

Understanding and addressing needs of community stroke survivors in a low resource setting: Improving outcomes for Rwandan stroke survivors

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TITLE PAGE

Understanding and addressing needs of community stroke survivors in a low resource setting: Improving outcomes for Rwandan stroke survivors

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LAY ABSTRACT

The issue of post-stroke disability is significant in Rwanda due to limited resources for stroke survivors. To improve the resources available for stroke survivors in such settings, it is important to understand their specific needs and explore alternative approaches to provision of interventions.

We surveyed 337 patients from six hospitals in Rwanda to describe their functional unmet needs after stroke and at three months. Within 90 days of stroke, Rwandan stroke survivors have more moderate to severe functional needs in almost all usual activities, which is twice compared to post-stroke unmet needs for stroke survivors living in areas with post-stroke resources. Three months after leaving the hospital, over half of the participants still have moderate to severe functional needs in mobility and other usual activities, working, and social/recreational activities. Rwandan stroke survivors identified that not being able to use therapy services made it difficult to address these needs. These data indicate it is crucial to focus on community-based interventions to address the needs of stroke survivors.

In my research, I investigated whether Community Health Workers (CHWs) could administer rehabilitation treatment in resource-limited areas. Although the effectiveness of physical rehabilitation by CHWs is uncertain, there is potential for CHWs to participate in delivering rehabilitation. It is worth considering the use of CHWs for post-stroke rehabilitation. In order to successfully implement CHW-delivered interventions, two important steps were considered. First, an intervention was developed. Second, an operational team is being established to ensure the intervention's success.

The process of designing a new evidence-informed post-stroke community-level mobility intervention suitable for resource-limited areas, consisted of multiple phases. The Rehabilitation Treatment Specification System was used to design and describe the intervention accurately so that it could be replicated easily. The next phase involves examining if the intervention is practical, efficient, and can be successfully implemented in areas with limited resources.

ABSTRACT

Stroke survivors in low-resource settings like Rwanda often face high levels of disability, and access to rehabilitation care is limited. To effectively allocate resources, it is crucial to understand and address the most significant concerns of stroke survivors and explore contextually appropriate approaches to post-stroke care.

We conducted a needs assessment survey of 337 patients from six hospitals in Rwanda, collecting data at discharge and three months post-stroke. Rwandan stroke survivors have similar unmet functional needs as those in high-resource settings. However, over half of the participants still reported moderate to severe mobility, usual activities, and social/recreational activities needs at three months post-discharge. Stroke survivors indicate that limited access to services was a significant barrier to addressing these needs. Community-based interventions may be an important method for addressing these needs; however, rehabilitation services are limited, warranting the need to consider alternative strategies to address these needs.

The thesis explores the potential of involving community health workers (CHWs) in providing rehabilitation interventions for stroke survivors in community settings. Although the effectiveness of CHWs in providing physical rehabilitation interventions in low-resource settings remains uncertain and sustainability of these interventions outside the studied context is also unclear. Subsequent the use of CHWs for post-stroke rehabilitation is a worthwhile endeavor. To facilitate the implementation of CHW-delivered interventions, two crucial steps were considered: the development of an intervention and establishing an operational team that will ensure implementation success.

A multi-phased process was used to design a new evidence-informed post-stroke community-level mobility intervention suitable for low-resource settings. The Rehabilitation Treatment Specification System enabled the intervention design and description toward facilitating its accurate replication. The next step is to test the intervention's feasibility, effectiveness, and implementation in low-resources settings.

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LIST OF ABBREVIATIONS

- CHWs:** Community health workers
- LMICs:** Lower middle-income countries
- HICs:** Higher-income countries
- mNAQ:** modified Needs Assessment Questionnaire
- BADL:** Basic activities of daily living
- IADL:** Instrumental activities of daily living
- CI:** Confidence interval
- ORs:** Odd ratios
- aOR:** adjusted odds ratios
- mRS:** modified Rankin Scale
- PT:** Physiotherapy
- OT:** Occupational therapy
- VHVs:** Village Health Volunteers
- CBR:** Community-Based Rehabilitation
- ADLs:** Activities of Daily Living
- QOL:** Quality of Life
- ROBINS-1:** Risk of Bias in Non-randomised Studies - of Interventions
- GRADE:** Grading of Recommendations Assessment, Development and Evaluation
- RCTs:** Randomized Control Trials
- CCT:** Circuit Class training
- RTSS:** Rehabilitation Treatment Specification System
- TIDieR:** Template for Intervention Description and Replication
- CPGs:** Clinical practice guidelines
- 6MWT:** Six-minute walk test
- 10MWT:** Ten-minute walk test

DECLARATIONS OF ACADEMIC ACHIEVEMENT

My thesis consists of a general introduction, three separate manuscripts, where I am the first author, and an overall discussion. Chapter 3 was published in the Human Resources for Health on June 21, 2023, chapter 2 was submitted to the International Journal of Stroke on July 25, 2023, and I am waiting for a decision. Chapter 4 was submitted to the Archives of physical Medicine and Rehabilitation on July 30, 2023, and a response is pending. All chapters were conceptualized by Anne Kumurenzi, who also led the data collection (chapter 2) and analysis for chapters 2, 3, and 4. Below, I have provided a summary of the contributions made to each manuscript.

CHAPTER 2:

Kumurenzi, A., Jesus, T., Richardson, J., Thabane, L., Kagwiza, J., Cockburn, L., Langhorne, P., DePaul, V., Melifonwu, R., Bidulka, P., Hamilton, L., Urimubenshi, G., Kaddumukasa, M., Bosch, J. Understanding the functional needs of community-dwelling stroke survivors in Rwanda: a prospective observational cohort study. Submitted to the International Journal of Stroke.

Contributions

Conceptualization, AK, JB, data curation, AK, JB, formal analysis, AK, JB, LT, investigation, AK, JB, methodology, AK, JB, LT, JR, project administration, AK, JB, resources, AK, JB, software, JB, AK, supervision, JB, JR, LT, JK, validation, AK, JB, visualization, AK, JB, TS, LT, JR, writing-original draft, AK, and writing-review & editing, JB, TS, JR, LT, JK, LC, PL, LH, DV, GU, MK, RM, PB.

CHAPTER 3:

Kumurenzi, A., Richardson, J., Thabane, L., Kagwiza, J., Urimubenshi, G., Hamilton, L., Bosch, J., Jesus, T. Effectiveness of interventions by non-professional community-level workers or family caregivers to improve outcomes for physical impairments or disabilities in low resource

settings: systematic review of task-sharing strategies. Published with the Human Resources for Health Journal.

Contributions

AK designed the systematic review under the supervision of JB. AK and TJ performed a systematic literature search. AK, GU, or LH independently performed article screening and selection, data extraction, and quality appraisal. AK and JB synthesized the data. AK wrote the first draft of the manuscript. JR, LT, and JK revised the draft. AK, JB, and TJ revised the subsequent version of the manuscript.

CHAPTER 4:

Kumurenzi, A., Bosch, J., Jesus, T., Richardson, J., Thabane, L., Langhorne, P., Kagwiza, J., Turkstra, L. A novel method for developing an evidence-based, community health workers delivered, mobility intervention for stroke survivors in low-resource settings. Submitted to Archives of Physical Medicine and Rehabilitation.

Contributions

Conceptualization, AK, JB, LST, literature review and analysis, AK under the supervision of JB, screening and selection of studies, and data extraction, AK and JB synthesized the data. AK wrote the first draft of the paper. JR, LT, JK, and TJ revised the draft. AK, JB, TJ, and LST revised the subsequent version of the paper.

CHAPTER 1: INTRODUCTION

Background

Stroke is a major health concern in low and middle-income countries (LMICs), resulting in a high number of deaths and disabilities.^{1,2} LMICs are particularly affected, with over 70% of post-stroke related death burden.³⁻⁵ In Africa, where 81% of the countries are considered LMICs, the estimated annual stroke incidence rate is 316 per 100,000⁶ and the prevalence rate is 1,460 per 100,000.⁷ In Rwanda, stroke is the third leading cause of death,⁸ with an age-adjusted stroke mortality rate of 105.6 per 100,000,⁹ considerably higher than the Canadian rate of 12-13.4 deaths per 100,000.¹⁰

More than 80% of post-stroke disabilities are reported in LMICs, mainly in Africa.¹¹ A conservative estimate of post-stroke disability in Rwanda indicates that 37% of stroke survivors experience moderate to severe disability one year after stroke.¹² The estimate is likely an underestimate, as 20% of participants were lost to follow-up. Strokes are more common and result in more death and disability in LMICs, such as Rwanda, compared to higher-income countries, highlighting the urgent need for action.

In high-resource settings (usually found in (HICs)), stroke patients typically have access to specialized stroke units and inpatient rehabilitation services.^{13,14} Patients also have access to home or community-based care after discharge.¹³ However, in LMICs, mainly in low-resource settings, those experiencing a stroke do not always have access to hospital,¹⁵ and if admitted, stroke units are rare and inpatient rehabilitation services are limited.^{12,16-18} Like van Zyl et al, low resource settings as settings with structural constraints in the financial, infrastructure, equipment, informational, or human resources required for optimal healthcare delivery.¹⁹

In low resource settings, most stroke patients are admitted to hospital long after the onset of symptoms and are discharged as soon as they are medically stable, often within a short period of time, and before rehabilitation can be provided.^{17,20} In Rwanda, patients present to the hospital after a significant delay from the onset of symptoms (mean time of 76.8 hours after symptoms

first appear).¹² They are admitted for a short period (~10 days) [Urimubenshi, unpublished data 2021], and when medically stable are often discharged without receiving rehabilitation or training.^{17 12} The burden of care is assumed by the family. As family members often live together, the family is often faced with loss of wages from the stroke survivor and the family member who must care for them.²¹ Although there are no data specifically on expenditures in Rwanda, among the uninsured in the United States, 75% of stroke survivors experience catastrophic health care expenditures (defined by the World Health Organization as an expenditure of greater than 40% or more of the capacity to pay).²² The situation emphasizes the urgent need for community support since community care is non-existent in low-resource regions like Rwanda. It is crucial to develop strategies that provide rehabilitation and support to stroke survivors in the community, considering their specific needs and the resources available.

Research has demonstrated that rehabilitation interventions can enhance mobility and functional ability for individuals who have experienced a stroke.^{23,24} However, in regions with limited resources like Rwanda, access to stroke rehabilitation services is restricted and the services provided may be inconsistent.²⁵⁻²⁸ Stroke survivors in low-resource settings face various complex challenges in accessing rehabilitation services. These challenges include financial constraints, limited access to services, and the absence of follow-up care from healthcare professionals.^{16,29,30} Furthermore, post-stroke care interventions in HICs may not always apply to low-resource settings for reasons such as underlying factors like limited or lack of skilled human and other resources and lack of community support and ongoing rehabilitation after hospital discharge.^{3,13,31,32} Therefore, rehabilitation interventions for use in low resource settings should address the following considerations:

The severity of stroke cases presenting at hospitals: In LMICs, where stroke cases may present with greater severity, implementing appropriate rehabilitation strategies are even more critical.^{14,15,33,34} These strategies could be restorative and include early initiation of rehabilitation, task-oriented treatment, and community-based interventions. The strategies may also need to be compensatory, as the extent of the disability may be restorable, but with adaptation to tasks or environment, the stroke survivor may be able to independently function in key activities (e.g., toileting, eating, dressing).

The age of stroke survivors: In LMICs, stroke affects younger populations more significantly than in high-income settings.³⁴ There is a significant difference between LMICs and HICs regarding age at time of stroke (63.1 years vs. 68.6 years, $p < 0.01$),³⁴ particularly in Africa.^{13,27} The younger age of stroke survivors in LMICs increases the economic implications of stroke, as there is a greater potential loss of productivity and income with associated expense in caring for the stroke survivors.^{34,35} Stroke survivors of all ages often struggle to resume work because their disability affects their ability to return to previous work, and the work force is not designed to accommodate those with disability.^{27,30,36} The situation is particularly challenging in countries like Rwanda, where many individuals continue to work beyond the age of 65 (retirement age). To help stroke survivors overcome these financial obstacles and rebuild their lives, it is essential to provide vocational rehabilitation and help advocate for suitable employment opportunities.^{37–39}

Access to post-stroke care and rehabilitation services is limited: Accessibility of post-stroke care and rehabilitation services is worse in many LMICs compared to HICs.⁴⁰ The scarcity of resources and funding of rehabilitation services contributes to the lack of availability and quality of post-stroke care and rehabilitation services.^{14–16,41} In rural areas, where most of the population resides (82% of the Rwandan population), resources are even further limited. Alternative strategies must be explored to address post-stroke rehabilitation and community support in resource constrained settings. Strategies may include but are not limited to involving lower cost health care resources, such as community health workers (CHWs) or family caregivers in the delivery of basic rehabilitation interventions.^{42–45} They can be trained or supervised by skilled healthcare professionals to deliver basic, effective, and culturally acceptable healthcare programs at the community level.^{46,47}

Maintaining independence in performing daily activities: Evidence has shown that physical rehabilitation interventions are highly effective in improving functional recovery, with a standard mean deviation (SMD) of 0.78 and a 95% confidence interval (CI) of 0.58 to 0.97.⁴⁸ In particular, mobility can be significantly enhanced with an SMD of 0.46 and a 95% CI of 0.32 to 0.60. The level of improvement in functional activities and mobility for patients can vary

depending on several factors. These factors include the severity of the impairment, which tends to be worse in low-resource settings.⁴⁹⁻⁵¹ Additionally, the type and intensity of rehabilitation can be limited due to resource constraints.¹⁴ Furthermore, adherence to treatment may be cut short due to the costs of services and transportation to facilities that provide rehabilitation.¹⁴

Enabling stroke survivors to engage in home and community activities: Active participation in the home and community is crucial for the functional recovery and well-being of stroke survivors.⁵² However, factors such as limited resources, lack of access to rehabilitation services, transportation, and distance to healthcare facilities can significantly impact stroke survivors' ability to engage in their home and communities.^{14,53,54} The situation is especially true in LMICs, where resources may be scarce. Implementing community-based programs becomes even more critical in such situations. These programs can bridge the gap in access to formal rehabilitation services by training and supporting caregivers^{45,55} and CHWs⁴³ to provide essential rehabilitation interventions to stroke survivors. Involving caregivers and CHWs ensures that stroke survivors receive continuous care and attention in their homes, leading to improved functional outcomes, independence, participation, and a reduced caregiving burden.^{42,56}

Knowledge gap

My research program aims to enhance the functional outcomes of stroke survivors in low-resource regions, particularly in Rwanda. Figure 1 illustrates the overall aim and the research activities I undertook to achieve the aim and outcome of my program. Based on research and personal experience, I identified several resources that can be utilized to achieve my aim, including stroke survivors, their families, healthcare professionals, and clinical practice guidelines. I have gathered information from these resources to help me achieve my research objectives.

My approach to improve functional outcomes after stroke involved addressing three key gaps:

1. Assessing the most pressing needs of stroke survivors in Rwanda
2. Exploring alternative strategies for providing physical rehabilitation interventions in low resource settings.

3. Creating an evidence-based community-based intervention applicable for low-resource settings.

One of the essential gaps was the lack of understanding of the needs of Rwandan stroke survivors, I conducted a needs assessment study to collect data on the functional needs of stroke survivors after they were discharged from the hospital. I also conducted a systematic review of different approaches to physical rehabilitation services, with considerations of the available resources. And while clinical practice guidelines are a resource, the applicability in the Rwandan context is limited so I conducted a literature review of mobility rehabilitation interventions and created an evidence-informed community mobility intervention for use in low-resource settings.

The individual components of my thesis focussed on addressing the gaps and are described below.

Assessing the needs of stroke survivors

Most of the available data on the needs stroke survivors are obtained from HICs,^{57,27,30,36} Findings from these studies may not apply directly to the unique challenges faced by stroke survivors in low-resource settings. Differences between high-resource and low-resource settings such as healthcare infrastructure, workforce skills, socio-economic status, and cultural factors,^{14,16,40} could result in stroke survivors in low resource settings experiencing different needs. To confirm if the needs of Rwandan stroke survivors are similar to those in HICs, I conducted a needs assessment study to:

- i. Investigate the unmet functional needs of Rwanda stroke survivors at the time of hospital discharge.
- ii. Examine the trajectory of needs 3-months after hospital discharge to identify the changes in unmet functional needs over time and explore the factors associated with continued unmet needs.

This study was conducted to determine the needs of stroke survivors after being discharged from the hospital. The purpose was to find ways to address these needs. Since stroke survivors who live in low-resource settings like Rwanda have limited resources, it would be important to have a

community-based intervention that is evidence-based and can be implemented in low-resource settings.^{27,30,36} Community-based models would be more feasible to such settings than facility-based rehabilitation.³³ In regions with limited resources, family and CHWs play an important role, so exploring alternative approaches to rehabilitation is important.

Alternative strategies for providing physical rehabilitation interventions in low resource settings.

When addressing the need for rehabilitation in low-resource settings, it's crucial to consider the method of delivering interventions.⁵⁸ This is due to financial and human resource limitations.^{14,15} This section explores the possibility of involving community-level agents like CHWs or informal caregivers to provide stroke rehabilitation interventions in community settings. This approach can help address the shortage of skilled healthcare professionals in low resource settings. CHWs in Rwanda perform a variety of activities including health promotion, referrals to health facilities, home visits and check-ins.⁵⁹ These activities are funded by the government and some international non-governmental organizations (INGOs) like Partners in Health. Rwandan CHWs could provide basic and structured rehabilitation interventions and support for stroke survivors, as they are likely to visit stroke survivors for follow-up after stroke and can provide follow-up care to bridge the healthcare gap.^{59,60} CHWs with local knowledge and healthcare training could be trained to provide basic rehabilitation interventions and improve access to rehabilitation services.^{14,61} Despite substantial involvement of CHWs in the health care field,^{46,47,62,63} their involvement in rehabilitation service delivery has received comparatively less attention.

Therefore, I undertook a systematic review to:

- i. Examine evidence on the effectiveness of physical rehabilitation interventions delivered by community-level agents in improving physical functioning (e.g., mobility, activities of daily living [ADLs]).
- ii. Describe the characteristics of the interventions that demonstrated positive effects.
- iii. Assess the impact of these interventions on other health-related outcomes, including quality of life (QOL), social participation, self-management behaviors, service access and service utilization, as well as key care processes, such as care coordination for community transitions.

The purpose of this review was to determine if there is evidence to support the delivery of community-based interventions delivered by CHWs or informal caregivers in low-resource settings, with the intent of applying these results to the provision of rehabilitation interventions to stroke survivors. I also aimed to identify the most effective interventions and evaluate the role of community-level agents, such as CHWs in providing physical rehabilitation interventions.

Developing an evidence-based, community intervention specifically tailored for low-resource settings.

Upon considering alternative strategies to providing rehabilitation, I recognized the unique roles of CHWs in healthcare and their potential to deliver basic and context acceptable community-level healthcare programs,^{46,47} including programs for stroke patients.⁴² Also, the need to increase access to rehabilitation care with a focus on low-resource settings has been increasingly emphasized as a global health as well as rehabilitation priority.⁶⁴⁻⁶⁶ To respond to the need, I created a CHW-delivered post-stroke community-based mobility intervention.

CHWs are non-specialized, non-credentialed community-level workers or volunteers who can be trained or supervised by specialist human resources to deliver basic, effective, and culturally acceptable community-level healthcare programs.^{46,47} CHWs have played a crucial role in improving healthcare outcomes including chronic disease management for conditions, such as improving high blood pressure,⁶⁷ mental health support,⁶⁸ including educative programs for stroke patients.⁴²

To my knowledge, there are no evidence-based post-stroke rehabilitation guidelines, programs, or interventions that are specific to (i.e., designed for and tested or implemented) low-resource settings, in particular by CHWs, and that do not require substantive human or specialized equipment. Additionally, much of the evidence on post-stroke rehabilitation (e.g., for mobility outcomes), comes from high-resource contexts and is not directly translatable to many low-resource settings, emphasizing the importance of developing context-specific interventions.

To be widely implementable and sustainable in low-resource community-level contexts, rehabilitation interventions must require under minimal equipment and include programs that are deliverable by CHWs, appropriately trained and supported. Additionally, to be implementable by CHWs, rehabilitation programs or interventions must provide sufficient program detail, descriptions, and illustrations to be accessible to and accurately delivered by workers who typically have no post-secondary education or rehabilitation training. The Rehabilitation Treatment Specification System (RTSS) offers an alternative, comprehensive method for describing interventions,^{69,70} based on intervention targets, ingredients, and ingredients' effects on targets by some mechanism of action.⁷¹

My primary objective was to follow a systematic process and develop an evidence-informed yet context-sensitive post-stroke, community-level rehabilitation intervention specifically designed for low-resource settings. To address mobility problems, a crucial yet unaddressed issue for stroke survivors in Rwanda. Specifically, I aimed to use the RTSS to develop an evidence-informed mobility-training module for post-stroke rehabilitation, adapted to low-resource settings (e.g., with no substantive equipment requirements) and deliverable by community-level agents such as CHWs.

I followed a four-phase systematic approach to develop a post-stroke mobility intervention that accommodates low-resource settings:

- 1) Searching for the applicable evidence base;
- 2) Selecting effective interventions fitting low resource criteria;
- 3) Extracting details from the effective interventions implementable in low-resource settings; and
- 4) Designing the new low-resource intervention based on the evidence-based extractions.

The approach of developing an evidence-informed yet context-sensitive post-stroke rehabilitation program that can be delivered by CHWs in low-resource settings is a valuable contribution to community-level rehabilitation. Also, the intent of developing a structured process for the development of the mobility module was to create a process that could be replicated for the development of other evidence-based post-stroke community interventions delivered by CHWs.

The following chapters provide a detailed description of my research activities in addressing the need to improve functional outcomes after stroke in low-resource settings like Rwanda. By identifying the knowledge gaps, I provide valuable information and potential solutions for enhancing stroke outcomes and support for stroke survivors in a low-resource setting. In the last chapter, I will describe how I use the knowledge and experience I have gained from the different research activities to further enhance research, outcomes of stroke survivors and community-based care, particularly in low-resource settings. It is important that my research activities have a lasting impact and that the intervention developed is tested and implemented.

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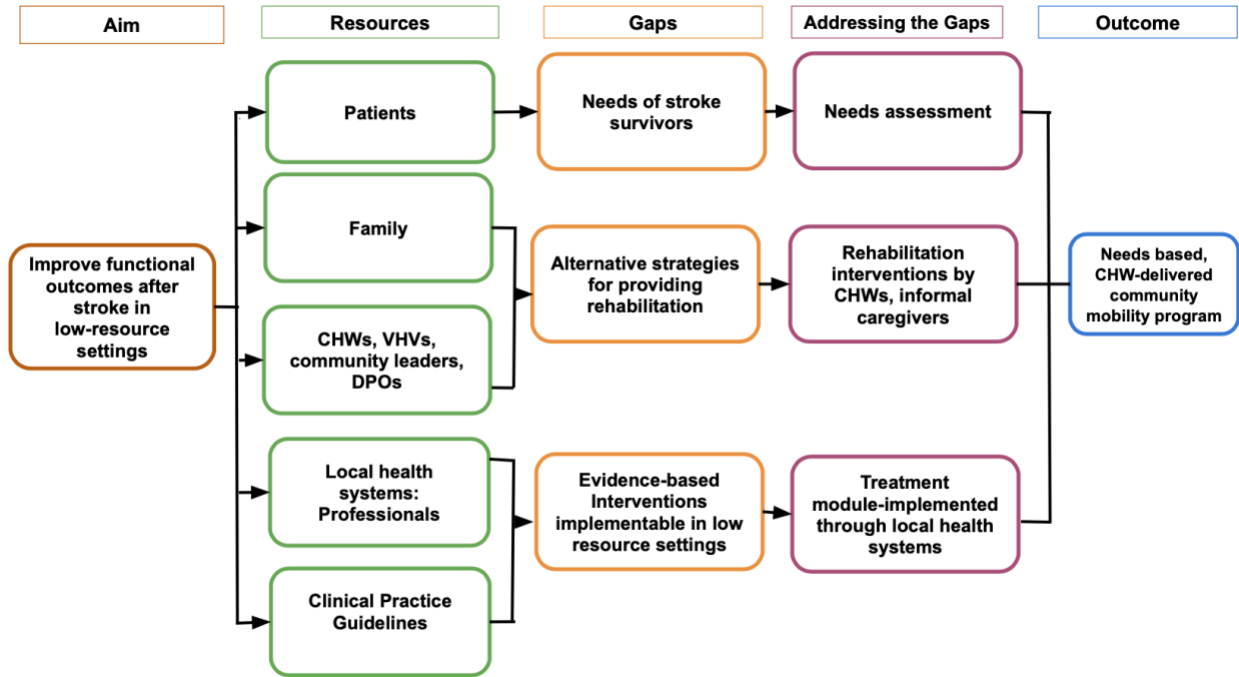
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Figure 1: Research Model



CHWs: community health workers, VHVs: village health volunteers, DPOs: disability program organizations.

CHAPTER 2: UNDERSTANDING THE FUNCTIONAL NEEDS OF COMMUNITY-DWELLING STROKE SURVIVORS IN RWANDA: A PROSPECTIVE OBSERVATIONAL COHORT STUDY.

Kumurenzi, A., Jesus, T., Richardson, J., Thabane, L., Kagwiza, J., Cockburn, L., Langhorne, P., DePaul, V., Melifonwu, R., Bidulka, P., Hamilton, L., Urimubenshi, G., Kaddumukasa, M., Bosch, J. To be submitted to the International Journal of Stroke

Abstract

Background

Post-stroke disability is common in low-and middle-income countries, like Rwanda. With limited resources, it is essential to focus support on the needs that are most important to stroke survivors.

Aims: The primary aim of our study was to assess the trajectory of unmet functional needs of stroke survivors from the hospital discharge to a 3-month follow-up. The secondary aim was to understand the service-related factors (e.g., patient-reported barriers and use of post-hospitalization rehabilitation services) and other factors (socio-demographic, type of stroke and disability-related) associated with unmet functional needs for those alive at 3 months.

Methods

At six hospitals, a multi-center, prospective observational study was conducted using the Needs Assessment Questionnaire. This questionnaire was adapted to suit the Rwanda context and the data is reported as binary outcomes. The data collected was analyzed using descriptive and logistic regression models.

Results

A total of 337 participants were consecutively recruited at discharge from six hospitals. Participants' mean age was 61 years (standard deviation, [18]), most were female (n=198, 59%),

70% (n=234) had an ischemic stroke, and 71% (n=238) had hypertension. By three months, complete follow-up was available for 253 (78%) of participants and 22% (n=71) had died. At discharge, most participants reported moderate to severe needs, mainly in mobility (96%) and in basic activities of daily living (98%). After three months, over half of the participants still reported moderate to severe needs, particularly in mobility (76%) and instrumental activities of daily living (85%). Regression modelling showed that those with unmet needs, mainly in working (odds ratio [OR] 1.29, 95% confidence interval [CI] 1.18-1.41, $p < 0.001$), Interaction/communication (OR 1.27, 95% CI 1.15-1.40, $p < 0.001$), social/recreation (OR 1.21, 95% CI 1.06-1.38, $p = 0.004$), and BADL (OR 1.05, 95% CI 1.00-1.10, $p = 0.019$), were likely to continue to have unmet needs in these domains at 3 months. Stroke survivors in Rwanda consider limited access to services a major barrier in addressing needs.

