify signs and symptoms of dysarthria. Both terminology and identification of signs and symptoms relate to a lack of knowledge and would therefore be categorised as a personal system barrier.

Other personal system barriers to compliance with SLT rehabilitation suggestions to which participants 'strongly agreed' included: lack of knowledge (31%) and lack of training (27%). Disagreeing with the recommendations made by the SLT was identified by 14% of the participants. The social system barriers identified were time constraints (35%) and a heavy workload (46%).

From the open-ended question, an interpersonal system barrier was identified by 18% of the participants who indicated that they would not adhere to the recommendations made by the SLT if they were not directly discussed with them. Clinical notes being written in another language other than their home language was identified as a barrier for 19% of the participants. This could pose as another interpersonal system barrier because of its effect on the communication between the nurse and the SLT.

Only 17 (65%) of the participants responded to the open-ended question requesting suggestions to increase compliance to SLT recommendations. The suggestions included: the need for in-service training (71%), direct communication of recommendations (24%) and improving multidisciplinary teamwork (6%).

Study Two

Methodology

The study design, sampling method, participant eligibility criteria, measurement tool (i.e. questionnaire) and data analysis were the same as Study One.

Setting

The study setting was an inpatient rehabilitation centre in the Western Cape. This setting was selected as it offered hospital-level care to persons with stroke who require MDT input, which included nursing and SLT services.

Participants

The researchers ensured that all possible participants working both the day and night shifts, during the 2-month data collection period (i.e. May–June 2018), had an equal chance of being included. This was done by setting up data collection times to allow the researchers to approach all the potential participants.

Measurement

The researchers addressed the face and content validity of the questionnaire for this new setting by including an expert review (the resident SLT and the head of nursing). Neither recommended any changes to the wording or layout of the questionnaire.

Results

A total of 16 out of a potential sample of 21 participants were included in the study (response rate of 76%). One potential participant was willing to complete the questionnaire but did not meet all the inclusion criteria. No reasons were provided by the remaining four potential participants who declined to participate.

It appears as if dysphagia-related terminology of a medical nature such as 'nasogastric tube' (88%), 'aspiration' (75%) and 'gastroesophageal reflux' (81%) was better understood than the diagnosis of dysphagia (69%).

As seen in Figure 3.3, participants had better knowledge of dysphagia than of the communication disorders. Participants

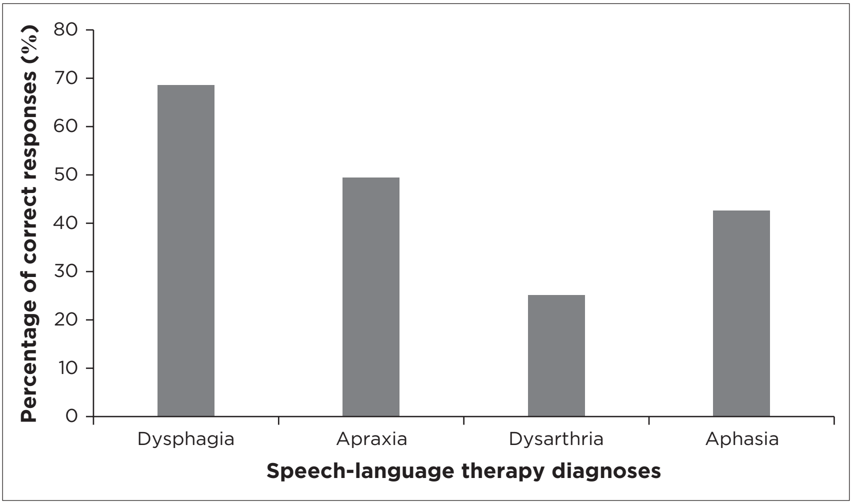


FIGURE 3.3: Knowledge of speech-language therapy diagnoses in an inpatient rehabilitation centre in the Western Cape (Study Two).

showed better knowledge of the speech-motor disorder of apraxia (50%) than of that of dysarthria (25%), whilst 43% had knowledge of the language disorder of aphasia. More than half of the participants (56%) could identify signs and symptoms of aphasia and apraxia, but only 31% could identify signs and symptoms of dysphagia and dysarthria.

The Likert-scale items in Section D was only completed by 15 participants. A lack of knowledge (44%), a lack of training (44%) and disagreeing with the recommendations made by the SLT (16%) were other personal system barriers identified to which participants 'strongly agreed'. The social system barriers identified were time constraints (62%) and a heavy workload (69%).

Only 5 (33%) participants responded to the open-ended question to provide suggestions to increase compliance to SLT recommendations. This suggestion was for the provision of in-service training.

Study Three

Methodology

Study design

A cross-sectional, mixed method research design was employed, which followed a sequential explanatory format.

Setting

Data collection was conducted in two academic tertiary hospitals, one in the Western Cape and the other in the Free State in South Africa. These facilities were chosen based on the presence of nurses working with persons with stroke.

Participants

Sampling: Purposive sampling was employed as per the first two studies to ensure that as many relevant participants as possible could be included in the study.

Eligibility criteria: Participants must have had a formal nursing qualification and be permanently employed at one of the relevant hospitals. They must have had 1 year's experience working in neurology wards with patients who present with dysphagia. This was deemed as an appropriate amount of time for participants to become familiar with dysphagia management, as well as the format of clinical notes and the terminology used by SLTs.

Measurement

The data from Study Three reported in this chapter came from sections E and F of the questionnaire utilised in the study (see Appendix B). Section E focused on nurses' information preferences during training and consisted of seven statements, using a 5-point Likert scale. The responses on the scale included: 'Strongly disagree', 'Disagree', 'Neither agree nor disagree',

'Agree' and 'Strongly agree'. These information preferences items provided in the questionnaire were informed by Eames et al. (2011), Hafsteindóttir et al. (2018) and Bellardie and Harris (2008).

☐ Validity

A pilot study was conducted to test the validity of Section E in the questionnaire by addressing possible ambiguity, phrasing of questions, appropriate response selection and content. Ten nurses working in the oncology wards at each of the hospitals were included. They were selected for inclusion as they also had experience in caring for persons with dysphagia and implementing recommendations made by the SLT. These nurses were not generally involved in providing care to persons with stroke; however, they had knowledge of SLT engagement for people with other conditions. By involving these nurses, the potential participants in the wards of interest were not over-sampled. The pilot study participants deemed the questionnaire to be comprehensive, concise and easily interpretable, and no changes were recommended.

Section F outlined the questions used for the semi-structured interview, providing additional qualitative data related to possible personal, interpersonal and social system barriers to nurses' compliance to the recommendations made by the SLT regarding dysphagia.

☐ Trustworthiness

Time sampling and member checking was used to address credibility in the interview findings, as recommended by Korstjens and Moser (2018). Time sampling was undertaken by collecting data in various wards in different facilities and across different work shifts. This ensured that the researcher obtained representative responses and appropriately interpreted participants' responses. Member checking was included by reading participants' responses back to them at the time of interview. This allowed participants to confirm or rephrase their responses.

To address confirmability, interviewer bias was avoided by making use of a fixed set of questions. Interviews were audio-recorded with the participant's consent, which allowed for multiple opportunities to analyse and re-check data, as well as for the reporting of verbatim quotes.

Data analysis

For Section E responses, descriptive statistics were applied, generally as frequency of responses.

For Section F, interpretative phenomenological analysis (IPA) was used to analyse the qualitative data. The IPA approach aims to explore and understand the experiences and perceptions of participants as it acknowledges that different people experience phenomena in different ways (Smith & Osborn 2004). This involved immersion in the data followed by preliminary coding, allowing for themes to emerge. These themes were then clustered according to the connections between them.

Results

A total of 81 participants completed the questionnaire (i.e. 43 from the Western Cape and 38 from the Free State). Although the total possible sample size could not be determined because of high staff turnover, invitation to participate in the study was distributed via the relevant unit managers, who helped to select the most appropriate participants who met the study's inclusion criteria.

Only 18 participants from the Western Cape agreed to be interviewed. The remaining participants at both hospitals cited a lack of time as the reason for declining to be interviewed.

Quantitative data

Being provided with information in a written format was preferred by 88% ('strongly agree' 26% and 'agree' 62%) of the participants, 74% ('strongly agree' 21% and 'agree' 53%) indicated a preference

TABLE 3.2: Information preferences for training.

Preference	Strongly agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly disagree (%)
Written	26	62	4	3	5
Verbal	21	53	8	14	4
Combination of written and verbal	25	62	4	4	5
Computer	7	27	18	40	8
Face-to-face	24	66	5	4	1
Role play	21	56	4	14	5

for a verbal form of input. There was a strong preference for using a combination of verbal and written information with 25% 'strongly agree' and 62% 'agree' with this method of training.

Almost half of the participants ('disagree' 40%, 'strongly disagree' 8%) responded that they 'disagreed' with the use of computers during training and 18% were 'neutral' in their response. The result indicated that most of the participants ('strongly agree' 24% and 'agree' 66%) preferred training being presented face-to-face. The use of role play was preferred by 21% ('strongly agree') and 56% ('agree'), respectively (see Table 3.2 for a summary of information preference results).

Qualitative data

The barriers to compliance that emerged from the qualitative data included: lack of knowledge and training (personal system barriers), patient-related barriers such as poor cooperation from patients (interpersonal system barriers) and working environment barriers, such as staff shortages, time constraints and heavy workloads (social system barriers). The relevant qualitative responses cited in Study Three are represented in Box 3.1.

Discussion

The findings of the three studies clearly identified barriers within the CSN framework's personal, interpersonal and social systems,

BOX 3.1: Quotes from qualitative data related to barriers to compliance.

1. Personal system barriers

Lack of knowledge and training

'We only do the CVA patients and conditions'. (P26, age unknown, gender unknown)
'No training at all'. (P47, age unknown, gender unknown)
'I have not received training'. (P53, age unknown, gender unknown)

2. Interpersonal system barriers

Patient-related

'They [healthcare professionals] prescribe a NGT and they [patients] pull it out'. (P26, age unknown, gender unknown)
'They have special needs, so that makes it more difficult'. (P30, age unknown, gender unknown)
'It's a challenge for them [patients] to understand you'. (P31, age unknown, gender unknown)

3. Social system barriers

Work environment

Staff shortage
'We have a staff shortage at times, then we struggle'. (P5, age unknown, gender unknown)
Time constraints
'We are short staffed … It influences how much time they can spend with a patient'. (P58, age unknown, gender unknown)
Heavy workload
'We have a lot of patients with dysphagia … This place is very busy. We don't always have the time'. (P37, age unknown, gender unknown)

CVA, cerebrovascular accident; NGT, nasogastric tube.

which could affect nurses' compliance with recommendations made by SLTs for persons with stroke.

Personal system barriers

The personal system barriers identified as deficiencies in knowledge, skills and attitudes can significantly affect the standard of care provided to persons with stroke who present with communication difficulties and dysphagia. There was a consistent lack of familiarity with SLT terminology found across the three studies, which is congruent with findings in the current literature (Albini et al. 2013; Diendéré et al. 2016; Dziewas et al.

2017; Rhoda & Pickel-Voigt 2015; Wang, Lu & Chang 2014). Familiarity with terms such as 'dysphagia' could be because of increased exposure to the condition, and its related terms in the workplace, as other healthcare professionals such as medical doctors might use similar terminology during interaction with nurses. Dysphagia terminology might also be perceived as important, as inadequate management of dysphagia could contribute to life-threatening complications, whilst poor knowledge of communication terminology does not generally pose a risk to patients' physical health.

As nurses are often expected to manage patients with dysphagia and/or communication disorders in the absence of an SLT, nurses should be aware of signs and symptoms of the various SLT diagnoses. Nurses in acute healthcare settings being able to better identify the signs and symptoms of dysphagia than those of communication disorders might be attributed to an increased number of patients who experience dysphagia in the acute phase of illness.

Nurses might also be more familiar with speech-motor disorders because of increased exposure to these terms, as other members of the MDT, such as occupational therapists and physiotherapists, use similar terminology such as 'apraxia' in their hospital notes. It should also be considered that speech-motor disorders are perceptually more salient and therefore would be easier to identify by someone not trained as an SLT.

It is possible that a lack of awareness of the role of the SLT could contribute to barriers to care. If nurses are not familiar with the role of the SLT in the management of persons with stroke, it is possible that they do not become familiar with the various conditions in which SLT management plays a role, or subsequently do not receive adequate exposure to the terminology used by SLTs. Frequent contact between nurses and SLTs could promote knowledge-exchange and task-sharing.

Nurses could disagree with the recommendations made by the SLT and it might be because of misunderstanding the rationale for the recommendations. It is also possible that nurses might view themselves as the patients' primary caregivers and might consider that they are the most familiar with the patient's recovery needs, which could include perceptions of communication and dysphagia that are contradictory to those of the SLT.

A lack of training in the management of persons with stroke was identified in all the studies. Concerns about the lack of training, specifically with regards to dysphagia, had previously been noted (Dziewas et al. 2017; McGinnis et al. 2019) along with the importance of continuous training of the MDT team to provide optimal patient care (Bryer et al. 2011). The lack of dysphagia training could be a result of the depth in which the content is covered in the nurses' undergraduate training, where stroke management may be covered as a broad concept, with limited discussion of its various sequelae.

Personal system barriers to care such as lack of training, limited knowledge of the terminology and signs and symptoms of diagnoses used by SLTs could contribute to inadequate implementation of SLT recommendations. This could compromise the sustained management of the dysphagia and communication needs of person with stroke and ultimately yield poorer health outcomes, decreased success of rehabilitation efforts and decreased QoL.

Interpersonal system barriers

Aspects that could compromise communication between nurses and the SLTs were identified as interpersonal system barriers. This included clinical notes being written in a language other than the nurses' home language.

Participants in Study One also indicated that not having the recommendations directly discussed with them was a barrier. However, considering staff shortages for both nurses and SLTs in South Africa (and other developing countries), such individual or case-based discussions might not be possible on a consistent basis.

Considering the constant interaction between nurses and persons with stroke, SLTs also need to be aware of possible patient-related interpersonal barriers. Persons with stroke often present with medical comorbidities and a wide variety of stroke sequelae, including physical, cognitive, emotional and communication impairments. Given this myriad of complicating factors, it is not unexpected that nurses might perceive persons with stroke as being challenging to manage. Communication impairments such as poor comprehension and difficulty expressing wants, needs and medical concerns as a result of a stroke can cause communication breakdowns, which could hinder effective nurse–patient interaction. Non-compliance with SLT guidelines could often be the result of time constraints as communication difficulties add to the time nurses spend with an individual patient.

Another nurse–patient-related barrier could be poor cooperation from patients during meals or refusal of modified meals. This correlates with findings by Chadwick et al. (2006) who indicated patient-related barriers such as dislike of modified diets and alternative feeding utensils. The poor compliance of persons with stroke with modified diets or SLT feeding guidelines could be attributed to factors such as denial of dysphagia, poor comprehension of the rationale behind the modified diet or dislike of the consistency or texture of food provided. Unfortunately, in the context of a developing country, alternatives for modified diets are not always available, resulting in a limited variety of thickening agents, diets or textures and supplements. Adaptations to modified diets can therefore not necessarily be made to accommodate patients' individual preferences, possibly contributing to poor compliance during mealtimes.

Social system barriers

Both personal and interpersonal system barriers could be exacerbated by social system barriers, which were frequently reported. This was reported as the primary barrier faced by nurses in caring for persons with stroke in a South African hospital (Mhango 2018), and international research also recognises the concerns of heavy workloads, time constraints and staff shortages (Colodny 2001; Eygelaar & Stellenberg 2012; Parmelee et al. 2009; Ross et al. 2011). The interaction between factors such as staff shortages and time constraints can result in nurses being unable to comprehensively implement feeding recommendations, communication strategies or consult the SLT in the case of uncertainty or misunderstandings. Social system barriers can therefore contribute to vocational dissatisfaction, resulting in reduced quality of care, as investigated in recent South African studies (George, Gow & Bachoo 2013; Steyn et al. 2015). Social system barriers in the South African context are unavoidable in view of the lack of both SLTs (Kathard & Pillay 2013) and nurses (African Institute for Health and Leadership Development 2017). This could result in heavy workloads as well as limiting time available to address the needs of persons with stroke. As such, measures need to be taken to address personal and interpersonal system barriers to minimise the influence of these on existing social system barriers.

The clinical implications of the integrated findings of the three studies reported in this chapter are that interventions should aim to address relevant personal, interpersonal and social system barriers in order to improve compliance with the communication and dysphagia recommendations made by the SLT.

Providing in-service training to nurses about SLT diagnoses related to stroke could reduce barriers to compliance. However, planning for the specific training requirements of the nurses needs to be a collaborative process. The SLT would be required to determine nurses' prior knowledge, further content required and the format and context in which training could occur. It is therefore recommended that the role of the SLT, speech therapy-related care, and signs and symptoms of various speech therapy-related diagnoses be included in training sessions.

When training is provided, the format in which it is presented needs to be considered. Written and verbal information has been indicated as the information delivery methods of choice, along with practical demonstrations. This correlates with findings from Eames et al. (2011). Written and verbal communication could be regarded as the most practical option of training, but not necessarily the most effective way of training in an already time-constrained clinical environment. The benefits of written information include distributing notes to which nurses could refer, whilst verbally presented information could allow for flexible knowledge-exchange. However, this training modality requires face-to-face contact, which might not be viable in time-constrained settings. A dislike of computer-based training was identified in Study Three, which could be because of limited familiarity with this training modality, as well as restricted resources. In the African context, factors such as a lack of available electronics and limited Internet access need to be considered (Asah 2013; Bharuthram & Kies 2013).

Other barriers to in-service training might be accommodating various shifts and limited availability of SLTs to provide training. As such, contextual constraints in the environment should guide decisions regarding training opportunities. In contexts where group-based in-service training is not viable, options such as telepractice could be considered, where the SLT can provide training from a remote site via real-time electronic means (Burns et al. 2017; Giucci et al. 2016). A nurse can also be delegated to attend training, after which he or she can provide onsite workplace-based peer learning.

Allen (2012) emphasises the importance of adequate supervision and peer learning in providing effective healthcare in rural settings, as novice nurses can gain appropriate knowledge and skills under the guidance of an experienced nurse. By grouping experienced and trained nurses with novices, knowledge can be shared and problems solved within a discipline.

A core consideration to further address barriers to care would be to recognise the importance of the MDT in view of its inherent value for collaboration and support. Personal, interpersonal and social system barriers can be addressed by knowledge-exchange between the nurses and SLTs by encouraging small adjustments such as the SLT performing dysphagia assessments or demonstrating techniques during mealtimes when the nurses are already present. Recommendations can be communicated directly to the nurses and they can also be involved in the decision-making process thus addressing interpersonal system barriers. It is also a good example of using a clinical activity within an MDT context to increase the familiarity and ease with which the nurses manage persons with stroke. This method of engagement could have another positive outcome for nurses as it could provide the necessary recognition and value of their role. It could also provide a practical basis and time-effective manner of training, as well as another opportunity to promote interdisciplinary teamwork and include task-sharing, which can assist in decreasing workloads. The goal of knowledge-exchange is to connect nurses and SLTs with each other to allow for discussion of cases so that they can learn from one another to ultimately improve patient outcomes. It also facilitates a continuous learning process based on experience and application to improve the management of persons with stroke (UNICEF 2015). Epstein (2014) not only discusses the numerous benefits of the MDT for nurses and other team members but also for persons with stroke. Benefits include improved health outcomes, better use of resources and increased vocational satisfaction of all team members.

However, considering staff shortages for both nurses and SLTs in South Africa, these individual or case-based discussions might not consistently be possible. In contexts where an SLT is not readily available, telepractice could be implemented, whereby an SLT could provide consultation electronically to healthcare facilities that cannot easily be accessed on a frequent basis.

It is important for SLTs to consider nurses’ opinions and views when drawing up management plans, as they often have valuable observations and insights into their patients that are not shared by other healthcare professionals. These insights are obtained from spending a considerable portion of their time each day with patients (Smith et al. 2015). Facilitators to compliance need to be identified in healthcare settings, as these facilitators can serve as the impetus for increasing nurses' compliance with SLT recommendations. Facilitators such as empathy, a desire to learn more about the various SLT diagnoses and a willingness to be actively involved in an MDT, need to be capitalised on to strengthen nurses' positive attitudes towards SLT recommendations. Positive attitudes can facilitate mutually supportive interactions, including role-sharing, between the SLT and nurse, that can greatly contribute to improved health outcomes for patients (McGinnes et al. 2019).

To reduce nurse–patient-related barriers, the SLT needs to facilitate effective communication between nurses and persons with stroke, which includes discussing the rationale of modified diets and/or feeding postures with both parties, involving them in the development of a modified diet, and by providing communication aids to persons with stroke, if needed. Nurses should also be encouraged to report any patient-related barriers to the SLT instead of forgoing feeding recommendations. The importance of effective communication is also highlighted by the fact that nurses describe it as an essential component of good caring encounters with persons with stroke (Eriksson et al. 2016).

Resources that may provide further written support could include a list of definitions, a glossary of terms and frequently used abbreviations and visual illustrations of frequently used techniques. It is also recommended that SLTs make consistent use of standard terminology to avoid confusion and misunderstanding of SLT recommendations.

Exposure to relevant concepts and skills as part of undergraduate training for nurses has also been recommended (Allen 2012). Strasser and Neusy (2010) reason that early clinical contact can increase the meaningful application of theoretical knowledge. It is recommended that undergraduate nursing students be trained regarding the basic theory, signs and symptoms, and management of various SLT diagnoses to promote adequate care in the absence of an SLT and to facilitate appropriate referrals and caseload management in the MDT.

The SLT could reduce the barriers that the nurses experience by involving persons with stroke in the decision-making process regarding their rehabilitation and the specific communication and dysphagia techniques employed. The SLT could therefore provide the necessary counselling and motivation to facilitate understanding and acceptance of the agreed-upon communication and dysphagia techniques. This could reduce time constraints by decreasing the patient's resistance to management and thereby increase compliance with recommendations by nurses.

Challenges and limitations

Although similar barriers to compliance were identified across the component studies, the data reported in this chapter were sourced from separate research endeavours. The sample sizes across the studies varied, with a range of nursing qualifications and years of experience represented.

The purposive sampling may have introduced selection bias, which may have influenced the representativeness of the sample. However, it was hoped that as sampling occurred at each type of shift over a period of time in each study, selection bias may have been minimised. The studies only included three sites in the South African context thus limiting generalisability to other South Africa sites as well as the larger African context.

Recommendations for future research

Future research could include gathering data about the perceived barriers to care of nurses of the management of communication difficulties and dysphagia in persons with stroke in other South African sites and other African countries. Research could aim to compare different types of trained nurses in different clinical settings (e.g. private and public hospitals) to establish and compare differences in perceived barriers to care. This would enable more defined comparisons of compliance across, or between, the different levels of training (e.g. registered nurse versus enrolled auxiliary nurses). Investigating aspects that nurses and SLTs perceive to be facilitators to compliance could inform training by including and building on aspects that already support the MDT process.

Future research could also focus on specific training required to reduce perceived barriers, which could include development of appropriate training material and the influence of peer learning as a mechanism for teaching and support. It is recommended that research focuses on developing a country-wide guideline for addressing perceived barriers to care, aimed at improving compliance to recommendations across settings and contexts.

The studies included in this chapter have initiated another research project aimed at developing a training programme for nurses to address the identified barriers. The initial phase is focused on investigating the perceptions of nurses and SLTs on the roles and responsibilities of their team member with regards to dysphagia. Subsequent phases will aim to determine the training needs of nursing personnel, the development and feasibility of a dysphagia training programme for nurses and to investigate the support material that could be used in dysphagia management. The outcomes and effectiveness of the training programme will also be determined.

■ Conclusion

The results of the three studies highlighted a range of barriers to compliance by nurses, with recommendations made by SLTs for persons with stroke. These findings concurred largely with international studies, albeit with specific South African contexts. Barriers within all three systems of the CSN developed by King (1971, 1981 as cited in Gunther 2014) were identified. The possible interaction between these systems had implications for addressing the identified barriers through education as SLTs could aim to provide knowledge that could reduce personal system barriers, which could in turn improve functioning in interpersonal systems. Improved functioning of interpersonal systems could yield more focused discussions regarding patient care needs within clinical contexts, which could ultimately influence social system changes, by equipping nurses with training and skills to aid their management of persons with stroke.

The findings not only provided insight into nurses' needs in terms of knowledge and possible collaboration with the SLT but also their preferences regarding the format for CPD training. Training opportunities should therefore reflect their needs and learning preferences whilst also considering available resources and the clinical context. Strategies for increasing compliance and facilitating increased multidisciplinary teamwork were also addressed in this chapter.

THEME 3

Mental health and wellbeing

Chapter 4

The effect of interventions to support mental health post-stroke in Africa: A systematic review

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■ Abstract

Background: At least one in three stroke survivors in Africa can be expected to have post-stroke depression (PSD). Mental health problems, post-stroke, are associated with poorer rehabilitation outcomes and reduced QoL. However, mental health interventions are seldom available to stroke survivors. The aim of this systematic review was to describe the effectiveness of non-pharmacological interventions for mental health post-stroke in Africa.

Methods: We conducted a systematic review following the preferred reporting items for scoping review and meta-analyses (PRISMA) guidelines in Academic Search Complete, Africa Online, Africa Wide, CINAHL PLUS, MEDLINE, netd.ac.za (online theses platform), PsycINFO, SABINET, SciELO and Scopus. Data were extracted and evaluated using National Health and Medical Research Council (NHMRC) Levels of Evidence, place, race, occupation, gender or sex, religion, education, socioeconomic status and social capital plus (PROGRESS-Plus), the Template for Intervention Description and Replication (TiDIER) Checklist, McMaster Quantitative Review Form and effect size calculation.

Findings: The literature search yielded 429 studies, of which only five met the inclusion criteria. Interventions included cognitive rehabilitation therapy (CRT) and psychoeducation (Level II), a nursing care strategy (Level III-2), brisk walking, standardised PT and social networks (Level III-3). Reporting was poor, with a median of 9 of 18 participant characteristics (PROGRESS-Plus), and only 3 of 11 TiDIER items adequately reported. The effects of the CRT and nursing care strategy were very large and huge, respectively. Brisk walking had no effect on depression (p = 0.058). Reporting was inadequate to determine the effect of standardised PT or social networks.

Conclusion: There is insufficient evidence of interventions to address mental health needs of stroke survivors in Africa. The evidence that is available is poorly reported.

Keywords: Mental health; Depression; Stroke; Well-being; Anxiety.

■ Introduction

A stroke can have devastating consequences for stroke survivors and their extended families (Haley et al. 2015; Pearce et al. 2015). It therefore comes as no surprise that during the process of recovering from a stroke, many also experience mental health problems. The WHO (2004) defines mental health as:

> [*A*] state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community. (p. 231)

Within the medical model, mental health may also be understood as the absence of symptoms that meet the criteria for psychiatric illness using either the ICD-10 or DSM-V. Conceptualisations of health in different contexts may therefore vary according to geographical location, understandings of health as individual or social spaces (Arcaya, Arcaya & Subramanian 2015). For the purpose of this review, the above-mentioned WHO definition for mental health was used.

There is a high prevalence of depression amongst stroke survivors in SSA as reported in a recent systematic review and meta-analysis of the prevalence and characteristics of PSD in 17 studies in SSA (Ojagbemi et al. 2017a). This review found that almost one-third of 1483 stroke survivors (31% pooled frequency) met the cut-offs for depression in the various measures used. Other African prevalence studies confirm that at least one in three stroke survivors will experience PSD (Saadi et al. 2018; Sarfo et al. 2017b), whilst 1:5 will present with symptoms of severe anxiety (Ojagbemi et al. 2017b). Over half will experience cognitive decline as a result of the stroke (Hackett et al. 2005). Together with stigma, these mental health conditions contribute to decreased QoL post-stroke. A strong association between being woman and experiencing PSD (Sarfo et al. 2017b) and anxiety (Ojagbemi et al. 2017b) was reported. However, the factors most associated with PSD were low levels of education (SE = 0.04, Weight = 38.8%), cognitive impairment (CI) (SE = 0.08, Weight = 37.6%) and physical disability (SE = 0.34, SE = 21.0). Divorced marital status was also associated with PSD, but to a lesser extent than the other three factors (SE = 1.41, Weight = 2.4%).

In their cross-sectional study of PSD in Ghana, Sarfo et al. (2017b) similarly found that 36.5% of their participants who were attending a specialist neurology clinic at a tertiary hospital, met the cut-offs for depression in both the Center for Epidemiologic Studies Depression (CES-D) Scale and Geriatric Depression Scale (GDS). In that study, for every point increase in disability on the Modified Rankin scale, the odds of depression increased. In addition, being divorced significantly predicted depression. In their study of the relationships between depression, social support and disability, Saadi et al. (2018) found that nearly one-third of the 81 stroke survivors in Tanzania who participated in their prospective study 90 days post-stroke reported at least mild depressive symptoms, using the Patient Health Questionnaire-9 (PHQ-9). Participants who had a weak social support network, and higher levels of disability, were also more likely to be depressed, although the study could not hypothesise on causality because of the cross-sectional study methods.

Although the majority of research on mental health and well-being following stroke has focused on depression, there is emerging evidence of high levels of anxiety as well. In their study on the prevalence and predictors of anxiety post-stroke in 391 stroke survivors in Nigeria, Ojagbemi et al. (2017b) found that almost 20% recent stroke survivors presented with clinically significant levels of anxiety (using the Hospital Anxiety and Depression Scale [HADS]), and that most of these participants also had comorbid depression. Women were more likely than men to present with symptoms of anxiety. The authors suggest that in a context where resources are few and access to basic health and economic services is poor, high levels of worrying about the future may contribute to this high prevalence, in comparison to that of the general population. Anxiety may also be explained by widespread levels of poverty and deprivation that means that stroke survivors do not have access to adequate physical and mental health rehabilitation services.

In addition to depression and anxiety, stroke survivors with severe impairments reported a high level of stigma. For example, a Ghanaian study found that four out of five stroke survivors experienced stigma (Sarfo et al*.* 2017c). Furthermore, participants who experienced stigma, using the Stigma Scale for Chronic Illness, were also more likely to have a lower QoL ($p = 0.03$) and more likely to be depressed using the GDS ($p = 0.01$) and the CES-D ($p = 0.03$) (Sarfo et al. 2017b). On the other hand, social support networks provide emotional, practical and educational support (Saadi et al. 2018), which may explain why those with a good support system were also less likely to be depressed. Saadi et al. (2018) also suggest that the financial support offered by social networks in Tanzania may be a contributing factor to reduced depression because most of their participants were still of working age.

The management of stroke in middle- and low-income countries mainly focuses on addressing the physical symptoms of the condition. Conversely, the Royal College of Physicians' National Clinical Guideline for Stroke suggests a tiered approach for the management of mental health concerns ranging from psychological support to specialised and collaborate (Intercollegiate Stroke Working Party 2016). All people with stroke are at risk of cognitive loss; mood, behaviour or cognitive disturbances that might include anxiety, emotionalism, depression; denial and difficulty coping emotionally and psychologically with the stroke, which impedes recovery; and problems with orientation, memory and inappropriate behaviour (Gillham & Clark 2011). A comprehensive approach, including physical and psychological care for people with stroke, and their families, may facilitate improved management of the impact of stroke on their lives. Because of caregiver burden in the recovery period post-stroke there may be a need to broaden the scope of post-stroke care interventions (Dankner et al. 2016).

Mental health seems to be neglected on the African continent with only 1:27 people with mental health problems in low-income or middle-income countries benefit from effective treatment (Thornicroft et al. 2017). Similarly, only 42% of Sub-Saharan African countries have officially adopted a mental health policy, which underscores the need for addressing mental health care issues (Lund et al. 2015). It is therefore important that stroke services in Africa address their patients' mental health needs with the same level of care as their physical rehabilitation needs. When this is done in partnership with caregivers and families it may lead to improved rehabilitation outcomes and better QoL for stroke survivors and their families. Of the 17 studies included in a systematic review, five found that the most significant outcomes of PSD were poor QoL, functional dependency and reduced sexual functioning (Ojagbemi et al. 2017b). Badaru, Ogwumike and Adeniyi (2015) captured factors that were associated with health-related quality of life (HRQoL) in a critical review of literature from the African region. Of the 19 articles included in their review, 11 found mental health problems, predominantly depression, to be associated with lower HRQoL (Badaru et al. 2015). Responses to the HRQoL in Stroke Patients Questionnaire, in Sarfo et al.'s (2017b) study in Ghana, also indicated that depression is associated with decreased QoL in the physical, psychosocial, cognitive and ecosocial domains (Sarfo et al. 2017b).

Owolabi (2013) aimed to identify determinants of post-stroke HRQoL that remained constant, despite differences in socio-demographic and disparate cultures. He found stroke severity and post-stroke emotional well-being to be the ‘principle consistent determinants of physical, psycho-emotional, cognitive and ecosocial HRQoL after stroke’ in both Nigerian and German cohorts (Owolabi 2013:318). Dependency in performing ADLs, and QoL, were strongly correlated to PSD amongst Iranian stroke survivors. In fact, Haghgoo et al. (2013) found that the higher the level of PSD, the lower the QoL.

The recent South African Contextualised Stroke Rehabilitation Guideline (SA-cSRG) (2019) includes a number of recommendations relevant to post-stroke mental health. A consistent recommendation is made for an MDT care in acute stroke units. The professions named in this CPG include team members with competencies required to address the mental health needs of stroke survivors, including occupational therapists, clinical psychologists and social workers. Another consistent recommendation is for comprehensive assessment of rehabilitation needs which include psychological function (cognitive and emotional) and communication. The guideline does not recommend specific assessments or outcome measures of psychological functioning. Nevertheless, the American Heart Association (AHA) or American Society of Anesthesiologists (ASA) Scientific Statement (Towfighi et al. 2017) suggests PHQ-9 as a pragmatic and highly sensitive tool for detecting PSD. Simultaneously, the National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party 2016) recommends psychological screening and assessment tools for people with aphasia and CI.

The SA-cSRG (2019) found interim support for the use of motivational interviewing principles, problem solving and the teaching of self-management strategies within education programmes for stroke survivors. However, there was insufficient evidence that one-to-one psychological therapies prevent PSD and that each MDT has access to a clinical psychologist (SA-cSRG 2019).

The AHA or American Stroke Association's scientific statement on PSD identified seven trials (*n* = 775) of brief psychosocial interventions (Towfighi et al. 2017). Findings from three recent trials that were not conducted on the African continent suggest that psychosocial interventions provided by nurses or psychologists that last between 9 and 20 weeks are effective in treating or preventing the development of PSD.

Whilst one trial used a cognitive-behavioural therapy approach, the other two focused on adapting to changes in stroke and mood, problem solving and participating in valued activities, observing behaviour, being family focused and coordinating therapies. All interventions were provided individually. The findings of a further five trials suggest that PSD can be prevented, although more research with a broader range of stroke survivors using more robust study designs is needed (Towfighi et al. 2017).

Within the SA-cSRG (2019), there were also consistently strong recommendations that social participation should be encouraged and community reintegration should be supported. These interventions may include patient education, counselling and social support, which are recommended by the AHA or American Stroke Association as components of post-stroke treatment for depression that may be considered (Towfighi et al. 2017). Exercise programmes are another intervention that may be considered. Whilst the AHA or ASA Scientific Statement (2017) (Towfighi et al. 2017) recommends programmes of at least 4 weeks duration, the ASG (2017) guidelines recommend programmes that are structured and of high intensity (SA-cSRG 2019). In contrast, there was insufficient evidence to support the recommendation that when a person's social behaviour causes distress to themselves or their families that the underlying cause of the behaviour is assessed by an appropriately trained health professional and advice given on management (SA-cSRG 2019). Nevertheless, the SA-cSRG (2019) recommends that when behaviour is causing distress, the problem is explained to family members, caretakers, people in social contact and rehabilitation team members. These people should be trained in how to respond to inappropriate or distressing behaviour. At the same time, the stroke survivor should be helped to learn the most appropriate way to interact.

The National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party 2016) recommends a matched care model when choosing the level of psychological support that a person needs. A previous guideline for improving psychological care post-stroke recommends three levels of care (Gillham & Clark 2011). At Level 1, the focus is on stroke survivors who display none to mild levels of mental health problems, with interventions provided by peers or stroke practitioners (Gillham & Clark 2011). Level 2 considers stroke survivors with mild to moderate mental health difficulties, with care provided by stroke practitioners under the supervision of a clinical psychologist. At Level 3, intervention for those with severe depression or stroke survivors who are suicidal is provided by specialist mental health practitioners including psychiatrists (for psycho-pharmacological treatment) and clinical psychologists with a specialisation in stroke care. Gillham and Clark (2011) recommend screening for all stroke survivors, effective referral pathways and involvement of stroke survivors and their families in the development of interventions.

Finally, there is consistent evidence that stroke survivors should be monitored and re-assessed at regular intervals (SA-cSRG 2019). The SA-cSRG (2019) suggests that these intervals increase as the person reaches a functional plateau, but at least at 6 months and up to 12 months post-discharge from hospital. For mood and cognitive disturbance, specifically the recommendation from the National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party 2016) is assessment should be done within 6 weeks post-stroke, and again at 6 months and 12 months.

A number of systematic reviews in Africa have considered the causes and consequences of post-stroke mental health problems. However, none of these studies have evaluated the evidence for interventions to address mental health after stroke. Furthermore, the ASA or AHA Scientific Statement on PSD identified no randomised controlled trials of interventions in Africa (Towfighi et al. 2017). The high prevalence of mental health problems post-stoke together with the impact of these factors on recovery and QoL provided impetus for a systematic review of the effect of interventions to support mental health post-stroke in Africa.

Aim

To synthesise the evidence of non-pharmacological interventions for mental health post-stroke in Africa.

Review question: What is the effectiveness of non-pharmacological interventions for mental health in people with stroke living in Africa?

Objectives

1. To describe the characteristics of people with stroke included in eligible studies using PROGRESS-Plus criteria.
2. To assess the quality of reporting the mental health interventions using the TiDIER Checklist.
3. To describe the outcome measure used in eligible studies and frequency of measurement.
4. To ascertain the effect of mental health interventions reported in studies included in the review.
5. To critically appraise the methodological quality of eligible studies.
6. To extract recommendations and limitations reported in eligible studies.

Methodology

We conducted a systematic review of effectiveness following the PRISMA guidelines (Liberati et al. 2009), including four phases of identification, screening, assessment of eligibility and inclusion. The review protocol was not registered.

Eligibility criteria

Study design:

- We included primary quantitative studies listed on the NHMRC hierarchy for intervention studies. These included RCTs; pseudo-randomised controlled trials; non-randomised, experimental trials; cohort studies; case-control studies; interrupted time series with a control group and case series.

Population:

- We included studies reporting on people with stroke living in any African country.

Intervention:

- Any non-pharmacological interventions, including but not exclusive to counselling, support strategies, psychoeducation, motivational interviewing or participation in structured activities were considered.

Comparison:

- Any comparison or no comparison was considered. Comparisons could include any intervention not directed at supporting mental health directly.

Outcomes:

- Any form of mental health-related outcome (such as mood, anxiety and other symptoms of mental illness).

Search strategy

The focus of this review was on the treatment of mental health conditions that developed as a consequence of the stroke. Therefore, studies that focused on people with stroke with pre-existing mental health conditions were excluded. Studies where only pharmacological interventions were used were also excluded. Whilst the efficacy of medications to treat mental health conditions is well-known, these medications are not always accessible to stroke survivors in Africa (Lund et al. 2010). In the case of systematic reviews without meta-analysis, the original articles identified in those reviews were included for screening.

The search string was developed with the assistance of an SU librarian and included the terms: stroke, CVA, cerebrovascular accident, mental health, depression, depressive disorder, well-being, wellness, anxiety and Africa. In addition, the researchers replaced 'Africa' with the names of the countries which were known to have people actively involved in rehabilitation research: Benin, Burkina Faso, Egypt, Ghana, Nigeria, Mauritania, Morocco, Rwanda, South Africa, Tanzania, Tunisia and Uganda. The reference lists of systematic reviews and primary studies that met the inclusion criteria were also searched manually to identify potentially eligible studies that had not been identified by the primary search approach.

The research databases searched comprised Academic Search Complete, Africa Online, Africa Wide, CINAHL PLUS, MEDLINE, netd.ac.za (online theses platform), PsycINFO, SABINET, SciELO and Scopus. These nine databases covered a comprehensive sample of the available literature, including literature published in Africa that may not be listed in major research databases (e.g. MEDLINE). Papers published up to July 2019 were included. We did not place limits on any of the searches conducted. The final search was completed on 15 July 2019. The researchers contacted the authors of included articles where more information about the research was needed or where certain parts were unclear.

Once the search was completed, the results were uploaded to Covidence, a review management software program (covidence.org). The researchers independently screened the titles of all articles identified in the search and then the abstracts. Decisions on inclusion and exclusion were made by at least two reviewers independently. Conflicts were identified using Covidence and resolved by discussion. Full-text articles for final review were uploaded to Mendeley, a reference management system (mendeley.com). At least two researchers read through each full-text article simultaneously, then agreed on inclusion or exclusion. Reference lists of the included papers were also scanned for additional papers that had not been identified in the primary search.

Data extraction was completed using the parameters set in the study objectives. Each researcher charted half of the included articles, sitting together but working independently during the process. Data charting was completed using the PROGRESS-Plus health equity categories of the Cochrane Collaboration (O'Neill et al. 2014), the Guidelines for Critical Review Form – Quantitative Studies (Law et al. 1998) and the TiDIER Checklist for reporting of interventions (Hoffmann et al. 2014). Across the three tools, articles were rated on a three-point scale: 'adequately reported', 'not adequately reported' and 'not reported'.

Evidence grading

Studies were assigned into a hierarchy of evidence using the NHMRC criteria (Merlin, Weston & Tooher 2009) to provide an overview of the research designs identified in the search as follows:

- Level 1: Systematic review of randomised controlled trials.
- Level II: Properly designed randomised controlled trial.
- Level III-1: Properly designed pseudo-randomised controlled trial.
- Level III-2: Comparative studies (including systematic reviews) with concurrent control group and non-random allocation,

cohort studies, case-control studies and interrupted time series with control group.
- Level III-3: Comparative studies with historical control group, >2 single arm studies and interrupted time series with no parallel control group.
- Level IV: Case series, post-test, and pre-test or post-test.

Appraisal of methodological quality

The methodological quality of articles was appraised by charting the critical review components of each article using the McMaster Quantitative Review Form (Law et al. 1998). A score was not allocated to each article. Instead, the researchers reached an overall conclusion about the quality of the research considering all the components. The critical review components included the following:

- Study purpose (was it clearly stated?).
- Literature (was relevant background literature reviewed?).
- Study design (what design was used and was it appropriate?).
- Bias evident in the research (sample or selection bias, measurement or detection bias and intervention or performance bias).
- Study sample (how many, was it described in detail and was the sample justified?).
- Outcomes used.
- Intervention (described in detail and contamination avoided?).
- Results (statistical significance, appropriate analysis methods and clinical importance reported?).
- Drop-outs (reported?).
- Conclusions and clinical implications.

Assessment of equity

The extent to which the findings could be applied or extrapolated to disadvantaged populations was determined by applying an equity lens to the reported interventions. The PROGRESS acronym suggested by O'Neill et al. (2014) was used including

Place of residence, Race (ethnicity, culture or language also included), Occupation (employment status plus level of employment), Gender or sex, Religion, Education (highest level of attainment), Socioeconomic status and Social capital. In addition, the researchers considered personal characteristics that could be associated with discrimination, such as age, level of disability and human immunodeficiency virus (HIV) status; features of relationships (marital status and smoking status) and the time post-stroke at which the intervention was delivered. Data charting for each item was completed on each article, including an indication where an item was not reported at all.

Evaluating the reporting of intervention

The quality of intervention reporting was determined using the TiDIER Checklist (Hoffmann et al. 2014). This checklist was developed to improve the reporting, and therefore the replicability, of interventions. The checklist includes 12 items (Brief name of intervention, why and what [materials and procedures], who provided the intervention, how, where, when and how much, tailoring to individual needs, modifications during the trial period, how well the intervention was planned and how well it was actually implemented [treatment fidelity]). The researchers developed a three-point scoring system that indicated whether each item was 'reported', 'reported but in insufficient detail to allow replication' (Not Adequately Reported, N.A.R.) or 'not reported at all' (Not Reported, N.R.).

Evaluating the effectiveness of the interventions

First the methods of outcome measurement used in each study were examined, including the assessment tools used and the measurement intervals. Reporting of the reliability and validity of assessments was also assessed.

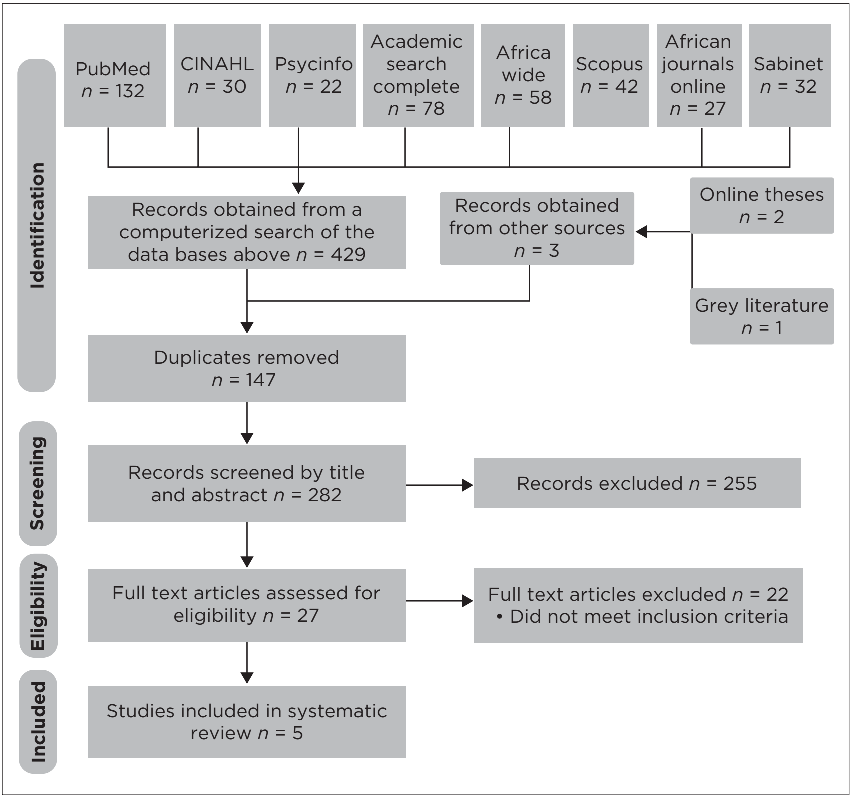
Then narrative methods were used to describe the effectiveness of the interventions as reported in each study, using the statistical analysis reported in the results and/or discussion of each article. In the final step of analysis, the effect size was calculated using Glass's delta for non-equivalent standard deviations (Sawilowsky 2009) and where sufficient data were reported.

Results

The initial searches yielded 429 hits of which 147 duplicates were removed, leaving 282 studies to screen by title and abstract. With the screening, 255 studies were excluded and 27 studies were assessed for full-text eligibility. Of those 27 studies, 22 were excluded. Four studies were published more than 10 years ago. In six studies, there was no intervention evidence. Four studies were systematic reviews. Five studies did not evaluate mental health and well-being outcomes. Three studies were not completed in Africa. A total of five studies were included in the final review (see Figure 4.1).

Evidence grading

Six different interventions across five studies were identified. These included a nursing care strategy (Ali 2013), brisk walking (Batcho, Stoquart & Thonnard 2013), standardised PT (Gbiri et al. 2015), CRT and psychoeducation (Olukolade & Osinowo 2017), and social networks. Ali (2013) and Olukolade and Osinowo (2017) conducted a controlled quasi-experimental (Level III-2) and randomised clinical trial (Level II), respectively. The other three studies all used prospective longitudinal single-cohort designs (Level III-3). Whilst Batcho et al. (2013) and Gbiri et al. (2015) included repeated measures, Saadi et al. (2018) only measured participants at two time points.



Source: Adapted from Liberati et al. (2009).

FIGURE 4.1: Preferred reporting items for scoping review and meta-analyses diagram showing search strategy and results.

Assessment of equity

Interventions to support the mental health of people with stroke are being evaluated in four African countries including Egypt, Benin, Nigeria and Tanzania (see Table 4.1). Using PROGRESS-Plus (O'Neill et al. 2014) and Law et al. (1998), participant samples were poorly reported. Of 18 PROGRESS-Plus items, studies

TABLE 4.1: Characteristics of people with stroke receiving mental health interventions.

Type of characteristic	Characteristic	Ali (2013)	Batcho et al. (2013)	Gbiri et al. (2015)	Olukolade and Osinowo (2017)	Saadi et al. (2018)
Sample	Sample size (*n*)	60	34	55	30	76
	Sampling	Convenience	Convenience	Convenience	Purposeful (BDI > 11)	Convenience
	Sample size justification	N.R.	Yes	N.R.	N.R.	N.R.
	Informed consent	Yes	Yes	Yes	Yes	Yes
Demographic characteristics	Place of residence	Helwan City, Egypt (*n* = 60; 100%)	Belgium (*n* = 15; 44.1%)	Ibadan, Nigeria	Ibadan, Nigeria (*n* = 30; 100%)	Dar-es-Salaam, Tanzania (*n* = 76; 100%)
	Race or ethnicity or culture or language	N.R.	N.R.	N.R.	N.R.	N.R.
	Occupation	Housewife/retired (*n* = 10; 33.3%) Working (*n* = 20; 66.7%)	Non-retired (*n* = 23; 67.6%) Retired (*n* = 11; 32.4%)	Students (*n* = 3; 5.5%) Non-skilled (*n* = 16; 29.1%) Semi-skilled (*n* = 17; 30.9%) Skilled (*n* = 8; 14.6%) Professional (*n* = 4; 7.3%) Retiree (*n* = 3; 5.5%) Unemployed (*n* = 3; 5.5%)	N.R.	N.R.

BDI, Beck Depression Inventory; HIV, human immunodeficiency virus; N.A.R., not adequately reported; N.R., not reported; SIAS, Stroke Impairment Assessment Set.

Table 4.1 continues on the next page→

TABLE 4.1 (Continues...): Characteristics of people with stroke receiving mental health interventions.

Type of characteristic	Characteristic	Ali (2013)	Batcho et al. (2013)	Gbiri et al. (2015)	Olukolade and Osinowo (2017)	Saadi et al. (2018)
	Female	*n* = 16 (53.3%)	*n* = 10 (29%)	*n* = 27 (49.1%)	*n* = 17 (56.7%)	*n* = 33 (43%)
	Male	*n* = 14 (46.6%)	*n* = 24 (71%)	*n* = 28 (50.9%)	*n* = 13 (43.3%)	*n* = 43 (57%)
	Religion	N.R.	N.R.	N.R.	N.R.	N.R.
	Education	N.R.	N.R.	No formal (n = 10; 18.2%) Primary (n = 6; 10.9%) Secondary (n = 25; 45.5%) Post-secondary (n = 4; 7.2%) University (n = 10; 18.2%)	No formal (n = 5; 16.7%) Primary (n = 8; 26.7%) Secondary (n = 5; 16.7%) Tertiary (n = 9; 30%) Doctoral (n = 3; 10%)	N.R.
	Socio-economic status	N.R.	N.R.	N.R.	N.R.	N.R.
	Social capital	N.R.	N.R.	N.R.	N.R.	N.R.
Personal characteristics associated with discrimination	Age	45	58	57.4	N.R.	54.1
	Mental health diagnosis	N.R.	N.R.	N.R.	BDI > 11	N.R.
	Disability	N.A.R. Moderate to high	N.A.R. SIAS = 56.5 at Baseline	N.A.R. 39 patients scored 50% and above in functional performance at 3-month post-stroke	N.R.	N.A.R. 90 days mRS, 24 (32%) had a score indicating moderately severe to severe disability.
	HIV status	N.R.	N.R.	N.R.	N.R.	HIV+ 4 (5%)

BDI, Beck Depression Inventory; HIV, human immunodeficiency virus; N.A.R., not adequately reported; N.R., not reported; SIAS, Stroke Impairment Assessment Set.

Table 4.1 continues on the next page→

TABLE 4.1 (Continues…): Characteristics of people with stroke receiving mental health interventions.

Type of characteristic	Characteristic	Ali (2013)	Batcho et al. (2013)	Gbiri et al. (2015)	Olukolade and Osinowo (2017)	Saadi et al. (2018)
Features of relationships	Marital status or living arrangements	Single (*n* = 1; 3.3%) Married (*n* = 29; 96.7%)	Living alone (*n* = 4; 11.8%) Living in community (*n* = 30; 88.2%)	Single (*n* = 3; 5.5%) Married (*n* = 40; 72.7%) Widowed (*n* = 11; 20.0%) Separated (*n* = 1; 1.8%) Not married (*n* = 15; 27.3%) Monogamy (*n* = 23; 41.8%) Polygamy (*n* = 17; 30.9%)	N.R.	Single (*n* = 22; 29%) Married (*n* = 54; 71%)
	Smoking	No (*n* = 22; 73.3%) Yes (*n* = 8; 26.7%)	N.R.	N.R.	N.R.	N.R.
Time-dependent relationships	Time since stroke	Within 1-month post-stroke	6 months post-stroke	Immediately post-stroke	N.R.	Within 14 days post-stroke
Characteristics of the stroke	Paretic side				N.R.	N.R.
	Left	N.R.	*n* = 18 (53%)	*n* = 11 (20%)		
	Right	N.R.	*n* = 16 (47%)	*n* = 44 (80%)		
	Type of stroke				N.R.	
	Ischaemic	0	*n* = 20 (61.7%)	*n* = 26 (47.2%)		*n* = 29 (38.2%)
	Haemorrhagic	*n* = 60 (100%)	*n* = 5 (14.7%)	*n* = 29 (52.7%)		*n* = 47 (61.8%)
	Unknown	0	*n* = 8 (23.6%)	0		0
Total items reported	**Score/18**	**9**	**10**	**10**	**5**	**8**

BDI, Beck Depression Inventory; HIV, human immunodeficiency virus; N.A.R., not adequately reported; N.R., not reported; SIAS, Stroke Impairment Assessment Set.

reported a median of 10 items (Range: 6–11). None of the studies reported race, ethnicity, culture or language. Similarly, none reported religion, socio-economic status or social capital. There was no subgroup analysis based on any of the health equity items included in the PROGRESS-Plus framework. Convenience and purposeful sampling were used in all studies, with small sample sizes (Range: 30–76). No studies reported the method or time of recruitment, nor included sample size calculations, except that by Batcho et al. (2013). Ali (2013) allocated 60 conveniently sampled participants into two equal groups (*n* = 30). Olukolade and Osinowo (2017) purposefully selected people with stroke with at least mild depression (*n* = 30, BDI [Beck Depression Inventory] score > 11) and then randomly assigned them to three groups (*n* = 10), including stratification by gender and educational qualification.

When examining participants' demographic characteristics, only Gbiri et al. (2015) reported the residential location of participants including urban (67.7%), semi-urban (28.7%) and rural (3.6%) areas. Across the three studies that referred to occupation (Ali 2013; Batcho et al. 2013; Gbiri et al. 2015), more people with stroke were working (*n* = 71.1%) than retired. Non-skilled (29.1%) and semi-skilled (30.9%) workers predominated as demonstrated in Gbiri et al. (2015). More participants across three studies had received secondary education or lesser (*n* = 67.4%), as compared to those with post-secondary or tertiary qualifications (Gbiri et al. 2015; Olukolade & Osinowo 2017). The proportion of men to women was almost equal across four studies, except in Batcho et al. (2013), where more men participated (71%) as compared to women (29%).

