Protocol for a Formative Study to Develop a Self-rehabilitation Intervention for Functional Mobility Among Community-Dwelling Stroke Survivors in Lmics

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Study protocol

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Abstract

Background

Stroke is a significant source of acquired adult neurological disability. The increased burden of stroke in Low and Lower-middle Income Countries is currently approaching epidemic level. The consequences of stroke have long-standing effects and require long-term management of the resultant limitations. However, lack of resources, inadequate number of professionals, poor awareness, and lack of technical capacity have made the accessibility and availability of stroke rehabilitation services difficult in Low and Lower-middle Income Countries. Moreover, the effect of the COVID 19 pandemic has worsened the already existing challenges faced by stroke rehabilitation in these regions.

The development of specific and appropriate stroke rehabilitation approaches that can be self-administered, targeting community-dwelling stroke survivors in Low and Lower-middle Income Countries settings, is highly important.

Methods

A formative research design is proposed to support the development of a culturally-adaptable Task-Specific Training programme to be delivered through tele-rehabilitation that can be self-administered by community-dwelling stroke survivors.

Focus group discussions with community-dwelling stroke survivors will be conducted to gather information regarding challenges they faced in carrying out daily activities. The gathered information will be used to inform the development of a Task-specific self-rehabilitation Training model. A Delphi technique will be employed to refine the items in the initial model and come up with a Task-specific, self-rehabilitation programme target at improving functional ability among community-dwelling stroke survivors.

Discussion

Stroke rehabilitation services are grossly inadequate in countries categorized as Low and Lower-middle Income, particularly for community-dwelling stroke survivors in sub-Saharan Africa. This paper presents the methods for the development of a culturally-suitable intervention model for improving functional mobility among community-dwelling stroke survivors in Low and Lower-middle Income Countries.

Background

Stroke is one of the most disabling neurological conditions. The increased burden of stroke in countries categorized as Low and Lower-middle Income Countries (LMICs), including Nigeria, is currently approaching epidemic level. A systematic review\(^1\) examining the worldwide incidence of stroke using data from 119 population-based studies published from 1990 to 2010, recounted that there are differing
trends in stroke incidence among High Income Countries (HICs) and LMICs. The trend suggested a 42% decline in age-adjusted stroke incidence in the HICs and a more than 100% increase in the LMICs.

Stroke is a significant source of acquired adult neurological disability. Impairments of motor function, cognitive ability, speech and mental disorders are the most recognizable leading causes of disabilities and participation restriction after stroke. These limiting impairments have made no less than half of all stroke survivors partly or fully dependent on caregivers for key activities of daily living (ADL). These consequences of stroke have long-standing effects and require long-term management of the resultant limitations. It is obvious that as the population of stroke survivors increases and the number of survivors with disability and prolonged care needs rises, the need for rehabilitation care will amplify.

The increasing incidence of stroke in LMICs also suggests that the demand for rehabilitation and therapy will be higher in these regions of the world, however, lack of resources, inadequate number of professionals, poor awareness, and lack of technical capacity have made the accessibility and availability of therapy and rehabilitation services for stroke difficult.

In Nigeria, like in other parts of LMICs, there is generally limited evidence on available rehabilitation approaches for community-dwelling stroke survivors. The development of specific rehabilitation approaches that can be self-administered, targeting community-dwelling stroke survivors is highly important, as it will promote stroke rehabilitation in this population. Considering the low literacy level in Nigeria and in many parts of LMICs, especially those in sub-Saharan Africa (SSA), a self-rehabilitation model in the form of audio-visuals in the local language could be the most appropriate approach to stroke self-rehabilitation delivery that also targets the unlettered population of stroke survivors typically found within communities in LMICs.

The focus of this study therefore is to develop a task-specific training (TST) programme that could be self-administered through tele-rehabilitation among Hausa-speaking community-dwelling stroke survivors.

**Methods**

**Aim and objectives of the study**

The main aim of this study is to conduct formative research to support the development of a culturally-adaptable TST programme to be delivered through tele-rehabilitation that can be self-administered by Hausa community-dwelling stroke survivors to improve and promote stroke rehabilitation in a LMICs setting.