Conclusion

For Rwanda's stroke survivors, basic functional needs were found to be highly prevalent at hospital discharge and remained largely unmet three months later. These unmet needs are likely due to the severity of disability for those presenting to the hospital, limited access to hospital rehabilitation services and post-hospitalization community-level rehabilitation. There is a pressing need to strengthen discharge planning, basic post-acute rehabilitation care, and post-hospitalization support services in the community.

Data access statement

The datasets are available from the corresponding author (AK) on reasonable request.

Introduction

Globally, stroke is the second leading cause of death and disability,^{1,2} with over 87% post-stroke related disability reported in low- and middle-income countries (LMICs).⁶⁶ In Rwanda, stroke is the third leading cause of death.⁹ Among those who survive one year after a stroke, more than one-third are estimated to have moderate to severe disability.¹² Rehabilitation interventions have been shown to improve mobility and functional outcomes for stroke survivors.^{20,21} However, in countries like Rwanda and many LMICs, access to rehabilitation is limited, and where provided, it is not consistently available.^{22–25} In high-income countries (HICs), rehabilitation is usually provided by credentialed, skilled health professionals, such as rehabilitation physicians, psychologists, physiotherapists, occupational therapists, speech and language pathologists, orthotists and prosthetists, and nurses. However, in some LMICs, there is a shortage of skilled rehabilitation workers.⁵⁴ When resources are limited, it is even more critical to prioritize and address the most important health and functional needs of stroke survivors.

Data on stroke survivors' health and functional needs have been primarily obtained through research conducted in HICs, such as the United Kingdom (UK), Australia, the Netherlands, and Canada.^{23,25,67–71} Studies conducted in LMICs are lacking, with a few exceptions, such as China, India, and Nigeria.^{24,35,36} HIC and LMIC studies have identified common post-stroke functional needs that arise after hospital discharge, including fatigue, muscle weakness, decreased mobility and self-care, falls, bowel and bladder control issues, depression, cognitive and communication issues.^{24,25,36,67,68} Family and community activities and returning to work, were also affected. Several factors exacerbate these functional needs, including a lack of information on stroke and related services, inaccessible health services, unemployment rates, and lack of financial support.^{24,35,36}

The rehabilitation systems in many LMICs, including Rwanda, are underdeveloped.^{14,39,54} This lack of adequate rehabilitation contributes to a higher prevalence of functional needs among stroke survivors in LMICs compared to HICs.^{24,35,36} In Rwanda specifically, stroke survivors with functional needs often encounter a lack of post-hospitalization rehabilitation training and community support.^{16,72}

Aims:

The primary aim of our study was to assess the trajectory of unmet functional needs of stroke survivors from the hospital discharge to a 3-month follow-up. The secondary aim was to understand the service-related factors (e.g., patient-reported barriers and use of post-hospitalization rehabilitation services) and other factors (socio-demographic, type of stroke and disability-related) associated with unmet functional needs for those alive at 3 months.

Methods

The reporting of this study follows the Strengthening the Reporting of Observational Studies in Epidemiology STROBE checklist⁷³ (Supplemental Appendix 1).

Study design and setting

The study was a multicenter, observational prospective cohort study, with data collected within one week before or after hospital discharge and three months thereafter. We chose a 3 month follow up window as spontaneous recovery would be complete by this time allowing for a more accurate estimate of ongoing functional abilities.⁷⁴

Patients were identified at six hospitals throughout Rwanda. Hospitals were purposively selected for maximum variation sampling (Supplemental Appendix 2 describes the Rwandan health system). We obtained approvals from the Rwandan National Ethics Committee (Ref: No.853/RNEC/2021), the Ministry of Health (No. 20/5933/DPMEHF/2021), and relevant authorities from the selected hospitals. Signed informed consent was obtained from all participants.

Participants

From September 2021 to November 2022, trained data collectors consecutively identified and recruited both inpatients and outpatients. Patients were eligible if they: 1) had been diagnosed with stroke by a physician within the last month, 2) were 18 years or older, and 3) provided

informed consent (after they were provided and understood information on the study). If patients had severe cognitive or communication impairments as determined by an informal evaluation with the family caregiver, consent was sought from family caregiver and interviewed (for consent process) if available; otherwise, the participant was excluded.

Sample size

The sample size on stroke survivors in Rwanda was based on the estimated prevalence of stroke in Nigeria (14.6 per 1000)⁸ and the population of Rwanda (13.6). The sample size was calculated by i) estimating the prevalence rate of 0.0146% (14.6/1000) of stroke survivors, ii) based on the Rwandan population of 13.6 million, this means there are approximately 198,560 stroke survivors (0.0146*13,600,000). To determine the appropriate sample size for the study, the Raosoft sample size calculator software was used.⁷⁵ The sample size estimate of 323 was calculated based on a 5% margin error, a 95%, confidence level and a 70% probability distribution of the response variables.

Outcome Measures and Scoring

The primary outcome measure was the modified self-reported Needs Assessment Questionnaire (mNAQ).²² The mNAQ is a reliable and valid assessment tool consisting of 160 items in 12 domains describing functional and other needs (11 domains) as well as barriers to functioning (1 domain).²³ The tool was initially developed to assess the needs of Canadian stroke survivors, then adapted for use in Nigeria.²⁴ We modified the Nigerian version (141 items) for use in Rwanda. Fifty-seven items were removed, with 84 items in the final version (64 needs and 20 barriers (Supplemental Appendix 3). The process for this context-sensitive modification included: i) a review by three Rwandan experts in rehabilitation (a mixture of academicians, researchers, and clinicians) to assess the contextual relevance of the items for the Rwandan context, and ii) pilot testing for feasibility with 15 Rwandan stroke survivors in two hospitals (university and district) prior to the big study.

The six functional domains of the mNAQ were included in this analysis: mobility, basic activities of daily living (BADL), instrumental activities of daily living (IADL), interaction/communication, working, and social/recreational activities. The assessments were scored by first, summing up the number of times a need was reported as small (1), moderate (2), large (3), and very large (4) (Supplemental Appendix 3). The number of needs were counted, with each need being counted independently. For example, within the mobility domain, a participant reporting a need for standing and for walking outdoors was computed as two functional needs.

Disability was measured using the modified Rankin Scale (mRS), a clinician-reported tool used to assess the level of disability.⁷⁶ It is a 7-level measure of disability with scores from 0-2 (no symptoms to significant disability), 3-5 (increased level of disabilities), and 6 (dead).

Data collectors were physiotherapists [PTs]), trained on study procedures and assessment tools. Data were collected in person at hospital discharge, while data collected at 3 months were either at the hospital, in patients' homes or by phone.

Statistical Analysis

The needs were dichotomized into two categories: met (either not a need, already met, not applicable, or performed with assistance or equipment) and unmet (ranging from small to severe needs). Note: To analyze the proportions of unmet functional needs, we considered unmet needs as moderate to severe needs) The analysis was managed as a binary outcome. Items in all the six domains are summed into global functional unmet needs. The disability scores using the mRS system were divided into low disability (scores of 0-2) and high disability (scores of 3-5). The analysis was also managed as a binary outcome. We calculated the proportion of unmet functional needs at discharge and three months. To analyze the trajectory of those needs over the period, we performed a univariable logistic regression analysis to assess the association between needs at 3 months compared to discharge (Supplemental Appendix 4); the odds ratios (ORs), 95% confidence intervals (95% CIs), and p-values were recorded. Then, we performed a multiple logistic regression analysis to assess the association of primary independent factors (patient-reported barriers and use of post-hospitalization rehabilitation) and covariates (age, sex, working

status, type of stroke, and level of disability) with unmet functional needs at 3 months. We first conducted univariate logistic regressions for each potential variable in isolation to determine the set of factors to include in the final multiple logistic regression model. A 95% confidence level was used for the final multiple logistic regression model. All analyses were performed using STATA-16.

Results

Participant enrollment and characteristics

Figure 1 provides the flowchart of the data collection. A total of 337 participants were recruited from six hospitals.

1.1 Baseline characteristics

Participants had a mean age of 61 years (standard deviation [18]) and were predominantly female, 59% (n=198) (Table 1). More than half, 68% (n=228), had six years or less of formal education, were married or lived with a partner, 52% (n=174), or were working, 67% (n=225), before the stroke. Seventy percent (n=234) had an ischemic stroke, 71% (n=238) reported a history of hypertension, and 69% (n=233) were on anti-hypertensive treatment at discharge. Ninety-nine percent (n=327) reported a moderate to severe disability (mRS score between 3-5). At the time of the assessment, 88% (n=297) of the sample had received rehabilitation, mainly physiotherapy 85% (n=287), of whom 42% (n=123) received it three times per week.

1.2 Three-month Follow-up

Data were available on 78% (n=253) participants and 22% (n=71) had died (Figure 1). More than half, 52% (n=130), were married or lived with a partner (Supplemental Appendix 5). Of the 68% (n=225) working before their stroke, 85% (n=192) had not returned to work at three months. Sixty-two (n=198) had mRS scores of 3-5. Sixty-seven percent (n=169) had received

rehabilitation, mainly physiotherapy 64% (n=161), of whom 15% (n=38) received it three times per week.

1. Proportion of functional needs at baseline and three months

At discharge, almost all participants reported at least one type of moderate to severe functional needs, mainly in mobility (96% [95% CI, 0.93-0.98]) and in basic activities of daily living (BADL [98% [95% CI, 0.95-0.99]]) (Table 2). At 3 months, over half of participants still reported moderate to severe needs in at least one or more domains (94% [95% CI, 0.90-0.97]), with instrumental activities of daily living and mobility the most common, i.e., reported by 85% (95% CI, 0.80-0.89) and 76% (95% CI, 0.70-0.81).

2. Relationship between unmet functional needs at discharge and 3-months

Table 3 displays results of a univariable logistic regression analysis. Those experiencing unmet needs at discharge were likely to report to having the same unmet needs at 3-months in the following areas; working (OR 1.29, 95% CI 1.18-1.41, $p<0.001$), in interaction/communication (OR 1.27, 95% CI, 1.15-1.40, $p<0.001$), in social/recreational activities (OR 1.21, 95% CI, 1.06-1.38, $p=0.004$), and in BADL (OR 1.05, 95% CI, 1.00-1.10, $p=0.019$). There was no such significant association either for the mobility or IADL domains.

3. Factors associated with unmet functional needs at 3-months

Univariate logistic regression analysis (Supplemental Appendix Table 6) demonstrated that working status (pre-stroke), post-stroke disability level as measured through the mRS and patient-reported barriers were significantly associated with unmet functional needs in at least one of the measured domains. Table 4 shows the results of the multiple logistic regression analysis. After adjusting for the age, sex, type of stroke, pre-stroke employment, and disability severity, we found that patient-reported barriers to therapy services were independently associated with unmet needs in global needs mainly in BADL (adjusted Odds Ratio [aOR] 4.69, 95% CI 1.75-12.56, $p=0.002$), social/recreation activities (aOR 2.95, 95% CI 1.17-7.42, $p=0.022$), and working (aOR 2.58, 95% CI 1.06-6.30, $p=0.037$).

4. Disability (mRS) at discharge and after three months

At discharge, 99% (n=327) of the sample had an mRS 3-5, which improved to 62% (n=198) at 3 months. Of note, 22% (n=71) had died, and the mean mRS score at discharge for those who died was 5 (Figure 2).

Discussion

This study is the first to investigate the unmet functional needs of stroke survivors in Rwanda after they are discharged from the hospital and reintegrated into the community. The average age of the stroke survivors in the population studied was 61 years, consistent with other data indicating that stroke survivors in Africa tend to be younger than those in Western countries.¹³ Additionally, the study population was predominantly female, which aligns with previous findings that more women than men in Africa experience strokes.^{13,24} There were more ischemic than hemorrhagic stroke cases observed.

The majority of participants exhibited moderate to severe disability following their stroke. Consequently, it is unsurprising that over 95% of the participants reported various levels (moderate to severe needs) of unmet functional needs across all usual activities at discharge. Although the specific types of needs reported did not differ significantly from previous studies,^{24,25,36,67,68} a high percentage of Rwandans reported moderate to severe needs at discharge, with more than half of the participants at 3 months. Although participants reported a slight decrease in unmet needs, those with unmet needs in BADL, working, interaction/communication, and social/recreational activities were likely to continue to have unmet needs in these domains at three months. The odds ratios of these unmet needs ranged from 1.05 to 1.29 ($p < 0.05$), indicating that the presence of unmet functional needs at the time of hospital discharge is a stronger predictor of continued unmet needs at 3 months. Thus, a persistent demand for support in these areas. Our findings contrast to other studies conducted in HICs, such as 6.5% in England,⁷⁸ 25% in the UK,²⁵ 35% in Canada,²³ and 46% in Australia,⁶⁹ which reported lower proportions of stroke survivors reporting mobility unmet needs post-hospitalization. In addition, unmet functional needs in activities of daily living were reported by 9.5% of stroke survivors in England⁷⁸ and by 17% for those in Australia.⁶⁹ However, it should be noted that these studies used different methodologies, had different sample sizes and could have included more milder strokes than the present study.

In LMICs like Rwanda, it is likely that only the most severe cases of stroke present at the hospital,¹² which might explain the higher proportion of unmet functional needs reported in our study. These data show the need to strengthen basic post-acute rehabilitation care. In many LMICs, the availability of specialized rehabilitation professionals like PTs and occupational therapists (OTs) is limited,^{54,79} healthcare professionals, such as nurses, could be trained to provide rehabilitation services⁴¹ to stroke survivors while they are still in the hospital.^{54,79} By empowering nurses and other healthcare professionals with the necessary skills and knowledge to provide basic post-acute rehabilitation care, we could expand the reach of rehabilitation services and ensure stroke survivors receive the care they need to recover in the community.⁸⁰ Also, in the planning of patient discharge, it is essential for nurses, PTs, and OTs to provide training and education to the family who will be involved in the care of stroke survivors after they leave the hospital.¹⁴

Family members can better support the ongoing rehabilitation and address the high proportions of unmet functional needs reported by stroke survivors at 3 months. The study also found that participants who had unmet needs in BADL, social/recreational, working, and interaction/communication were likely to still have unmet needs in these domains after three months. The reasons for these unmet needs can be multifactorial and require further investigation. It is possible that limited discharge planning contributes to the lack of appropriate community care and support for stroke survivors.^{14,16}

Limited access to therapy was identified as a significant barrier to addressing the needs related to BADL, working, and social/recreational activities at three months. These findings highlight the substantial need for community-based support for stroke survivors. In Rwanda, as in many other LMICs, rehabilitation professionals and services are scarce,^{14,39,54,79} and the limited available services are often concentrated in hospitals,^{14,54} making them inaccessible or unavailable at the community level for post-hospitalization care. Before hospital discharge, 88% of the study participants had received some form of rehabilitation, mainly physiotherapy. However, only 64% and 19% of participants reported receiving physiotherapy and occupational therapy (OT) services, respectively, after three months. Nevertheless, many participants still had unmet

mobility and basic activities of daily living needs after three months despite receiving rehabilitation care. Addressing these concerns requires a comprehensive approach. It involves strengthening discharge planning processes to ensure stroke survivors and their families receive adequate education, resources, and support before leaving the hospital.¹⁴ Additionally, efforts should be made to improve community-level care and support services, such as training community health workers (CHWs) to support stroke survivors after hospital discharge.⁵⁸

Previous studies have identified age, sex, and type of stroke as factors associated with unmet needs.^{24,35,68,77} These factors did not show significant associations in the current study when analyzed univariably and adjusted. Instead, working status and level of disability (measured by mRS scores of 3-5) were significantly associated with unmet in at least one of the measured domains. The association between working status and unmet needs is particularly noteworthy in Rwanda. While in many Western countries, the mean age of stroke patients is beyond the retirement age, in Rwanda, where the retirement age is 65, a significant portion of the workforce is still employed and relies on their income for livelihood prior their stroke.

https://www.minaloc.gov.rw/fileadmin/user_upload/Minaloc/Publications/Policies/National_Older_Policy_final.pdf). This shows that many stroke survivors will need to continue working after their stroke. However, OT, which is crucial for helping participants regain working skills,⁸¹ was rarely reported as received by the participants. As a result, it is not surprising that working remained unmet for many participants even three months after hospital discharge. One of the existing programs that help stroke survivors return to work is the Life After Stroke Centre in Onitsha, Nigeria. Developing such programs and support services to assist stroke survivors in reintegrating into the workforce can play a crucial role in addressing their unmet needs and improving their overall quality of life.⁸² Given the limited financial and specialist human resources available in contexts like Rwanda and many other LMICs, alternative service delivery options can optimize resource utilization.

Some potential strategies to consider include:^{44,83-85} 1) enhancing discharge planning that involves coordinated efforts between healthcare professionals, rehabilitation specialists, and community support services; 2) educating and training informal caregivers to equip them with the knowledge and skills needed to support the rehabilitation process at home;⁸⁶ 3)

telemonitoring technologies or other digital health technologies (those that are low-cost and easy to use),^{53,87} to remotely monitor stroke survivors' progress, provide ongoing assessment, and deliver virtual rehabilitation interventions. This approach can enhance accessibility and reach, particularly in geographically dispersed areas where access to specialist care is limited;¹⁴ 4) training CHWs⁵⁸ and health volunteers^{83,84} to deliver basic rehabilitation care and support to improve access to rehabilitation services and support stroke survivors' recovery and reintegration into their communities. This approach is effective in managing other chronic diseases, such as mental health care and blood pressure management,^{88,89} and can be adapted for stroke care. However, it is important to ensure that CHWs, health volunteers or family caregivers are appropriately trained and supported and work collaboratively with specialist rehabilitation professionals to provide coordinated and integrated care.¹⁴

Limitations

The study had several limitations; firstly, we relied primarily on self-reported data, which introduces the possibility of response bias. The subjective perspectives of participants and their caregivers may not always accurately reflect the actual situation. Secondly, a needs assessment tool designed for HICs may not have captured important needs specific to LMICs like Rwanda, although modified for us in Nigeria. Thirdly, throughout the study, data collectors required additional clarification to distinguish certain levels of the mNAQ. It is possible that the early participants' data may not have accurately captured the intended information, despite the principal investigator reviewing previously reported data. Fourthly, all data collectors were full-time PTs at the study sites. This could have made it challenging to consecutively recruit participants, potentially introducing selection bias into the sample. Fifthly, within the sample, 22% of participants died within 3 months, limiting the information on the unmet needs of those at the highest risk of death. To address this limitation, we plan to conduct a separate paper describing the needs of participants who died. Finally, stroke survivors may continue to experience improvement beyond the three-month timeframe examined for the study. To address the need for long-term follow-up, we are collecting one-year follow-up data to capture changes in needs over time.

Conclusion

The findings of this study highlight the significant unmet functional needs of Rwandan stroke survivors, both at the time of hospital discharge and at the three months follow-up. These unmet needs are likely due to the severity of disability for those presenting to the hospital, limited access to hospital rehabilitation services, and post-hospitalization community-level rehabilitation and support services. These findings emphasize the urgent need to improve discharge planning. Implementing alternative strategies like task-sharing (delivered by trained and supervised CHWs or caregivers) may help address the barrier of accessible and affordable health services to address needs. These approaches may help improve access to rehabilitation services and support and ultimately enhance the functional recovery of stroke survivors in resource-constrained settings.

Data availability

The datasets are available from the corresponding author (AK) on reasonable request.

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Declarations of interest

The authors declare no conflict of interests.

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Figures

Figure 1: Flowchart for completeness of data

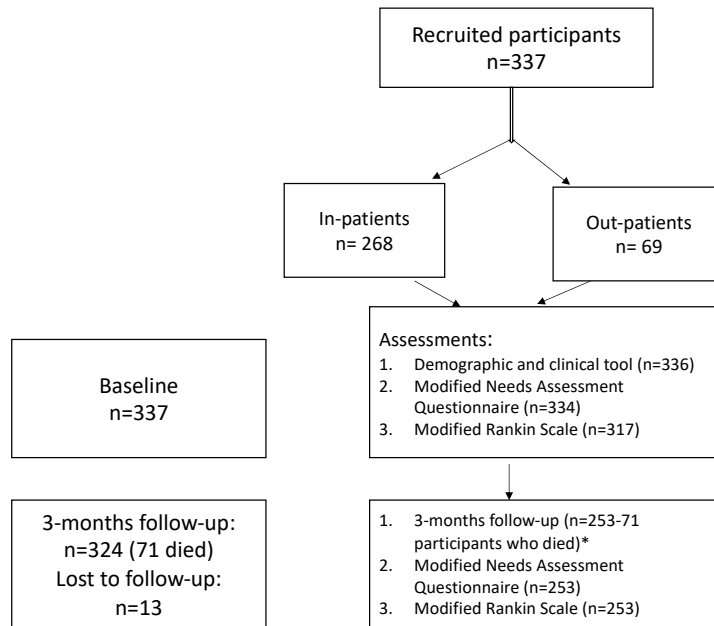
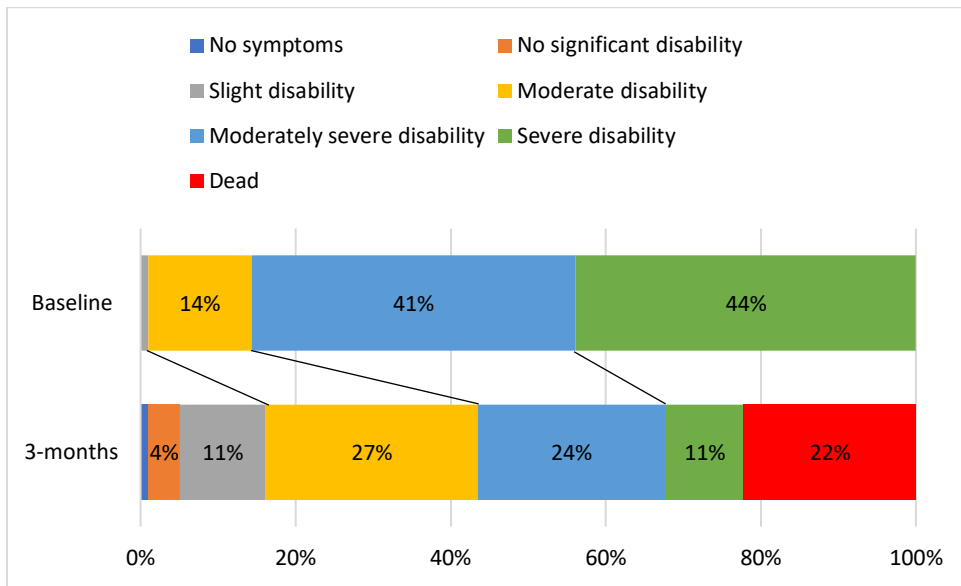


Figure 1: Flow chart showing recruitment and completeness of assessment forms.

*13 who were lost to follow-up are not included

Figure 2: Disability at discharge and 3 months



Distribution of modified Rankin Scale scores at the time discharge and 3 months after.

Tables

Table 1: Baseline characteristics

Characteristics	N=337	
	Mean	SD
Age (years)	61	18
	n	%
18-64	181	54
≥ 65	155	46
Female	198	59
Male	138	41
Six years or less of formal education	228	68
Married/living with a Partner	174	52
Working	225	67
Farmers	115	34
Main source of household income	229	69
Living with 6-10 people	103	31
Residence-Urban	191	57
<i>Stroke type, medical history</i>		
Ischemic	234	70
Hemorrhagic	90	27
Unknown	7	2
Diagnosed with CT	310	92
Recurrent stroke	62	19
<i>Co-morbidities, medications</i>		
Hypertension	238	71
Diabetes	49	14
Depression and Anxiety	34	10
Aspirin	161	48
Other anti-hypertensive (Nifedipine, Losartin)	72	21
Diuretics	63	19
<i>Rehabilitation post-stroke</i>		
Received rehabilitation in hospital	297	88

Physiotherapy	287	85
Occupation therapy	18	5
<i>Level of disability (mRS) n=331</i>		
0-2	4	3
3-5	327	97

SD: Standard deviation, CT: computed tomography, mRS: modified Rankin Scale

Table 2: Proportion of unmet functional needs at discharge and 3-months for those alive and dead at 3 months

Domain	Baseline (Alive at 3 months) N=253 n (% , 95% CI)	3months N=253 n (% , 95% CI)	Baseline (Dead at 3 months) N=71* n (% , 95% CI)
Global	253 (100%)	242 (96%, 0.92-0.97)	71 (100%)
BADL	249 (98%, 0.95-0.99)	211 (83%, 0.78-0.87)	71 (100%)
IADL	249 (98%, 0.95-0.99)	228 (90%, 0.85-0.93)	71 (100%)
Mobility	244 (96%, 0.93-0.98)	214 (85%, 0.79-0.88)	70 (99%, 0.90-0.99)
Social & recreational	243 (96%, 0.92-0.97)	202 (80%, 0.75-0.85)	68 (95%, 0.87-0.98)
Interaction & Communication	238 (94%, 0.90-0.96)	205 (80%, 0.74-0.84)	69 (97%, 0.89-0.99)
Work	192 (76%, 0.70-0.80)	176 (70%, 0.63-0.74)	40 (56%, 0.44-0.67)

CI: confidence interval, BADL: Basic activities of daily living, IADL: Instrumental activities of daily living

*13 who were lost to follow-up are not included

Table 3: The relationship between unmet functional needs at discharge and at 3-months

Domain	OR	95% CI	p-value
Global	1.05	1.02-1.09	<0.001
BADL	1.05	1.00-1.10	0.019
IADL	0.94	0.85-1.04	0.249
Mobility	1.03	0.99-1.06	0.055
Social & recreational	1.21	1.06-1.38	0.004
Work	1.29	1.18-1.41	<0.001
Interaction & communication	1.27	1.15-1.40	<0.001

Reference: Baseline unmet functional needs, OR: Odd ratio, CI: Confidence interval, p: p-value, BADL: Basic activities of daily living, IADL: Instrumental activities of daily living.

Global functional unmet needs are determined by totaling items from all six domains, which are reported as a binary outcome (either met or unmet needs). The six domains are also reported as binary outcomes.

Table 4: Factors associated with 3-months functional needs, from the multiple logistic regression analysis

Domains	Global aOR (95% CI)	BADL aOR (95% CI)	Inter & Comm aOR (95% CI)	Work aOR (95% CI)	Social and recreation aOR (95% CI)
Covariates					
Age (≤ 65)	Reference				
≥ 65	1.44 (0.20-10.19)	1.54 (0.60-3.94)	0.69 (0.32-1.49)	0.95 (0.49-1.85)	1.07 (0.47-2.45)
Sex (Male)	Reference				
Female	1.34 (0.29-6.06)	0.97 (0.42-2.21)	1.30 (0.64-2.63)	0.96 (0.51-1.79)	1.44 (0.68-3.03)
Working before stroke- Not working	Reference				
Working	4.84 (.092-25.38)	1.71 (0.66-4.44)	1.12 (0.49-2.51)	6.49 (3.34-12.63)**	2.99 (1.30-6.91)*
Type of stroke- Ischemic	Reference				
Hemorrhagic	0.68 (0.13-3.42)	0.78 (0.33-1.87)	0.72 (0.34-1.50)	0.59 (0.30-1.16)	0.94 (0.42-2.09)
Unknown	0.29 (0.01-4.74)	0.68 (0.09-5.09)	1.70 (0.16-17.87)	0.73 (0.09-5.47)	0.26 (0.03-1.89)
Level of disability (mRS 0-2)	Reference:				
mRS 3-5	43.73 (4.43-430)*	10.32 (4.37-24.36)**	6.70 (3.04-14.77)**	1.26 (0.56-2.81)	6.71 (2.92-15.41)**
Primary independent factor					
Access to healthcare: Not a barrier	Reference				
A barrier	5.83 (1.24-27.44)*	4.69 (1.75-12.56)*	1.85 (0.72-4.72)	2.58 (1.06-6.30)*	2.95 (1.17-7.42)*

BADL: Basic activities of daily living, IADL: Instrumental activities of daily living, inter & comm: interaction & communication, mRS: modified Rankin Scale aOR: Adjusted odds ratio, CI: confidence interval.