When examining personal characteristics associated with discrimination, the mean age of participants across the studies was 53.6 years and level of disability was moderate to high. Only one study reported the HIV status (5% positive) of participants (Saadi et al. 2018). Few participants lived alone, with most participants being either married or 'living in community'

(71%–96%) (Ali 2013; Batcho et al. 2013; Gbiri et al. 2015; Saadi et al. 2018). Analysis of the characteristics of the stroke indicated that people with both ischaemic and haemorrhagic strokes, as well as left- and right-sided hemiparesis were represented across the studies. Only two studies reported the affected side (Batcho et al. 2013; Gbiri et al. 2015). Four reported the type of stroke (Ali 2013; Batcho et al. 2013; Gbiri et al. 2015; Saadi et al. 2018). Most interventions began within 1 month of the stroke (Ali 2013; Gbiri et al. 2015; Saadi et al. 2018), except Batcho et al. (2013) who commenced their intervention at 6 months. Olukolade and Osinowo (2017) did not report the time post-stroke for commencement of intervention.

Evaluating the reporting of interventions for post-stroke mental health

As illustrated in Table 4.2, none of the studies reported on all 12 items included in the TiDIER Checklist (Hoffmann et al. 2014). The studies adequately reported a median of three items, ranging from one item (Saadi et al. 2018) to three items (Ali 2013; Batcho et al. 2013; Gbiri et al. 2015). None of the interventions is replicable using the information provided in the studies.

Ali (2013) implemented an individualised nursing care strategy with people 1-month post-stroke, based on the rationale that nursing care strategies can prevent disability and enable people with stroke to return to normal life. The intervention started with an assessment phase that determined the physical and functional needs of participants at Elnasr Insurance Hospital, Helwan City, Egypt. In the planning phase, individualised care plans were developed, based on the assessment findings, priorities, goals and expected outcomes. During the implementation phase, participants attended three sessions per week for 3 months, with a 60- to 90-min duration. This session included a theoretical component that taught participants and their family essential information about post-stroke care and a practical component in

TABLE 4.2: Reporting of interventions using the TiDIER Checklist.

TiDIER Checklist item	Ali (2013)	Batcho et al. (2013)	Gbiri et al. (2015)	Olukolade and Osinowo (2017)	Saadi et al. (2018)
Name of intervention	Nursing care strategy	Brisk walking	Standardised physiotherapy	Cognitive rehabilitation therapy	Social networks
Why: Rationale, theory or goal	√	√	√	√	√
What: Materials	N.R.	√	N.R.	N.R.	N.R.
What: Procedures	√	N.A.R.	√	N.A.R.	N.A.R.
Who: Intervention provider	N.A.R.	N.A.R.	N.A.R.	N.R.	N.A.R.
How: Mode of delivery	√	√	√	√	N.A.R.
Where: Location	N.A.R.	N.A.R.	N.A.R.	N.A.R.	N.A.R.
When and how much	N.A.R.	N.A.R.	N.A.R.	N.A.R.	N.A.R.
Tailoring	N.A.R.	N.A.R.	N.A.R.	N.R.	N/A
Modification	N.R.	N.R.	N.R.	N.R.	N/A
How well: Planned intervention fidelity and adherence	N.R.	N.R.	N.R.	N.R.	N/A
How well: Actual intervention fidelity and adherence	N.R.	N.A.R.	N.A.R.	N.R.	N.A.R.
Items adequately reported	3	3	3	2	1

Source: Adapted from Hoffmann et al. (2014).
N/A, not applicable; N.A.R., not adequately reported; N.R., not reported.

which skills in post-stroke care were taught (e.g. mobilisation of the affected limb). Participants implemented the knowledge and skills in a self-administered home programme under the supervision of their family members. Specific recommendations for thinking and mood problems included saving energy for the most important activities, trying to sleep well, organising priorities, avoiding rushing tasks, performing one activity at a time, asking for help when it was needed, avoiding getting anxious and practising relaxation (Ali 2013).

Batcho et al. (2013) implemented a brisk walking group intervention in Benin and Belgium 6-months post-stroke. Walking is a commonly reported activity that is important to functional independence. In addition, the social support provided in the group setting would provide support from other people with stroke and endorse exercise behaviour. The intervention occurred three times per week over 3 months in local sports facilities, supervised by a physical therapist. Participants walked at a pace faster than normal that left them breathless, but still able to maintain a conversation. Interventions were individualised to either include continuous walking, or intermittent walking and resting using a heart-rate monitor and pedometer. All included participants completed at least 85% of the sessions and reasons for drop-out were reported (Batcho et al. 2013).

Based on the rationale that rehabilitation improves neurological functioning and functional outcomes, Gbiri et al. (2015) implemented a standardised PT intervention between the first 24 h after admission to 12 months. For the first 2 weeks, daily PT was provided at the University College Hospital, Ibadan, Nigeria. Thereafter, standardised PT was provided every other day for 12 months. The treatment protocol included a graded approach to achieve ambulatory re-education and training, functional performance of the affected upper limb and prevent over-dependence on informal caregivers. Participants advanced from one phase in the standardised treatment protocol to the next based on their individual rate of recovery (Gbiri et al. 2015).

Olukolade and Osinowo (2017) recruited people with stroke who had a BDI score above 11, indicating mild to severe depression. Time since stroke was not specified. Over three and a half months, participants attended nine intervention sessions at the University College Hospital, Ibadan, Nigeria. The cognitive rehabilitation intervention included activity stimulation (Session 1–3), negative thoughts (Session 4–6) and people contacts (Session 7–9). As a comparison intervention, Olukade and Osinowo (2017) also implemented a psychoeducation intervention in nine sessions spread over three and a half months. This addressed knowledge of stroke and PSD. A third control group received usual care, as well as weekly mobile text messages including a greeting and words of support (Olukolade & Osinowo 2017).

Saadi et al. (2018) did not directly deliver an intervention to people with stroke, but instead examined the relationship between social networks, disability and depression over the first 90 days post-stroke, based on the theory that social networks improve functional recovery. The intervention in this case was the social support offered by spouses, close friends and family, participants' religious affiliations and membership of other community groups. This social support was provided in participants' own communities in Dar-es-Salaam, Tanzania (Saadi et al. 2018).

Evaluating the effectiveness of the interventions

Outcome measurement

The number of outcome measures used ranged from one (Ali 2013) to nine (Gbiri et al. 2015). The only assessment used by more than one study was the United States National Institute for Health Stroke Scale – Stroke Severity (Gbiri et al. 2015; Saadi et al. 2018). Four mental health outcomes were used including the HADS (Batcho et al. 2013), CES-D (Gbiri et al. 2015), Beck BDI (Olukolade & Osinowo 2017) and the PHQ-9 (Saadi et al. 2018). Ali (2013) used a modified version of the Stroke-Specific Quality of Life Scale (SS-QoL). Mood was measured using five items within the physical domain. The physical domain also included items related to vision, language, mobility, thinking and upper extremity function.

As illustrated in Table 4.3, all studies included a pre-test and 3-month post-test. Other than these two intervals, the frequency of measurement varied substantially between studies. Only Ali (2013) reported any testing of reliability and validity of the outcome measures. No studies reported translation, language of administration or cross-cultural validity of tools. In Ali (2013) and Gbiri et al. (2015), self-reported measures were sometimes completed by relatives on behalf of the person with stroke.

Evaluating the effectiveness of the interventions

Analysis showed a huge effect of the Nursing Intervention Strategy on the QoL (Ali 2013) and very strong effect of CRT on depression (Olukolade & Osinowo 2017; Sawilowsky 2009). However, a critical review using Law et al. (1998) and the TiDIER (Hoffmann et al. 2014) checklists revealed poor levels of reporting the interventions and methodology. There was no evidence that contamination and co-intervention were avoided in the studies. The methods of data analysis for each study objective were not clear, and in most cases the reporting of test results was poor. Whilst all the studies reported the statistical significance of their findings, none reported clinical significance even though all the

TABLE 4.3: Outcome measures and measurement intervals.

Author	Outcome	Baseline	Pre-test	Measurement intervals					Reliability	Validity
				3 weeks/ session	6 weeks/ session	3 months/ session 9	6 months	12 months		
Ali	SS-QoL		√			√	√		Cronbach σ	Face validity
Batcho	HADS	√	√			√	√		N.R.	N.R.
Gbiri	CES-D		√	√	√	√	√	√	N.R.	N.R.
Olukolade and Osinowo (2017)	BDI		√	√	√	√			Cronbach σ Test–retest	N.R.
Saadi et al. (2018)	PHQ-9		√			√			N.R.	N.R.

BDI, Beck Depression Inventory; CES-D, Center for Epidemiologic Studies Depression Scale; HADS, Hospital Anxiety and Depression Scale; N.R., not reported; PHQ-9, Patient Health Questionnaire-9; SS-QoL, Stroke-Specific Quality of Life Scale.

outcome measures used have clear cut-offs for depression. Four of the five studies reported 'drop-outs' but intervention fidelity was unclear in most studies.

Because no means or standard deviations were reported for the mood component in Ali's (2013) study, the researchers of this review analysed the effectiveness of the intervention using the domain and the total QoL scores. Using the Kruskall–Wallis Test, Ali (2013) found that physical and function QoL, and total QoL improved significantly in the intervention and control groups at post-intervention (3 months) and at the 6-month follow-up ($p < 0.001$). However, the improvement in the intervention group was much larger. A multiple linear regression analysis showed that being in the intervention group significantly predicted better improvement in QoL ($\beta = -34.05$, t [59] = 15.09, $p < 0.001$, CI [95%]: -38.51 to -29.59). Effect size calculation using Glass's delta for non-equivalent standard deviations indicated a huge effect of the nursing intervention strategy for physical ($d = 5.45$) and functional ($d = 5.05$) domains of QoL, as well as total QoL ($d = 5.93$).

Using a one way ANOVA, Olukolade and Osinowo (2017) found a significant difference between the cognitive rehabilitation, psychoeducation and waiting list control groups, $F(2, 27) = 8.64$, $p < 0.01$. Post hoc analysis using independent *t*-tests showed a significant difference between CRT and the control group (-8.40, $p < 0.05$) and between cognitive rehabilitation and the psychoeducation group (-9.40, $p < 0.05$). As illustrated in Table 4.4, there was a gradual improvement in depression scores in the CRT group over the course of the intervention. In contrast, the psychoeducation group improved slightly by Session 3 but then did not improve further. The waitlist control group was only measured at pre-test and post-intervention. Cognitive rehabilitation therapy was more effective than either psychoeducation or usual care in improving PSD (Olukolade & Osinowo 2017). Analysis of effect size using Glass's delta showed that CRT had a very large effect on depression in

TABLE 4.4: Efficacy in Level II and Level III-2 studies.

Study	Comparison	Preintervention		During intervention		Post-intervention		Follow up		Test statistic	Sig.	Effect size – Glass delta
		Int	Con	Int	Con	Int	Con	Int	Con			
Ali (2013)	Control	25.95 (7.45)	23.63 (4.16)			78.37 (16.07)	32.38 (8.44)	91.95 (9.0)	36.12 (10.45)	Kruskall–Wallis	$p < 0.001$	5.45
	Control	21.4 (2.16)	20.82 (1.18)			72.05 (15.81)	26.73 (8.97)	88.25 (10.99)	33.93 (8.99)	Kruskall–Wallis	$p < 0.001$	5.05
	Control	23.60 (4.18)	22.22 (2.24)			75.22 (14.16)	29.51 (7.71)	90.09 (8.78)	35.03 (8.99)	Kruskall–Wallis	$p < 0.001$	5.93
Olukolade and Osinowo (2017)	CRT vs. PET	16	17.3	8.9	14.7	4.9 (2.07)	14.3 (7.64)			Ind *t*-test	$p < 0.001$	1.23
	CRT vs. control	16	14.8	8.9	N.R.	4.9 (2.07)	13.3 (5.45)			Ind *t*-test	$p < 0.001$	1.54

Con, control group; CRT, cognitive rehabilitation therapy; Ind t-test, independent t-tests; Int, intervention group; PET, psychoeducation treatment; Sig., significance.

comparison to the psychoeducation intervention ($d = 1.23$) and control group ($d = 1.54$).

The three prospective observational cohort studies provided insufficient evidence for the effectiveness of brisk walking, standardised PT and social networks in improving mental health post-stroke. In Batcho's (2013) study, there was no significant effect of brisk walking on PSD using the HADS ($p = 0.058$). Gbiri et al.'s (2015) standardised PT intervention demonstrated a statistically significant change in depression over 12 months ($p < 0.05$) using the CES-D. Although CES-D scores were not reported, the proportion of participants with severe depression decreased from 100% at 4-weeks post-stroke, to 0% at 12 months. Simultaneously, the proportion of participants with no depression increased from 0% at 4 weeks to 79.6% at 12 months. Saadi et al. (2018) only reported that 39% had no depression on commencement of the study. Depression scores using the PHQ-9 were not reported.

Recommendations and limitations reported in eligible studies

Batcho et al. (2013) acknowledged the limitation of the prospective cohort design and the difficulty generalising their findings to other people with stroke, whilst Olukolade and Osinowo (2017) acknowledged their small sample size. Saadi et al. (2018) reported many limitations in their research. These included the small sample size with a high mortality rate, their inability to recruit people with stroke who were unable to access hospital care, the validity of the PHQ-9 in Tanzania, the exclusion of participants with aphasia, the use of proxy responders for self-report questionnaires, missing data because questions were not understood and their inability to determine depression prevalence at pre-test. Finally, they acknowledge that the conceptualisation of social support represented in the measures they used may not be equivalent to the way social support is viewed in Tanzania.

Based on their findings and limitations, all studies made recommendations for either interventions to address mental health post-stroke or for further research. These are illustrated in Table 4.5 and Box 4.1.

TABLE 4.5: Reported recommendations for treatment of mental health post-stroke.

Author	Recommendation
Ali (2013)	Address multiple physical and functional aspects affecting QoL post-stroke Include family members Maximise independence, lifestyle and dignity
Batcho et al. (2013)	Brisk walking efficiently improves impairment, balance, walking endurance and facilitates performance of ADLs Intervention found to be cost-effective Highlights the challenge of designing strategies that facilitate participation in physical activity for stroke survivors
Gbiri et al. (2015)	Rehabilitation should start immediately after stroke and be offered most intensively for the first 6 months post-stroke Early restoration of functional independence, perception that recovery is ongoing, early community reintegration and early restoration of role performance may contribute to alleviation of depressive symptoms Good spousal support contributes to alleviation of emotional difficulties post-stroke
Olukolade and Osinowo (2017)	Some form of treatment for depression must be provided as soon as it presents
Saadi et al. (2018)	Educate healthcare workers about psychosocial implications of stroke Screen for depression at community level to target those at highest risk Improve mobility and ability to engage outside the home through basic environmental adaptations Provide interventions that improve or develop new social connections post-stroke Include community health workers Reintegrate stroke survivors in religious groups

ADLs, activities of daily living; QoL, quality of life.

BOX 4.1: Reported recommendations for research.

Assess the effect of individualised nursing care interventions on caregiver burden (Ali 2013)

Replicate results of study with a larger sample (Olukolade & Osinowo 2017)

Compare individualised to group intervention (Olukolade & Osinowo 2017)

Refine outcome measures for African context (Saadi et al. 2018)

Investigate cultural conceptualisations of social support in an African context (Saadi et al. 2018)

■ Discussion

There is an urgent need for high-quality, well-reported, intervention studies that address the burden of mental health post-stroke in Africa. Our systematic review found little evidence in only five studies on the effectiveness of mental health interventions post-stroke in Africa. Although we found one Level II study using CRT (Olukolade & Osinowo 2017), reporting quality was poor. In another Level III-2 study of a nursing support intervention (Ali 2013), changes in mental health were not specifically reported. Nevertheless, the interventions appear to be substantially effective. Amongst the three Level III-3 studies, reporting quality was so low that we were unable to draw any conclusions about the effectiveness of standardised PT or social networks on mental health (Gbiri et al. 2015; Saadi et al. 2018). Brisk walking was found to be ineffective for depression (Batcho et al. 2013).

Our findings of the paucity of interventions for the prevention and treatment of PSD are supported by other systematic and literature reviews (Kaadan & Larson 2017; Towfighi et al. 2017; Urimubenshi et al. 2018). Urimubenshi et al. (2018) conducted an extensive review of stroke care across all African countries and they found seven articles on stroke rehabilitation. None of these papers included any reference to improving mental health or any mental health-related outcomes. This is despite multiple studies and systematic reviews that demonstrated a high prevalence of depression and anxiety post-stroke in Africa (Ojagbemi et al. 2017b).

People with stroke receiving interventions for mental health in Africa are young and married, with secondary education or lesser, and are employed (71%) in mainly unskilled or semi-skilled jobs. The young mean age of participants across the five studies (53.6 years) was noteworthy, given that prevalence estimates in HICs point to low prevalence up to age 54 (<1%) (Krueger et al. 2015). In their systematic review of 17 studies with 1 483 people with stroke in SSA, Ojagbemi et al. (2017a) suggest that economic and social factors may be the strongest contributors to PSD in SSA. This is because of reduced social and economic resilience, especially amongst those with little formal education or spousal support. It was therefore surprising that the five studies in our review failed to report many of these characteristics. In addition, because HIV+ status and smoking are both risk factors for stroke (D’Ascenzo et al. 2015), it was surprising that only one study reported participant status on each of these characteristics. Most notably, in five studies that evaluated the effect of interventions on mental health post-stroke, only Olukolade and Osinowo (2017) and Batcho et al. (2013) reported mean scores at pre-test and post-test using a recognised mental health outcome measure. The prevalence of depression across participants in the five studies is therefore unknown.

Regular and ongoing assessment of mental health is important in post-stroke care because results from the works of Gbiri et al. (2015) and Batcho et al. (2013) both show evidence of continuing mild depression at 12 months using the CES-D and HADS, respectively. The four outcome measures used in the studies identified were the PHQ-9, the HADS, the CES-D scale and the BDI. The clinical utility of these assessments in Africa should be investigated because each is short and easy to administer (9, 14, 20 and 21 items, respectively). The PHQ-9 and CES-D are freely available and have been investigated for validity in Africa (Baron, Davies & Lund 2017). Saadi et al. (2018) recommend screening for depression at the community level to target those at highest risk. In addition, the National Health Service Guidelines for improving psychological care post-stroke recommend assessment 1 month after stroke or pre-discharge, 6 weeks later, and then at 3 months, 6 months and 12 months post-stroke (Gillham & Clark 2011).

Rehabilitation interventions, provided by a range of stroke rehabilitation professionals, have the potential to significantly improve post-stroke mental health in Africa. However, better reporting of interventions is critical if we wish to understand why the interventions are effective. The interventions that improved mental health (Ali 2013; Olukolade & Osinowo 2017) included multiple individual sessions over 3 months. The feasibility of similar approaches in real-world clinical settings should be investigated. The timing of interventions may also be important. Ali's (2013) nursing care strategy commenced within 1 month and was hugely effective. In contrast, Batcho et al. (2013)'s brisk walking programme commenced 6 months post-stroke and had no effect on depression. The content of interventions also needs to be reported in substantially more detail. Although education is recommended by the ASA or AHA (Towfighi et al. 2017), Olukolade and Osinowo (2017) found that psychoeducation was ineffective. In contrast, Ali's (2013) intervention, which included a substantial education component, was hugely successful. It is also important to consider whether group interventions, which may be more cost-effective and facilitate social support and have the same effectiveness as individual interventions.

When designing future interventions for post-stroke mental health, it is also important to consider the rehabilitation service models that are most effective. In a recent systematic review of rehabilitation service models for LMIC, there was moderate to high-quality evidence from 578 studies including 202 307 participants that: (1) people with major depression can be treated effectively at the primary care level, (2) those who become suddenly and severely disabled (e.g. through stroke) should be admitted to a multidisciplinary specialist unit and (3) those who suddenly develop less severe disabilities should be treated in multidisciplinary CBR centres (Furlan et al. 2018). This means that interventions for PSD could be most effectively provided within primary care and CBR centres.

Community health workers are well-placed to provide psychosocial support within a task-shifting framework. Task shifting occurs when non-specialists provide psycho-pharmacological and psychosocial interventions, supervised by mental health specialists (Petersen, Bhana & Baillie 2012). Petersen et al. (2012) showed that an adapted Interpersonal Therapy group delivered over 12 weeks by trained community health workers (CHWs) led to significant decrease in depression amongst 30 women who presented at primary healthcare clinics in KwaZulu-Natal, South Africa with symptoms of depression, in comparison to 30 controls. Improvements were maintained at 24 weeks from baseline. In the qualitative process evaluation of that study, participants highlighted the value of supporting each other in the group. There was also evidence that the social support networks developed in the groups were sustained after the intervention was complete (Petersen et al. 2012).

Interventions to support the family caregivers of stroke survivors are an essential component of any intervention to promote mental health post-stroke because good spousal support appears to be an important predictor for mental health and well-being post-stroke. Gbiri et al. (2015) and Saadi et al. (2018) report participants who reported good spousal support recovered from depressive symptoms faster when compared to other participants. Ali (2013) also highlights the value of involving caretakers in their intervention. The findings of Jacobs-Nzuzi Khuabi et al. (2020) in this e-book also suggest that this support should include finding ways of coping with the changes in roles and relationships caused by the change in functional abilities of the stroke survivor. Interventions for caretakers should also include ways of helping the stroke survivor become as independent as possible, rather than becoming over-dependent on the family caregivers (Ali 2013; Gbiri et al. 2015).

Finally, the whole multidisciplinary stroke team should be educated about the psychosocial implications of stroke and take responsibility for monitoring and addressing mental health concerns so that it becomes part of the team culture. Gillham and Clark (2011) recommend that all staff are trained in the identification of potential mental health problems including administrative, domestic and clinical staff because stroke survivors may disclose their difficulties first to the staff members they feel most comfortable with. The success of training community healthcare workers to provide intervention under the supervision of a specialist has already been described (Petersen et al. 2012). However, physiotherapists, occupational therapists, nurses and doctors working in rural communities may also need training to provide the specialist interventions needed when stroke survivors are severely depressed or suicidal and do not have access to psychiatric services. Whilst this training should begin during undergraduate training, Project ECHO (Extension for Community Healthcare Outcomes) is one online case-based approach which may be effective for qualified professionals (Strumminger et al. 2017).

■ Conclusion and recommendations

There is insufficient evidence on which to recommend an evidence-based critical care pathway to promote mental health and well-being amongst stroke survivors in Africa. Our systematic review found almost nothing is being done to address the mental health needs of stroke survivors in Africa, and there is little evidence to support the development of interventions that are effective in the African context.

We recommend that all members of the MDT include assessment of mental health outcomes within their routine clinical evaluations and should take responsibility for preventing and treating mild mental health problems. For people with stroke with moderate to severe depression, intervention should be provided by team members with appropriate skills (e.g. occupational therapists and social workers) or referred to specialist services. Researchers in the field of stroke rehabilitation need to urgently improve the planning and reporting of clinical studies. The Equator Network (http://www.equator-network.org/) contains many resources to improve the reporting of intervention studies. In addition, urgent research is needed on the effectiveness of interventions for mental health post-stroke, especially those at Level II and Level III-2 evidence.

Education providers must ensure that rehabilitation professionals have the graduate attributes necessary to treat mental health conditions. Mental health is not clearly considered in major rehabilitation policies internationally, even though it is a significant risk post-stroke. Reaching maximum rehabilitation potential is only possible if we treat people with stroke as doing, thinking and feeling individuals who need holistic care at a time of crisis.

Chapter 5

The well-being of family members as informal caregivers of persons with stroke in an African context: Understanding their lived experience

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Abstract

Background: Family members may experience changes in their daily lives, once they assume the role of an informal caregiver for a person affected with stroke. These informal caregivers may experience strain as they attempt to balance their other roles. Many existing studies explore informal caregiver strain and support needs. There is a scarcity of literature that explores how informal caregivers balance their personal needs with that of the person with stroke and the impact this has on their well-being.

Aim: This study explored the well-being of informal caregivers of family members who have survived a stroke.

Methods: Qualitative research with a phenomenological design utilising individual semi-structured interviews was conducted. Eight informal caregivers from the Cape Metropole were selected purposively and after eight interviews data saturation was reached, data were analysed inductively using Burnard's framework.

Findings: Five overarching themes include: role change, time usage, types of support and the relief it brings, merged identity and the essence of caring. The findings reveal that the role as a caregiver added additional tasks and responsibilities which infringe on the informal caregivers' time to pursue their own needs. This could negatively impact their well-being over time.

Conclusion: Findings reiterate the need for health professionals to ensure that stroke management does not solely focus on the well-being of the person with stroke but also prioritises the well-being of the informal caregivers given the pivotal role they fulfil in the lives of the persons with stroke. These findings could inform health professionals about informal caregiver needs to facilitate their well-being.

Keywords: Stroke; Informal caregivers; Well-being; African context; Lived experience.

■ Background

Globally, stroke is a leading cause of disability (Thompson & Ryan 2009). Persons with stroke experience changes in body functions and structures that may lead to a variety of impairments in physical, mental and social areas of functioning. Whilst there are individual variations in the severity of these impairments, typically these are ongoing and result in activity limitations and participatory restrictions (Pendleton & Schultz-Krohn 2011). This associated loss of independence necessitates that persons with stroke require assistance from caregivers.

A caregiver may be formally employed or the employment may be of an informal nature. Informal caregivers provide unpaid physical and emotional care to family members, friends or neighbours with disabilities or illness within their home contexts (Jimenez-Martin, Prieto & Cristina 2008; Mthembu et al. 2016).

Motivation to do the caring, instead of getting paid help, varies from socio-economic reasons to more altruistic reasons (Hankey 2004; Van den Berg, Bleichrod & Eeckhoudt 2005). In developing contexts such as South Africa, a family member customarily assumes this role as an informal caregiver because of the lack of financial and or geographical access to formal caregiver services on a consistent and reliable basis (Perry et al*.* 2006). This phenomenon may also be attributed to cultural expectations that family members primarily care for their loved ones following the onset of an illness or disability (Kleineibst 2007). Research shows that factors such as familial relationship could have an impact on outcomes of persons with stroke (Ong & Koh 2016).

The role of informal caregivers of persons with stroke

Numerous authors have illuminated the pivotal role that informal caregivers fulfil within post-stroke management (Hassan, Visagie & Mji 2011; Kleineibst 2007; Mthembu et al*.* 2016). The role of an informal caregiver is varied and includes the provision of physical, psycho-emotional and lifestyle support. In addition, the caregiver often assumes roles that were previously the responsibility of the person with stroke.

Caregivers provide physical support to persons with stroke by assisting them with the execution of their ADLs such as eating, washing, dressing, toileting and mobility (Kleineibst 2007). This is reflected in the South African context, where it was found that in under-resourced communities, 87% of survivors required assistance with mobilisation and 66% requiring assistance with the execution of their ADLs 12 months post-stroke (Mudzi 2010). They further provide psycho-emotional support to persons with stroke to assist with their adaptation given the abrupt and sudden change in abilities and skills post-stroke. In addition, caregivers are often required to deal with residual cognitive-behavioural impairments post-stroke (Hassan et al. 2011; Kleineibst 2007).

Caregivers play a crucial role in providing lifestyle support by encouraging persons with stroke to make the necessary changes in their diet and to execute their exercise programmes. This is important to prevent the onset of secondary strokes and to optimise the person's functional recovery post-stroke (Hassan et al. 2011; Kleineibst 2007). Caregivers also experience an expansion of their own roles as they often have to assume the responsibility of roles in the family and household that were previously the responsibility of the person affected with stroke (Kleineibst 2007; Mortey 2017).

The multiple dimensions of the caregiver role results in the caregiver investing a significant amount of personal (i.e. time and energy) and financial resources to assist the person with stroke with the residual effects post-stroke. This may result in a perceived burden of care by caregivers of persons with stroke (Vincent et al. 2009).

The burden of care of informal caregivers of persons with stroke within an African context

The levels of strain associated with the burden of care experienced by informal stroke caregivers in a developing context such as South Africa are thought to be as high as between 43% and 58% (Hassan et al. 2011; Kleineibst 2007; Wasserman, De Villiers & Bryer 2009). This burden of care manifests as physical, psychological, social and financial strain (Hassan et al. 2011; Khondowe, Rhoda & Mpofu 2017; Kleineibst 2007; Mthembu et al. 2016; Sanuade & Boatemaa 2015; Wasserman, De Villiers & Bryer 2009).

Factors that influence the extent of the burden of care experienced include caregiver characteristics (e.g. gender, age, work, socio-economic status and the caregiver's health profile) as well as person with stroke characteristics (e.g. degree of motor or mental impairment). The perceived burden of care may also be heightened by factors such as the duration of caring for the person with stroke as well as by the intimacy of the relationship with the person with stroke (Hilton 2011).

There are numerous challenges in Africa that may contribute to the burden of care experienced by informal caregivers of persons with stroke who are family members. Policies that promote community-based care at a primary healthcare level, have resulted in shorter acute bed stays in hospitals (Presidency of South Africa 2012; Western Cape Department of Health 2014), which often results in the early discharge of acutely ill patients who are then dependent on their family members once they return home. In lower resourced settings, persons with stroke often return to homes which are small, densely populated with outside toilet facilities. This is compounded by a lack of training of the family members who need to fulfil the role of a primary caregiver to the person with stroke and places significant burden on families (Hassan et al. 2011; Kleineibst 2007; Wasserman et al. 2009). The lack of family training adds to caregiver burden as families experience physical and emotional strain as they are not equipped with the basic handling and mobility skills to optimally assist the person with stroke within their home contexts (Hassan et al. 2011; Mthembu et al. 2016; Khondowe et al. 2017; Kleineibst 2007; Wasserman et al. 2009).

In South Africa, the trajectory of care is such that most persons with stroke do not receive inpatient rehabilitation as there are few specialised inpatient facilities (Hassan et al. 2011). In the lower resourced or rural communities, most families do not have ready access to CBR services as they may not be available in the person with stroke’s vicinity. Families may not own vehicles and the cost of hiring private transport is often high (Mortey 2017). Public transport is often inaccessible and expensive, especially in instances where persons with stroke are wheelchair users and they are then expected to pay for their seat as well as for the transportation of the wheelchair (Khondowe et al. 2017). Kleineibst (2007) reported that within a peri-urban setting in South Africa, the lack of transport meant that family members pushed the persons with stroke to the community health centres (CHCs) in order for them to access the CBR services. Access to these services was often hindered by unfavourable weather conditions. A lack of consistent access to rehabilitation services impacted on the rehabilitation outcomes of the person with stroke; thus, they remained dependent on their families for the execution of ADL. This further heightened the burden of care the caregivers experienced (Vincent et al*.* 2009).

When family members assume the role as an informal stroke caregiver, they often have to give up their current jobs. This loss of income places significant financial stress on the caregiver (Hassan et al. 2011; Khondowe et al. 2017; Kleineibst 2007; Mthembu et al*.* 2016; Wasserman et al. 2009).

Caregivers expressed the concern that caring for the person with stroke resulted in social strain as it consumed a considerable amount of their personal time. This negatively impacted on their social interaction. The lack of respite care facilities and the unavailability of other family members to temporarily relieve the caregivers of their care duties meant that they were unable to pursue their own interests. This heightened the burden of care experienced by the caregivers of family members with stroke (Hassan et al. 2011; Kleineibst 2007). Caregivers also often experience stress, depression, anxiety and poor sleeping patterns as a result of caring for the person with stroke. The lack of focus on their support needs as part of the package of post-stroke management services resulted in significant psychological strain (Hassan et al. 2011; Makganye 2015; Mthembu et al*.* 2016; Oni et al. 2019).

The needs of informal caregivers of persons with stroke within an African context

Research has been undertaken in the African context to explore the needs of caregivers of persons with stroke who experience strain, in an endeavour to address the burden of care

(Hassan et al. 2011; Khondowe, Rhoda & Mpofu 2017; Kleineibst 2007; Mthembu et al*.* 2016; Wasserman et al. 2009). In the earlier stages of recovery (i.e. up 2 years post-stroke), caregivers of persons with stroke reported higher needs in terms of physical and socio-economic support as well as education. Physical support referred to the need for assistance with the physical handling of a person with stroke specifically during transfers and mobility. Educational needs related to knowledge pertaining to the causes, signs and management of stroke; handling skills during mobility; the facilitation of home exercise programmes and assisted execution of ADLs. Socio-economic support referred to the need for increased access to affordable and accessible transport and to functional assistive devices such as wheelchairs (Hassan et al. 2011; Khondowe et al. 2017; Kleineibst 2007; Mthembu et al*.* 2016; Wasserman et al. 2009).

Two years post-stroke, the needs of the caregiver appear to shift to that which is largely psychosocial and emotional in nature. This mainly included respite care to allow informal caregivers the personal time to pursue their own interests and opportunities to socialise. Caregivers highlighted the need for psychological and emotional support from a support network comprising family as well as rehabilitation personnel who conduct home visits to provide follow-up intervention (Khondowe et al. 2017; Kleineibst 2007). The shift in the need from more practical support to psychosocial and emotional support can be attributed to the fact that recovery mainly occurs in the first 18 months post-stroke and either the person with stroke therefore with time may require less hands-on assistance from their caregivers (Gillen 2015) or improvement in the caregivers' abilities leads to lessened assistance needed (Khondowe et al. 2017; Kleineibst 2007).

Strategies to lessen caregiver burden within an African context

Numerous studies have highlighted the needs of the caregivers of persons with stroke who experience strain. The findings of these studies have led to the development of strategies to minimise the burden of care. Internationally these strategies include:

- Caregiver education and family training sessions during rehabilitation (Pierce et al. 2007; Schure et al. 2006; Visser-Meily et al. 2005).
- Home visits to ensure that input can be given regarding environmental limitations and to ensure that training is applicable to the person with stroke's context (Hassan et al. 2011).
- Telephonic follow-up to assist caregivers of persons with stroke to solve any challenges experienced with the transition from hospital to home (Friedman & Grant 2003).
- The provision of 'adult day care and respite care' facilities for persons with stroke (Kalra et al. 2004; Schure et al. 2006).
- Access to home-based carers to provide physical support with the execution of ADLs (Kleineibst 2007; Western Cape Department of Health 2014).
- The development of support groups for the caregivers of persons with stroke to obtain emotional support through the shared experiences they have with other members of the support group (Pierce et al. 2007).

Within an African context, Kleineibst (2007) developed a caregiver support intervention programme (CSIP) based on the needs of informal caregivers in a low-resourced area in South Africa. The five CSIP sessions informed informal caregivers on topics regarding the available resources in the community (such as home-based carers and/or social workers who were able to assist with the application of a carer-dependency grant). Caregivers were further informed regarding how to access these services; provide effective transfer skills; improve facilitation skills for persons with stroke-related to personal care activities such as washing, dressing, eating and bathing; and theoretical knowledge concerning warning signs, causes, risk factors and prevention of stroke. Informal caregivers who made use of the

CSIP stated that they appreciated the group interaction they received at the programme which contributed to a decrease in their stress levels and further contributed to a fulfilment in their emotional needs (Kleineibst 2007). Whilst this is a promising intervention, Hassan et al. (2011) pointed out that in their study informal caregivers indicated that support groups need to be sustainable. These authors hence recommend that support groups should progress to the level where the participants of the group take ownership of it to ensure its sustainability. Within a developing context, there are also personal and logistical limitations impacting on caregivers' involvement in support groups. Personal limitations included a lack of time because of household and family commitments, the inability to find someone to attend to the person with stroke and other social problems. Logistical limitations included bad weather and a lack of transport (Kleineibst 2007).

A further strategy included the development of a training manual that was a joint initiative between a university and a specialised rehabilitation centre. It was developed to equip therapists to empower the caregivers with the knowledge and skills needed to care for a person with stroke. This entails a 4 h training programme specific to a South African context of home or institution-based care (Scheffler & Visagie 2015). This happens within groups. The focus of this CSIP is mainly on developing the caregiver's knowledge and skills about stroke and the physical handling of the person with stroke. The socio-emotional needs of the caregivers may be addressed indirectly but it is not one of the main focus areas of intervention.

Within low-resourced communities in South Africa, non-governmental organisations can offer training to members of the community to equip them to fulfil the role of a home-based carer. These home-based carers provide a basic nursing service to patients with a variety of disabilities, including those with stroke. They offer support to informal caregivers by providing hands-on assistance with the execution of the person with stroke's ADLs (Kleineibst 2007; Western Cape Department of Health 2014, 2019).

A specialised inpatient rehabilitation centre in the public sector in South Africa based their approach for the training of informal caregivers of family members with stroke, on a model used in the Netherlands (Visser-Meily et al. 2005). As part of the training, informal caregivers were invited to visit the rehabilitation centre and participate in a full day of the rehabilitation programme along with their family member. This would ideally take place prior to the person with stroke's first weekend home. The aim of the training was to teach the informal caregiver the necessary knowledge and skills to safely and correctly assist the person with stroke at home (Hassan et al. 2011; Visser-Meily et al. 2005). Upon evaluation of their participation in the training, informal caregivers indicated that they felt more competent to care for their family member. These caregivers also stated that they valued the training experience as it allowed them to feel included within the rehabilitation process (Hassan et al. 2011). Unfortunately, as stated previously, inpatient rehabilitation services in the public healthcare sector are a very limited resource.

The perceived well-being of informal caregivers of persons with stroke

Once family members assume the role of informal caregiver, there are numerous changes that take place in their lives (Morais et al. 2012). As literature has shown these informal caregivers may experience strain. This strain predisposes informal caregivers to health risks such as social isolation, mental and physical health conditions, which may negatively impact on their well-being (Mortey 2017). It could be argued that informal caregivers of family members with stroke find it difficult to balance the demands of the multiple roles they need to fulfil. Most of the existing studies explore informal caregiver strain and support needs. There is a scarcity of literature that explores how these informal caregivers balance their personal needs with that of the person with stroke and the impact this has on their well-being (Mthembu et al. 2016). The exploration of the well-being of informal caregivers is imperative as caregivers' well-being could influence the quality of the care and support that is provided to the person with stroke (Morais et al. 2012). This study hence sought to explore the perceptions of well-being of informal caregivers of family members who have survived stroke, in an African context.

There are varied viewpoints of well-being (Fieldhouse & Banningan 2017). In this study, well-being is operationalised as (Pentland & McColl 2009):

> [*T*]he flourishing condition that derives from a life where there is congruence between the different occupational performance areas of a person's life and their values and meaning they derive from participation. (p. 169)

Hence well-being will be explored in terms of the effect of caring, for a family member who survived stroke, on a caregiver's:

- personal time
- participation in the occupational performance areas of work, leisure, personal and community living and social interaction
- the meaning derived from the activities in which he or she participates (Wagman, Håkansson & Björklund 2011).

■ Aim and objectives

The aim of the study was to explore the perceptions of informal caregivers regarding their well-being as they care for family members who have survived a stroke, in an African context.

The objectives of the study were to explore the effect of caring for a family member who has survived a stroke:

- on the caregiver's personal time
- on the caregiver's participation in the occupational performance areas of work, leisure, personal and community living and social interaction
- on the meaning caregivers derive from participation in activities.

Methodology

Design

The qualitative research study design made use of a phenomenological approach, which is situated in an interpretive paradigm. The study design investigates a phenomenon from the participants' perspective to obtain a deeper understanding of their lived experience. The family members' perspective of their well-being whilst providing informal care for the person with stroke has not been comprehensively explored in a South African context (Krieger, Feron & Dorant 2016).

Sampling

The study population consisted of informal caregivers who provided care to a family member who survived a stroke in the Cape Metropole, Western Cape. A purposive sampling method was used to select participants who have experienced the key phenomenon of caring for a family member who has had a stroke.

Participants were selected based on the following criteria:

- an informal caregiver of a family member who survived a stroke and lives within the Cape Metropole area of the Western Cape, South Africa
- able to communicate in English, Afrikaans and/or isiXhosa, as these are the three predominant languages spoken in the province.

Participant recruitment and the data collection process

The process of participant recruitment commenced after the study obtained ethical approval from the Human Research Ethics Committee of SU (#U18/10/33).

Occupational therapists working at all levels of public healthcare facilities and private practices who provide services to stroke surviving clients living in the Cape Metropole were approached by the researchers. The aim was to determine the number of potential participants who met the selection criteria. These healthcare providers were seen as gatekeepers, who assisted with participant recruitment (Bless, Higson-Smith & Sithole 2013). For those institutions where there were potential study participants, permission was obtained from the heads of the respective institutions before participant recruitment commenced.

Once permission was granted by the institutions, the gatekeepers contacted potential participants and explained the purpose of the study in order to obtain their permission for the disclosure of their personal contact details. The researchers telephoned potential participants to obtain verbal consent and arrange the logistics for the interview that was convenient for the participant. All of the interviews were scheduled to take place in the participants' home environment. On the day of the interview, written informed consent was obtained from the participant and the interview was conducted in the preferred language of the participant.

Each interview lasted for approximately 45–60 min. During the interviews two researchers were present. One conducted the interview whilst the other made field notes on possible prompts. The interview was audio-recorded on a dictaphone.

During the course of the interviews, researchers made use of a semi-structured interview guide. This guide utilised four predetermined open-ended questions focusing on the research objectives and predetermined prompts were used where necessary. The open-ended questions were as follows:

- What does a typical day in your life as carer for X look like?
- What are your feelings towards the number and variety of activities you are doing?
- How did your day-to-day activities change since you started caring for X?
- Explain which activities or tasks are meaningful to you and indicate which of these you would like to continue.

Data management

Recorded interviews were transcribed verbatim and stored on a password-protected computer. Each recorded interview, and accompanying transcript, was coded using pseudonyms to maintain participant confidentiality.

Data analysis

Analysis commenced after reviewing the first interview to determine whether further probing could obtain a richer data set. Inductive data analysis was done according to Burnard's framework (Burnard 1991). The researchers adopted a system of open coding with peer-checking throughout. Subcategories were decided on by collapsing codes that are similar in nature. Repetitive concepts were also removed during this process. Similar subcategories were further collapsed to create categories and from this process, overarching themes emerged.

Ethical considerations

The study was conducted according to the ethical guidelines and principles of the International Declaration of Helsinki (WMA 2013), South African Guidelines for Good Clinical Practice (DoH 2006) and the Medical Research Council Ethical Guidelines for research.

The following ethical considerations were applied.

Respect and autonomy

In this study, all participants were given the right to autonomy and their decisions were respected. Participants voluntarily participated in the study and they were free to withdraw without negative consequences (Bless et al. 2013).

Each of the participants was informed about the aim of the research, what was expected of them as a study participant as well as the study's risks and benefits (both direct and indirect). This was communicated verbally and included as part of the written consent form. This information was relayed in the participant's preferred language (i.e. English or Afrikaans or isiXhosa). All of these were explained without the use of professional jargon. Each participant signed a consent form after they were given the opportunity to ask any questions regarding the research.

Confidentiality was maintained through the use of pseudonyms to de-identify the participants. A list of the names of the participants and their corresponding pseudonyms were kept in the eventuality that participants required referral for follow-up support. This list in addition to the transcripts from the participants' interviews were saved on a password-protected computer.

☐ Protection from harm

Steps were taken to protect the participants through ensuring that the necessary approval was obtained from the relevant ethics committee and applicable authorities in the Department of Health prior to the recruitment of participants (Bless et al. 2013). During the research process, emotionally traumatic experiences linked to the participants' caregiving experience may have been elicited or participants may have become distressed by probing questions. Should any participant have become emotionally distressed as a result of participation in this study, it would have been communicated to the relevant gatekeeper who would then have referred the participant for the necessary follow-up support. None of the participants required referral.

☐ Justice

Justice is based on handling and treating all people equally and not discriminating between individuals (Bless et al. 2013). In this research study, the researchers ensured that every participant was treated the same way and that there was no discrimination based on gender, income level, race and disability.

Trustworthiness and rigour

Krefting's (1991) four strategies were applied to ensure trustworthiness. These include: (1) credibility, (2) transferability, (3) dependability and (4) confirmability.

Credibility

In credibility, the emphasis was on recurrence and it required 'adequate submersion in the research setting to enable recurrent patterns to be identified and verified' (Krefting 1991:217). From the information obtained from participants, the researchers ensured that the said information was from the perspective of the participants who experienced the phenomena. To further ensure credibility, member checking and triangulation were used, specifically investigator triangulation. In this study, more than one researcher was used to gather and interpret data which reflected investigator triangulation. All the researchers in this study gathered and interpreted data from the interviews using the same method. Member checking was achieved through conducting follow-up visits to the participants, by the original interviewer, to verbally verify whether the analysed data were portraying their intended meaning (Bless et al. 2013).

Transferability

Transferability refers to the transferability of the conclusions of the study to other similar situations (Krefting 1991). In this research study, the researchers provided detailed descriptions of the participants and their contexts in which the data were collected (Bless et al. 2013).

Dependability

Dependability is the consistency of conclusions that arose from the research study. Dependability thus depends on the type of data collection and data analysis used in a research study, and this process should be explained thoroughly (Krefting 1991).

The researchers ensured that dependability was implemented by a detailed description of the research process. Data analysis was conducted effectively, by using Burnard's framework (1991). This process ensured that consistent findings emerged in this particular research study.

☐ Confirmability

Confirmability refers to the degree to which the study findings and conclusion display the data collected (Krefting 1991). The researchers ensured confirmability within the study by means of triangulation and peer-checking of the data collected.

■ Findings

The aim of the study was to explore the perceptions of well-being of informal caregivers of family members who have survived a stroke, in a developing context. It was anticipated that this would provide an improved understanding of how caring for the person with stroke impacts on a carer's personal time, participation in the occupational performance areas of work, leisure, personal and community living and social interaction as well as the meaning they derive from the activities they participate in.

The findings were obtained from semi-structured interviews held with eight informal caregivers of family members who have survived a stroke. The demographic information of each informal caregiver is depicted in Table 5.1. This is followed by a dense description of each informal carer in accordance with the importance of contextualisation in strengthening the rigour of the findings (see Box 5.1). All of the participants had at some stage received family or carer training from rehabilitation professional(s).

From the data analysis, five major themes emerged, namely: (1) role change, (2) time usage, (3) types of support and the relief it brings, (4) merged identity and (5) the essence of caring (see Box 5.2).

TABLE 5.1: Demographic profile of the participants.

Participant pseudonym	Age	Gender	Level of education	Duration of caregiving	Relation to person with stroke
1	57	Female	Gr 12	11 years and 6 months	Wife
2	72	Female	Gr 12+ degree	7 years	Wife
3	64	Female	Gr 6	3 months	Wife
4	48	Female	Gr 12	1 year and 9 months	Daughter
5	63	Male	Gr 10	3 months	Cousin
6	35	Female	Gr 10	2 months	Sister
7	65	Male	Gr 8	3½ months	Husband
8	71	Female	Gr 5	3 months	Wife

Gr, grade.

BOX 5.1: Dense descriptions of each informal caregiver.

Participant 1 is from a middle socio-economic background. She is currently unemployed. Her highest level of education is grade 12. She stopped working at a hotel to care for her husband, who had a brainstem stroke that resulted in him presenting as a quadriplegic. He thus requires assistance with the execution of all ADLs. She has been the sole caregiver of her husband since the incident 11 years ago. She receives assistance from a formal caregiver (who is paid for by a family friend) once a week to allow her time to relax and indulge in socialising activities such as going to the beach, going to the mall and cinema with a friend. She also enjoys spending time with her two children and two grandchildren.

Participant 2 is from an affluent socio-economic background. She obtained a degree in education and worked as a pre-school teacher for 40 years. She is currently retired. She now spends her time attending craft classes every 2 weeks. She also attends a support group that meets four times a year. She volunteers as a teacher at a township school every Wednesday. She has Multiple Sclerosis and misses walking because of its effects on her physical functioning. She has two children and her son visits every night to walk their dogs. She has been caring for her husband for 7 years. Her caregiving tasks include laying out her husband's clothes every morning, food preparation and driving.

Participant 3 is from a low socio-economic background and she is currently retired. She previously worked for a cleaning company for 10 years. She has been caring for her husband for 2 months and they have been married for 40 years. They have five children and nine grandchildren. A community-based carer comes three times a week to bathe her husband; however, the services are not consistently on time, so she occasionally bathes him by herself and they assist with transferring him to his wheelchair. Since her husband's stroke and her assuming the caregiver role, she has experienced a decrease in time to partake in grooming activities (i.e. applying makeup and styling her hair), which she particularly enjoys doing. Similarly, her favourite pastime of reading has also declined for the same reason. On weekends, she is relieved of some of her caregiving duties as her children come to assist in caring for their father.

(Box 5.1 continues on the next page→)

BOX 5.1 (Continues…): Dense descriptions of each informal caregiver.

Participant 4 is from a low socio-economic background and she is currently unemployed. She is the mother of three children and her highest level of education is grade 12. She has been the sole caregiver of her mother for the past 9 months. She received basic training for caregiving at a local community rehabilitation centre. A few leisure time activities that she has only recently found time to participate in are going for walks, singing in the church choir, needlework, taking her grandson to karate practice as well as attending church services on a weekly basis. She cares for her mother 2–3 days a week. Her mother resides in a three-bedroom home with her boyfriend who is unemployed and occasionally assists with caregiving tasks. She stated that to facilitate her well-being she relies heavily on her religion and support from her partner and children.

Participant 5 is from a middle socio-economic background and he is currently retired. His highest obtained level of education is grade 10. He has been caring for his male cousin for 3 months. He drives his cousin on errands and provides supervision to him throughout the day. His cousin requires minimal assistance with feeding, washing and toileting. Participant 5 is married for 38 years and has one daughter who is 17 years old. He has previously cared for his wife because of a shooting incident. He currently feels that as a result of caring for his cousin he is neglecting caring for his wife as she still requires minimal assistance with self-care tasks. He enjoys reading, cooking and fixing things around the home which he is able to do whilst his cousin is asleep. He received basic training from a local rehabilitation centre.

Participant 6 is from a low socio-economic background, and she is currently unemployed. Her highest obtained level of education is grade 10. She is a mother to a son who attends primary school. She is one of three sisters who all currently occupy the same RDP home, which includes their brother who requires care. She, however, is the sole caregiver for her brother for the past 2 months. Her tasks include assisting her brother with washing, dressing, feeding and toileting. He struggles to communicate because of the stroke and attends speech therapy at the local community rehabilitation centre. She also has previous experience with caring for persons with stroke as both her brother and father had strokes. Her intermittent time off from caring is spent shopping and socialising with her friends, who now visit her at her home.

Participant 7 is from a low socio-economic background and he is currently unemployed. He previously worked for a company for 28 years before being retrenched in 2008. He has been caring for his wife for 3 months. His leisure activities include drinking coffee on the porch in the mornings whilst smoking a cigarette and reading the newspaper, completing woodwork activities, cleaning the yard and fixing miscellaneous objects in his home. Previously, he enjoyed cleaning the church hall on Saturdays and taking afternoon naps, but he is currently unable to complete these activities because of his caregiving duties. These caregiving duties encompass washing and dressing his wife, brushing her hair and household activities such as meal preparation.

Participant 8 is from a low socio-economic background and she is currently unemployed. She has previously worked in factories and as a housekeeper. She has been caring for her husband for the past 3 months and they have four children. The caregiving tasks that she completes include the setup of her husband’s self-care activities which he is able to perform with minimal assistance. She further assists her husband with toileting as he occasionally experiences incontinence. The youngest son (18) currently lives at home and he assists his mother with the caring tasks upon her request. Care for her husband on weekends alternates between their three other children. This allows her free time on weekends which she spends resting and enjoying her alone time.

ADLs, activities of daily living; RDP, Reconstruction and Development Programme.

BOX 5.2: Themes: role change, time usage, types of support and the relief it brings, merged identity and the essence of caring.

Theme 1: Role change This theme reflects the new role as an informal caregiver that family members assumed once they took on caring for their family member with stroke. This new role brought about additional tasks and responsibilities. In addition, the new role resulted in the informal caregiver experiencing relational changes within the existing relationship with the person with stroke and/or in their social networks. Over time caregivers adapted to this new role

Category	Quotes
Additional tasks or responsibilities associated with assuming the new caregiver role	
The new caregivers experienced an increase in their tasks and responsibilities because they were physically caring for the person with stroke in conjunction with taking over the household tasks that were previously the responsibility of the person with stroke	'I get his breakfast, I get water, towel and washcloths and stuff … I only supervise him but where he cannot manage or reach, I will help him'. (Participant 5, 63-year-old male, lines 51–54) 'I had to stay up in the early mornings and late night in case he coughs and then I must see to him … and then he wants to pee and I have to take him to the toilet … I couldn't sleep for round about the whole night because I must always keep an eye on him …'. (Participant 8, 71-year-old female, lines 31–35) 'Or if there is something that is not right, something a man should fix I will do that'. (Participant 5, 63-year-old male, line 191)
Complexities of relationships	
There was a change in the interpersonal interactions and relationship between the primary caregiver and the person with stroke. The familial role is now superseded by the role of caregiver	'It is not a normal life. He can't touch my hand; he can't touch my leg. There is no physical contact … I am almost like a widow or a divorced woman now … the children still has a father, a home to come to, the grandchildren still has a grandfather …'. (Participant 1, 57-year-old female, lines 362–373) 'But it's almost like looking after a child. He's my child every day, this husband of mine'. (Participant 8, 71-year-old female, lines 77–78) 'So, we started getting distant, because there was nothing that we could do together anymore. So, there it already started'. (Participant 4, 48-year-old female, lines 224–225)
Change was also experienced in caregivers' social relationships, with them becoming more restricted and confined to their homes	'Always just sit here, I used to sit outside for a little bit but now I must sit here where I can hear what he says. I cannot stand by the gate and talk to the neighbours anymore. They hardly see me anymore'. (Participant 3, 64-year-old female, lines 210–212)

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BOX 5.2 (Continues…): Themes: role change, time usage, types of support and the relief it brings, merged identity and the essence of caring.

Complexities of relationships	
There was a change in the interpersonal interactions and relationship between the primary caregiver and the person with stroke. The familial role is now superseded by the role of caregiver	'We don't see them [friends] that often anymore, we don't braai anymore and can't visit them as he needs my attention. That's the problem'. (Participant 3, 64-year-old female, lines 224–225)
Change was also experienced in caregivers' social relationships, with them becoming more restricted and confined to their homes	'So, you have to make an effort to get people to come and visit you, because you can't always go to them. Or you have to meet them somewhere. But you have to put in effort to keep your friendships, not because they don't love you, but because your life changes and their lives goes on as normal'. (Participant 1, 57-year-old female, lines 117–121)
Adaptation over time	
Improvements in the caregivers' competency in handling the person with stroke as well as improvements in the person with stroke's level of independence over time, lessened the caregivers' feelings of being anxious and overwhelmed by tasks	'Went from not doing anything for himself, he can go to the shower, he can shower himself and collect his towels … I lay out his clothes … I just hover maybe I do some emailing and things until he had his shower'. (Participant 2, 72-year-old female, lines 20–24) 'When he was first discharged from … it was very difficult for me. It was a bit too much for me … I couldn't sleep for round about the whole night … but now he sleeps right through the night. … now he gets up by himself at night'. (Participant 8, 71-year-old female, lines 30–37) 'There are many tests and obstacles, that is a test for you and how do I accept it, in the beginning it's difficult. But every day with her – you get used to it'. (Participant 7, 65-year-old male, lines 148–150) 'So, then we learned through having him here on weekends … you actually learn very fast. And no nurse, nobody can look after him the way I do'. (Participant 1, 57-year-old female, lines 246–248)
Theme 2: Time usage This theme highlights the fact that caregivers experienced restrictions in their personal time and that the needs of the person with stroke restricted the flexibility of the caregivers' routine. The needs of the person with stroke further dictated the activity participation of the caregiver	

(Box 5.2 continues on the next page→)

BOX 5.2 (Continues…): Themes: role change, time usage, types of support and the relief it brings, merged identity and the essence of caring.

