



## Experience of using an interdisciplinary task force to develop a culturally sensitive multipronged tool to improve stroke outcomes in Nigeria



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### ABSTRACT

The burden of stroke is on the rise in Nigeria. A multi-faceted strategy is essential for reducing this growing burden and includes promoting medication adherence, optimizing traditional biomarker risk targets (blood pressure, cholesterol) and encouraging beneficial lifestyle practices. Successful implementation of this strategy is challenged by inadequate patient health literacy, limited patient/medical system resources, and lack of a coordinated interdisciplinary treatment approach. Moreover, the few interventions developed to improve medical care in Nigeria have generally been aimed at physicians (primarily) and nurses (secondarily) with minimal input from other key health care providers, and limited contributions from patients, caregivers, and the community itself. The Tailored Hospital-based Risk Reduction to Impede Vascular Events after Stroke (THRIVES) study is assessing the efficacy of a culturally sensitive multidimensional intervention for controlling blood pressure in recent stroke survivors. A key component of the intervention development process was the constitution of a project task force comprising various healthcare providers and administrators. This paper describes the unique experience in Sub-Saharan Africa of utilizing of an interdisciplinary Task force to facilitate the development of the multipronged behavioral intervention aimed at enhancing stroke outcomes in a low-middle income country.

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### 1. Introduction

The burden of non-communicable diseases (NCD) including cardiovascular risk factors is on the increase globally and higher in developing countries [1,2]. Stroke is the second leading cause of mortality worldwide [3]. From 1990 to 2010, the age-standardized incidence of stroke significantly decreased by 12% in high-income countries, and increased by 12% in low-income and middle-income countries [3]. In Africa, community-based studies revealed an age-standardized annual stroke incidence rate of up to 316 per 100,000 [4] and age-standardized prevalence rate of up to 981 per 100,000 [5].

Nigeria, the most populous black nation in the world is at present experiencing a strain on its economy and it stands the risk of further strain on its resources as a result of the increasing prevalence of stroke and other cardiovascular diseases due to epidemiological transition. In 1977, the report of a Stroke Registry in Ibadan, Nigeria calculated the incidence of stroke as 26/100,000 people [6]. More recently, an urban

community in Lagos measured an overall crude prevalence rate of 1.14/1000 while the 30-day case fatality rate is estimated to be as high as 40% [7,8].

Due to the significant public health problem that stroke causes, prevention is key to the reduction of the disease impact in countries with poor resources. Thus, the need to improve stroke preventative care is therefore particularly pressing in Nigeria where resources are few and the burden of stroke is disproportionately heavy. Prevention strategies depend on risk factor modification [9]. This is the focus of the Tailored Hospital-based Risk Reduction to Impede Vascular Events after Stroke (THRIVES) project. The overall aim of THRIVES is to determine whether a culturally-sensitive multipronged post-discharge intervention can significantly reduce blood pressure, enhance achievement of guideline recommended targets for risk factor control, and lower recurrent vascular events in Nigeria.

One of the strategies employed in meeting the objectives was the involvement of a diverse membership Task force to provide professional guidance and review procedural issues both prior to and during the intervention implementation process. The involvement of a task force can be essential when a project involves complex issues, or in situations

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when feasibility solutions may necessitate change. Drawing upon a varied selection of individuals often serves to enhance a project's likelihood of success as task force members bring together different skills and ideas, advocate for the project, discourage rumors regarding the project and incorporate solutions into their recommendations in anticipation of implementation challenges [10]. Such is the case in the THRIVES study, in which the input of task force members shed light on the adaptability clinical value of various protocols and intervention procedures, and thereby promoted "greasing the wheels" for implementation [10].

## 2. Methodology

The THRIVES study design and Phase 1 protocol have been previously published [11].

### 2.1. Study setting

The THRIVES project is housed among four hospital sites in southwest Nigeria. The hospitals were categorized by ownership and type of clientele. University College Hospital Ibadan, a public facility owned by government, is the main referral center for the care of stroke patients. The Blossom Center for NeuroRehabilitation is a private non-governmental neuro-rehabilitation center located in Ibadan. Its clientele consists of those who seek private services perceived to be devoid of the bureaucratic procedure of public facilities and able to pay for such services. The Federal Medical Center Abeokuta, like the University College Hospital, is a government owned tertiary public health facility and referral center. Finally, the Sacred Heart Hospital also located in Abeokuta is a community-level mission hospital with a patient population characterized by low-income levels and poor health seeking behaviors.