* $p < 0.05$, ** $p < 0.001$.

Global functional unmet needs are determined by totaling items from all six domains, which are reported as a binary outcome (either met or unmet needs). The six domains are also reported as binary outcomes.

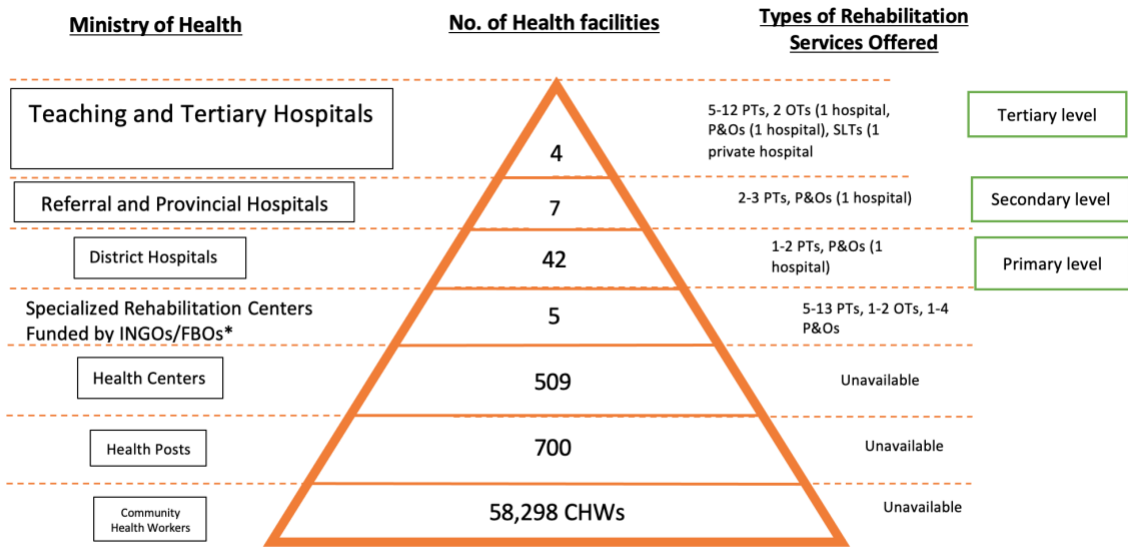
Appendices

Appendix 1: The STROBE Checklist

	Item No	Recommendation	Page No
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	
			1-3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up (b) For matched studies, give matching criteria and number of exposed and unexposed	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6
Bias	9	Describe any efforts to address potential sources of bias	
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) If applicable, explain how loss to follow-up was addressed (e) Describe any sensitivity analyses	7
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7
		(b) Give reasons for non-participation at each stage	
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7-8
		(b) Indicate number of participants with missing data for each variable of interest	
		(c) Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	Report numbers of outcome events or summary measures over time	8
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	8-9
		(b) Report category boundaries when continuous variables were categorized	
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	9
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	11
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	9-10
Generalisability	21	Discuss the generalisability (external validity) of the study results	
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	7

Appendix 2: Organization of the Rwandan health sector



*INGOs/FBOs: International non-governmental organizations/faith-based organizations *PTs: Physiotherapists, *OTs: Occupational therapists, *P&Os: Prosthetists & Orthotists

Appendix 3: Needs Assessment Tool

Baseline 3-month 12-month

For each statement, please rate your current need by checking one of the five boxes to the right indicating the amount of need for each item e.g. "Not a need", to "A very large need".

1. Needs related to your ability to move from place to place

I need ...	Not a need Or Already met	Small need	Moderate need	A large need	A very large need	Not Applicable (N/A)	Perform activity with assistance or equipment
To be better able to move around in bed							
To be better able to get in and out of bed or chairs							
To be better able to get on and off the toilet							
To be better able to stand for long periods time							
To learn how to get down and up from the floor							
To be better able to walk in my home							
To be better able to walk outdoors							
To be better able to ascend and descend stairs							

2. Needs related to your ability to take care of yourself.

I need...	Not a need Or Already met	Small need	Moderate need	A large need	A very large need	Not Applicable (N/A)	Perform activity with assistance or equipment

To be better able to feed myself							
To be better able to chew and swallow food							
To control my saliva (drooling)							
To improve control of my bladder							
To improve control of my bowels							
To improve my ability to wash and bathe myself							
To be better able to dress my lower body (wear pants, shoes)							
To improve my ability to dress my upper body (shirt, dress)							

3. Needs related to taking care of your own home and affairs

I need...	Not a need Or Already met	Small need	Moderate need	A large need	A very large need	Not Applicable (N/A)	Perform activity with assistance or equipment
To be able to use the telephone better							
To be able to write better							
To be able to do home chores (cook, clean, wash clothes)							
To be able to go shopping/market							
To be able to care of others (family members)							
To be better able to reach to get things that you need							

4. Needs related to interacting and communicating with family, friends and others.

I need ...	Not a need Or Already met	Small need	Moderate need	A large need	A very large need	Not Applicable (N/A)	Perform activity with assistance or equipment

To be better able to visit with family							
To better understand when people speak to me							
To be better able to have a conversation with friends/family							

5. Needs related to services in my home or in the community

I need...	Not a need Or Already met	Small need	Moderate need	A large need	A very large need	Not Applicable	Perform activity with assistance or equipment
More accessible public transport for people with disabilities (i.e., wheelchair accessible buses and cars)							
More information on available community services							
More say regarding the care/community services I receive							

6. Needs related to Employment or working

I need...	Not a need Or Already met	Small need	Moderate need	A large need	A very large need	Not Applicable (N/A)	Perform activity with assistance or equipment
To be better able to perform my job							
To use equipment, materials, I use at work							

7. Needs related to other supports in the community

I need...	Not a need Or Already met	Small need	Moderate need	A large need	A very large need	Not Applicable (N/A)	Perform activity with assistance or equipment
Expert advice on how to make my home accessible							
Expert advice on bladder or bowel control/incontinence							
Expert advice on equipment to help me wash/dress myself							
Expert advice on what foods I should be eating							
To learn more about my stroke and my health							
(More) education for my family regarding stroke							

8. Needs related to my feelings, memory, and emotions.

I need...	Not a need Or Already met	Small need	Moderate need	A large need	A very large need	Not Applicable (N/A)	Perform activity with assistance or equipment
To feel less anxious or fearful							
To feel less confused							
To reduce my forgetfulness							
To feel less depressed							
To stop feeling like I am a burden on my family							
To worry less about my health							
To feel less self-conscious about my appearance							
To be less irritable or angry							

To speak to a trained counselor about my feelings							
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9. Needs related to my physical symptoms related to the stroke

I need...	Not a need Or Already met	Small need	Moderate need	A large need	A very large need	Not Applicable (N/A)	Perform activity with assistance or equipment
Relief from pain in my shoulder arm or other parts of							
To improve my vision since my stroke							
Advice on how to cope with my vision problems							
To improve my ability to carry things							
To improve my ability to use my hand(s)							
To improve my ability to use my leg(s)							
To sleep better at night							
To feel less fatigue							
To be more steady on my feet							
To be stronger in my arm(s)							
To be stronger in my leg(s)							
To feel less dizzy							
To reduce the muscle tightness (spasticity) in arms or legs							

10. Needs related to social and recreational activities

I need...	Not a need Or Already met	Small need	Moderate need	A large need	A very large need	Not Applicable	Perform activity with assistance or equipment
To be able to read better							

To better participate in family/community activities/events							
More accessible/convenient public transportation							
To be able to get into buildings (restaurants, religious buildings							

11. Needs related to financial assistance or government assistance

I need...	Not a need Or Already met	Small need	Moderate need	A large need	A very large need	Not Applicable (N/A)	Perform activity with assistance or equipment
Financial support to buy personal supplies and equipment like incontinence pads, wheelchair							
Someone to help me access financial support I may be entitled to (e.g., disability insurance)							

12. Please indicate how much the following items are a barrier to you enjoying life to its fullest since your stroke condition.

What are barriers that prevent you from enjoying your life to its fullest?	Not a barrier	A small barrier	Moderate Barrier	A large barrier	A very large barrier	NA
The physical symptoms of my stroke.						
The weakness in my arm						
The weakness in my leg						
My balance problems						
My difficulties with speaking or understanding others						
My lack of energy						

The lack of home care services (Environmental/services)						
The lack of health care services in my community (Services)						
A lack of enough money to afford the services I need (Services)						
Difficulty accessing the therapy services I need (Services)						
Lack of knowledge about my stroke						
Not able to eat and drink the things I used to enjoy						
My fear of falling						
The attitudes of other people regarding my abilities						
Lack of friends or family nearby						
My family or friends' lack of understanding of my condition and needs						
Lack of contact with people outside my home						
My fear of having another stroke						
Health workers' lack of understanding of my needs (Services)						
Lack of skilled physiotherapist and health care providers (Services)						

Appendix 4: Summary table of objectives with explanatory variables, hypotheses, and methods of analysis

Objectives	outcomes	Explanatory variable (if applicable)	Hypothesis	Method of analysis
Primary objective				
1. Estimates of the levels of unmet functional needs at discharge and 3-months after	% of unmet functional needs	NA	NA	Estimates of proportions of unmet functional needs at 95% CI
Secondary objectives				
2. Association between unmet functional needs at 3 months based on those at discharge	People who have unmet functional needs	Baseline Vs 3-months	More unmet needs at discharge compared to 3-months	Binary logistic regression
3. Identify the factors associated with functional unmet needs at 3 months	People who have unmet functional needs	- Age category (young Vs. Old) - Sex (female Vs male) - Type of stroke (ischemic Vs hemorrhagic) - Level of disability (mild-moderate Vs severe) - Working (employed Vs unemployed) - Received rehabilitation (Yes vs No)	- Participants who are young, males, with hemorrhagic, unemployed, did not receive rehabilitation are likely to report higher unmet needs than the old, females, ischemic, employed, and received rehabilitation.	Binary logistic regression Multiple logistic regression*
4. Assess the levels of disability at discharge and 3-months	People who have disabilities	Baseline Vs 3-months	Higher levels of disability at discharge than 3-months	% of levels of disability
5. Assess the barriers to functioning at discharge and 3-months	People who have barriers to functioning	Baseline Vs 3-months	Higher barriers to functioning at discharge than 3-months	% of barriers to functioning

*Adjusted for: sex, age, type of stroke, level of disability, working status, received rehabilitation.

Appendix 5: Three months follow-up

Variable n=253	n	%
Age		
18-64	154	61%
≥ 65	99	39%
Females	138	55%
Males	115	45%
Not working-3 months	219	86%
Did not return to work-3 months	192	85%
Person living with participants since stroke-Spouse	130	52%
Person living with participants prior to stroke-Spouse	135	54%
On medications	174	84%
Aspirin	64	25%
Other anti-hypertensive (Nifedipine, Losartin)	110	43%
Diuretics	18	7%
Dead-Post-stroke complications*	56	79%
Unknown	15	21%
<i>Rehabilitation post-stroke</i>		
Rehabilitation after discharge	169	67%
Physiotherapy	161	64%
Occupational therapy	19	8%
<i>Level of disability (mRS) (n=319)</i>		
0-2	50	16%
3-5	198	62%
6 (Dead)	71	22%

*Another stroke, brain ischemia, cardiac arrhythmia, cerebral hemorrhage, hypertensive cardiopathy, hypoxia, pneumonia, pressure sores infection, pulmonary embolism, respiratory distress, suicide

Appendix Table 6: Factors associated with 3-months functional needs, from the univariable logistic regression analysis

Domains	Global OR (95% CI)	BADL OR (95% CI)	Inter & Comm OR (95% CI)	Work OR (95% CI)	Social and recreation OR (95% CI)
Covariates					
Age (≤ 65)	Reference				
≥ 65	3.01 (0.63-14.23)	2.01 (0.96-4.22)	1.10 (0.58-2.08)	0.63 (0.36-1.09)	1.36 (0.70-2.63)
Sex (Male)	Reference				
Female	1.46 (0.43-4.92)	1.24 (0.64-2.41)	1.45 (0.78-2.69)	0.85 (0.50-1.47)	1.38 (0.73-2.60)
Working before stroke- Not working	Reference				
Working	2.22 (0.65-7.52)	1.18 (0.57-2.43)	1.08 (0.55-2.13)	6.68 (3.65-12.23)**	2.15 (1.11-4.15)*
Type of stroke- Ischemic	Reference				
Hemorrhagic	0.64 (0.17-2.33)	0.73 (0.35-1.51)	0.62 (0.32-1.19)	0.70 (0.39-1.26)	0.80 (0.40-1.61)
Unknown	0.14 (0.01-1.51)	0.25 (0.04-1.62)	0.85 (0.09-7.94)	0.57 (0.09-3.53)	0.13 (0.02-0.85)*
Level of disability (mRS 0-2)	Reference				
mRS 3-5	49.5 (6.16-397)**	12.39 (5.82-26.34)**	6.96 3.47- 13.94)**	1.09 (0.55-2.12)	7.06 (3.49-14.29)**
Primary independent factors					
Received Rehab- No	Reference				
Yes	1.20 (0.34-4.25)	1.05 (0.52-2.14)	0.58 (0.28-1.18)	1.38 (0.78-2.43)	0.94 (0.47-1.85)

Access to healthcare: Not a barrier	Reference				
A barrier	10.36 (2.94-36.44)**	5.91 (2.62-13.35)**	2.56 (1.13-5.78)*	2.86 (1.33-6.14)*	3.97 (1.78-8.85)*

BADL: Basic activities of daily living, IADL: Instrumental activities of daily living, inter & comm: interaction & communication, mRS: modified Rankin Scale OR: odds ratio, CI: confidence interval

*p<0.05, **p< 0.001.

CHAPTER 3: EFFECTIVENESS OF INTERVENTIONS BY NON-PROFESSIONAL COMMUNITY-LEVEL WORKERS OR FAMILY CAREGIVERS TO IMPROVE OUTCOMES FOR PHYSICAL IMPAIRMENTS OR DISABILITIES IN LOW RESOURCE SETTINGS: SYSTEMATIC REVIEW OF TASK-SHARING STRATEGIES.

Anne Kumurenzi^{1,2}, Julie Richardson¹, Lehana Thabane^{3,4,5}, Jeanne Kagwiza², Gerard Urimubenshi², Leah Hamilton⁶, Jackie Bosch⁷, Tiago Jesus⁸

Abstract

Background: In low-resource settings, access to basic rehabilitation could be supplemented by community-level interventions provided by community health workers, health volunteers, or family caregivers. Yet, it is unclear whether basic physical rehabilitation interventions delivered to adults by non-professional alternative resources in the community, under task-shifting or task-sharing approaches, are effective as those delivered by skilled rehabilitation professionals. We aim to synthesize evidence on the effectiveness of community-level rehabilitation interventions delivered by non-professional community-level workers or informal caregivers to improve health outcomes for persons with physical impairments or disabilities.

Methods: We performed a systematic review with a PROSPERO registration. Eight databases were searched for (PubMed, CINAHL, Global Health, PDQ Evidence, Scopus, ProQuest, CENTRAL, and Web of Science), supplemented by snowballing and key-informant recommendations, with no time restrictions, applied. Controlled and non-controlled experiments were included if reporting the effects of interventions on mobility, activities of daily living (ADLs), quality of life, or social participation outcomes. Two independent investigators performed the eligibility decisions, data extraction, risk of bias, and assessed the quality of the evidence using the GRADE approach.

Results: Ten studies (five randomized controlled trials [RCTs]) involving 2149 participants were included. Most common targeted stroke survivors ($n=8$); family caregivers were most frequently used to deliver the intervention ($n=4$); and the intervention was usually provided in homes ($n=7$), with training initiated in the hospital ($n=4$). Of the four RCTs delivered by family

caregivers, one demonstrated a statistically significant improvement in mobility (effect size: 0.3; confidence interval [CI]:121.81-122.19; [$p=0.04$]) and another one in ADLs (effect size: 0.4; CI: 25.92-35.08; [$p=0.03$]). Of the five non-RCT studies by community health workers or volunteers, one demonstrated a statistically significant improvement in mobility (effect size: 0.3; CI: 10.143-16.857; [$p<0.05$]); while two demonstrated improved statistically significant improvement in ADLs (effect size: 0.2; CI:180.202-184.789 [$p=0.001$]; 0.4; CI: -7.643-18.643; [$p=0.026$]). However, the quality of evidence, based on GRADE criteria, was rated as low to very low.

Conclusion: While task-sharing is a possible strategy to meet basic rehabilitation needs in low-resource settings, the current evidence on the effectiveness of delivering rehabilitation interventions by non-professional community-level workers and informal caregivers is inconclusive. We can use the data and experiences from existing studies to better design studies and improve the implementation of interventions.

PROSPERO Registration number: CRD42022319130

Key Words: Systematic review, physical disabilities, community health workers, non-healthcare providers, health volunteers, family caregivers, physical function, adults, low-resource settings

Background

Physical rehabilitation interventions can optimize function and minimize disability for those with physical impairments⁹⁰ but are often inaccessible to populations living in low-resource settings^{91–93}. A growing burden of health conditions that lead to physical impairments has been observed in low-resource countries⁷⁹, wherein the Years Lived with Disability amenable to physical rehabilitation interventions more than doubled from 1990 to 2017⁹⁴. However, rehabilitation service provision and skilled human resources remain scant in low-resource settings^{54,79}. Here, we follow the standpoint that low-resource settings are not limited to low or middle income countries (LMICs) but include settings with structural health resource limitations, including financial shortages (of the system or those accessing the system), suboptimal service delivery systems, undeveloped physical infrastructure, or human resources limitations in workforce size or skills¹⁸.

In high-resource settings, physical rehabilitation is usually provided by credentialed, skilled health professionals, such as (but not limited to) rehabilitation physicians, rehabilitation psychologists, physiotherapists, occupational therapists, speech and language therapists, orthotists and prosthetists, and nurses. However, in low-resource settings, the availability of skilled rehabilitation workers is insufficient to meet the high and increasing population needs ⁵⁴. In low-resource settings, non-professional community-level health workers or informal caregivers may provide a valid and feasible alternative, extension, or complement to the care provided by rehabilitation specialists. These non-professional human resources include community health workers (CHWs), Accredited Social Health Activists in India, family caregivers, health volunteers, and lay personnel ⁹⁴⁻⁹⁷. These alternative resources are essential for the deployment of “task-shifting” and “task-sharing” approaches likely needed to improve population access to basic rehabilitation in low-resource settings ^{89,98}. In these approaches, skilled health care workers train, provide support or oversight to the non-professional community-level workers or informal caregivers ^{53,87}. Yet, it is unclear whether basic rehabilitation interventions delivered by non-professional human resources are effective.

Currently, rehabilitation in low-resource community settings is mainly provided through non-governmental organizations or community-based rehabilitation (CBR) approaches, often a part of the formal health sector. CBR is a cross-sectoral, community-level approach to addressing the health but also the educational, social, and other holistic needs of people with disabilities ⁹⁹. Two systematic reviews addressed the effectiveness of CBR in low-resource contexts ^{99,100}; however, these reviews include interventions and outcomes that are not necessarily health-oriented (e.g., focused on social inclusion and economic dimensions) ^{99,100}, did not focus exclusively on the effectiveness of health interventions (e.g., including qualitative studies ¹⁰⁰), included a wide range of people with disabilities such as those arising from mental or intellectual impairments⁹⁹, and finally did not include recent studies (published in 2012 and 2016) ^{99,100}. Our focus is specifically on the effectiveness of health-based interventions for the rehabilitation of physical impairments or disabilities, excluding those arising from mental health and intellectual conditions - as the scope of the health interventions, health outcomes, and the skill set of the health workforce vary.

Our primary study question is:

- Are physical rehabilitation interventions delivered by non-professional community-level workers or informal caregivers effective in improving physical functioning (mobility, activities of daily living [ADLs])?

Our secondary research questions are:

- What are the characteristics of the interventions that demonstrated an effect?
- Are the physical rehabilitation interventions delivered by non-professional community-level workers or informal caregivers effective in improving other health-related or health system outcomes, such as quality of life (QOL), social participation, self-management behaviors, service access and service utilization, and in improving key care processes (e.g., care coordination for community transitions).

Methods

The systematic review protocol was registered with PROSPERO (CRD42022319130). The reporting of this review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist¹⁰¹-see Supplemental Appendix 1. In addition, the GRADE approach¹⁰² was used to assess the quality evidence of studies.

Search strategy

Eight databases were searched: PubMed, CINAHL (through EBSCO), Global health (through EBSCO), PDQ Evidence, Scopus, ProQuest, the Cochrane Central Register of Controlled Trials (CENTRAL), and Web of Science. No time restrictions were applied. Supplemental Appendix 2 provides a complete search strategy for each of the eight databases. In short, the search strategy combined alternative sets of keywords and indexed terms for: 1) non-professional community-level workers or informal caregivers (CHWs, health volunteers, family caregivers, lay personnel) or community-level forms of service delivery; 2) rehabilitation service, physical function,

disability, or related outcomes; 3) low-resource settings in any country as well as entire LMICs; 4) study types addressing the efficacy or effectiveness of programs or interventions; 5) adult populations; and 6) the exclusion of articles focused on mental health conditions or psychiatric rehabilitation. Additionally, reference lists from included studies and published systematic reviews on partly related topics (e.g., CBR) were screened for references (snowballing). Finally, supplied with our preliminary list of the inclusions, three key informants (e.g., external scholars) who had published on community-level or CBR topics respectively in Africa, Asia, and Latin America were also contacted to determine if there were any unpublished or undetected studies relevant to the review.

Eligibility criteria

Population

We included studies of adults (aged 18 and older) with physical impairments or disabilities from possibly debilitating health conditions such as chronic non-communicable diseases (e.g., stroke, cancer, respiratory conditions, arthritis, low back pain), traumatic injuries (e.g., head injuries, spinal cord injuries), or communicable diseases (e.g., HIV/AIDs) and that were conducted in low-resource settings as defined by Van Zyl et al (2021)¹⁸. The option to address low-resource settings overall expands from our early registered protocol definitions focused on LMICs. We excluded studies of adults that focused on impairments or disabilities secondary to mental health or cognitive deterioration.

Interventions

We included studies of physical rehabilitation interventions delivered by non-professional community-level workers or volunteers (e.g., CHWs, community/health volunteers, lay workers), or informal caregivers in the community (e.g., community centers) or home-based settings, either individually or in groups, initiated, trained, or supervised by skilled health professionals (i.e., the “task-shifting” or “task-sharing” component).

Control/comparator(s)

Any comparator/control (such as usual or conventional care with follow-up), active or passive, was accepted. We also included non-controlled intervention studies (pre- and post-test).

Outcomes

Studies were included that reported on at least one of the following study outcomes: physical functioning (mobility, ADLs) as primary outcomes or QOL or social participation as secondary outcomes.

Study Type

We included randomized controlled trials (RCTs), non-randomized controlled experiments, non-controlled experiments (e.g., pre- and post-test designs; interrupted time series), and longitudinal observational studies (cohort studies, case-control studies) on the impact of a program or intervention.

Language

No restrictions were applied to the language of the full texts, provided that a title and abstract were available in English, French, Spanish, or Portuguese. Collectively, the research team had the capacity to review papers in these languages.

Time

No time restrictions were applied to the date of study publication.

Selection of studies

Titles and abstracts of studies detected by the searches were uploaded to a systematic review software: COVIDENCE (Melbourne, Australia)¹⁰³. First two independent reviewers (AK and JB) screened titles-and-abstracts. Then two independent reviewers (reviewer 1: AK; reviewer 2: LH or GU) performed the full-text assessments, followed by one round of reviewers' discussion toward agreement; the senior authors (TJ and JB) decided on any prevailing disagreements.

Data extraction

The following data were extracted: country/setting, study design, participants (sample size, number of groups in the intervention, health condition/disability, demographic characteristics [age, sex/gender]), intervention (type, personnel providing intervention, setting), outcomes measures, and study's outcomes. Two independent reviewers (reviewer 1: AK; reviewer 2: LH or GU) performed data extraction as adapted from the Cochrane Consumers and Communication Review Group's Data Extraction Template for Cochrane Reviews¹⁰⁴ and the COVIDENCE tool for data extraction.

Risk of bias assessment

For RCTs, we used the Cochrane handbook for systematic reviews¹⁰⁵, and reviewer 1: AK; reviewer 2: LH or GU rated each study as either low, unclear, or high risk of bias for each domain and provided explanations to justify. For non-RCTs, we used the ROBINS-I tool¹⁰⁶, and reviewer 1: AK; reviewer 2: LH or GU rated each study as either low, moderate, serious, critical risk of bias and no information on which to base the judgment.

Grading strength evidence

The quality of evidence and recommendations was further assessed and graded using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) guidelines as "high", "moderate", "low" or "very low". The quality of evidence assessments was performed by two independent reviewers (reviewer 1: AK; reviewer 2: LH or GU), with a consensus reached after discussions with the senior authors (TJ and JB).

Synthesis

Due to the heterogeneity of the studies (in study design, intervention details, outcome measures), a meta-analysis was not possible. Therefore, we performed a tabular and narrative synthesis of the results, organizing findings by RCTs and non-RCTs.

Results

Figure 1 provides the PRISMA flowchart of this review. From 610 deduplicated records, 117 underwent full-text screening; ten were eligible for inclusion. The most common reasons for exclusion were ineligible study designs, interventions delivered primarily by health professionals, and studies not reporting the effect of results.

Study Characteristics

Table 1 describes the Population, Intervention, Comparator and Outcome types (PICOs) as well as the country, study design, and the key findings of each of the ten included studies: five were RCTs^{42,44,86,107,108} (Table 1a), and five were non-RCT studies: one non-randomized controlled experiment⁸⁵, three pre- and post-test designs^{83,84,109}, and one comparative observational study¹¹⁰ (Table 1b). Studies were published between 2001¹⁰⁸ and 2021⁸⁴, with the majority of studies conducted either in Thailand ($n=3$) or China ($n=3$). Sample sizes varied from 11⁸⁴ to 1250⁸⁶, with 2149 participants included in this review. Stroke was the most frequently addressed condition ($n=8$). Family members ($n=4$) and village health volunteers ($n=3$) were the personnel most frequently used to deliver the intervention. The most common setting where rehabilitation was provided was the patients' home ($n=7$), of these, four provided initial training of trainers in the hospital. All five RCTs compared interventions to usual care (passive), and most studies assessed mobility ($n=5$), ADLs ($n=5$), and QOL ($n=5$).