Personal ‘me’ time	
Caregivers longed for some time away from their caregiving tasks and responsibilities albeit on their own or with others	‘Just to be somewhere alone where I can’t be disturbed without anyone calling me or asking something from me or where I can just sit alone and watch TV, you just want to be alone’. (Participant 6, 35-year-old female, lines 79–81) ‘I can’t take my afternoon naps that I was used to taking’. (Participant 7, 65-year-old male, line 101) ‘I’m sure if I had the time I would have walked more or joined a walking club. But it’s not the reality’. (Participant 3, 64-year-old female, lines 275–276) ‘There was no time while I was still working, and there is still no time, so I actually haven’t stopped working. You just change the one type of work for the other. It’s a work where you work in your own house, you are housebound. And the night is also not yours because he gets physically turned during the evening’. (Participant 1, 57-year-old female, lines 276–278)
Set routine	
Caregivers expressed the fact that attending to the needs of the person with stroke resulted in a lack of flexibility with regard to how they structure their days	‘But basically, everyday has the same routine. Doing the same thing every day. And sometimes it can become frustrating. You don’t feel like doing the same thing every day’. (Participant 4, 48-year-old female, lines 130–136) ‘When she is sleeping, I will clean the yard first. Then I will sweep the house and dust and when she wakes up, I’m relaxed with a cigarette and a cup of coffee’. (Participant 7, 65-year-old male, lines 200–203).
Person with stroke first	
The needs of the person with stroke dictate the caregivers’ time usage and activity participation	‘You can’t plan anything like a normal human. If you want to go to the restaurant, you have to call before the time and ask if it’s “wheelchair-friendly”. If you want to go on holiday, which we haven’t done in a while because it’s a lot of effort’. (Participant 1, 57-year-old female, lines 82–84) ‘If he says “toilet now”, then I have to leave everything. If I am in the middle of baking a cake, I have to leave it right away and go to him. And then I can carry on again. So, things get done according to another rhythm’. (Participant 1, 57-year-old female, lines 128–130)

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BOX 5.2 (Continues…): Themes: role change, time usage, types of support and the relief it brings, merged identity and the essence of caring.

Theme 3: Types of support and the relief it brings This theme reflects the physical, socio-emotional, financial, educational and spiritual support that assist caregivers within the process of caring

Financial support from others

This reflects financial support that allows for increased access to support services which allow the caregiver the time to pursue their personal interests	‘Our friends pay for a carer that comes once a week. But that means I leave the house at 11 and at 4 I am back’. (Participant 1, 57-year-old female, lines 156–157)

Physical support

This refers to the physical assistance that informal caregivers received with regards to the care of the person with stroke. In most instances, this assistance came from family members. Physical support allowed caregivers the time to pursue their personal interests and lessened their experience of physical strain	‘Supper my daughter bought yesterday – chicken and broccoli – just have to put it in the oven. That he can eat 3–2 days, … so everything is in order and I can sit and read’. (Participant 7, 65-year-old male, lines 145–149)
	‘On weekends, my children come, and they are here to help me – my two daughters. Then I can relax a little bit, or we go to them and they look after him. My son also comes. My son shaves him and bathes him and then I sit’. (Participant 3, 64-year-old female, lines 116–117).
	‘And his children come on weekends. His daughter takes him one weekend and his son from … comes all the way here and takes him to … for the weekend. And my son from …, also comes and take him for the weekend and then brings him back’. (Participant 8, 71-year-old female, lines 80–83)
Functional assistive devices were regarded as a source of physical support in that it helped to minimise the caregiver’s physical strain during the physical handling of the person with stroke	‘No last time I hurt my back, he is very fast and shaky, so I hurt my back by bending down. He didn’t have a wheelchair yet, so I had to pick him up and make him walk till here and then I hurt my back. We finally got a wheelchair and I am very happy’. (Participant 3, 64-year-old female, lines 151–153)

Socio-emotional support

This refers to the emotional support that primary caregivers receive from their social networks. It is through socialising that caregivers have the opportunity to debrief, have informal discussions and receive comfort, encouragement and reassurance. This helps to lessen their experience of emotional strain	‘We really are one of the lucky ones, strokes are not good. Having said that ooh there’s a little group of us that meet with an occupational therapist called, oh what is she called again … oh whatever she’s from … and a lot of her patients, there are about six of us with various degrees of handicaps and we all get together about four times a year? And we do all sort of things, we’ve been to Kirstenbosch and Butterfly World. And we all meet up together and they call themselves stroke heroes’. (Participant 2, 72-year-old female, lines 407–413)

(Box 5.2 continues on the next page→)

BOX 5.2 (Continues…): Themes: role change, time usage, types of support and the relief it brings, merged identity and the essence of caring.

	'They take some white wine or red wine and so we'll have conversation. Then we'll come in, put on some music and dance a bit. So, it goes what I always did with them. Then I feel the stress is off'. (Participant 3, 64-year-old female, lines 118–120) 'I just make things, whether it's sewing, so yes, I just joined a group of ladies, its therapy'. (Participant 2, 72-year-old female, lines 1001–101)
Educational support	
Training from the health professionals involved in the person with stroke's rehabilitation helped primary caregivers to acquire the knowledge and skills with regards to the physical handling of the person with stroke	'I sit with her in the sessions [occupational therapy sessions]. And it helps to see it in the sessions'. (Participant 4, 48-year-old female, line 302)
Conversely, where family members did not receive training this did not prepare them for their new role as an informal caregiver	'I was not there; I could not see what they had done in therapy. When he came home it was something new to me. Because I do not know the types of therapy'. (Participant 5, 63-year-old male, lines 156–157)
Spiritual support	
This refers to the role of spirituality in helping caregivers to cope and experience some degree of connectivity	'I see things happen when I pray. It's not always easy but when something good happens, you know from where it is from'. (Participant 4, 48-year-old female, lines 288–290) 'They come here to see him and the youth sings for him and brings him Holy Communion'. (Participant 3, 64-year-old female, line 195)
Theme 4: Merged identity This theme highlights the dependence of the person with stroke on the caregiver and the impact this has on the caregivers' sense of individuality as they assimilate the role of informal caregiver (i.e. activities, emotions and thoughts)	
Your whole life revolves around him	
The caregiver's life is centred around the person with stroke	'When I stop at the shops and I am away for longer than 2 hours, then I know I better have to get home. Then I am stressed … The bottom line is, everything is about him. More or less. … that's how it feels for me'. (Participant 1, 57-year-old female, lines 136–143) 'The social gets influenced through him not being able to speak and because he can't eat by himself, in other words I have to stand and sit next to him and feed him. If we are at a dinner, and I go and talk to someone on the other side. I have to be aware of him all the time and let someone talk to him so that he doesn't sit alone, otherwise it's an issue'. (Participant 1, 57-year-old female, lines 337–341)

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BOX 5.2 (Continues…): Themes: role change, time usage, types of support and the relief it brings, merged identity and the essence of caring.

	‘You feel like you aren’t being appreciated any more … that it’s normal that you should be here. How would you say it? I don’t know what the right word is. It’s a given fact that you are here. You don’t get appreciated in the idea of: “do you realise how much I do for you”’. (Participant 1, 57-year-old female, lines 392–395) ‘I always take him – my feeling is that it mustn’t be nice to just to be housebound so will go out’. (Participant 2, 72-year-old female, lines 53–54)
Interwoven tasks and emotions	
Caregivers’ activities and emotions are dependent on the person with stroke	‘When she goes to sleep then I sleep’. (Participant 7, 65-year-old male, line 311) ‘When he’s sitting reading then I’ll read’. (Participant 2, 72-year-old female, line 154) ‘And the moods she went through makes you depressed. If she is angry, then you start to feel edgy. And then I feel like I am on the edge to explode’. (Participant 4, 48-year-old female, lines 254–256)
Theme 5: The essence of caring The essence of caring is two-folded: namely, the reasons for assuming the caregiver role and the meaning derived from fulfilling this role	
The value system underpinning the caring role	
In this category, carers alluded to different motivation for assuming the role of caregiver albeit moral, religious or family values	‘Yes, because it is not only my responsibility, it is everyone’s responsibility, because we no longer have parents, it is only us brothers and sisters. One brother and three sisters and that’s our other brother. So, it is our duty to care for him … that is what our parents would have wanted’. (Participant 6, 35-year-old female, lines 184–187) ‘Because he was a working man, I was short of nothing … So now it’s my turn to look after him’. (Participant 8, 71-year-old female, lines 78–80) ‘Where I started learning was when my mom cared for my grandmother and my aunt who was also in the house with us. We had a big family like a close family, and everyone in one house always came to my grandmother. And so, this is how we grew up’. (Participant 8, 71-year-old female, lines 75–78)

(Box 5.2 continues on the next page→)

BOX 5.2 (Continues...): Themes: role change, time usage, types of support and the relief it brings, merged identity and the essence of caring.

	'We will all need help one day, therefore, we should not turn to anyone and say he is not good enough for my help, be it your sister or brother, because you do not know who the Lord sends us to'. (Participant 5, 63-year-old male, lines 275–277)
Personal meaning derived from caring	
For some, the caring role provides a sense of purpose and an opportunity for new experiences	'It helps me with my exercises. I do something new every day and we move around a lot'. (Participant 5, 63-year-old male, lines 174–175) 'They tell me you are retired why are you doing all this, then I only say there are people who need my help'. (Participant 5, 63-year-old male, lines 236–237)

Discussion

This study aimed to explore the perceptions of well-being of informal caregivers of family members who have survived stroke, in an African context. The pivotal concept of this study was well-being as defined by Pentland and McColl (2009). It was anticipated that this would provide an improved understanding of how caring for the person with stroke impacts on a carer's personal time, participation in the occupational performance areas of work, leisure, personal and community living and social interaction as well as the meaning they derive from the activities they participate in.

The main findings of the study indicate that caregivers caring for family members with stroke undergo a change in role function and identity. Participants reported to have restructured their lives and daily routine to enable them to care for their family member. This process of change presented them with several challenges regarding setting new priorities for their personal and leisure activities in order to balance their own needs with that of the family member. This balance was not easy to achieve; and it negatively affected some of the participants' well-being. This iterates the findings of a previous study in which the majority of participants expressed that they were often unable to separate their personal needs from those of the person with stroke and this had a negative impact on their well-being (Denham et al. 2019).

Family members expressed that the role change to that of an informal caregiver was accompanied by changes in the dynamics of the relationship with the person with stroke. The relationship became characterised by a state of dependence of the person with stroke on the informal caregiver. In instances where a spouse fulfilled the role of an informal caregiver, there were often changes in the level of intimacy in the marital relationship. Some participants alluded to changes in the functioning of the person with stroke resulting in the perception of the person with stroke being a new person with whom the family member needed to get acquainted as part of their new caregiving role. In addition, these informal caregivers had to deal with the emotional difficulty of grieving the loss of who their family member was prior to the onset of the stroke. This finding concurs with existing literature, where it was found that caregivers experienced emotional distress as they grieved the former life and identity of the person with stroke (Denham et al. 2019).

The findings of this study highlighted five categories of needs for informal caregivers of persons with stroke. Physical, socio-economic and educational needs appear to be well-researched; however, there is a paucity of research on the emotional and psychosocial needs of informal caregivers. Participants in this study expressed physical, socio-emotional and educational needs as factors that impacted on the fulfilment of the new caregiver role. They specifically mention the need for physical support that includes family members either assisting with the execution of the self-care tasks of the person with stroke or providing respite care for brief periods of time. Caregivers' socio-emotional needs include having time to spend on socialising with others outside of the everyday routine. Many of the caregivers identified educational needs around managing the person with stroke. The above findings are congruent with existing literature where informal caregivers of stroke survivors have expressed similar needs (Hassan et al. 2011; Khondowe et al. 2017; Kleineibst 2007; Mthembu et al. 2016; Wasserman et al. 2009). Initially, the lack of knowledge on how to care for a person with stroke contributed to caregivers experiencing feelings of anxiety and uncertainty regarding how they would assume responsibility for the additional tasks underpinning the caregiver role as well as for those tasks that were previously the responsibility of the person with stroke. As supported in literature, the informal caregivers in this study expressed that with time they were able to adapt to this new role, as caring became more manageable as a result of the improvement in the person with stroke independence and as their feelings of competency in caring for the person with stroke increased (Khondowe et al. 2017; Kleineibst 2007).

Literature alluded to a positive link between rehabilitation outcomes for persons with stroke and care given by family members. This may be attributed to the availability of the caregiver as well as a result of the closeness of the relationship (Ong & Koh 2016). Findings from this study highlight the fact that the closeness of the relationship between informal caregivers and the family member they cared for, impacted on their sense of individuality. Fulfilling a caregiver role often meant that they were not only physically invested (as with a paid caregiver) but also emotionally invested which made it difficult for the informal caregiver to live a separate life from the person with stroke.

Participants in this study relate to an experience of merged identity where their daily routines and tasks were interwoven with that of the person with stroke. This merged identity often resulted in changes in the caregiver's external relationships with their support networks as tasks that underpin the caregiver role took priority over opportunities for social interaction. It appeared that the person with stroke needs superseded that of the caregiver and activity participation was focused on tasks related to the caring of the person with stroke with little time for informal caregivers to pursue their personal interests and fulfil their own needs. The set routine of caring for the person with stroke reportedly restricted the degree of flexibility and spontaneity with which informal caregivers were able to participate in activities. This echoes the findings of other research in which it was reported that caring for the person with stroke often limited the caregivers' personal time and their freedom to explore their personal interests which affected their sense of autonomy (Denham et al*.* 2019; Mthembu et al*.* 2016).

This study's findings illuminate psychosocial and emotional support as the main needs of informal caregivers of persons with stroke. Most of the participants identified their social networks as their usual source of psycho-socio-emotional support but that access to this support became restricted as a result of the demands of caring for the person with stroke. It would appear that the very thing that informal caregivers need with this role change (i.e. psycho-socio-emotional support) is the very thing that this role change takes away from them (i.e. opportunities for social interaction). These findings correlate with existing literature that has indicated that informal caregivers do require physical, socio-economic and educational support. Over time, these physical and educational needs were met but the need for psychosocial and emotional support grew (Makganye 2015).

It was evident in this study that the motivation and meaning derived from caring are very personal for each caregiver. Participants reported that the motivation for caregiving was from a value base, either influenced by religious beliefs, benevolence or reciprocity as seen in previous generations of caring. The above finding is in contrast to other studies that found that family members opt to provide informal care because of the high cost of professional care, perceived low quality of professional care or family members feeling obligated to fulfil the informal caregiver role (Hankey 2004; Van den Berg et al. 2005). Furthermore, some participants indicate that caregiving does provide personal meaning and a sense of purpose and may be perceived as less of a burden if they obtain the necessary emotional and psychosocial support. Caregiving can be a positive role to undertake provided that all five categories of needs are adequately met. There needs to be a shift from the initial focus on tasks associated with caring to the psychosocial and emotional needs of the caregiver in the long run. The above strategy will help to promote well-being as congruence will be established between the different occupational performance areas (work, leisure, social interaction, and personal and community living) of the caregiver and the value and meaning they derive from taking on the role of caring for the person with stroke.

■ Conclusion

Previous studies have mainly focused on the practical needs of the informal caregiver in terms of physically handling and caring for the person with stroke. This study focused on the person fulfilling the role of informal caregiver and their well-being. Study findings reflect that the two occupational performance areas that were most restricted by caring include social interaction and leisure. Informal caregivers’ time to pursue their personal needs and interests were superseded by the needs of the person with stroke. Informal caregivers in this study, particularly those in the role for a year and more, identified a strong need for personal unstructured time away from the person with stroke. This allowed informal caregivers opportunities to relax, pursue their own interests and connect with those in their social networks. This was important in terms of lessening the emotional and social strain associated with caring, thus increasing the capacity of informal caregivers to balance the multiple roles that they need to fulfil and ultimately promote their well-being. Findings reiterate the need for health professionals to ensure that stroke management does not solely focus on the well-being of the person with stroke but also prioritises the well-being of the informal caregivers given the pivotal role they play in the lives of the persons with stroke.

Recommendation for practice and further research

- The well-being of caregivers could be improved with added focus on their socio-emotional needs over time. Input for the caregiver could focus on creating awareness of the importance of scheduling sufficient time alone, socialisation time and opportunities to pursue their own interests. This is important to build informal caregivers' coping resources that will enable them to provide support to the person with stroke and ensure their own well-being.
- Empower caregivers with the knowledge and skills to advocate for support to allow them respite and time to fulfil their personal needs.
- It is recommended that health professionals should foster the establishment of a support group, focused on the knowledge and skills related to providing care for the person with stroke and over time shift to a greater focus on ensuring that the emotional and psycho-socio-emotional needs of the caregivers are met. This would necessitate that the focus of support groups become less driven by health professionals and become more caregiver- or peer-driven to ensure that the caregivers psycho-socio-emotional needs become a priority.
- Further research is needed in rural contexts where there may be limited access to rehabilitation services and support structures and how that may influence the well-being of informal caregivers of persons with stroke.

Limitations of the study

These findings may not be generalisable to other groups of caregivers, for example, informal caregivers who are not relatives of the persons with stroke, formal caregivers or those based in developed contexts.

THEME 4

Outcome measurement considerations

Chapter 6

Complexities related to the measurement of activity, participation and quality of life amongst people with stroke within the African context: A scoping review

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■ Abstract

Background: Most patient-reported outcome measures (PROMs) commonly used in research and practice are developed in HICs and may not be contextually appropriate for low- to middle-income countries like those found in Africa. Cross-cultural adaptation (CCA) and cross-cultural validation (CCV) of PROMs in stroke rehabilitation are imperative for use in the unique African context.

Aim: To collate the current literature reporting on the CCA and CCV of PROMs used in stroke rehabilitation within an African context, and to highlight considerations for future research and clinical use.

Methods: A five-step scoping review methodological framework was followed. Studies reporting on the CCA and/or CCV of PROMs that assessed activity and/or participation according to the International Classification of Functioning, Disability and

Health (ICF) framework, as well as QoL, amongst people living with stroke in Africa, were targeted.

Findings: Nine studies published in the English language between 2006 and 2019 were included. The PROMs adapted and/or validated were the SS-QoL 2.0, the Maleka Stroke Community Reintegration Measure (MSCRIM), the Activity Limitations Stroke questionnaire (ACTIVLIM-Stroke), the Locomotion Ability (ABILOCO) questionnaire, the London Handicap Scale (LHS), the World Health Organization Quality of Life BREF 9 (WHOQoL-BREF) and the Hand Function Ability Stroke questionnaire (ABILHAND-Stroke).

Conclusion: The process of CCA and CCV of PROMs is known to be a labour-intensive activity. However, when conducted in an African population it may be even more difficult to conduct CCA and CCV of PROMs because of the diverse and unique social and environmental challenges.

Keywords: Stroke; Rehabilitation; Outcome measurement; Cross-cultural adaptation; Cross-cultural validation; Africa.

■ Background

To gauge the effect of person-centred rehabilitation services on reaching predefined outcomes, healthcare professionals typically use PROMs. These outcome measures obtain information about the patients' understanding of their symptoms, functional status and HRQoL (Albach et al. 2018) and help to identify the most effective and efficient rehabilitation modalities to be used within different diagnostic groups. Patient-reported outcome measures therefore need to be standardised, reliable and valid (Lundgren-Nilsson et al. 2005) and should have a concrete conceptual basis (i.e. alignment with a framework, for example the ICF) as well as adequate psychometric properties (Lundgren-Nilsson et al. 2005). Because PROMs are designed to measure health domains in all individuals, it would allow for comparisons of health status between different populations and disease groups across the globe (Albach et al. 2018).

When compared to the developed world, people living with stroke in Africa are often confronted with different functional challenges because of unique environmental, social and cultural contexts (Joseph & Rhoda 2013). These contextual factors include high levels of poverty, unavailability of appropriate means of transport (Baatiema et al. 2017), long geographical distances to healthcare facilities (Rhoda et al. 2015; Sarfo et al. 2018; Soeker & Olaoye 2017; Wasserman, De Villiers & Bryer 2009), bad terrains and poor infrastructure (Urimubenshi 2015). The appropriateness of directly administering PROMs, which have often been developed in HICs, in LMICs found in Africa, is therefore questioned because the original PROM typically speaks to and often only targets the original population (Lima et al. 2016; Morris et al 2012). The diversity of cultural subgroups within populations typically occur in terms of language, dialect, lifestyle, morals, values, behaviour, customs, beliefs, perceptions of life and expression of disease (Beaton et al. 2000). De Klerk, Buchanan and Jerosch-Herold (2018) assert that contextual variations would result in differences in the experience and execution of daily activities by patients from diverse settings. Therefore, the direct administration of the existing, previously validated versions of PROMs within a different patient group in other non-comparable populations is not recommended (Beaton et al. 2000; Morris et al 2012). The CCA and CCV of PROMs in stroke rehabilitation are thus imperative especially when targeted for use in the unique African context.

Cross-cultural adaptation of PROMs often involves translating items to ensure that the same constructs are assessed and that the adapted outcome measure remains clear and relevant to the target population. The consequences of using linguistically or culturally inappropriate PROMs across populations with cultural diversity are extensive not only in terms of decision-making on effective care but also in terms of health policy development (Beaton et al. 2000). Cross-cultural adaptation of existing PROMs is a unique and appropriate method for developing reliable outcome measures for use in another country, culture and/or language context (Beaton et al. 2000; Uysal-Bozkir, Parlevliet & De Rooij 2013). The purpose of CCA is to ensure equivalence between the original PROM and the target versions of that outcome measure (Beaton et al. 2000), and the process often requires that some of the items on the questionnaire be excluded, changed or that new items are added (Uysal-Bozkir et al. 2013). According to Beaton et al. (2000), the process of CCA includes initial translation, synthesis, back translation, expert committee review and pre-testing of the draft translated questionnaire.

Epstein et al. (2015:n.p.) differentiates between the process of translation, which includes 'the production of a document from a source to a target language', from the process of CCA, which encompasses 'a process that ensures equivalence in meaning', and further discriminates between CCA and CCV. Once the process of CCA has been completed, it is imperative that the adapted version of the PROM, be evaluated for its psychometric properties because there will be uncertainty as to whether the new adapted PROM has retained the validity and reliability of the original outcome measure following the CCA process (Beaton et al. 2000; Epstein et al. 2015; Uysal-Bozkir et al. 2013). This process is known as CCV and is described as the degree to which the performance of the items on a translated or culturally adapted PROM is at an adequate level reflecting that of the original version of the PROM. Cross-cultural validation can be performed by using either the Classical Test theory or the Item Response Theory approaches (Mokkink et al. 2010a). According to the Consensus-based Standards for the selection of health status Measurement Instruments checklist (Mokkink et al. 2010a), evaluation of the methodological quality of studies reporting on CCV of PROMs include the following psychometric testing parameters: internal consistency, reliability, measurement error, content validity (including face validity), construct validity (structural validity, hypotheses testing and CCV), criterion validity, responsiveness and interpretability (Mokkink et al. 2010b). Therefore, compliance with comprehensive

CCA and CCV processes of newly adapted PROMs will enable healthcare professionals to assess the health status of each patient in their unique cultural context and allow for the comparison of research conducted on different populations or different contexts (Uysal-Bozkir et al. 2013), specifically within the African context.

The aim of this chapter was to thus collate the current literature reporting on the CCA and/or CCV of PROMs used in stroke rehabilitation within an African context, and to specifically highlight considerations (in terms of semantics, experiential/cultural and conceptual) which researchers need to pay attention to when attempting to find equivalence between the original and newly adapted version of a measure. Patient-reported outcome measures that assessed activity and/or participation according to the ICF framework as well as QoL measures were specifically targeted.

Methodology

Review framework

The reviewers followed the guidelines of a five-step scoping review methodological framework recommended by Levac, Colquhoun and O'Brien (2010), which involves: (1) identifying the research question; (2) identifying the relevant studies; (3) selecting the studies; (4) charting the data; and (5) collating, summarising and reporting the review results. The reviewers also followed the reporting guidelines for scoping reviews as stipulated by Tricco et al. (2018).

Step 1: Identifying the review question and defining the objectives

This initial stage of the review provided a roadmap for the entire process and clearly defined the breadth and depth of the scoping review. In accordance with the purpose of scoping reviews, our approach was broad with a special emphasis on studies that reported on CCA and/or CCV of PROMs which are used in stroke rehabilitation to assess activity and/or participation as per the ICF framework and QoL, within the African context.

The primary objectives of this scoping review were to:

1. Systematically search the current literature reporting on the CCA and/or CCV (including but not limited to face validity, content validity, construct validity, structural validity and longitudinal validity of PROMs) used in stroke rehabilitation, to assess activity and/or participation as per the ICF framework and QoL, within the African context.
2. Describe the African populations (viz. geographic and socio-demographic characteristics) within which CCA and/or CCV of PROMs used in stroke rehabilitation, to assess activity and/or participation as per the ICF framework and QoL.
3. Report on the current evidence for and type of CCA and/or CCV as well as the procedures followed for the CCA and/or CCV of PROMs used in stroke rehabilitation, to assess activity and/or participation as per the ICF framework and QoL, within the African context.
4. Report on the complexities faced by researchers when conducting CCA and/or CCV of PROMs used in stroke rehabilitation, to assess activity and/or participation as per the ICF framework and QoL, within the African context.

Step 2: Identifying relevant studies

Search strategy

A comprehensive electronic search was conducted by four of the five reviewers, and every step of the process was recorded. Six different computerised bibliographic databases were accessed through the University of Stellenbosch library services to conduct the searches, namely: PubMed, EBSCOHost (CINAHL, African Wide), ProQuest Medical Library, African Journals Sabinet and African Journals Online (AJOL) and Science Direct.

The following key search terms were used: (Stroke); (CVA); (Hemiplegia, rehabilitation, cross-cultural adaptation); (cross-cultural validity, validity); (validation); (valid, Africa, international classification of function, disability and health); (ICF, outcome measures); (outcome measurements); (instruments); (tools assessment); (evaluation, activity); (task); (function); (occupation); (ADL, participation); (reintegration); (performance) and (occupation, QoL). In order to ensure comprehensiveness, the reviewers repeated the search process by replacing the word 'Africa' with the names of the various African countries.

The reviewers included studies which met the following criteria: primary/secondary publications which reported on the CCA and/or CCV of PROMs used in stroke rehabilitation within the African context, published in English, Afrikaans or French; published from 2001 onwards (since this was the publication year of the ICF); included male and female African participants with stroke; included adults aged 18 years and over; studies conducted in Africa; included participants who may have had a stroke as a result of any cause (modifiable or non-modifiable risk factors); reported on PROMs used in stroke rehabilitation to assess activity and/or participation as per the ICF framework, as well as QoL within the African context.

The following document types were not included in this review: grey literature, that is unpublished theses, conference proceedings, government policy documents and legal/court documents. Studies reporting on outcome measures used in stroke rehabilitation to assess impairments as per the ICF framework were also not included. Studies reporting on the development of outcome measures for an African population were not considered.

Each database was independently searched by one of the reviewers, and articles were included or excluded at the following levels: title search, abstract search and full-text search according to the inclusion and exclusion criteria established in this review. All reviewers were involved in selection of the final included studies and the reasons for exclusion of other studies were recorded. Secondary searching (namely PEARLing) was conducted in order to identify additional relevant studies. Manual searching for articles was however not included because this method is difficult to reproduce.

Step 3: Study selection

Selection of studies for inclusion in this review was done in two stages. In stage 1, two reviewers independently scrutinised the titles and abstracts of all potentially relevant studies for eligibility assessment. In stage 2, the same two reviewers independently screened the full texts of the studies identified as potentially relevant in stage 1, in order to determine whether they met the inclusion criteria or not. In cases of disagreement amongst reviewers on the eligibility of studies, a final determination was made through a discussion until consensus was reached.

Data extraction and management

During this stage of the review process, the following basic descriptive data were extracted from the included studies: author(s), study title, publication year, country of publication, study aim, study type, outcome measure(s) studied, study setting, participant description, sample age, sample gender and sample size. The procedures which were followed in CCA process were extracted and compared to the five steps for CCA reported by Beaton et al. (2000). Similarly, data related to any procedural challenges experienced by the primary researchers were sought and recorded. The type of CCV conducted and/or validation processes (e.g. as per the Rasch model) employed in the selected studies were also identified.

Furthermore, considerations related to adaptation of the PROM for the target population were extracted and categorised according to the following three common themes, namely, (1) semantic equivalence, (2) experiential equivalence (cultural, social, etc.) and (3) conceptual equivalence. According to Epstein et al. (2015), these key themes are defined as:

1. *Semantic equivalence*: It occurs when the meaning of items on an outcome measure is the same in both cultures.
2. *Experiential equivalence*: It relates to social/cultural and other aspects that need to be considered to ensure equivalence of items between the original and new version of PROM.
3. *Conceptual equivalence*: It occurs when domains have the same relevance, meaning and importance regarding the explored concept in both cultures.

Reviewers worked in pairs and extracted data from the included studies randomly assigned to each pair. Within each pair, reviewers extracted data independently from each other. A reviewer-developed Microsoft (MS) Excel spreadsheet was used to capture all extracted data and data extracted were cross-checked for any discrepancies. Where there were discrepancies, another reviewer from another pair was consulted.

■ Results

The combined results of the six database searches identified 1767 studies. Removal of duplicates and screening of the titles and abstracts resulted in 13 potentially relevant articles. The full texts were retrieved, and four studies were further excluded based on the inclusion criteria (Kossie et al. 2018a, 2018b; Odentude et al. 2017; Owolabe et al. 2011). Finally, nine studies were found eligible and were included in this review (Akinpelu, Adegoke & Maruf 2006; Akinpelu Odetunde & Odole 2012; Batcho, Tennant & Thonnard 2012; Hamza, Nabilla & Loh 2012; Hamzat & Peters 2009; Kamwesiga et al. 2016; Natta et al. 2019; Okoye et al. 2016; Sogbossi, Thonnard & Batcho 2014). The PRISMA flow diagram of the scoping review process is depicted in Figure 6.1.

The nine studies which were included in this review were published in the English language between 2006 and 2019.

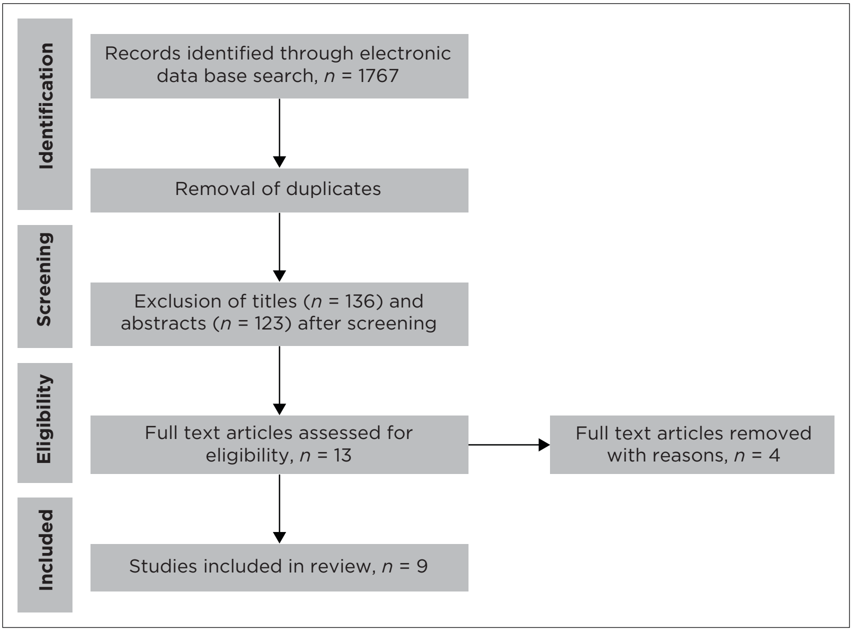

FIGURE 6.1: Preferred reporting items for scoping review and meta-analyses flow diagram for the scoping review process.

Five studies were conducted in Nigeria (Akinpelu et al. 2006; Akinpelu et al. 2012; Hamza et al. 2012; Hamzat & Peters 2009; Okoye et al. 2016), three were conducted in Benin (Batcho et al. 2012; Natta et al. 2019; Sogbossi et al. 2014) and one was conducted in Uganda (Kamwesiga et al. 2016). All nine studies included people with either left- or right-sided stroke. Studies included male and female participants.

Characteristics of included studies

The review included a total of 527 participants, with individual study sample sizes ranging between 20 and 230 participants. The included studies were conducted in secondary, tertiary and quaternary government facilities. Table 6.1 illustrates the general

TABLE 6.1: Characteristics of included studies (*n* = 9).

Author	Country	Study aim	Outcome measure	Target population	Study setting	Population			Disease characteristics	
						N	**Age, mean, (SD, range) years**	**Gender (%)**	**Disease duration**	**Disease severity**
Akinpelu et al. (2006)	South-western Nigeria	To investigate the criterion-related validity of a Yoruba-translated version of the WHO-QoL-BREF	WHO-QoL-BREF	People with stroke (Yoruba people) in south-western Nigeria	PT outpatient clinics of tertiary hospitals	41	55.0 (10.7)	Male: 66% Female: 34%	2.37 (0.56) years Mean (SD)	Not reported
Hamzat and Peters (2009)	Nigeria	To evaluate the validity of a Yoruba-translated version of the LHS	LHS	People with stroke (Yoruba people) in south-western Nigeria	PT outpatient clinics at three tertiary hospitals and one secondary hospital	20	55.7 (13.4)	Male: 80% Female: 20%	1.67 (2.15) years Mean (SD)	Not reported

ABILHAND, Hand Function Ability Stroke questionnaire; ABILOCO, Locomotion Ability questionnaire; ACTIVLIM, Activity Limitations Stroke questionnaire; CCA, cross-cultural adaptation; CCV, cross-cultural validation; LHS, London Handicap Scale; MSCRIM, Maleka Stroke Community Reintegration Measure; N, number; PT, physiotherapy; SD, standard deviation; SIS, Stroke Impact Scale; SS-QoL, Stroke-Specific Quality of Life Scale 2.0; SSS, Scandinavian Stroke Scale; US, United States; WHOQoL-BREF, World Health Organization Quality of Life BREF.

Table 6.1 continues on the next page→

TABLE 6.1 (Continues...): Characteristics of included studies (*n* = 9).

Author	Country	Study aim	Outcome measure	Target population	Study setting	Population			Disease characteristics	
						N	Age, mean, (SD, range) years	Gender (%)	Disease duration	Disease severity
Akinpelu et al. (2012)	South-western Nigeria	To cross-culturally adapt the SS-QoL 2.0 to Yoruba and to carry out the initial construct validation	SS-QoL 2.0	People with stroke (Yoruba people) in south-western Nigeria	CCA: PT outpatient clinic of tertiary hospital CCV: PT outpatient clinics of tertiary and secondary hospitals	CCA: 30 CCV: 35	CCA: 57.6 (11.6) CCV: 58.54 (11.3)	CCA: Male: 80% Female: 20% CCV: Male: 65% Female: 35%	CCA:2.4 (2.3) years Mean (SD) CCV:2.37 (2.26) years Mean (SD)	Not reported

ABILHAND, Hand Function Ability Stroke questionnaire; ABILOCO, Locomotion Ability questionnaire; ACTIVLIM, Activity Limitations Stroke questionnaire; CCA, cross-cultural adaptation; CCV, cross-cultural validation; LHS, London Handicap Scale; MSCRIM, Maleka Stroke Community Reintegration Measure; N, number; PT, physiotherapy; SD, standard deviation; SIS, Stroke Impact Scale; SS-QoL, Stroke-Specific Quality of Life Scale 2.0; SSS, Scandinavian Stroke Scale; US, United States; WHOQoL-BREF, World Health Organization Quality of Life BREF.

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TABLE 6.1 (Continues...): Characteristics of included studies (*n* = 9).

Author	Country	Study aim	Outcome measure	Target population	Study setting	Population			Disease characteristics	
						N	Age, mean, (SD, range) years	Gender (%)	Disease duration	Disease severity
Hamza et al. (2012)	Nigeria	The aim of the linguistic validation of the SIS 3.0 is to produce a translated version in the Hausa language with 'conceptual, semantic and operational equivalence' to the original US English version for use in clinical practice and research in Nigeria	SIS 3.0	People with stroke (Hausa culture) in Nigeria	Teaching hospital	30	50.5	Not reported	Not reported	Not reported

ABILHAND, Hand Function Ability Stroke questionnaire; ABILOCO, Locomotion Ability questionnaire; ACTIVLIM, Activity Limitations Stroke questionnaire; CCA, cross-cultural adaptation; CCV, cross-cultural validation; LHS, London Handicap Scale; MSCRIM, Maleka Stroke Community Reintegration Measure; N, number; PT, physiotherapy; SD, standard deviation; SIS, Stroke Impact Scale; SS-QoL, Stroke-Specific Quality of Life Scale 2.0; SSS, Scandinavian Stroke Scale; US, United States; WHOQoL-BREF, World Health Organization Quality of Life BREF.

Table 6.1 continues on the next page→

TABLE 6.1 (Continues...): Characteristics of included studies ($n = 9$).

Author	Country	Study aim	Outcome measure	Target population	Study setting	Population			Disease characteristics	
						N	**Age, mean, (SD, range) years**	**Gender (%)**	**Disease duration**	**Disease severity**
Batcho et al. (2012)	Benin	To calibrate and validate the ACTIVLIM for patients with stroke in Benin	ACTIVLIM-stroke	People with stroke in Benin	Rehabilitation centres	108	57.1 (13.4)	Male: 63.7% Female: 36.3%	1.79 (2.03) years Mean (SD)	Not reported
Sogbossi et al. (2014)	Benin	To calibrate and validate the Benin version of ABILOCO, a Rasch-built scale developed to assess locomotion ability in stroke patients	ABILOCO	People with stroke in Benin	Rehabilitation centres	230	51.0 (11.6)	Male: 63.4% Female: 36.6%	1.83 (2.18) years Mean (SD)	Not reported

ABILHAND, Hand Function Ability Stroke questionnaire; ABILOCO, Locomotion Ability questionnaire; ACTIVLIM, Activity Limitations Stroke questionnaire; CCA, cross-cultural adaptation; CCV, cross-cultural validation; LHS, London Handicap Scale; MSCRIM, Maleka Stroke Community Reintegration Measure; N, number; PT, physiotherapy; SD, standard deviation; SIS, Stroke Impact Scale; SS-QoL, Stroke-Specific Quality of Life Scale 2.0; SSS, Scandinavian Stroke Scale; US, United States; WHOQoL-BREF, World Health Organization Quality of Life BREF.

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TABLE 6.1 (Continues...): Characteristics of included studies ($n = 9$).

Author	Country	Study aim	Outcome measure	Target population	Study setting	Population			Disease characteristics	
						N	Age, mean, (SD, range) years	Gender (%)	Disease duration	Disease severity
Okoye et al. (2016)	South-eastern Nigeria (Igbo land)	To cross-culturally adapt and validate the urban version of the MSCRIM amongst stroke survivors from Igbo culture in Nigeria	MSCRIM	People with stroke (Igbo culture) in Nigeria	CCA: PT outpatient clinic from one tertiary hospital CCV: PT outpatient clinics from five tertiary hospitals and one secondary hospital	CCA: 9 CCV:54	CCA: 56.56 (12.41) CCV: 56.58 (10.42)	CCA: Male: 67.0% Female: 33.0% CCV: Male: 63.0% Female: 37.0%	Not reported	Not reported
Kamwesiga et al. (2016)	Uganda	To culturally adapt and determine the psychometric properties of the SIS 3.0 in the Ugandan context on a small scale	SIS 3.0	People with stroke in Uganda (Kampala city and surroundings) – English and Luganda speaking	National referral hospital, PT division at hospital, stroke rehabilitation centre and homes of patients with stroke	CCA: 5 CCV: 95 (51 English and 44 Luganda speaking)	52.4 ±14.5 (16–75)	Male 44% Female 56%	*N* = 24 (3–6 months) *N* = 48 (6–12 months) *N* = 23 (1–2 years)	Mild (SSS 45–58), moderate (SSS 29–44) and severe (SSS 0–29)

ABILHAND, Hand Function Ability Stroke questionnaire; ABILOCO, Locomotion Ability questionnaire; ACTIVLIM, Activity Limitations Stroke questionnaire; CCA, cross-cultural adaptation; CCV, cross-cultural validation; LHS, London Handicap Scale; MSCRIM, Maleka Stroke Community Reintegration Measure; N, number; PT, physiotherapy; SD, standard deviation; SIS, Stroke Impact Scale; SS-QoL, Stroke-Specific Quality of Life Scale 2.0; SSS, Scandinavian Stroke Scale; US, United States; WHOQoL-BREF, World Health Organization Quality of Life BREF.

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TABLE 6.1 (Continues…): Characteristics of included studies (*n* = 9).

Author	Country	Study aim	Outcome measure	Target population	Study setting	Population			Disease characteristics	
						N	**Age, mean, (SD, range) years**	**Gender (%)**	**Disease duration**	**Disease severity**
Natta et al. (2019)	Benin	To perform a CCV of the ABILHAND-Stroke questionnaire for post-stroke patients living in Benin, a West-African country	ABILHAND-Stroke questionnaire	People with stroke living in Benin	CCA: not reported CCV: Outpatient rehabilitation centres	223	CCV: 54 ± 9.7	CCV: Male 66.8% Female 33.2%	27 (6–99) months median (range)	Not reported

ABILHAND, Hand Function Ability Stroke questionnaire; ABILOCO, Locomotion Ability questionnaire; ACTIVLIM, Activity Limitations Stroke questionnaire; CCA, cross-cultural adaptation; CCV, cross-cultural validation; LHS, London Handicap Scale; MSCRIM, Maleka Stroke Community Reintegration Measure; N, number; PT, physiotherapy; SD, standard deviation; SIS, Stroke Impact Scale; SS-QoL, Stroke-Specific Quality of Life Scale 2.0; SSS, Scandinavian Stroke Scale; US, United States; WHOQoL-BREF, World Health Organization Quality of Life BREF.

characteristics of all included studies, the sample size and demographic description of the participants.

■ Outcome measures

The CCA and/or CCV of a range of outcome measures for stroke rehabilitation were reported in different studies. These outcome measures included: the SS-QoL 2.0 (Akinpelu et al. 2012), the MSCRIM (Okoye et al. 2016), the ACTIVLIM-Stroke (Batcho et al. 2012), the ABILOCO questionnaire (Sogbossi et al. 2014), the LHS (Hamzat & Peters 2009), the WHOQoL-BREF (Akinpelu et al. 2006) and the ABILHAND-Stroke questionnaire (Natta et al. 2019). The outcome measures studied in the reviewed studies are typically used to measure participation, QoL, community reintegration, locomotion and activity limitations amongst people with stroke.

The use of condition-specific outcome measures in research and clinical practice has increasingly become common in recent years, particularly, their use across different cultures. The SS-QoL (Akinpelu et al. 2012), ACTIVLIM (Batcho et al. 2012), LHS (Hamzat & Peters 2009) and the WHOQoL-BREF (Akinpelu et al. 2006) are widely used and have been translated into different languages and validated in different cultures; however, they are not available in any of the large indigenous ethno-graphic languages in sub-Sahara Africa, and therefore making assessment of people with stroke from these communities difficult. On the other hand, the ABILOCO (Sogbossi et al. 2014) is one of the most recent outcome measures designed to assess functional locomotion ability, specifically in people with stroke. Table 6.2 describes the various outcome measures studied, the purpose of each measure as well as the type of validation conducted and any adaptations made to the measure.

Cross-cultural adaptation procedures reported in the included studies

Information related to the procedures followed during the CCA process by the included studies was extracted and compared to the steps of CCA reported by Beaton et al. (2000). According to Beaton et al. (2000), CCA involves the following five steps: initial translation/translation, synthesis of translations, back translation, expert committee review and pre-testing. If, however, the population for which the PROM is being cross-culturally adapted speaks the same language, translation of the PROM is not required. Further validation of the newly adapted PROM may occur after the initial adaptation. Table 6.3 depicts the CCA and CCV reported on by the included studies. Table 6.4 depicts the procedures of CCA as per the Beaton et al. (2000) framework followed, and which steps of the adaptation process were not conducted. Table 6.4 also shows the procedures followed for CCV.

The four studies (Batcho et al. 2012; Kamwesiga et al. 2016; Natta et al. 2019; Sogbossi et al. 2014) which implemented a Rasch analysis included all required steps, that is missing response, category discrimination, scale targeting, item-trait interaction, item fit to the model, differential item function, local dependency and uni-dimensionality.

Semantic, experiential and conceptual equivalence

Considerations related to adaptation of the PROM for the target population were extracted and categorised according to the following three common themes, namely, (1) semantic equivalence, (2) experiential equivalence (cultural, social, etc.) and (3) conceptual equivalence. Box 6.1 depicts the changes made to the original items in the questionnaire/outcome measure to achieve these categories of equivalence.

TABLE 6.2: Characteristics of the studied outcome measures (*n* = 9).

Author (year)	PROM name	Constructs	Mode of administration (self-report; interview based; parent or proxy report)	(Sub) Scale (number of items)	Response options	Range of scores/ scoring	Original language	Instrument administration (language)
Akinpelu et al. (2006)	WHOQoL-BREF	QoL	Self-report questionnaire	26	Very poor, poor, neither poor nor good, good and very good	Five-point scale	English	English and Yoruba
Hamzat et al. (2009)	LHS	Participation (ICF) (previously Handicap – ICIDH)	Self-report questionnaire or interview based	6	None to extreme	Six-point scale	English	English and Yoruba
Akinpelu et al. (2012)	SS-QoL 2.0	Quality of life	Self-report questionnaire	49	Strongly agree, moderately agree, neither agree nor disagree, moderately disagree and strongly disagree	Five-point scale	English	Yoruba
Hamza et al. (2012)	SIS 3.0	Activity limitation and quality of life	Self-report questionnaire	59		0–100	English	Hausa
Batcho et al. (2012)	ACTIVLIM	Activity limitation	Self-report questionnaire	20	Impossible/ difficult/easy	Three-point scale	French and Dutch	French

ABILHAND, Hand Function Ability Stroke questionnaire; ABILOCO, Locomotion Ability questionnaire; ACTIVLIM, Activity Limitations Stroke questionnaire; ICF, International Classification of Functioning, Disability and Health; LHS, London Handicap Scale; MSCRIM, Maleka Stroke Community Reintegration Measure; PROM, patient-reported outcome measure; QoL, quality of life; SIS, Stroke Impact Scale; SS-QoL, Stroke-Specific Quality of Life Scale 2.0; WHOQoL-BREF, World Health Organization Quality of Life BREF.

Table 6.2 continues on the next page→

TABLE 6.2 (Continues...): Characteristics of the studied outcome measures (*n* = 9).

Author (year)	**PROM name**	**Constructs**	**Mode of administration (self-report; interview based; parent or proxy report)**	**(Sub) Scale (number of items)**	**Response options**	**Range of scores/ scoring**	**Original language**	**Instrument administration (language)**
Sogbossi et al. (2014)	ABILOCO	Activity limitation	Self-report questionnaire or interview based	15	Impossible/ difficult/easy	0, 1, 2	French	French
Okoye et al. (2016)	MSCRIM	Community reintegration	Interview based	40	Not reported 'Not applicable' was added	0–2/0–3	English	Igbo culture English
Kamwesiga et al. (2016)	SIS 3.0	Activity limitation and QoL	Self-report questionnaire	59		0–100	English	English and Luganda
Natta et al. (2019)	ABILHAND-Stroke questionnaire	Activity limitation (manual ability)	Self-reported questionnaire	59	Impossible, very difficult, difficult and easy	Four-point scale	French	Beninese French

ABILHAND, Hand Function Ability Stroke questionnaire; ABILOCO, Locomotion Ability questionnaire; ACTIVLIM, Activity Limitations Stroke questionnaire; ICF, International Classification of Functioning, Disability and Health; LHS, London Handicap Scale; MSCRIM, Maleka Stroke Community Reintegration Measure; PROM, patient-reported outcome measure; QoL, quality of life; SIS, Stroke Impact Scale; SS-QoL, Stroke-Specific Quality of Life Scale 2.0; WHOQoL-BREF, World Health Organization Quality of Life BREF.

TABLE 6.3: Cross-cultural adaptation and cross-cultural validation reported by studies.

Author (year)	**Original outcome measure**	**Target version**	**CCA and CCV**
Akinpelu et al. (2006)	WHOQoL-BREF	Yoruba- translated WHOQoL-BREF	CCA: Initial translation; synthesis of the translations; back translation and involvement of expert committee CCV: Construct validity
Hamzat and Peters (2009)	LHS	Yoruba- translated LHS	CCA: Initial translation; synthesis of the translations; back translation CCV: Construct validity
Akinpelu et al. (2012)	Adapted English Version SS-QoL 2.0	Yoruba-translated SS-QoL Scale	CCA: Initial translation; synthesis of the translations; back translation; expert committee; test of the pre-final version CCV: Construct validity
Hamza et al. (2012)	SIS 3.0	Hausa-translated SIS	CCA: Initial translation, synthesis, back translation, expert committee review, finalisation – pre-testing CCV: Construct validity
Batcho et al. (2012)	ACTIVLIM-Stroke	Not applicable	CCA: Not performed CCV: Structural validity (IRT-Rasch model); Reliability (IRT): Convergent validity (CCT); test–retest reliability (CCT)
Sogbossi et al. (2014)	ABILOCO	Benin-translated ABILICO	CCA: Not performed CCV: Construct validity; expert committee; test–retest reliability
Okoye et al. (2016)	MSCRIM	Igbo-translated (adapted) MSCRIM	CCA: Initial translation; synthesis of the translations; expert committee; test of the pre-final version CCV: Construct validity; test–retest reliability; internal consistency
Kamwesiga et al. (2016)	SIS 3.0	Luganda-translated SIS 3.0	CCA: Expert committee; forward and back translation, test of the pre-final version CCV: Construct validity
Natta et al. (2019)	ABILHAND-Stroke Questionnaire	Benin-ABILIHAND stroke questionnaire	CCA: Expert committee; test of the pre-final version CCV: Construct validity

ABILHAND, Hand Function Ability Stroke questionnaire; ABILOCO, Locomotion Ability questionnaire; ACTIVLIM, Activity Limitations Stroke questionnaire; CCA, cross-cultural adaptation; CCT, Classical Test Theory; CCV, cross-cultural validation; IRT, Item Response Theory; LHS, London Handicap Scale; MSCRIM, Maleka Stroke Community Reintegration Measure; SIS, Stroke Impact Scale; SS-QoL, Stroke-Specific Quality of Life Scale 2.0; WHOQoL-BREF, World Health Organization Quality of Life BREF.

TABLE 6.4: Procedures followed during cross-cultural adaptation or cross-cultural validation by studies.

Author (year)	Step 1: Initial translation CCA	Step 2: Synthesis of translation CCA	Step 3: Back translation CCA	Step 4: Expert committee review CCA	Step 5: Pre-testing CCA	CCV
Akinpelu et al. (2012)	Yes Two language experts fluent in English and Yoruba	Yes Two Yoruba language experts, two physiotherapists, one neurologist, a person with stroke and a layperson	Yes Two independent translators who were blind to the forward translation	Yes Two Yoruba language experts, two physiotherapists, one neurologist, a person with stroke and a layperson	Yes 30 Yoruba-speaking people with stroke	35 patients completed both the adapted English version and the Yoruba version of the SS-QoL in a 2 h interval
Akinpelu et al. (2006)	Yes One Yoruba language expert	Yes Three nurses and three school teachers	Yes Three nurses and three school teachers	Yes Language expert and the study researchers	Yes 41 people with stroke	41 patients participated in the correlational survey by completing both the English and Yoruba WHOQoL-BREF versions in a 2 h interval.
Hamza et al. (2012)	Yes Multi-professional team of five bilingual (English and Hausa) experts	Yes Multi-professional team of five bi-lingual (English and Hausa) experts	Yes One professional translator (native Hausa) who is fluent in English and had no prior knowledge of the tool	Yes Two physiotherapists who are fluent in English and Hausa	Yes 30 people with stroke	Two physiotherapists and 30 people with stroke reviewed the pre-final version of the Hausa-Version of the SIS, by completing the tool and face-to-face interviews.

ABILHAND, Hand Function Ability Stroke questionnaire; ABILOCO, Locomotion Ability questionnaire; ACTIVLIM, Activity Limitations Stroke questionnaire; BI, Barthel Index; CCA, cross-cultural adaptation; CCV, cross-cultural validation; FIM, Functional Independence Measure; LHS, London Handicap Scale; MSCRIM, Maleka Stroke Community Reintegration Measure; OT, occupational therapy; PT, physiotherapy; SIS, Stroke Impact Scale; SS-QoL, Stroke-Specific Quality of Life Scale 2.0; WHOQoL-BREF, World Health Organization Quality of Life BREF.

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TABLE 6.4 (Continues...): Procedures followed during cross-cultural adaptation or cross-cultural validation by studies.

Author (year)	Step 1: Initial translation CCA	Step 2: Synthesis of translation CCA	Step 3: Back translation CCA	Step 4: Expert committee review CCA	Step 5: Pre-testing CCA	CCV
Okoye et al. (2016)	Not applicable (translation not necessary because the document was already in target language-dialect)	Yes Nine adults with stroke who were attending PT	Not applicable (translation not necessary because the document was already in target language-dialect)	Yes Four researchers, four physiotherapists and a person with stroke	Yes 54 people with stroke attending PT	Adapted MSCRIM was administered twice to 54 people within 4 days
Hamzat and Peters (2009)	Yes Linguist from a local university	Yes Not reported	Yes Three independent experts (one medical doctor and two physiotherapists)	Yes Not reported	Yes 20 people with stroke	20 patients completed both the English and Yoruba versions of the LHS within a 2-week interval
Kamwesiga et al. (2016)	Yes Two translators from a local university	No 15 OT students, four OT teachers and six senior occupational therapists	Yes Two translators different from the ones who did forward translation	Yes 19 Luganda-speaking occupational therapists	Yes 95 people with stroke	Rasch analysis; Both the English and Luganda version of SIS 3.0 were administered to 95 people in a face-to-face interview

ABILHAND, Hand Function Ability Stroke questionnaire; ABILOCO, Locomotion Ability questionnaire; ACTIVLIM, Activity Limitations Stroke questionnaire; BI, Barthel Index; CCA, cross-cultural adaptation; CCV, cross-cultural validation; FIM, Functional Independence Measure; LHS, London Handicap Scale; MSCRIM, Maleka Stroke Community Reintegration Measure; OT, occupational therapy; PT, physiotherapy; SIS, Stroke Impact Scale; SS-QoL, Stroke-Specific Quality of Life Scale 2.0; WHOQoL-BREF, World Health Organization Quality of Life BREF.

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TABLE 6.4 (Continues...): Procedures followed during cross-cultural adaptation or cross-cultural validation by studies.