The specific objectives include:

1. To explore the experiences of stroke survivors about life following stroke. These experiences include challenges faced in the performance of daily activities within the community, exercises done as part
of self-rehabilitation as well as any form of support received from a person or an organization;

2. To explore the needs and expectations of community-dwelling stroke survivors regarding post-stroke rehabilitation and outcomes;

3. To explore and understand the experiences and preferences of community-dwelling stroke survivors towards the development of rehabilitation models and/or programmes to improve outcomes post-stroke;

4. To explore traditionally/culturally-based tasks that can be adopted in a structured TST model; and

5. To develop and validate a culturally-suitable Task-specific, Self-rehabilitation Training (TASSRET) model that can be self-administered by Hausa community-dwelling stroke survivors through tele-rehabilitation.

General outline

In order to achieve the first three objectives of the formative research, we will employ qualitative research methodology among community-dwelling stroke survivors in seven selected communities of North-western Nigeria. Focus group discussions (FGDs) will be conducted among the community-dwelling stroke survivors to explore their experiences about stroke survivorship including the common everyday activities they perform and the challenges they face in doing so. The FGDs are expected to highlight the major activities of daily living (ADL) of the stroke survivors and how they are carried out, and these will inform the design of the TASSRET and the tasks to be included in the model.

To meet the fourth objective, we will use the Delphi approach to come up with a TASSRET model that can suitably be administered among community-dwelling stroke survivors. (see Fig. 1 for the study flow diagram)

Procedure

The FGDs

Focus group discussions will be used for data collection as a suitable method to achieve the study’s objectives of exploring the experiences of stroke survivors about life following stroke. These experiences include the challenges faced in the performance of daily activities within the community, exercises done as part of self-rehabilitation as well as any support received from a person or an organization.

Study Sites

This study will be conducted in seven communities in Northwestern Nigeria. These communities were selected based on the following criteria: one community in each of the seven states of the North West, and a minimum of 100,000 populations as at 2006.
Participants Recruitment and Sampling Strategy

A blend of purposive and convenience sampling will be employed to recruit participants from the identified communities. Information will be provided by a local community contact indicating community leaders and some identified stroke survivors within the communities that can be appropriate recruitment machineries for prospective participants.

The community leaders will be contacted and the research project will be explained to them, and they would be asked to communicate to stroke survivors within the community who may wish to participate. Stroke survivors who indicate interest in the study will be followed up. Focus group discussions will be scheduled with participants who meet the inclusion criteria and who consent to participate in audio-recorded discussions.

Sample size

A sample size to capture various perspectives of life experiences of stroke survivors within their community of dwelling would be sought. We anticipate that seven FGDs (one in each community) with 10–12 stroke survivors in a group would be adequate to reach theoretical saturation for this study. However, if after the seven FGDs, more information is required to achieve the objectives of the study, additional FGDs will be conducted until theoretical saturation is achieved.

Study instruments

A semi-structured discussion guide will be used to elicit the required information from the participants. It will cover the following domains:

A. Exploring the stroke survivors’ experiences with basic ADL within their living environment, including ambulating, feeding, dressing, personal hygiene and toileting.
B. Exploring the stroke survivors’ experiences with physical exercises and trainings within the living environment.
C. Perceived expectations and needs of stroke survivors in terms of physical rehabilitation as well as any form of support received.

Data quality assurance

Prior to data collection, a one-day interactive training session will be conducted for all the research team members, including the principal investigators, FGDs moderators, research assistants, transcribers and translators. The objectives of the study, data collection procedures as well as ethical issues will be discussed during the training; test running of all the relevant tools will also be conducted during this session. During the FGDs, transcription and translation of data collected will be done simultaneously and
will continuously be shared with the study team to ensure high quality of the data. All transcripts will be reviewed throughout the data collection process to ensure appropriateness of content and quality of data. Because the FGDs will be conducted in Hausa language, then transcribed and translated into English, back-translation of the English version will be done to ensure translation accuracy.

Data management

The audio recordings of the FGDs will first be transcribed verbatim in the original language (Hausa) used for data collection, using a structured transcription format. Verbatim transcription will be done close to the time of completion of the FGDs to maintain the originality of the discussion without loss of themes. Field notes, comprising observations and assessments, will be taken during the FGDs and will be used to complement the transcripts. Transcription of data will be conducted by an expert transcriber under the supervision of a designated social scientist who will review it for completeness. Translation of the transcripts into English will be performed by an independent English language translator. All translated transcripts will be checked for consistency by the designated social scientist in order to maintain high data quality. The audio recordings and transcribed files will be managed by the social scientist, who will transfer them electronically to the principal investigator. Transcripts will be imported into Atlas.ti computer software and stored on a password-protected computer accessible only to the principal investigator. Participants will only be identified by a unique identifier code; their names and personal information will not be recorded.