Quality appraisals

For the RCTs, figure 2a shows the risk of bias within RCTs while figure 2b shows the risk of bias across the RCTs; detailed justifications for individual RCT assessments are presented in Supplemental Appendix 3. In a synthesis, none of the five RCTs had information on the concealment of allocations prior to assignment. In turn, one did not blind outcomes assessors¹⁰⁸. While none of the RCTs blinded participants and personnel, that is inherent to most studies of rehabilitation interventions.

For the non-RCTs, table 2 shows their appraised risk of bias detailed justifications for individual study assessments are presented in Supplemental Appendix 4. The only non-randomized controlled experiment⁸⁵ had mixed risk of bias appraisals (e.g., from a *low* risk of bias due to confounding to a *serious* risk of bias in measuring outcomes). The other four studies, i.e. three pre- and post-test designs and one comparative observational study^{83,84,109,110}, were appraised as having a *serious* or *critical* risk of bias (or *no information* to determine the risk) in all assessed domains; the single exception was a *low* risk of bias in one criterion (i.e., the selection of the reported results) of one particular study⁸⁴.

Finally, based on the GRADE criteria, table 3 presents an outcomes-based summary of findings stratified by RCTs and non-RCTs. For the mobility, ADLs, and QOL outcomes in randomized trials, the confidence in the strength of the evidence on the effectiveness of the tested interventions was all appraised at a *low* quality. In contrast, the observational studies were appraised at a *very low* quality.

Effects on outcomes

In this section, we first detail the effects of mobility and ADL outcomes (our primary study question) and those related to our secondary study questions.

Effects on physical functioning (mobility, ADLs): interventions by family caregivers

Two RCTs^{44,86}, totaling 1494 stroke participants, assessed the impact of family intervention to improve mobility (Table 1a). One study⁴⁴ demonstrated a statistically significant improvement in mobility for those randomized to intervention after adjusting for confounders, with a small effect size of 0.3; confidence interval (CI): 121.81-122.19; (p=0.04) (Table 1a). In contrast, the other study found no statistically significant difference in mobility outcomes⁸⁶.

Three RCTs^{44,86,107}, totaling 1555 stroke participants, reported on interventions by family caregivers to improve ADL outcomes. These studies used various tools to measure ADLs

(Barthel Index and the Nottingham extended ADL scale) and one of the three studies that used the Barthel Index¹⁰⁷ demonstrated a statistically significant improvement in ADL for the intervention group (unadjusted analysis), with a small effect size of 0.4; CI: 25.92-35.08; (p=0.03) (Table 1a).

Effects on physical functioning (mobility, ADLs): interventions by community health workers or volunteers

One RCT⁴² with 76 participants with HIV/AIDs assessed interventions by CHWs and found no statistically significant difference in mobility using various outcomes⁴².

Of the three non-RCTs, one study with interventions by village health volunteers (VHVs) demonstrated a statistically significant improvement in mobility at post-test versus pre-test, with an effect size of 0.3; 10.143-16.857; (p<0.05) among stroke patients⁸³.

Of the two non-RCTs, one with 365 participants that investigated interventions to improve ADL outcomes by community rehabilitation workers⁸⁵ demonstrated a statistically significant improvement for the intervention group compared to the control (effect size 0.2; CI:180.202-184.789; [p<0.001]). Another pre-and post-study by VHVs⁸⁴ among eleven stroke participants demonstrated a statistically significant improvement after the intervention was compared to baseline (effect size of 0.4; CI: -7.643-18.643; [p=0.026]) (Table 1b)⁸⁴.

Effects on Quality of life: interventions by family caregivers

Two RCTs, totaling 305 participants, investigated interventions by family caregivers and reported no greater effect of the intervention on QOL outcomes (using the EuroQol-5D) (Table 1a).^{44,107}

Effects on Quality of life: interventions by community health workers or volunteers

One RCT with interventions by CHWs, totaling 76 participants, reported no effect of the intervention on improving QOL outcomes⁴² (Table 1a).

Of the two non-RCTs that reported on QOL outcomes, a pre-post study by VHV's demonstrated a statistically significant improvement with a large effect size of 1.3; CI: 8.492-16.508; ($p < 0.000$)¹⁰⁹. In contrast, an observational comparison of two interventions (community compared with the hospital) did not demonstrate a difference¹¹⁰ (Table 1b).

No evidence was found for other outcomes such as social participation or changes in processes of interest.

Characteristics of the interventions by family members/caregivers that demonstrated an effect

Mobility outcomes were improved (adjusted analysis) in one RCT of an intervention by family caregivers once trained in-hospital by nurses for three days, 15-30 minutes, followed by phone calls every 2-4 weeks after hospital discharge⁴⁴; caregivers were recommended to support patients regularly for the eight weeks.

ADL outcomes were improved in an RCT study where nurses provided the caregivers' training in-hospital for 60 minutes once a day, three times, followed by a teach-back technique to assess if the caregivers had mastered the training¹⁰⁷.

Characteristics of the interventions by community health workers or volunteers that demonstrated an effect

Mobility outcomes were improved in an observational study by VHV's, trained at the community rehabilitation centers by rehabilitation professionals for 7 hours in one day (3 hours of theory and 4 hours of practical sessions)⁸³. VHV's were given a manual with pictures and explanations that were easy to read (e.g., by those not in the medical field) and were required to conduct home visits once weekly (1 hour per visit) for eight consecutive weeks.

For the non-RCTs that reported on ADL outcomes, the intervention was delivered by rehabilitation professionals trained community rehabilitation workers in groups in community rehabilitation centers⁸⁵, while VHVs provided the intervention in patients' homes in the other⁸⁴. The interventions in both non-RCT studies were provided twice a week for 1-1.5 hours, with at-home practice expected five times per week for 1.5 hours⁸⁵. The programs lasted eight⁸⁴ to 12 weeks⁸⁵. ADL outcomes in both studies were improved.

Finally, for QoL outcomes, the non-RCT study that demonstrated improvements in this measure type¹⁰⁹ used interventions delivered by VHVs, who were trained by rehabilitation professionals for 10 hours in one day (4 hours theory and 6 hours practical sessions). A manual detailing the intervention with pictures and explanations was provided to VHVs and families of stroke patients; VHVs were required to score 80% or more on their intervention skills to provide rehabilitation services. Patients were expected to participate in the rehabilitation program in the community rehabilitation center twice a week, 1.5 hours each time, for three months¹⁰⁹.

No study among those reporting improvements in mobility or ADL outcomes provided details about the expected time or amount (i.e., dose) of rehabilitation activities conducted with or by the patient.

Discussion

This review synthesizes the evidence of the effectiveness of health-related outcomes of basic physical rehabilitation interventions delivered to adults with physical impairments by non-professional community-level workers or informal caregivers using a task-shifting or task-sharing approach in the community. Ten studies were included, of which five were RCTs. Studies were mainly conducted in Asia ($n=6$), most commonly with stroke survivors ($n=8$), family caregivers were most frequently used to deliver the intervention ($n=4$), and the intervention was usually provided in the patient's homes ($n=7$), with training initiated in the hospital by health professionals ($n=4$). A total of 2149 participants were involved in these studies.

The results of the studies included in this review were inconclusive, either due to the mixed findings (e.g., small effect sizes to no effect) or the methodological shortcomings (e.g., graded evidence all appraised as *low* to *very low* confidence, even when arising from RCTs).

Compared with usual care, non-professional community-level workers and informal caregivers delivered physical rehabilitation interventions did not consistently improve mobility, ADLs, or QOL. Interestingly none of the studies that demonstrated benefits in either mobility, ADLs, or QOL had an effect in any other domain. Although there is inconsistency in outcomes and methodological weaknesses, reported characteristics of interventions that demonstrated to have an effect were those with the expertise of the trainers (i.e., skilled professionals), the amount of training for intervention providers, and a prescribed home practice plan.

Although Zhou et al⁴⁴ demonstrated some effect of the intervention on mobility outcomes, the authors noted that the way nurses were tasked to train family caregivers on rehabilitation interventions was not optimal, as nurses were just asked to accumulate a new set and tasks and skills into their loaded schedules. Lack of rehabilitation intervention expertise may have also accounted for the lack of effect on other domains, including ADLs. In addition to the trainer's expertise, it is important to consider the amount of training for intervention providers. Two studies^{44,86}, commented that the amount of training provided was inadequate. On average, these studies provided 45 minutes for three training days for intervention providers (i.e., enabling task-shifting or task-sharing).

When training those without experience with rehabilitation interventions, it is important to allow enough time and practice for intervention providers to become comfortable with the intervention, and to test for fidelity of the intervention delivery. Keeping interventions simple and providing follow-up training opportunities are also important means to improve intervention fidelity^{44,86}. Although few studies described the amount of practice intended with the patient (i.e., the dose of intervention), a prescribed home practice plan, coupled with regular follow-up, may contribute to the ability first to assess and then improve the intervention fidelity. Overall, fidelity issues need to be addressed to ascertain better the effectiveness of task-shifting and task-sharing interventions for the delivery of basic rehabilitation in the community.

In addition to those lessons learned from the studies included in this review, there are other novel approaches to intervention design and delivery that may also improve the effectiveness of these interventions. For example, digital health technologies, especially those that are low-cost and easy to use, might facilitate training^{53,87}. A recent study of the use of an mHealth strategy by CBR workers in India compared to control, showed that the CBR workers who used the mHealth strategy were more confident and able to implement adaptive feeding interventions for families of children with cerebral palsy better than their counterparts in the control group¹¹¹. Moreover, this approach was preceded by a culturally-sensitive needs assessment that was used to inform the training modules¹¹² and mHealth support given to the CBR workers in the active group. Such an approach aligns with the recognized need to account for the socio-cultural milieu and overall cultural acceptability of the approaches that may enable community-level workers to deliver task-sharing strategies more effectively. In addition, digital health technologies could help to improve supervision and the amount of at-home practice^{113,114}.

We may also be able to improve the provision of the intervention as well as the amount of practice by using primary care services to initiate, refer to, and provide basic rehabilitation services in low-resource settings^{115,116}. While the evidence-base for doing so is still on its infancy, research, and development on improving integration of rehabilitation services into primary care (with the subsequent improved outreach to local populations) is an agenda that the WHO has been pushing forward as one that is likely feasible and efficient to make basic rehabilitation available to underserved populations^{115,116}. Aligned with that call, a recent research report from South Africa unraveled a 10-year process that led to rehabilitation referral recommendations being considered for inclusion in South Africa's primary health care guidelines which, albeit with hurdles, indeed increased referrals to rehabilitation from primary health care¹¹⁷.

In summary, carefully considering by whom and how non-professional community-level workers or informal caregivers are trained, keeping interventions simple, and clearly defining the type and amount of practice are important considerations and may be key in determining whether task-sharing approaches are effective. In addition, digital technology, context-sensitive training

materials, and rehabilitation-inclusive primary care structures are also potential considerations to improve the quality of rehabilitation interventions delivered through task-sharing.

This review demonstrated that research into the effectiveness of non-professional community-level workers and informal caregivers providing rehabilitation interventions is starting, and suboptimal methodological quality may contribute to a lack of consistency in results. It is key to ensure that more robust studies are designed and implemented to enhance the body of knowledge in this area¹¹⁸. In addition, this review identified that Asian countries and stroke patients were the most frequently studied geographical contexts and patient populations. Even though we were open to include and indeed locate papers addressing low-resource settings of high-income countries, we found none fully met our eligibility criteria. Therefore, there is likely a need to enlarge the contexts, in countries across income levels, under which task-sharing approaches for delivering community-level rehabilitation interventions are being studied to meet the rehabilitation needs of underserved populations.

Limitations

The review had a variety of limitations. First, titles and abstracts needed to be in English, French, Spanish, or Portuguese, and the searches were conducted in English, which may lead to a suboptimal representation of studies reported in other languages. To partly offset this limitation, as well as the insufficiencies of scientific database searches, we approached three relevant external scholars as key informants – with expertise across three resource-poor world regions - for identifying any additional studies, including those of local scope. Second, we could not extract data from the studies that indicated the details about the expected amount of practice and progression of skills by the patient, which might affect the replicability of these interventions as well as their comparison in this systematic review. Finally, meta-analyses or sub-group analyses were not possible due to the heterogeneity of the studies (in study design, outcome measures, intervention details, and implementation strategies).

Conclusion

While task-sharing is a possible strategy to increase access to unmet basic rehabilitation needs in low-resource settings, the current evidence on the effectiveness of delivery of rehabilitation interventions by non-professional community-level workers and informal caregivers is inconclusive. We can use the data and experiences from existing studies to better design studies and improve the implementation of interventions. We can also consider novel approaches to improve training and adherence to the intervention. While the results of this review show that the data are inconsistent, there are important lessons from positive as well as neutral studies to improve both study and intervention design in future studies.

List of abbreviations

LMICs: Low and Middle Income Countries

CHWs: Community Health Workers

VHVs: Village Health Volunteers

CBR: Community-Based Rehabilitation

ADLs: Activities of Daily Living

QOL: Quality of Life

ROBINS-1: Risk of Bias in Non-randomised Studies - of Interventions

GRADE: Grading of Recommendations Assessment, Development and Evaluation

RCTs: Randomized Control Trials

Declarations

Ethics approval and consent to participate.

Not applicable

Consent for publication

Not applicable

Availability of data and materials

The datasets used and or analyzed during the current study are available from the corresponding author (AK) on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

Not applicable

Author's contribution

AK designed the systematic review under the supervision of JB. AK and TJ performed a systematic literature search. AK, GU, or LH independently performed article screening and selection, data extraction, and quality appraisal. AK and JB synthesized the data. AK wrote the first draft of the manuscript. JR, LT, and JK revised the draft. AK, JB, and TJ revised the subsequent version of the manuscript.

Acknowledgment

Not applicable

Supplementary information

Appendix 1: PRISMA checklist

Appendix 2: Detailed search strategy for all databases

Appendix 3: Risk of Bias for RCTs

Appendix 4: Risk of Bias for non-RCTs

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Figures

Figure 1: PRISMA flow diagram

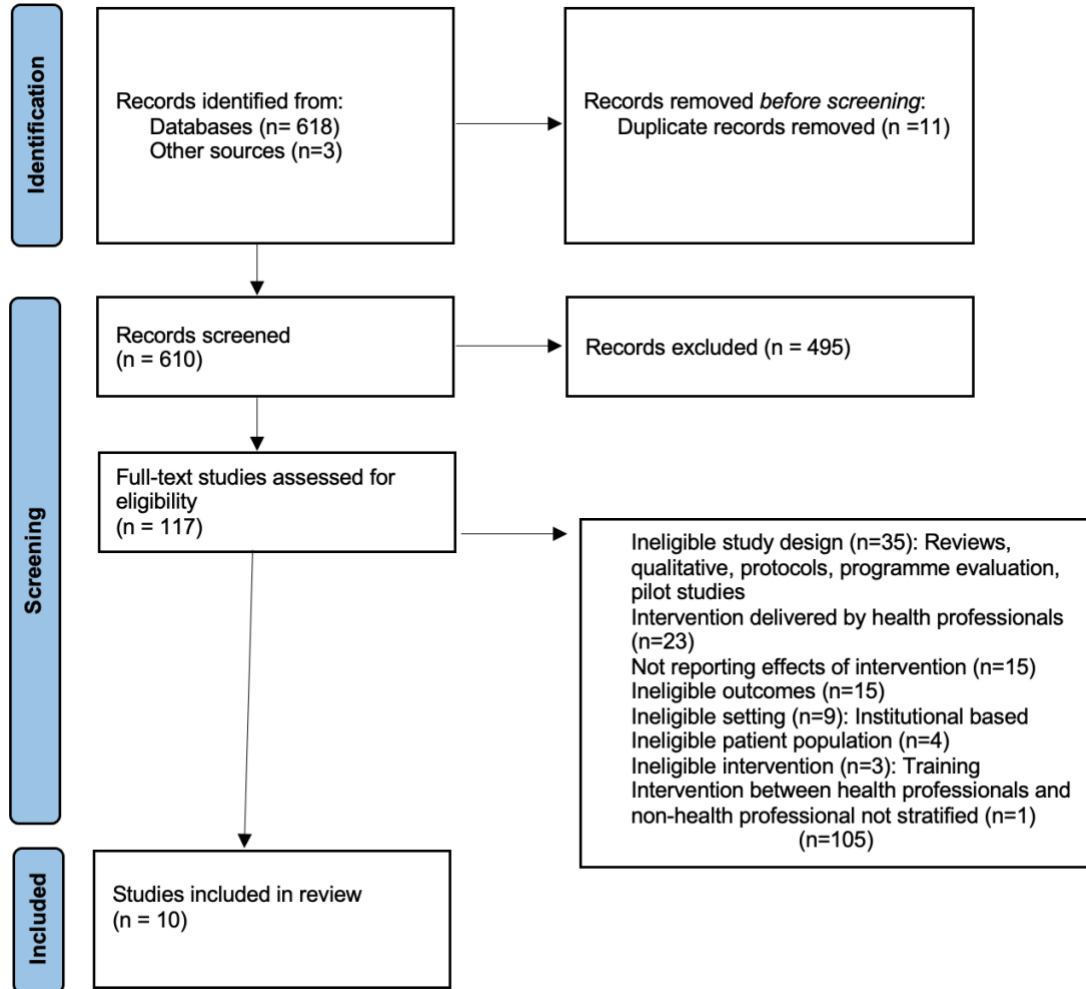
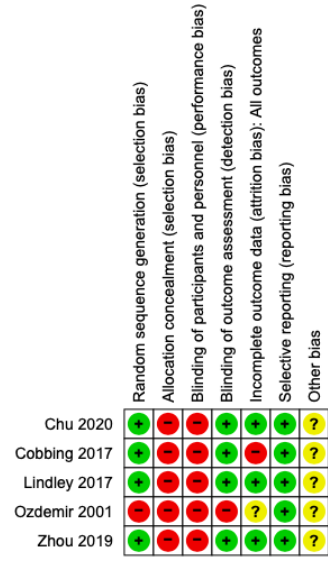


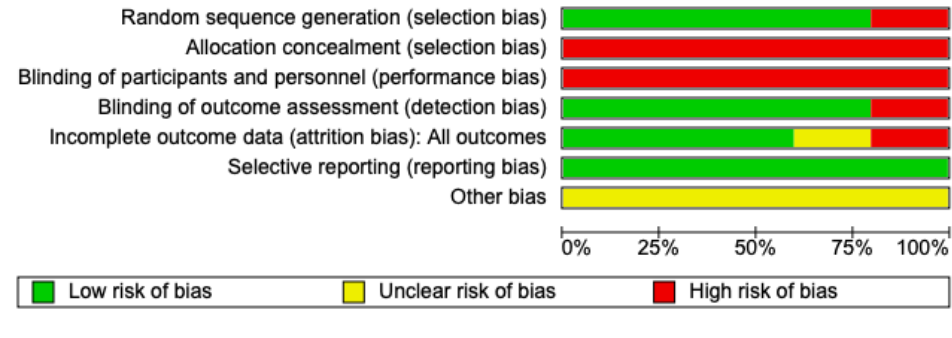
Figure 2: Cochrane Risk of Bias Assessment

Figure 2a: For individual RCTs



Red (-) =high risk of bias; Yellow(?)= unknown risk of bias; Green (+) = low risk of bias

Figure 2b: Overall



Tables

Table 1: Summary of study characteristics and main findings

Author & Year	Methods (country, design)	Participant: sample size, age (mean or mean & SD) female % primary diagnosis (Dx)	Intervention (type, personnel, setting, brief description of intervention)	Comparison	Follow-up period	Outcomes and tools	Key Findings At 6-months		
							Inter*	Cont*	p value
Table 1a: RCTs									
Chu, K. et al., 2020	China, RCT	N= 61: Age: intervention 62.84 (9.71) control 66.17 (8.51) female: intervention 68% control 53% Dx: stroke Ischemic 59%	Family delivered, in-homes after training in hospital. Mobility: bed transfer and chair transfer, walking on level ground, going up and down stairs; grooming, eating, dressing, bathing; bowel & bladder control, toilet use. In-hospital training: once a day, 60 mins for 3 days	Conventional care, no post-discharge rehabilitation	6 months	ADLs: BI (0-100) mean (SD)	72.6(21.18)	61.00(34.63)	0.03
						QOL: EQ-5D mean (SD)	1.55(0.39)	1.56(0.54)	0.91
Zhou, B. et al., 2019	China, RCT	N= 244: Age: intervention 64.3 control 66.2 female: intervention 54% control 56% Dx: stroke ischemic 73%	Caregiver delivered, in-home after training in hospital. Mobility: bed, balance, walking ADL: grooming, feeding, dressing, bathing, toileting Continenence: bowel & bladder control In-hospital training: 15-30mins for 3 days	Conventional care, no post-discharge rehabilitation	6 months	ADLs: BI (0-100) mean (SD)	70.1(25.5)	74.1(23.0)	p=0.27*
						Walking: FAC (0-5) mean (SD)	4.6(1.7)	5.0(1.4)	0.04*
						QOL: EQ-5D (0-1) mean (SD)	0.7(0.3)	0.8(0.3)	0.15*
Lindley, R. et al., 2017	India, RCT	N= 1250: Age: intervention 57.5(12.92) control 58 (14.21) female: intervention 68%	Family delivered, in-homes after training in hospital. ADL: task specific activities Mobility: limb positioning In-hospital training: 1h for 3 days	Post-discharge care varying from no therapy to some outpatient therapy sessions	6 months	ADLs: BI (0-100) mean (SD)	82.1(23.09)	82.6(23.19)	0.74
						ADLs: NEADL (0-66) mean (SD)	31.0(17.67)	31.2(17.52)	0.86
						Mobility: EQ-5D-3L (Proportion with	237/529(45%)	228/510(45%)	0.32

		control 66% Dx: stroke ischemic 77%				some or severe deficits)			
						Selfcare: EQ-5D-3L (Proportion with some or severe deficits)	251/529(47%)	230/510(45%)	0.75
Cobbing, S. et al., 2017	South Africa, RCT	N=76 Age: intervention 43.4 control 44.7 female: intervention 76.3% control 76.3% Dx: HIV	CHWs-delivered in-homes. Mobility: Aerobic exercise, strength, stretch (upper and lower limbs) and functional exercises (sitting to standing and bridging) and walking. Training duration for CHWs: >1month and visited patients once weekly	Conventional care, no rehabilitation in the community	6 months	Mobility: WHODAS (0-4), mean (SD)	0.18(0.56)	0.21(0.59)	>0.05
						Mobility: RMI (0-15) mean (SD)	14.24 (1.50)	13.82 (2.33)	>0.05
						Walking: 6MWT (distance), mean (SD)	327.71 (73.61)	303.29 (92.48)	>0.05
						QOL: WHOQOL (1-5) mean (SD)	3.62 (0.70)	3.41 (0.93)	>0.05
Ozdemir, F. et al., 2001	Turkey, RCT	N= 60 Age: intervention 61.8(9.2) control 59.1(5.9) female: control 30% intervention 63% Dx: stroke hemorrhagic 77%	Family-delivered, in-homes after training in hospital. Mobility: Convenient bed positioning and exercises. Splints, orthoses, and devices were also provided. A rehabilitation physician and a PT regularly visited patients for 2 hrs. Duration: Family provided therapy 2h a day for 7 days	Hospitalized patients performed therapeutic exercises and neuromuscular facilitation exercises, physical agents such as ice, hot packs, transcutaneous electric nerve stimulation, and ultrasound for 2hr for 5 days, had regular OT and physician assessments	5 months	Function independence: FIM (18-126), mean change score (SD)	59.63(14.19)	12.30(13.38)	0.001

Table 1b: Non-RCTs

Author & Year	Methods (country, design)	Participant: sample size, age (mean or mean & SD) female % primary diagnosis (Dx)	Intervention (type, personnel, setting, brief description of intervention)	Comparison	Follow-up period	Outcomes and tools	Key Findings		
							CRAT	Cont.	p
Ru, X. et al., 2017	China, Non-randomized controlled experiment	N= 365 Age: 61.9(9.5) female: 28.9% Dx: stroke Cerebral hemorrhage:	CRAT by community rehabilitation workers and family caregivers in community centers and patients' home.	No special intervention	3 months	ADLs: BI (0-100) (Proportion of severity of disease: ≥3 and <4; ≥4)	82.3 (21.3)	76.7(23.5)	0.001
							84.2 (21.9)	79.9(21.7)	0.001

Author & Year	Methods (country, design)	Participant: sample size, age (mean or mean & SD) female % primary diagnosis (Dx)	Intervention (type, personnel, setting, brief description of intervention)	Comparison	Follow-up period	Outcomes and tools	Key findings		
							Pre-test	Post-test	p-value
		70(20%)	Exercises were given based on functional limitations: Mobility: Lying, sitting, sitting-to-standing, and standing. Home-based training: 1.5h for 5 times			mean (SD)			
						Function: Fugl-Meyer Motor Function Assessment (0-100) (Proportion of severity of disease: ≥ 3 and < 4 ; ≥ 4) mean (SD)	76.7(23.5)	58.7(28.9)	0.001
							66.9(25.4)	57.6(26.7)	0.023
Chinchai, P. et al., 2021	Thailand, Pre and post-test	N= 11: Age (range): 41-80 female: 27% Dx: stroke	Rehabilitation education by VHWs in community rehabilitation centers. Fundamental knowledge of stroke Mobility: physical exercise and gait training, UE function training ADL: selfcare, bed mobility, transfers, home chores, community mobility Duration: 1.5hr, twice per week for 2 months	No control group	2 months	Basic ADLs: The ADL assessment tool (BADL) (23-155) mean (SD)	67.41(23.31)	75.50(21.17)	0.026
Chinchai, P. et al., 2020	Thailand, Pre and post-test	N= 25 age (range): 30-80 female: 40% Dx: stroke	Rehabilitation education by VHWs in community rehabilitation centers. Basic knowledge of stroke, Mobility: exercise and gait, transfers, UE functional training ADL: dressing, grooming Duration: 1.5hr, twice per week for 3 months	No control group	3 months	QOL: WHOQOL-BREF-THAI (0-100) mean (SD)	71.44(8.38)	84.88(12.07)	0.000
						Community integration: Community integration questionnaire (0-29) mean [SD]	9.80(3.96)	11.44(4.68)	0.006
Chinchai, P. et al., 2017	Thailand, Pre and post-test	N= 27: age range: 30-80 female: 37%	Rehabilitation education by VHWs in patients' homes.	No control group	2 months	Walking: Ten-Meter Walk Test mean (SD)	34.73(8.48) 0.17 meters/sec	32.18(9.32)	0.000 p<0.05

		Dx: stroke	Basic knowledge of stroke, Mobility: gait training, balance, and UE (reaching out, holding, carrying) & LE function. Duration: 1 hr per week for 2 months					0.19 meters/sec	
						UE function: FMA (0-44) mean (SD)]	36.81(9.59)	37.26(9.6 7)	0.474
Balasubramanian, M.M. et al., 2012	India, Comparative observational	N= 30: Age: IBR 37(18.13) CBR 54(13.55) Dx: Locomotor disabilities	IBR by healthcare professionals. *	CBR by CBR workers	*Not described	Function: FIM (18- 126) mean (SD)	IBR: 117.40(3.0 4)	CBR: 111.60(12 .02)	>0.05
						QOL: WHOQOL- BREF: (1-5) mean (SD)	IBR: 4.20(0.414)	CBR: 4.00(1.60 4)	>0.05