Author (year)	**Step 1: Initial translation CCA**	**Step 2: Synthesis of translation CCA**	**Step 3: Back translation CCA**	**Step 4: Expert committee review CCA**	**Step 5: Pre-testing CCA**	**CCV**
Natta et al. (2019)	Not applicable (translation not necessary because the document was already in target language-dialect)	No Not reported	Not applicable (translation not necessary because the document was already in target language-dialect)	Yes One person with stroke and seven rehabilitation professionals	Yes 233 people with stroke	Rasch analysis; 233 people with stroke were assessed for manual ability using the ABILHAND-Benin version compared to ACTIVLIM
Sogbossi et al. (2014)	Not performed	Not performed	Not performed	Not performed	Not performed	Rasch analysis; Seven experts (physiotherapists and physicians) reviewed items in the original ABILOCO and took part in test–retest validation.
Batcho et al. (2012)	Not performed	Not performed	Not performed	Not performed	Not performed	Rasch analysis; Participants' results compared between ACTIVLIM, BI and FIM-motor and test–retest within 1–4 weeks

ABILHAND, Hand Function Ability Stroke questionnaire; ABILOCO, Locomotion Ability questionnaire; ACTIVLIM, Activity Limitations Stroke questionnaire; BI, Barthel Index; CCA, cross-cultural adaptation; CCV, cross-cultural validation; FIM, Functional Independence Measure; LHS, London Handicap Scale; MSCRIM, Maleka Stroke Community Reintegration Measure; OT, occupational therapy; PT, physiotherapy; SIS, Stroke Impact Scale; SS-QoL, Stroke-Specific Quality of Life Scale 2.0; WHOQoL-BREF, World Health Organization Quality of Life BREF.

BOX 6.1: Changes to original items in questionnaire or outcome measure to achieve semantic, experiential and conceptual equivalence for target cultural contexts.

Semantic equivalence	
Akinpelu et al. (2006)	Back translation of items 7, 15 and 26 of the WHOQoL-BREF was done twice by different panels of experts because the Yoruba version had distorted the actual meaning.
Akinpelu et al. (2012)	The words: physical condition, slur, wheelchair, mood, discouraged, confidence, personality, irritable, preparing food, shower, hobbies and recreation in the SS-QoL 2.0 were translated and semantically adjusted into Yoruba to ensure correct equivalence to English.
Hamza et al. (2012)	The terms 'stroke' was not comprehensible in Hausa language when literally translated from English and was therefore translated into 'Sikelin' in the adapted LHS, a term which has a medical connotation, and which is culturally agreeable.
Experiential equivalence	
Akinpelu et al. (2012)	Respondents reported that items SC 1 ('did you have trouble preparing food') and W1 ('did you have trouble doing daily work around the house') in the original WHOQoL-BREF were not applicable to them because culturally men are not involved in house chores in Yoruba. However, the expert committee decided to retain these items because the process of CCA does not allow major alterations.
Hamzat et al. (2009)	There was no correlation between English and Yoruba versions of the LHS for the domain which assesses work and leisure activities of the patients because some of the items under this domain (3) assess constructs such as gardening, sports, hobbies and going on holidays; yet such things are not cWharacteristic of the ordinary Nigerian Yoruba population.
Batcho et al. (2011)	Items which are not commonly related to patients with stroke in Benin were deleted from the original ACTIVLIM, for instance, 'getting on an escalator'.
Sogbossi et al. (2014)	Items which were not relevant in local context in Benin were removed from the original ABILOCO tool. For instance, 'ice skating, going up/down the escalator, taking the train or the underground railway'. Further, more items were deleted during the Rasch model process.

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BOX 6.1 (Continues…): Changes to original items in questionnaire or outcome measure to achieve semantic, experiential and conceptual equivalence for target cultural contexts.

Okoye et al. (2016)	The following changes in terms were made in line with the Igbo cultural practices/experiences to the adapted MSCRIM: • The terms ‘bucket’ was added to ‘kettle/basin’ as examples of water containers as a bucket is more commonly used in the Igbo culture. • ‘Wells/underground water reservoirs’ was added as an example of a source for water. • ‘Burial society’ was replaced with ‘social club’ as the structure burial society does not exist in Igbo culture and more examples of social clubs, for example kindred meetings, neighbourhood associations, clan associations and town unions were provided for ‘other structures meeting’. • The activity milking of livestock, for example cows, was removed as it is an unusual practice in Igbo culture; chicken and sheep were included in the list of domestic animals.
Okoye et al. (2016)	• Examples of common transportation means (bus, taxi cabs, motorcycle [*okada*] and tricycle [*keke napep*]) were added for better understanding amongst the Igbo people. *Okada* and *keke napep* are nick names for commercial motorcycles and tricycles respectively for transporting people in Nigeria. • ‘School football field/commercial television viewing centre’ was provided as an additional location where one can watch a soccer match. In Igbo land, international football matches are usually watched at commercial television viewing centres because many people cannot afford the subscription for cable television stations that show these matches live. In addition, a few people who can afford the subscription opt for these centres for companionship. On the other hand, local matches are usually played at primary/secondary school football fields. • ‘Chemist/pharmacy’ was added to clinic and hospital as an additional source of medical care as people in Igbo land find it easier to consult pharmacists than going to the hospital to consult doctors. • Two examples of activities, that is ‘Are you able to wash or clean your car’ and ‘to carry out minor repair work at home, e.g. changing light bulbs’ were added as non-gender-specific tasks.

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BOX 6.1 (Continues…): Changes to original items in questionnaire or outcome measure to achieve semantic, experiential and conceptual equivalence for target cultural contexts.

	• The activity ‘singing in the choir’ was replaced with ‘singing and dancing in age groups/grades meeting’ as an example of community activity to fit the Igbo cultural context. • The activity ‘singing in the choir’ was moved from the category ‘community activity’ to the category ‘religious activity’ as it is an activity that is more recognised as appropriate by the Igbo culture. • The activity ‘mudding the floor with cow dung’ was replaced with ‘mop or scrub the floor’ as an example of cleaning the house as it is not practiced in the Igbo culture. • Shopping bags were replaced with 20 litre jerry can of water/oil and a crate of bottled/soft drink as an example of heavy objects.
Kamwesiga et al. (2016)	The following changes were made in order to adapt the SIS 3.0 into the Ugandan context: • The item ‘cut your food with a knife and fork’ was altered to ‘feed yourself with a hand fork/spoon’. • In the item ‘get to the toilet on time’, the word ‘latrine’ was added because some people use latrines. • The item ‘go shopping’ was altered to ‘buy items from the shop’ because people go to small shops to buy one specific item at a time in a day. • The examples given for ‘heavy household chores’ were changed from vacuum. • Cleaning, laundry and yard work to sweeping, washing and cleaning the compound. • In the domain mobility, the term ‘walk a block’ was changed to ‘walk 100 metres’ because there are no standard blocks in Uganda. ‘Climb one flight of stairs’ was changed to ‘climb a staircase once’. • In the domain hand function, an example of carrying heavy objects such as ‘bag of groceries’ was altered to a ‘5 litre jerry can of water’ because people commonly carry water containers in their daily activities. • The term ‘turn doorknob’ was altered to ‘turn door handle’ and the term ‘pick up a dime’ was changed to ‘pick up a coin’.

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BOX 6.1 (Continues…): Changes to original items in questionnaire or outcome measure to achieve semantic, experiential and conceptual equivalence for target cultural contexts.

Natta et al. (2019)	The following terms were added to adapted ABILHAND: • Using a matchstick to light a fire. • Praying with a rosary. • Tying a loincloth around the waist. • Using a toothpick to ‘clean your teeth’ and ‘shake someone’s hand’.
Conceptual equivalence	
Okoye et al. (2016)	The following changes were made to the adapted MSCRIM to ensure conceptual equivalence amongst the Igbo community: • ‘Cultural/traditional’ was removed as a qualifier for cooking as it is not usually classified in this manner amongst Igbo people. • The term ‘chief/councillor’ was replaced with ‘leaders’ as conveners of community meetings.
Hamza et al. (2012)	The sentence describing the second domain ‘These questions are about your memory and thinking’ tended to be misinterpreted. Respondents assumed that the sentence describing the domain was referring to the ‘process’ and not the ‘act’ of memorisation and thinking. The sentence was therefore made to be more culturally appropriate and translates as ‘*Wadannan tambayoyi sun shafi yadda kake/kike ji dangane da sauyin da ka/ki ka samu na yanayin walwala da kuma yadda kake/kike iya shawo kan damuwarka/ki bayan samun mutuwar barin jiki*’ in the adapted LHS.
Hamza et al. (2012)	Description of the item 60 ‘Stroke recovery’, where a patient is asked to assess his or her global perception of recovery was consistently reported as not specific, and therefore it was changed to ‘The Process of your Stroke Recovery’ which translate as ‘*Yadda ake samun sauki daga matsalar ta bugun jini*’ in the adapted LHS.
Hamza et al. (2012)	The following terms and expressions were changed in the adapted LHS to culturally sufficient equivalents after they were identified as inapplicable by the committee. Their appropriate replacements were agreed upon: • ‘Burden’ was changed to ‘that which is borne with difficulty’ (*babban nauyi*). • ‘Concentrate’ was changed to ‘bring one’s faculties to bear’ (*mayar da hankali kan abubuwa*).

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BOX 6.1 (Continues…): Changes to original items in questionnaire or outcome measure to achieve semantic, experiential and conceptual equivalence for target cultural contexts.

	• ‘Conversation’ was changed to ‘the spoken exchange of thoughts’ (*hira*). • ‘Nervous’ was changed to ‘fraught with or showing anxiety’ (*tsoro*). • ‘Blame’ was changed to ‘accuse’ (*Dorawa kai laifi*). • ‘Mood’ was changed to ‘frame of mind’ (*walwala*). • ‘Bowels’ was changed to ‘entrails’ (*bayan gida*).
Kamwesiga et al. (2016)	Some items in the various SIS domains were altered in order to have relevant meanings in the Ugandan context: • In participation, ‘go shopping’ was altered to ‘buy items from the shop’. • In mobility, ‘get to the toilet on time’, the word latrine was added. • In hand function, ‘cut your food with a knife and fork’ was altered to ‘feed yourself with a hand fork/spoon’. • In ADL/IADL, the examples given for ‘heavy household chores’ were changed from vacuum cleaning, laundry and yard work to sweeping, washing and cleaning the compound.
Natta et al. (2019)	Amongst the initial 56 items of the original ABILHAND, two items were discarded because they did not match the socio-cultural realities in Benin: • ‘Tearing open a pack of chips’ and ‘preparing crepe batter’. • The following four items were modified: • ‘Spreading butter on a slice of bread’ was modified to ‘buttering a slice of bread’. • ‘Eating a sandwich’ became ‘eating a sandwich (bread with filling)’. • ‘Cracking nuts’ became ‘cracking nuts (or palm nuts)’. • ‘Opening a letter’ became ‘opening a letter (closed envelope)’.
Combination types of equivalence	
Semantic and Conceptual equivalence	
Akinpelu et al. (2012)	During the pre-testing of the Yoruba version of the SS-QoL 2.0, the word ‘family’ in item FR5 was noted to be unclear to stroke participants as to whether it referred to a nuclear or an extended family. The expert committee therefore replaced the word ‘family’ with ‘relations’.

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BOX 6.1 (Continues…): Changes to original items in questionnaire or outcome measure to achieve semantic, experiential and conceptual equivalence for target cultural contexts.

Hamza et al. (2012)	Most of the reflection used within items could not be rendered to ‘literal translation’ in Hausa and therefore were translated to culturally acceptable linguistic equivalents in the adapted LHS. Respondents easily comprehend the meaning of the expressions when they were alternatively stated as illustrated below: • Item 11: ‘Solve everyday problems’ was changed to ‘Solve your routine predicaments’ (*Warware matsaloli na yau da kullum?*). • Item 16: ‘Blame yourself for mistakes that you made’ was changed to ‘Guilty of your wrong doings’ (*Dorawa kai laifi a kan kurakuran da ka aikata?*). • Item 18: ‘Feel quite nervous’ was changed to ‘Feeling of unease or frightened’ (*Jin tsoro?*). • Item 19: ‘Feel that life is worth living’ was changed to ‘Hopeful despite challenges’ (*Jin in dai da rai akwai rabon za a iya samun lafiya?*). • Item 25: ‘Participate in a conversation with a group of people’ was changed to ‘Get into conversation with others’ (*Shiga cikin hira da sauran jama‘a?*). • Item 28: ‘Cut your food with a knife and fork’ was changed to ‘Eat with cutlery sets’ (*Yanka abinci da wuka da cokali mai yatsu?*). • Item 33: ‘Control your bladder (not have an accident)’ was changed to ‘Ability to control the passage of urine efficiently’ (*Iya rike fitsari ba tare d kuskure ba?*). • Item 34: ‘Control your bowels (not have an accident)’ was changed to ‘Ability to control the passage of faeces efficiently’ (*Iya rike bayan gida ba tare da kuskure ba?*). • Item 38: ‘Stay sitting without losing your balance’ was changed to ‘Sit upright without reclining’ (*Iya zama daram ba tare da jirkicewa ba?*). • Item 39: ‘Stay standing without losing your balance’ was changed to ‘Stand upright without leaning’ (*Iya tsayuwa kyam, ba tare da karkacewa ba?*). • Item 54: ‘Quiet recreation (crafts, reading)’ was changed to ‘Indulge in simple, pleasurable chores like reading or artistry’ (*Ayyukan nishadantarwa masu sauki kamar karatu da yar karamar sana’ar hannu*).

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BOX 6.1 (Continues…): Changes to original items in questionnaire or outcome measure to achieve semantic, experiential and conceptual equivalence for target cultural contexts.

	• Item 55: 'Active recreation (sports, outings, travel)' was changed to 'Indulge in pleasurable, energy demanding chores like exercise and long walk' (*Ayyuka Nishadantarwa masu bukatar kuzari*) (*kamar wasannin motsa jiki da tafiya mai nisa*). • Item 58: 'Your ability to control your life as you wish' was changed to 'Run your life as you desire' (*Yadda kake/kike iya tafiyar da rayuwar ka/ki bisa son ranka/ki?*).
Hamza et al. (2012)	Changes were made to ensure semantic and experiential equivalence as well as cultural appropriateness between the original and adapted LHS. For instance, the sentence 'These questions are about your memory and thinking' was misinterpreted, as respondents assumed that the sentence was referring to the 'process' not the 'act' of memory and thinking. Therefore, it was changed to make it more culturally appropriate and translates as '*Wadannan tambayoyi sun shafi yadda kake/kike ji dangane da sauyin da ka/ki ka samu na yanayin walwala da kuma yadda kake/kike iya shawo kan damuwarka/ki bayan samun mutuwar barin jiki*'.
Hamza et al. (2012)	The following change was made in item 18 of the adapted LHS in order to make it culturally appropriate in the Hausa community: 'Feel quite nervous?' was changed to 'Feeling of unease or frightened?' Also, all concerns raised, and problems encountered during the processes, were addressed in consultations with experts in linguistics and the original developers. This was intended to ensure conceptual equivalence and the credibility of the translation procedures utilised.
Kamwesiga et al. (2016)	The translators indicated that not all words in English had direct translation equivalent words in Luganda, and occasionally, expressions in English were used to translate to Luganda. Such words/terms included; emotion, feeling nervous and concentration. Instead, expressions in Luganda were used as a substitute for one specific word in the adapted SIS.

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BOX 6.1 (Continues…): Changes to original items in questionnaire or outcome measure to achieve semantic, experiential and conceptual equivalence for target cultural contexts.

Semantic and Experiential equivalence	
Akinpelu et al. (2012)	The expert committee added examples relevant to the Yoruba-speaking community for some of the items of SS-QoL 2.0 during the first CCA phase. These items included SC4, UE2 and UE6. In item SC4, culture-specific dressing activities and dresses ('tying wrapper, tying headgear or putting on buba or cap') were added. In item UE2, the activity, 'putting on underpants' was added because many Nigerians do not have to put on socks throughout their lifetime. In item UE6, 'opening a bottle or a keg' was added because the terms bottle and keg are more frequently used than the term 'jar' in south-western Nigeria.
Okoye et al. (2016)	The response option, 'Not applicable' in the adapted MSCRIM was added to enable the user to differentiate between activities that respondents find difficult to perform and those they do not have to perform. A typical example: 'Are you able to collect water from the river/communal tap?'.

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■ Discussion

This chapter reports on the current evidence from published literature regarding the CCA and/or CCV of PROMs used in stroke rehabilitation within an African context. This chapter specifically highlights the complexities which are typically experienced by researchers when conducting CCA of stroke rehabilitation PROMs for African populations in terms of semantic, experiential and conceptual equivalence. A scoping review methodology approach was used in this study and the review focused specifically on the CCA and/or CCV of PROMs linked to activity limitations and participation rather than impairment. In addition, the CCA and/or CCV of PROMs linked to QoL were also considered. Articles published post-ICF implementation era (the year 2001 and onwards) were included.

The systematic search of the literature identified nine eligible studies for inclusion in this review. Africa consists of 54 independent countries as recognised by the United Nations (UN) and therefore at face value, it seems that the included studies do not adequately represent Africa by a large margin. Due consideration should however also be given to various challenges which plague the African researchers when trying to publish their work. For example, African studies may not be published in journals indexed in well-known databases such as PubMed, thus limiting its accessibility to others (Mutula 2009; Ngobeni 2012; Sawyerr 2004). These studies may instead remain on an internal research repository or libraries of an African University, and therefore never become fully accessible to the global public. In addition, these African universities may not have the infrastructure to publish theses and project data online because of limited resources. Lastly, African researchers may also not publish in open-access journals because of the high costs associated with publication (Mutula 2009; Ngobeni 2012; Sawyerr 2004). Therefore, the challenges encountered by African researchers when pursuing publication of their research data should be considered when doing a review on African research.

When conducting CCA of a PROM, one should consider the fact that the culture of a person/population may affect how the person answers a question presented to them (Epstein et al. 2015). It is therefore essential for researchers to establish the equivalence of the items between the original and the adapted version of the PROM. Equivalence can be achieved at various levels of the adaptation process, but achieving equivalence is often beset with problems (Epstein et al. 2015). Often, the new culture may not have an equivalent term, or the concept may not be familiar at all. Relating to equivalence, several specific challenges experienced by researchers during the CCA and CCV of the PROM used in stroke rehabilitation within the African context were reported. The considerations relating to equivalence of items between the new and original PROM were extracted from the included articles and were assigned themes according to the following categories: semantic, experiential (culture/social) and conceptual equivalence and discussed.

Considerations related to semantic equivalence

The most common challenges encountered by researchers in Africa when conducting CCA of any PROM for stroke rehabilitation is finding similar terms or concepts available in the new/target language or new cultural context for a task or activity. These specific considerations relate to the sematic equivalence of a term. The original item may therefore not be directly translatable into the target language or an equivalent term may not be available. Epstein et al. (2015) reiterate that the replacement term for the new target language may not actually evoke the same response that the original PROM was designed to evoke. In many instances, an item on the original PROM could not be replaced or translated into a term familiar to the new population because such a term did not exist in the local target language.

Such items were often consequently excluded from the new version of the measure, which may have had undesired effects. For example, Hamzat and Peters (2009) reported that the lack of correlation between the English and Yoruba-translated versions of the LHS could have been because of items under various domains not being applicable or characteristic of the Nigerian Yoruba culture. Items such as gardening, sports hobbies and going on holidays may not be familiar to the target population, neither be relevant or comprehensible. This is typically the issue amongst many African nations, where certain concepts are simply non-existent or completely unfamiliar to its citizens. The researchers reported that the Yoruba translations of certain items were not frequently used terms or phrases in the day-to-day activities of the common Nigerian, and therefore adequate replacement terms could not be found (Hamzat & Peters 2009). It is therefore a challenge when there are no terms to replace the original items during the CCA of a PROM, and it may seem easier to develop a new measure for a given setting or population than to adapt a PROM developed for Western populations, considering contextual and resource challenges.

Another example reported by Akinpelu et al. (2012) was during the CCA of the SS-QoL 2.0 into the Yoruba language. More specifically, two English words, namely 'zip' and 'button', have no equivalent terms in the Yoruba language, because the Yoruba alphabet does not include 'Z' and words in Yoruba generally end with vowels and not consonants. In these instances, it will be even more difficult to find equivalent terms and at times words may have to be made up or borrowed. Furthermore, as reported by Okoye et al. (2016), the terms such as 'burial society', 'milking' and 'cultural/traditional cooking' were replaced with Igbo culture equivalent English terms because these particular terms do not exist or are not practiced in the Igbo culture in Nigeria as performed in South Africa where the original PROM was developed. As a result, the term 'burial society' had to be removed from the domain. Although this adaptation is in keeping with the recommendations by Beaton et al. (2000) that a newly adapted scale should contain terms equivalent to the original terms for that specific culture or be removed if irrelevant, this particular challenge in finding adequate replacements highlights the variations between populations and the difficulty in directly implementing PROMs from developed nations as they are not automatically relevant in other settings. Therefore, when adapting a tool, one should consider all challenges linked to culture-sensitive terminology including words which depict ADL.

Considerations related to experiential (cultural/social) equivalence

Another challenge typically faced by those living in Africa and reported by the researchers is that many of the original items on a PROM may refer to activities related to water and/or access to water and other amenities. The lack of water supply or access to water and other amenities in various geographical areas in Africa (Adams 2018; Edokpayi et al. 2018) may make the inclusion of these items and related activities irrelevant. For example, because there is inadequate public water supply in many cities in south-eastern Nigeria, and similarly other African countries, many house owners are required to build wells or boreholes, and therefore they have no need to fetch water from the local river nor use communal taps (Okoye et al. 2016). The item in the original tool may therefore refer to fetching water, but for those who use boreholes, the activity is deemed irrelevant.

Furthermore, as there are various roles within families, it may not be the responsibility of the participant completing the tool to fetch the water, therefore making the activity irrelevant (Okoye et al. 2016). Similar concepts and terms contained within a tool should therefore be scrutinised and its relevance to the culture should be ascertained. Simply translating terms/concepts is therefore not always applicable, and the relevance of the activity to the target population/culture should be clarified. The process of translation/back translation is not always applicable for all PROMs. Proper CCA includes scrutiny of all activities at all levels along with the use of contextually appropriate language to relay or describe these activities and/or items on the PROM.

One of the most interesting complexities related to the African context is the various roles evident within its societies, and how these roles are often more intricate and entrenched in cultural beliefs and therefore, not as easily defined as in developed countries. Typical role differences are generally applicable between different gender and age groups within the African populations. For example, the role of men and women can differ depending on what is required of that culture to survive and do not conform to the roles seen in other parts of the world (Kotzé 2003). Okoye et al. (2016) reported that various items on the MSCRIM, a South African developed measure, not only required adaptation for a different African country but also needed to be made applicable to both genders within Nigeria. For instance, these researchers needed to include an additional response category, namely ‘not applicable’, because the activity described simply did not apply to a specific gender (Okoye et al. 2016). For example, when enquiring about cooking a meal, it is typically the responsibility of women to maintain the home and prepare meals for their families amongst the majority of African populations (Kotzé 2003), this therefore means that this activity would be viewed as irrelevant for men in certain communities. Another aspect to consider in the administration of PROM is the cultural and religious sensitivity of not only the measure but the process of recruitment and interaction with participants (Kamenou 2007). For example, in a strict Islamic African country, it might be inappropriate for researchers to directly approach female Muslims and even then a same gender researcher would most likely be needed to conduct the interview. Sensitivity towards these differences, be it towards cultural or religious needs, norms and practices, should be exercised when conducting CCA of any PROM for an African nation. Furthermore, one should consider the developments in understanding gender and sex in research, and how sensitivity around these concepts should be practiced (Deutsch 2007). There are no longer two clearly defined genders/sexes and tools should consider all definitions when developing or adapting PROMs.

Roles specific to age groups is another complexity to consider when conducting research in Africa (Oppong 2006). The roles of the younger versus the older members in a society depend on the cultural context and how these age groups are viewed and valued. Again, when adapting PROMs, the activities included in the measures need to be specific for the target audience and related to the age of that target group, despite the differences it may show compared to the roles amongst people in developed countries. However, when considering age-specific roles within a society, one should account for the health transition currently affecting people with stroke in Africa, where the double burden of NCDs and infective conditions such as HIV and/or AIDS (acquired immunodeficiency syndrome) has resulted in younger individuals experiencing stroke (Maredza, Bertram & Tollman 2015).

Further examples of other socio-cultural differences amongst African nations include the use of public transportation or lack thereof. For instance, in many African nations, the most common and preferred type of transportation is the motorcycle (Abuhamoud, Rahmat & Ismail 2011; Ehebrecht, Heinrichs & Lenz 2018). Therefore, reference to cars or buses in a PROM for these settings would be contextually irrelevant and unfamiliar to participants.

Considerations related to conceptual equivalence

Conceptual equivalence of an item when conducting CCA of a specific PROM for another culture involves whether the individual item or the domain within the PROM have the same relevance, meaning and importance regarding the explored concept in both cultures. In the included studies, a few considerations regarding conceptual equivalence were highlighted.

For example, Hamza et al. (2012) found that the second domain of the SIS 3.0 was misinterpreted as respondents assumed the domain was referring to the 'process' and not the 'act' of memorisation and thinking. The concept of 'memory and thinking' as an 'act' was not conceptually understood by the target population. For this reason, the original domain and its meaning had to change to ensure respondents in the new population understood exactly what was being questioned. Hamza et al. (2012) also reported that the concept of 'clipping toenails' had to be changed to 'cutting toenails' as the concept of clipping one's toenails was not understood by the target audience. Okoye et al. (2016) reported that items related to conveners of community meetings such as 'chief/councillor' in the MSCRIM were replaced with 'leaders' as this concept was deemed more appropriate for the Igbo culture. In addition, the term 'cultural/traditional cooking' was changed, as cooking is not classified as either cultural or traditional in this culture (Okoye et al. 2016). Natta et al. (2019) reported that specific concepts in the ABILHAND tool had to be removed as they were not understood by the target populations. These included; 'tearing open a pack of chips' or 'preparing crepe batter'. The concept of a 'pack of chips' and 'crepes' does not exist in this population and was therefore inappropriate. Therefore, when adapting any PROM, it is important for researchers to ensure that conceptual equivalence is considered for all the domains and individual items. Essentially, the misinterpretation of concepts is possible in different cultures and it cannot be assumed that there is universal understanding of concepts (Epstein et al. 2015).

Considerations related to administrative challenges

It was noted in this review that some studies reported on the sheer administrative challenges faced when conducting CCA of a PROM within the African context. As identified by Kossi et al. (2018) in an unpublished thesis, limitations concerning the administration procedures such as via mail, by post or by self-report for some measures is typically evident when administering PROMs amongst African nations, where few people have a postal address (Kossi et al. 2018).

In addition, low literacy levels across Africa means that a small percentage of Africans can read or write in their home language, with even fewer able to follow a second language such as English, which remains the language most Western-developed PROMs would be published in. Therefore, such language barriers and the overall lack of health literacy further complicates administration of PROMs in low-income countries of Africa.

Another administrative challenge relates to sampling and recruitment of participants amongst people with stroke in Africa. Generally, robust research practices require the sample of participants being studied to be representative of the larger population to which the findings could be generalisable (Petersen, Minkkinen & Esbensen 2005). However, the unique psychosocial and environmental barriers such as poor transport and poverty, access to research (as well as researchers to people with stroke) which typically prohibit people with stroke from accessing healthcare in Africa, should likely be considered. The sampling strategy in terms of where participants are recruited from therefore requires closer scrutiny as those who were able to access healthcare services in an urban setting close to a tertiary hospital, for example, would most likely face different challenges compared to those who reside in more distant rural settings. Therefore, participant selection would most likely be biased towards stroke patients who have greater access to healthcare and researchers should guard against overgeneralisation. Deliberate efforts should be made to include a truly representative sample to ensure that CCA involved the most representative audience.

Methodological considerations for future research

Researchers who embark on CCA and CCV of an outcome measure should allow additional time and resources if any steps of the adaptation process need to be repeated, such as additional rounds of ‘forward’ and ‘back translation’. These additional steps were necessary in the studies conducted by Akinpelu et al. (2006) and Akinpelu et al. (2012). Akinpelu et al. (2012) reported that the Yoruba translation of the SS-QoL 2.0 was subjected to two rounds of back translation and review by the expert committee before the pre-final version was tested with 30 people with stroke. The final version of the Yoruba version of the SS-QoL 2.0 was determined by yet another expert committee meeting after incorporation of the feedback received during the cognitive debriefing interviews of the people with stroke who participated in the pre-test of the PROM. However, in most African populations, the repetition of the steps in the CCA and CCV of a PROM may be more difficult to conduct because of transport and resource challenges. It may also be more difficult to track participants again following the initial procedure as they may not have had a permanent residence to begin with or reliable communication channels may change or never have existed. Researchers should therefore consider the need for repetition of certain procedures when planning their research and should adequately prepare on how to deal with these challenges when they present.

Akinpelu et al. (2012) made a reference to a previous study conducted by their group highlighting the low literacy levels of people with stroke in Nigeria, with up to 45% of the people with stroke attending PT outpatient clinics of teaching hospitals in south-western Nigeria not being literate in English (Akinpelu et al. 2012). These researchers argue that to ensure such individuals are not excluded from the assessment of QoL, it is important that standardised HRQoL scales are cross-culturally adapted to Yoruba, which is the indigenous language of the population of south-western Nigeria. Akinpelu et al. (2012) reported low levels of literacy and English-speaking people with stroke as motivation to support CCA of PROMs. However, one could also argue that access (identification and recruitment) to appropriately educated individuals during the adaptation process may prove challenging for researchers in certain low-resourced contexts in Africa. In addition, more men than women were included in this study as more men were literate in English and Yoruba. Furthermore, people with higher education were more readily included in this study as participants needed to be literate in both English and the Yoruba languages (Hamzat et al. 2009). Finding participants proficient in both the language of the original PROM, which in most cases would be English and the target language, require access to a literate and more educated sample. Consideration for the challenges related to the possibility of always finding such sample in an African context needs to be given.

Conclusion and recommendations

Given the burden imposed by stroke on many African nations, measurement of activity and participation within these nations is important to ensure that effective healthcare and rehabilitation management strategies are developed and implemented. Priority setting and efficient use of already limited resources in these constrained settings could be guided by the judicious use of appropriate and sensitive outcome measures that are able to describe the unique needs of local patients or communities. Using sensitive and context-specific measures could help motivate the development of adequate infrastructure to deliver health and rehabilitation services to those most in need, often those in more rural settings. The process of CCA and CCV of PROMs is known to be a labour-intensive activity and equivalence of items or domains may not be easily achieved, but when conducted in an African population it may be even more difficult because of the diverse and unique social and environmental challenges typically faced by the communities being studied and the resource constraints and methodological expertise needed by researchers conducting said studies. This may in part explain why such a small number of studies could be located for this review.

It is recommended that future studies should consider all aspects of a culture, the specific terms/concepts relevant and appropriate to the study setting, the religious and value systems held within those communities, relevant and specific activities typical to that population, differing cultural and gender roles, to name but a few, when embarking on CCA and/or CCV of any PROM in Africa. Researchers who conduct these studies should not only share their results but also their experiences during the process, especially the lessons learnt and how unique challenges were overcome or not. This will ensure that future CCA and CCV projects attain greater chances of success. As mirrored in the South African tradition of '*ubuntu*', explained as the belief in a universal bond of sharing that connects all humanity, African researchers are in a unique position to share their findings to benefit people with stroke on the continent and become the forerunners in developing appropriate, sensitive and robust measures for local contexts. The distinctiveness and diversity which is synonymous with Africa offers fertile ground for advances in this field of study related to the CCA and CCV of PROMs.

Based on the findings of this scoping review, we therefore recommend considering the following when doing research in Africa or when reviewing African research related to CCA and CCV of an outcome measure:

- African researchers face various challenges when trying to publish their work, that is limited resources and infrastructure, limited funds and opportunities to publish in open-access journals, etc.
- The culture of a person/population may affect how the person answers a question presented to them, so it is therefore essential to establish equivalence of the items between the original and the adapted outcome measure.
- When adapting a tool, one should consider all challenges linked to culture-sensitive terminology including words which depict ADL.
- Scrutinise all activities along with the use of contextually appropriate terminology to relay or describe these activities and/or items authentically and appropriately on the outcome measure.
- Consider developments in the understanding of gender and/or sex in research, and how sensitivity around these concepts should be practiced.
- Consider age-specific roles within various societies and account for the health transition currently affecting people with stroke in Africa, where the double burden of NCDs and infective conditions such as HIV and/or AIDS has resulted in younger individuals suffering a stroke.

- Be sensitive towards cultural and/or religious needs, norms and practices during the CCA process.
- Ensure that conceptual equivalence is considered for all domains of the outcome measure.
- Consider that language barriers and an overall lack of general and health literacy will further complicate administration of the outcome measures in low-income countries of Africa.

In addition, we also recommend that clinicians conscientiously select outcome measures in daily clinical practice, specifically considering whether or not the outcome measure is indeed culturally and contextually appropriate for their target population/patient. It is further recommended that clinicians upskill themselves in understanding CCA and CCV to ensure they can make informed decisions about whether the processes followed in the CCA and/or CCV of a particular outcome measure were appropriate, adequate and methodologically sound.

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Chapter 7

Measurement of stroke-related balance dysfunction in Africa

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Abstract

Background: Balance assessment post-stroke should be evidence-based, comprehensive and sensitive. It is unknown how balance dysfunction post-stroke is measured in Africa.

Aim: The overall aim of the chapter was to investigate how balance dysfunction post-stroke was measured in Africa and to report the potential benefits of multifaceted assessments.

Methods: The scoping review explored measurement tools used to assess balance dysfunction, and the pre–post longitudinal study illustrated combining clinical and quantitative balance assessments in South African stroke inpatients. Eight databases were systematically searched for balance measures reported in primary and secondary published stroke research in Africa and reported narratively. The longitudinal study compared clinical Berg balance scale (BBS) and pressure mat balance measures (centre of pressure [COP] velocity), anteroposterior (AP) and mediolateral (ML) sway and partial weight bearing asymmetry (PWBA). Statistical analyses were performed using STATA version 14.2 and statistical significance was at 5%.

Findings: Sixteen studies were included in the review. The BBS was used in 11 (69%) studies. Only one study used an instrumented quantitative system. In the pre–post longitudinal study, 41 of 49 participants (mean age 48) completed discharge reassessments. All BBS items improved significantly ($p < 0.001$), demonstrating low fall risk at discharge. Anteroposterior sway ($p = 0.004$) and velocity ($p = 0.019$) of COP improved significantly, but ML sway ($p = 0.055$) and PWBA did not improve ($p = 0.161$).

Conclusion: Although quantitative measures were rarely used for balance assessment in Africa, such assessments might hold value as individuals with a low fall risk according to BBS might have ongoing impairments.

Keywords: Stroke; Balance; Measurement; Outcome measure; Africa.

Introduction

Impaired balance significantly impacts post-stroke function regardless of age, gender and time since stroke (Vincent-Onabajo et al. 2018b). Reportedly, 26%–35% of people with stroke experience a fall by 6 months of post-incident because of balance dysfunction (Minet et al. 2015). Impairments in motor, sensory and cognitive function, and the complex interactions between these systems that are required for balance control are amongst the primary stroke-associated deficits that may disturb equilibrium and contribute to falls (Bhatt, Dusane & Patel 2019). Common balance impairments in people with stroke include poor standing ability, asymmetrical weight distribution, difficulties in shifting weight and increased postural sway (Alghadir et al. 2018). Fall consequences include fractures, compounded long-term disability and increased healthcare utilisation (Weerdesteyn et al. 2008). In contrast, the ability to maintain balance effectively has been correlated with greater functional independence (specifically in terms of mobility) and QoL (Verheyden et al. 2006). Given the complexity of balance control and the significant consequences of balance dysfunction, an evidence-based, comprehensive and sensitive assessment is imperative to identify impairments and risk, and to inform the design of targeted balance exercise programmes for fall prevention, functional optimisation and reduced burden of care.

Balance is multidimensional, complex and depends on various sensorimotor processes and behavioural strategies. Balance involves the control of the body’s position in space to obtain both postural orientation and equilibrium (stability) during static and dynamic daily functional activities. Postural orientation is defined as the active alignment of the trunk and head with respect to gravity, support surfaces, the visual surround and internal references. Postural equilibrium, on the other hand, is thought to involve the coordination of movement strategies to stabilise the centre of body mass during both self-initiated (anticipated) and externally triggered (unexpected) perturbations of stability (Sirois-Leclerc, Remaud & Bilodeau 2017; Shumway-Cook & Woollacott 2017; Cho et al. 2014; Young & Tolentino 2009). The sensory systems, which include visual, vestibular and somatosensory subsystems, provide feedback on body awareness and positions including the environmental context. Cognitive processing results in the interpretation of this 'input' information and facilitates the movement and behavioural strategies ('output') that are needed for maintaining balance (Horak 2006).

The Systems Framework for Postural Control proposed by Horak (2006) lists six major components required for maintaining balance:

1. constraints on the biomechanical system
2. movement strategies
3. sensory strategies
4. orientation in space
5. dynamic control
6. cognitive processing.

The framework highlights that dysfunction in each underlying component and type of control could independently lead to a balance dysfunction. To facilitate effective and efficient interventions targeting balance post-stroke, a thorough assessment of balance and its various components is therefore indicated (Horak 2006). Comprehensive balance assessment may pose unique challenges to clinicians and researchers, as the outcome measurements would need to be multifaceted. Post-stroke balance assessment should be able to not only identify but also monitor dysfunction at all system levels and may include some or all of the following:

1. individual impairments, for example, hemisensory loss in the foot
2. system integration problems, for example, loss of cerebellum function to allow motor learning
3. strategy challenges, for example, loss of stepping strategy because of lower limb hemiparesis
4. loss of dynamic functional balance control, for example, resulting in a slow gait pattern.

Sibley et al. (2015) cautioned that the choice of balance measure may ultimately limit the interpretation of an individual's balance ability. Understanding the theoretical or conceptual basis and psychometric properties of balance-specific outcome measures should be key considerations in the selection of appropriate measures in clinical and research practice (Sibley et al. 2015).

Various outcome measures for balance are reported in stroke rehabilitation. Therapists often use clinical scales such as the BBS or the timed-up-and-go test (TUG) to assess the functional impact of poor balance control (Alghadir et al. 2018). Clinical scales provide good insight into global balance disability and how it affects ADL, and are useful for fall risk screening. However, they may lack sensitivity to individual balance impairments, types of balance dysfunction and underlying biomechanical factors influencing balance control and fall risk (e.g. balance strategies and movement quality) (Alghadir et al. 2018). The development of customised balance rehabilitation strategies may subsequently be hindered (Sibley et al. 2015; Horak 2006). This seems especially true in high-functioning individuals, where subtler impairments (or improvements) may be overlooked because of high floor and ceiling effects of outcome measures, as they have, for example, been reported for the BBS (Salter et al. 2013).

Robust quantitative measures may be useful to complement clinical assessment, as these provide a more comprehensive and accurate description of balance dysfunction post-stroke (Sawacha et al. 2013). Posturography is an instrumented method that provides quantitative analysis of balance responses in different postures. It uses a variety of indicators of postural control, which are quantifiable, including biomechanical outcomes (kinematics and kinetics). Kinematics is the study of different body segmental movements and the relationship between segments, often measured by optical motion capture and wearable sensors (Shumway-Cook & Woollacott 2017). Kinetic measures allow the analysis of how internal forces, muscle activity, measured using electromyography, and external forces, for example, COP, produce movement (Shumway-Cook & Woollacott 2017). The COP (resultant application point of the vertical force's action on the support surface) is the most common posturographic measure used for quantitative postural control assessment and is most often assessed using force plates (considered the gold standard). Quantitative posturography can predict fall risk (Hyndman, Pickering & Ashburn 2009), evaluate therapeutic efficiency (Mancini & Horak 2010), have demonstrated good to excellent reliability for measures such as COP and weight bearing asymmetry (Eng & Chu 2002; Gray et al. 2014) and have shown correlations with clinical measures (Sawacha et al. 2013). In addition, some disadvantages of clinical balance tests can be overcome, including sensitivity to small changes, subjective scoring and variability within and across different examiners (Visser et al. 2008).

A major barrier to the uptake of quantitative measures into clinical practice has been their expense, lack of accessibility and time-consuming use (Brouwer et al. 2019). However, pressure mapping systems offer another option for quantitative balance assessment. As they are portable and relatively more affordable, they provide a practical solution to the clinical accessibility limitations of force plates, and thus, they may offer an opportunity for conducting instrumented balance assessments in clinical settings. Pressure mapping systems map out plantar pressures and COP movement as balance control is maintained within the base of support (BOS) (Brenton-Rule et al. 2012; Chong et al. 2014) and can record and objectively quantify various parameters such as postural sway and weight bearing asymmetry. Such measures enable the assessor to ascertain impairments related to a specific parameter (Frykberg et al. 2007; Piirtola & Era 2006).

It is well known that increased survival rates of post-stroke in Africa have led to a growing disabled group and thus also longer-term disability (Mayosi et al. 2009). The consequences include an increase in the burden on the economy and the caregivers (Bryer et al. 2010; Di Monaco et al. 2010; Mayosi et al. 2009). Therapists involved in stroke rehabilitation in Africa are therefore under pressure to effectively and efficiently improve balance control to facilitate greater levels of participation and further community reintegration for people with stroke. Optimising rehabilitation of these individuals within resource-constraint public healthcare services in Africa should drive the timely identification of underlying reasons of balance dysfunction and evidence-based monitoring of the impact of interventions in diverse clinical settings. It, however, remains unclear whether quantitative assessments of balance have been incorporated in sub-Saharan African people with stroke, and whether such assessments may offer additional insights. The overall aim of the chapter was, therefore, to investigate how balance dysfunction post-stroke was measured in Africa and to report the potential benefits of including quantitative assessments of balance. The chapter is divided into two sections. The scoping review explored measurement tools (including clinical and quantitative) used to assess balance in people with stroke in Africa, and a primary pre–post longitudinal study that compared clinical and quantitative balance assessments in a Western Cape cohort of South African people with stroke.

Section 1: Measurement tools used for assessing balance dysfunction in people with stroke in Africa: A scoping review

Methods

Research design

A scoping review was conducted to systematically search the available literature reporting on the use of outcome measurements for balance assessment in people with stroke living in Africa. The review was conducted according to a recommended methodological framework for scoping reviews (Levac, Colquhoun & O'Brien 2010) involving five steps, namely, (1) research question identification, (2) study identification, (3) study selection, (4) data charting and (5) collating, summarising and reporting results. Reporting of the review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews guidelines (Tricco et al. 2018).

Review objectives

The main constructs of the scoping review included synthesis of evidence relating to the assessment of postural balance in people with stroke in Africa, including any outcome measurement tools used in stroke rehabilitation within the African context. Specifically, the review objectives were to:

1. systematically search, summarise and synthesise existing literature on balance assessment measures used in stroke rehabilitation within the African context
2. describe the populations of people with stroke within which balance was assessed
3. describe the type of balance (static or dynamic) and positioning (sitting or standing), in which balance was assessed

4. describe the types of measurement tools (clinical vs. quantitative measures) used by researchers or clinicians when assessing balance in stroke rehabilitation in Africa.

☐ Eligibility criteria for study selection

Studies were included if they (1) were primary or secondary studies, (2) were published in peer-reviewed journals, (3) had full texts available in English or Afrikaans, (4) included adult (aged 18 and older) male and/or female participants with stroke, (5) were conducted in African countries only and (6) implemented and reported on any outcome measurement tools for balance assessment in people with stroke. Conference proceedings were excluded from this review.

☐ Information sources and search strategy

Eight databases, accessed through the SU Medical Library Services, were searched in April 2019: African Journals Online (AJOL), African Wide, African Journals Sabinet, CINAHL, EBSCOHost, PubMed, Scopus and Web of Science. PEARLing was conducted to source additional relevant publications not indexed in the searched databases. Each database was searched from inception according to its function and where possible, the following limits applied: age (18 years and older) and language (English or Afrikaans). Key search terms included ‘stroke’, ‘cerebral vascular accident’, ‘hemiplegia’, ‘Africa’, ‘outcome measure’, ‘instruments’, ‘tools’, ‘assessment’, ‘evaluation, balance’, ‘postural stability’ and ‘postural control’.

☐ Study selection

Four reviewers (G.I.J., H.S., M.B. and T.H.) independently searched the databases. Based on the eligibility criteria, these researchers independently reviewed titles, abstracts and finally full-text articles retrieved in the searches. Full-text articles were retrieved by accessing electronic journals or directly via the databases. The researchers compared the eligible studies selected for inclusion, and disagreements regarding accepting full texts were discussed until consensus was reached. Each step of the search process was documented.

Data charting

Data were extracted and captured on a custom Microsoft Excel spreadsheet. Extracted data included the following categories: citation, country, study type, participants (including the number of participants, mean ages and gender), outcome measures to assess balance or postural control (including validity and reliability and specific to the study population), results and implications. Data extracted were cross-checked for completeness and accuracy. The methodological quality or risk of bias of the included studies was not appraised, which is consistent with guidance on scoping review conduct (Tricco et al. 2018).

Synthesis of results

The extracted data were summarised narratively using text and tables. The following predetermined categories of information were described:

1. participant characteristics and rehabilitation settings within which balance outcome measurements were used
2. types or domains of balance assessed (e.g. static vs. dynamic) and the assessment positions (e.g. sitting vs. standing) if reported
3. type of outcome measure (e.g. clinical vs. quantitative).

Results

Search results

Of the initial 25 hits yielded by the search, 20 studies, abstracts and full-text articles were screened after removal of duplicates.

After applying eligibility criteria to the full texts, four studies were excluded: two studies did not assess balance, one focused on participants with traumatic brain injuries only and one study reported findings on the same sample already reported in another study by the same author. Thus, 16 studies were finally included in the review (Figure 7.1).

Characteristics of included studies

Table 7.1 summarises study characteristics. Of the 16 included studies, only one study included a subsample of non-African participants (Batcho, Stoquart & Thonnard 2013). Most of the studies (9/16; 56.25%) were conducted in Nigeria; other countries included South Africa (4/16; 25%), Benin (1/16; 6.25%)

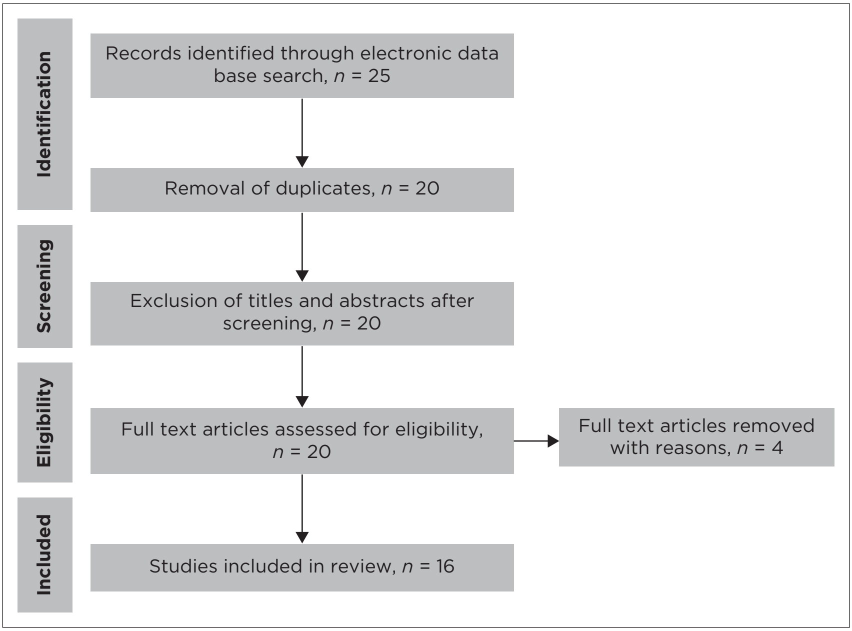

FIGURE 7.1: Preferred reporting items for scoping review and meta-analyses flow diagram of literature search and identification of eligible studies.

TABLE 7.1: Description of included studies.

Author	Country, setting	Study aim	Study design	Sample size	Age in years, mean (SD)	Gender F:M	Stage of stroke; Level of functioning	Clinical measure	Quantitative measure	Findings related to the outcome measure
Batcho et al. (2013)	Belgium Benin Outpatient	To test efficacy of group-based regular brisk walking on functional recovery	Basic time series	44	Sample: 64.8 (11.8) Benin subsample: 62.6 (6.7)	14:30	Chronic; Various levels of function	BBS	–	Those with a risk of fall (BBS score ≤42; *n* = 13) at baseline reported lower ADL performance compared with those with a BBS score above 42 (*n* = 21)
Ekechukwu, Olaleye and Hamzat (2017)	Nigeria Inpatient	To investigate clinical and psychosocial predictors of community reintegration 3-month post inpatient discharge	Predictive correlation	55	61.2 (11.3)	29:26	Acute subacute; Various levels of function	ABC BBS FES	–	Age, motor function, balance and fall self-efficacy at discharge is predictive of community reintegration at 3-month post-discharge, FES more predictive than BBS
Hamzat and Fashoyin (2007)	Nigeria Outpatient	To determine the efficacy of stepper in training balance and assess the effects of change in balance performance on motor function	Pre-test, post-test	8	61.4 (6.0)	2:6	Chronic; Higher functioning (independent standing and walking)	BBS	–	BBS was able to capture improvements after 6-week stepper training. Individual BBS item scores, instead of total sum score, assist clinicians more to localise specific tasks for targeted rehabilitation. BBS was successfully used in this resource-constrained clinical setting

ABC, activities-specific balance confidence scale; ADL, activities of daily living; BBS, Berg balance scale; BI, Barthel Index; BOS, base of support; CI, cognitive impairment; COP, centre of pressure; DG, domiciliary group; Exp, experimental; F:M, female to male ratio; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; MDC, minimal detectable change; NCI, non-cognitive impairment; OM, outcome measure; PASS, postural assessment scale for stroke; PHCG, primary healthcare group; PT, physiotherapy; RCT, randomised controlled trial; SD, standard deviation; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

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TABLE 7.1 (Continues...): Description of included studies.

Author	Country, setting	Study aim	Study design	Sample size	Age in years, mean (SD)	Gender F:M	Stage of stroke; Level of functioning	Clinical measure	Quantitative measure	Findings related to the outcome measure
Hamzat and Kobiri (2008)	Ghana Outpatient	To observe social participation and balance and compare the performance of those walking with a cane and without a cane	Descriptive correlation	50 AD: 25 Without AD: 25	AD: 59.9 (12.0) Without AD: 55.8 (11.3)	23:27	Chronic; Higher functioning (walking with or without AD)	BBS	–	Stroke patients with AD had poorer balance (lower BBS scores) and reduced participation compared with those walking without AD
Knox, Stewart and Richards (2018)	South Africa Outpatient	To evaluate low-dose task-oriented gait training approach delivered in a circuit training mode and walking competency	RCT	144 Task: 51 Strength: 45 Control: 48	50 (*no SD reported*)	72:72	Acute Subacute chronic; Higher functioning (walking with or without AD)	BBS TUG	–	All groups showed gains in BBS ($p = 0.16$) and TUG scores ($p = 0.32$) post-intervention, and these gains were maintained or augmented at follow-up. Mean change in BBS scores doubled in the task group, the only change to attain MDC in this group. TUG mean change scores in all three groups exceeded the MDC

ABC, activities-specific balance confidence scale; ADL, activities of daily living; BBS, Berg balance scale; BI, Barthel Index; BOS, base of support; CI, cognitive impairment; COP, centre of pressure; DG, domiciliary group; Exp, experimental; F:M, female to male ratio; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; MDC, minimal detectable change; NCI, non-cognitive impairment; OM, outcome measure; PASS, postural assessment scale for stroke; PHCG, primary healthcare group; PT, physiotherapy; RCT, randomised controlled trial; SD, standard deviation; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

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TABLE 7.1 (Continues…): Description of included studies.

Author	Country, setting	Study aim	Study design	Sample size	Age in years, mean (SD)	Gender F:M	Stage of stroke; Level of functioning	Clinical measure	Quantitative measure	Findings related to the outcome measure
Obembe, Olaogun and Adedoyin (2014)	Nigeria Outpatient	To assess gait parameters and balance performance	Descriptive correlation	52	53.5 (10.4)	24:46	Chronic; High functioning (independent walking)	ABC FRT	–	Higher gait speeds present in participants with better balance self-efficacy and higher cadences with higher FRT distances. Gait speed and cadence therefore related to balance performance. Significant differences in FRT distance ($p = 0.016$) and ABC scores ($p = 0.001$) between fallers and non-fallers. No significant relationship ($p > 0.05$) between FRT distance and balance self-efficacy (ABC)

ABC, activities-specific balance confidence scale; ADL, activities of daily living; BBS, Berg balance scale; BI, Barthel Index; BOS, base of support; CI, cognitive impairment; COP, centre of pressure; DG, domiciliary group; Exp, experimental; F:M, female to male ratio; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; MDC, minimal detectable change; NCI, non-cognitive impairment; OM, outcome measure; PASS, postural assessment scale for stroke; PHCG, primary healthcare group; PT, physiotherapy; RCT, randomised controlled trial; SD, standard deviation; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

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TABLE 7.1 (Continues...): Description of included studies.

Author	Country, setting	Study aim	Study design	Sample size	Age in years, mean (SD)	Gender F:M	Stage of stroke; Level of functioning	Clinical measure	Quantitative measure	Findings related to the outcome measure
Okonkwo et al. (2018)	Nigeria Outpatient	To determine if task-specific balance training will have comparable beneficial effects on the balance control status of sub-acute ischemic stroke survivors with CI and without CI	Basic time series	100 CI: 50 NCI: 50	CI: 53.9 (9.3) NCI: 49.3 (12.2)	CI: 23:27 NCI: 28:22	Sub-acute; Various functioning levels	BBS	–	BBS scores in both groups improved significantly with large effect sizes: CI participants ($p < 0.001$; ES 0.690) and NCI group ($p < 0.001$; ES 0.544). BBS reasonably reliable to record trends in balance control of participants with and without CI. The miniBEST was recommended as alternative to address limitations of BBS
Olaleye, Hamzat and Owolabi (2014)	Nigeria Outpatient (PHCG) and patient's home	To investigate the feasibility and clinical effectiveness of stroke rehabilitation at a primary health centre compared with domiciliary rehabilitation	RCT	52 PHCG: 25 DG: 27	PHCG: 60.60.2 (*no SD reported*) DG: 61.78.4 (*no SD reported*)	PHCG: 18:7 DG: 10:17	Sub-acute; Various functioning levels	SF-PASS	–	Statistically significant improvement in SF-PASS scores (postural balance) in both groups ($p < 0.01$). Balance training was task related and used domains of BBS

ABC, activities-specific balance confidence scale; ADL, activities of daily living; BBS, Berg balance scale; BI, Barthel Index; BOS, base of support; CI, cognitive impairment; COP, centre of pressure; DG, domiciliary group; Exp, experimental; F:M, female to male ratio; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; MDC, minimal detectable change; NCI, non-cognitive impairment; OM, outcome measure; PASS, postural assessment scale for stroke; PHCG, primary healthcare group; PT, physiotherapy; RCT, randomised controlled trial; SD, standard deviation; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

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TABLE 7.1 (Continues...): Description of included studies.