Data Analysis Plan

In-depth debriefing sessions will be conducted (both physically and remotely) between the principal investigator and the research assistants on a jointly agreed schedule, to appraise interview guides and field notes, identify potential questions or scenarios of interest or misperception for clarification, and to ensure consensus agreement. To keenly comprehend information in the data, verbatim transcription of audio recordings from the FGDs will be done immediately after each FGD. This will give the researcher a sense of understanding of emerging information before proceeding with further FGDs. The transcripts for all FGDs conducted will be read and re-read to have complete understanding or the whole picture of what is being described by each participant. The transcript of each interview will then be analysed via line by line coding. This will enable capturing of the underlying meaning of texts in the transcripts thereby enhancing understanding of the participants’ responses.

Coding will be done manually for each transcript; this will enable easier and quicker comparison of data. Similar descriptions and direct quotes that emerge from line by line analysis of the data will be aggregated to form categories. Thereafter, patterns and relationships that connect the categories will be analysed to form themes. This process will be repeated for all transcripts before cross analysis of all transcripts is done. This will provide a clear picture of the commonalities between transcripts. All other
rules/measures to ensure authenticity, such as bracketing, trustworthiness, triangulation consistency and confirmability, will be strictly adhered to in managing the data.

The information obtained from the FGD results regarding the common daily activities performed by Hausa community-dwelling stroke survivors will be studied by three physiotherapists and a kinesiologist. Different tasks will be isolated and itemized, similar tasks that involve the use of the upper extremities, lower extremities and the trunk will be grouped accordingly and will be termed the emerged tasks (EmTs). These EmTs will further be reviewed by the three physiotherapists and itemized based on the body part involved (i.e., upper extremities, lower extremities and the trunk) to come up with a TST package.

**The Delphi method**

The Delphi technique has increasingly become an essential tool used to address matters in health and medicine and an attractive method for developing consensual guidance on best practice.\(^{11,12}\) The main purpose of the Delphi technique is the realization of agreement or the exploration of a field beyond existing knowledge and the current conceptual world.\(^{13,14}\)

The Delphi technique will be employed for validation of the tasks identified. This will be in three stages. First will be the establishment of content validity for items in the model. Second will be the content validation of the whole TASSRET, and finally, experts will be invited to consider their scores, based on group responses in relation to the overall responses received, and decide/suggest what they deem appropriate between their rating and average opinion of other respondents. Thirty stroke rehabilitation experts (comprised of ten from Nigeria, ten from other parts of Africa and ten from other parts of the world) from diverse professional groups involved in stroke rehabilitation, will be contacted for consent to participate as Delphi expert panelists. We put the number of panelists at 30 in the expectation that not all the invited experts will respond or consent to participate. A copy of the developed set of tasks will be sent to each of the panelists, and they will be asked to examine and rate each item of the model in terms of its relevance to the underlying construct as described by Lynn.\(^{15}\) All correspondence with the panelists will be via e-mail. The panelists will be given a period of three weeks to respond and will be reminded weekly. Detailed instructions on rating/scoring of the items included in the model will also be forwarded to the panelists.

The items will be rated on a 4-point scale to avoid a neutral and ambivalent midpoint.\(^{15}\) The rating interpretation will be as follows: 1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, and 4 = highly relevant. After all the content experts have finished the ratings, the responses will be retrieved and aggregated. The computation of the item validity will be as follows: for each item, the number of experts giving a rating of 3 or 4 divided by the total number of experts will be computed. A content validity score of \(\geq 0.78\) for an item will be accepted.\(^{15}\) Any item that scores < 0.78 will either be modified or removed.

In the second stage, the panelists will establish the content validity of the whole model. The computational procedures for the validation of the model will be as follows: the proportion of items given
a rating of 3 or 4 divided by the total number of items in the model.\textsuperscript{16} A content validity of $\geq 0.8$ will be accepted based on available procedural evidence.\textsuperscript{17,18,19}

**Translation to Hausa Language**

After the establishment of content validity, the model will be translated into Hausa language at the Department of Nigerian Languages in Bayero University, Kano. Two independent translators will individually translate the model into Hausa. The principal investigator (native Hausa) and two other research assistants who are also native Hausa, will relate the two translations and pool them together to get a translation with more clarity without losing the scientific and related meanings.