SD: standard deviation, RCT: Randomized control trial, Inter.: Intervention, Cont.: control, ADLs: Activities of daily living, QOL: Quality of life, *p-value adjusted for confounders, NEADL: Nottingham extended ADL scale, FAC: functional ambulation category, HIV: human immunodeficiency virus, CHWs: community health workers, WHODAS: world health organization disability assessment schedule, RMI: Rivermead mobility index, 6MWT: six minute walk test, WHOQOL: world health organization quality of life, PT: physiotherapy, OT: occupational therapy, FIM: functional independence measure, CRAT: community-based rehabilitation appropriate technique, UE: Upper extremity, LE: lower extremity, VHVs: village health volunteers, WHOQOL-BREF: World health organization quality of life-BREF, FMA: Fugl-Meyer Assessment, IBR: Institutional-based rehabilitation, CBR: Community-based rehabilitation, *Description of intervention not described

Table 2: Risk of bias for non-RCTs

Non RCTs (Cochrane risk of bias [ROBINS-I])							
Study	Pre-intervention domains		At intervention domain	Post-intervention domains			
	<i>Bias due to confounding</i>	<i>Bias due to selection of participants</i>	<i>Bias due to classification of interventions</i>	<i>Bias due to deviations from intended interventions</i>	<i>Bias due to missing data</i>	<i>Bias in measurement of outcomes</i>	<i>Bias in selection of the reported results</i>
Ru, X. et al., 2017	Low risk	Serious risk	Moderate risk	No information	Moderate risk	Serious risk	Low risk
Chinchai, P. et al., 2021	Serious risk	Critical risk	No information	Critical risk	Serious risk	Serious risk	Low risk
Chinchai, P. et al., 2020	Serious risk	Critical risk	No information	No information	Serious risk	Serious risk	Serious risk
Chinchai, P. et al., 2017	Serious risk	Critical risk	No information	No information	Serious risk	Serious risk	Serious risk
Balasubramanian, M.M. et al., 2012	Serious risk	Critical risk	Critical risk	No information	No information	Serious risk	Serious risk

Low risk of bias: The study is comparable to a well performed randomised trial with regard to this domain

Moderate risk of bias: The study is sound for a non-randomised study with regard to this domain but cannot be considered comparable to a well performed randomised trial

Serious risk of bias: The study has some important problems

Critical risk of bias: The study is too problematic in this domain to provide any useful evidence on the effects of intervention

No information: on which to base a judgement about risk of bias for this domain

Table 3: Quality of the evidence included in the review (GRADE)

Certainty assessment						№ of Patients		Quality of the evidence (GRADE)	Comment
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Intervention	Usual care		
Randomized trials									
Mobility (assessed with FAC, EQ-5D, WHODAS; follow-up: 6 months)									
3	randomised trials	not serious ^a	serious ^b	not serious ^c	serious ^b	779	793	⊕⊕○○ Low	One study reported an effect after adjusting for confounders (Zhou et al) effect size of 0.3 ($p=0.04$).
Activities of daily living (assessed with BI; follow-up: 6 months)									
3	randomised trials	not serious ^a	serious ^d	not serious ^e	serious ^d	772	785	⊕⊕○○ Low	One study reported an effect (Chu et al) effect size of 0.40 ($p=0.0312$)
Quality of life (assessed with EQ-5Q & WHOQOL; follow-up: 6 months)									
3	randomised trials	not serious ^a	serious ^f	not serious ^e	serious ^f	187	196	⊕○○○ Very low	All studies showed no effect of intervention
Non-RCT studies									
Activities of daily living (assessed with BI and BADL assessment tool; follow-up: 2 to 3 months)									
2	observational studies (non-RCTs)	serious ^a	not serious ^g	serious ^h	serious ^g	376		⊕○○○ Very low	Both studies reported statistically significant improvements, effect size for Ru et al (0.2, $p<0.001$) and Chinchai et al 2021 (0.4, $p=0.026$)
Quality of life (assessed with WHOQOL-BREF; follow-up: 3 months)									
2	observational studies (non-RCTs)	very serious ⁱ	not serious ^d	serious ^j	serious ^d	55		⊕○○○ Very low	One study reported statistically significant improvement, Chinchai et al 2020 (effect size of 1.3 ($p<0.05$))

Explanations

- a. Most information is from studies at a low risk of bias (Blinded outcome assessors)
- b. Studies used various tools to measure the outcome, and only one study demonstrated an effect
- c. Assessed different populations, same interventions and comparison (usual care), and outcome
- d. Studies used the same tools to measure the outcome, and only one study demonstrated an effect

- e. Assessed same populations, same interventions and comparison (usual care) and outcome
- f. Studies used various tools, and none of the studies demonstrated an effect
- g. Studies used various tools to measure the outcome, and both demonstrated an effect
- h. Assessed the same populations, interventions, and outcomes (ADLs).
- i. Most information is from studies at low or unclear risk of bias
- j. Assessed different populations, same interventions and outcome

Grading:

No serious concerns exist, do not downgrade quality from baseline quality (e.g., for RCTs)

Serious concern exists, downgrade the evidence one level, e.g., from high to moderate (- 1)

Very serious concern exists, downgrade the evidence two levels, e.g., from high to low (- 2)

Quality of the evidence:

⊕⊕⊕⊕ High: We are very confident that the true effect lies close to that of the estimate of the effect

⊕⊕⊕○ Moderate: We are moderately confident in the effect estimate: the true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different

⊕⊕○○ Low: Our confidence in the effect estimate is limited: the true effect may be substantially different from the estimate of the effect.

⊕○○○ Very low: We have very little confidence in the effect estimate: the true effect is likely to be substantially different from the estimate of effect.

Appendices

Appendix 1: PRISMA checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	2
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	3
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	4

Section and Topic	Item #	Checklist item	Location where item is reported
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	3
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	3
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	4-5
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	5
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	4
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	4
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	5
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	5

Section and Topic	Item #	Checklist item	Location where item is reported
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	5
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	6
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	NA
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	5
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	6
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	
Study characteristics	17	Cite each included study and present its characteristics.	6
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	6
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	6-7

Section and Topic	Item #	Checklist item	Location where item is reported
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	6
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	6
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	8-9
	23b	Discuss any limitations of the evidence included in the review.	10
	23c	Discuss any limitations of the review processes used.	10
	23d	Discuss implications of the results for practice, policy, and future research.	9-10
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	3
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	3
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	4
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	11
Competing interests	26	Declare any competing interests of review authors.	11

Section and Topic	Item #	Checklist item	Location where item is reported
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	

Appendix 2: search strategy

Search Report – All Scientific Databases

February 18th, 2022

Total entries: 1185 with duplicates; 1011 with the EndNote automatic deduplication

PubMed: (210 entries)

("Adult"[Mesh] NOT "Child"[Mesh] NOT "Infant"[Mesh]) AND ("Community Health Workers"[Mesh] OR "community health worker"[Text Word] OR "community based rehabilitation"[Text Word] OR "community intervention*"[Text Word] OR "Home Health Aides"[Mesh] OR "community health agent"[Text Word] OR "lay health worker"[Text Word] OR "Caregivers"[Mesh] OR "Family-led"[Text Word] OR "Community Support"[Mesh] OR "community health assistant*"[Text Word] OR "cadre"[Text Word] OR "volunteer health worker"[Text Word] OR "Homemaker Services"[Mesh] OR "Delegation, Professional"[Mesh] OR "Task shifting"[Text Word] OR "Task sharing"[Text Word]) AND ("Rehabilitation"[Subheading] OR "Rehabilitation"[Mesh] OR "Rehabilitation"[tw] OR "Recovery of Function"[Mesh] OR "Activities of Daily Living"[Mesh] OR "Self Care"[Mesh] OR "continuity of care"[Text Word] OR "community integration"[Text Word] OR "community support"[Text Word] OR "Disability Evaluation"[Mesh] OR "Disabled Persons"[Mesh] OR "Disability Studies"[Mesh] OR "disability"[Text Word] OR "disabilities"[Text Word] OR "impairment"[Text Word] OR "impairments"[Text Word] OR "Self-Management"[Mesh]) AND ("Developing Countries"[Mesh] OR "low and middle income"[Text Word] OR "Argentina"[Mesh] OR "Africa"[Mesh] OR ("China"[Mesh] NOT "Hong Kong"[Mesh] NOT "Macau"[Mesh]) OR "Democratic People's Republic of Korea"[Mesh] OR "Mongolia"[Mesh] OR "Asia, Central"[Mesh] OR "Asia, Northern"[Mesh] OR "Bangladesh"[Mesh] OR "Bhutan"[Mesh] OR "India"[Mesh] OR "Nepal"[Mesh] OR "Pakistan"[Mesh] OR "Sri Lanka"[Mesh] OR "Afghanistan"[Mesh] OR "Iran"[Mesh] OR "Iraq"[Mesh] OR "Jordan"[Mesh] OR "Lebanon"[Mesh] OR "Syria"[Mesh] OR "Turkey"[Mesh] OR "Yemen"[Mesh] OR "Cambodia"[Mesh] OR "Indonesia"[Mesh] OR "Laos"[Mesh] OR "Malaysia"[Mesh] OR "Myanmar"[Mesh] OR "Philippines"[Mesh] OR "Thailand"[Mesh] OR "Timor-Leste"[Mesh] OR "Vietnam"[Mesh] OR "Mexico"[Mesh] OR "Belize"[Mesh] OR "Costa Rica"[Mesh] OR "El Salvador"[Mesh] OR "Guatemala"[Mesh] OR "Honduras"[Mesh] OR "Nicaragua"[Mesh] OR "Cuba"[Mesh] OR "Dominica"[Mesh] OR "Dominican Republic"[Mesh] OR "Grenada"[Mesh] OR "Haiti"[Mesh] OR "Jamaica"[Mesh] OR "Saint Lucia"[Mesh] OR "Saint Vincent and the Grenadines"[Mesh] OR "Bolivia"[Mesh] OR "Brazil"[Mesh] OR "Colombia"[Mesh] OR "Ecuador"[Mesh] OR "Paraguay"[Mesh] OR "Peru"[Mesh] OR "Suriname"[Mesh] OR "Venezuela"[Mesh] OR "Albania"[Mesh] OR "Bosnia and Herzegovina"[Mesh] OR "Bulgaria"[Mesh] OR "Kosovo"[Mesh] OR "Republic of North Macedonia"[Mesh] OR "Montenegro"[Mesh] OR "Moldova"[Mesh] OR "Republic of Belarus"[Mesh] OR "Serbia"[Mesh] OR "Ukraine"[Mesh] OR "Transcaucasia"[Mesh] OR "Kazakhstan"[Mesh] OR "Kyrgyzstan"[Mesh] OR "Uzbekistan"[Mesh] OR "Samoa"[Mesh] OR ("Micronesia"[Mesh] NOT "Guam"[Mesh] NOT "Palau"[Mesh])

OR "Fiji"[Mesh] OR "Papua New Guinea"[Mesh] OR "Vanuatu"[Mesh] OR "Tonga"[Mesh]) AND ("Study Characteristics" [Publication Type] OR "Feasibility Studies"[Mesh] OR "Pilot Projects"[Mesh] OR "Support of Research" [Publication Type]) AND ("intervention"[Text Word] OR "program"[Text Word] OR "trial"[Text Word] OR "delivery"[Text Word] OR "training"[Text Word] OR "education"[Text Word] OR "Rehabilitation"[Subheading] OR "Rehabilitation"[Mesh]) NOT ("Mentally Ill Persons"[MeSH] OR "Psychiatry"[Mesh] OR "Psychiatric Nursing"[Mesh] OR "Mental Disorders"[Mesh] OR "Mental Health Recovery"[Mesh] NOT "Psychiatric Rehabilitation"[Mesh])

CENTRAL (172 entries)

Filtered for: Trials

("Community Health Workers" OR "community based rehabilitation" OR "lay health worker" OR "Caregiver-led" OR "Family-led" OR "Caregiver-delivered" OR "Family-delivered" OR "community health assistants" OR "cadre" OR "volunteer worker" OR "Task shifting" OR "Task sharing") AND ("Rehabilitation" OR Disability OR Disabilities OR "impairment" OR "impairments") AND (intervention OR program OR trial OR delivery OR training OR education) NOT (mental OR psychiatric OR child OR children OR schizophrenia OR depression OR diabetes) AND ("low income country" OR "low income countries" OR "middle income country" OR "middle income countries" OR "developing country" OR "developing countries" OR Africa OR Angola OR Algeria OR Bangladesh OR Belize OR Benin OR Bhutan OR Bolivia OR Cabo Verde OR Cambodia OR Cameroon OR Comoros OR Congo, Rep. OR Côte d'Ivoire OR Djibouti OR Egypt, Arab Rep. OR El Salvador OR Eswatini OR Ghana OR Haiti OR Honduras OR India OR Indonesia OR Iran, Islamic Rep OR Kenya OR Kiribati OR Kyrgyz Republic OR Lao PDR OR Lesotho OR Mauritania OR Micronesia, OR Mongolia OR Morocco OR Myanmar OR Nepal OR Nicaragua OR Nigeria OR Pakistan OR Papua New Guinea OR Philippines OR Samoa OR São Tomé and Príncipe OR Senegal OR Solomon Islands OR Sri Lanka OR Tanzania OR Tajikistan OR Timor-Leste OR Tunisia OR Ukraine OR Uzbekistan OR Vanuatu OR Vietnam OR West Bank and Gaza OR Zambia OR Zimbabwe OR Albania OR American Samoa OR Argentina OR Armenia OR Azerbaijan OR Belarus OR Bosnia and Herzegovina OR Botswana OR Brazil OR Bulgaria OR China OR Colombia OR Costa Rica OR Cuba OR Dominica OR Dominican Republic OR Equatorial Guinea OR Ecuador OR Fiji OR Gabon OR Georgia OR Grenada OR Guatemala OR Guyana OR Iraq OR Jamaica OR Jordan OR Kazakhstan OR Kosovo OR Lebanon OR Libya OR Malaysia OR Maldives OR Marshall Islands OR Mauritius OR Mexico OR Moldova OR Montenegro OR Namibia OR North Macedonia OR Panama OR Paraguay OR Peru OR Romania OR Russian Federation OR Serbia OR South Africa OR St. Lucia OR St. Vincent and the Grenadines OR Suriname OR Thailand OR Tonga OR Turkey OR Turkmenistan OR Tuvalu OR Afghanistan OR Burkina Faso OR Burundi OR Central African Republic OR Chad OR Congo, Rep. OR Eritrea OR Ethiopia OR Gambia, The OR Guinea OR Guinea-Bissau OR Korea OR Liberia OR Madagascar OR Malawi OR Mali OR Mozambique OR Niger OR Rwanda OR Sierra Leone OR Somalia OR South Sudan OR Sudan OR Syrian Arab Republic OR Togo OR Uganda OR Yemen)

Scopus: (176 entries)

(TITLE-ABS-KEY ("Community Health Worker*") OR TITLE-ABS-KEY ("community based rehabilitation") OR (community PRE/2 aid*) OR (lay PRE/2 worker*) OR (community PRE/2 assistant*) OR (volunteer PRE/2 worker*) OR TITLE-ABS-KEY (cadre) OR TITLE-ABS-KEY ("task shift*") OR TITLE-ABS-KEY ("task shar*") OR (family W/5 rehabilitation) OR TITLE-ABS-KEY (caregiver W/5 rehabilitation)) AND (TITLE-ABS-KEY (rehabilitation) OR TITLE-ABS-KEY ("self care") OR TITLE-ABS-KEY ("Activities of Daily Living") OR TITLE-ABS-KEY ("disabilit*") OR TITLE-ABS-KEY (impairment) OR TITLE-ABS-KEY (assistive) OR TITLE-ABS-KEY ("self management") OR INDEXTERMS (rehabilitation)) AND (LIMIT-TO (AFFILCOUNTRY , "India") OR LIMIT-TO (AFFILCOUNTRY , "China") OR LIMIT-TO (AFFILCOUNTRY , "South Africa") OR LIMIT-TO (AFFILCOUNTRY , "Brazil") OR LIMIT-TO (AFFILCOUNTRY , "Turkey") OR LIMIT-TO (AFFILCOUNTRY , "Malaysia") OR LIMIT-TO (AFFILCOUNTRY , "Pakistan") OR LIMIT-TO (AFFILCOUNTRY , "Nigeria") OR LIMIT-TO (AFFILCOUNTRY , "Uganda") OR LIMIT-TO (AFFILCOUNTRY , "Russian Federation") OR LIMIT-TO (AFFILCOUNTRY , "Thailand") OR LIMIT-TO (AFFILCOUNTRY , "Kenya") OR LIMIT-TO (AFFILCOUNTRY , "Jordan") OR LIMIT-TO (AFFILCOUNTRY , "Jamaica") OR LIMIT-TO (AFFILCOUNTRY , "Rwanda") OR LIMIT-TO (AFFILCOUNTRY , "Papua New Guinea") OR LIMIT-TO (AFFILCOUNTRY , "Viet Nam") OR LIMIT-TO (AFFILCOUNTRY , "Bulgaria") OR LIMIT-TO (AFFILCOUNTRY , "Cambodia") OR LIMIT-TO (AFFILCOUNTRY , "Peru") OR LIMIT-TO (AFFILCOUNTRY , "Benin") OR LIMIT-TO (AFFILCOUNTRY , "Mozambique") OR LIMIT-TO (AFFILCOUNTRY , "Togo") OR LIMIT-TO (AFFILCOUNTRY , "Tunisia") OR LIMIT-TO (AFFILCOUNTRY , "American Samoa") OR LIMIT-TO (AFFILCOUNTRY , "Bolivia") OR LIMIT-TO (AFFILCOUNTRY , "Ecuador") OR LIMIT-TO (AFFILCOUNTRY , "Lebanon") OR LIMIT-TO (AFFILCOUNTRY , "Senegal") OR LIMIT-TO (AFFILCOUNTRY , "Albania") OR LIMIT-TO (AFFILCOUNTRY , "Algeria") OR LIMIT-TO (AFFILCOUNTRY , "Barbados") OR LIMIT-TO (AFFILCOUNTRY , "Gabon") OR LIMIT-TO (AFFILCOUNTRY , "Germany (Democratic Republic, DDR)") OR LIMIT-TO (AFFILCOUNTRY , "Kazakhstan") OR LIMIT-TO (AFFILCOUNTRY , "Mauritania") OR LIMIT-TO (AFFILCOUNTRY , "Myanmar") OR LIMIT-TO (AFFILCOUNTRY , "Nicaragua") OR LIMIT-TO (AFFILCOUNTRY , "Niger") OR LIMIT-TO (AFFILCOUNTRY , "Russia") OR LIMIT-TO (AFFILCOUNTRY , "Seychelles") OR LIMIT-TO (AFFILCOUNTRY , "Solomon Islands") OR LIMIT-TO (AFFILCOUNTRY , "Somalia") OR LIMIT-TO (AFFILCOUNTRY , "Suriname") OR LIMIT-TO (AFFILCOUNTRY , "Trinidad and Tobago") OR LIMIT-TO (AFFILCOUNTRY , "Uzbekistan")) AND (LIMIT-TO (DOCTYPE , "ar")) AND (LIMIT-TO (SUBJAREA , "HEAL") OR LIMIT-TO (SUBJAREA , "PSYC") OR LIMIT-TO (SUBJAREA , "NURS") OR EXCLUDE (SUBJAREA , "ENGI") OR EXCLUDE (SUBJAREA , "AGRI") OR EXCLUDE (SUBJAREA , "BIOC") OR EXCLUDE (SUBJAREA , "DENT") OR EXCLUDE (SUBJAREA , "EART")) AND (EXCLUDE (EXACTKEYWORD , "Child") OR EXCLUDE (EXACTKEYWORD , "Depression") OR EXCLUDE (EXACTKEYWORD , "Schizophrenia") OR EXCLUDE (EXACTKEYWORD , "Adolescent")

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Applied Filters:

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Filtered for: Primary Studies

Appendix 3: Risk of Bias for RCTs

Author & Year	Bias arising from the randomization	Bias due to deviations from intended intervention	Bias due to missing outcome data	Bias in measurement of the outcome	Bias in selection of the reported result	Overall bias
Cobbing, S. et al., 2017	<p>Low risk of bias</p> <p>-stratified randomization was employed using a computerized method to ensure an even number of male and female participants in the intervention and control groups</p> <p>- No concealment of allocations prior to assignment</p>	<p>High risk of bias</p> <p>-participants and therapists were not blinded</p> <p>-No deviation from the intended intervention is mentioned</p>	<p>Low risk of bias</p> <p>-an intention to treat analysis was performed</p> <p>-intervention group (n=38): 11% lost to follow-up (1 died, 1 moved and 2 were unable to attend)</p> <p>-control group (n=38): 11% lost to follow-up (1 moved and 3 unable to contact)</p>	<p>Low risk of bias</p> <p>-Outcome assessors were not aware of the intervention received by study participants</p>	<p>Low risk of bias</p> <p>- all intended outcome measures (primary and secondary) mentioned in the protocol are completed</p>	Low risk of bias
Lindley, R. et al., 2017	<p>Low risk of bias</p> <p>-Patients were randomly assigned (1:1) to intervention or a usual care control group via a secure web-based central randomisation system with minimisation by site and stroke severity</p> <p>- No information to assess concealment of allocations</p>	<p>High risk of bias</p> <p>-participants and therapists were not blinded</p> <p>-No deviation from the intended intervention is reported</p>	<p>Low risk of bias</p> <p>- an intention to treat analysis was performed</p> <p>-Intervention (n=623): at 6mnths: 16(3%) lost to follow-up</p> <p>-Control (n=627): at 6mnths:22(4%) lost to follow-up</p>	<p>Low risk of bias</p> <p>- Outcome assessors were blinded</p>	<p>Low risk of bias</p> <p>- all the outcome measures mentioned in the protocol are reported in the study</p>	Low risk of bias

	prior to assignment					
Zhou, B. et al., 2019	<p>Low risk of bias</p> <p>Randomized via a secure, central internet- based system, with randomly variable block sizes</p> <p>No information to assess concealment of allocations prior to assignment</p>	<p>High risk of bias</p> <p>-Participants and therapists were not blinded</p> <p>- No deviation from the intended intervention is reported</p>	<p>Low risk of bias</p> <p>- an intention to treat analysis was performed</p> <p>-intervention (n=116): 2(2%) died</p>	<p>Low risk of bias</p> <p>- Outcome assessors were blinded</p>	<p>Low risk of bias</p> <p>- all the outcome measures mentioned in the protocol are reported</p>	<p>Low risk of bias</p>
Chu, K. et al., (2020)	<p>Low risk of bias</p> <p>-Eligible patients were randomly assigned either to intervention group or to control group through a secure, internet-based system</p> <p>-No information to assess concealment of allocations prior to assignment</p>	<p>High risk of bias</p> <p>Participants and therapists were not blinded</p>	<p>High risk of bias</p> <p>An intention to treat analysis was performed</p> <p>Intervention(N=31):29% (1 patient died, 4 lost to follow-up, 3 refused to participate and 1 for other reason)</p>	<p>Low risk of bias</p> <p>-Outcome assessors were blinded</p>	<p>Low risk of bias</p> <p>-All intended outcome measures (primary and secondary) mentioned in the protocol are reported in the study</p>	<p>Low risk of bias</p>
Ozdemir, F. et al., 2001	<p>High risk of bias</p> <p>Patients were enrolled into 2 equal groups by selecting patients consecutively, one by one, according to when</p>	<p>High risk of bias</p> <p>Participants and therapists were not blinded</p>	<p>High risk of bias</p> <p>No information to assess</p>	<p>High risk of bias</p> <p>Outcome assessors were aware of the participants' assigned intervention</p>	<p>High risk of bias</p> <p>Outcomes measures are presented but no protocol to affirm if the data was collected as planned</p>	<p>High risk of bias</p>

	they enrolled in the study. -This method of allocations patients into groups suggests lack of concealment					
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Appendix 4: Risk of bias for non-RCTs

Author & Year	Pre-intervention domains		At intervention domain	Post-intervention domains			
	Bias due to confounding	Bias due to selection of participants	Bias due to classification of interventions	Bias due to deviations from intended interventions	Bias due to missing data	Bias in measurement of outcomes	Bias in selection of the reported results
Ru, X. et al., 2017	Moderate risk Participants in both control and intervention communities were similar and the stroke survivors were sampled using a random-number generator	Serious risk Patients with severe dysfunction were unable to receive CRAT treatment. Accordingly, there is a possibility that the study suffered from a selection bias, which may have led to better ADLs estimate in the recruited participants and may explain the mean baseline BI score	No Information on which to base the judgment	Serious risk Participants were not blinded of the intervention -Therapists delivering the intervention were not blinded to participants' assigned intervention -No deviation from the intended intervention is mentioned	Serious risk CRAT/intervention group (n=365): 23(6%) discontinued treatment -No intention to treat was reported	Serious risk Treatment effect evaluators were not blinded	Serious risk Results from all measurements were reported but no protocol
Chinchai, P. et al., 2017	Serious risk -some socio-demographic data are reported -pre and post study (we could consider pre as control)	Serious risk -purposive sampling- not randomly selected -sample:27 participants out of 4 municipalities While invitations were sent to 10 municipalities	No information on which to base the judgment	Serious risk -research teams made phone calls to VHV's once every two weeks and VHV completing home visits	No information on which to base the judgment. The paper does not show any missing data (no information of patients who couldn't complete)	Serious risk - data (pre/post) were collected by different research assistants (2 OTs with 2 years' experience in the field.	Serious risk All results for the measurements were reported but no protocol to verify
Chinchai, P. et al., 2020	Serious risk -Some socio-demographic data are presented - pre and post study	Serious risk -purposive sampling- not randomly selected	No information on which to base the judgment	No information on which to base the judgment	No information on which to base the judgment The paper does not show any missing data (no information of patients who	Serious risk -outcome data were collected by research assistants (PTs) collecting	Serious risk - Results from all measurements were reported as per research

		-sample:25 out of 4 rehab centers			couldn't complete)	data were unaware of the study goals	question but no protocol -clinical significancy not reported?
Chinchai, P. et al., 2021	Serious risk of bias: - pre and post study - no control group	Serious risk: Participants were selected using purposive sampling	No information on which to base the judgment	No information on which to base the judgment	No information on which to base the judgment The paper does not show any missing data (no information of patients who couldn't complete)	Serious risk Patients and outcome assessors were not blinded	Serious risk: It seems the results from all measurements were reported but no protocol
Balasubramanian, M.M. et al., 2012	Serious risk Substantive difference in mean age (CBR:53 vs. IBR: 37) -Sample of only men -No socio-demographic data presented	Serious risk - purposive sampling- not randomly selected from a comprehensive list of target individuals (not representative)	Serious risk -IBR vs CBR but the type of care/interventions are not specified) -possible that patients were in both programs or recently quit IBR for CBR for example	No information on which to base the judgment	No information on which to base the judgment	Serious risk -2 outcome measures (self-reported) are presented -Likely staff knew allocation -Period in the program not reported	Serious risk -presented some of the domains of FIM and WHOQOL and presented overall summary -no protocol to verify

CHAPTER 4: A NOVEL METHOD FOR DEVELOPING AN EVIDENCE-BASED, COMMUNITY HEALTH WORKERS DELIVERED, MOBILITY INTERVENTION FOR STROKE SURVIVORS IN LOW-RESOURCE SETTINGS.