Author	Country, setting	Study aim	Study design	Sample size	Age in years, mean (SD)	Gender F:M	Stage of stroke; Level of functioning	Clinical measure	Quantitative measure	Findings related to the outcome measure
Olawale, Ajiboye and Maduagwu (2003)	Nigeria Outpatient	To examine the relationship between dynamic balance and the muscular strength of the unaffected lower limbs	Descriptive correlation	18	60.4 (5.6)	6:12	Sub-acute chronic; Various functioning levels	Dynamic balance procedure	–	Dynamic balance performance was significantly related to torque produced by hip flexors and extensors, knee flexors and extensors of unaffected lower limbs, that is, greater muscular strength of unaffected lower limb related to better dynamic balance performance and less balance deficit
Olawale and Ogunmakin (2006)	Nigeria Outpatient	To evaluate the effect of exercise training on balance and incidence of falls	Pre-test, post-test	23	57.6 (10.4)	9:14	Sub-acute chronic; Higher functioning (independent standing)	BBS	–	Significant improvement in BBS scores ($p < 0.05$) and could be because it addressed specific balance impairments of the patients. However, non-significant reduction in incidence of falls

ABC, activities-specific balance confidence scale; ADL, activities of daily living; BBS, Berg balance scale; BI, Barthel Index; BOS, base of support; CI, cognitive impairment; COP, centre of pressure; DG, domiciliary group; Exp, experimental; F:M, female to male ratio; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; MDC, minimal detectable change; NCI, non-cognitive impairment; OM, outcome measure; PASS, postural assessment scale for stroke; PHCG, primary healthcare group; PT, physiotherapy; RCT, randomised controlled trial; SD, standard deviation; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

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TABLE 7.1 (Continues...): Description of included studies.

Author	Country, setting	Study aim	Study design	Sample size	Age in years, mean (SD)	Gender F:M	Stage of stroke; Level of functioning	Clinical measure	Quantitative measure	Findings related to the outcome measure
Onigbinde, Awotidebe and Awosika (2009)	Nigeria Outpatient	To determine the effect of a wobble board exercise program on static and dynamic balance	Pre-test, post-test	17 Exp: 10 Control: 7	*No mean or SD reported*	*Not reported*	Sub-acute; Higher functioning (independent standing)	Modified version TBT FSST	–	Significant improvement in both static (TBT with eyes closed) and dynamic balance (FSST) with wobble board exercise program
Puckree and Naidoo (2014)	South Africa Outpatient	To quantify the effect of a balance and stability exercise program on balance and stability and to compare it with a traditional program of PT	RCT	50 Exp: 25 Control: 25	*Not reported*	24:26	Sub-acute chronic; Various functioning levels	BBS PASS	–	Balance exercise intervention focused on repeated practice of functionally oriented stability and balance exercises, reinforced by exercises at home. PASS scores in experimental group improved significantly compared with pre-test and control post-test values (p = 0.004). BBS scores for the experimental group improved significantly compared with pre-test and control post-test values (p < 0.001). Qualitative feedback from participants was aligned with PASS and BBS scores. PASS and BBS used successfully in this low-resource setting

ABC, activities-specific balance confidence scale; ADL, activities of daily living; BBS, Berg balance scale; BI, Barthel Index; BOS, base of support; CI, cognitive impairment; COP, centre of pressure; DG, domiciliary group; Exp, experimental; F:M, female to male ratio; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; MDC, minimal detectable change; NCI, non-cognitive impairment; OM, outcome measure; PASS, postural assessment scale for stroke; PHCG, primary healthcare group; PT, physiotherapy; RCT, randomised controlled trial; SD, standard deviation; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

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TABLE 7.1 (Continues…): Description of included studies.

Author	Country, setting	Study aim	Study design	Sample size	Age in years, mean (SD)	Gender F:M	Stage of stroke; Level of functioning	Clinical measure	Quantitative measure	Findings related to the outcome measure
Puckree and Uthum (2014)	South Africa Outpatient	To quantify the effect of a traditional programme of PT on stability, balance and function in a poorly resourced community setting	Descriptive correlation	25	59 (*no SD reported*)	14:11	Sub-acute chronic; Various functioning levels	BBS PASS	–	Five per cent normalised mean increase in PASS scores, with 10% of items reaching optimal scores versus 3% normalised mean increase in BBS scores, with 8% of items reaching optimal scores. A strong correlation was found between BBS and PASS post-test scores ($r = 0.846$, $p = 0.000$). Authors ascribe minimal changes in BBS scores to small changes in PASS as stability would be needed for functional balance improvement (BBS). The PASS and BBS may not have been sensitive enough to detect small changes

ABC, activities-specific balance confidence scale; ADL, activities of daily living; BBS, Berg balance scale; BI, Barthel Index; BOS, base of support; CI, cognitive impairment; COP, centre of pressure; DG, domiciliary group; Exp, experimental; F:M, female to male ratio; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; MDC, minimal detectable change; NCI, non-cognitive impairment; OM, outcome measure; PASS, postural assessment scale for stroke; PHCG, primary healthcare group; PT, physiotherapy; RCT, randomised controlled trial; SD, standard deviation; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

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TABLE 7.1 (Continues...): Description of included studies.

Author	Country, setting	Study aim	Study design	Sample size	Age in years, mean (SD)	Gender F:M	Stage of stroke; Level of functioning	Clinical measure	Quantitative measure	Findings related to the outcome measure
Turnbull, Charteris and Wall (1996)	South Africa Outpatient	To investigate the deficiencies of weight shifts in hemiplegic subjects by comparing them with controls	Descriptive correlation	20	57.2 (10.7)	8:12	Chronic; Higher functioning (independent standing and walking)	–	Chattecx dynamic balance system	Marked deficiencies in voluntary shift weight over LL compared to normal participants, that is, range was half of controls. Hemiplegic participants could not displace COP towards periphery of BOS. This system examines deficiencies in weight shifting ability with feet placed in positions more relevant to gait cycle, but findings must be considered in light of the static nature of these tests

ABC, activities-specific balance confidence scale; ADL, activities of daily living; BBS, Berg balance scale; BI, Barthel Index; BOS, base of support; CI, cognitive impairment; COP, centre of pressure; DG, domiciliary group; Exp, experimental; F:M, female to male ratio; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; MDC, minimal detectable change; NCI, non-cognitive impairment; OM, outcome measure; PASS, postural assessment scale for stroke; PHCG, primary healthcare group; PT, physiotherapy; RCT, randomised controlled trial; SD, standard deviation; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

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TABLE 7.1 (Continues...): Description of included studies.

Author	Country, setting	Study aim	Study design	Sample size	Age in years, mean (SD)	Gender F:M	Stage of stroke; Level of functioning	Clinical measure	Quantitative measure	Findings related to the outcome measure
Vincent-Onabajo et al. (2018a)	Nigeria Outpatient	To examine the prevalence and determinants of balance impairment	Cross-sectional study	95	54.8 (13.1)	48:47	Sub-acute chronic; Various functioning levels	BBS	–	Better balance function (BBS) significantly increased the likelihood of attaining functional independence (BI) post-stroke (odds ratio = 1.33; 95% CI = 1.11–1.58), irrespective of the stroke survivors' age, sex and post-stroke duration
Vincent-Onabajo et al. (2018b)	Nigeria Outpatient	To examine the independent impact of balance function on functional independence	Descriptive correlation	95	58.4 (13.1)	48:47	Sub-acute chronic; Various functioning levels	BBS	–	Age, gender and post-stroke duration showed independent and significant association with balance impairment (BBS). Older age, females and acute or sub-acute phase increased odds of balance impairment

ABC, activities-specific balance confidence scale; ADL, activities of daily living; BBS, Berg balance scale; BI, Barthel Index; BOS, base of support; CI, cognitive impairment; COP, centre of pressure; DG, domiciliary group; Exp, experimental; F:M, female to male ratio; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; MDC, minimal detectable change; NCI, non-cognitive impairment; OM, outcome measure; PASS, postural assessment scale for stroke; PHCG, primary healthcare group; PT, physiotherapy; RCT, randomised controlled trial; SD, standard deviation; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

and Ghana (1/16; 6.25%). The majority of studies (10/16; 62.5%) followed a quasi-experimental pre–post design. Other designs included correlation studies (4/16; 25%) and randomised controlled trials (2/16; 12.5%). Sample sizes in individual studies varied from 8 to 144 participants, contributing to a total sample size of 848. Mean participant ages ranged from 20 to 75 years. Study settings included both inpatient (1/16; 6.25%) and outpatient (majority of studies) hospitals, as well as CHCs.

Overview of outcome measures used to assess balance post-stroke

Clinical outcome measures used to assess balance

Most of the studies (11/16; 68.8%) used the BBS, either alone or in combination with other clinical tests. Other clinical scales included the full and short version of the postural assessment scale for stroke (PASS), the functional reach test (FRT), the TUG test and the four square step test (FSST). Ekechukwu et al. (2017) incorporated both the activities-specific balance confidence scale (ABC scale) and the falls efficacy scale (FES) along with the BBS. Onigbinde et al. (2009) was the only study to use the modified version of the timed balance test (TBT) described by Bohannon et al. (1984), with eyes opened and eyes closed for assessing static balance, and the FSST to assess dynamic balance.

Quantitative measures used to assess balance post-stroke

Only one study used an instrumented system to assess balance in stroke patients (Turnbull et al. 1996), namely, the Chattecx dynamic balance system.

Type of balance and position in which balance was assessed

The clinical assessment scales evaluated static and dynamic functional performance, the efficacy of interventions, the need for balance rehabilitation and falls risk, whilst the quantitative measure explored impairments underlying static standing. Table 7.2 outlines the various types and positions in which balance was assessed. Five of the reported clinical outcome measures allowed variations of balance assessment (e.g. static or dynamic conditions, sitting or standing postures and functional activities), namely, the BBS, ABC, FES and the PASS.

Description of individual balance outcome measures

Activities-specific balance confidence scale

The ABC is a self-efficacy scale designed to measure an individual's confidence in his or her ability to perform daily activities without falling. The tool takes 10–20 min to administer and was originally developed for elderly adults. The ABC scale evaluates confidence in 16 daily functional activities, nine of them outside the home (Lord & Rochester 2005). Botner et al. (2005) reported excellent total score test–retest reliability for the ABC in chronic stroke participants (ICC = 0.85; 95% confidence interval: 0.68–0.93) and found that it correlated adequately with the BBS score ($r = 0.36$, $p < 0.001$). The ABC demonstrates excellent internal consistency with a Cronbach's α of 0.94 and its total score is not likely to suffer floor or ceiling effects (Salbach et al. 2005). A cut-off score has been proposed to classify fallers (ABC score < 67%) and non-fallers (ABC score > 67%) (Lajoie & Gallagher 2004; Obembe et al. 2014). In the Nigerian study by Obembe et al. (2014), there were significant differences in ABC scores ($p = 0.001$) between fallers and non-fallers.

TABLE 7.2: Description of types and positions of balance testing.

Clinical measure	Type of balance assessed		Testing position			Specific functional activities	Authors
	Static stability	Dynamic stability	Sitting	Standing	Mobility and/or functional activities		
ABC	Yes	Yes	Yes	Yes	Yes	• Walking around the house • Walking up or down stairs • Bending over to pick up a slipper from the front of a closet floor • Reaching for a small can off a shelf at eye level • Standing on tiptoes and reaching for something above head • Standing on a chair and reaching for something • Sweeping the floor • Walking outside the house to a car parked in the driveway • Getting into or out of a car • Walking across a parking lot to the mall • Walking up or down a ramp • Walking in a crowded mall where people rapidly walk past you • Walking and bumped into by people whilst walking through the mall • Stepping onto or off an escalator whilst holding onto a railing • Stepping onto or off an escalator whilst holding onto parcels such that you cannot hold onto the railing • Walk outside on icy sidewalks	**Ekechukwu et al. (2017); Obembe et al. (2014)**

ABC, activities-specific balance confidence scale; BBS, Berg balance scale; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; N/A, not applicable; PASS, postural assessment scale for stroke; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

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TABLE 7.2 (Continues…): Description of types and positions of balance testing.

Clinical measure	Type of balance assessed		Testing position			Specific functional activities	Authors
	Static stability	**Dynamic stability**	**Sitting**	**Standing**	**Mobility and/or functional activities**		
BBS	Yes	Yes	Yes	Yes	Yes	• Sitting to standing • Standing to sitting • Transfers • Reaching forward with outstretched arm • Retrieving object from floor • Turning to look behind • Turning 360°	**Batcho et al. (2013); Ekechukwu et al. (2017); Hamzat and Fashoyin (2007); Hamzat and Kobiri (2008); Knox et al. (2018); Okonkwo et al. (2018); Olawale and Ogunmakin (2006); Puckree and Naidoo (2014); Puckree and Uthum (2014); Vincent-Onabajo et al. (2018a, 2018b)**

ABC, activities-specific balance confidence scale; BBS, Berg balance scale; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; N/A, not applicable; PASS, postural assessment scale for stroke; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

Table 7.2 continues on the next page→

TABLE 7.2 (Continues...): Description of types and positions of balance testing.

Clinical measure	Type of balance assessed		Testing position			Specific functional activities	Authors
	Static stability	Dynamic stability	Sitting	Standing	Mobility and/ or functional activities		
FES	No	Yes	No	Yes	Yes	• Taking a bath or shower • Reaching into cabinets or closets • Walking around the house • Preparing meals not requiring carrying heavy or hot objects • Getting in and out of bed • Answering the door or telephone • Getting in and out of a chair • Getting dressed and undressed • Personal grooming (i.e. washing your face) • Getting on and off of the toilet	**Ekechukwu et al. (2017)**
FRT (standing)	No	No	No	Yes	No	*N/A*	**Obembe et al. (2014)**
FSST	No	Yes	No	Yes	No	*N/A*	**Onigbinde et al. (2009)**
PASS	Yes	Yes	Yes	Yes	Yes	• Rolling to both sides • Lying to sitting over the edge of bed and back to lying • Sitting to standing, and back to sitting down • Standing picking up a pencil from the floor	**Puckree and Naidoo (2014); Puckree and Uthum (2014)**

ABC, activities-specific balance confidence scale; BBS, Berg balance scale; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; N/A, not applicable; PASS, postural assessment scale for stroke; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

Table 7.2 continues on the next page→

TABLE 7.2 (Continues...): Description of types and positions of balance testing.

Clinical measure	**Type of balance assessed**		**Testing position**			**Specific functional activities**	**Authors**
	Static stability	**Dynamic stability**	**Sitting**	**Standing**	**Mobility and/or functional activities**		
SF-PASS	Yes	Yes	Yes	Yes	Yes	• Lying to sitting over the edge of bed and back to lying • Sitting to standing, and back to sitting down	**Olaleye et al. (2014)**
TUG	No	Yes	No	No	Yes	• Sitting to standing • Walking • Turning • Standing to sitting down	**Knox et al. (2018)**
Dynamic balance procedure	No	Yes	No	No	Yes	*N/A*	**Olawale et al. (2003)**
Modified TBT	Yes	No	No	Yes	No	*N/A*	**Onigbinde et al. (2009)**
Chattecx dynamic balance system	Yes	No	No	Yes	No	*N/A*	**Turnbull et al. (1996)**

ABC, activities-specific balance confidence scale; BBS, Berg balance scale; FES, falls efficacy scale; FRT, functional reach test; FSST, four square step test; N/A, not applicable; PASS, postural assessment scale for stroke; SF-PASS, short-form-postural assessment scale for stroke; TBT, timed balance test; TUG, timed-up-and-go test.

Berg balance scale

The BBS is a 14-item performance measure of static and functional balance in common everyday activities (Berg et al. 1992) and was used by many of the African studies included in this review. Individual items are scored on a five-point ordinal scale, ranging from 0 (lowest functional level) to 4 (highest functional level) with a maximum total score of 56. A score of 0–20 indicates a high fall risk, 21–20 medium fall risk and 41–56 a low fall risk. Individuals who score <45 on the BBS may be at a greater risk of falling (Berg et al. 1992). The BBS has been described as a valid and reliable tool to determine change in functional standing balance over time (Stevenson 2001), to assess patients at different recovery stages after stroke (Mao et al. 2002) and to estimate the approximate length of stay and eventual discharge destination in stroke (Wee et al. 2003). The scale has become the gold standard in balance assessment post-stroke. Mao et al. (2002) demonstrated excellent internal consistency (Cronbach's α of 0.92–0.98) for the BBS, whilst Berg, Wood-Dauphinee and Willians (1995) reported excellent interrater (ICC = 0.98) and intrarater reliability (ICC = 0.97) in 70 acute patients with stroke. More recently, Hiengkaew, Jitaree and Chaiyawat (2012) found excellent test–retest reliability (ICC = 0.98) in 60 participants in the chronic phase post-stroke. However, the BBS has also demonstrated high floor and ceiling effects and is only moderately responsive to detect changes under 90 days since stroke onset (Mao et al. 2002), suggesting that it may not be able to detect minor improvements in high-functioning individuals post-stroke (Salter et al. 2013). This was evident in a few of the studies implementing the BBS in Africa (Okonkwo et al. 2018; Puckree & Uthum 2014). The shortened version, called the miniBEST, was recommended as an alternative to address these limitations of the original BBS (Okonkwo et al. 2018).

Falls efficacy scale

The FES is also known as the Tinetti FES, after its original developers (Tinetti, Richman & Powell 1990). It was developed for the elderly but has since been used in other populations including stroke. The Tinetti FES has 10 items that assess confidence in a patients' ability to perform daily tasks without falling as an indicator of how fear of falling impacts their physical performance. Hellstrom and Lindmark (1999) reported excellent test–retest reliability (ICC = 0.97) of the FES in participants with chronic stroke (*n* = 30; mean age = 65 [11] years; stroke onset between 5 and 84 months prior to assessment). In a geriatric population, the FES had proven sensitivity (59%) and specificity (82%) in a sample of 53 individuals living in two residential care facilities for the elderly (Harada et al. 1995). Age, motor function, balance and fall self-efficacy at discharge is predictive of community reintegration at 3-month post-discharge, with the FES being more predictive than the BBS (Ekechukwu et al. 2017).

Functional reach test

The FRT was originally developed to predict fall risk in the elderly and frail adults (Duncan et al. 1990). Using a wall-mounted ruler, the tool measures the maximum distance in centimetres (cm) that an individual can reach forward horizontally beyond arm's length whilst maintaining a fixed BOS in standing without using an assistive device. In Obembe et al. (2014), each participant was given two practice trials, followed by three trials with a 15-s rest in between. The final three trials were recorded and averaged for analysis. Stroke participants are classified as fallers (FRT distance < 17.8 cm) and non-fallers (FRT distance > 17.8 cm) using their FRT distances. The FRT has demonstrated a good validity in sub-acute stroke patients (*r* = 0.71) and an excellent intrarater reliability (ICC = 0.89) with a minimal detectable change (MDC) of 6.97 cm (Outermans et al. 2010). Obembe et al. (2014) reported that participants with higher FRT distances also presented with higher gait speeds, better balance self-efficacy and higher cadences, and therefore concluded that in their African sample, gait speed and cadence were related to balance performance. There were significant differences in FRT distance (*p* = 0.016) and

ABC scores (p = 0.001) between fallers and non-fallers in this sample. However, no significant relationship between FRT distance and balance self-efficacy measured with the ABC (p > 0.05) was found.

Four square step test

The FSST assesses dynamic balance. It involves stepping over low objects (2.5 cm), movement in four directions and stepping over one side of a square before moving in another direction. The time taken (in seconds) to revolve in four directions is recorded. Dite and Temple (2002) found the FSST to be a reliable and valid clinical tool with good utility as it is easy to score, quick to administer, requires little space and no special equipment. These authors reported high reliability for interrater (n = 30, ICC = 0.99) and retest reliability (n = 20, ICC = 0.98). The FSST also revealed a sensitivity of 85%, a specificity of 88%–100% as well as a positive predictive value of 86% (Dite & Temple 2002). Using the FSST, a significant improvement in dynamic balance was reported in a Nigerian cohort that was exposed to a wobble board exercise program for 6 weeks (Onigbinde et al. 2009).

Postural assessment scale for stroke and short-form-postural assessment scale for stroke

The full 12-item PASS was designed to be used with individual's post-stroke specifically and assesses their ability to maintain stable postures in lying, sitting and standing as well as equilibrium during position changes such as sitting to standing. According to Mao et al. (2002), the PASS is a valid and reliable measure of postural balance with internal consistency (Cronbach's α of 0.94–0.96), excellent interrater reliability for individual items (average α = 0.88, ranging between 0.64 and 1) as well as for the total PASS scores (r = 0.99, p < 0.001). These authors also report excellent concurrent validity of the PASS with the BBS (p = 0.92–0.95).

Puckree and Naidoo (2014) successfully used the full PASS in a low-resourced community-based setting in South Africa. Their study aimed to evaluate the effectiveness of a balance exercise intervention focused on repeated practice of functionally oriented stability and balance exercises that were reinforced by exercises at home. They reported that the PASS scores in the experimental group improved significantly compared with pre-test and control post-test values ($p = 0.004$). Qualitative feedback from their participants was also aligned with positive PASS score changes. Puckree and Uthum (2014), however, found minimal changes in PASS scores in their South African cohort and found that post-test PASS scores were also strongly correlated with low BBS post-test scores ($r = 0.846$, $p = 0.000$). These authors reported that the PASS may not have been sensitive enough to detect small changes in their higher functioning community-based chronic stroke participants.

The modified short-form-postural assessment scale for stroke (SF-PASS) assesses postural balance in five items only. Independence in the performance of these tasks is graded on a 3-point scale (0, 1.5 and 3). Chien et al. (2007) reported that the SF-PASS had excellent internal consistency (Cronbach's α of 0.96), excellent test–retest reliability (ICC = 0.84) as well as concurrent validity with the original PASS (ICC = 0.98). These authors also reported good predictive validity of the SF-PASS for participants with stroke on admission to inpatient rehabilitation (ICC = 0.82). Olaleye et al. (2014) reported a statistically significant improvement in SF-PASS scores, measuring postural balance, in both groups ($p < 0.01$), which were exposed to a task-specific balance training using the domains of BBS in a Nigerian cohort. The two groups received the same intervention either at a primary health centre or at their home.

Timed-up-and-go test

The TUG test assesses the risk of falling and progress in functional balance, sit-to-stand and walking. Knox et al. (2018) reported a change of 2.9 s in the TUG score as clinically meaningful. Flansbjer et al. (2005) established excellent test–retest reliability for the TUG (ICC = 0.96) and reported an excellent predictive correlation between the TUG and the 6-min walk test with r = 0.92. Knorr, Brouwer and Garland (2010) also found excellent convergent correlation between the TUG and the BBS (ρ = -0.70, p < 0.001) in participants in the chronic phase post-stroke. In a comparative South African study, Knox et al. (2018) evaluated the effectiveness of a low-dose task-oriented gait training approach delivered in a circuit training mode and found that all participants showed gains in TUG scores (p = 0.32) post-task-specific gait training with these gains being maintained or augmented at follow-up. The TUG mean change scores in all their groups exceeded the MDC for the TUG.

Dynamic balance procedure

Olawale et al. (2003) adapted a dynamic balance procedure, originally described by Sellers (1988) in the quality scale for antigravity and postural control tasks they developed for paediatric participants. The dynamic balance procedure subsection of the Sellers scale is a four-point scoring system ranging from 0 (inability to perform the task) to 3 (controlled and smooth execution), and not timed in seconds as used by Olawale et al. (2003). Although the original Sellers (1988) qualitative measure demonstrated high interrater reliability (r = 0.90), Olawale et al. (2003) did not provide any information regarding the psychometric properties of their adapted version of the dynamic balance procedure nor if it was validated in stroke populations.

Modified timed balance test

Onigbinde et al. (2009) used a modified version of the TBT originally described by Bohannon et al. (1984) to assess static standing balance. Participants stood barefoot on a hard level surface inside a rectangular (50 cm × 45 cm) wooden frame and lifted the unaffected leg to maintain it at the knee level of the affected limb. Time to maintain balance was monitored. Timing started when the unaffected foot was lifted and ended when any imbalance was demonstrated. Two trials were allowed for both eyes opened and eyes closed tests and the best time for each test condition was used for data analysis. Onigbinde et al. (2009) did not provide any information on the psychometric properties of the modified version of the TBT.

Chattecx dynamic balance system

The Chattecx balance system (Chattecx Corp., Hixon, TN) is a computerised system that assesses postural sway by measuring body weight distribution whilst participants stand on four independent footplates (for forefeet and hindfeet) installed with electronic pressure transducers. Both static and dynamic balances are assessed. Notably, the study employing this instrument was conducted in 1996, and the technology has since become outdated. The Chattecx system demonstrated varying results for reliability in patients with hemiplegia, showing ICCs between 0.58 and 0.92 for using a static platform, 0.46 and 0.83 for linear translation and 0.62 and 0.89 for angular rotation motions. It was recommended at the time that measures showing high or moderate reliability may be useful for demonstrating progress in hemiplegic patients (Levine et al. 1996).

Section 2: Comparing clinical and quantitative measures of balance dysfunction in people with stroke: A preliminary pre–post longitudinal study in the Western Cape of South Africa

Methods

Study objectives

The study aimed to compare clinical and quantitative measures for assessing balance dysfunction in a Western Cape cohort of South African people with stroke. The specific study objectives were to (1) compare admission (baseline) and discharge BBS scores in adults with stroke, (2) compare admission (baseline) and discharge pressure mapping parameters in adults with stroke, (3) determine correlations between BBS total score and pressure mapping parameters at admission and at discharge in adults with stroke and (4) determine correlations between BBS standing balance items and pressure mapping parameters at admission and at discharge in adults with stroke.

☐ Study design and setting

A prospective preliminary longitudinal cohort study with repeated measures (pre–post) was conducted over a 6-month period at an inpatient rehabilitation centre in the Western Cape Province of South Africa.

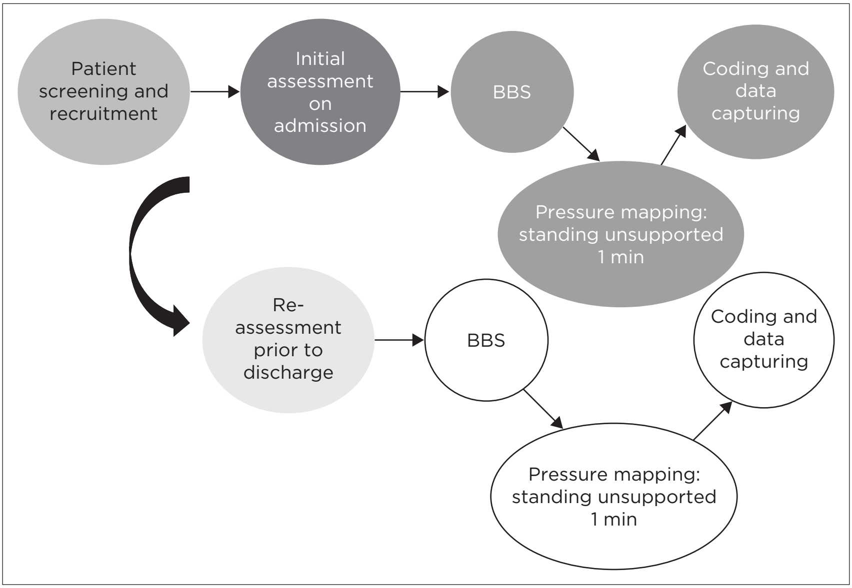
☐ Participants

Approval for the study was obtained from the Health Research Ethics Committee (HREC) at SU (S15/10/232), and all participants provided a written informed consent. Participants were recruited between July and December 2016.

Recruitment took place at the Western Cape Rehabilitation Centre (WCRC), a specialised rehabilitation centre for persons with physical disabilities. The WCRC is located in Cape Town, and its catchment area comprises the Western Cape and surrounding provinces including the Northern and Eastern Provinces of South Africa. During the recruitment period, using a convenient sampling method, all patients who admitted to the WCRC post-stroke and who met the inclusion criteria were recruited. No sample size was calculated as this was a preliminary study. Included participants had to (1) be adults (18 years or older), (2) have experienced a first-ever stroke and (3) be able to understand and respond to verbal commands in three of the main local languages (English, Afrikaans or isiXhosa). Patients were excluded if they had a history of psychiatric disorders, previous stroke(s) (i.e. most recent stroke not first-ever stroke), cardiac, renal or liver impairment, or systemic infections.

☐ Procedures and outcome measures

Figure 7.2 outlines the study procedures. Demographic information and medical history were extracted from participants' medical files and captured on a custom data collection sheet. This study had a pre- and post-repeated measures design, looking at various outcomes that included static and dynamic balance in different positions, for example, sitting, standing and transfers between positions. All outcomes were assessed on admission and again on discharge. The balance-related outcome measures used were (1) the BBS, which assessed balance and safety with mobilisation and (2) the MatScan pressure mapping platform. The BBS has good reliability and validity in assessing risk of falling in stroke patients and requires easily accessible items



BBS, Berg balance scale.

FIGURE 7.2: Flowchart of procedural steps during primary pre–post longitudinal study.

suitable for low-resource settings (Salter et al. 2013; Berg et al. 1995). Moreover, the BBS is the most commonly used balance assessment tool in post-stroke rehabilitation (Blum & Komer-Bitensky 2008). In addition, it was the most commonly used tool in African settings as reported by the scoping review. Impaired postural balance, found in stroke patients and which negatively impacts mobility and increases risk of falling, is commonly assessed by measuring COP (Gasq et al. 2014). The MatScan Versatek (sensor model 3150E, Tekscan, Boston, MA), used in this study, is a high-resolution dynamic pressure mapping platform, is portable, easy to use and has been used to assess standing balance parameters (COP and weight bearing asymmetry) in people with stroke (Lee & Lee 2013). This MatScan device is a floor mat with a low profile (0.6 cm thick) consisting of resistive sensors with a sampling frequency of up to 440 Hz. The use of COP parameters as well as weight bearing asymmetry has been reported in various patient populations (Adegoke, Olaniyi & Akosile 2012; Mansfield & Inness 2015).

Participants who were able to stand independently were asked to stand barefoot on the pressure mapping system and to look straight ahead. Pressure mapping data were collected over 1 min during quiet unsupported bipedal standing. The pressure mapping system was connected to a laptop containing Tekscan software, which recorded the selected parameters with a frequency set at 400 Hz, as well as a camera to record the sessions. Participants were given three trials, with a 2-min break in between after which the average was calculated. Raw data from the Tekscan system were then transferred to an Excel spreadsheet for data analysis. The pressure mapping system was recalibrated weekly at the Stellenbosch Movement Analysis Laboratory.

The three pressure parameters chosen to assess static standing were: (1) the PWBA or weight distribution between feet, as stroke often results in less weight being taken through the affected side; COP sway via (2) COP velocity; and; (3) distance travelled by COP in both AP and ML directions. Although controversial, some researchers report that the faster and further the COP sways, the more unstable the participant; and the greater PWBA they will have (Kamphuis et al. 2013; Adegoke et al. 2012). The norms for these variables have yet to be established (Kumar et al. 2014).

Statistical analysis

Data were coded and captured in a custom-designed MS Excel datasheet. Statistical analyses were subsequently performed using STATA version 14.2 (StataCorp 2015). Continuous data were summarised using median and interquartile range (IQR) and empirical 95% CIs. Categorical data were presented using frequencies and percentages. Associations between categorical variables were assessed using the Chi-squared or Fisher's Exact test. Differences in the distribution of continuous variables over different levels of a categorical variable were evaluated using the Kruskal–Wallis test. Statistical significance was assessed at the 5% level. To assess the correlation between nonparametric data, which included the BBS and pressure mapping outcomes, Spearman's correlation coefficient (r_S) was used. Correlations were interpreted as follows: 0.20–0.39 = weak; 0.40–0.59 = moderate; 0.60–0.79 = strong and 0.80–1.00 = very strong (Mukaka 2012).

Results

Sample demographics

Table 7.3 summarises the sample characteristics. A total of 49 participants consented to participate in the study. Of the 49 participants, who completed baseline (admission) assessments, 6 were discharged earlier than expected and 2 died prior to discharge; hence, 41 participants completed the reassessment at discharge. The median age of participants was 48 years. Most participants had an infarction-type stroke (89.90%), and an almost equal amount of left- and right-sided hemiplegia was observed. Hypertension and diabetes were the most common stroke risk factors (73.47% and 28.57%, respectively), as well as a low CD4 count in participants with HIV (*n* = 9; median CD4 count: 130).

TABLE 7.3: Demographic and stroke-related characteristics in the pre–post longitudinal study.

Stage of hospitilisation	**Sample size (*n*)**
Admission	49
Discharge	41
Age	Mdn (IQR)
Age	48 (39–60)
Gender	*n* (%)
Female	25 (51.02)
Risk factor	*n (%)*
No known risk factor	2 (4.08)
Hypertension	36 (73.47)
Diabetes	14 (28.57)
Cholesterol	6 (12.24)
Smoking	16 (32.65)
Substance abuse	3 (6.12)
Opportunistic infections	3 (6.12)
HIV-1 infection	9 (18.37)
CD4 count, mdn (range)	130 (54–883)
Type of stroke	*n (%)*
Infarction	44 (89.80)
Right CVA (left hemiplegia)	25 (51.02)
Factors related to time	Days Mdn (IQR)
Time (days) between stroke incident and admission, mdn (IQR)	20 (14–28)
Length of stay (days)	53 (46–60)

CVA, cerebrovascular accident; HIV, human immunodeficiency virus; IQR, interquartile range; Mdn, median.

Comparison between admission and discharge Berg balance scale scores

The median total BBS score on admission was 29 (IQR: 9–50; 95% CI: 24–42; $n = 49$), indicating a medium fall risk, and improved to 47 (IQR: 35–55; 95% CI: 35–52; $n = 41$) on discharge, indicating a low fall risk. This score change was significant ($p < 0.001$). Most participants had improved in all BBS items upon discharge, except for unsupported sitting (Table 7.4 and Table 7.5). This item showed that a smaller percentage of participants were able to sit unsupported upon discharge compared to admission ($p = 0.039$). Items that showed the largest percentage changes for improvement along with statistical significance were standing to sitting, transfers and standing with eyes closed (all $p < 0.001$), followed by standing unsupported ($p < 0.001$). The remaining BBS items also showed significant score changes, but as items became more challenging, fewer participants attained maximum scores. On admission and discharge, high (>15%) floor (participants achieving a score of 0) and ceiling (participants achieving a score of 4) effects were observed for most of the BBS items.

Comparison between admission and discharge pressure mapping platform parameters

The median PWBA showed a decrease in weight shift to the affected side by 2% (Table 7.6). The change in score on discharge was, however, not significant ($p = 0.161$). The score changes for COP velocity for static standing improved significantly by 0.01 m/s ($p = 0.019$). The MDC in AP COP sway is 0.21 cm and ML COP sway is 0.48 cm (Martello et al. 2017). Anteroposterior sway of COP decreased by 0.53 cm and ML sway decreased by 0.62 cm, both exceeding the MDC. The improvement on discharge for AP sway was significant ($p = 0.004$), whereas no significance was found in the change in ML sway on discharge ($p = 0.055$).

TABLE 7.4: Berg balance scale on admission and discharge (items 1–7).

BBS item	**BBS score**	**Participants obtaining score on admission, *n* (%) *n* = 49 (100%)**	**Participants obtaining score on discharge, *n* (%) *n* = 41 (100%)**	**Percentage change**	***p***
1. Sitting to standing	0	8 (16.33)	2 (4.08)	−12.25	<0.001
	1	8 (16.33)	2 (4.08)	−12.25	
	2	4 (8.16)	0 (0.00)	−8.16	
	3	16 (32.65)	10 (20.41)	−12.24	
	4	**13 (26.53)**	**27 (55.10)**	**28.45**	
2. Standing unsupported	0	15 (30.61)	4 (8.16)	−22.45	<0.001
	1	0 (0.00)	0 (0.00)	0.00	
	2	2 (4.08)	1 (2.04)	−2.04	
	3	14 (28.57)	6 (12.24)	−16.33	
	4	**18 (36.73)**	**30 (61.22)**	**24.49**	
3. Sitting unsupported	0	1 (2.04)	0 (0.00)	−2.04	0.039
	1	1 (2.04)	0 (0.00)	−2.04	
	2	1 (2.04)	1 (2.04)	0.00	
	3	4 (8.16)	0 (0.00)	−8.16	
	4	**42 (85.71)**	**40 (81.63)**	**−4.08**	

Table 7.4 continues on the next page→

TABLE 7.4 (Continues...): Berg balance scale on admission and discharge (items 1–7).

BBS item	**BBS score**	**Participants obtaining score on admission, *n* (%) *n* = 49 (100%)**	**Participants obtaining score on discharge, *n* (%) *n* = 41 (100%)**	**Percentage change**	***p***
4. Standing to sitting	0	4 (8.16)	2 (4.08)	−4.08	<0.001
	1	8 (16.33)	1 (2.04)	−14.29	
	2	8 (16.33)	1 (2.04)	−14.29	
	3	15 (30.61)	8 (16.33)	−14.28	
	4	**14 (28.57)**	**29 (59.18)**	**30.61**	
5. Transfers	0	3 (6.12)	1 (2.04)	−4.08	<0.001
	1	11 (22.45)	2 (4.08)	−18.37	
	2	10 (20.41)	3 (6.12)	−14.29	
	3	10 (20.41)	5 (10.20)	−10.21	
	4	**15 (30.61)**	**30 (61.22)**	**30.61**	
6. Standing with eyes closed	0	16 (32.65)	4 (8.16)	−24.49	<0.001
	1	0 (0.00)	0 (0.00)	0.00	
	2	0 (0.00)	2 (4.08)	4.08	
	3	21 (42.86)	8 (16.33)	−26.53	
	4	**12 (24.49)**	**27 (55.10)**	**30.61**	
7. Standing with feet together	0	18 (36.73)	5 (10.20)	−26.53	<0.001
	1	3 (6.12)	0 (0.00)	−6.12	
	2	3 (6.12)	1 (2.04)	−4.08	
	3	13 (26.53)	11 (22.45)	−4.08	
	4	**12 (24.49)**	**24 (48.98)**	**24.49**	

TABLE 7.5: Berg balance scale on admission and discharge (items 8–14).

BBS item	**BBS score**	**Participants obtaining score on admission, *n* (%) *n* = 49 (100%)**	**Participants obtaining score on discharge, *n* (%) *n* = 41 (100%)**	**Percentage change**	***p***
8. Reaching forward	0	16 (32.65)	5 (10.20)	−22.45	0.001
	1	1 (2.04)	0 (0.00)	−2.04	
	2	0 (0.00)	0 (0.00)	0.00	
	3	6 (12.24)	4 (8.16)	−4.08	
	4	**26 (53.06)**	**32 (65.31)**	**12.25**	
9. Retrieving object	0	22 (44.90)	6 (12.24)	−32.66	<0.001
	1	1 (2.04)	2 (4.08)	2.04	
	2	0 (0.00)	1 (2.04)	2.04	
	3	14 (28.57)	9 (18.37)	−10.2	
	4	**12 (24.49)**	**23 (46.94)**	**22.45**	
10. Turning to look behind	0	16 (32.65)	5 (10.20)	−22.45	<0.001
	1	1 (2.04)	0 (0.00)	−2.04	
	2	2 (4.08)	0 (0.00)	−4.08	
	3	15 (30.61)	9 (18.37)	−12.24	
	4	**15 (30.61)**	**27 (55.10)**	**24.49**	
11. Turning 360°	0	28 (57.14)	11 (22.45)	−34.69	<0.001
	1	2 (4.08)	2 (4.08)	0.00	
	2	6 (12.24)	6 (12.24)	0.00	
	3	4 (8.16)	3 (6.12)	−2.04	
	4	**9 (18.37)**	**19 (38.78)**	**20.41**	

Table 7.4 continues on the next page→

TABLE 7.5 (Continues...): Berg balance scale on admission and discharge (items 8–14).

BBS item	**BBS score**	**Participants obtaining score on admission, *n* (%) *n* = 49 (100%)**	**Participants obtaining score on discharge, *n* (%) *n* = 41 (100%)**	**Percentage change**	***p***
12. Placing alternate foot	0	30 (61.22)	15 (30.61)	−30.61	<0.001
	1	2 (4.08)	1 (2.04)	−2.04	
	2	0 (0.00)	3 (6.12)	6.12	
	3	6 (12.24)	3 (6.12)	−6.12	
	4	**11 (22.45)**	**19 (38.78)**	**16.33**	
13. Standing with feet together	0	28 (57.14)	18 (36.73)	−20.41	<0.001
	1	8 (16.33)	3 (6.12)	−10.21	
	2	2 (4.08)	2 (4.08)	0.00	
	3	7 (14.29)	6 (12.14)	−2.15	
	4	**4 (8.16)**	**12 (24.49)**	**16.33**	
14. Standing on one foot	0	28 (57.14)	12 (24.49)	−32.65	<0.001
	1	5 (10.20)	4 (8.16)	−2.04	
	2	1 (2.04)	4 (8.16)	6.12	
	3	6 (12.24)	9 (18.37)	6.13	
	4	**9 (18.37)**	**12 (24.49)**	**6.12**	

TABLE 7.6: Pressure mapping platform parameters on admission and discharge.

Pressure mapping variables	Pressure mapping variables on admission *n* = 33 (67.35%)	Pressure mapping variables on discharge *n* = 37 (90.24%)	Median difference between admission and discharge	*p*
Weight bearing asymmetry (%), mdn (IQR)	14 (11–23)	18 (10–24)	2 (−4 to 10)	0.161
COP velocity (m/s), mdn (IQR)	0.03 (0.02–0.04)	0.02 (0.02–0.03)	0.01 (0.00–0.01)	0.019
COP AP sway (cm), mdn (IQR)	3.05 (2.44–3.76)	2.43 (2.02–2.08)	0.53 (−0.11 to 1.50)	0.004
COP ML sway (cm), mdn (IQR)	3.04 (1.81–4.63)	2.44 (1.61–3.43)	0.62 (−0.70 to 2.82)	0.055

AP, anteroposterior; COP, centre of pressure; IQR, interquartile range; mdn, median; ML, mediolatera.

Correlation between Berg balance scale total score and pressure mapping parameters

On admission, a strong and significant negative correlation was noted between BBS total score and ML sway (r_s = –0.754, p < 0.001) (Box 7.1). Moderate, significant negative correlations were noted between BBS total score and COP velocity (r_s = –0.529, p = 0.002) and AP sway (r_s = –0.565, p = 0.001). A weak, non-significant negative correlation was evident between BBS total score and difference in weight bearing symmetry between the two lower limbs (r_s = –0.275, p = 0.128).

On discharge, a moderate, significant negative correlation was seen between BBS total score and COP velocity (r_s = –0.509, p = 0.001). Weaker but significant negative correlations were seen between BBS total scores and ML sway (r_s = –0.380, p = 0.20) as well as weight bearing difference (r_s = –0.372, p = 0.028). A trend for a moderate negative relationship was seen between BBS total score and AP sway, but this result was not significant (r_s = –0.322, p = 0.052).

BOX 7.1: Correlations between total Berg balance scale score and pressure mapping parameters (Spearman's rho).

Total BBS score versus weight bearing asymmetry (%)	**Admission**	**Discharge**
Correlation coefficient	−0.275	−0.372
p	0.128	0.028
Total BBS score versus COP velocity (m/s)	**Admission**	**Discharge**
Correlation coefficient	−0.529	−0.509
p	0.002	0.001
Total BBS score versus COP AP sway (cm)	**Admission**	**Discharge**
Correlation coefficient	−0.565	−0.322
p	0.001	0.052
Total BBS score versus COP ML sway (cm)	**Admission**	**Discharge**
Correlation coefficient	−0.754	−0.380
p	0.000	0.020

AP, anteroposterior; COP, centre of pressure; ML, mediolateral.

Correlations between Berg balance scale standing balance items and pressure mapping parameters

When looking at the individual BBS item 2 of 'Standing unsupported' on admission, a strong, significant negative correlation was noted with ML sway ($r_s = -0.641$, $p = 0.001$) (BOX 7.2:). A moderate, significant negative correlation was seen between BBS item 2 and AP sway ($r_s = -0.453$, $p = 0.031$). A trend towards a weak negative correlation was noted between BBS item 2 and COP velocity, but this result was not significant ($r_s = -0.389$, $p = 0.086$). This was also the case for difference in weight bearing symmetry ($r_s = -0.343$, $p = 0.159$).

A trend towards a moderate negative correlation was noted between BBS item 2 and weight bearing difference on discharge, but this result was not significant ($r_s = -0.409$, $p = 0.051$). A trend towards a weak negative correlation was seen between BBS item 2 and velocity, but this result was not significant ($r_s = -0.224$, $p = 0.287$); this was also the case for ML sway ($r_s = -0.206$, $p = 0.287$). A trend towards a very weak negative correlation was seen between BBS item 2 and AP sway, where this correlation remained non-significant ($r_s = -0.175$, $p = 0.494$).

Item 6 (‘Standing with eyes closed’) on the BBS assesses static standing balance without potentially compensatory visual input. A strong, significant negative correlation was noted between this BBS item 6 and ML sway ($r_s = -0.662$, $p < 0.001$) (Box 7.3). Moderate and significant correlations were noted between BBS item 6 and AP sway ($r_s = -0.556$, $p = 0.002$), COP velocity ($r_s = -0.529$, $p = 0.003$) as well as weight bearing difference ($r_s = -0.418$, $p = 0.020$).

In discharge, trends towards weak negative correlations were noted between BBS item 6 and the following outcomes, but none of these results were significant: COP velocity ($r_s = -0.374$,

BOX 7.2: Correlations between Berg balance scale item 2 (standing unsupported) and pressure mapping parameters (Spearman’s rho).

BBS item 2 versus weight bearing asymmetry (%)	**Admission**	**Discharge**
Correlation coefficient	−0.343	−0.409
p	0.159	0.051
BBS item 2 versus COP velocity (m/s)	**Admission**	**Discharge**
Correlation coefficient	−0.389	−0.224
p	0.086	0.287
BBS item 2 versus COP AP sway (cm)	**Admission**	**Discharge**
Correlation coefficient	−0.453	−0.175
p	0.031	0.494
BBS item 2 versus COP ML sway (cm)	**Admission**	**Discharge**
Correlation coefficient	−0.641	−0.206
p	0.001	0.287

AP, anteroposterior; COP, centre of pressure; ML, mediolateral.

BOX 7.3: Correlations between Berg balance scale item 6 (standing with eyes closed) and pressure mapping parameters (Spearman's rho).

BBS item 6 versus weight bearing asymmetry (%)	**Admission**	**Discharge**
Correlation coefficient	−0.418	−0.316
p	0.020	0.112
BBS item 6 versus COP velocity (m/s)	**Admission**	**Discharge**
Correlation coefficient	−0.529	−0.374
p	0.003	0.055
BBS item 6 versus COP AP sway (cm)	**Admission**	**Discharge**
Correlation coefficient	−0.556	−0.273
p	0.002	0.241
BBS item 6 versus COP ML sway (cm)	**Admission**	**Discharge**
Correlation coefficient	−0.662	−0.145
p	0.000	0.644

AP, anteroposterior; COP, centre of pressure; ML, mediolateral.

$p = 0.055$), ML sway ($r_s = -0.145$, $p = 0.644$), AP sway ($r_s = -0.273$, $p = 0.241$) and weight bearing asymmetry ($r_s = -0.316$, $p = 0.112$).

Discussion

This chapter aimed to summarise evidence regarding measurement tools used to assess balance in people with stroke in Africa and to report the potential value of quantitative measures to assess balance dysfunction in a pre–post cohort study. The main findings are that although quantitative measures are rarely used for balance assessment in African settings, there may be value in such assessments as individuals with a low fall risk according to clinical scores may have ongoing subtle impairments. This was evident from our primary study – only the second in Africa to assess balance post-stroke using instrumentation (and the first to use modern technology).

Published literature in Africa revealed that clinical balance outcome measures continue to dominate amongst African researchers, even in studies as recently published as 2018. The observation that the BBS was the most commonly used measure across the stroke care continuum is consistent with observations from high-income settings (Korner-Bitensky et al. 2006). Unfortunately, the BBS suffers both floor and ceiling effects (Mao et al. 2002) (also evident from the primary study in this chapter) and has poor interrater reliability in people with stroke, who score in the mid-range of the scale (Berg et al. 1995). This is particularly concerning, considering that the African stroke population in the review included individuals as young as 20 – reflecting a potentially higher functioning cohort. Mansfield and Inness (2015) further stated that the total BBS score, other than not informing patient-specific impairments, may reflect how some patients use compensatory strategies to achieve a higher score, which the BBS is not able to differentiate. Thus, 'normal' BBS scores may mask persisting stroke-related primary impairments, limiting the use of the measure in stroke rehabilitation (Patterson et al. 2017) as well as fall prediction (Harris et al. 2005). We found that in Africa, specific balance impairments are not well-assessed by any of the clinical measurement scales. There may thus be a knowledge gap regarding specific balance impairments underlying functional deficits and falls in African people with stroke. Distinguishing primary impairments from compensatory strategies is important to guide patient-centred treatment planning and more targeted reassessment (De Oliveira et al. 2008; Visser et al. 2008).

Comprehensive balance assessment using biomechanics technologies is increasingly used in international research to provide quantitative information. Advances in such instrumented tools are also making them increasingly practical for clinical environments (Mancini & Horak 2010), yet this is not reflected in African research. This raises the question of why such technologies have not been implemented in stroke research in Africa. Although the current review does not shed light on barriers specific to Africa, for most clinical settings, key barriers include cost, lack of accessibility, infrastructure, space needed for equipment, the initial training and familiarisation period required to interpret data and technological support for equipment and processing of clinical reports (Pak et al. 2015; Visser et al. 2008). A Canadian qualitative study (Pak et al. 2015) explored the perspectives of physiotherapists on the use of biomechanics technology to assess balance and mobility during stroke rehabilitation. Although therapists were conflicted regarding its influence on treatment planning, they found the detailed assessment results of the new technology valuable for confirming their clinical reasoning and monitoring changes in clients more precisely over time and were open to the evolution of practice. Instrumented analyses may play an important role in improving understanding of the basic pathomechanics of balance control in stroke. Educating clinicians on the quantitative parameters of abnormal balance may improve clinical care and alert clinicians to the potential limitations of many clinical measures currently employed.

Findings from the primary pre–post longitudinal study in this chapter support the above and concur with previous observations in people with stroke of a combination of functional balance changes without physiologic or primary impairment change (Patterson et al. 2017; Mansfield & Inness 2015; Harris et al. 2005). Balance impairments were seen in most participants in relation to both their BBS scores and quantitative measures on admission to inpatient rehabilitation. Median total BBS scores of participants changed significantly between admission and discharge so much so that they shifted in the cut-off scores from average medium fall risk to the low fall risk category. Improvements were noted in all BBS items, specifically in the standing unsupported and transfer items. In contrast, quantitative outcomes showed significant improvements in COP velocity AP sway, but not PWBA and ML sway. The decrease in sway distance as shown in the current study sample is indicative of increased stability and made detectable changes as shown in Table 7.6. However, overall, most participants still struggled with PWBA and ML COP sway on reassessment prior to discharge. It has been reported that increased COP amplitude and larger PWBA in quiet standing in stroke patients increase fall risk (Hugues et al. 2017;

Maki, Holliday & Topper 1994). Specifically, ML sway is considered as the best predictor for revealing balance impairment and fall risk in hemiparetic patients (De Haart et al. 2004). Thus, individuals who deemed to have low fall risk or normal balance based on BBS score may still have ongoing impairments such as ML instability that could increase their risk of falling, revealed only by instrumented outcomes.

Improvements in the BBS function items could be indicative of greater motor control by way of increased strength or improved sensorimotor integration (Tyson et al. 2006). One may conclude that as the majority of participants were able to sit and stand independently on admission, this sample may have had a good prognosis for recovery of balance, being more functionally independent in ADL and possibly reaching improved mobility outcomes post-rehabilitation (Braun et al. 2016; Gorst et al. 2016; Schmid et al. 2012; Michael et al. 2005). The insignificant change in ML sway and WBA in the current study may be because of the unilateral presentation of stroke. Because of patients depending more on the unaffected limb, this decreases the symmetry of weight bearing equally between limbs, thus as a compensatory mechanism, it increases ML sway in the direction of the unaffected limb (Pilkar, Arzouni & Nolan 2018). However, in this high-functioning cohort, the BBS did not reveal these remaining impairments on discharge – a finding replicating that of previous studies (Patterson et al. 2017), where 43% of stroke patients classified as having no fall risk by their BBS score still showed ML COP displacement values indicating fall risk.

Of the 16 studies included in the scoping review, six studies reported baseline and follow-up BBS scores (Knox et al. 2018; Okonkwo et al. 2018; Vincent-Onabajo et al. 2018; Puckree & Naidoo 2014; Batcho et al. 2013; Olawale & Ogunmakin 2003). The median age of the study cohort in the chapter's primary pre–post longitudinal study (48 years) was younger than the age range of these six studies (49.3–64.8 years). It appears that balance control remained affected in this younger cohort of participants undergoing stroke rehabilitation as their baseline admission (29/56) and discharge BBS scores (47/56) still fell within the same range as their older African counterparts. Therefore, the younger cohort, even with potentially greater neural plasticity because of their younger age, would still require continued rehabilitation to address their balance dysfunction before resuming greater independence in life roles such as returning to work. It is also noteworthy that despite the proposed BBS cut-off of 44/56 as an indicator of fall risk, a longitudinal study by Harris et al. (2005) found that BBS total scores were not able to distinguish community-dwelling people with stroke, who fell from those who did not fall.

Both the BBS total score value and COP variables have been reported to be indicators of risk of fall (Gasq et al. 2014; Salter et al. 2013). However, because of the BBS total scores containing items associated with sitting and dynamic standing balance activities, the BBS items 'standing independently' and 'standing with eyes closed' were correlated separately with MatScan variables. We found negative correlations between BBS scores and pressure mapping variables. This was expected because BBS scores increased as participants progressed, whereas pressure mapping variables decreased as participants progressed. Stronger correlations were noted on admission compared to discharge. This could have been because of certain participants being able to stand on discharge and not admission, potentially skewing data. In addition to this, correlations may have been weakened by the high ceiling effects (>15%) noted for BBS scores and items in the current cohort. As found in higher income settings, the BBS may not be sensitive enough to pick up balance disturbances in higher functioning participants in African settings; hence, the drastic change in scores varied between outcome measures (Salter et al. 2013).

Considering the correlations between BBS scores and quantitative outcomes provides insight into which components of the clinical test may be most useful in a younger cohort such as in the current pre–post longitudinal study. The first observation was that correlations between BBS scores and quantitative measures were stronger on admission than discharge. Because participants improved on all BBS components and were classified as low risk for falling, the cohort was higher functioning at discharge. This suggests that the BBS had larger utility in lower functioning individuals and that this utility (at least in terms of being indicative of quantitative primary impairments) reduced in higher function. The second observation was that BBS total score and the individual items of standing unsupported and standing with eyes closed correlated strongly with ML sway (a strong predictor of falls), and moderately with AP sway, COP velocity (total score only) and PWBA (eyes closed only). On discharge, significant (albeit weaker) correlations were still observed for total scores, whilst no correlations remained significant for the individual items. Patterson et al. (2017) suggested that such a disconnect between clinical and quantitative observations may relate to the interaction between the hemiparetic nature of impairments post-stroke and how the BBS is employed. For the standing unsupported item, for example, the individual receives a maximum score of 4 if he or she can stand safely for 2 min; this high score can be achieved regardless of whether the affected limb makes an active contribution to balance control. Quantitative measures, especially those that measure COP displacement under both feet, may better reveal such compensatory strategies (Patterson et al. 2017).

In previous studies, comparing clinical and laboratory quantitative measures of balance in the geriatric and stroke populations, the BBS showed moderate correlations with COP measures, with stronger correlations in static items (Bower et al. 2014; Nguyen et al. 2012; Frykberg et al. 2007). Nguyen et al. (2012) deduced that clinical and laboratory quantitative measures could either measure different aspects of balance, hence could complement each other, or one of the measures may be poorer in assessing balance than the other. Further research is required to make an accurate conclusion. Geurts et al. (2005) reported quiet standing COP measurements in stroke to reflect not only body sway but also lower limb mechanisms used to stabilise body position. Because of the force plate only assessing static balance, the authors report that one would question the validity of using the force plate to assess postural control in dynamic activities. Yet Geurts et al. (2005) found several studies assessing balance in stroke, showing a moderate to strong association between functional measures (of balance and gait) and force plate parameters, particularly COP velocity. Hence, the pressure mapping system has been shown to be a useful tool in identifying underlying issues affecting balance and risk of falls, thus using it in combination with clinical measures may be beneficial in practice.