### 2.2. Selection of task force members

Task force members were actively sought by THRIVES research team members in Ibadan and Abeokuta sites using existing links with the communities. Criteria used in the selection included persons with a direct link to patients who have had a stroke, individuals who were culturally representative of the study communities, and persons involved in the management and care of patients with stroke. Other criteria considered for membership included: (a) knowledge and/or experience unique to the responsibility of the committee or task force to which they were being appointed; (b) availability for service and to complete potentially short-term time-sensitive tasks or decisions; (c) compliance with formal application requirements; and (d) willingness to participate in a collaborative manner and evidence of understanding community issues.

Proposed members initially received a letter indicating they had been nominated to join the THRIVES Task force team. The letter introduced the THRIVES study, outlined details of Task force membership, and the respective role that members would play in order to provide oversight functions. A total of 22 candidates (18 in Ibadan and 4 in Abeokuta) confirmed their interest and responded in the affirmative. The final determination of the THRIVES Task force committee consisted of physician investigators, stroke survivors, caregivers, statisticians, medical social workers, health educators, pharmacists, nurses, dietitians, physical therapists, record personnel, administrators, health economist, and policy makers represented by the Director Non-Communicable Disease of the State Ministry of Health, a telecommunication expert, religious leaders, media personnel, a community mobilizer and the President of the Nigerian Stroke Society.

### 2.3. Meeting schedule

The inaugural meeting of the THRIVES Task Force (TTF) was held in Ibadan on April 12, 2014. The objective of the meeting was for members to get to know each other, reiterate the role of participation, and set an

agenda for upcoming activities. At this meeting, the principal investigator presented a brief overview of the THRIVES project and a snapshot of the findings from the qualitative phase of the study was presented by the qualitative experts on the team. Topics covered included the report card, group clinic, patient support groups, action plan, family management strategies, as well as barriers and facilitators that influence adherence in stroke victims and beliefs of the patients and community towards stroke. A decision was reached on meeting frequency, venue and time. Members adhered to the agreed-upon schedule and all meeting proceedings were documented with written notes and audio recording.

### 2.4. Terms of reference

The TTF was charged with oversight of project function, the review of three-pronged intervention strategies, the creation of recommendations concerning local adaptations in order to facilitate implementation at each site and the assessment of the extent of implementation. Specifically, the THRIVES study employs three intervention strategies: the patient report card, the short message service and the video on stroke. Adapting these interventions was key since the THRIVES study aims to provide acceptable, patient-inclusive, and culturally sensitive interventions with the input of all stakeholders involved.

## 3. Findings

### 3.1. Outcome of review of the patient report card

An extensive review of the patient report card (PRC) was carried out. The TTF members translated the PRC into the local language, Yoruba. Several members expressed concerns over the mode of administration of the PRC considering the low literacy level of most patients. Reference was made to the fact that most THRIVES indices are not written in simple terms. This fear was addressed through the assisted administration of the PRC as it was designed to be a prompt discussion between the stroke patient and physician with the goal of designing action plans to improve stroke patients' adherence to recommended risk factor control. The physiotherapist on the team recommended that there should be a 'constraints column' on the PRC for patients to discuss barriers limiting their adherence to recommended stroke risk factor control strategies; these constraints could comprise a preference for traditional drugs and supplements as well as reasons related to spirituality, economic freedom and health system lapses.

On diet index, the policy maker asserted that difficulties may be encountered by stroke patients and caregivers when interpreting and acting on: '5 servings of fruits and vegetables, less than one third of daily intake attributable fat, 2 servings of fish per week means' (options 1, 3 & 4 of diet index on the PRC). It was suggested that this prescription be translated and transcribed into a statement that patients and caregivers could relate with on a cultural level.

A similar point was identified for the physical activity index. Given the poor health literacy levels, stroke patients may have difficulty relating with and interpreting what is meant by 'physical activity'. It was suggested that phrases such as taking a walk, walking to the car, bus could be used to explain the term.