Kumurenzi, A., Bosch, J., Jesus, T., Richardson, J., Thabane, L., Langhorne, P., Kagwiza, J., Turkstra, S. L. To be submitted to the Archives of Physical Medicine and Rehabilitation

Abstract

Background: Rehabilitation interventions are often developed, tested, and implemented in high-resource settings, using equipment and human resources insufficiently available in low-resource settings, thereby not implementable.

Objective: To use the Rehabilitation Treatment Specification System (RTSS) to develop an evidence-informed mobility-training module for post-stroke rehabilitation, adapted to low-resource settings and deliverable by community-level agents.

Methods: Four-phase development: 1) Searching for the applicable evidence base; 2) Selecting effective interventions fitting low-resource criteria; 3) Extracting details from the effective interventions implementable in low-resource settings; and 4) Designing the new low-resource intervention based on the evidence-based extractions. The RTSS was used for the last two phases.

Results: Out of 44 clinical practice guidelines (CPGs) identified, eight were eligible for inclusion and contained 10 mobility recommendations; three were appraised as *low-resource* implementable. An additional 32 studies were identified (19 not from CPGs); eight of these were finally selected. The final mobility-training module, deemed implementable in low-resource contexts, follows the RTSS specifications and consists of a circuit of five stations with a total of 31 exercises.

Conclusions: To help bridge the knowledge and service-delivery gap from high- to low-resource settings, a multi-phased process was used to design a new, evidence-informed, post-stroke community-level mobility intervention, likely implementable in low-resource settings. The new context-sensitive intervention can now be tested on its feasibility, effectiveness, and implementation in low-resource settings. The RTSS enabled the intervention design and description toward facilitating its accurate replication.

Keywords: Stroke patients, mobility, rehabilitation interventions, clinical practice guidelines, low-resource settings, Rehabilitation treatment specification system

List of abbreviations:

CCT: Circuit Class Training/Therapy

RTSS: Rehabilitation Treatment Specification System

TIDieR: Template for Intervention Description and Replication

CPGs: Clinical practice guidelines

Introduction

Evidence-based interventions for improving mobility after stroke abound. Examples include rhythmic auditory cueing/stimulation,¹ treadmill training,² electromechanical assistance training,³ and virtual reality (VR) training.⁴ However, these and other interventions have been often developed, tested, and implemented in well-resourced settings,⁵ using specialized equipment and rehabilitation professionals often unavailable or insufficiently available in low-resource settings. Overall, much of the evidence on post-stroke mobility rehabilitation has been produced in high-resource settings and is not directly translatable to many low-resource settings. Like van Zyl et al, here we frame low-resource settings as contexts with structural constraints in the financial, infrastructure, equipment, informational, or human resources required for optimal healthcare delivery.⁶ These limitations can be found in many low- and middle-income countries (LMICs), and in low-resource areas (e.g., rural or medically underserved) of high-income nations as well.^{7,8} It is unsurprising that interventions developed in and for high-resource settings, with

equipment and skilled human resource requirements, have failed to be translated in low-resource settings.⁹ It is likewise not surprising that Clinical Practice Guidelines (CPGs) have not translated to settings with limited equipment and human resources.⁵

Stroke survivors living in low-resource areas have been especially underserved by rehabilitation providers, and their rehabilitation needs continue to be largely unmet.¹⁰⁻¹² While rehabilitation needs have increased somewhat in high-income nations, needs in LMICs more than doubled from 1990 to 2017.¹³ Health conditions resulting in neurological impairments, such as stroke, have contributed to the rise of physical rehabilitation needs, especially in LMICs.^{14,15} While there have been recent efforts to develop new tools and initiatives to scale up the rehabilitation services and workforce in low-resource settings,^{16,17} the magnitude of this task means that there must also be service delivery alternatives that are effective and can still operate under low-resource circumstances, especially at the community level.¹⁸ The need to increase access to rehabilitation care with a focus on low-resource settings has been increasingly emphasized as a global health as well as rehabilitation priority.¹⁹⁻²¹

To be widely implementable and sustainable in low-resource community-level contexts, rehabilitation interventions must require under minimal equipment and include programs that are deliverable by community health workers (CHWs), appropriately trained and supported. CHWs are non-specialized, non-credentialed community-level workers or volunteers who can be trained or supervised by specialist human resources to deliver basic, effective, and culturally acceptable community-level healthcare programs.^{22,23} CHWs have played a crucial role in improving healthcare outcomes including chronic disease management for conditions, such as improving high blood pressure,²⁵ mental health support,²⁶ including educative programs for stroke patients.²⁴

To our knowledge, there are no evidence-based post-stroke mobility rehabilitation guidelines, programs, or interventions that are specific to (i.e., designed for and tested or implemented in) low-resource settings, in particular by CHWs, and that do not require substantive human or specialized equipment.

To be implementable by CHWs, rehabilitation programs or interventions must provide sufficient program detail, descriptions, and illustrations to be accessible to and accurately delivered by workers who typically have no post-secondary education or rehabilitation training. Frameworks like the Template for Intervention Description and Replication (TIDier)^{29,30} were developed to increase the level of detail in rehabilitation-intervention reporting; however, the TIDier structure does not provide enough detail on how the intervention is delivered or which parts are important for improving patient outcomes.^{31,32}

The Rehabilitation Treatment Specification System (RTSS) offers an alternative, comprehensive method for describing interventions,^{33,34} based on intervention targets, ingredients, and ingredients' effects on targets by some mechanism of action.³² In the RTSS, targets are defined as the aspect of the recipient's function that the clinician desires to change (e.g., increased hip flexor strength, increased knowledge about safety strategies); and ingredients are defined as clinician actions or objects the clinician provides to effect that change (e.g., cues, instructions, or assistive devices). The RTSS has been used to specify treatments by a variety of different disciplines and in multiple settings,^{31,35-38} and has several benefits, including providing sufficient detail for a treatment to be replicated,^{31,35,37,39} which is critical for a treatment that will be delivered by CHWs.

In the whole context above, this Special Communication reports the process and output of developing an evidence-informed yet context-sensitive post-stroke, community-level rehabilitation program specifically designed for low-resource settings. Specifically, we aimed to use the RTSS to develop an evidence-informed mobility-training module for post-stroke rehabilitation, adapted to low-resource settings (e.g., with no substantive equipment requirements) and deliverable by community-level agents such as CHWs.

Methods

To develop a post-stroke mobility intervention that accommodates low-resource settings, we used a four-phase process: 1) searching for the applicable evidence base, 2) selecting effective interventions that fit low-resource criteria; 3) extracting details from the effective interventions

implementable in low-resource settings; and 4) designing the new low-resource intervention based on the evidence-based extractions. The RTSS was used for the last two phases. Details of each phase are described below.

Phase 1: Searching for the applicable evidence base

Phase 1a. Search for community-based, post-stroke mobility programs

I conducted a scoping search, and looked for evidence-based mobility programs that would fit low-resource requirements and could find only two programs,^{27,28} and both required equipment not be readily accessible in many community-level low-resource settings. I moved on to phase two after realizing that the community-based programs identified required extra equipment such as chairs, steppers/raisers, wedges, and ankle weights, which were excluded.

Phase 1b. Searching for clinical practice guidelines

We searched for CPGs for mobility rehabilitation after stroke. To identify the CPGs, we searched Medline (through Ovid), PubMed, Embase, PEDro, and Web of Science. The search strategy used a combination of keywords for practice guidelines, rehabilitation, stroke, adults, mobility, and walking (see search strategy in **Supplementary Appendix 1**). We used the same keywords to search Google Scholar, for unpublished guidelines or guidelines in the journals not included in the searched scientific databases. Also, we searched seven websites where key practice guidelines could be found, either for healthcare in general (e.g., the United Kingdom's National Institute of Health and Care Excellence) or specifically related to stroke (Canadian Stroke Best Practice Recommendations). **Supplementary Appendix 1** provides a full list of websites searched.

Criteria for CPGs were that they: a) included post-stroke mobility rehabilitation recommendations, b) were published in English after 2013 - if updated CPGs existed, we used the latest version, and c) met a quality threshold. For the latter, we used the Appraisal of Guidelines for Research and Evaluation [AGREE] II, notably its domains that focused on i)

adequate search strategy, ii) robust selection criteria, and iii) description of the strengths and limitations. Although AGREE II does not provide specific cutoff scores to determine the quality of each domain,³² we included CPGs that scored 75% and above as a quality threshold of the three analyzed domains.

All eligibility decisions were taken by the first author, AK, who has had primary reviewer roles in previous research^{33–35} and has extensive *in vivo* experience of post-stroke mobility rehabilitation in low-resource settings. These preliminary eligibility decisions were reviewed by two senior scholars (JB and LST) with expertise in post-stroke rehabilitation in low-resource settings, evidence-based medicine, and the RTSS; and decisions were reached by consensus.

As the most recent guidelines were in 2021, we additionally searched the same scientific databases from February 2021 onwards for studies not cited in guidelines due to their recency. We used the same search strategy except for guidelines-related keywords. We also hand-searched references lists of any review articles to expand the corpus of studies informing our new intervention design.

Phase 2: Selecting effective interventions fitting low-resource criteria

The goal of this phase was to select primary research studies that provided evidence of effectiveness of interventions that could be implementable in low-resource settings. To identify studies, we hand-searched CPG reference lists for studies that met the following criteria:

1. Focused on the post-stroke mobility rehabilitation interventions or outcomes, with “mobility” being understood as stroke patients’ capacity or performance related to lower extremity mobility, such as standing, walking, and balancing;
2. Randomized Controlled Trials (RCTs);
3. Results that showed efficacy or effectiveness, i.e., a statistically significant benefit ($p < 0.05$) for primary mobility outcomes; and
4. Interventions that fit all of the following *low-resource* criteria:
 - a. Delivered through group-based intervention, to optimize the limited human and infrastructure resources.

- b. Did not require intervention equipment typically unavailable or insufficiently available in low-resource settings for community-level, posthospitalization forms of rehabilitation. Examples include but are not limited to virtual reality, robotics, non- and body-weight-supported treadmill training, weights (ankle weights), and electrical stimulation modalities. Equipment like weights might not be readily available in some low resource settings.
- c. Delivered or feasibly deliverable by non-professional community-level agents – e.g., after being trained for the program delivery and/or periodically supervised or telemonitored by rehabilitation professionals.

Phase 3: Extracting details from the effective interventions implementable in low-resource settings.

For each RCT, we extracted the title of the study, targets, ingredients, dosage, outcomes, key findings, and effect sizes. We identified targets and ingredients per the RTSS manual.³⁶ AK completed primary data extraction for each study, and finally by round of discussions with JB on appropriate classification and synthesis. Quality assessment was not completed for RCTs in CPGs assessed by AGREE II as meeting minimum quality thresholds.

Phase 4: Designing the new low-resource intervention based on the evidence-based extractions

In the final phase, we used the RTSS to create a mobility training module that can be implemented in low resource settings by CHWs. AK did the initial target specification, and LST and JB reviewed the full process to ensure it aligned with the classification systems, the evidence extracted, and overall integrity of the whole new intervention design.

Results

Figure 1 is a flowchart showing each phase of the process. Phase 1 yielded 44 CPGs, eight of which met criteria for inclusion (see **Supplementary Table 1** for eight CPGs and **Supplementary Table 2** for exclusion and their reasons). From the CPGs, we identified a total of 10 recommendations for mobility interventions and three met criteria for phase 1, i.e., were

low-resource implementable. These three were circuit class training or therapy (CCT), repetitive task-oriented training, and exercises that did not require equipment (**Supplementary Table 3**). We identified 19 primary studies for the three interventions, to which we added 13 studies from other sources (e.g., studies published after February 2021). The final total was 32 unique primary research studies, whose full texts were assessed for final eligibility. Of these 32 studies, eight met the final eligibility criteria for implementation in low-resource settings (see **Supplementary Table 4** exclusions and their reasons) and were advanced to phase 3.

In phase 3, for each of the eight studies we extracted targets, ingredients, dosage, and outcomes. Details are provided in **Table 1**. Interventions were mainly delivered in a circuit form, and aimed to improve walking speed,⁴⁵⁻⁵⁰ walking distance,^{46,47,49} lower limb muscle strength,⁴⁵ and balance.^{45,49,51} Outcome measures showing significant treatment effects included the six-minute walk test [6MWT],^{45-49,52} ten-minute walk test [10MWT],^{46,47,49} BERG balance scale,^{45,49,51} muscle strength (Isometric knee extension),⁴⁵ and Time-up and go.⁵⁰⁻⁵²

The mobility training module was designed in a circuit format and contained five stations with a total of 31 exercises (see Draft Module-**Supplementary Appendix 2**). Circuits are completed by groups and total circuit duration is 60 minutes. Aims are to improve lower limb muscle strength, balance, walking, and endurance.⁵³ As there were no warm-up activities in sources we identified, we added warm-up and cool-down activities from the evidence-based Fitness and Mobility Exercise Program (FAME)²⁷, to help frame the group-based circuit session. FAME is a group community-based program initially developed for Canadian stroke survivors to improve post-stroke balance, muscle strength, and fitness. Altogether, the five stations were: warm-ups (5 exercises), functional training for lower limb muscles (7 exercises), balance training (6 exercises), endurance/fitness training (8 exercises), and cool-downs (6 exercises). The module is meant to be completed in three days per week for a total of 12 weeks, estimated per the dose of the included studies. The dose was estimated based on the included studies. By specifying the targets and ingredients, we provide a clear guidance and instructions for CHWs to implement the community-based mobility intervention in low-resource settings.

Discussion

Most studies of rehabilitation for mobility after stroke were completed in high-resource settings with service-delivery requirements that are not available in low-resource settings. We used this literature base to develop a mobility intervention that can be delivered in a low-resource context. Doing so required explicitly accounting for resource requirements from the beginning of the intervention design stage. We used a systematic process that included the use of the RTSS framework to produce an evidence-informed post-stroke mobility intervention that can be delivered in low-resource, community-level contexts by CHWs.

For our *low-resource* intervention design, we initially searched for, identified, and extracted evidence from *quality* studies - many of which were included in high-quality guidelines. We then used the RTSS framework to extract the targets, ingredients and dosage of the post-stroke mobility interventions that were identified as effective but also met our *a priori* low-resource requirements. The next step is to test this intervention to determine its feasibility, acceptability, effectiveness and effectiveness when implemented by CHWs in low-resource community-level contexts.

To develop and test effective rehabilitation interventions that fit low-resource and community-level requirements is more than a timely issue. The prevalence of functional impairments caused by stroke is at a growing trajectory worldwide, but especially in LMICs, with the global health advances and the rise of population ageing.^{14,54} Moreover, evidence of underserved patients and populations abound in LMICs¹⁸ and in low-resource setting of high-income nations,^{7,8} while skilled human and other resources for rehabilitation available or deployed to those areas are still far from the enough to being capable of meeting the populations needs. In low-resource settings, patients have been often discharged rapidly from inpatient acute and rehabilitation care, with no form of community-level support or continued rehabilitation.^{55,56} Basic, post-hospitalization, community-level rehabilitation activities need to be more accessible to stroke patients that live in those low-resource settings, for an improved global health and rehabilitation equity. The work initiated here is one step in that much needed direction.

The use of RTSS framework for the evidence extraction and intervention design stages provided a structured framework that was highly useful in designing the intervention. It enabled us to specify the intervention in sufficient detail to be replicated across low-resource implementation contexts. As such, it can improve the intervention fidelity and replication by facilitating a reliable training and intervention delivery by community-level agents such CHWs, who are not skilled rehabilitation human resources. It should be noted, however, that many of the included studies lacked the information necessary to replicate and implement the interventions, which is a pervasive limitation of intervention research.³² Details that were missing included whether the interventions were designed for groups or individuals, specific equipment needed, how patients were instructed or otherwise supported in doing activities, and who could deliver the intervention (professionals or non-professionals). These details are crucial for successful implementation of community-based programs, especially in low-resource settings. The RTSS system is a good intervention extraction tool if the underlying evidence base and intervention description are adequate. There is considerable room for improvement in this realm.

Our program's exercises were framed to be delivered in periodic sessions as well as in a group-based and circuit format. Circuit Class Training/Therapy (CCT) has been recognized as a cost-efficient strategy for resource constrained countries,⁵⁷ where patients are grouped together in a circuit format to optimize resources and provide rehabilitation to a larger number of individuals and with the potential ability to be delivered by non-professional, non-rehabilitation specialist like CHWs. Also, CCT has been identified as a valuable rehabilitation approach, capable of addressing multiple aspects of training patients to improved mobility, notably walking.⁵⁷ Although promising and evidence-informed, widespread implementation should follow the testing of this designed intervention as whole, across low-resource community-level contexts and delivered by CHWs. Future research might also determine which supports might be in place for the intervention to be effective and effectively implemented. Finally, this mobility intervention may be tested in low-resource contexts alone and/or in combination with similar modules for other components of poststroke rehabilitation (e.g., Selfcare, upper extremity mobility).

Study Limitations

Our search was limited to English language publications, and thus may have missed studies in countries where English is not the primary language of scientific publications, which may include many LMICs. While including only RCTs allowed a focus on higher level of evidence, but it is also true that RCTs typically exclude patients with comorbidities, so study participants included in these trials may not fully represent the characteristics and diversity of underserved populations in a given study context. Not only stages to identify the evidence base involved a second independent reviewer; at all stages, there was periodic scrutiny and discussion meeting of the primary reviewer with senior authors with relevant expertise. Also, that search stage was used to inform a new intervention design, still subject to testing, and should not be understood as a systematic review endeavor or a standalone product establishing or synthesizing the evidence on post-stroke mobility rehabilitation.

Conclusion

To help bridge the knowledge and service delivery gap from high- to low-resource contexts, a multi-phased process was used to design a new, evidence-informed, post-stroke community-level mobility intervention, likely implementable in low-resource contexts, due to the low-resource requirements. The new context-sensitive intervention can now be tested, on its whole, regarding its feasibility, effectiveness, and implementation in low-resource settings. The RTSS enabled the intervention design and description toward facilitating its accurate replication.

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Figure

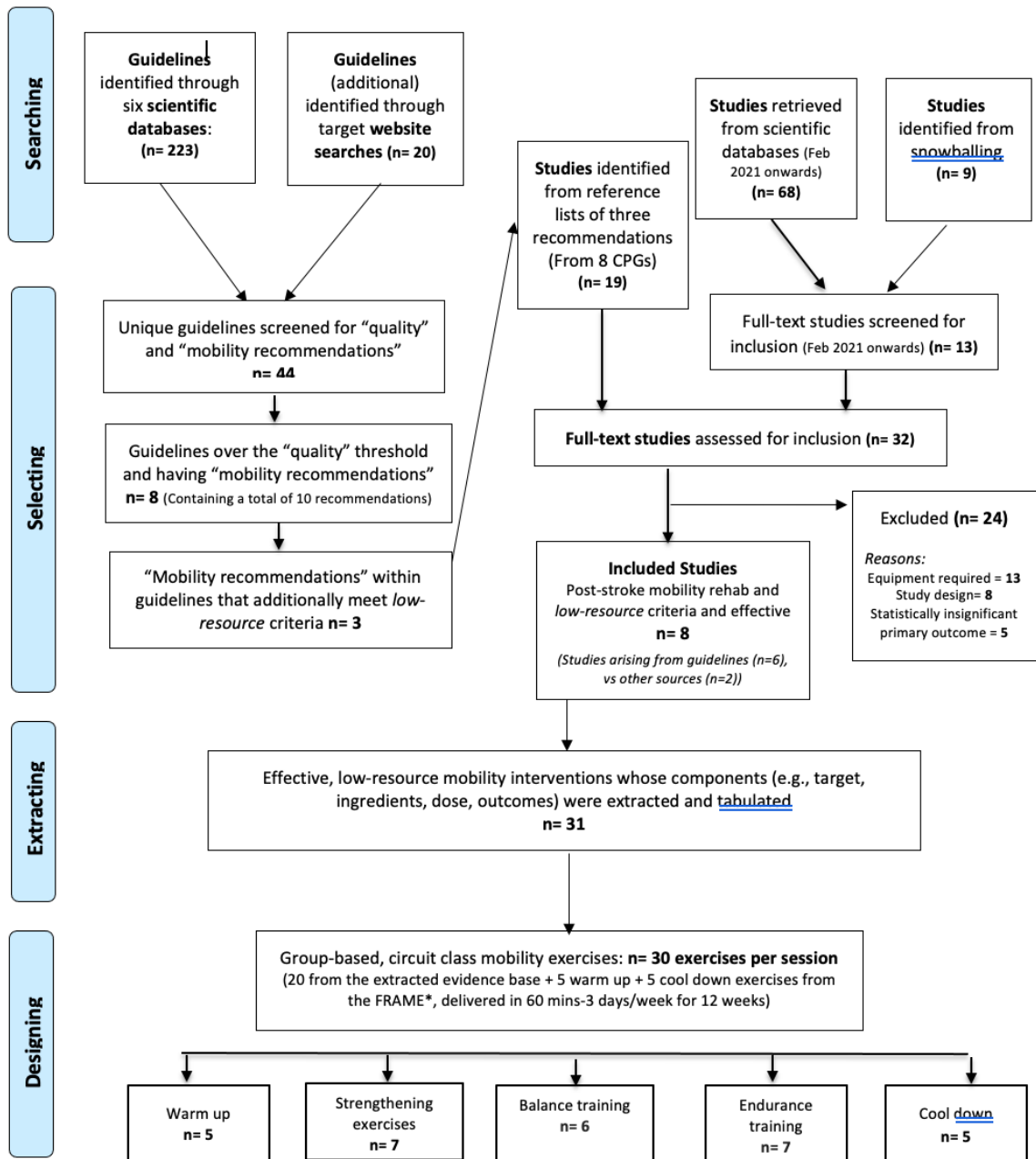


Figure 1: Flowchart of the development process for the new intervention design, adapted for the purpose from the PRISMA statements for systematic reviews.

Table 1: Specification targets, ingredients and outcomes of the included studies

Study & Author	Sample size	Recommendation	Targets	Ingredients	Dosage	Effect				Estimated Effect Size
						Outcome	Inter.	Cont.	P-value	
Studies from CPGs										
1. Exercise to Enhance Mobility and Prevent Falls After Stroke: The Community Stroke Club Randomized Trial ⁴⁶	N= 151 Inter: 76 Cont: 75	Exercises-CCT	Improve walking	- Warm-up <u>Circuit</u> - Calf raisers while standing - Sit-stand - Step-ups - Standing-reduced BoS - Graded reaching activities in standing - Forward, backward, and sideways stepping and walking	- 40 weeks, - 3 times per week, - 45 to 60 minutes with home exercise program	Ten-minute walk test (10MWT): mean (SD)	0.89 (0.39) m/s	0.80 (0.37) m/s	0.03	0.2
						Six-minute walk test (6MWT): mean (SD)	273 (133) m	224 (135) m	0.001	0.4
2. Exercise leads to faster postural reflexes, improved balance and mobility, and fewer falls in older persons with chronic stroke ⁵¹	N= 48 Inter: 22 Cont: 26	Exercises (community-based)	Improve balance and walking	- warm-up (walking and light stretching) - cool-down (light stretching) <u>Exercises:</u> - Standing in various postures - Walking with various challenges	- 1-hour session - 3-times/week - 10 weeks	Berg Balance Scale (BBS)/56: mean (SD)	49.1(5.0)	48.1(5.7)	<0.001	0.2

Study & Author	Sample size	Recommendation	Targets	Ingredients	Dosage	Effect				Estimated Effect Size
						Outcome	Inter.	Cont.	P-value	
				<u>Additional exercises</u> - Sit-to-stand - Eyes-closed conditions and foam surfaces were incorporated						
						Time-up & go (TUG): mean (SD)	20.2(10.8) s	17.0(10.7) s	<0.001	0.3
3. Circuit-Based Rehabilitation Improves Gait Endurance but Not Usual Walking Activity in Chronic Stroke: A Randomized Controlled Trial ⁴⁷	N= 58 Inter: 31 Cont: 27	CCT	Improve walking	<u>Circuit</u> - Sit to stand - Self sway - Standing balance - Step ups -Balance beam - Standing-hamstring curl - Tandem walk - Swiss ball squats - Tandem stance - Calf raises - Backward walk. - Lunges - Side leg lifts - Marching in place - Obstacle course	- 3 days a week - 4 weeks	Gait speed (10MWT): mean (SD)	0.73 (0.02) m/s (adjusted)	0.69 (0.02) m/s (adjusted)	0.090**	2
						Gait endurance (6MWT): mean (SD)	253 (6.0) m (adjusted)	233 (6.5) m (adjusted)	0.030	3

Study & Author	Sample size	Recommendation	Targets	Ingredients	Dosage	Effect				Estimated Effect Size
						Outcome	Inter.	Cont.	P-value	
4. A Community-Based Fitness and Mobility Exercise Program for Older Adults with Chronic Stroke: A Randomized, Controlled Trial ⁴⁵	N= 63 Inter: 32 Cont: 31	Exercises-CCT	Enhance walking & cardiovascular fitness	- Brisk walking - Sit-to-stand - Alternate stepping onto low risers - Walking in different directions - Tandem walking - Obstacle course walking - Stops and turns during walking - Walking on different surfaces	- 60 mins/day - 3-times/week - 19 weeks	6MWT: mean (SD)	392.7 (151.1)	342.4 (133.4)	0.03	0.3
			Enhance muscle strength	- Partial squats -Toe raises		Strength: mean (SD)	223.2(99.9)	205.3(79.4)	0.02	0.2
			Improve balance	- Standing on foam, balance disc, or wobble board - Standing with one foot in front of the other - Kicking ball with either foot		BBS/50: mean (SD)	49.6(4.4)	49.2(5.8)	0.85**	0.1
5. Task-Oriented Circuit Class Training Program with Motor Imagery for Gait Rehabilitation in Poststroke Patients: A	N= 30 Inter: 15 Cont: 15	Task-oriented-CCT	Enhance walking-Motor imagery (MI)	-Walking in a real-life situation -Previous way of walking -Practice of a missing component during walking	- 40 mins - 7 days - 2 weeks	Functional ambulation classification	4(4)	3(3)	0.001	0.3

Study & Author	Sample size	Recommendation	Targets	Ingredients	Dosage	Effect				Estimated Effect Size
						Outcome	Inter.	Cont.	P-value	
Randomized Controlled Trial ⁴⁸				<ul style="list-style-type: none"> -Walking with long steps -Weight bearing on the affected & unaffected lower limbs -Fast walking, running -Jumping -Symmetrical walking -Goal-directed walking 						
			Enhance standing and walking	<ul style="list-style-type: none"> - Sit to stand - Standing unsupported - Standing with eyes closed - Standing unsupported with feet together - Reaching and picking object and turning while standing - One limb standing (both the affected & unaffected LLs) 		Rivermead Visual Gait Assessment	20.13 (6.42)	30.53(9.52)	0.049	1.3
			Enhance walking	<ul style="list-style-type: none"> - Walking through obstacles - Walking for a goal (at a distance of 5 m) 		6MWT: mean (SD)	199.20(17.12)	111.70 (61.62)	0.005	2