The participants of the current primary pre–post longitudinal study may benefit from continued rehabilitation to address impairments causing instability in standing, such as poor muscle tone, somatosensory deficits, weakness and impairment in spatial awareness (Genthon et al. 2008). Whereas all BBS scores improved from admission to discharge, the parameter that most strongly associated with the BBS test scores on admission (ML sway – also the parameter most associated with falls in stroke) did not demonstrate a significant improvement from admission to discharge in this cohort. This may imply that the interventions that patients received between admission and discharge, whilst being effective in improving function and, perhaps, compensatory strategies, may not have been specific enough to improve more subtle fall-associated balance impairments. However, our interpretation was limited because of the lack of COP variables standardisations or normative values (Low, Walsh & Arkesteijn 2017). Whether this is of clinical importance requires further research and is worth investigating.

Limitations

The scoping review may suffer publication bias because of the inclusion of only English papers, as Arabic and French are the predominant languages of many African countries. Even though the number of international and Africa-specific databases that were searched for the review may be viewed as a strength, it may still not have been able to capture all relevant African studies.

Some studies may not be published in indexed databases because of publication costs being too expensive for African researchers. The illustrative primary pre–post longitudinal study is limited by the small sample size, affecting statistical power. Time and financial constraints associated with an MSc project limited data collection to 6 months, which resulted in the small sample size. Furthermore, the dropout rate in the small sample also introduces bias and may have deviated results. Interpretation of results may be limited because of the lack of standardisation regarding COP variables. Finally, results may not be generalisable to all people with stroke in Africa, as the study was conducted at a single Western Cape inpatient rehabilitation site.

Conclusion and recommendations

Our findings reveal that evidence relating to the use of outcome measurement tools to assess balance in people with stroke residing in Africa remains limited to clinical outcome measures. Although many clinical outcome measurement tools are reasonably quick, simple and low-cost, they may lack sensitivity to detect a change in higher functioning individuals post-stroke. Most clinical functional balance assessment scales currently used in African research, as evidenced by the findings of the scoping review we conducted, do not differentiate specific balance deficits contributing to functional outcomes. The primary pre–post longitudinal study was only the second to employ quantitative balance assessment in an African setting, and the first to correlate such measures with a clinical assessment. Although the BBS is well correlated to fall-related quantitative parameters in lower functioning inpatients, it may not be adequate for distinguishing persistent fall-related primary impairments as function improves. Furthermore, a BBS score indicating low fall risk should be interpreted cautiously in higher functioning individuals.

We propose that considering a quantitative approach may bring more sensitive and responsive balance assessment to clinical practice and help to identify the most useful clinical test for use in primary care. The choice of the most suited measurement modalities should depend on the clinical goal, the available resources and the functional level of the patient. Even in resource-constrained healthcare settings, the use of quantitative measures in selected groups, such as higher functioning and younger people with stroke, may prove to be more directive in resource utilisation and treatment planning, as well as provide closer monitoring of the impact of balance rehabilitation interventions. The primary pre–post longitudinal study included in this chapter, however, only provides preliminary data. Future studies should include larger, justifiable samples and multisite cohorts. Moreover, studies to establish normative data regarding COP variables in varying populations including stroke are required to standardise assessment and to produce more meaningful results. Future research should explore pragmatic and cost-effective quantitative tools for measuring balance impairments in people with stroke in Africa, and correlations with clinical functional tests in African populations. In addition, the feasibility and cost-effectiveness of such methods in low-resource settings should be investigated.

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THEME 5

Illuminating social determinants

Chapter 8

The social determinants of health in rural and urban South Africa: A collective case study of Xhosa women with stroke

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Abstract

Background: Social determinants of health (SDH) focus attention on environmental factors that often create health inequalities and impact participation in daily life for individuals with disabilities. A better understanding of the complex interactions between women with stroke and their unique SDH, and the resulting experience of disability is needed to address health inequalities and foster an inclusive society.

Aim: This chapter aimed to illuminate the SDH experienced by Xhosa women with stroke and how these impacted their perception of role performance.

Methods: This chapter drew on findings of a collective case study of 19 isiXhosa-speaking women residing in rural or urban environments of South Africa. Data collection for the case study comprised semi-structured interviews and a self-designed demographic and environmental (D&E) questionnaire. For the purpose of this chapter, a rating scale was developed to describe SDH.

Findings: This study illuminated the interconnectedness of SDH experienced by these women. Younger women with stroke, especially in rural settings, needed to care for and support their families; however, a lack of opportunities and skills to participate in paid employment was identified. Housing in rural settings lacked running water and sanitation, whilst in urban settings, safety and space to be active proved problematic. None of the participants had access to safe and well-designed transport systems.

Conclusion: This case study highlighted the importance of considering SDH in stroke rehabilitation and healthcare programmes in low socio-economic settings. Not only the SDH influenced access to good work, adequate housing and food but also the environmental barriers affected the nature of activities that amplify participation restrictions.

Keywords: Stroke; Social determinants of health; Xhosa; Rural; Urban; Women; Environment.

Introduction

Addressing health inequalities has become an ethical imperative in the 21st century in order to reduce the high burden of illness and premature mortality (Marmot et al. 2008). Health inequalities are caused by the unequal distribution of structural determinants such as power, income and resources. The Centers for Disease Control and Prevention (2014) note that:

> Complex, integrated, and overlapping social structures and economic systems are responsible for most health inequities. These social structures and economic systems include the social environment, physical environment, health services, and structural and societal factors. Social determinants of health are shaped by the distribution of money, power, and resources throughout local communities, nations, and the world. (n.p.)

Thus, structural determinants and conditions of daily life constitute SDH (Marmot et al. 2008; Solar & Irwin 2010). These refer to nonmedical factors such as sociopolitical, economic, environmental and cultural factors (Marmot et al. 2008; Solar & Irwin 2010). The impact of SDH follows a person's life course (Scott et al. 2017) as these affect the circumstances in which people are born, grow up, live, work and age (Solar & Irwin 2010).

Building on the millennium development goals, the UN proposed an agenda for sustainable development to address social inequalities (UN 2015). The agenda presents 17 sustainable development goals (SDGs) that incorporate economic, social and environmental dimensions (UN 2015). The SDGs target a range of issues, from eradicating poverty (goal 1) and ensuring availability of water and sanitation (goal 6) to making human settlements inclusive and safe (goal 11) (UN 2015). Reducing health inequalities will require an understanding of the SDH specific to each country's context (Ataguba, Day & McIntyre 2015), especially in African settings.

In Africa, wide inequalities exist within countries, especially in South Africa (Scott et al. 2017). Historically, policies and economic development focused on the needs of the urban population, which led to underinvestment in rural communities, thus contributing to their marginalisation (Marmot et al. 2008). This intensified poverty and poor living conditions for these marginalised communities, often consisting of indigenous populations, such as the amaXhosa people. The amaXhosa are the second largest ethnic group in South Africa (Statistics South Africa [StatsSA] 2012). The majority of the Xhosa people live in the Eastern Cape, part of which was formerly designated as a 'homeland' for the Xhosa people by the Apartheid government. During this period, such homelands saw very little development, and they have remained predominantly rural to this day (Fay 2015; Neves & Du Toit 2013). In rural areas of the Eastern Cape, people are dependent on subsistence farming and government social grants for their livelihood (Fay 2015; Neves & Du Toit 2013). Agricultural tasks are generally distributed between men and women. However, as a result of high male migration from rural to urban environments for employment, many households in rural areas are headed by women, who carry the bulk of household responsibilities (Fay 2015; Geere, Hunter & Jagals 2010; Ghosal et al. 2014; Matinga 2012; Wasserman, De Villiers & Bryer 2009).

In South Africa, a quadruple burden of disease is associated with poverty and deprivation (Ataguba et al. 2015; Omotoso & Koch 2018). One such example is the increase in vascular risk factors derived from both non-communicable and communicable diseases resulting in an increased incidence of stroke in a younger economically active population (Kahn 2011; Syed & Sani 2013).

It has been estimated that, on average, strokes occur 15 years earlier in people living in LMICs compared with HICs (Mbatha et al. 2017). The consequences of a stroke on an individual are complex, and a myriad of body function impairments can result in people's inability to participate in previously valued activities, especially returning to or gaining employment (Cawood, Visagie & Mji 2016; Maleka, Stewart & Hale 2012; Nicholson et al. 2013). Participation is further restricted through conditions of daily life and environmental barriers (Jellema et al. 2017; Scheffler & Mash 2019; Vergunst et al. 2017). Studies conducted with Xhosa people with disabilities highlighted the environmental barriers that impact on their function and social participation (Eide et al. 2008; Maart et al. 2007).

Women with stroke are at risk of having less social support and being overlooked in the health system because other adults in the home are expected to assume their household responsibilities and may even need to migrate to urban areas in search of work (Ghosal et al. 2014). People with stroke, who were previously the caregivers within their households, experience a role reversal, as they are now dependant on family members to care for them (Anderson & Whitfield 2011; Maleka et al. 2012; Pundik et al. 2012). According to a World Health Survey conducted by the WHO, women reported poorer health compared with men across all age groups in all regions of the world, but SDH had a larger attribution in African countries compared with Europe (Hosseinpoor et al. 2012).

For the healthcare sector to deliver accessible and appropriate services and programmes, it is essential that healthcare providers understand the needs of healthcare users, the health inequalities they face in each context and the influence of SDH (Jellema et al. 2016; Marmot et al. 2008). In South Africa, addressing SDH is the cornerstone of the National Department of Health's (NDoH's) re-engineering of primary healthcare strategy (Scott et al. 2017). The three major SDH that influence good health in South Africa are knowledge and education; social protection (including employment); and housing and infrastructure (Ataguba et al. 2015).

The complex interactions between individuals' unique SDH and their resulting experience of disability are poorly understood (Frier, Barnett & Devine 2017; Pettersson, Pettersson & Frisk 2012). Ataguba et al. (2015) argued that the WHO Commission on Social Determinants of Health's findings does not necessarily reflect the underlying health inequality factors in complex settings such as Africa, and that specific African SDH research is needed to facilitate better health for all. This chapter aims to provide a better understanding of the SDH experienced by Xhosa women with stroke and how SDH impact their role performance in low socio-economic rural and urban settings within South Africa.

Method

The chapter drew on a subset of findings from a larger descriptive, cross-sectional collective case study, undertaken to describe how contextual barriers influenced Xhosa women's participation and experiences, and the activities required to fulfil their major life roles. The findings reported in this chapter focus on the SDH experienced by the participants, as informed by (1) quantitative data obtained from a self-developed D&E questionnaire and (2) qualitative data obtained from individual semi-structured interviews.

Study setting

This study was conducted in two settings: a rural setting of the Eastern Cape (King Sabata Dalindyebo municipality) and an urban setting of the Western Cape, City of Cape Town Metropole, where the majority of the amaXhosa population live in South Africa. As rural environments are characterised by poor socio-economic conditions, the urban study site was purposively selected to reflect a similarly low-resourced setting. The study sites displayed typical characteristics of rural and urban settings as defined by local and international literature, supporting the transferability of study findings to similar settings. The two research settings are described and compared later.

Rural setting

Rural areas in South Africa are characterised by sparsely populated land with small villages or towns, where the population is mainly dependent on farming, government grants and migrant labour for survival (Fay 2015; Maredza, Bertram & Tollman 2015; National Treasury 2011; Neves & Toit 2013). Such areas are often former homelands, which are also characterised by traditional communal land tenure systems (Fay 2015; National Treasury 2011).

The rural site chosen for this study was the Mqanduli sub-district of King Sabata Dalindyebo municipality of the O.R. Tambo District in the Eastern Cape Province, South Africa. This area formed part of the former Transkei homeland allocated to the amaXhosa people during the Apartheid era. Today 98.4% of the population in O.R. Tambo District is isiXhosa-speaking residents (StatsSA 2012).

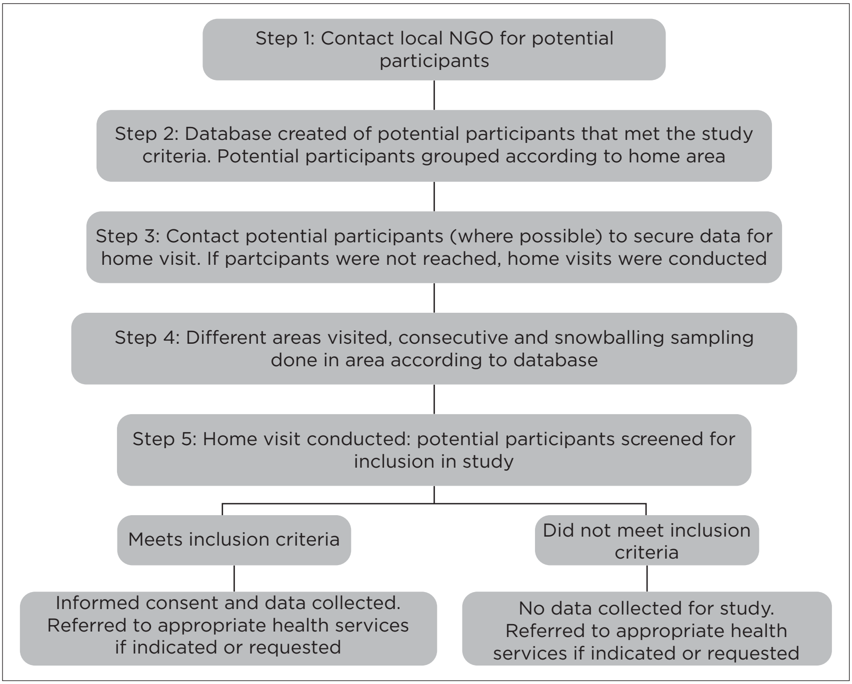
Urban setting

Urban areas are characterised by towns with high population density and extensive development of infrastructure, including business and industrial districts (National Treasury 2011). Most of the urban populations in South Africa have non-agricultural jobs (StatsSA 2013).

Three urban settings were purposively sampled in the Cape Metropole of the Western Cape province, South Africa. The three areas were characterised by a high percentage of isiXhosa-speaking residents and similarly poor socio-economic conditions as the rural environment. The urban study sites were Khayelitsha, Du Noon and Delft.

Recruitment of participants

The flow diagram in Figure 8.1 illustrates the steps taken to recruit participants in all study sites. More information is provided on each step in the recruitment process later.



Source: Enright (2017).
NGO, non-governmental organisation.

FIGURE 8.1: Recruitment procedure of study participants.

Non-governmental organisations (NGOs) working in the field of disability were contacted in all sites to generate a database of women meeting the criteria for the study. A standard email was sent to the organisations to explain the aim of the study and what it would entail, along with a study synopsis and proof of ethical clearance by the SU HREC (reference number: S13/08/156).

As the database of potential participants gathered from each site was relatively small, consecutive sampling was implemented from the databases, including snowballing to recruit further candidates. Home visits were conducted consecutively to potential participants according to their residential areas. Each household was asked whether they knew anyone else in the area who had had a stroke. If additional people were identified, these would be added to the database and visited to establish their eligibility for inclusion in this study. Data collection continued until all available candidates had been assessed for inclusion, within the limits of available resources.

Community workers from the NGOs or community members associated with NGO programmes accompanied the research team to potential participants' homes. All participants volunteered to be included in the study and they provided a written informed consent. A series of questions was asked to screen the participants for eligibility, and where possible, their responses were corroborated by family members. Clinical observations were made by the researchers to confirm the nature of neurological deficit, and to identify any communication or cognitive difficulties that might preclude participants from responding during interviews.

☐ Eligibility criteria

This study sample included Xhosa women with stroke who:

1. were at least 18 years old at the time of recruitment
2. presented with typical post-stroke unilateral neurological deficit (on observation)
3. had suffered only one stroke and had no prior history of disabilities
4. had suffered the stroke a minimum of 6 months and a maximum of 10 years before recruitment
5. lived in their current location for at least 6 months before suffering the stroke.

The second and third criteria sought to ensure a reasonable similarity in body function impairments between participants. The third criterion, together with the fifth, also ensured that participants had an experience of normal functioning in their ADLs and social roles in their current environmental context prior to suffering the stroke. The lower limit on time since stroke aimed to exclude women who were still in the early stages of adjustment to life after the stroke, whilst the upper limit ensured that participants would most likely have remained in the same life stage as described by Armstrong (2007).

Participants were excluded if they:

1. suffered from cognitive, mental health, physical, visual or any other impairments and limitations that potentially hindered their independence in ADLs, and participation in residential and community roles, before suffering the stroke
2. required a proxy to complete the questionnaire or interview because of receptive, expressive or global aphasia, and/or impaired executive functions.

Assessing the effect of communication disorders on participation and activity requirements was beyond the scope of the study.

Research assistant

An isiXhosa-speaking research assistant was employed to assist with translation of research tools, data collection, transcription of interviews and translation of transcriptions. The same research assistant participated in data collection in both the rural and urban study sites.

The research assistant was trained by the researcher on the background of the study, ethical aspects and the various instruments to be used. Specific aspects covered in the training included:

- the type of study
- aims and objectives of the study
- ethical principles and documentation, specifically completion of written informed consent
- procedural protocol for the study
- quantitative data collection tools
- the qualitative interview schedule, and how to facilitate semi-structured interviews.

After an initial pilot of the semi-structured interview guide and data collection procedure, constructive feedback was given to the research assistant by the researcher regarding facilitation and translation of the semi-structured interviews. The researcher was always present during the data collection and any queries or concerns raised by the research assistant were discussed at the time for joint problem-solving.

Data collection tools

A D&E questionnaire was designed by the research team to gather information relating to participants' demographic characteristics, relevant stroke-related information and environmental factors. To ensure comprehensiveness, questions pertaining to environmental factors were informed by the environmental domain as reported in the ICF (WHO 2001). A panel of experts within stroke rehabilitation and CBR in South Africa reviewed the questionnaire. Minor changes were made to the phrasing of few questions to facilitate clarity prior to translating it into isiXhosa.

The D&E questionnaire was first translated into isiXhosa by the research assistant. The isiXhosa version of the survey was then back-translated into English by an independent isiXhosa-speaking person, who was not involved in developing the questionnaire. The researcher and research assistant reviewed the back translation and decided that no changes to the original translation were necessary. Pre-testing of the questionnaire was then conducted with two isiXhosa-speaking women with stroke living in the Cape Metropole, to check clarity of questions, ease of administration and utility, before commencing the main study. No additional changes were required to the D&E questionnaire.

Summary and descriptive statistics were used to report data derived from the D&E questionnaire. The quantitative data were recorded and analysed using Microsoft Excel (version 2016). The relevant quantitative data were used to inform appropriate sections of the framework developed to report the results.

Individual semi-structured interviews were then conducted in each participant's natural home setting. Interviews sought to describe how participants perceived their life roles, obtain descriptions of the activity requirements to fulfil these perceived roles within their context and capture the contextual barriers experienced whilst living with a stroke. A semi-structured interview guide with potential probing questions was designed to elicit participant perceptions and experiences.

The guide was pretested with two participants, who met the inclusion criteria at the rural site in the Eastern Cape. During pre-testing, these participants had difficulty in answering the original opening question, which was phrased as 'How has your life changed since the stroke?'. The question seemed too broad as participants appeared to struggle with understanding and interpreting it. The question was therefore rephrased as 'What are you struggling with now that you used to do before?' This question offered more context to the participants, and they could immediately start talking about their perceived participation restrictions and activity limitations. This opening question was retained for the rest of the study. The follow-up question aimed to gather information on the participant's perception of changes in life roles, activity limitations and contextual barriers experienced following the stroke. Clarifying questions followed to gain clarity on these restrictions, limitations and contextual barriers. The follow-up questions aimed to unpack the participation of the participant in relation to self-care, roles as a carer (looking after family members or children), leisure activities, work or employment, religion, community meetings or responsibilities, cooking, bathing, mobility, toileting, transport and perceived support from family and community members.

The interviews were conducted in isiXhosa by the trained research assistant, who was fluent in both English and isiXhosa, under the supervision of the researcher. Field notes were captured independently during the interviews to document participant observations. The anonymity of all study participants was assured by allocating a number to each study participant, for use on all data collection tools and research records. All interviews were recorded using a digital voice recorder, transcribed and then translated to English in preparation for content analysis. Any identifying information was deleted. The transcriptions were prepared using MS Word for coding. During analysis, the transcripts and field notes were consulted to assist in formulating emergent codes and categories.

Member checking was carried out verbally throughout the interviews to ensure descriptions and experiences expressed by participants were correctly understood by the researcher and research assistant (Creswell et al. 2011; Houghton et al. 2013). The primary researcher and research assistant worked collaboratively in the translation and transcription of interviews. By doing so, the researcher was able to compare understandings and check meanings with the research assistant as a key informant on Xhosa culture.

The UK Health Foundation's quick guide on 'What makes us healthy: An introduction to social determinants of health' (Lovell & Bibby 2018) was used to develop an SDH framework used in the analysis of the qualitative data. The SDH framework comprises eight domains, namely, education and skills; good work; money and resources; family, friends and community; housing; our surroundings; the food we eat; and transport. Productivity was a supplementary domain added by the authors to appraise the participants' ability to maintain their own and family needs, such as self-care and domestic tasks. Four elements were identified within each of the nine SDH framework domains. These were developed by a focus group of experts by selecting the most contextually appropriate descriptors from the Health Foundation's quick guide (Lovell & Bibby 2018) (see Table 8.1). Each domain was given an equally weighted response as the aim of this chapter was to describe the characteristics of the SDH experienced by Xhosa women with stroke and not necessarily rate the level of impact.

TABLE 8.1: Framework, derived from the Health Foundation's quick guide on what makes us healthy, used to quantify the social determinants of health experienced by participants.

Domain	Criteria	Score
Education and skills	Education and skill development to access opportunities for maintenance of healthy habits	0/1
	Education and skill development to find good work	0/1
	Education and skill development to afford to live and work in a safe environment	0/1
	Education and skill development to feel empowered and valued	0/1
Good work	Work comprised of regular work	0/1
	Work with good wages	0/1
	Work in a safe environment with good working conditions	0/1
	Work that matches competence and interest	0/1
Money and resources	Enough money to access support and services needed for participation in society	0/1
	Enough money to access support and services needed for participation in health	0/1
	A monetary safety net is available to reduce stress	0/1
	Investment for the future	0/1
Family, friends and community	Positive family life	0/1
	Supportive relationships	0/1
	Feeling part of a community	0/1
	Taking part in community life	0/1
Housing	Homes that are affordable	0/1
	Homes that are warm and stable	0/1
	Homes offering safety and space within which to develop	0/1
	Homes with running water, electricity and sanitation	0/1
Our surroundings	Vibrant spaces that are accessible	0/1
	Good places that allow people to feel safe and be active	0/1
	Easy access to important facilities	0/1
	Sustainability of these spaces	0/1

Table 8.1 continues on the next page→

TABLE 8.1 (Continues...): Framework, derived from the Health Foundation's quick guide on what makes us healthy, used to quantify the social determinants of health experienced by participants.

Domain	Criteria	Score
The food we eat	Enough food	0/1
	Healthy food	0/1
	Food for healthy living, which is easily accessible	0/1
	Food for healthy living, which is affordable	0/1
Transport	Safe and well-designed transport system that is available	0/1
	Transport system that is accessible	0/1
	Transport system that is affordable	0/1
	Transport system that is efficient	0/1
Productivity	Self-care	0/1
	Domestic tasks such as cleaning, cooking and laundry	0/1
	Home maintenance such as gardening	0/1
	Caring for family	0/1

A deductive analysis was undertaken, and the semi-structured interviews were coded according to the different domains of the framework in Table 8.1. Two reviewers analysed the responses and awarded points accordingly. Complementary data from the D&E questionnaire that related to the different domains and categories of the framework were used to support and strengthen the results. Further peer review took place to ensure trustworthiness during data analysis, as two researchers initially coded the transcriptions and then presented the results to the research team of experts for further deliberation to reach an agreement.

Results

This section describes and discusses the SDH, which impact on the role performance of Xhosa women in rural and urban settings within South Africa. By distinguishing between the two cohorts, the difference in SDH in urban and rural contexts is highlighted.

Demographic information

Information was gathered from 19 Xhosa women living with stroke, with Table 8.2 summarising the findings. In the rural site, a total of 14 participants were screened for inclusion, but four were excluded from the study because of:

- aphasia (1)
- diagnosis not a stroke, that is, peripheral neuropathy (1) and general joint pain (1)
- more than 10 years since the stroke (1).

In the urban site, a total of 20 participants were screened for inclusion, but 11 were excluded because of:

- gender (5)
- incorrect diagnosis (3), that is, TB spine (1), rheumatoid arthritis (1) and spinal cord injury (1)
- aphasia (2)
- more than 10 years since the stroke (1).

Framework used to illustrate social determinants of health

In Table 8.3, the results of the different categories within each determinant are presented whilst also distinguishing between

TABLE 8.2: Demographic detail in terms of age and rural and urban setting.

Age and stroke-related factors	Rural setting (*n* = 10)	Urban setting (*n* = 9)
Age of women in years (median, range)	49 (24–72)	56 (31–65)
Time since stroke in years (median, range)	5 (1–7)	3 (1–6)
Age of women at stroke incident in years (median, range)	44 (23–69)	51 (28–60)

TABLE 8.3: The results of quantifying the social determinants of health subdomains and distinguishing between participants in rural and urban settings.

Domain	Criteria	Rural (n = 10)	Urban (n = 9)	Total (n = 19)
Education and skills	Education and skill development to access opportunities for the maintenance of healthy habits	2	4	6
	Education and skill development to find good work	1	2	3
	Education and skill development to afford to live and work in a safe environment	0	0	0
	Education and skill development to feel empowered and valued	4	1	5
Good work	Work comprised of regular work	0	1	1
	Work with good wages	0	1	1
	Work in a safe environment with good working conditions	0	0	0
	Work that matches competence and interest	0	1	1
Money and resources	Enough money to access support and services needed for participation in society	6	1	7
	Enough money to access support and services needed for participation in health	9	7	16
	A monetary safety net is available to reduce stress	6	5	11
	Investment for the future	2	1	3
Family, friends and community	Positive family life	5	2	7
	Supportive relationships	8	8	16
	Feeling part of a community	5	2	7
	Taking part in community life	5	2	7
Housing	Homes that are affordable	10	8	18
	Homes that are warm and stable	8	3	11
	Homes offering safety and space within which to develop	10	0	10
	Homes with running water, electricity and sanitation	0	5	5

Table 8.3 continues on the next page→

TABLE 8.3 (Continues…): The results of quantifying the social determinants of health subdomains and distinguishing between participants in rural and urban settings.

Domain	Criteria	Rural (n = 10)	Urban (n = 9)	Total (n = 19)
Our surroundings	Vibrant spaces that are accessible	0	3	3
	Good places that allow people to feel safe and be active	10	0	10
	Easy access to important facilities	4	8	12
	Sustainability of these spaces	10	3	13
The food we eat	Enough food	8	6	14
	Healthy food	8	1	9
	Food for healthy living, which is easily accessible	8	9	17
	Food for healthy living, which is affordable	7	1	8
Transport	Safe and well-designed transport system available	0	0	0
	Transport system that is accessible	7	7	14
	Transport system that is affordable	6	6	12
	Transport system that is efficient	1	6	7
Productivity	Self-care	7	7	14
	Domestic tasks, such as cleaning, cooking and laundry	4	4	8
	Home maintenance, such as gardening	1	1	2
	Caring for family	3	3	6

the rural and urban cohort. The rural participants presented with unique characteristics in family, friends and communities; money and resources; housing; our surroundings; and the food we eat, which positively affected the participants' participation. In both cohorts, education and employment contributed to poor SDH.

Each SDH will be further described to highlight the characteristics of SDH, which impacted the participants in rural and urban settings.

Education and skills

Education and vocational skills were seen as strong determinants for acquiring good work and were associated with managing one's own health. Only six of the participants (31.6%) had received sufficient education and skill for them to maintain their health effectively. This included the understanding of health-related habits needed to manage their condition and a good understanding of health needs to access necessary health services:

> 'I was at the clinic on Tuesday and will only go back in June. I take one tablet a day and they gave me a lot. I don't forget to take the medication. My youngest grandchild always reminds me when it is 7 o'clock'. (Participant 3, 57-year-old female, rural setting)

The large proportion of participants who did not have sufficient knowledge to optimally manage their own health needs (e.g. prevention of pressure ulcers) is particularly concerning when the severity of these health conditions is considered:

> '[*I am sad*] because I cannot stand up and I don't know what is causing this'. (Participant 8, 72-year-old female, rural setting)

Skills needed to find good work were even lower with only three participants (15.8%), who had marketable skills related to their previous jobs as a nurse, traditional healer and small business entrepreneur; of which two participants no longer had the functional ability to perform these jobs. The need for reskilling was thus clear. One participant's entrepreneurial skill empowered her to continue with the valued life role of providing for her household after the stroke.

Good work, money and resources

A large majority of the participants in this study fell within the economically active age range. As such, the need for people with stroke to participate in work is increasingly important to provide for their households. Work is a unique SDH that has the potential to influence a person's social interaction, personal development and self-esteem. Concomitantly, the income generated through work is of utmost importance for families to meet other needs, which include the education needs of children, for them to secure work in the future.

☐ Good work

Most of the women had been employed before the stroke. As such, they could contribute financially to their households. Before the stroke, most of the participants worked as domestic workers, whilst one earned a living through recycling, another practiced as a traditional healer and one participant was an informal trader. The only skilled worker was a woman who worked as a nurse. One participant, an informal trader, was able to continue working after suffering a stroke; however, she required hired assistance to procure goods. All of the other participants were unable to return to work after the stroke because they no longer seemed to have the functional capacity to fulfil the inherent requirements of their previous work activities. Mobility skills, balance and bilateral hand integration were often expressed as the underlying impairments that most hindered their work performance. However, none of the participants underwent a work assessment; it is therefore not clear whether they might have been able to pursue alternative types of work.

Because the participants in this study were deemed unable to return to work, government grants were available to all participants and played an essential role to ensure access to basic amenities. Five participants received a Grant for Older Persons and 14 received a Disability Grant. Despite the financial value of these government grants being small, the impact on the lives of participants was of importance as shown by the findings. However, many participants continued to struggle to make ends meet, as the disability grant of R1780 is significantly lower than the wages they earned whilst employed, and far below South Africa’s minimum wage of R3500 per month (Isaacs 2016). Being unemployed was a huge burden and stressor for these women who now struggled to live with only a government grant. Not only were they unemployed, but they incurred additional expenses in paying others to assist with domestic tasks:

> ‘Yo, it has changed so much Sisi, I do not want to lie. I even lost some weight because I am not used to stay here and look at a small amount of money. It doesn’t solve all the problems here; it just covers the food that R1 000. I can’t afford clothes, I have nothing’. (Participant 21, 56-year-old female, urban setting)

> ‘Sometimes if you need to smear the lime you will need to hire somebody and pay more money. Now it has changed as it is me who has to pay for everything. Even the wood that is outside I paid. I have to hire someone because I cannot go to the forest anymore, so I buy it’. (Participant 6, 32-year-old female, rural setting)

☐ Money and resources

The rural participants scored higher in the *money and resources* domain compared with their urban counterparts. These findings could be explained by rural participants occurring less expenses in rent and food as compared with the higher cost of living in the urban setting. The biggest discrepancy is that 60.0% of the rural participants had enough money to participate in society compared with only 11.1% of the urban participants. Many of the community-dwelling rural participants reported they would attend traditional community events such as weddings, funerals or community meetings. Attending these events contributed to the participants feeling more supported and included in society, with minimal monetary cost outlay. The events often occurred in their community, accessible for those who were community-dwelling, and community members would share what they could towards the event. The women reported that, after the stroke, the community would understand their situation and they would not have to contribute to the event:

> ‘Everyone understands me. For example, when there is something taking place in my community I will go and just sit not having to help with preparations’. (Participant 6, 32-year-old female, rural setting)

The discrepancy between the two cohorts was smaller when it came to the affordability of healthcare. Saving seemed to be less of a priority, with only 3 (15%) of the 19 participants investing in the future. However, a household surviving from a government grant did not necessarily provide them the capacity to save for the future. Eleven participants had a financial safety net, which came in the form of support provided by family members or Child Support grants.

☐ Family, friends and community

Xhosa women play an integral part in traditional social, religious and cultural events within their communities, but after the stroke, only 36.0% of the participants were reintegrated into their communities. Community mobility and access to transportation were often expressed as restricting factors.

Most of the participants (86.0%) reported having supportive relationships; however, these were not necessarily with a family member. In both settings, participants were surrounded by fewer family members, often just a spouse or child. The primary caregiver burden often fell on children who themselves were dependants. The role reversal experienced by the participants and burden of care placed on the smaller households resulted in the participants expressing a negative family life:

> ‘I am dependent on this child … as this child is doing everything’. (Participant 10, 56-year-old female, rural setting)
>
> ‘I see myself as a baby. I am even much younger than this baby. I am being fed and even if I have relieved myself, I must report myself to the children’. (Participant 18, 56-year-old female, urban setting)

A contributing factor for poor family support was the migration of the participants or other family members from their traditional homes to find employment opportunities in urban areas. Participants who experienced social isolation and negative family life often relied on religious organisations for support. Religion and going to church formed an integral part of community life for the women in both rural and urban settings. Where feasible, congregation members would visit the women at home if they were not able to attend church gatherings, offering both emotional and financial support:

> 'I no longer go [*to church*]. They come here now. They will come and praise'. (Participant 11, 66-year-old female, rural setting)
>
> 'It's mostly church people who assist me … When there is no electricity, they will be able to give us a R50 so we can buy electricity'. (Participant 21, 56-year-old female, urban setting)

In contrast, some participants experienced good family support and a positive family life, which gave them a sense of belonging and inclusion. Participants were satisfied to relinquish certain roles and responsibilities to other family members such as domestic tasks including home maintenance:

> 'As you know, I am a daughter at my father's family and they have to include me, even if I am like this now. Even if I am this scrap I am still a daughter and they must come and fetch me'. (Participant 5, 42-year-old female, rural setting)

☐ Housing

The housing domain offered a snapshot of different types of homes seen in low socio-economic settings of South Africa. Large discrepancies in favour of the rural housing were noted in the categories: homes that are warm and stable, and homes that offer safety and space to develop.

In the urban setting, five participants (55.5%) rented low-cost reconstruction and development programme homes, shown in Figure 8.2, from their local municipality. These were stable structures with access to water, electricity, sanitation and municipal service; however, some participants reported poor insulation.

The other four urban participants (44.4%) lived within informal settlements where they erected their own informal dwellings, illustrated in Figure 8.3, constructed from corrugated iron and

Source: Photograph taken by Marlie Giljam-Enright, in Delft, South Africa, June 2015, published with permission from Marlie Giljam-Enright.

FIGURE 8.2: A row of low-cost reconstruction and development programme homes in the urban setting.

wood. These structures were unstable, poorly insulated and did not have adequate access to water, sanitation and other municipal services.

The participants had to make use of shared municipal community taps within their neighbourhood to access clean running water. These informal dwellings generally suffer significant damage during rainy and windy months, and they pose a high fire risk because of the dense population:

> 'My main challenge is that I still have to stay here [*informal settlement*]. That is the thing that is making me not right as I have to go and fetch the water. If I can stay in a place that has [*running*] water my life will be much better'. (Participant 16, 36-year-old female, urban setting)

Source: Photograph taken by Marlie Giljam-Enright, Du Noon, South Africa, August 2015, published with permission from Marlie Giljam-Enright.

FIGURE 8.3: Informal settlement characterised by informal dwellings constructed of corrugated iron and wood with only narrow pathways between the homes.

> ‘The other thing is that I live in the informal settlement as there is the problem of fire’. (Participant 17, 42-year-old female, urban setting)

In the rural setting, the participants often lived in traditional huts, shown in Figure 8.4, which were stable and well insulated, made

Source: Photograph taken by Marlie Giljam-Enright, Nzulwini, South Africa, April 2015, published with permission from Marlie Giljam-Enright.

FIGURE 8.4: A traditional Xhosa homestead encompassing several huts and a large garden.

of clay bricks and thatched roofs, but lacked access to water and sanitation. All rural participants had to collect raw water from the nearest river, the quality of which is often poor, and accessibility was problematic after the stroke. Three rural participants (30.0%) did not have adequate social support to complete home maintenance tasks, which resulted in poor roof insulation:

> 'As you can see this house's roof is not properly thatched. This hurts me badly too as when it rains, I have to put buckets, because the water is dripping in'. (Participant 10, 56-year-old female, rural setting)

All the rural participants lived in a safe environment that offered a space to develop further. Rural areas are characterised by sparsely populated land and small villages. The participants had ample space around their homesteads to develop further, illustrated in Figure 8.4.

In contrast, the urban settings were characterised by a high population density. Informal settlements are characterised by dwellings cramped into small spaces with only narrow pathways between them, as illustrated in Figure 8.3. The lack of implementation of legislation relating to town and municipal planning negatively affects the safety and sustainability of these areas.

In the absence of safe running water, all the rural and four urban participants made use of either pit latrine, communal toilets or they would choose to relieve themselves in nearby fields or forest. The lack of basic sanitation amenities inside the home made it necessary for the women to mobilise outside their home and negotiate rough terrain, which they found problematic:

> 'I don't have one [*toilet*]. We all go to the forest. I will limp and go there'. (Participant 12, 62-year-old female, rural setting)

> 'The challenge is when it's raining there is a lot of water which makes it difficult to cross to that side [*to the communal toilets*]'. (Participant 19, 31-year-old female, urban setting)

Only one urban participant reported the high cost of rent, imposed by her landlord, which affected the affordability of her home. None of the rural participants paid rent in accordance to the traditional communal land system of the traditional homeland of the amaXhosa people. Families would build homesteads and farm on land allocated to them by the local chief.

☐ Our surroundings

The participants' surroundings contributed both barriers and facilitators to their health, well-being and participation. All the rural participants' surroundings offered safe spaces where they could be active in sustainable areas rich in greenery and natural resources. Participants would extract resources, with assistance from family members after the stroke, to help build their homes and use the rich soil to grow vegetables. The women in rural areas recalled activities such as walking in their surroundings and working in the garden as meaningful:

> ‘I would walk with my feet to there [*community events*]. When I was able to walk, I would wash myself and walk to the place I need to go to’. (Participant 5, 42-year-old female, rural setting)
>
> ‘I enjoyed working in the garden’. (Participant 9, 26-year-old female, rural setting)

In contrast, the urban participants did not feel their environment was safe, and there were limited accessible areas where participants could be active. In the low socio-economic urban areas, especially informal settlements, the lack of natural resources and municipal services negatively affected the sustainability of the environmental conditions. In Figure 8.5, the lack of adequate sanitation facilities in an informal settlement is illustrated with a nearby water source increasing the risk of disease.

In addition, access to vibrant spaces was restricted for the majority of participants (84.2%), which negatively affected their ability to socialise and integrate into society. In rural areas, the lack of economic development meant that vibrant spaces were limited to bigger towns often inaccessible for participants with mobility or transportation barriers. The latter was also a barrier for urban participants to access vibrant city centres. However, 88.9% of urban participants indicated that they had access to important facilities such as healthcare services and shops with only 40.0% reporting the same in rural settings. These findings could contribute to the notion that important services are less accessible in marginalised communities influencing their health and well-being.

☐ The food we eat

Healthy food and adequate nutrition play an indispensable role in body function, and this provides energy for people to participate in meaningful tasks. The biggest incongruities

Source: Photograph taken by Marlie Giljam-Enright, Du Noon, South Africa, August 2015, published with permission from Marlie Giljam-Enright.

FIGURE 8.5: Communal toilets within informal settlement.

between the two cohorts in this study related to the affordability and consumption of healthy food. In the rural setting, 80.0% of the participants consumed healthy food sourced from gardens either in their homesteads or from communal fields. The participants valued these gardening activities and found meaning in providing and cooking for their families. After the stroke, many of the women relied on family members to manage the gardens and do the cooking, because of their mobility and upper limb impairments.

In the urban areas, the main food source were local grocery shops. Only 66.66% of the urban participants felt they had access to enough food, with many of them struggling to provide for their families using the government grant:

> 'Yo, it has changed so much Sisi, I do not want to lie. I even lost some weight because I am not used to stay here and look at a small amount of money'. (Participant 21, 56-year-old female, urban setting)

Many of the urban participants were more inclined to make poor nutritional food choices, often opting for starch-based items, because of the lower food cost and the satiety it offered. Only one urban participant reported eating a variety of healthy foods, which can be contributed to her ability to supplement her disability grant with an income from a small trade store.

☐ Transportation

After the stroke, participants in both settings were dependant on public transportation to reintegrate into their communities; however, participants lacked access to well-designed and safe transportation systems. Public transportation for participants consisted mainly of taxis, which, in this study, refer to minibuses travelling set routes within a geographical area. These taxis provided the public an affordable mode of transport in South Africa. These non-metered taxis are privately owned with routes and fares governed by Taxi Associations. In the rural setting, taxis could be minibuses, or in more remote locations, single-cab pick-up trucks (Figure 8.6), as roads in these areas are less accessible to normal modes of transportation. The general quality of these vehicles was often unsatisfactory, as shown in Figure 8.6, raising safety concerns.

None of the participants felt that they had access to a well-designed and safe transportation system. Respondents were equally split between rural and urban settings with regard to access and affordability. Access to transportation for people with limited mobility was often problematic, and participants would either be dependent on family members to escort them to

Source: Photograph taken by Marlie Giljam-Enright, Jalamba, South Africa, April 2015, published with permission from Marlie Giljam-Enright.

FIGURE 8.6: A single-cab pick-up truck used as a taxi in remote rural settings.

transport or in many cases, they were unable to attend community events. Participants had to commute long distances, especially in rural areas, to access taxis at a central location in order to attend health check-ups or to collect medication and social grants. Walking to access transport was often difficult as participants struggled to mobilise long distances because of physical impairments post-stroke:

> ‘Sometimes I crawl on the pathways because the fences are too far [*to hold on to*]. I will kneel down holding on with one hand and then crawl. I will do like this’. (Participant 4, 24-year-old female, rural setting)

Participants in both settings were dependant on others to push them in wheelchairs, but at times, the issued wheelchair could not traverse the terrain to access taxis. The combination of inclement weather and uneven terrain created barriers to reach public transport and in rural areas, the wet conditions would often make transport completely inaccessible:

> 'I get it [*taxi*] here at the road. The children will push me to there [*in the wheelchair*] … [*if it is raining*] I don't go anywhere. I stay here at home … even at the grant pay out, if it's raining, I don't go. The ones who can walk will go. I wait until the weather gets better …'. (Participant 5, 42-year-old female, rural setting)

Thirty-six per cent of participants found transport to be efficient, but this was notably better in the urban setting (n = 6 urban, n = 1 rural). This contributed to an increased need for private transport services in rural areas as public transport was scarce. Private transportation included private vehicles owned by community members, who would pick up participants at their homes. Participants struggled to afford the private vehicle cost, which left them isolated from their communities:

> 'That is my reason why I don't go [*to community meetings*]. If I go, I have to hire and pay someone [*for transport*]. I cannot afford to pay someone for transport to go to community meetings. They must just say what they want to say there and then send someone to tell me'. (Participant 8, 72-year-old female, rural setting)

Apart from accessibility barriers, many participants also expressed difficulty in transferring in, or out of, taxis. Concerns were raised regarding the additional costs incurred for assistive devices or accompanying caregivers when using taxis. Therefore, even if transport was available, it would often not be usable because of its burdensome financial implications. Community reintegration after the stroke was subsequently restricted because of problems with community mobility and transportation challenges:

> 'I can't balance with this leg as the taxi is a bit high. I will have to let people struggle to get me in as I am heavy [*overweight*]. So, I prefer using a wheelchair'. (Participant 15, 57-year-old female, urban setting)

□ Productivity

The SDH experienced by the participants not only influenced their health and well-being but also affected the nature of activities and ability to participate in previous life roles. The lack of access to homes with fully equipped bathrooms and running water meant women in both settings did not make use of a shower or bathtub, but rather washed themselves using a washbasin filled with water. The women had to complete extra tasks, such as boiling water, carrying it to the basin and then washing themselves:

> 'Now someone needs to wash me … [*Before the stroke*] I was able to cook water. I will pour water in the basin and then I will bath. Even if it's a big washing basin [*bigger basin*] I will get in and I will bath'. (Participant 12, 62-year-old female, rural setting)

Participants in rural areas or informal settlements, who did not have access to running water inside their dwellings, had to complete the additional task to procure water. Procuring water was also essential for domestic tasks such as doing the laundry, cooking and cleaning. In order to do their laundry, rural participants had to carry their clothing and blanket to the nearest river, whilst some urban participants went to communal taps. In both settings, women struggled to complete these additional tasks and had to either rely on family members or pay someone for assistance:

> 'I no longer go to the river. I will lose my balance and I will fall, and I will struggle to get up. It is very painful. I fall easily and it's very muddy and there are stones'. (Participant 6, 32-year-old female, rural setting)

Xhosa women traditionally bear the responsibility for most of the labour-intensive home maintenance activities in rural settings, whilst urban participants generally paid for home maintenance services. In rural settings, the activities constituted extracting natural resources such as soil, water, cow dung and grass to produce bricks, preparing the grass for thatching and maintaining the home by smearing the walls and floors with a mixture of soil, cow dung and water:

> ‘I will go to the river you saw when you came and get it from there. And we will cross the river putting it on your heads and we will walk on that rough terrain up from the river and carry it to our homes’. (Participant 10, 56-year-old female, rural setting)
>
> ‘Ok, I would call someone and pay him to fix it for me … I will hire and I still do now’. (Participant 14, 65-year-old female, urban setting)

Preparing the soil mixture entailed walking with the extracted resources, traditionally balanced on the woman’s head, which assisted with freeing up the upper limb and distributing the load through her whole spine. All of these traditional activities, including smearing the walls and floors, were meaningful activities for the women who, from a young age, were trained to do so:

> ‘There where the car is. You dig there and then carry it to right in front of the house. You also still need to fetch water from the river and put it on your head. Then you prepare the mud and start smearing the walls and floors. And then you prepare the lime and then smear it on the walls, but I can’t [*ikalika*]’. (Participant 6, 32-year-old female, rural setting)
>
> ‘Yes that [*smearing the floors*] was one of my favourite things to do even in my childhood. It is something I use to learn when I was a child until I reached my adulthood and became a woman. Those were one of the things we were learned. After learning how to maintain the hut you then learn how to cook, how to go to the forest [*to fetch wood*]’. (Participant 8, 72-year-old female, rural setting)

The intensive labour required to complete these tasks meant that only one of the rural participants was able to do so post-stroke. If family members were not able to fulfil these responsibilities, the women experienced a loss of role, which influenced their self-worth. They could no longer participate in these meaningful activities and could not take pride in their homes. For the younger women, it also meant that they were unable to fulfil the role of a newlywed, and if they were single, it would make them unsuitable for marriage.

Some of the women had to look after children who were still dependant on them and they struggled with changing nappies, bathing and dressing the children. In both urban and rural settings, the women were required to look after not only their own children but also other family members' children. This was especially true in rural settings, where the children's own parents were deceased or had migrated to urban areas to find work:

> 'Those [*children*] who are here are my sister's. They are the ones that are supposed to look after me if we are all staying together, but they are not here ... They went to find employment as domestic workers'. (Participant 6, 32-year-old female, rural setting)

The role of carer was further complicated by the fact that some of these women needed to be cared for themselves. Often the only people who could care for them were children. This increased the burden of care on both the person with stroke and the children. This had the potential to lead to the participants caring both for elders and children whilst needing care themselves.

In summary, the major SDH affecting these women with stroke, in both urban and rural settings, were lack of financial resources, access to well-designed transport systems and skills needed to generate an income to provide for their families. In urban settings, women reported more social isolation, poor quality housing, surroundings that were unsafe and a lack of healthy, accessible and affordable food. Rural settings were characterised by a lack of infrastructure and municipal services, such as clean running water, sanitation and vibrant spaces.

■ Discussion

The experiences of the women in this study highlighted the interconnectedness of SDH; for example, education and employment linked to a person's ability to access adequate housing and healthy food. This discussion thus does not aim to deliberate on each SDH, but rather seeks to identify key healthcare and rehabilitation priorities to address health inequalities of the participants of this study.

The limitations of this study restrict the generalisability of the findings and recommendations to South Africa and Africa at large. However, the rich in-depth descriptions of the SDH of these women could steer the transferability of these findings and recommendations to similar contexts and settings.

The key themes discussed in these sections relate to the unique participation restrictions of younger women with stroke: the necessity to create a livelihood whilst living with a disability, addressing adequate support capacity at community level and the role the healthcare sector plays in building an inclusive society for these women.

The rehabilitation needs of a younger population with stroke

In South Africa, the quadruple burden of disease has been associated with an increased risk for vascular risk factors and higher prevalence of stroke compared with HICs (Ataguba et al. 2015; Kahn 2011; Krishnamurthi et al. 2013; Omotoso & Koch 2018; Syed & Sani 2013). The median age of the women in both cohorts of this study falls within the economically active population (aged between 15 and 64 years) (StatsSA 2011). In HICs, stroke has been viewed as affecting the population over the age of 65 years (Krishnamurthi et al. 2013); for example, the average age for someone to have a stroke in England is 68 years for men and 73 years for women (Coyle & Bellamy 2018). However, findings of the present study correlate with recent literature that in LMICs, the age at which a stroke occurs is much younger when compared with HICs (Johnson et al. 2016; Mbatha et al. 2017). Other South African studies have shown the same trend with 40% of participants being 60 years old or younger (78% were 70 years or younger) (Cawood et al. 2016). Eight of the women, from this study, could be classified as young adults with stroke as they were under the age of 45 years when the stroke occurred (Smajlović 2015).

The young median age of the women in the sample raises important considerations with regards to their life role, as they might be responsible for caring, and providing for others in their households. Several studies conducted in South Africa found that majority of participants with stroke, especially in a younger population, experienced challenges in finding and participating in employment activities (Cawood et al. 2016; Rhoda et al. 2015). This correlates with our study findings as all women were dependant on government social grants, whilst only one participant was able to participate in an income-generating activity by utilising her entrepreneurial skills. This study advocates that rehabilitation services should prioritise and support higher-level outcomes for these young women with stroke by, for example, providing these women with skills to return to major life roles and provide for their families.

Livelihood creation after stroke

Work and education are both high-priority concerns with strong links to health and well-being; this is particularly true in LMICs, where income generated through work is often the only means to combat poverty and access health and other basic services. Education is an obvious requirement for good work, especially in LMICs where precarious work conditions are prevalent, and many employees count amongst the working poor (Marín 2013). The findings of this study align with the UNs' SDGs that advocate for the promotion of sustainable and inclusive economic growth through decent work for all (UN 2015).

Participation in work has many advantages, including positive identity construction, ongoing development, social interaction and meaning derived from making a contribution. Apart from being one of the SDH, work is the origin of many important determinants of health as it can provide financial security, social status, personal development, social relations and self-esteem (Marmot et al. 2008). Good work also offers protection from physical and psychosocial hazards. Without an income that is obtained through work, access to the other SDH is restricted. In some LMICs, health services might be offered for free, but the scope and quality of such services are generally insufficient to support the health and rehabilitation needs of people with stroke. In such cases, the absence of work exacerbates potential poor health outcomes.

When people are no longer able to continue work because of illness or disability, the importance of employment legislation that prevents unfair dismissal is highlighted. Rehabilitation professionals should join forces with disability organisations to advocate for legislation that protects workers against unfair dismissal on the grounds of illness and disability in countries where such legislation does not exist. Furthermore, rehabilitation professionals should note that informality of work is a growing trend (Kuhn, Milasi & Yoon 2018); they should advocate against. work contracts, which stipulate conditions of work, are an important consideration with direct influence on access, duration and quality of rehabilitation. It should be noted that non-standard works, including part-time, casual, on demand and informal contracts, generally do not offer protection; in fact, these forms of work often pose risks to workers (Campbell 2018). Efforts by unions to ensure decent work conditions should be supported by rehabilitation professionals.

Return to the same job following a stroke will usually require temporary or permanent job modifications. These must be made in collaboration with the employer and in accordance with the concept of reasonable accommodation (UN 2006:4). Such a process involves terms of adjustments required in the workplace to enable a person with disability to continue working, without causing undue hardship to the employer. When a working age person with a stroke is not able to return to his or her previous job, alternative work should be considered, and the work transition supported in order to optimise successful outcome.

Without vocational assessment and rehabilitation services, people who might otherwise have been able to maintain work might end up unemployed. When the outcome of a work assessment determines that a person no longer has the functional ability to participate in work, they should at the very least be counselled in order to prevent unfair dismissal on the grounds of illness or disability and to determine eligibility for employment insurance payments if relevant.

Building social support capacity at a community level

The findings of this study highlight that social support impacted several of the women's determinants. Family or community members not only assisted with valued activities such as self-care, community mobility, home maintenance tasks and accessing food but also ensured a financial safety net. Similar findings were found in a descriptive study from South Africa, where at 6 months post-stroke, participants were still dependant on family members for basic self-care and mobility tasks (Rhoda, Mpofu & De Weerdt 2011). These findings also correlate with a systematic review that highlighted social support in the form of family, friends or community organisations, being integral to all valued activities (Jellema et al. 2017).

However, women in both settings felt isolated from their communities and reported negative family lives. A unique finding was that because of the young age of the women, the burden of care often fell on young children. A systematic review on the experiences of young carers found that, for many, their new-found role restricted their social lives, friendships and exploring alternative identities (Rose & Cohen 2010). This study corroborates the findings of Mudzi, Stewart and Musenge (2015) who advocated for caregiver education programmes with good support structures at community level to alleviate the burden of care. Uphoff et al. (2013) proposed that by building social capital within a neighbourhood, one can decrease people's vulnerabilities and buffer the effect of poverty on health. Based on the findings of our study and current literature, the development of social cohesion and supportive networks should be prioritised at community level, using government and non-government organisations to address health equity, minimising physical barriers and improving access to quality services for these women with stroke (Córdoba & Farquharson 2008; Marmot et al. 2008).

Towards inclusive and sustainable communities

According to the WHO commission on SDH, access to good quality housing, clean water and sanitation are basic human rights and thus essential for good health (Marmot et al. 2008). In this study, most of the women's basic human rights were infringed by not having access to clean running water and sanitation. Poor housing in combination with inadequate water and sanitation not only exacerbates health inequalities but also predicts poor functional outcomes for people with stroke (De Villiers et al. 2011). The women in both cohorts had to either complete additional tasks to source water or incur additional financial expenses by hiring assistance. Several studies from South Africa have advocated for a shift in rehabilitation from body function impairments, especially when it has plateaued, to focusing on environmental barriers that restrict participation in valued activities (Cawood et al. 2016; Mudzi, Stewart & Musenge 2013).

The current study's findings align with the UN SDG 6, regarding equitable access to safe and affordable drinking water and sanitation (UN 2015). The UN also calls on local communities to support and strengthen participation in improving water and sanitation management. Water sustains life and forms an essential part of preparing meals, completing self-care activities and household chores. The health and rehabilitation sector not only can no longer be concerned with health and effects of disease but should also be leaders in ensuring that health equity is addressed in different sector policies, systems and programmes (Marmot et al. 2008; Scott et al. 2017). This links with the UN SDG 17 that advocates for intersectoral collaboration where strategic partnerships are needed to address the wide scope of health inequality (UN 2015).