**Development of the Video Version**

The booklet will be used as a script in the production of the video version of the TASSRET model. A Hausa film director and two actors (male and female) would be involved in the development of the video version and the video coverage will be done by a professional videographer. The setting for the video will be a typical Hausa community setting.

Prior to the commencement of the video production, all those involved will be informed and trained on the purpose of the project and the specific role each is expected to play. After recording, the video will be edited by the videographer and converted into video clips which will be stored on a portable hand device for easy delivery through the tele-rehabilitation approach.

**Result**

Ethical approval (NHREC/06/12/5) to conduct this study has been sought and obtained. The study sites had been selected and as at February 2020, two FGDs had been conducted. FGDs were temporarily halted due to the COVID-19 pandemic and the lockdown.

**Discussion**

This paper presents the methods for the development of a culturally-suitable intervention model for improving functional mobility among community-dwelling stroke survivors (coded as TASSRET).

Stroke rehabilitation services are grossly inadequate in countries categorized as LMICs, particularly for community-dwelling stroke survivors.\textsuperscript{20} Most of the evidence for self-rehabilitation for improving outcomes post-stroke, including those that involve the use of best practice clinical guidelines, are found in studies conducted in HICs,\textsuperscript{21,22} and these studies used models that are mainly suitable for HIC settings and may not be feasible and/or affordable for administration in LMICs.\textsuperscript{9}
A recent systematic review identified lack of high-quality evidence-based studies on interventions for physical function with features of self-administration post-stroke. This inadequacy was further exposed in the time of the COVID-19 pandemic and the resulting lockdown. The development of stroke intervention protocols with features of self-administration which can be delivered through tele-rehabilitation will hugely promote and benefit stroke rehabilitation in LMIC settings.

This study involves gathering of information from stroke survivors regarding the common daily activities they perform, and extracting the kinematics involved in performing those activities to develop them into a set for a TST model which can be self-administered, and using a panel of experts to validate the items in the model. We believe that the result of this study will provide a stroke rehabilitation option to a host of stroke survivors living in communities of North-western Nigeria and other Hausa-speaking communities. This study protocol is expected to be useful for researchers in planning and developing culturally-adaptable intervention programmes with similar characteristics.

Conclusions

This paper presented the methodology of a formative study for a culturally-suitable task-specific training model for improving functional ability post-stroke, which will be delivered to Hausa community-dwelling stroke survivors via tele-rehabilitation. Focus group discussions will be conducted with stroke survivors to identify the common daily activities they have difficulty in performing based on which relevant TST will be identified and appraised through the Delphi method, using experts in stroke rehabilitation. This study protocol is expected to be useful for researchers in the planning and implementation of similar studies.

Abbreviations

LMICs
Low and Lower-middle Income Countries
HICs
High Income Countries
ADL
Activities of Daily Living
TST
Task-Specific Training
TASSRET
Task-Specific, Self-Rehabilitation Training
FGD
Focus Group Discussion
EmTs
Emerging Tasks

Declarations
**Ethics approval and consent to participate:**

This study will be conducted according to the ethical principles for medical research involving human subjects as contained in the Declaration of Helsinki statement. Ethical approval (NHREC/06/12/5) to conduct this study has been granted by the College of Health Sciences Human Research Ethics Committee, Bayero University, Kano. It will be ensured that the consent of all participants (stroke survivors and the Delphi panelists) is sought and obtained through a written informed consent before included in the study. The individuals that will appear in the pictures and the audio-visuals, will be well-informed about the purpose of the work and what it will be used for, and it will be ensured that they understand these things and provided a written consent.

**Consent for publication:**

Not applicable

**Availability of data and materials:**

Not applicable

**Competing interests**

The authors declare that they have no competing interests.

**Funding**

No funding has so far been received for the conduct of this study.

**Authors’ contributions**

RI and IUL conceived the idea of the study. RI wrote the initial draft of the protocol manuscript including the figure. IUL and CJ reviewed the initial manuscript, and developed the final version. All authors read and approved the final manuscript.

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**References**


Figures

![Figure 1](Image)

**Figure 1**

**Study Flow Diagram**