Study & Author	Sample size	Recommendation	Targets	Ingredients	Dosage	Effect				Estimated Effect Size
						Outcome	Inter.	Cont.	P-value	
				<ul style="list-style-type: none"> - Walking while picking up objects from the floor - Walking and carrying an object - Stepping-forward & sideward - Stair climbing - Fast walking 						
6. Short-term and long-term effects of a progressive resistance and balance exercise program in individuals with chronic stroke: a randomized controlled trial ⁴⁹	N= 67 Inter: 34 Cont: 33	Exercise-CCT	Enhance balance	<ul style="list-style-type: none"> - Warm-up <i>Circuit</i> - Squat - Body weight transfer - Standing up from sitting - Side and forward lunge - Step-up - Walking forward in tandem gait - Walking in various directions - Walking with turns - Walking over obstacles - Step onto and over boxes - Walking on a soft surface 	<ul style="list-style-type: none"> - 55 mins - 2-3 days - 2 times/week - 3 months 	BBS/56 mean (SD):	1.3 (5.4)	-0.6 (3.4)	0.06*	0.4
						Walking speed (6MWT): mean (SD)	-29 (114.2) m	-0.5 (85.9) m	0.77*	0.3

Study & Author	Sample size	Recommendation	Targets	Ingredients	Dosage	Effect				Estimated Effect Size
						Outcome	Inter.	Cont.	P-value	
						Walking distance (10MWT): mean (SD)	0.08 (0.37) m/s	-0.0 (0.25) m/s	0.034	0.2
Studies not from CPGs										
1. A randomized controlled trial of motor imagery combined with structured progressive circuit class therapy on gait in stroke survivors ⁵²	N= 40 Inter: 20 Cont: 20	Motor imagery-CCT	Enhance walking-motor imagery	<ul style="list-style-type: none"> - Stepping forward, backwards & onto a block - Standing up from a chair, walking (3 m), and return to the chair - Symmetrical walking (8 m) - Walking at a fast speed (8 m) 	<ul style="list-style-type: none"> - 90 mins (25 mins [motor imagery] and 65 mins [CCT]) - 3 times/week - 4 weeks 	Gait speed (TUG): mean (SD)	0.78(0.21) s	0.58(0.27) s	0.015	0.8
				<ul style="list-style-type: none"> - Warm-up <i>Circuit</i> - Stepping forward-backwards onto a block - Stepping sideways onto a block - Heel lifts in standing - Standing with a decreased base and reach for an Object - Standing up from a chair, walking a short distance, 		Cadence: mean (SD)	94.13(17.09) steps/min*	78.88(26.35) steps/min*	0.036	0.7

Study & Author	Sample size	Recommendation	Targets	Ingredients	Dosage	Effect				Estimated Effect Size
						Outcome	Inter.	Cont.	P-value	
				and returning to the chair - Symmetrical walking - Walking at a fast speed						
2. Effectiveness of motor imagery combined with structured progressive circuit class training on functional mobility in post-stroke individuals: a randomized controlled trial ⁵⁰	N= 40 Inter: 20 Cont: 20	CCT	Enhance walking	- Forward and backward step up - Lateral step up - Heel raise and lower - Reaching in standing - Transition from sit to stand, walk, and then back to sit - Walking with even steps - Quick walk Note: 1, 5,6, 7 (used for MI)	- 90 min - 3- times/week - 4 weeks	Step test	11.35(0.64) m	9.15(0.61) m	<0.001	3.5
						6MWT: mean (SD)	256.75(19.49) m	203.60(26.28) m	<0.001	2.2
						TUG: mean (SD)	11.64(1.12) s	23.35(4.13) s	<0.001	4

Supplementary material

Supplementary Appendix 1: Search strategy for community-based mobility programs, clinical practice guidelines (CPGs), and studies not retrieved from CPGs

Medline

1. clinical guidelines.mp. or Practice Guideline/
2. Ischemic Stroke/ or Hemorrhagic Stroke/ or stroke.mp. or Stroke/
3. Neurological Rehabilitation/ or Rehabilitation/ or Rehabilitation Research/ or Cardiac Rehabilitation/ or Stroke Rehabilitation/ or rehabilitation.mp.
4. mobility.mp. or Mobility Limitation/
5. 1 and 2
6. 3 and 5
7. 4 and 6

Embase

1. practice guideline/ or clinical guidelines.mp.
2. stroke.mp. or cerebrovascular accident/
3. joint mobility/ or physical mobility/ or limited mobility/ or mobility.mp.
4. rehabilitation care/ or community based rehabilitation/ or rehabilitation research/ or geriatric rehabilitation/ or gait rehabilitation electrical stimulation system/ or rehabilitation/ or stroke rehabilitation/ or rehabilitation.mp. or heart rehabilitation/
5. 1 and 2
6. 3 and 4
7. 5 and 6

Pubmed

1. (((clinical guidelines) AND (stroke)) AND (rehabilitation)) AND (mobility)
2. Government publication
3. Guideline
4. Practice guidelines

PEDro

1. Clinical practice guidelines
2. Stroke
3. Post-stroke mobility
4. Rehabilitation

Web science

(((TI=(clinical practice guidelines)) AND AB=(stroke)) AND AB=(mobility)) AND AB=(rehabilitation)

Guideline international and professional organizations:

National Institute of Health and Care Excellence: <https://www.nice.org.uk/>

Turning research into practice: <https://www.tripdatabase.com/>
Canadian Stroke Best Practice Recommendations: <https://www.strokebestpractices.ca/>
American Heart Association/ American Stroke Association Statements and Guidelines: <https://professional.heart.org/en/guidelines-and-statements>
European stroke organization-Guidelines for stroke management: <https://eso-stroke.org/guidelines/eso-guideline-directory/>
National stroke foundation-Australia clinical guidelines for stroke management: <https://strokefoundation.org.au/what-we-do/for-health-professionals/clinical-guidelines>
Royal college of physicians of London National clinical guidelines for stroke: <http://www.rcplondon.ac.uk/guidelines-policy/stroke-guidelines>
Scottish intercollegiate guideline network: <https://www.sign.ac.uk/>

Supplementary Tables

Supplementary Table 1: Included clinical practice guidelines for enhancing mobility.

Clinical practice guideline	Author/publisher & year	Country /design	Quality Score
1. Australian and New Zealand living clinical guidelines for stroke ⁵⁸	Stroke Foundation (2021)	Australia and New Zealand	Search strategy 7/7 Selection criteria 7/7 Strength and limitations 7/7
2. Canadian Stroke Best Practice Recommendations ⁵⁹	Heart and Stroke Foundation of Canada (2019)	Canada	Search strategy 7/7 Selection criteria 7/7 Strength and limitations 7/7
3. USA-Guidelines for adult stroke rehabilitation and recovery a guideline for healthcare professionals from the American Heart Association/American Stroke Association ⁶⁰	Winstein et al (2016)	United States of America	Search strategy 7/7 Selection criteria 7/7 Strength and limitations 6/7
4. National clinical guideline for stroke ⁶¹	Intercollegiate Stroke Working Party (2016)	United Kingdom	Search strategy 6/7 Selection criteria 6/7 Strength and limitations 5/7
5. Clinical practice guideline to improve locomotor function Following Chronic Stroke, incomplete spinal cord injury, and brain injury ⁶²	Hornby et al (2020)	Systematic review	Search strategy 7/7 Selection criteria 7/7 Strength and limitations 6/7
6. Robotic-assisted gait rehabilitation following stroke: a systematic review of current guidelines and practical clinical recommendations ⁶³	Sorrentino et al (2021)	Systematic review	Search strategy 7/7 Selection criteria 7/7 Strength and limitations 6/7
7. Examining clinical practice guidelines for exercise and physical activity as part of rehabilitation for people with stroke: A Systematic Review ⁶⁴	Church et al (2022)	Systematic review	Search strategy 6/7 Selection criteria 6/7 Strength and limitations 4/7
8. Synthesizing practice guidelines for the development of community-based exercise programmes after stroke ⁶⁵	Poltawski et al (2013)	Review of literature	Search strategy 6/7 Selection criteria 6/7 Strength and limitations 5/7

Supplementary Table 2: Excluded clinical practice guidelines

Guidelines/recommendations	Author & year	Reasons for exclusion
1. Ottawa Panel Evidence-Based Clinical Practice Guidelines for Post-Stroke Rehabilitation	The Ottawa Panel (2004)	Published more than 10 years
2. Clinical guideline stroke management- Australia	National stroke foundation (2010)	Published more than 10 years
3. Evidence-based stroke rehabilitation: An expanded guidance Document from the European stroke organization (ESO) Guidelines for management of ischemic stroke and transient Ischemic attack 2008*	Terence et al (2009)	Published more than 10 years
4. New Zealand clinical guidelines for stroke management 2010	Stroke foundation of New Zealand and New Zealand guidelines (2010)	Published more than 10 years and an updated guideline already exists
5. Physical Activity and Exercise Recommendations for Stroke Survivors An American Heart Association Scientific Statement From the Council on Clinical Cardiology, Subcommittee on Exercise, Cardiac Rehabilitation, and Prevention; the Council on Cardiovascular Nursing; the Council on Nutrition, Physical Activity, and Metabolism; and the Stroke Council	Gordon et al (2004)	Published more than 10 years
6. Management of patients with stroke: Rehabilitation, prevention and management complications, and discharge planning. A national clinical guideline.	Scottish Intercollegiate Guidelines Network (2010)	Published more than 10 years
7. Task-oriented training in rehabilitation after stroke: systematic review	Rensink et al (2009)	Published more than 10 years
8. Examining Clinical Practice Guidelines for Exercise and Physical Activity as Part of Rehabilitation for People with Stroke: A Systematic Review	Church et al (2022)	No recommendation on mobility
9. Synthesizing practice guidelines for the development of community-based exercise programmes after stroke	Poltawski et al (2013)	No recommendation on mobility
10. Japan Stroke Society Guideline 2021 for the Treatment of Stroke	Miyamoto et al (2022)	No recommendation on mobility
11. Rehabilitation after stroke: summary of NICE guidance	Dworzynski et al (2013)	No recommendation on mobility
12. Standardizing evidence strength grading for recommendations from multiple clinical practice guidelines: a South African case study	Grimmer et al (2018)	No recommendation on mobility
13. The South African guideline for the management of ischemic stroke and transient ischemic attack: recommendations for a resource-constrained healthcare setting	Bryer et al (2011)	No recommendation on mobility
14. South African guideline for management of ischemic stroke and transient ischemic attack 2010: A guideline from the South African Stroke Society (SASS) and the SASS Writing Committee	Bryer et al (2010)	No recommendation on mobility

Guidelines/recommendations	Author & year	Reasons for exclusion
15. Physical Activity and Exercise Recommendations for Stroke Survivors A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association	Billinger et al (2014)	Poor quality
16. Aerobic Exercise Recommendations to Optimize Best Practices in Care After Stroke: AEROBICS 2019 Update	MacKay-Lyons et al (2020)	Poor quality
17. Canadian stroke best practice recommendations: Stroke rehabilitation practice guidelines, update 2015	Herbert et al (2016)	There is already an updated guideline
18. Canadian Stroke Best Practice Recommendations: Rehabilitation, Recovery, and Community Participation following Stroke. Part One: Rehabilitation and Recovery Following Stroke; 6th Edition Update 2019	Teasell et al (2020)	There is already an updated guideline
19. The Management of Stroke Rehabilitation: A Synopsis of the 2019 U.S. Department of Veterans Affairs and U.S. Department of Defense Clinical Practice Guideline	Sall et al (2019)	Poor quality and no recommendations on mobility
20. Quality of stroke rehabilitation clinical practice guidelines	Hurdowar et al (2006)	No recommendations on mobility and published more than past 10 years
21. Practice Guidelines in Neurorehabilitation	Platz et al (2017)	No recommendations on mobility
22. Chinese Stroke Association guidelines for clinical management of cerebrovascular disorders: executive summary and 2019 update on organizational stroke management	Lou et al (2020)	No recommendations on mobility
23. Moving Stroke Rehabilitation Research Evidence into Clinical Practice: Consensus-Based Core Recommendations From the Stroke Recovery and Rehabilitation Roundtable	Janice et al (2019)	No recommendations on mobility
24. The national clinical guidelines for stroke-UK	Rudd et al (2000)	Published more than 10 years and no recommendations on mobility
25. Occupational Therapy Practice Guidelines for Adults with Chronic Conditions	Fields et al (2022)	No recommendations on mobility
26. Updating contextualized clinical practice guidelines on stroke rehabilitation and low back pain management using a novel assessment framework that standardizes decisions	Gambito et al (2015)	No recommendations on mobility
27. Systematic review of clinical practice guidelines to identify recommendations for rehabilitation after stroke and other acquired brain injuries	Jolliffe et al (2018)	No recommendations on mobility
28. A Review of the Evidence for the Use of Telemedicine within Stroke Systems of Care A Scientific Statement from the American Heart Association/American Stroke Association	Schwamm et al (2009)	Published more than 10 years and no recommendations on mobility
29. Canadian stroke best practice recommendations-Acute stroke management-7 th edition	Canadian stroke best practice recommendations advisory committee (2022)	No recommendations on mobility

Guidelines/recommendations	Author & year	Reasons for exclusion
30. Systematic review of clinical practice guidelines to identify recommendations for rehabilitation after stroke and other acquired brain injuries	Jolliffe et al (2018)	No recommendations on mobility
31. Rehabilitation of patients with stroke: summary of SIGN guidance	Smith et al (2010)	Published more than 10 years
32. Task-oriented training in rehabilitation after stroke: systematic review	Rensink et al (2009)	Published more than 10 years
33. Aerobic Exercise Recommendations to Optimize Best Practices in Care After Stroke: AEROBICS 2019 Update	MacKay-Lyons, (2019)	Poor quality
34. Development of clinical guidelines for service provision of functional electrical stimulation to support walking: mixed method exploration of stakeholder views	Bulley et al (2021)	Poor quality
35. Current physical therapy practice and implementation factors regarding the evidence-based Rehabilitation of Mobility after Stroke (ReMoS) guideline in Germany: a cross-sectional online survey	Scheffler et al (2022)	Poor quality
36. Brazilian practice guidelines for stroke rehabilitation: part II	Minelli et al (2022)	Poor quality

Supplementary Table 3: Recommendations for mobility interventions applicable in low-resources settings

Recommendation	<i>Low-Resource eligibility criteria</i>		
	Evidence based on group intervention	Equipment Free	Community Level Agent Implementation
Strengthening training ⁵⁹⁻⁶²	Yes	No	No
Circuit class training ⁵⁸⁻⁶¹	Yes	Yes	Yes
Repetitive-task oriented training ⁵⁸⁻⁶⁰	Yes	No*	No*
Treadmill Training ⁵⁸⁻⁶¹	No	No	No
Electromechanical and robotic assisted gain training ⁵⁸⁻⁶³	No	No	No
Rhythmic auditory stimulation/cueing ⁵⁸⁻⁶⁰	No	No	No
Virtual reality training ^{58-60,62}	No	No	No
Functional electrical stimulation ^{58,59,61}	No	No	No
Biofeedback ⁵⁸⁻⁶⁰	No	No	No
Exercises ^{59,60,64,65}	No*	No*	No*

*Recommendation does not mention method of delivery, equipment requirement or skills required for administering although some of the specific trials referenced in the recommendation may provide these details

Supplementary Table 4: Excluded studies

Study & Author	Design	Improves walking	Equipment Free	Effect			
				Outcome	Inter.	Cont.	p-value
Studies from CPGs							
1. Additional task-related practice improves mobility and upper limb function early after stroke: A randomized controlled trial ⁶⁶	RCT	Yes	No	Six-minute walk test (6MWT): mean (SD)	183 (85)- 404 (101) m	181 (85)-288 (124) m	0.01
				Timed Up and Go Test (TUGT)	24.3 (7.0)- 11.5 (3.8)s	25.3 (17)-19.1 (14.4)s	0.02
2. Circuit class therapy or seven-day week therapy for increasing rehabilitation intensity of therapy after stroke (CIRCIT): a randomized controlled trial ⁶⁷	RCT	Yes	No	Six-minute walk test (6MWT): mean (SD)	33(110.4)- 116(179)m	31.3(120)- 105(197)m	0.99
3. Clinical application of circuit training for subacute stroke patients: a preliminary study ⁶⁸	Preliminary study	Yes	No	Berg Balance Scale (BBS): mean(SD)	36.3(11.7)- 46.7(9.4)	39(8.7)-49.8(4.6)	<0.01
				6MWT: mean (SD)	167.5(121.8)- 261(115.4)	157.5(64)- 276(69.8)	<0.01
4. A community-based exercise and education scheme for stroke survivors: a randomized controlled trial and economic evaluation ⁶⁹	RCT	Yes	No	Subjective index of Physical and Social Outcome: Physical/20	119-109	123-120	
5. What is the benefit of a high-intensive exercise program on health-related quality of life and depression after stroke? A randomized controlled trial ⁷⁰	RCT	Yes	No	SF-36: Physical: mean(SD)	30.8 (8.3)	30.8(10.7)	
6. Effects of Community Exercise Therapy on Metabolic, Brain, Physical, and Cognitive Function Following Stroke: A Randomized Controlled Pilot Trial ⁷¹	RCT-Pilot	Primary outcome not mobility	Yes				
7. Effect of the class and individual applications of task-oriented circuit	RCT	Yes	No	Cadence (step/min): mean(SD)	90.5 (16.5)-99.9 (15.7)	76(23.4)- 85.6(18.8)	

Study & Author	Design	Improves walking	Equipment Free	Effect			
				Outcome	Inter.	Cont.	p-value
training on gait ability in patients with chronic stroke ⁷²							
				Two minute walk test: mean(SD)	57.6 (20.5)-73.9(27.2)m	51.0 (24.1)-64(26.0)m	
8. Exercise-induced changes in cardiovascular function after stroke: a randomized controlled trial ⁷³	RCT	Yes	No	6MWT: mean(SD)	278.2(128.5)-298.1(134.2)m	322.2(142)-331.5(149.2)m	0.02
9. Task-oriented circuit training improves ambulatory functions in acute stroke: a randomized controlled trial ⁷⁴	RCT	Yes	No	6MWT: mean(SD)	278.7(20.4)m	251.6(18.9)m	0.007
				10MWT	40.2 (2.9)	46.3(2.7)	0.001
				Functional Ambulatory Category	3.8 (0.5)	3.3(0.5)	0.024
10. Task-Related Circuit Training Improves Performance of Locomotor Tasks in Chronic Stroke: A Randomized, Controlled Pilot Trial ⁷⁵	RCT-Pilot	Yes	No	Six-minute walk test (6MWT): mean score baseline and study end provided, no change score provided, p for change	207.9 (119)-250 (135) m*	259.6 (154.6)-261.5 (157.3) m*	P<0.05
				Timed Up and Go Test (TUGT)	27.4 (23.2)-19.5 (14.1)* s	29.1 (29.4)-26.1(25.4)* s	na
11. Effects of a high-intensity task-oriented training on gait performance early after stroke: a pilot study ⁷⁶	RCT-Pilot	Yes	No	6MWT: mean(SD)	518.7 (165.2): 54(65.2)m (change score)	422.4 (127.9): 21.4 (43.2)m (change score)	0.02
				10MWT: mean(SD)	1.7 (0.5): 0.3(0.3)m/s (change score)	1.4 (0.4): 0.0(0.1)m/s (change score)	0.03
				BBS/56: mean(SD)	54.1 (3.0): 1.0(1.5) change score	54.1 (1.7): 0.9(1.3)	0.45

Study & Author	Design	Improves walking	Equipment Free	Effect			
				Outcome	Inter.	Cont.	p-value
12. A multidisciplinary group programme in rural settings for community-dwelling chronic stroke survivors and their carers: a pilot randomized controlled trial ⁷⁷	RCT-Pilot	Yes	No	Stroke Impact Scale (SIS): Mobility	78.2 (17.2)-80.8(14.3)	75.4(22.3)-80.8 (24.6)	
				SIS: strength	66.7 (25.2)-69.8 (22.7)	62(28.1)-58.2(28.5)	
13. Effects of circuit training as alternative to usual physiotherapy after stroke: randomized controlled trial ⁷⁸	RCT	Yes	Yes	Stroke Impact Scale/100 (mobility): mean (SD)	87.27 (12.38)	83.73 (13.25)	0.94
Studies not from CPGs							
1. Task-Oriented Circuit Training for Mobility in Outpatient Stroke Rehabilitation in Germany and Austria: A Contextual transferability analysis (Diermayr et al [2020])	Contextual analysis						
2. Effectiveness of a structured circuit class therapy model in stroke rehabilitation: a protocol for a randomized controlled trial ⁷⁹	RCT-Protocol						
3. Technology-assisted stroke rehabilitation in Mexico: a pilot randomized trial comparing traditional therapy to circuit training in a Robot/technology-assisted therapy gym ⁸⁰	RCT-Pilot	Yes	No	Fugl-Meyer/34: mean (SD)	23.1(6.37)-26.4(4.70)	20.1(5.78)-20.6(6.41)	0.033
				6MWT: mean (SD)	214.6(118.46)-228.1(126.53)m	105.5(95.51)-107.4(92.42)m	0.025
				10MWT: mean(SD)	30.9 (37.25)-26.7(26.20s)	71.9(52.33)-74.1(62.25)s	0.019
				TUG: mean (SD)	34.9(37.52)-31.6(33.05)s	77.1(54.97)-78.8(63.39)s	0.051

Study & Author	Design	Improves walking	Equipment Free	Effect			
				Outcome	Inter.	Cont.	p-value
4. The effect of game-based in comparison to conventional circuit exercise on functions, motivation level, self-efficacy and quality of life among stroke survivors ⁸¹	RCT-Protocol	Yes	Yes				
5. Efficacy of task-specific training on physical activity levels of people with stroke: Protocol for a randomized controlled trial ⁸²	RCT-Protocol	Yes	Yes				
6. Comparison of Two Circuit Class Therapy Programs on Walking Capacity, Gait Velocity and Stair Ambulation among Patients with Chronic Stroke: a Parallel Pretest-Post-test Pilot Study ⁸³	Pre & post-test pilot study	Yes	Yes				
7. Effects of class circuit therapy on balance and gait in hemiparetic patients ⁸⁴	Pre and post intervention	Yes	Yes				
8. Implementing circuit class training can increase therapy time and functional independence in people with stroke receiving inpatient rehabilitation: findings from a retrospective observational clinical audit ⁸⁵	Retrospective clinical audit	Yes	Yes	Functional Independence Measure-walk: mean (SD)	3.3(1.9)-5.6(1.3)	3.2 (1.8)-5.4(1.8)	0.066
9. Group therapy task training versus individual task training during inpatient stroke rehabilitation: a randomised controlled trial ⁸⁶	RCT	Yes	Yes	Stroke Impact Scale: mean (SD) Baseline to 6 weeks	13.57(13.97) change score	14.29 (17.93) change score	0.79
10. Effect of circuit gait training vs traditional gait training on mobility performance in stroke ⁸⁷	RCT (intervention not detailed)	Yes	Yes	BBS: mean (SD)	51.00(6.39)	41.26(8.89)	0.002
11. Six hours of task-oriented training optimizes walking competency post stroke: a	RCT	Yes	Yes	6MWT: mean (SD)	260 (136) m	236 (127) m	0.29

Study & Author	Design	Improves walking	Equipment Free	Effect			
				Outcome	Inter.	Cont.	p-value
randomized controlled trial in the public health-care system of South Africa ⁸⁸							
				Fast walking: mean (SD)	0.95 (0.47)	0.86 (0.5)	0.41
				BBS	49 (7)	46 (10)	0.16
				TUG	22.3 (19.8)	20.7 (17.1)	0.32

Life After Stroke Program

Module 1:

Community-based mobility training

Administered by:

Community Health Workers

JUNE 2023

Overall aim of the training session:

- To improve post-stroke ambulation.

Outcome measures:

- Fatigue Assessment Scale
- Borg perceived exertion scale
- Manual Muscle Strengthening
- Berg Balance Test
- Six-Minute Walk Test
- Ten-Minute Walk Test

Type of training: Circuit Class Training (CCT)

Instructions for Circuit Class Training:

Five Stations: Overall 60 mins sessions (with 2minutes break in between the sessions if needed)

Station one: Warm-up exercises: 10 mins

Station two: Lower limb muscle functional Training: 15 mins

Station three: Balance training: 15 mins

Station four: Endurance exercises: 15 mins

Station five: Cool-down exercises: 5 mins

Overall Instructions for Community-Health workers to follow during session:

1. Community-Health workers (CHWs) should meet therapists before the session to discuss the plan.
2. CHWs will meet the caregivers and patients to discuss the plan.
3. CHWs will give the instructions to the patients regarding the CCT.
4. CHWs will divide patients into different CCT groups of approx. 6-8 patient in each group based on their level of functionality.
5. Each CHWs will be assigned to a particular group of patients and they have to observe and guide patients during the session (consider asking for fatigue, any other physical symptoms).
6. CHWs will start the session with the assigned group based on the description of CCT above (please refer to the instructions above).
7. CHWs need to encourage all the patients to participate fully during the session
8. Based on the level of progression CHWs will have to consider the following instructions:
 - a) Increase the number of repetitions (within the given time for each station).
 - b) Increase complexity of exercises at each workstation:
 - a. increase distance in reaching activities.
 - b. reducing the height of the chair during sit to stand activity.
 - c. increase the height of the blocks during stepping exercises.
9. Once the session is completed, CHWs will meet patients individually and in group to discuss about the challenges and facilitators during the session.
10. They will give verbal instructions for the home program to patients after each session.
11. CHWs will provide instruction manual for the home program and a home dairy to keep the record of exercises performed by patient at home

Station one: Warm-up exercises

Warm-up exercises: 5 exercises			Dosage
Target type	Target	Ingredients	
Representation	Increase knowledge on how to perform tasks/activities safely	Patients will be given instructions and guidance to perform warm-up exercises	
Skill & Habits	To prepare for exercises, increases flexibility, performance levels	<ol style="list-style-type: none"> 1. Marching: Alternate knee raises at your own pace. 2. Marching with arm swing: <ul style="list-style-type: none"> - Alternate knee raises at your own pace - Swing left arm when the right leg is raised, and alternate. 3. Knee circles: <ul style="list-style-type: none"> - With knees bent, place both hands over top your knees - Move both knees at the same time in a circle (Switch directions) 4. Ankle rotations: <ul style="list-style-type: none"> - Sit on a chair or stand if able - Extend one leg off the ground - Perform full circles with your ankle (Switch direction) - Switch with the other ankle 5. Butt kicks: <ul style="list-style-type: none"> - Bring one heel backwards as far as possible - Alternate with the other heel as frequently as you are comfortable with. 	10 mins

Station two: Lower limb muscle functional training

Instructions:

- Give patients instructions and guidance for specific tasks/activities.
- Decrease height of seat in sit to stand, start with to no support on the chair.
- In heel or toe raises start with two legs to one leg
- Start with to no support on the wall.
- Start with decreased to increased speed.