In the Western Cape Province, South Africa, during the Apartheid regime, relatively informal settlements, such as Khayelitsha, were built for migrant workers, and despite 24 years passing since democracy, these settlements still have limited infrastructure and inadequate municipal services that impact on ADLs (Legg & Penn 2013). The dense population in these low socio-economic and informal settlements in the City of Cape Town Metropole gives rise to high incidents of communicable and NCDs (Legg & Penn 2013; Smit et al. 2016). In addition, none of the participants had access to well-designed and efficient transportation systems, which hindered their participation and inclusion in their communities. A systematic review by Nicholson et al. (2013) found that one of the major service-related environmental barriers, limiting community reintegration of people with stroke, was transportation. Public transportation services are often inaccessible and private transportation is unaffordable to many (Cawood & Visagie 2015; Mlenzana, Eide & Frantz 2018; Nicholson et al. 2013).

This study's findings support the UN SDG 11, which promotes the development of inclusive, safe, resilient and sustainable human settlements through investing in adequate housing, accessible transportation systems and the development of rural areas to relieve the pressure of migration to urban areas (UN 2015). Health and rehabilitation organisations play an important leadership role in ensuring health is addressed in all policies, systems and services to build an inclusive and equitable society for all.

Conclusion

The complex burden of disease in South Africa is potentially increased by the socio-economic disparities between different population groups. This contributes to the increase of cardiovascular risk factors related to both non-communicable and communicable diseases, resulting in the rising incidence of stroke, especially amongst a younger economically active component of the population.

This study illuminates the interconnectedness of SDH experienced by these women. Not only the SDH influenced their ability to access good work, adequate housing and food but also the environmental barriers influenced the nature of activities, which further amplified their participation restrictions. The findings of this study offer strong support for the provision of accessible services in order to decrease the environmental barriers and health inequalities faced by women with stroke when caring for themselves and their families. Government institutions and other organisations need to address these disparities, beginning with education, water and sanitation services and infrastructure development for communities in low socio-economic settings as illuminated in this study's findings. The healthcare sector plays a pivotal leadership role in advocating and facilitating collaboration with other sectors to address the SDH and ensure the implementation of the UN SDGs.

Recommendations for future research

This study offers a foundation for similar research to be undertaken into other traditional ethnic groups in Africa, particularly in rural and marginalised communities, to assist in identifying common areas of need. Further validation is recommended for the framework used for data analysis presented in this chapter, possibly as an easy-to-use assessment tool for SDH. It is recommended that future research on this topic should aim for a larger sample population that includes men, and people with stroke who present with communication impairments, to ensure that their needs are identified and addressed.

This chapter recommends that for clinical practice, people with stroke who are of working age should be referred for vocational rehabilitation as directed in the United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol, Article 27 (UN 2006:19). In the absence of vocational rehabilitation, a work assessment is recommended to determine whether such a person will be able to return to the same job or whether they might have residual function to enable them to do a different job (Finger et al. 2012).

The findings of this study also suggest the need for further research to determine the most appropriate and effective skills-training interventions for people with stroke (especially in a younger population) to generate an income. Further research should also be undertaken to explore the most appropriate research methodology to monitor and evaluate action on SDGs, and the effect on participation and health of people with stroke.

■ Limitations

The use of NGOs to recruit participants possibly meant that the study participants were not representative of the wider population of women with stroke. One significant limitation of this study was the exclusion of women with stroke, who had communication impairments. By excluding these potential participants, valuable and relevant insight in understanding their unique needs is lost.

As stated in the discussion, the small sample size limits the generalisability of the study findings to South Africa and Africa as large. The data obtained from this study, however, provide a rich in-depth description of the SDH experienced and the impact they have on these women, which could facilitate the transferability of this study's findings to similar contexts and settings. It is the opinion of the authors that this chapter's finding can thus contribute to the understanding of the impact of SDH and could enhance decision-making in similar contexts.

THEME 6

Contextualised evidence-based rehabilitation and pathways

Chapter 9

South African stroke rehabilitation pathways and associated rehabilitation costs

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■ Abstract

Background: Access to timely and efficient stroke rehabilitation are important aspects to optimise stroke recovery. The delivery of best practice stroke rehabilitation in South Africa is constrained by the diverse economic and geographic circumstances present in the country.

Aim: We aimed to obtain an understanding of the different ways in which people with stroke enter, progress and exit South African rehabilitation service options as this was the first step in developing relevant clinical guidance.

Methods: In this chapter, we described the process of establishing 'typical' clinical pathways that South African adults might follow after sustaining a stroke. These pathways covered the time from stroke onset to reintegration into the community. We provided the representative case studies drawn from clinician experiences and estimated the potential costs of rehabilitation services in different care settings to demonstrate the differences between the various patient pathways.

Findings: Clear patient pathways through the healthcare system provided clinically relevant frameworks within which evidence-based recommendations could be framed to support implementation of best practice care. The case examples and estimated rehabilitation service costs presented validated the patient pathways described and demonstrated the variability with which people with stroke might access acute care and rehabilitation services in South Africa.

Conclusion: Determining typical clinical pathways provided a potential way, in which cost of healthcare could be estimated. However, because there was limited research on the costs to the government associated with stroke rehabilitation in South Africa, this should be investigated in future research.

Keywords: Stroke; Patient pathway; Rehabilitation; Estimated costs; Case studies; Public sector; Private sector.

■ Background

Suffering a stroke negatively affects productivity and incurs considerable financial and emotional costs on a range of stakeholders (the person with stroke, caregivers, the extended family, the community and broader society) (Demaerschalk et al. 2010; Fatore et al. 2012; Godwin et al. 2011; Johnson et al. 2016; Kolominsky-Rabas et al. 2006; Mittmann et al. 2012). The consequences of stroke disability can be diminished QoL, limitations on capacity to earn a living (because of caregiving demands) and diminished social and emotional interactions with others outside the family (Haley et al. 2015). Timely and efficient stroke care and rehabilitation are thus important considerations to limit the impact of stroke on those affected. International comparison of stroke cost studies confirm that stroke worldwide constitutes 2%–7% of the healthcare cost expenditure per annum (Demaerschalk et al. 2010; Dicarlo et al. 2013). Strokes therefore impact significantly on countries, such as South Africa, that have developing economies.

A major challenge to equitable and accessible stroke rehabilitation in South Africa is its geography (McLaren, Ardington & Leibbrandt 2013). Many people living with the effects of stroke in rural or remote settings are prevented from accessing rehabilitation for many reasons – for instance, lack of knowledge about stroke and rehabilitation, lack of safe or affordable transport, long distances (and time), often on rough terrain, to travel to consult a healthcare provider and/or availability of evidence-based rehabilitation (Dizon et al. 2016a; Ned et al. 2017). Moreover, an important consideration in South Africa is the influence of religion and cultural beliefs on patients' views regarding causes and management of stroke. This may influence health-seeking behaviours and therefore, culturally appropriate care is needed (Bham & Ross 2005). Thus, for the above reasons, effective, optimal and contextually relevant rehabilitation services often cannot be provided in many South African settings (Dookie & Singh 2012; Sherry 2015; Visagie & Swartz 2016).

It is unclear how many South Africans access and receive rehabilitation services after sustaining a stroke, what rehabilitation is provided to them, how effective this rehabilitation is and what the implications are, of receiving inadequate, or even no, rehabilitation (Department of Health [DoH] 2014; Sherry 2015). South Africa has committed itself to the WHO vision of achieving equitable, evidence-based rehabilitation for all by 2030 (DoH 2014; Sherry 2015; WHO 2017). Understanding the different ways in which people with stroke in South Africa access rehabilitation is essential to define current systems and gaps, patient and caregiver needs, and to identify areas for future improvements in rehabilitation services in South Africa. This information will assist in informing a forward-thinking, aspirational, equitable and effective rehabilitation framework for the South African context that benefits individuals, families, communities and the country.

■ Aims

The aims of this chapter are to:

- describe the process of determining the different ways in which people with stroke access, progress and exit rehabilitation services (typical patient pathways through the South African healthcare system)
- populate these pathways with exemplar cases derived from clinician experiences
- estimate potential healthcare costs that may be incurred in these different stroke pathways.

This chapter is divided into three sections:

- **Section 1:** Establishing stroke rehabilitation pathways.
- **Section 2:** Validating the pathways with South African case examples.
- **Section 3:** Estimating potential costs of providing care in these pathways.

Section 1: Establishing stroke rehabilitation pathways

Constructing South African-contextualised patient pathways in stroke was undertaken as an early and essential step when writing the SA-cSRG (2019). The notion of defining patient pathways as part of writing a CPG was pioneered by Gonzalez-Suarez et al. (2012) in the Philippines, as an element of writing CPGs for the management of people with stroke in this geographically diverse country. Gonzalez-Suarez et al. (2012) found that establishing a typical stroke patient pathway provided the framework within which the scope and purpose of a question could be set, as well as a structure within which contextually appropriate recommendations could be written. A contextualised patient pathway for stroke care enables guideline methodologists, policy makers and healthcare providers to consider issues of essential equipment, standards, resources, training and workforce, which are essential to underpin the provision of evidence-based care in the intended context. Building on the experiences reported by Gonzalez-Suarez et al. (2012), the

SA-cSRG working party used patient pathways to underpin the core elements of CPG construction, namely, defining scope and purpose, establishing target end-users and defining key questions (Schünemann et al. 2014).

Establishing the different pathways that patients may follow when accessing stroke rehabilitation in South African healthcare settings also underpinned preliminary attempts to estimate costs of rehabilitation in South Africa (Harrison, McArthur & Quinn 2013; Lexell & Downham 2005). There are emergent data from developed countries internationally on costs of rehabilitation (Kaur et al. 2014), but little directly relevant to the diversity of South African healthcare settings (Sherry 2015). Estimating costs for different exemplar patient pathways in South Africa using the case examples is presented in the section 'Section 3: Estimated healthcare and rehabilitation costs' of this chapter. We took several steps to establish 'typical' patient pathways in different South African rehabilitation settings for adults with acute and chronic stroke.

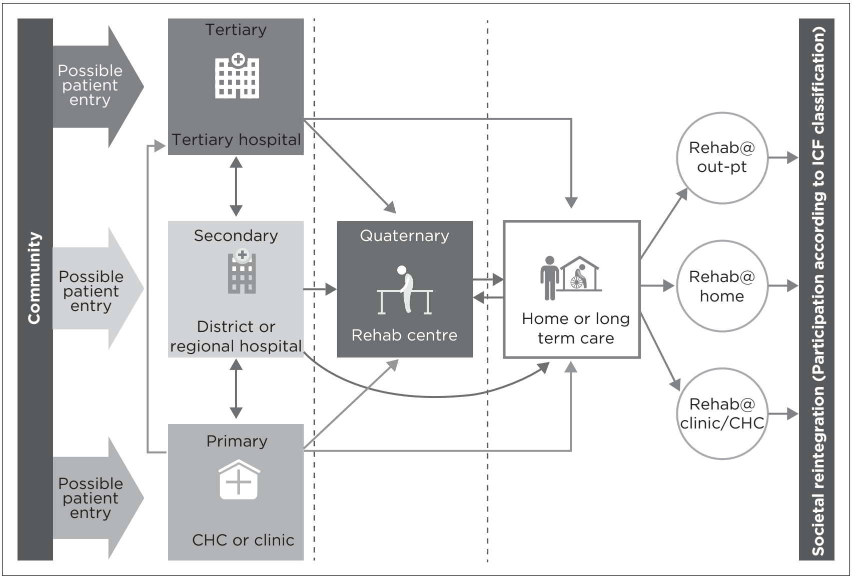
We conducted a rapid review of the peer-reviewed literature in an attempt to identify published information on patient pathways within the rehabilitation journey in, or extrapolatable to, South African settings. Literature could deal with pathways from the onset of stroke to community integration of people with stroke. The search was conducted in Google Scholar, Scopus and PubMed using the search terms 'Stroke' OR 'CVA', 'Africa' OR 'South Africa', 'rehabilitation', 'patient journey' OR patient 'pathway'. The search yielded no relevant articles:

- The stroke methodology group then posed structured open-ended questions (via email) to key rehabilitation informants in order to determine information pertinent to stroke patient journeys. These key informants were from various rehabilitation professions (physiotherapists, occupational therapists and speech therapists), represented different service ranks and were from various levels of care in diverse geographical areas in South Africa. We employed a snowball sampling methodology, and a total of 20 invitations were sent out.

Twelve rehabilitation professionals (six occupational therapists and six physiotherapists) responded to the invitations and were interviewed. The methodological group then synthesised the information from these interviews in an attempt to draft an initial patient pathway. It quickly became apparent that there was not one clear pathway of how people with stroke accessed rehabilitation in the available healthcare settings across metropolitan, urban, regional, rural and remote South Africa. Therefore, multiple referral pathways, as well as multiple entry and exit points from the different types of care facilities in the South African public and private healthcare systems were identified. This first draft of the patient pathway was sent back to the key informants to obtain feedback, and an updated patient journey was created.

- The updated patient journey was presented to the SA-cSRG working party in two provinces, Gauteng and the Western Cape. This team comprised national and provincial policy makers, methodologists, managers, clinicians and patient representatives representing four provinces (Western Cape, Gauteng, Mpumalanga and KwaZulu-Natal). Participants from those provinces provided rich input about the range of healthcare sectors, settings and rehabilitation options in their areas. The SA-cSRG working party was requested to work in small groups to validate the patient journeys from entering to exiting, the South African public and private healthcare systems. Contextual factors, such as social circumstances, distances and terrain travelled, to care, costs, affordability and access to care, types of available care (including healthcare provider availability and training), the influence of traditional health providers, language, literacy, healthcare beliefs and engagement of families and local communities, were found to play important roles in determining how South Africans access different stroke rehabilitation pathways. The initial draft pathway endeavoured to map and integrate the stroke rehabilitation service delivery options in South Africa. Despite its limitations, it established a tangible framework for discussion of when, and where, the rehabilitation guidance was required (see Figure 9.1).

- During this process, key decision-making points were also established, relevant to patient pathways. This preliminary work established that the important settings to consider in South African stroke rehabilitation pathways were primary, secondary (district or regional), tertiary, quaternary, community, home or long-term care and society.
- We then sought expert clinician input to describe representative cases of stroke rehabilitation to validate, and add context to, the draft rehabilitation pathways. We asked for exemplar cases in tertiary, secondary and primary care provided as relevant, in metropolitan, urban, regional and rural or remote settings, which described entry and exit from available healthcare options. These pathways enabled the team to consider multiple



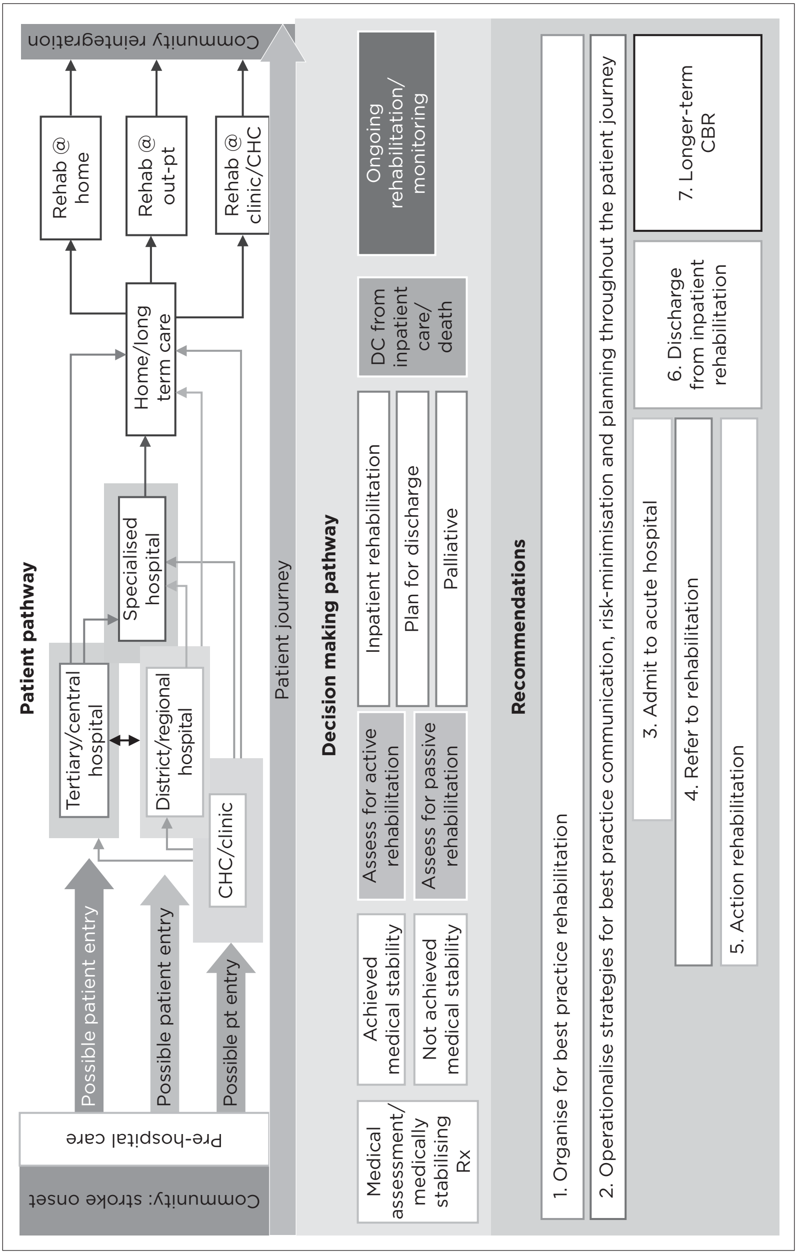
Source: SA-cSRG (2019).

CHC, community health centre; ICF, International Classification of Functioning, Disability and Health.

FIGURE 9.1: Initial mapping of stroke patient pathways, with critical care decisions or options in the pathways.

entry points and referral mechanisms, as well as contextual factors (e.g. distance from a healthcare centre, costs of travel, appropriate or accessible travel, traditional health providers, health literacy, and family and social circumstances). These case studies are outlined in the section 'Section 2: Exemplar patient case studies in South African settings' of this chapter.

- Questions that were addressed in the stroke rehabilitation CPG were then identified by the SA-cSRG working party. Question identification was assisted by the critical decision-making points along the pathway (as outlined in Figure 9.1). Thirty-eight questions were identified. These were then mapped to the different settings in which rehabilitation was delivered, as outlined in Figure 9.1. These questions have been published in a previous study (Grimmer et al. 2018).
- Broad stakeholder workshops were then convened to disseminate information on the SA-cSRG work to date, and to seek further (and broader) input into the questions, the recommendation areas and the patient pathway(s). Policy makers (national and provincial), managers of different-sized facilities, which delivered allied healthcare to patients with stroke, allied health clinicians engaged in rehabilitation (mostly PT, OT and speech, language and hearing therapy) and survivors of stroke attended four meetings to discuss the different ways in which patients with stroke interacted with South African health systems for rehabilitation. The pathways were refined, and the broad areas of recommendations were consolidated into seven overarching themes, which were then mapped to a revised pathway (see Figure 9.2). The themes comprised: (1) organising for best practice rehabilitation (considering the structures and processes required for it), (2) operationalising strategies for best practice communication, risk minimisation and planning throughout the patient journey, (3) admission to acute hospital, (4) referral to rehabilitation, (5) actioning rehabilitation, (6) discharge from inpatient rehabilitation and (7) longer term CBR.



Source: SA-cSRG (2019).

CBR, community-based rehabilitation; CHC, community health centre; DC, discharge; pt, patient.

FIGURE 9.2: Revised patient pathway and question themes mapped to it.

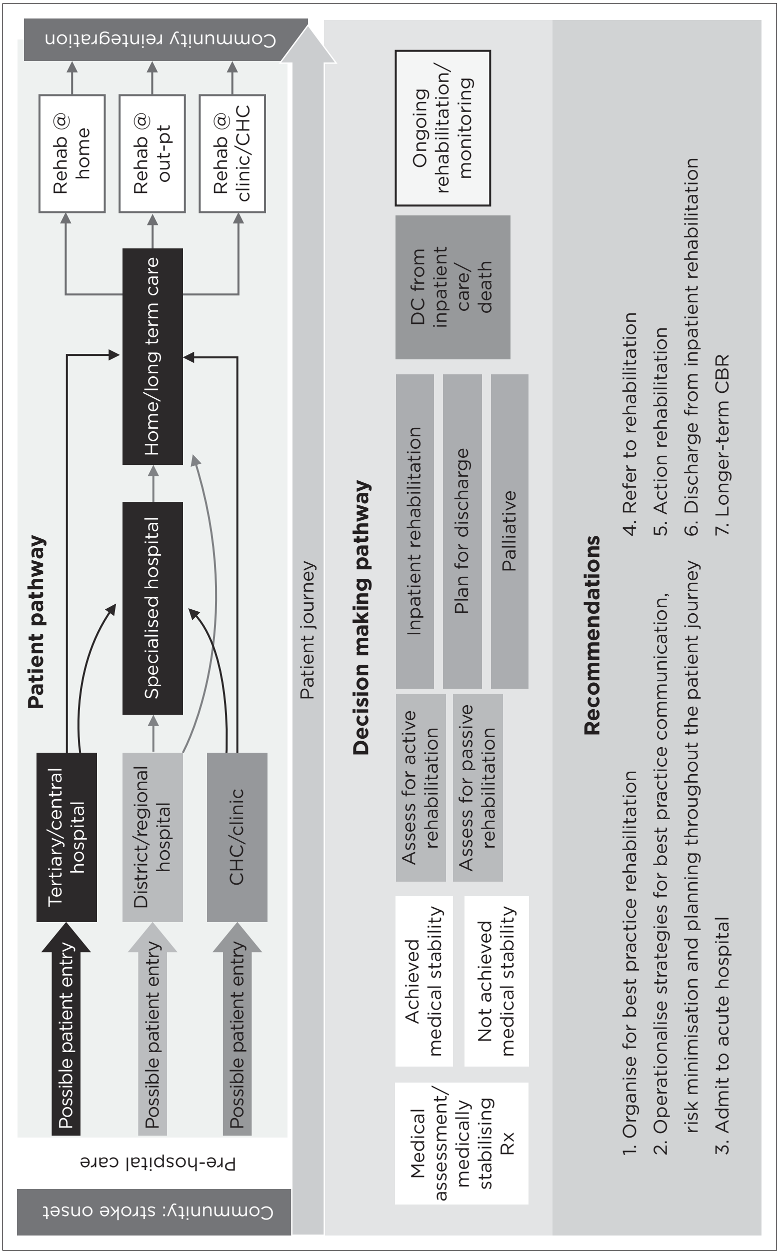
- The patient pathway was revised one more time to incorporate final feedback from the stakeholder meetings and to refine the SA-cSRG layout for easier reading (see Figure 9.3). The top section of Figure 9.3 was then separated into an independent figure for the final draft of the SA-cSRG.

Lessons learnt

The exercise of establishing typical South African patient pathways for stroke rehabilitation was not straightforward, and many participants in the CPG writing meetings expressed surprise at their lack of understanding of the multiple ways in which patients could enter and leave rehabilitation service options around the country. The patient pathways combined stakeholder's knowledge of different healthcare sectors (primary, secondary, tertiary and quaternary) as well as different types of locations where care could be provided (metropolitan, urban, regional and rural or remote). Determining the patient pathways was a critical step in establishing questions for the CPG, as without the pathways to guide thinking, the need for guidance and the appropriate questions may not have been asked. When the CPG rehabilitation working party writes a South African Clinical Practice Guideline (SA-CPG) for other conditions, establishing patient pathways will be an essential first step.

Section 2: Exemplar patient case studies in South African settings

The SA-CPG working party identified scenarios of exemplar patients with stroke accessing different rehabilitation options. This step was undertaken to test the patient pathways established in the section 'Section 1: Establishing stroke rehabilitation pathways' and to determine likely costings (see the section 'Section 3: Estimated healthcare and rehabilitation costs'). Exemplar cases were:



Source: SA-cSRG (2019).
CBR, community-based rehabilitation; CHC, community health centre; DC, discharge.

FIGURE 9.3: The final version of the pathway.

1. metropolitan city cases admitted to an acute public hospital stroke unit with inpatient rehabilitation
2. metropolitan city cases admitted to a general public hospital ward with outpatient department (OPD) rehabilitation
3. regional tertiary public hospital cases with OPD rehabilitation
4. regional primary cases with no hospital admission (two options in terms of follow-up): option 1 – discharged from CHC with public OPD rehabilitation; and option 2 – discharged to home from CHC with no rehabilitation
5. rural cases with no hospital admission, a CHW notified and then the patient receives a home visit
6. private insurance pathway cases with patients admitted to an acute care private hospital until benefits and private resources are exhausted (two options in terms of follow-up): option 1 – discharged to a 'step down' facility then to nursing or frail care facility; and option 2 – discharged to home with private OPD care.

Case 1: A metropolitan city setting where a person with stroke is admitted to an acute public hospital stroke unit with inpatient rehabilitation

Mr Adams is a 68-year-old male pensioner who sustained a left middle cerebral artery stroke 1 month before, as a result of uncontrolled HPT. He is overweight and a smoker with newly diagnosed diabetes. He is married with two employed adult children, who live nearby. He lives with his wife in a three-bedroom house with all amenities. They both have vehicles and enjoy spending time visiting family.

Mr Adam's son was able to take him to Groote Schuur Hospital's emergency unit in Cape Town on the night of his stroke, which was a mere 10-min drive from home. He was immediately admitted to hospital and medically stabilised. Within 2 days, the physician transferred him to the acute stroke unit for early rehabilitation management by the physiotherapist, occupational therapist and speech therapist. He was aphasic, had limited hand function but could stand with some assistance. The rehabilitation team recommended inpatient rehabilitation, as he showed potential for improvement.

He was then transferred to a local rehabilitation centre, the WCRC, and progressed well during 3 weeks of inpatient rehabilitation. The rehabilitation team educated his wife and son regarding stroke secondary prevention and his self-maintenance programme. At the time of writing this case, 2 months after the stroke, Mr Adams can now walk independently with an ankle-foot orthosis and a walking stick, and he is looking forward to being discharged to home in the next few weeks (see Box 9.1 for the costs associated with Mr Adam's stroke).

Case 2: A metropolitan city setting where a person with stroke is admitted to a general public hospital ward with outpatient rehabilitation

Mrs Baker is a 56-year-old widow with a history of ischemic heart disease and previous mitral valve replacement surgery. She has worked as a seamstress in a clothing factory for 30 years but leads a relatively sedentary lifestyle. She lives with her 25-year-old daughter in a two-bedroom flat. She defaulted on taking her regular anticoagulant therapy and subsequently sustained a stroke at work, 2 months before. She was taken to Johannesburg General Hospital in an ambulance.

Two days after the admission to the general medical ward, Mrs Baker was screened by the physiotherapist, occupational therapist and speech therapist for rehabilitation potential. Early rehabilitation was provided for a few days, and her daughter was educated on ongoing home management before discharge.

BOX 9.1: Predicted costs of Mr Adams's stroke.

Groote Schuur Hospital

- ED costs
- Acute care bed day costs (2 days)
- Acute Stroke Unit bed day costs (how many days?)
- Physician costs (if not incorporated into bed day costs)
- Investigations (MRI, etc.) if not incorporated into bed day costs
- Rehabilitation (PT, OT and speech pathology) (how many sessions? and what cost?)

Western Cape Rehabilitation Centre

- Bed day costs (how many days?)
- Physician costs (if not incorporated into bed day costs)
- Rehabilitation (PT, OT and speech pathology) (how many sessions? and what cost?)

Devices

- Ankle-foot orthosis
- Walking stick

Family costs

- Time off work to attend appointments with rehabilitation staff
- Travel costs to visit Mr Adams

ED, emergency department; MRI, magnetic resonance imaging; OT, occupational therapy; PT, physiotherapy.

Because of the demand for hospital beds, the medical officer decided to discharge Mrs Baker, provided that she returned for weekly OPD therapy at the hospital. Her daughter, who was very supportive, agreed to accompany her mother to her appointments. They have to use public transport and Mrs Baker requires assistance getting in and out of the taxi (see Box 9.2 for the costs associated with Mrs Baker's stroke).

BOX 9.2: Predicted costs of Mrs Baker's stroke.

Johannesburg General Hospital

- ED costs
- General ward bed day costs (how many days?)
- Physician costs (if not incorporated into bed day costs)
- Investigations (MRI, etc.) if not incorporated into bed day costs
- Rehabilitation (PT, OT and speech pathology) (how many sessions? and what cost?)

OPD

- Rehabilitation session costs (how many? and what type?)

Family costs

- Time off work to assist Mrs Baker to attend rehabilitation
- Travel costs to attend appointments

ED, emergency department; MRI, magnetic resonance imaging; OPD, outpatient department; OT, occupational therapy; PT, physiotherapy.

Case 3: A regional tertiary public hospital setting where a person with stroke receives outpatient rehabilitation

Mr Clark is a 42-year-old gardener with a history of tuberculosis (TB) and HIV. He has successfully completed his course of TB treatment some time before and is currently on antiretroviral treatments to manage his HIV. He sustained a stroke 1 month before and was admitted within 12 h of his stroke to Frere (public) Hospital in East London for acute medical care. He lives with his wife and three school-going children in an informal settlement. His wife is a domestic worker. Once medically stabilised, Mr Clark commenced PT and OT. Within 3 days, he remained unable to walk, but because of limited hospital beds, the doctor discharged him to home. The physiotherapist measured him for a wheelchair although there were no wheelchairs available immediately and gave him an appointment to return for OPD therapy. Because of an existing backlog of OPD appointments, Mr Clark could only be seen a month after discharge. In order for him to access OPD care, Mr Clark's wife must take a day off work to accompany him to his appointments. He does what he can at home to exercise (see Box 9.3 for the costs associated with Mr Clark's stroke).

BOX 9.3: Predicted costs of Mr Clark's stroke.

Frere Hospital costs

- ED costs
- General ward bed day costs (3 days)
- Physician costs (if not incorporated into bed day costs)
- Investigations (MRI, etc.) if not incorporated into bed day costs
- Rehabilitation (PT, OT and speech pathology) (how many sessions? and what cost?)

OPD

- Rehabilitation (PT, OT and speech pathology) (how many sessions? and what cost?)
- Devices (wheelchair)

Family costs

- Mr Clark cannot work and therefore has lost his income
- His wife must take time off work to accompany him to OPD
- Travel costs to attend rehabilitation
- Need for someone else to care for children when his wife is accompanying Mr Clark to OPD

ED, emergency department; MRI, magnetic resonance imaging; OT, occupational therapy; OPD, outpatient department; PT, physiotherapy.

Case 4: A regional primary care setting where a person with stroke has no hospital admission, with two options of follow-up

Option 1 – managed at a community health centre with rehabilitation

Mr Davids is a 72-year-old retired man with a history of HPT and hypercholesteremia, attending the local CHC for monthly check-ups and to collect his chronic medication. He lives alone in a small single-room informal wooden dwelling, called a 'wendy house', in his neighbour's backyard. He receives a government pension.

He sustained a stroke 3 weeks ago but did not recognise the symptoms at the time. He reported feeling weaker on one side of his body and noticed that his speech was slightly slurred. He stayed in bed for a week and once he was able to stand, he called his neighbour to take him to the CHC. He was surprised when the nurse informed him that he might have had a stroke. The nurse referred him for PT at the CHC. He has received one session of PT and is supposed to attend every 2 weeks. His neighbour has agreed to take him to the CHC for his PT appointments for a small fee (see Box 9.4 for the costs associated with Mr David's stroke).

BOX 9.4: Predicted costs of Mr Davids's stroke.

CHC

- Nurse consultations
- Rehabilitation (PT, OT and speech pathology) (how many sessions? and what cost?)

Family costs

- Costs paid to neighbour to take him to rehabilitation

CHC, community health centre; OT, occupational therapy; PT, physiotherapy.

☐ Option 2 – managed at a community health centre with no rehabilitation

Mrs Erasmus is a 63-year-old woman who sustained a second stroke a week before because of uncontrolled HPT. She had defaulted on her anti-hypertensive medication. She was seen by the medical officer at the local CHC, given additional education on stroke prevention and discharged with medication. The CHC does not offer any rehabilitation services.

She has been receiving a disability grant for 5 years since her first stroke. Mrs Erasmus lives with her 83-year-old mother and 58-year-old brother. The brother is the family breadwinner and works as a taxi driver. He is concerned that his sister was not given proper advice or therapy as she is unable to wash and dress herself. She was mobile and independent after her first stroke but requires assistance with most activities now (see Box 9.5 for the costs associated with Mrs Erasmus's stroke).

BOX 9.5: Predicted costs of Mrs Erasmus's stroke.

CHC

- Medical officer costs
- Medications
- Rehabilitation (PT, OT and speech pathology) (how many sessions? and what cost?)

Family costs

- Burden of providing home support for Mrs Erasmus

CHC, community health centre; OT, occupational therapy; PT, physiotherapy.

Case 5: Rural setting where a person with stroke has no hospital admission, the community health worker is notified and then the patient receives a home visit

Mr Frank is a 45-year-old man living in a *rondawel* [a traditional circular African dwelling with a thatched roof] in rural Eastern Cape with his mother, wife and four children (aged 17–25 years). The family is dependent on the grandmother's disability grant. They live far from the closest road and were therefore unable to go to the nearest clinic or hospital. His wife notified the CHW at the nearest community clinic (20 km away) that her husband was not able to stand or walk by himself. He received a visit from a '*Sangoma*' [a South African traditional healer], who prepared some herbal medicine for him (https://www.lexico.com/definition/sangoma). Three weeks later, he received a home visit from the physiotherapist and CHW and was informed he had a stroke. The CHW noted that he has a long history of HPT and had previously been given medications. He requested that his wife monitors his medications daily.

BOX 9.6: Predicted costs of Mr Frank's stroke.

CHC

- CHW costs
- Physiotherapist costs
- Wheelchair

Family costs

- Costs of consulting the *Sangoma*
- Medications
- Time needed to assist Mr Frank with daily activities

CHC, community health centre; CHW, community health worker.

The family also mentioned that they had been struggling to transfer Mr Frank from his mattress on the floor, to the chair, and that he required assistance with most of the daily activities. The therapist educated his wife on transfers and self-care, demonstrated simple home exercises to her and gave Mrs Frank a book of exercises to do with her husband. The physiotherapist and CHW plan to return in 6 weeks to follow up on his progress and to issue Mr Frank with a wheelchair (see Box 9.6 for the costs associated with Mr Frank's stroke).

Case 6: Private insurance pathway – Patient admitted to an acute care hospital with ongoing private rehabilitation

Option 1 – discharged to step down facility and then to nursing or frail care facility

Mr Green is a 80-year-old male pensioner who sustained a stroke at home 6 weeks before whilst playing chess with his neighbour. He suffered from ischaemic heart disease and had a heart attack 8 years ago, but recovered well and has been on medication for his heart condition since. He lives on his own in a two-storey house with stairs. He has one child who lives in another province. He has a medical insurance scheme with a hospital plan. Following the stroke, his neighbour was able to take him to the nearest private hospital 1 km away where he was admitted. Three days later, he was transferred to the hospital's acute stroke unit for early rehabilitation management by the physiotherapist, occupational therapist and speech therapist. He was aphasic, had limited hand function and was in a wheelchair.

He remained in the acute stroke unit for 2 weeks, but because of slow progress with his mobility, the rehabilitation team recommended that it would not be safe for him to return home on his own. The family had already been exploring purchasing a flat in a local retirement village and decided it was best that

Mr Green be transferred to the frail care unit of the retirement village for long-term care. After a motivation letter from the acute stroke unit physiotherapist, Mr Green's medical aid agreed to 12 OPD PT sessions but rejected further sessions. At the retirement village, he is still receiving PT and OT once a week. His medical insurance savings have run out, so his son now pays for his ongoing therapy sessions. He remains in a wheelchair and requires assistance with most ADL (see Box 9.7 for the costs of Mr Green's stroke).

BOX 9.7: Predicted costs of Mr Green's stroke.

Local private hospital

- ED costs
- Acute care bed day costs (how many days?)
- Acute Stroke Unit bed day costs (how many days?)
- Physician costs (if not incorporated into bed day costs)
- Investigations (MRI, etc.) if not incorporated into bed day costs
- Rehabilitation (PT, OT and speech pathology) (how many sessions? and what cost?)

OPD

- Rehabilitation (PT, OT and speech pathology) (12 sessions, what cost?)

Family costs

- Purchase of frail or aged care unit
- Rehabilitation
- Wheelchair
- Frail or aged care support costs

ED, emergency department; MRI, magnetic resonance imaging; OT, occupational therapy; OPD, outpatient department; PT, physiotherapy.

☐ Option 2 – discharged to home with private OPD care

Mrs Holmes is a 45-year-old librarian, who suffered an ischemic stroke as a result of uncontrolled HPT 3 weeks ago. She is a smoker and sometimes forgets to take her HPT medication. She lives with her husband and two children in a four-bedroom house. Her husband works as a full-time accountant. Her two daughters are students at the local university. All family members have drivers' licences and their own vehicles. They are all on a comprehensive cover medical insurance plan. One of her children was at home when she had her stroke and called an ambulance. The ambulance took 15 min to arrive and another 5 min to take her to the nearest private hospital. She received tissue plasminogen activator within an hour of admission. She was initially unable to speak or move her limbs but could communicate after the treatment. She spent a further week in hospital where she received daily PT and OT. As she was medically stable, the treating physician decided to discharge her home, provided that she continued with private OPD rehabilitation at the hospital. As her medical insurance only covers 24 private OPD therapy sessions, it was possible that she would need to access care in public facilities.

When Mrs Holmes returned home from hospital, she was able to walk independently with a stick but needed ongoing assistance with her arm function. Her husband hired a part-time carer for a few hours a day during the week to support her whilst the family was out of the house. One of her daughters was able to take her to a private OPD PT and OT sessions at the private hospital twice-weekly, and when this funding source ran out, she continued at the local public day hospital with one appointment every 2 weeks or so, where she continued to show good progress. Mrs Holmes plans to go back to work once her arm function had improved sufficiently. However, her husband says that there is no rush as he is able to support the family financially in the meantime (see Box 9.8 for the costs associated with Mrs Holmes's stroke).

BOX 9.8: Predicted costs of Mrs Holmes's stroke.

Private hospital

- Ambulance costs
- ED costs
- TPA cost
- General bed day costs (how many days?)
- Physician costs (if not incorporated into bed day costs)
- Investigations (MRI, etc.) if not incorporated into bed day costs

Private hospital OPD

- Rehabilitation (PT, OT and speech pathology) (24 sessions, what cost?)
- Walking stick

Day hospital OPD

- Rehabilitation (PT, OT and speech pathology) (24 sessions, what cost?)

Family costs

- Part-time carer
- Cost of transport to OPD rehabilitation
- Time lost from university for daughter to take mother to OPD appointments
- Mrs Holmes's lost wages.

ED, emergency department; MRI, magnetic resonance imaging; OPD, outpatient department; OT, occupational therapy; PT, physiotherapy; TPA, tissue plasminogen activator.

Lessons learnt

The above case studies validated the patient pathways described in the section 'Section 1: Establishing stroke rehabilitation pathways' and demonstrated the variability with which people with stroke might access acute care and rehabilitation services in South Africa. The cases also demonstrated the need for rehabilitation services as well as the lack of rehabilitation primary healthcare sectors. This section highlighted the potential inequities of the current healthcare system with regards to accessible, affordable, patient-centred, efficient and effective stroke care, as well as the different timelines of access to care, depending on where the patients live in South Africa. The case studies also show the importance of family and community support and the importance of primary and secondary stroke prevention.

Section 3: Estimated healthcare and rehabilitation costs

Quality healthcare requires the implementation of the principles of value-based healthcare (Porter 2009). Globally, there is an urgent need to conceptualise what the term 'value' means regarding rehabilitation, especially in terms of the ways in which it contributes to the individual, family, community, society and the country's economy. Determining the value of rehabilitation requires at least two sets of information: outcomes or benefits of care (effectiveness, patient satisfaction and safety) and costs of care. Details on the value of rehabilitation in the South African context will provide much needed information for the National Development Plan and will inform the initiatives to *address* the WHO Rehabilitation 2030 goals. Without an estimate of 'value', there is no evidence that rehabilitation offers a benefit to South Africans (Morris et al. 2019). Such benefits may include benefits for the individual, the healthcare system and the economy. The benefits of efficient stroke care include improving the function and QoL of persons with stroke, enhancing the rates of return to work after stroke, reducing dependence on social grants, enhancing community integration, providing evidence of value for money, improved access to care and education or chances of employability. Without such evidence for the value of rehabilitation, it could be argued that people with disabilities may suffer no harm if they receive no rehabilitation at all (Morris et al. 2019).

In this chapter, we focus on the cost of rehabilitation following a stroke. There is little in the literature about the economic value of rehabilitation. A recent systematic review (Howard-Wilsher et al. 2016) included 64 studies about the economic value of rehabilitation for various conditions, including spinal or other pain conditions, age-related problems, stroke, musculoskeletal disorders, heart diseases, pulmonary conditions, mental health problems and injury. The review identified that there is limited information about the economic value of rehabilitation services in African countries. There is a small number of studies on cost implications of stroke rehabilitation in Africa (Owolabi et al. 2015). The cost-effectiveness approach to an economic evaluation of stroke rehabilitation may be insufficient in providing a comprehensive picture, as it does not allow comparisons to be made across different interventions and it gives little consideration for wider effects of stroke rehabilitation such as productivity costs, patient education and impact on carers (Craig et al. 2014). Policy makers should consider the potential trade-offs between costs and benefits when assessing the impact of stroke rehabilitation.

The patient pathways outlined in the section ‘Section 1: Establishing stroke rehabilitation pathways’ provided a first step in the process of quantifying costs of rehabilitation. Physiotherapists, occupational therapists and speech therapists are the most common providers of rehabilitation services in primary, secondary, tertiary and quaternary South African healthcare settings (Maillacheruvu & McDuff 2014; Ned et al. 2017). The 2011 South African census indicated that approximately 18% of these allied health providers were employed in the public sector (StatsSA 2011). Other rehabilitation providers include community healthcare workers, who may act under instructions from allied healthcare providers to support patients in the community. As seen from some of the case studies, family members often act as informal and unpaid caregivers when assisting patients at home with ADLs, mobility and exercise programmes prescribed to them by healthcare providers.

To provide preliminary insights into the cost of stroke rehabilitation in the South African healthcare system, we used publicly available costs for: (1) hospital daily rates, and (2) hourly rates for service providers in the public and private sectors, respectively. In the public healthcare sector, two information sources were used to determine the service provision cost for each case example, namely, the income category, as determined by the NDoH's Uniform Patient Fee Schedule (2020), and the level or type of healthcare facility (Western Cape Department of Health 2018). The costs for the private sector cases were estimated using information from Netcare Hospital's 2019 Private Patients' Tariffs.

Box 9.9 provides details on the subsidisation framework. We calculated the estimated healthcare costs, using the different types of rehabilitation pathways outlined in the section 'Section 1: Establishing stroke rehabilitation pathways', together with the information from the different authentic patient cases presented in the section 'Section 2: Exemplar patient case studies in South African settings'. The estimated costs are outlined in Table 9.1 and

BOX 9.9: Subsidisation framework used in South African public healthcare system.

Four income categories as determined by the South African National Department of Health's Uniform Patient Fee Schedule:

- Full subsidisation H0: pensioners and the unemployed
- Partial subsidisation H1: less than R70 000 single income or R100 000 family income per year
- Partial subsidisation H2: from R70 000 to R100 000 single income or R250 000 to R350 000 family income per year
- Partial subsidisation H3: more than R250 000 single income or R350 000 family income per year
- Three levels of hospitals from least expensive to most expensive:
- Level 1: district hospitals where there are limited specialist services
- Level 2: regional hospitals that have at least two specialist services
- Level 3: academic hospitals that have most specialist services

Source: NDoH (2020).

Table 9.2. These costs are indicative only and are provided as examples of the range of costs for stroke rehabilitation that could be expected in different healthcare settings. These estimated costs also do not take into account different pay scales for healthcare providers in public or private settings, or 'gap' payments that might be required from patients (see Box 9.9 for the subsidisation framework used in the South African public healthcare system).

It is not possible to predict rehabilitation needs in South Africa, or their likely costs, as there is no South African information on the prevalence of any condition requiring rehabilitation. Data on disability prevalence have, to date, been extrapolated from research projects in specific South African regions, or from individual provinces or the national census. This may not provide a true estimate of need, or of the different ways that patients access rehabilitation.

Ensuring that stroke rehabilitation is of value to patients and their families is a challenge which as yet, cannot be met in South Africa, particularly in light of the national shortage of rehabilitation providers (Maillacheruvu & McDuff 2014; Ned et al. 2017). Access to rehabilitation, especially in rural and remote areas, is further impeded by issues such as transport, its costs and environmental factors such as difficult terrain or crime-ridden areas that need to be crossed (Bateman 2012; Chetty & Hanass-Hancock 2016; Grut et al. 2012; Ned et al. 2017). As a consequence (and as outlined in some case studies), rehabilitation often cannot be provided on a regular basis in these settings for it to be effective and efficient (Dookie & Singh 2012). Moreover, whilst there is some information on direct rehabilitation costs from developed countries such as Britain and Australia, little is known about indirect costs (medication, transport and out of pocket expenses) as well as direct, indirect and opportunity costs to informal caregivers (Tummers et al. 2012).

TABLE 9.1: Cost (in South African Rand) for subsidised patients using government facilities (2018 rates).

Cost of different pathways	**Service**	**Government facility (partial subsidisation – H2)**			**Government facility (partial subsidisation – H3)**			**Government facility (full paying patients)**		
		Level 1	Level 2	Level 3	Level 1	Level 2	Level 3	Level 1	Level 2	Level 3
Case 1: Inpatient fee (level 3, H2) for 7 days + three complex evaluation (H2) + five sessions rehabilitation (H2, level 3) + 21 days inpatient chronic care + 20 sessions rehabilitation (H2, level 2) = 1205+175+420+600 = R2400 *Case 2:* Emergency transport + inpatient fee 3 days (level 3) + three times complex evaluation (H2) + three rehabilitation sessions (H2) + seven OPD consultations (H2) = 400+465+120+245 = R1230	Inpatient acute care facility fee (hospital bed and overnight stay)	90	110	155	761	969	1832	1832	1832	1832
	Day patient (hospital bed no overnight stay)	55	65	90	633	800	1170	1170	1170	1170
	Inpatient chronic care facility fee (rehabilitation hospital)	20	20	20	67	67	67	233	233	233
	Outpatient consultation (no hospital bed)	40	40	40	94	94	113	103	103	126

OPD, outpatient department.

Table 9.1 continues on the next page→

TABLE 9.1 (Continues...): Cost (in South African Rand) for subsidised patients using government facilities (2018 rates).

Cost of different pathways	Service	Government facility (partial subsidisation – H2)			Government facility (partial subsidisation – H3)			Government facility (full paying patients)		
		Level 1	Level 2	Level 3	Level 1	Level 2	Level 3	Level 1	Level 2	Level 3
Case 3: Inpatient fee 3 days (level 2) + two complex evaluation (H2) + six rehabilitation sessions (H2) + four OPD consultations (H2) = 330+80+180 = R590	Patient emergency transport service (within 100 km radius)		40			400			400	
Case 4: Option 1	Complex evaluation from allied health professional		40			113			326	
Day patient (level 1) + one level 1 OPD consultation (H2) = 55+40 = R95 Option 2 Day patient level 1 (H2) = R55 *Case 5*: Complex evaluation level 1 + home visit + rehabilitation session = 0 (no charge as H1 patient)	Rehabilitation session rate with allied health professional	30	30	35	62	62	62		756	

OPD, outpatient department.

TABLE 9.2: Cost (in South African Rand) for patients using private facilities (2019 rates).

Estimated cost of different pathways	Service	Cost (Rand)
Case 6: *Option 1* 17 days inpatient fee + 14 rehabilitation sessions + 25 rehabilitation sessions at nursing home = 69 564 + 11 816 + 24 700 = R106 080 *Option 2* Emergency transport fee + 7 days inpatient fee + 14 rehabilitation sessions = 1000 + 28 644 + 11 816 = R41 260	Inpatient facility fee (hospital bed and overnight stay)	4092
	Sub-acute step-down facility	2833
	Day patient (6 h)	2390
	Patient emergency transport service	1000
	Treatment at nursing home (rehabilitation + nursing home visit costs)	988
	Rehabilitation session rate	844

Source: Adapted from Netcare (2019).

Lessons learnt

The different stroke patient care pathways, and options for care, entailed potentially different costs and may indicate differences in value regarding healthcare received. The inequity of access to rehabilitation was evident from the case studies, and whilst the people least able to access rehabilitation potentially cost the least in monetary terms, they and their families potentially paid the highest price in terms of lost functional capacity, inability to work or contribute to the family, and the need for family to provide basic daily care. Thus, to calculate the true cost of care for stroke was not a simple exercise for any pathway. It is important to note that although information on the cost of resources is valuable, it does not provide information about how the different pathways influenced patient outcomes. However, the information in this section provides information for future investigations regarding value-based healthcare and, in particular, the costs and benefits of stroke care and rehabilitation, within the different pathways of care.

■ Discussion

The typical pathways that people with stroke might follow in South Africa demonstrate the multiple entry and exit points, and referral pathways for rehabilitation, depending on the location and socio-economic status of patients. There is real inequity in access to stroke care in South Africa, and particularly in the public sector, where access to stroke rehabilitation outside metropolitan cities is significantly constrained (Sherry 2015). Contextual factors such as belief in traditional health providers, patient education, health literacy and family and social circumstances, and healthcare system factors play important roles in the rehabilitation pathways that patients may follow. An important finding of the patient pathway mapping exercise was that a subgroup of patients is discharged to home without receiving specialised and ongoing rehabilitation. This may impact on their healthcare outcomes, their ability to reintegrate into the community and the impact on the family. It is consistently recommended in CPGs that all patients should receive rehabilitation as soon as they are medically stable, and that CBR should commence upon discharge from acute healthcare settings. Our authentic cases demonstrate that this does not always happen in South Africa.

Moreover, there is limited research on the costs associated with stroke rehabilitation in Africa. This information is necessary to establish the true costs of stroke, the cost-effectiveness of different rehabilitation options and hence the value of stroke rehabilitation from different stakeholder perspectives. This chapter demonstrates the importance of obtaining contextual feedback from end users (patients, clinicians and families) when undertaking research to ensure that research questions are relevant, pragmatic and context specific. The earlier information is important, considering that the value of rehabilitation is determined by the benefits of care (effectiveness, patient satisfaction and safety) as well as costs of care.

In the section ‘Section 1: Establishing stroke rehabilitation pathways’, we established the different pathways, in which patients with stroke access rehabilitation in South Africa. In the section 'Section 2: Exemplar patient case studies in South African settings', these pathways were validated and further contextualised using typical patient case scenarios. These cases illustrate the reality of what happens to patients with stroke depending on which pathway of care they can access, a situation often based on their location and socio-economic situations. The section 'Section 3: Estimated healthcare and rehabilitation costs' discusses the costs of both hospital care and rehabilitation in the different pathways of care in South Africa. The pathways demonstrate that patients who are not based in metropolitan settings and do not have access to private care or public hospital OPD or rehabilitation centre resources may have limited access to rehabilitation following a stroke. Challenges of physical environments, particularly in rural areas, such as a lack of transport, the cost of transport services, long distances from facilities and inaccessible roads, often result in restricted access to rehabilitation services for persons who have experienced a stroke (Rhoda et al. 2015). In addition, it appears that much decision-making on continued stroke management is undertaken by doctors, nurses or even CHWs without input from rehabilitation professionals and from patients and their families or caregivers. As access to a hospital or even a CHC might not always be possible, rehabilitation interventions in these remote areas should be community-based and should include training and education of caregivers (Rhoda et al. 2015). Thus, people with stroke and their families need to be involved in decision-making and goal setting; however, this collaborative decision-making may be influenced by the healthcare literacy of patients and caregivers. In addition, clinicians need to demonstrate culturally sensitive treatment that demonstrates a collaboration between western and traditional medicine (Bham & Ross 2005).

There are few studies on the cost of stroke care in Africa (Olwabi et al. 2015). The sections 'Section 2: Exemplar patient case studies in South African settings' and 'Section 3: Estimated healthcare and rehabilitation costs' provided types and estimates of costs of care, within different pathways, which should provide the basis for future investigations of stroke care costs and outcomes. This chapter did not tackle the issue of how the different patient pathways influence specific patient outcomes. Information regarding outcome measures appropriate to stroke rehabilitation is provided in Chapter 2 of this book. Subsiding and improving post-stroke rehabilitation in South Africa will undoubtedly lead to better long-term recovery for patients as it will improve the quality of care for those who cannot afford specialised services.

Recommendations for future research

There is an impetus for future research focusing on value-based rehabilitation, which includes the outcomes and benefits of care and the cost of rehabilitation for stroke survivors in the South African context. The current evidence focuses on acute rehabilitation. The impact of medium- and long-term stroke rehabilitation and the cost implications for the individual, family and healthcare system remain unclear. Longitudinal studies on long-term rehabilitation post-hospital discharge are needed.

The patient pathway and outcomes for those who do not present for stroke rehabilitation and for those who delay presenting for rehabilitation are also unclear. It is therefore necessary to gain insight into a patient's perspective of their recovery journey using case studies. This will inform patient indicators for value-based healthcare. The development of specific value-based outcome measures is also urgently needed.

Conclusion

This chapter presents important information about clinical pathways, authentic patient cases and the rehabilitation costs associated with the stroke care and rehabilitation in a South African context. This chapter demonstrates the significant impact of contextual factors on post-stroke rehabilitation. Additionally, this chapter emphasises the need for research on patients' perspectives, family and caregiver perspectives, contextual influences, physical, social and emotional functioning needs, employment and occupational rehabilitation needs. A bigger focus on multisector collaboration is needed for the holistic intervention regarding improving the quality of care for people with stroke, which comprises of access to education, efficient transport and innovations for inaccessible terrain obstacles. Attention to above factors will influence the QoL of the persons with stroke, as well as the overall well-being of the population and the impact on the economy of a country.

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Chapter 10

Contextualised evidence-based rehabilitation recommendations to optimise function in African people with stroke

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Abstract

Background: The identification, contextualisation and uptake of evidence-based stroke rehabilitation strategies are important to optimise the patient and healthcare system outcomes.

Aim: This chapter aims to report on the innovative methods used to produce the SA-cSRG 2017–2018 (2019) and summarises the evidence-based recommendations for implementation in the African context.

Methods: The methodology consisted of eight steps: ask clinically relevant questions; acquire evidence; appraise the evidence; extract the evidence; extracting data; grade the evidence level; endorsement and stakeholder feedback. The quality of the included component guidelines, which answered these questions, was scored using the Appraisal of Guidelines Research and Evaluation, Version II (AGREE II). The extracted recommendations were graded according to a standardised strength of the body of evidence (SoBE) method. The recommendations were then contextualised to the local context based on stakeholder input.

Findings: Seventy-eight composite recommendations were developed. Twenty-three (29%) recommendations were supported by strong evidence. Thirty-six recommendations were supported by moderate evidence (46%) and 19 recommendations were supported by low levels of evidence, no evidence or contradictory evidence.

Conclusion: This chapter outlines steps undertaken to contextualise recommendations to the African setting. These steps provide a blueprint for future guideline writers in LMIC settings to efficiently produce evidence-based guidance for other conditions that can be implemented despite local barriers to evidence uptake.

Keywords: Evidence-based; Rehabilitation; Africa; Contextual barriers; Service performance; Evidence levels; Recommendations.