Lower limb muscle functional training: 7 exercises				
Target type	Target	Ingredients	Dosage	Outcome measure
Representation	Increase knowledge on how to perform tasks/activities safely	<ul style="list-style-type: none"> - Patients will be instructed on how to self-monitor: <ul style="list-style-type: none"> - Rest when necessary - Inform CHW when fatigued or experiencing pain during an activity. - Signs of fatigue (loss of balance, leaning heavily on the wall, walker, chair, shortness of breath, decreased quality of movement, task may not look coordinated. - If patients require one on one supervision, CHW or caregiver should stand nearby on the weak side and slightly behind. 		
Skills & Habits	Enhance muscle strength (increased number of repetitions of an exercise) and lower limb functioning.	<ol style="list-style-type: none"> 1. Sit to stand <ul style="list-style-type: none"> - Sit-to-stand from various heights including from chairs with and without arms-reduce height of the seat and increase speed. 2. Heel raises <ul style="list-style-type: none"> - Heel raises-standing flat on the ground 3. Toe raises <ul style="list-style-type: none"> - Progressed from bilateral to unilateral raises on either side. 4. Wall sits or semi/partial squats <ul style="list-style-type: none"> - Lean back against the wall. - Bend your knees and move body downwards, while back remains against the wall-Hold for 3 seconds. - Extend legs and return to starting position-Repeat the exercise - Progress depth of squat until thighs are parallel with ground, hold-progressed by increasing 3 seconds. - And then add weights to hands. 5. Step raises <ul style="list-style-type: none"> - Forward and lateral step raises-Patient places the affected leg on a step placed in front or to the side and raises him/herself onto step. 	<ul style="list-style-type: none"> - 15-minute station with some rests in between - Start with 2 sets, 5 reps at a given level/task. - Gradually increase to 3 sets, 10 reps for the same level before moving to the next - 3 to 5 exercises can be used to complete a - Participants who are able to easily complete 3 	Muscle manual testing

Lower limb muscle functional training: 7 exercises				
Target type	Target	Ingredients	Dosage	Outcome measure
		<p>6. Active hamstrings in sitting. - Patient will sit on a chair and bend affected knee as far as possible.</p> <p>7. Reaching in sitting: Reaching in various directions out of the base of support in sitting</p>	<p>sets of 10 reps can increase to 3 to 5 minutes of continuous repetitions to fit 3 to 5 exercises within a 15-minute station</p>	
Representation	Enhance participation in activities at the center	<ul style="list-style-type: none"> - Record participants performance and attendance - Participants work in pairs (one performing and the other observing) - Patients who arrive early at the center, can perform some independent exercises as they wait for the group exercises to begin. - Ask patient's opinions on the activities, intensity, time, easy or challenging. - Review patient's performance and give them feedback of their progress - Encourage the patient by discussing with them their progress. - Discuss with patient what would be the strategies for improvement 		

Station three: Balance training

Instructions:

- Give patients instructions and guidance for specific tasks/activities.
- Start with and no hand support.
- Start with decreased to increased speed.
- Increase repetitions.

Balance training: 6 exercises				
Target type	Target	Ingredients	Dosage	Outcome measure
Representation	Increase knowledge on how to perform tasks/activities safely	Same as above		
Skills & Habits	Improve balance	<p>1. Weight Shift-Forward & backward</p> <ul style="list-style-type: none"> - Bend left knee and shift weight onto the left leg. - Return to starting position. - Bend right knee and shift weight onto the right leg. <p>2. Reaching: Forward</p> <ul style="list-style-type: none"> - Reach to touch marks on a wall - Use different stance positions including feet together and tandem stance. - Return to starting position - Switch arms. <p>3. Reaching to pick up objects:</p> <ul style="list-style-type: none"> - Reach to pick up objects from low surfaces or the floor. - This exercise will be performed in pairs with patients passing objects to each other. <p>4. Standing: On one leg</p> <ul style="list-style-type: none"> - Raise one leg off the ground. - Switch to other leg. <p>5. Standing: Heel toe (Tandem standing)</p> <ul style="list-style-type: none"> - Place one foot (left) directly ahead of the other one, forming a straight line. - Return to starting position. - Repeat with right foot ahead of left foot. <p>6. Walking: Heel toe (Tandem walking)</p> <ul style="list-style-type: none"> - Walking with a heel-toe gait: walking forward, backwards, and sideways with the affected leg- alternating between crossing in front of, or behind the non-affected leg with each step. <p>Take 5 to 10 steps:</p> <ul style="list-style-type: none"> - forwards. 	<ul style="list-style-type: none"> - 15-minute station with some rests in between - Progress to the next level/task once able to complete 10 seconds at a given level/task - Gradually increase exercise duration to 2 min for a given level 	BERG balance scale

Balance training: 6 exercises				
Target type	Target	Ingredients	Dosage	Outcome measure
		<ul style="list-style-type: none"> - backwards. - sideways 		
Representation	Enhance participation in activities at the center	Same as above		

Stage 4: Endurance Exercises

Instructions:

- Start the activity with to without support, for example start near the wall, chair for balance, start with to without hand support.
- Start with a few steps to many across the room.
- Start with decreased to increased speed
- Start walking without with obstacles.

Endurance Exercises: 7 exercises				
Target type	Target	Ingredients	Dosage	Outcome measure
Representation	Increase knowledge on how to perform tasks/activities safely	Same as above		
Skills & Habits	Increase endurance/fitness improved scores on 6-minute walk measurement tool	<p>1. Stepping up and down</p> <ul style="list-style-type: none"> - Facing the stepper, start with low to increased height of step - Lift the left foot onto the stepper - Place right foot onto the stepper - Take a step down leading with the left foot, returning to the starting position. - Repeat with alternate lead foot. <p>2. Stepping- Side (Lunges)</p> <ul style="list-style-type: none"> - Level 1: Start with feet together. Sidestep leading with the left leg into lunge with left knee bent. Bring left leg back. Step out and lunge with right leg. Stay in the one spot. - Level 2: Sidestep to the left side. Bring right leg to meet left leg and continue to sidestep with the left for 10 steps moving in one direction. <p>3. Stepping Forward</p> <ul style="list-style-type: none"> - Patients will stand with feet in marked areas, then tap left foot out to touch marks on floor, repeating with the right foot. - Continue for 10 steps or from one side of room to the other <p>4. Marching: Fast high knee marching</p> <p>March on the spot as quickly and safely as possible.</p> <p>5. Fast & low steps</p> <ul style="list-style-type: none"> - Stand with feet shoulder width apart, with trunk and knees slightly bent. - Raise onto the balls of your feet. - Alternate tapping your feet in this position as fast as possible. 	<ul style="list-style-type: none"> - 15-minute station with some rests in between - Begin with 1 min of continuous exercise followed by 1 min of rest - Gradually increase exercise duration to 5 min for a given level 	6-minute walk test

Endurance Exercises: 7 exercises				
Target type	Target	Ingredients	Dosage	Outcome measure
		<p>6. Walking: Forward, Backward and Sideways</p> <ul style="list-style-type: none"> - Take 5 to 10 steps: <ul style="list-style-type: none"> - forward with hand support to the side or use gait aid. - backwards with hand support to the side or use gait aid. - Sideways with hand support to the side or use gait aid. <p>7. Walking around</p> <ul style="list-style-type: none"> - Obstacle courses including stepping over and around objects, up and down steps, over soft surfaces, and picking up objects from the floor. - Obstacle courses while carrying a tray of objects (for dual-task performance). 		
Representation	Enhance participation in activities at the center	Same as above		

Station 5: Cool down stretches and relaxation

Cool down stretches, relaxation: 6 exercises			
Target type	Target	Ingredients	Dosage
Representation	Increase knowledge on how to perform tasks/activities safely	Patients will be given instructions and guidance to perform warm-up exercises	
Skills & Habits	Improve flexibility and performance	<p>1. Trunk side stretch</p> <ul style="list-style-type: none"> - Stand with arms out to the side. - Side bend trunk to the left and reach overhead towards the left with your right arm. - Hold this position for 30 seconds. - Return to starting position & repeat towards the other direction. <p>2. Trunk & head rotation</p> <ul style="list-style-type: none"> - Place hands on hips and feet shoulder width apart. - Keep hips facing forwards as you turn your trunk and head towards the left. - Hold this position for 30 seconds. - Switch directions. <p>3. Calf muscle stretch</p> <ul style="list-style-type: none"> - Place hands against the wall for support. - Get into a lunge position, bending the front knee and extending the back leg. - Gradually increase the amount of knee bend until a stretch is felt in the back of the calf. - Hold this position for 30 seconds. - Switch feet position. <p>4. Thigh stretch</p> <ul style="list-style-type: none"> - In sitting, bend one knee and grasp your ankle to maintain the position. Feel a stretch in the front of the thigh. - Hold this position for 30 seconds. - Switch legs. <p>5. Buttocks stretch</p> <ul style="list-style-type: none"> - In sitting, bend one knee towards your chest. - Grasp around the front of the knee to maintain the position. - Hold this position for 30 seconds. - Switch legs. <p>6. Hamstring stretch</p> <ul style="list-style-type: none"> - In sitting, extend one leg ahead. - Lean forwards and try to reach hands towards your foot. The back of the leg should feel a stretch. - Hold this position for 30 seconds. - Switch legs. 	<ul style="list-style-type: none"> - Hold each stretch for 30 seconds per side - 5 mins

Homework

Target type	Target	Ingredients
Skills & Habits	Enhance participation in activities at the home	Perform: <ul style="list-style-type: none"> - Warm-up exercises: 10 mins - Lower limb/functional strengthening exercises: 15 mins - Balance exercises: 15 mins - Endurance/fitness exercises: 15 mins - Cool-down exercises: 5 mins
Representation		<ul style="list-style-type: none"> - A manual of instructions on how to perform the exercises will be given to each patient - A home diary for recording exercises completed, effects of exercise (e.g., muscle soreness) will be given to each patient. - Discuss with individual patients of the barriers that could hinder them from engaging in activities at home. Discuss strategies to address the barriers. - Discuss with individual patients of the facilitators to participating in activities at home. Build on the facilitators to enhance participation at home. -Family members and/or carers, will be encouraged to assist patient at home. - Patients will be provided a booklet with safety precautions, instructions and photographs of exercises for use at home.

Descriptions of participation scores⁸⁹

SN	Level of score	Score	Description
1	None	1	Participant refused to participate in any exercises in session
	Poor	2	Participant did not participate in at least half of activities/session.
	Fair	3	Participant participated in most or all of exercises but did not show maximal effort or finish most exercises or required much encouragement to complete the circuit exercises.
	Good	4	Participant participated in all exercises with good effort and finished most, but not all exercises and passively followed directions (rather than taking an active interest in exercises).
	Very good	5	Participant participated in all exercises with maximal effort and finished all exercises, but passively followed directions (rather than actively taking interest in exercises).
	Excellent	6	Participant participated in all exercises with maximal effort, finished all exercises, and actively took interest in exercises and/or future therapy sessions.

Note: If participant was unable to come at the center because of medical tests, doctor's bed rest orders, or scheduling conflict, do not mark any score.

CHAPTER 5: DISCUSSION

Overview

The work provided in this thesis serve as building blocks to create opportunities for Rwandan stroke survivors to access co-designed community-based care. The components include assessing unmet functional needs of stroke survivors (Chapter 2), evaluating alternative solutions to traditional models of delivering rehabilitation, (Chapter 3) and developing a CHW-based mobility intervention (Chapter 4). The road to providing Rwandan stroke survivors with community-based care is long, and each of these steps provides data and a better understanding of possible directions in which to focus efforts to realize the goal of improved functional abilities of Rwandan stroke survivors.

In this chapter, I will explore into the relationships between the findings from previous chapters and the ways in which they inform the approach to community-based care. I will highlight the implications of the research and its support in achieving the aim of the thesis of enhancing community-based care for stroke survivors in low-resource regions. Furthermore, I will demonstrate the initiatives that will be implemented in Rwanda as a prime example of how this thesis can truly make a positive impact on stroke care in a broader context.

Assessing the needs of stroke survivors

In Chapter 2, I examined the functional needs of stroke survivors in Rwanda at hospital discharge and three months after stroke. Results indicated that stroke survivors experience moderate to severe needs in almost all aspects of daily living and many of the needs identified at discharge remain moderate to severe for most even after three months. The study provided insights about the distinct characteristics and challenges of Rwandan stroke survivors. The findings show that Rwandan stroke survivors are generally younger than those in western nations,¹ with more women being affected.^{1,2} Also, the study highlighted a greater number of unmet functional needs and substantial disability in stroke survivors upon discharge and at three months, compared to stroke survivors in western nations.³⁻⁶

Interventions to address the needs of Rwandan stroke survivors must consider the extent of unmet needs, levels of disability, and a lack of what kind of resources are needed. The data

presented on the number of stroke survivors affected and the specific areas, such as mobility, activities of daily living, working and social/recreation that are not adequately met guides on what interventions to develop. Considering that limited access to services was identified as a barrier to addressing the above-mentioned needs, in developing interventions to address the needs and disability, we need to recognize the settings in which patients live⁷ and the limited access to services is crucial.^{2,7,8}

Rwanda has a socialized healthcare system which funds hospital-based rehabilitation (both in and out patient).⁹ A few specialized rehabilitation centers funded by international non-governmental organizations (INGOs) offer limited community rehabilitation services, at a cost.⁹ To improve access to rehabilitation services, the Rwandan government is exploring options to expand hospital outpatient departments and integrate rehabilitation into primary healthcare systems.⁹ However, these initiatives will take many years to implement and it is important for healthcare providers, policymakers, and funders to consider these data to develop services that best support stroke survivors and family caregivers now.^{10,11}

As part of our approach to begin discussions, my supervisor and I held an investigators' meeting on July 22, 2022. A total of people, including data collectors, rehabilitation researchers, clinicians and a representative from Stroke Action Rwanda (SAR) attended the meeting. It was the first time the attendees participated in a meeting of this type. The inclusion of a Person with Lived Experiences at our meeting was a truly unique and important step towards integrating the concerns of stroke survivors and their families into the dialogue about both the design and interpretation of research studies that are relevant to their needs. We presented the data, discussed the meaning of the results, and considered how to improve the study design for a national level study on the needs of stroke survivors. There was agreement among attendees that registries that include both prevalence and implications of stroke are needed to best understand the extent of the needs of stroke survivors and their families.

The study's identification of a pressing need to support in the domain of post-stroke employment, where 85% of the participants expressed major concerns at three months, highlights

the practical significance of the registries. The trend is not uncommon among stroke survivors in low-resource settings like China,⁸ India,⁷ and Nigeria,² where the economic impact of stroke can be quite severe. The loss of productivity and income, as well as the increased expenses for caring for the stroke survivor, adds to the economic implications of stroke in low-resource settings.^{7,12,13} The economic impact of stroke is significant in low-resource settings, as the young are more affected,^{14,15} although stroke survivors of all ages find it difficult to resume work due to functional disabilities.^{7,13} The effects of a stroke are not limited to the survivor alone, but also affect their families who may rely on them for financial support.^{14,15} Additionally, society may experience a decrease in productivity and income due to the stroke survivor's inability to work. In many low-resource settings, stroke survivors are often the primary breadwinners for their families, and the inability to return to work can lead to a significant loss of income and difficulty accessing necessary healthcare services, including rehabilitation.^{7,12,16} Unfortunately, the work force in low-resource settings is often not equipped to provide accommodations for those with disabilities.^{2,7,8}

Community-based programs and interventions tailored for low-resource settings are crucial in addressing the challenges encountered by stroke survivors, particularly in terms of their successful reintegration into the workforce.

Alternative strategies for providing physical rehabilitation interventions in low resource settings.

Demonstrating the need to create community-based interventions, in Chapter 3 of the thesis, I examined different methods of delivering rehabilitation interventions in settings with limited resources. Physiotherapists are the primary providers of rehabilitation services in Rwanda and other low-resource areas, but their availability is limited. Due to resource constraints, increasing the number of physiotherapists delivering care in these settings, including Rwanda, may not be possible. Therefore, alternative methods must be explored.

My aim was to find a feasible option for providing rehabilitation services using available resources.¹⁷

In Rwandan villages with a population of at least 1000, there are typically 3-5 Community CHWs. CHWs have the important role of communicating with patients and referring them to

formal healthcare systems. They also promote health through various activities and conduct home visits and check-ins to ensure patients receive the care they need.^{18,19} In many low-resource settings, such as Rwanda, rehabilitation is not within the responsibilities of CHWs. I explored whether community-level agents, like CHWs, have been involved in providing rehabilitation in low-resource settings. This way, Rwanda can learn from their experiences and potentially implement a similar model.

My research investigated the effectiveness of the provision of basic physical rehabilitation interventions delivered by community-level agents, such as CHWs. I performed a systematic review and identified ten studies, five RCTs and five non-RCTs, that described effects of physical rehabilitation by CHWs, village health volunteers and informal caregivers in improving stroke survivors' outcomes, such as mobility, activities of daily living (ADLs) and quality of life (QoL). Of the ten studies, all had methodological shortcomings. It was found that physical rehabilitation interventions administered by community-level agents (such as CHWs or health volunteers) or informal caregivers did not consistently improve mobility, ADLs, or QoL when compared to usual care. When an effect was established, it was not consistent across all study outcomes. Several issues were identified that included inadequate training of the trainee.²⁰⁻²² The training time was limited, the structure and methods used for training were complex. Additionally, the trainers had heavy workloads that limited time to provide training.

The data suggest that CHWs could potentially provide rehabilitation services,²³ taking into account training time, methods, structure and proficiency. However, at present, this is not included in the responsibilities of CHWs in Rwanda.^{18,19} To make this possible, I considered a two-step process. Firstly, we need to create an intervention that is specifically designed for CHWs. Secondly, we should establish an operations team (OP team) to oversee the implementation activities of the intervention.

First, it is imperative to create evidence-based intervention that are explicitly designed for delivery by CHWs. These interventions must be customized to incorporate specific task details with defined protocols for CHWs to be trained by healthcare professionals.¹⁷ The protocol should entail precise instructions for exercise practices. Furthermore, assessing the CHWs' proficiency

in healthcare delivery is essential in designing an effective training package. A similar approach was successful in Rwanda, where community health volunteers were trained on non-communicable diseases (NCDs) and palliative care, resulting in 200 home-based practitioners who now apply the knowledge gained to provide care for patients with NCDs within their communities.

To ensure successful and effective community-based intervention, I intend to create an OP team that will oversee the implementation of intervention activities. The conclusions and implications section will provide details on this. The next section involves creating a community-based intervention that will be implemented by CHWs.

Developing an evidence-based, community intervention specifically tailored for low-resource settings.

In the previous chapter, I highlight the importance of creating rehabilitation interventions that are based on evidence and designed specifically for low-resource community contexts. While most stroke-rehabilitation evidence has focused on high-resource contexts and service-delivery requirements, it is crucial to consider resource availability from the intervention design stage. The intervention's resource requirements should be compatible with the resources available in the implementation context, including low-income and community-level settings. To achieve this, I followed a systematic process that utilized the Rehabilitation Treatment Specification System (RTSS) framework. To design and test rehabilitation interventions that are not only effective, but also cater to the low-resource and community-level requirements is crucial and timely.

Despite the advancements made in global health and the aging population, there still exists a shortage of skilled human resources and other rehabilitation facilities in many areas.^{25,26} Therefore, it was absolutely imperative to design an intervention easily accessible to stroke patients in low-resource contexts post-hospitalization to ensure equitable global health and rehabilitation. Though the unavailability of mobility programs, the available recommendations from Clinical Practice Guidelines and randomized controlled trials were not applicable to the Rwandan community context. Therefore, I identified the best evidence applicable to the context

and then used the RTSS framework to design a comprehensive mobility program, considering the varied requirements of stroke survivors, implementation by non-healthcare professionals and the need to clearly identify the key ingredients. This latter aspect is required to improve the replicability of the intervention across different settings.^{27,28} An evidence-informed post-stroke mobility intervention that can potentially be delivered by CHWs in low-resource, community-level contexts was created.

Through the process, I understood that designing interventions for low-resource and community-level settings requires adaptability and flexibility. I also learned the significance of innovation and creativity in finding cost-effective yet impactful solutions for interventions in settings with limited resources. Overall, following a systematic process using the RTSS framework is not only valuable for my specific intervention but informing the development of interventions or programs in similar contexts.

The mobility intervention is the first of the post-stroke community-based interventions being developed for use in a randomised control trial to evaluate their effectiveness in different settings, including Nigeria, Rwanda, and India. The Life After Stroke Centre (LASC) will serve as one of the settings where the interventions will be implemented. The LASC Program is a multidisciplinary, community-based program designed to improve outcomes for those with stroke in settings with little, if any, care available at the community level. The non-governmental organization Stroke Action Nigeria established the LASC and has been operating for more than four years in Onitsha, Nigeria. The LASC offers a range of services to stroke survivors, that include community-based interventions, secondary prevention strategies, and enables survivors of working age to become micro entrepreneurs, providing stroke support services to their peers.

Although the LASC has been regarded as successful by those involved in its implementation and participation in Nigeria, no rigorous research has been conducted to determine its effectiveness. This lack of evaluation makes it challenging to secure funding for the program. Therefore, it is crucial to provide evidence that supports post-stroke community-based interventions offered at LASC to sustain funding. Demonstrating that community-based interventions can enhance stroke survivors' outcomes and minimize long-term healthcare expenses may attract potential funders.

I am part of the Organized Stroke Care Across Income Levels (OSCAIL) study group, which includes a multinational and multidisciplinary team of healthcare professionals (physiotherapists, neurologists, geriatricians, nurses, occupational therapists), non-profit stroke associations, researchers (trialist and epidemiologist), and trainees. We are preparing to request funding for a Type II hybrid effectiveness-implementation study to demonstrate the effectiveness of post-stroke community-based interventions in low-resource areas. Our study will highlight both strengths and barriers to implementation²⁹ and use the Implementation Research Logic Model (IRLM) to focus on important elements of the implementation process and outcomes.³⁰ Our grant development work is based on data collected from the Needs Assessment Study, which has been invaluable in creating a post-stroke community-based intervention applicable not only in Rwanda but also other Sub-Saharan African countries, such as Nigeria, Malawi, South Africa, and Botswana.

I have also created an alliance with different system level support in Rwanda for developing community-based interventions. Letters of support for our study have been provided by the Manager of the NCDs division at the Rwanda Biomedical Center (RBC), the country manager of Humanity and Inclusion (an NGO), the vice-chancellor of the University of Rwanda, the Director of the Gahini Rehabilitation Center, and the legal representative of Stroke Action Rwanda (SAR). This support demonstrates the recognition for community-based care for stroke survivors and the wide range of partners, from government to hospitals to stroke survivors, who recognize the need. Despite submitting a proposal for the Women in Science Research and Innovation Grant provided by the National Council for Science and Technology, funding was not granted. However, we are continuing our efforts to secure funding through grant proposals for not only Rwanda but other settings.

Additionally, I am working with stroke specialists from Sub-Saharan African countries and professionals from developed nations such as Canada and the UK through the OSCAIL group to continue work to develop additional modules. This collaboration will not only support my research efforts on this study, but the researchers are keen to support my efforts as I move forward as an independent researcher. This partnership presents an opportunity for sharing

valuable information and working together to create and implement an effective community-based program for stroke survivors in resource-constrained settings.

Conclusions and Implications

In my thesis, I discuss three key points. Firstly, I explore the needs of stroke survivors in Rwanda, highlighting the significant functional needs that remain moderate to severe, particularly in the areas of mobility and daily activities. Secondly, I examine alternative strategies for providing rehabilitation in settings with limited resources, demonstrating that with adequate training on an evidence-based intervention and specific tasks, CHWs can provide basic rehabilitation. Lastly, I detail the creation of an evidence-informed intervention that can be administered by non-skilled rehabilitation workers like CHWs.

Based on these key messages, I have gained a better understanding which will allow me to pursue the following next steps:

Confirming and disseminating the needs of stroke survivors: I will conduct further validation studies to confirm the needs of stroke survivors and caregivers in Rwanda. I will conduct focus group discussions with stroke survivors to ensure that their needs and challenges have been accurately captured and identify gaps in my research findings. Caregivers play a crucial role in the recovery and support of stroke survivors,¹⁶ to enhance the well-being of stroke survivors, I intend to understand their needs and challenges.

I will share my research findings through academic conferences on stroke care (i.e., World Stroke Congress, African Stroke Organization meetings), rehabilitation (World Physiotherapy Congress), and NCDs (i.e., NCDs Alliance), peer-reviewed journals, and other platforms to contribute to the body of knowledge on stroke rehabilitation in resource constrained settings. It is through these platforms that I will get the opportunity of collaborating with researchers and organizations from other countries working on similar topics. Collaborating with others will provide me with many opportunities, such as exchanging knowledge and expertise, expanding my professional network, and equipping me with the necessary resources to tackle more

significant research problems. Attending conferences and meeting individuals with diverse expertise might provide me with a broader range of resources, such as research facilities and funding opportunities, which will enhance the scope of my research activities and intervention implementation.

Implementing the community-based intervention to support stroke survivors: I am currently working on implementing a community-based mobility intervention and have identified key strategies and steps required for its successful implementation. To begin with, I am assessing the existing support systems for CHWs and the local context to identify any challenges and opportunities that could impact the intervention's success. This includes reaching out and working with individuals responsible for stroke or non-communicable diseases in the country and CHWs. I have already initiated an alliance with the manager of the non-communicable diseases (NCDs) division at the Rwanda Biomedical Center (RBC), the legal representative of the Stroke Action Rwanda (SAR), and the CEO of the Rwanda NCDs Alliance. With their support, I plan to form an operations team (OP team) consisting of representatives from healthcare professionals, policy makers, funders, stroke survivors, and their families. The OP team's support will ensure that all the necessary resources and information are available before and after implementing the intervention, such as requirements for training CHWs, setting up the necessary infrastructure. Earlier in the chapter, I discussed a program that trained community health volunteers in Rwanda to provide palliative care. To prepare for my intervention, I will work with RBC personnel who were part of the training to discuss the potential opportunities and challenges that may arise during implementation.

I am collaborating with stroke specialists from Sub-Saharan Africa, as well as professionals from western countries like Canada and the UK, to obtain funding for a mobility intervention.

Currently, the intervention is in its initial stages, and the OSCAIL team is assisting me in enhancing its structure for implementation. I plan to create a training protocol that the OP team, with the assistance of OSCAIL, will help me improve its structure and implementation.

In a previous section, it was stated that in the investigators' meeting, participants had requested a stroke registry. To meet this need, the OP team, with the assistance of OSCAIL, we will create a stroke registry in Rwanda that will gather important information about stroke incidence,

prevalence, and outcomes Furthermore, we will establish multidisciplinary teams (MDT), including experts in rehabilitation, neurology or medicine, nursing, and social work, to develop stroke care registries in Rwandan hospitals. The OP, MDT, and the OSCAIL teams will work together to improve the quality of stroke care and conduct research on stroke in Rwanda.

I understand that there may be difficulties in creating and maintaining a successful OP team, as well as conducting and continuing my research. However, I am optimistic that seeking and securing ongoing funding, collaboration with government and non-governmental partners, and staying actively engaged in the OSCAIL group and other relevant groups will help me overcome any challenges that arise.

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