Introduction

Evidence-based rehabilitation can reduce variability in care, improve accountability and promote quality care to people with stroke to optimise patient and health service outcomes (Jesus et al. 2017; Urimubenshi et al. 2017). In Africa, there is no published information (Chapter 1) to indicate that rehabilitation offered is informed by evidence or that any form of evidence-based guidance is available for stroke rehabilitation. In most African countries, access to acute and/or long-term stroke rehabilitation remains limited because of an insufficient number of rehabilitation workers, scarcity of MDTs, cost of healthcare, lack of access to care, travelling distances, cost of transport, health literacy and cultural beliefs about stroke amongst patients and caregivers (Basri, Naseen & Naz 2017; Dizon et al. 2016a; Ekeh 2017; Ned, Cloete & Mji 2017). The evidence-to-practice gap may be lengthier in LMICs because of contextual and policy barriers to implementation of evidence-based care. The implementation of CPGs has been advocated to narrow this gap; however, it is important that contextual factors are considered during CPG development and implementation to ensure the applicability and acceptability of CPG recommendations for the specific African healthcare setting (Dizon et al. 2017; Kastner et al. 2013). It is therefore imperative that any form of guidance developed in Africa is done in collaboration with all key stakeholders, including people with stroke, to strengthen the health system.

The healthcare system of South Africa is in a process of transitioning to implement the National Health Insurance (NHI) plan. The NHI white paper (2017) guides for cost-efficient, evidence-informed CPGs to improve health services in South Africa. This guidance should, therefore, be developed for prevalent, long-term conditions such as stroke, and should include the key element of rehabilitation as a cornerstone of stroke care. To our knowledge, no rehabilitation guidelines are included in any national evidence-based guidelines in South Africa (Wilkinson et al. 2018); and this may be the status in other African countries as well. This lack of local guidance for post-stroke rehabilitation may indicate that stroke care varies within the country; that rehabilitation may not be equitable across different contexts and that access to stroke rehabilitation is arguably worse in the poorest communities. This notion is confirmed in Chapter 1, where one of the main findings was that there is generally a lack of commonly recommended rehabilitation services in Africa. Congruently, the WHO (2015) estimated that in Southern African countries, only 26%–55% of people receive the rehabilitation they need; and that people with disabilities were two times more likely to access healthcare, or equipment; and that they are about three times more likely to be denied care (WHO 2015). The deficiencies in rehabilitation policy and guidelines should urgently be redressed to improve the situation and meet the needs of the growing number of people in need of post-stroke rehabilitation.

Over the last 20 years, some evidence-based stroke rehabilitation guidelines have been developed for HICs (Grimmer et al. 2018). Guidelines developed in HIC reflect HIC circumstances (and research conducted in HIC service delivery settings) and they may therefore not be readily implementable in LMIC settings because of differences in the healthcare systems, socio-cultural, societal and policy contexts (Ernstzen, Hillier & Louw 2019; Gonzales-Suarez et al. 2012). Additionally, the labour-intensive process of developing CPGs from 'scratch' (*de novo* development) may be challenging for LMICs because of limited capacity, time and resources. However, given that the existing international evidence-base is being regularly synthesised in HIC CPGs, this may undoubtedly lead to resource-wastage by 'reinventing the wheel' (McCaul et al. 2018). The international literature may also have limited applicability in local African contexts. Adapting or simply adopting CPGs based largely on HIC evidence may not be feasible for the African context (Dizon et al. 2016b). In the current milieu of the African healthcare context, it may be more efficient to use the existing good quality evidence-based guidelines from HICs and contextualise the guideline recommendations to ensure that they are applicable and acceptable in local contexts. During contextualisation, recommendations are sourced from existing CPGs but may be tailored to address the specific needs of the context. This process considers how each recommendation might be relevant to local circumstances, and if so, how it might be implemented effectively.

In this chapter, we report on contextualised recommendations, using innovative methodological approaches (Grimmer et al. 2019) from existing CPGs about stroke rehabilitation. This chapter outlines the innovative *methods and focus* taken to produce the SA-cSRG 2017–2018 (SA-cSRG 2019:8) and *summarises the evidence-based recommendations* that could be implemented in the African context.

■ Methodology

The methodology that was developed by the guideline team consisted of eight steps. These steps are outlined below, and detailed methodology is published by Grimmer et al. (2018).

Ask clinically relevant questions

A stakeholder meeting was conducted to create a list of clinical questions applicable to stroke rehabilitation in the South African context. Therapists from different provinces in South Africa were contacted via email and asked to provide questions which they deemed necessary for their specific settings. A set of 38 questions regarding best practice of stroke rehabilitation in South Africa was then organised (or formulated) by the project team, based on the information obtained from the stakeholders. The questions are listed in the study by Grimmer et al. (2018).

Acquire evidence

The guideline team developed a search strategy (Grimmer et al. 2018) to identify relevant CPGs published from January 2010 to April 2017. The 7-year timeframe was set to identify the most recent CPGs that were available in full-text.

Systematic searches were conducted through www.google.com to identify potential CPGs. Specific searches were also conducted through international CPG clearing houses and CPG developers' websites, including, but not limited to: National Guidelines Clearing House; Scottish Intercollegiate Guidelines Network (SIGN) (UK) (www.sign.ac.uk/); National Institute of Health and Care Excellence (NICE) (UK) (https://www.nice.org.uk/); NHMRC (Australia) (www.NHMRC.gov.au/); and New Zealand Guidelines Group (www.nzgg.org.nz/). These websites are listed in the SA-cSRG (2019:16).

Appraise the evidence

The quality of the included component CPGs was scored using the AGREE II (2013; Dizon et al. 2016b). Potentially relevant components of CPGs were not excluded for poor quality, on the basis that any included CPG might provide answers to at least one SA-cSRG question. However, the quality of component

CPGs was taken into consideration when determining the overall strength of the body of evidence (SoBE) for each composite recommendation. To classify CPG quality for the purpose of determining the overall SoBE for each composite recommendation, arbitrary total overall CPG quality score classifications were established by the methodology team as:

1. more than 80% of the total possible AGREE II score denoted high-quality CPGs
2. between 60% and 79% of the total possible AGREE II score denoted moderate-quality CPGs
3. less than 60% of the total AGREE II score denoted poor quality CPGs.

Extract the evidence

What constituted a “recommendation” for data extraction purposes was initially determined by the methodology team and subsequently confirmed with Brian Alper and his colleagues (who are working in the same topic area of evidence synthesis) (Alper et al. 2018; Hillier et al. 2011; Schünemann et al. 2014). This confirmation occurred at the Global Evidence Summit in Cape Town in September 2017 (Haeseler 2017). The importance of determining consensus on what constituted a “recommendation” was to reduce variability and improve efficiency in data extraction.

The inclusion criteria for recommendations were:

- wording that was clearly labelled as a ‘recommendation’ in an included component CPG (appearing in designated recommendation boxes, specific fonts or tables) and accompanied by a SoBE grading (Grimmer et al. 2018)
- wording that appeared in the CPG text, that was not necessarily labelled ‘recommendation’ but which had the intent of a recommendation in terms of its wording (particularly the use of intention words such as ‘should’, ‘could’, ‘might consider’) (Grimmer et al. 2018). It would also have an associated SoBE grading.

The exclusion criteria were:

- wording which appeared in the body of the CPG text, but which was not labelled as a recommendation, nor had the intent of a recommendation (regarding wording), nor had a SoBE grading assigned to it. This information was often presented as descriptive text.

Extracting data

The guideline team developed purpose-built data extraction sheets for each SA-cSRG question and recorded component CPG details, extracted recommendations and associated SoBE grading from each relevant CPG. These were CPGs that provided an answer (in part, or total) to each SA-cSRG question. Recommendations which met the inclusion criteria were extracted verbatim from the relevant included component CPGs, along with the associated SoBE grade (in whichever way it was reported).

Grade the evidence level

The ways in which each included CPG reported gradings for its recommendations were collated. As has been reported by others when synthesising multiple CPG recommendations (Ernstzen et al. 2019; Gonzalez-Suarez et al. 2012; Hillier et al. 2011; Schünemann et al. 2014), CPGs often report SoBE gradings in different ways. Moreover, there is no one agreed approach to standardise SoBE grading descriptions. Thus, because multiple CPGs on stroke rehabilitation were included in the SA-cSRG, the guideline team developed an approach to standardise the component CPG SoBE gradings to assist in determining the overall SoBE discussions for composite recommendations. Thus, the different approaches in which SoBE gradings were reported in the component CPGs were extracted and aligned according to a standardised grading system for each of the extracted recommendation (Grimmer et al. 2018).

The guideline team developed a grading system for determining the SoBE for the composite recommendation, using an adapted version of the approach published by Alper et al. (2017) and Shiffman et al. (2012). However, additional criteria were used, consisting of the number of CPGs which provided recommendations for each SA-cSRG question, their methodological quality (high, moderate or poor) as determined from the overall AGREE II score (AGREE 2013; Dizon et al. 2006b) and where required, their currency (recency of publication). The grading decision-making system for the composite recommendation is reported in Grimmer et al. (2019). The detailed decision-making framework developed for each composite recommendation is available from the SA-cSRG (2019:50.

Endorsement and stakeholder feedback

We used two concurrent processes to contextualise the recommendations. The stakeholder groups assigned an endorsement level (A, B or C) according to a decision-making framework (Grimmer et al. 2019). 'A' denoted that a recommendation can be adopted and implemented without change; 'B' denoted that the recommendation could be implemented with contextualisation processes, whilst 'C' meant that the recommendation was implementable with the addition of local evidence. Depending on the level of endorsement, the group nominated practice and context factors (including barriers and facilitators) that would influence the implementation of that specific recommendation within the South African healthcare system. We specifically focused on identification and reporting of service implications, as well as performance indicators, which can be used to monitor implementation of the recommendations supported by strong evidence which are relevant to all levels of care.

Results

The guideline team produced 78 composite recommendations in total. The results are organised in three sections: the first section focuses on the recommendations that are supported by a high SoBE, the second section presents the service implications and performance indicators for the strong recommendations, and the third section presents contextual factors that were nominated by the stakeholder reference groups according to contextual factor categories. These were used to obtain information about local factors that could influence the effective implementation of recommendations.

Section 1: Recommendations supported by high-level evidence

Twenty-three (29%) of the 78 recommendations were supported by strong evidence. The strength of these recommendations is not likely to change with the subsequent addition of new research evidence. Therefore, these recommendations are deemed priority recommendations for immediate implementation in the rehabilitation journey of people living with stroke.

Table 10.1 illustrates the recommendations supporting strong evidence relevant to the health system, action for rehabilitation, information management, discharge planning and community integration. The levels of care for which the recommendation applies are also indicated in Table 10.1. Notably, many of the recommendations applied to more than one level of care.

The South African reference group endorsement is inserted as superscripts in Table 10.1. It is positive that many of these recommendations were deemed feasible for local implementation (endorsed at A or B level) within the South African context. However, the two recommendations related to falls assessment and prevention were deemed not to be immediately implementable in local contexts. Similarly, the implementation of the recommendation related to community integration may be challenging and further local research or resources may be needed.

Figure 10.1 illustrates the recommendations supported by strong evidence (Table 10.1) which apply to all levels of care. This figure presents a simplified rehabilitation care strategy which clinicians, managers, policymakers, etc. can use to facilitate the seamless implementation of the minimum standards for the rehabilitation of people with stroke. The recommendations

TABLE 10.1: Recommendations supported by a strong body of evidence (South African Contextualised Stroke Rehabilitation Guideline).

Recommendations	Health system factors	Action rehabilitation	Information management	Discharge planning and community integration
Recommendations relevant to multiple levels of care	People who suffer from a stroke should be seen by a multidisciplinary team/inter-professional/interdisciplinary stroke team for medical and rehabilitation assessment and management$^{\mathrm{B2}}$	Rehabilitation should commence as early as possible after the onset of the stroke, or when the person is medically stable, whichever comes first$^{\mathrm{A2}}$	Rehabilitation progress should be regularly evaluated and recorded in a standardised manner$^{\mathrm{A1}}$	Discharge planning for stroke survivors should commence from day 1 of admission to the acute hospital to community rehabilitation as an integral part of the patient journey$^{\mathrm{A2}}$
	Physiotherapists, occupational therapists, speech and language therapists and dieticians bring specific competencies and skills to patient assessment and rehabilitation planning$^{\mathrm{A1}}$	Pressure care risk assessment (monitor skin breakdown) and regular evaluation, done by trained personnel$^{\mathrm{B2}}$	Documentation should be recorded in a legible format in a central place accessible to the MDT$^{\mathrm{B2}}$	Discharge planning should include patients' capacity to be rehabilitated$^{\mathrm{A2}}$
	Rehabilitation plans and management strategies should be designed to meet person-centred goals and needs for recovery $^{\mathrm{A2}}$	Screened as early as possible for risks of adverse events$^{\mathrm{B1}}$	Information about patient progress should be recorded formally inpatient notes and shared at discharge planning meetings$^{\mathrm{A1}}$	Discharge planning should articulate patient and family circumstances$^{\mathrm{A1}}$
		Falls should be prevented$^{\mathrm{A2}}$		Occupational therapy (OT) home visits should be conducted before the patient returning home$^{\mathrm{B2}}$

All superscripts denote SA level of endorsement according to Grimmer et al (2019): $^{\mathrm{A1}}$, the recommendation can be endorsed and implemented within 6 months; $^{\mathrm{A2}}$, the recommendation can be endorsed and implemented within a timeframe that exceeds more than 6 months; $^{\mathrm{B1}}$, the recommendation can be endorsed and implemented with contextualisation processes within 6 months; $^{\mathrm{B2}}$, the recommendation can be endorsed and implemented with contextualisation processes within a timeframe that exceeds more than 6 months; $^{\mathrm{C1}}$, the recommendation is implementable with the addition of local evidence; $^{\mathrm{C2}}$, local evidence is needed to fill the gaps in knowledge.

OT, occupational therapy; MDT, multidisciplinary team.

Table 10.1 continues on the next page→

TABLE 10. 1 (Continues…): Recommendations supported by a strong body of evidence (South African Contextualised Stroke Rehabilitation Guideline).

Recommendations	Health system factors	Action rehabilitation	Information management	Discharge planning and community integration
		Subluxation of the hemiplegic shoulder should be prevented, and if it occurs, minimise pain and dysfunction^{A2} Patients with a stroke should be referred to a multidisciplinary stroke unit as soon as he/he is deemed medically stable^{B2} Fall risk assessment for all using a validated tool^{C2}		
Recommendations relevant to central, district and regional levels of care		Rehabilitation to commence in the acute setting as soon as the person is medically safe and/or able to participate^{A1} Video-fluoroscopic swallow studies (VSS, VFSS) or fibreoptic endoscopic examination of swallowing performed on all patients considered at risk for pharyngeal dysphagia or poor airway protection ^{B2}		

All superscripts denote SA level of endorsement according to Grimmer et al (2019): ^{A1}, the recommendation can be endorsed and implemented within 6 months; ^{A2}, the recommendation can be endorsed and implemented within a timeframe that exceeds more than 6 months; ^{B1}, the recommendation can be endorsed and implemented with contextualisation processes within 6 months; ^{B2}, the recommendation can be endorsed and implemented with contextualisation processes within a timeframe that exceeds more than 6 months; ^{C1}, the recommendation is implementable with the addition of local evidence; ^{C2}, local evidence is needed to fill the gaps in knowledge.

OT, occupational therapy; MDT, multidisciplinary team.

Table 10.1 continues on the next page→

TABLE 10. 1 (Continues…): Recommendations supported by a strong body of evidence (South African Contextualised Stroke Rehabilitation Guideline).

Recommendations	**Health system factors**	**Action rehabilitation**	**Information management**	**Discharge planning and community integration**
Recommendations relevant to intermediate and specialised healthcare centres	Access to specialist stroke service units with a MDT (where available) as early as the hyper-acute to acute stages of stroke and up to discharge ^{B2} Multidisciplinary acute stroke unit: physiotherapy, OT, speech-language pathology, dietetics, clinical psychology and social work (for stroke survivors as well as their families) ^{A2}			Multidisciplinary acute stroke unit: physiotherapy, OT, speech-language pathology, dietetics, clinical psychology and social work (for stroke survivors as well as their families)^{A2}
Primary care/ home/community		An interdisciplinary management plan should be initiated for all those identified as at risk of falls ^{C2}		Given support to reintegrate in the community and encourage social participation^{C2}

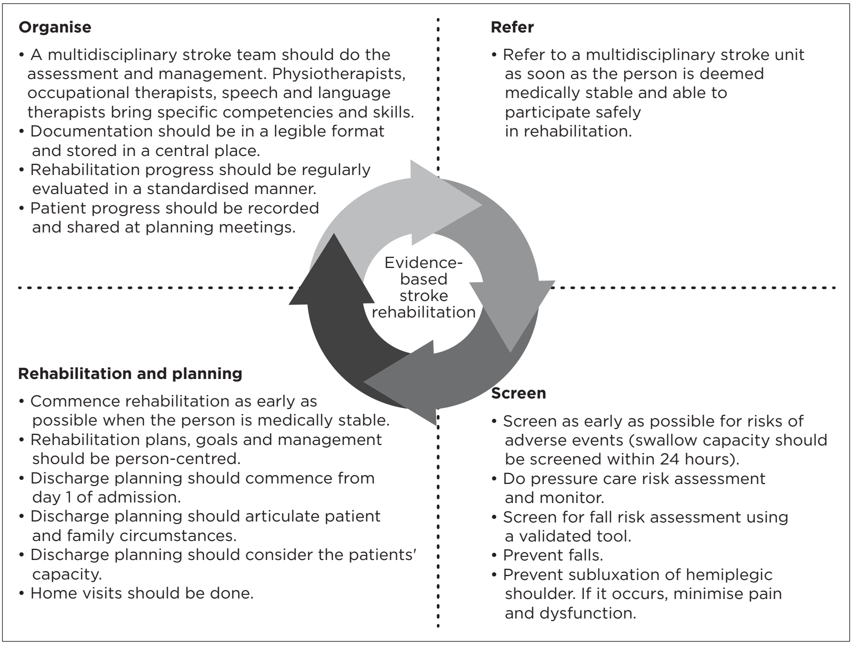
All superscripts denote SA level of endorsement according to Grimmer et al (2019): ^{A1}, the recommendation can be endorsed and implemented within 6 months; ^{A2}, the recommendation can be endorsed and implemented within a timeframe that exceeds more than 6 months; ^{B1}, the recommendation can be endorsed and implemented with contextualisation processes within 6 months; ^{B2}, the recommendation can be endorsed and implemented with contextualisation processes within a timeframe that exceeds more than 6 months; ^{C1}, the recommendation is implementable with the addition of local evidence; ^{C2}, local evidence is needed to fill the gaps in knowledge.

OT, occupational therapy; MDT, multidisciplinary team.

incorporate the organisation of the team, screening, referral to rehabilitation and rehabilitation and planning for ongoing care.

Section 2: Service and performance considerations of strong recommendations relevant to all service levels

Table 10.2 illustrates potential service delivery implications for implementation when teams consider the implementation of the 10 recommendations supported by a strong level of evidence (Table 10.1; Figure 10.1). As part of the endorsement and contextualisation process, stakeholder reference groups provided performance measures for the implementation of recommendations. Many service implications should be considered when planning the



Organise

- A multidisciplinary stroke team should do the assessment and management. Physiotherapists, occupational therapists, speech and language therapists bring specific competencies and skills.
- Documentation should be in a legible format and stored in a central place.
- Rehabilitation progress should be regularly evaluated in a standardised manner.
- Patient progress should be recorded and shared at planning meetings.

Refer

- Refer to a multidisciplinary stroke unit as soon as the person is deemed medically stable and able to participate safely in rehabilitation.

Rehabilitation and planning

- Commence rehabilitation as early as possible when the person is medically stable.
- Rehabilitation plans, goals and management should be person-centred.
- Discharge planning should commence from day 1 of admission.
- Discharge planning should articulate patient and family circumstances.
- Discharge planning should consider the patients' capacity.
- Home visits should be done.

Screen

- Screen as early as possible for risks of adverse events (swallow capacity should be screened within 24 hours).
- Do pressure care risk assessment and monitor.
- Screen for fall risk assessment using a validated tool.
- Prevent falls.
- Prevent subluxation of hemiplegic shoulder. If it occurs, minimise pain and dysfunction.

FIGURE 10.1: Recommendations supported by strong evidence that are relevant to all or multiple levels of care.

BOX 10.1: Service implications and performance measure of 10 selected recommendations supported by strong recommendations (South African Contextualised Stroke Rehabilitation Guideline) and Hebert et al. (2016).

There are consistent strong recommendations that people who suffer from a stroke should be seen by an MDT/interprofessional/interdisciplinary stroke team for medical and rehabilitation assessment and management

Service implications:

- Sufficient number of trained providers working in a coordinated manner
- Communication strategies in place to facilitate the sharing of all information

Performance measures:

- Multidisciplinary team with clearly defined roles as needed for their work context and regular team meetings
- Documented and visible, context-specific strategies/systems to coordinate rehabilitation within the MDT for team efficiency
- Regular audits of professional continuing education to ensure that team has updated training in stroke (including evidence-based recommendations)
- Documented systems of how all providers are integrated to deliver a team approach
- Documented and agreed communication strategies (to ensure time efficiency, early referral, continuity of care, prevent resource wasting and duplication of efforts) to which all team members are compliant

MDT, multidisciplinary team.

Box 10.1 continues on the next page→

BOX 10.1 (Continues...): Service implications and performance measure of 10 selected recommendations supported by strong recommendations (South African Contextualised Stroke Rehabilitation Guideline) and Hebert et al. (2016).

There are consistent strong recommendations that all patients who suffer from a stroke should have access to specialist stroke service units with an MDT (where available) as early as the hyper-acute to acute stages of stroke and up to discharge

Service implications:	**Performance measures:**
- Dedicated ward or unit for admission of acute stroke patients (with appropriately trained staff)	- Time to access to specialised inpatient (acute) stroke rehabilitation/care - The proportion of patients admitted to a stroke unit compared to the total number of stroke patients admitted/presented at emergency care/estimated number of people with stroke in the region or district

There are consistent strong recommendations that all documentation should be recorded in a legible format in a central place accessible to the MDT

Service implications:	**Performance measures:**
- Information management support must be available and known to all staff members - Staff competent in using standardised documentation - A provincial and national information system to collect data for service planning and monitoring	- The proportion of team compliant with standardised documentation practices - Decide on minimum data to collect about patient performance (outcomes) or other factors that can influence service planning/impact the health system

There are consistent strong recommendations that information about patient progress should be recorded formally inpatient notes and shared at discharge planning meetings

Service implications:	**Performance measures:**
- Standardised reporting templates to document patient progress - Guidelines and training on using standardised documentation as decided by the team	- The proportion of team members compliant with documentation guidelines (regular or automated audit of patient records) - Quality of documentation regularly monitored

MDT, multidisciplinary team.

Box 10.1 continues on the next page→

BOX 10.1 (Continues…): Service implications and performance measure of 10 selected recommendations supported by strong recommendations (South African Contextualised Stroke Rehabilitation Guideline) and Hebert et al. (2016).

There are consistent suggestions that achievable and agreed rehabilitation goals should be set and recorded formally inpatient notes

Service implications:	**Performance measures:**
- Discussion with all role-players including family to set achievable goals	- Frequency of team meetings to decide on goals (minutes of team meetings) - The proportion of patient notes with detailed and agreed rehabilitation goals

There are consistent strong recommendations that stroke survivors should be screened as early as possible for risks of adverse events

Service implications:	**Performance measures:**
- Clear and efficient referral mechanisms for screening patients promptly - Staff competent and knowledgeable about the screening of outcome measures - Initiatives to prevent complications and the recurrence of stroke should be communicated	- The proportion of patients that were screened timely - The proportion of patients who experience adverse events post-stroke

There are consistent strong recommendations that rehabilitation should start as early as possible after the onset of the stroke, or when the person is medically stable, whichever comes first

Service implications:	**Performance measures:**
- Define medically stable for your context in collaboration with all team members (communicate to all team members) - Team organisation to ensure that a rehabilitation specialist is available to deliver rehabilitation in a timely manner	- Number or percentage of stroke patients who had a rehabilitation assessment within 48 h (or when medically stable) - Average time from hospital admission for stroke to first rehabilitation assessment for each of the rehabilitation professionals (or a coordinated approach to which the rehabilitation team has agreed)

MDT, multidisciplinary team.

Box 10.1 continues on the next page→

BOX 10.1 (Continues…): Service implications and performance measure of 10 selected recommendations supported by strong recommendations (South African Contextualised Stroke Rehabilitation Guideline) and Hebert et al. (2016).

There are consistent strong recommendations that rehabilitation plans and management strategies should be designed to meet person-centred goals and needs for recovery, within their level of tolerance/ability

Service implications:	**Performance measures:**
- Outcome measurement procedures specified, and all staff are trained and compliant	- Change in functional status measured with a standardised outcome tool, from admission to discharged

There are consistent strong recommendations that discharge planning for stroke survivors should commence from day 1 of admission to the acute hospital to community rehabilitation as an integral part of the patient journey

Service implications:	**Performance measures:**
- Develop a discharge planning approach with all team members - All staff knowledgeable and trained to apply the agreed discharge planning approach	- The proportion of patients and family informed about their discharge plan before the discharge - The proportion of patients for whom discharge planning started on the first day of admission - The proportion of patient notes with documented discharge planning

There are consistent strong recommendations that patients should be given support to reintegrate in the community and encourage social participation

Service implications:	**Performance measures**
- Clear referral policies and trained and committed staff to ensure continuity of care	- Number (or %) of patients with stroke discharged to the community who received a referral for ongoing rehabilitation before discharge from hospital/inpatient rehabilitation setting - Time duration between referral for ongoing outpatient/ community rehabilitation to commencement of therapy - Follow-up to determine the number of patients receiving community rehabilitation - Degree of change in functional level, using a standardised measurement tool, for those engaged in community rehabilitation programmes

MDT, multidisciplinary team.

Box 10.1 continues on the next page→

implementation of the recommendations contained in the guideline. Also, rehabilitation teams and managers should select measures that will be feasible to monitor progress made with the uptake of the recommendations in practice (Table 10.2).

Recommendations supported by moderate level of evidence

Table 10.3 reports the 36 recommendations supported by moderate evidence (46% of all recommendations contained in the guideline). Although these recommendations are supported by a moderate level of evidence, some of these recommendations that are supported by a moderate level of evidence could lead to significant and costly adverse effects or death. In some instances, some of these recommendations could be considered as important as the recommendations for which there is already a strong body of evidence (Figure 10.1). For example, screening of swallowing capacity is critical to implement at all levels of care to prevent serious or fatal complications such as pneumonia. Therefore, rehabilitation teams should still consider these recommendations based on their local or institutional service needs, patient profile, capacity, resources, training, level of care, etc.

Section 3: Recommendations supported by low or no evidence

Table 10.4 illustrates the recommendations supported by low levels of evidence, no evidence or contradictory evidence (for which no clear judgement can be made regarding a recommendation). Although rehabilitation teams could consider the relevance of these recommendations, local applicability and importance of a specific context may be a primary reason for implementing these recommendations. It is important to note that in many instances, it is the lack of evidence (limited research) to support these recommendations, not evidence of no

BOX 10.2: Recommendations supported by a moderate level of evidence and implications (South African Contextualised Stroke Rehabilitation Guideline).

Assessment and outcome measurement

- Standardised outcome measures should be used to assess rehabilitation needs throughout the patient journey
- Swallowing capacity screened (e.g. a simple water swallow test) by a trained health professional before taking any food, drink and oral medication
- Comprehensive assessment of rehabilitation needs should include:
    - Previous functional abilities
    - Impairment of psychological functioning (cognitive and emotional) and communication
    - Impairment of body functions, including pain/orientation
    - Activity limitations and participation restrictions, for example positioning, moving, transfer and handling
    - Swallowing
    - Pressure area risk
    - Continence
    - Nutritional status and hydration
    - Environmental factors (social, physical and cultural)
- Standard assessment process should follow within 24–48 h of admission to hospital
- Routine use of standard outcome measures to detect changes over time and to underpin decisions regarding ongoing rehabilitation
- The Assessment for Rehabilitation Tool is a comprehensive international tool which enables comparisons amongst sites
- Achievable and agreed rehabilitation goals should be set and recorded formally inpatient notes

Communication and education

- Important that the public and health professionals are educated in the use of the F.A.S.T. (Facial drooping, Arm weakness, Speech difficulties and Time to call emergency services) assessment protocol
- Education is given to all healthcare providers about adverse events following stroke
- Formal and informal MDT meetings should occur regularly
- Patients, family and carers should be involved in planning rehabilitation goals and management, problem solving and decision-making, and be given formal and informal education on stroke rehabilitation
- Communication should include written information about stroke, the rehabilitation process, referrals, appointments, discharge summary individualised for the needs of the patients and carers; a mixture of education and counselling techniques; and behaviour change for long-term prevention. There is no evidence regarding the most optimal communication platform for the rehabilitation team
    - consider face-to-face or telephone communication/telemedicine

MDT, multidisciplinary team.

Box 10.2 continues on the next page→

BOX 10.2 (Continues...): Recommendations supported by a moderate level of evidence and implications (South African Contextualised Stroke Rehabilitation Guideline).

Generic rehabilitation aspects

- Stroke survivors should be screened as early as possible for rehabilitation potential
- Rehabilitation progress should be documented centrally and be accessible to all MDT members
- The more therapy is provided, the better the outcome
- Treatment decisions should be clearly documented
- Progression of rehabilitation programmes should be documented, including reason for progression and patient responses
- Walking aids should be considered only after a full assessment of the potential benefits and harms of the walking aid in relation to the individual patient's stage recovery and presentation. Ambulatory assistive devices (including Ankle-Foot Orthoses) should be used where appropriate, to optimise gait and balance impairments, and to improve mobility efficiency and safety
- Adaptive and assistive devices should be used for safety and function, if other methods of performing the task/activity are not available or cannot be learned or if the patient's safety is a concern
- Discharge plannings (DCPs) should be revised regularly throughout the patient journey (inpatient and after discharge to community care)
- Revision of DCPs should align with reassessments of patient progress and goals
- One member of the MDT should take overall responsibility of DCP to ensure continuity
- Discharge planning should be communicated early with community care providers, to ensure that appropriate care and supports are available for patients as soon as they are discharged from hospital and to facilitate transition
- Next, best level of care should be considered after discharge from hospital
- Every member of the MDT should take responsibility for planning and monitoring the continuation of care
- Longer-term care for stroke survivors should reflect their goals and circumstances
- Long-term rehabilitation should be patient and family and/or carer-centred

MDT, multidisciplinary team.

TABLE 10.2: Recommendations supported by limited, contradictory or no evidence.

Category	Interim support	Insufficient/no evidence	No clear judgement
Research opportunities in psychological management	The use of psychological principles from motivational interviewing and problem solving should be incorporated into education programmes for people with stroke	Offering routine psychological therapies in one-to-one format following a stroke will prevent post-stroke depression Each multidisciplinary team should have access to a clinical psychologist Patients with a stroke whose social behaviour is causing distress to themselves or others should be assessed by an appropriately trained healthcare professional to determine the underlying cause and advise on management	-
Research opportunities in communication with stroke survivors and their families	Communication should ideally be commenced and led by one nominated key worker identified by the MDT Communication between health professionals (medical and rehabilitation therapists) could occur via multidisciplinary meetings and case conferences, as well as in liaison with other health professionals through networks	No evidence that guides the appropriate timing of communication and meetings between the patients, family members and health professionals Alternative methods of communication and support (e.g. telephone visits, telehealth or web-based support), particularly for patients in rural settings	-

Table 10.4 continues on the next page→

TABLE 10.2 (Continues...): Recommendations supported by limited, contradictory or no evidence.

Category	Interim support	Insufficient/no evidence	No clear judgement
Research opportunities in self-management	Capacity for self-management could be assessed early in the hospital admission Patients could be trained for self-management to do compensatory techniques, to be able to overcome barriers to engagement in active activities and to engage in social and leisure activities	-	-
Rehabilitation approaches and assistive technology	-	-	Whether Ankle-Foot orthoses should be used for ankle instability or dorsiflexor weakness Wheelchairs should be used for non-ambulatory individuals or those with limited walking ability There is a range of treatment approaches to manage the manifestations of stroke, with different approaches recommended for different stages of stroke rehabilitation and recovery. The treatment approaches are underpinned by variable evidence

Table 10.4 continues on the next page→

TABLE 10.2 (Continues…): Recommendations supported by limited, contradictory or no evidence.

Category	Interim support	Insufficient/no evidence	No clear judgement
Research opportunities in discharge planning	-	-	Patients should be discharged from outpatient care when no more improvement is being reported, and/or when patients are managing well in the community Ongoing monitoring of stroke patients after discharge from rehabilitation
Referral to rehabilitation settings and community maintenance	-	A planned transition could be implemented from an individualised aerobic exercise to more self-directed physical rehabilitation at home or in the community to ensure long-term maintenance Criteria for admission to any rehabilitation setting should be standardised and communicated to all referring centres and services	-
Traditional medicine	-	Role of traditional healers (and other alternative medical practitioners) in local contexts.	-

effectiveness. Thus, further research is crucial. In instances where there is a real need for guidance (but an absence of evidence), rehabilitation teams could consider constituting an expert advisory panel to provide interim guidance. However, regular evidence assessment will be necessary to ascertain if evidence has become available for the specific clinical question.

Section 4: Contextual barriers and strategies to address barriers

Table 10.5 illustrates the framework used to identify barriers within the local context to implement a specific recommendation. This framework included elements related to the organisation, service delivery, communication and clinical care barriers into consideration. During expert reference group meetings, participating rehabilitation

TABLE 10.3: Barriers to implementation of selected recommendations and proposed strategies to overcome barriers (South African Contextualised Stroke Rehabilitation Guideline and Grimmer et al. 2019).

Category	Example barrier and suggestions to address barriers
Organisation • Resources • Type of workforce	**Barrier** Not all levels of care have access to an MDT consisting of doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, social workers, dieticians, clinical neuropsychologists/clinical psychologists **Suggestion** The available member of the MDT should assess a stroke patient to determine whether there is a need to be seen by a dietician, clinical neuropsychologist and/or clinical psychologist. If there is a need, a referral pathway should be in place to allow all stroke patients to have access to the specific member of the MDT, at a facility where such a service is available
Service delivery • Legislative responsibilities/ constraints • Availability of workforce	**Barrier** Not all people with acute stroke will have access to a specialist multidisciplinary stroke unit **Suggestion** Where a stroke unit is available, the patient should be assessed and admitted to the stroke unit using a clear and standard set of criteria. If a stroke unit is not available or the patient does not fit the admission criteria, then the patient should have access to an MDT for care

MDT, multidisciplinary team.

Table 10.3 continues on the next page→

TABLE 10.3 (Continues...): Barriers to implementation of selected recommendations and proposed strategies to overcome barriers (South African Contextualised Stroke Rehabilitation Guideline and Grimmer et al. 2019).

Category	Example barrier and suggestions to address barriers
Communication • People • Resources (phone, Internet and fax)	**Barrier** There is no clear judgement on whether contact with, and education by, trained staff should be offered to all people with stroke, and family or carers after discharge **Suggestion** Community health workers, rehabilitation community workers and peer support groups should stay in contact with and educate people with a stroke, their family and/or carers after discharge. Where rehabilitation community workers are available, they should steer and manage care. Referral pathways back into the healthcare system must be in place
Clinical care • Availability of workforce • Type of workforce • Capacity of workforce • Available equipment • Other available resources	**Barrier** It is not always possible to design rehabilitation plans and management strategies to meet person-centred goals and needs for recovery because of a lack of communication with family/caregivers, lack of support structures and no access to transport **Suggestion** It is important to take the contextual factors influencing recovery into account and to adapt rehabilitation plans and management strategies accordingly. Intersectoral collaboration is necessary to address barriers such as transport-related barriers

MDT, multidisciplinary team.

professionals nominated context-specific barriers and suggested strategies which could be applied to overcome those barriers within the South African context. Table 10.5 outlines example barriers and suggestions relevant to the recommendation for MDTs, stroke units, education of family members or community workers and involvement of the family in goal setting.

■ Discussion

There is little guidance in the implementation literature about taking recommendations from HIC settings and making them locally relevant in an LMIC. This chapter provides new information on the processes of sourcing, evaluating and contextualising clinically based recommendations derived from multiple CPGs to produce a composite, evidence-based stroke rehabilitation guideline that can be implemented in South African contexts. The SA-cSRG is unique, in that it considered international recommendations through the lens of local contextual factors that may influence optimum stroke care and rehabilitation around South Africa.

To date, there is very little information about the implementation, monitoring and assessment of the implementation of evidence-based stroke rehabilitation services in Africa (Chapter 1). The SA-cCRG for stroke rehabilitation (2019) provides evidence-based guidance not only for clinicians but also for managers and policymakers, enabling them to understand, plan, evaluate and monitor rehabilitation services. Working within an environment of scarce resources and a transitioning healthcare system, it is crucial to optimise patient outcomes as well as healthcare system outcomes. It is envisaged that the SA-cSRG will play an important role in optimising rehabilitation services in South Africa, heighten the visibility of rehabilitation services for policymakers and healthcare funders, and contribute towards a better QoL in people with stroke, irrespective of geographical location, socio-economic background and ethnicity. This will assist in securing more funding for rehabilitation, as well as retaining and strengthening existing rehabilitation services.

The SA-cSRG articulates with the goals of the NHI scheme in South Africa, as it can enhance the efficient use of resources within the South African health system and to enhance patient outcomes. It also provides a way in which the South African rehabilitation workforce can demonstrate its accountability. Chapter 1 highlights that greater accountability of rehabilitation professionals is needed to promote health professions, enhance the integration of rehabilitation into health systems, and ensure better use of scarce healthcare funds (Timmermans 2005). The process of contextualising evidence-based recommendations for stroke rehabilitation, as outlined in this chapter, thus has the capacity to empower rehabilitation professionals to become more accountable for the services they provide (not just for stroke, but for other conditions requiring rehabilitation). The issues that need to be considered when providing contextually relevant care based on current best evidence will also provide South African policymakers, managers and healthcare professionals with a framework to evaluate healthcare and patient outcomes. Developing and implementing key rehabilitation standards could facilitate a better understanding of what rehabilitation services entail, and their potential to impact on person-centred and health system outcomes. As indicated in Table 10.3, it is essential to monitor how well recommendations are translated into practice, and how they impact on healthcare outcomes and resource utilisation. This could be an incentive for developing and collecting a national evidence-based minimum dataset on stroke rehabilitation.

This is the first research that we know of, in an LMIC, that has developed a step-by-step approach to progress evidence statements to practical implementation actions. The innovative methodological approach can now serve as a blueprint for other LMICs seeking to develop national rehabilitation guidelines. Possibly the most important learning from this work was the opportunity to focus on implementation, which was largely because the task of developing a *de novo* evidence base, had been removed. Other learnings were that:

- the guideline team must include members with a range of skills (guideline methods, clinical expertise, knowledge of different healthcare settings, and policy or managerial and consumer perspectives). By bringing this collective knowledge to the table, the guideline team was able to identify and understand the different facets of guideline implementation, and present different scenarios within which to test implementation plans
- collaborative and documented decision-making was essential
- clear time frames assisted the team in effective discussions and maintaining deadlines.

The ongoing challenge in guidelines work internationally is the effective uptake of recommendations into everyday practice (Nilsen 2015). Evidence uptake is compounded in countries such as Africa, which have complex, multifaceted challenges to the consistent delivery of best care. Challenges include rehabilitation workforce scarcity, little accurate information on the prevalence of conditions requiring rehabilitation, unknown epidemiology of these conditions, variable patient literacy, complex healthcare beliefs and traditions, costs of accessing care, an overburdened rehabilitation workforce and dire socio-economic factors (such as poverty) that generally excludes people with a stroke from accessing services, even if rehabilitation services are available. The attention given to contextual factors, that may influence the effective implementation of CPG recommendations, such as the transitioning healthcare sector and features of LMIC healthcare system factors may play a key role in narrowing the evidence-to-implementation gap in African settings.

Having to navigate a many-paged guideline may be daunting for busy clinicians. This chapter therefore also presented a subset of key recommendations, focusing on those supported by a strong body of evidence. This approach was needed as the large number of recommendations contained in the SA-cSRG (2019:28–36) may also be perceived as a barrier to evidence implementation. Prioritising recommendations based on the strength of their evidence, and their ease of implementation, may initiate a stepwise implementation process which may be time and cost-effective, and hence acceptable in a transitional healthcare system.

Figure 10.1 in this chapter is thus useful as it provides a simplified infographic of selected key recommendations which can serve as a starting point when implementing recommendations. This infographic can be printed on a single page and/or poster and provides an easy-to-read summary of the evidence for healthcare professionals to implement into practice. It also offers a succinct summary for rehabilitation teams, managers and policymakers in other African countries who need to upscale stroke rehabilitation services. Whilst providing recommendations in an easy-to-read format may assist clinicians to get started with implementation, there must be global support for the consistent provision of evidence-based rehabilitation from national and provincial politicians, policy makers and bureaucrats, health facility managers, health insurers and patient advocacy groups. Engagement from the highest levels of government to healthcare workers should be supported by efficient communication strategies, sufficient resources and shared values. There is also an urgent need for the development of a minimum national dataset and performance indicators to assist in monitoring the quality of care, and the embedding quality assurance principles into rehabilitation.

There was a surprising number of recommendations that were able to be endorsed for immediate implementation. However, many others were not immediately implementable because of a variety of context-specific factors. One of the main factors was access to (or availability of) a rehabilitation team (human resources). To redress this requires intervention from NDoH and tertiary training institutions. Without a skilled rehabilitation workforce to implement the evidence-based recommendation contained in the SA-cCRG, ensuring equitable access to high-quality post-stroke rehabilitation in South Africa will remain a challenge. Another important contextual factor was the lack of efficient communication and information systems involving the different clinicians involved in stroke care, as well as family and/or caregivers. A national minimum dataset, and an innovative information system that captures and communicates data relevant to rehabilitation services, quality care and outcomes are urgently needed.

A side-benefit of the process of amalgamating and contextualising evidence-based recommendations from existing CPGs was the identification of gaps in knowledge. A better understanding of matters such as traditional medicine, self-management strategies that articulate with health literacy and health beliefs, and the use of telecommunication strategies is particularly important given the contextual realities of rehabilitation in African settings. A prioritised national staged research agenda to better understand effective rehabilitation in African settings is thus required.

Limitations and recommendations

The key limitation of this project was that there were unequal representation and involvement of the nine South African provinces. In some of the rural and remote areas of different provinces, access to email or even a computer was a challenge, and therefore it was challenging to contact clinicians and patients in these areas. Another limitation was that not all reference groups included facility managers and rehabilitation managers, which is key to the effective implementation of the evidence-based recommendations in local clinics. Future projects should consciously recruit a more comprehensive and representative group of stakeholders into the guideline reference group. Another important limitation was the lack of inclusion of an economic analysis of the cost of implementing the SA-cCRG. Although a cost estimate is not typically included in standard guideline development processes, it is a barrier for endorsement of guidelines by governing bodies in the African context because of constrained financial resources.

The recommendations presented in this chapter were contextualised for the South African context. The African continent presents many diverse settings and health contexts. Therefore, the recommendations presented in this chapter may not be generalisable to all African countries or region. We propose that the detailed contextualisation method described in this chapter is followed by African stroke rehabilitation teams to ensure that the recommendations are feasible for implementation in their local context. The methodological approaches can also be adopted and developed further by African guideline teams to develop evidence-based guidance for other conditions.

Conclusion

This chapter outlined the steps taken to consider the effective implementation of international evidence-based recommendations for stroke rehabilitation into African healthcare settings. It used existing evidence from international guidelines and distilled this into a composite set of recommendations that addressed clinical questions important to South African stakeholders. New processes were developed to determine a universal approach to describe the SoBE and to write one composite recommendation from multiple recommendations provided in multiple CPGs. Most importantly, however, this chapter outlines the steps undertaken to contextualise recommendations to African settings. These steps provide a blueprint for future guideline writers in LMIC settings to efficiently produce evidence-based guidance for other conditions that can be implemented despite local barriers to evidence uptake.

APPENDICES

Appendix A: Self-administered questionnaire for quantitative data (Study One and Study Two)

Section A

Participant number:
Gender:
Age:
Home Language:
Other Languages:
Where did you receive your tertiany training?
How long have you worked in neurology care?
What are your responsibilities in the neurology wards?

Section B

Please circle the most appropriate definition. You may choose only ONE OPTION.

1. **Aphasia**
   a. Language impairment due to neurological damage affecting planning of speech.
   b. Language impairment due to neurological damage affecting understanding and production of speech.
   c. Language impairment due to damaged or inactive muscles affecting speech production.
2. **Dysphagia**
   a. Swallowing difficulties causing food and liquids to take longer to move from the mouth to the stomach.
   b. Inability to taste food and liquids.
   c. Swallowing difficulty relating to the inability to digest solid foods and liquids.

3. **Apraxia**
   a. Disturbance resulting in the inability to move mouth structures due to weak muscles.
   b. Disturbance in the accurate production of speech due to damage of mouth structures.
   c. Disturbance in the planning of messages sent from the brain to the mouth causing the inability to move mouth structures for speech.
4. **Dysarthria**
   a. Neurological motor impairment causing uncoordinated and slow speech due to the abnormality of mouth muscles.
   b. Impaired speech production due to the brain's inability to plan speech movements.
   c. Impaired speech production due to slow language processing.
5. **NGT**
   a. Inserted to provide breathing compensation to the patient.
   b. Inserted to drain excess fluid from the body.
   c. Inserted to provide feeding for patients who are unable to swallow or sustain nutrition orally.
6. **Receptive language difficulties**
   a. Patient is unable to use speech and language in a way that makes sense.
   b Patient struggles to understand what you are saying.
   c. Patient is unable to correctly plan and programme what they want to say.
7. **Aspiration**
   a. Patient struggles to swallow food after chewing.
   b. Foods or liquid is breathed into the airway and lungs instead of being swallowed.
   c. Difficulties with die complete digestion of foods and liquids.
8. **Neologism**
   a. Patient produces incorrect words due to impaired oral muscles.
   b. Patient uses made-up words.
   c. Patient repeats words.

9. **Anomia**
    a. Difficulty in finding the correct words.
    b. Inability to produce difficult words.
    c. Repetition of specific words.
10. **Gastroesophageal reflux (GERDI)**
    a. Upward movement of gastrointestinal contents into the oesophagus and airway.
    b. Difficulty in digestion of foods due to increased acid in the stomach.
    c. Inability to consume acidic foods and liquids.
11. **AAC**
    a. An impairment in patients who are unable to produce sufficient speech.
    b. Repetition of important phrases by patients who cannot produce complex speech.
    c. A variety of communication systems which aids patient to communicate.
12. **Do you experience any challenges regarding the terminology used by the speech therapist in hospital documentation?**

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Section C

Carefully read each statement and decide whether the disorder, marches **ALL** *the signs. Mark* **ONLY** *TRUE or FALSE.*

1. **The following signs are related to APRAXIA.**
    a. Patient brings food or acid back up.
    b. Patient drools.
    c. Patient loses weight.

☐ **TRUE** ☐ **FALSE**

2. **The following signs are related to APHASIA.**
   a. Patient does not understand conversation.
   b. Patient's sentences are incomplete and does not make sense.
   c. Patient uses nonsense words.
   ☐ **TRUE** ☐ **FALSE**
3. **The following signs are related to DYSPHAGIA.**
   a. Patient struggles to move their facial muscles and mouth structures.
   b. Patient presents with slow, monotone and/or slured speech.
   c. Patient presents with nasal, strained, too soft or too loud voice.
   ☐ **TRUE** ☐ **FALSE**
4. **The following signs are related to DYSARTHRIA.**
   a. Patient's articulators grope to produce sounds and words.
   b. Patient substitutes, omits, distorts and/or adds sounds in words.
   c. Patient struggles with imitated or purposeful speech.
   ☐ **TRUE** ☐ **FALSE**
5. **Are there any signs or symptoms that you could match to ORAL APRAXIA?**

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Section D

Carefully read each statement and select the **OPTION** *or* **OPTIONS** *that best suits the statement.*

1. **The following signs are related to EXPRESSIVE LANGUAGE DIFFICULTIES.**
   a. Patient gives unreliable answers to yes/no questions.
   b. Patient struggles to find words.
   c. Patient shows a difficulty understanding figurative language (e.g. jokes, idioms).

2. **The following signs are related to GASTROESOPHAGEAL REFLUX DISEASE (GERD).**
   a. Patient presents with chronic coughing.
   b. Patient experiences pain during swallow.
   c. Patient presents with vomiting.
3. **The following signs are related to DYSARTHRIA.**
   a. Patient is vulnerable to aspiration.
   b. Patient may speak too fast or too slow.
   c. Patient's speech may be at an abnormal rhythm.
4. **The following signs are related to RECEPTIVE LANGUAGE DIFFICULTIES.**
   a. Patient is unaware of their errors.
   b. Patient has difficulty understanding figurative speech (e.g. humour).
   c. Patient gives unreliable answers to yes/no questions.
5. **Are there any other signs or symptoms that you can indicate, that relates to these disorders? Please specify (e.g. dysphagia, aphasia etc.)**

____

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Section E

The following statements describe possible barriers experienced by nursing personnel regarding the recommendations made by speech therapists when treating patients in the neurology care setting.

Use the following scale and circle the most appropriate number:				
Strongly disagree	**Moderately disagree**	**Moderately agree**	**Strongly agree**	
1	**2**	**3**	**4**	
I experience challenges with the speech therapist's recommendations in terms of patient care because...				
1. Time constraints play a role m the completion of the task.	1	2	3	4
2. I do not understand the terminology used by the speech therapist	1	2	3	4

3. I do not have the skills to perform or complete the task.	1	2	3	4
4. It is not my responsibility as a nurse.	1	2	3	4
5. The speech therapist uses a language other than my home language or that I do not understand.	1	2	3	4
6. I experience frustration due to the fact that I don’t receive training in the specific techniques used by the speech therapist.	1	2	3	4
7. A lack of self-confidence interferes with my ability to perform the suggested task.	1	2	3	4
8. I disagree with the speech therapist’s recommendations with regards to treatment.	1	2	3	4
9. The work load of nurses is already more than what can be handled by the personnel.	1	2	3	4
10. I find the completion of the task demeaning and that it should be completed by staff less qualified.	1	2	3	4
11. I expenence a feeling of hostility amongst intra- professional personnel.	1	2	3	4
12. I do not receive sufficient support from co-workers.	1	2	3	4
13. The patient disagrees with the recommendation made and refuses treatment.	1	2	3	4
14. Do you have any suggestions that could improve the chances of nursing staff implementing recommendations?				

Appendix B: Self-administered questionnaire for nurses' preferences during training (Study Three)

Protocol number: **S17/01/014**

Participant number:

Name of qualification:

Name of university/college:

Years of experience:	0-5 years	6-10 years	11-15+ years

Current hospital:

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Section A: Work environment					
1. I have enough time to sit and feed all the patients with swallowing difficulties					
2. It is not my responsibility to take care of patients with swallowing difficulties					
3. I have too much work to do to feed patients with swallowing difficulties					
4. There are enough nurses to take care of all the patients					
5. It is in my scope of practice to feed patients with feeding and swallowing difficulties					
6. It takes too long to feed patients with swallowing difficulties					
Section B: Speech language therapy recommendations					
7. I know what the role of the speech language therapist is in swallowing difficulties					
8. I am not sure how to give thickened liquids to a patient					
9. I know how to position a patient for feeding					

10. I know which patients are on special diets					
11. I am not familiar with the terminology used by the speech language therapist					
12. I know what a soft diet is					
13. The speech language therapist is not involved in swallowing difficulties					
14. Swallowing difficulties are not important for me or for the patient					
15. I have been taught how to feed a patient with swallowing difficulties					
16. I do not agree with the speech language therapist's recommendations					
17. I am not sure what a puree diet is					
18. I understand why certain diets are given to patients with swallowing difficulties					
19. I am comfortable with feeding patients with swallowing difficulties					
20. I am not familiar with the feeding postures that are prescribed by the speech language therapist					
21. Working with patients with swallowing difficulties makes me uncomfortable					
22. It is important to follow feeding recommendations					
	Strongly disagree	Disagree	Nerther agree ■ or disagree	Agree	Strongly agree
Section C: Patients					
23. It is difficult to feed patients with swallowing difficulties					
24. Patients do not like their special diets					
25. Patients with swallowing difficulties are cooperative when I feed them					
26. I find it easy to feed my patients with swallowing difficulties					
Section D: Training					
27.I have had enough training in working with patients with swallowing difficulties					
28.I would like to receive more training in working with patients with swallowing difficulties					

Section E: Information preferences					
29. When being trained, I prefer written information					
30. When being trained, I prefer verbal information					
31. When being trained, I prefer using a computer					
32. When being trained, I prefer face-to-face contact					
33. When being trained, I prefer both written and verbal information together					
34. When being trained, I prefer roleplay aid examples					
35. When being trained, I prefer a PowerPoint presentation					
ONLY COMPLETE UP TO HERE					
Section F (for researcher's use)					
Tell me about your work environment and how it influences your care of patients with dysphagia.					
Tell me how you feel about the recommendations that the speech language therapist makes.					
How do you feel about the dysphagic patients that you work with?					
Tell me about the training that you have received regarding dysphagia.					
Tell me about how you prefer to get information? For example, having it written down, having someone tell you, etc.					

Science direct search strings

Limits: Reviews and Research articles

2001–present

10 March

Appendix C: Example search string (Science Direct)

	Keywords
1	Cross-cultural adaptation and stroke and Africa
2	Adaptation and validation and stroke and Africa
3	Psychometric and stroke and Africa
4	Cross-cultural adaptation and hemiplegia and Africa
5	Adaptation and validation and hemiplegia and Africa
6	Psychometric and hemiplegia and Africa
7	Cross-cultural adaptation and hemiparesis and Africa
8	Adaptation and validation and hemiparesis and Africa
9	Psychometric and hemiparesis and Africa
10	Cross-cultural adaptation and cerebrovascular accident and Africa
11	Adaptation and validation and cerebrovascular accident and Africa
12	Psychometric and cerebrovascular accident and Africa

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Chapter 1

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Chapter 9

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Chapter 10

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Index

This book covers research findings from African countries to highlight the challenges faced by stroke survivors, as well as their caregivers and families. The authors highlighted that there is a need for integration of rehabilitation services into health systems and multidisciplinary team care at all levels of care wherever possible. They also emphasise the importance of both in and out of hospital rehabilitation services, including specialised rehabilitation units to improve rehabilitation outcomes. A subset of key stroke rehabilitation recommendations that are supported by a strong body of evidence are also presented in this book. This is the first set of stroke rehabilitation recommendations developed within an African context following a thorough process of literature review and consultations with stroke rehabilitation health professionals in clinical practice, academia and health facility administrators.

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This book is very relevant today, given the high prevalence of stroke in Africa, which is also a leading cause of death and disability. The strength lies in collating stroke rehabilitation research from different parts of the continent and coming up with contextual guidelines for practice. With rehabilitation services in Africa not being comprehensive, such guidelines are essential, and in line with the WHO Rehab 2030 plan. In my opinion, all the chapters in the book are relevant and sensible choices that are well organised, logically flowing from the one chapter to the next. The chapters and themes cover the necessary aspect of rehabilitation in a logical flow of the main conditions encountered in the average neurological physiotherapy practice. This book is highly scientific, yet easy to read and comprehend, and can be used by researchers. As a neuro-rehabilitation therapist I would definitely recommend this book. It is very important in this evidence-based era to have a resource of this nature to guide and inform research on rehabilitation policy and practice.

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