One of the greatest observed challenges in patient care and management is poor record keeping. This was in relation to in whose hand the PRC would be kept. It was clarified that the PRC would reside in the stroke patients' case note with a copy handed to the stroke patient for recording his or her scores across each index during clinic visits. This is hoped would be a springboard for improved communication between the provider and the stroke patient as well as empowering the patient to demand for services. For ease of use, the TTF suggested a replication of patient's total score on the first page of the PRC, which would enable patients track their progress towards recommended risk factor control at a glance.

The TTF proposed a rearrangement of the indices such that diet and exercise at the top would be followed by blood pressure. This would emphasize the most applicable risk factors to stroke patients at the top of the PRC, while smoking would be presented towards the lower rung of the PRC as it is the least applicable. Similarly, it was also recommended that the back cover of the PRC should illustrate a history of records (such as 1st, 2nd, 3rd) as well as subsequent visits. This layout would assist, at a glance, in determining stroke patient's improvement or regression over time. Also it was suggested that patient names, diagnosis, date of previous stroke experience were included in the PRC. Finally, differentiation between categorical options with letters or numbers was brought up in order to promote ease of reference.

Further clarification was requested on the rationale behind the sub-category '*told to stop medications*' seen across 3 out of the 7 clinical indices (blood thinner, cholesterol and pressure) in the PRC. This was brought to the forefront in a bid to prevent confusion among the clinicians should they encounter such a situation during PRC administration. To address this, the TTF felt that an additional sub-category '*told to stop medication but continued*' was needed: 'This sub-category would apply to stroke patients who might continue certain medications against medical advice and would thereby receive negative scoring just like those who neglected their medication when they were told to continue. The TTF members also thought that prior to the PRC implementation, training sessions should be organized for selected clinicians who would administer the PRC.

With respect to exercise, the TTF determined it was important for exercise to be prescribed and emphasized as a therapy (just as for a medication), not simply as a recommendation. By leaving exercise to patient choice, this could affect the patient's perception of physical activity, adherence to the recommendation and ultimately have a detrimental impact on a stroke patient's health outcomes in the long-run.

Study investigators were requested to consider subsidizing the cost of laboratory screening for cholesterol, as it is one of the parameters on the PRC.

### 3.2. Short message service (SMS)

Non-attendance of hospital outpatient appointments has been reported as a major burden on healthcare systems [12,13]. Failure to show up on these follow-up visits greatly reduces the efficiency and effectiveness of the delivery of outpatient healthcare and causes substantial financial losses for healthcare systems [14] due to its suboptimal use of clinical and administrative staff [15]. Patients' reasons for not attending their outpatient appointments have been documented and include forgetting appointments and confusion over the date, time and location of the appointment [16]. These issues are very relevant to the care of stroke patients from their cognitive affectation. To address these, the THRIVES study included the short message service intervention as one of the three-pronged interventions to reduce vascular events post-stroke. The text messaging service has been found to be an effective way to not only remind patients of their appointments [17] but also to improve medication compliance [18].

The success of the short message service (SMS) intervention hinges on who sends the messages to patients after the clinic, the type of message sent (i.e., personalized versus generalized), the feedback mechanism, logistics for text message dissemination and the language of the text messages themselves. A review of these components became necessary because effective deployment of SMS technology is dependent on the right content, delivered at the right time within the right context.

#### 3.2.1. Who sends the message

The TTF proposed that the attending physicians occupy a better role to send text messages to patients after clinic while trained nurses are better positioned to provide follow-up to the patients through clinic reminder calls and post-clinic text messages. The rationale for this sequence is to reinforce adherence to physicians' recommendations and

to document patients' experiences (such as challenges in course of adherence) that need to be addressed in his/her next visit by the physician. In order to promote the sustainability of THRIVES, a consensus was established to adopt a process that would be scalable even in the absence of research coordinators. Therefore, doctors and nurses who would always be available would take responsibility to send the messages.

#### 3.2.2. Type of messages

The review on type of messages borrowed from the principle: '*don't write long messages, think carefully about how to get your message across in 160 characters.*' Prompted by this, TTF members helped ensure that the message content was suitable for the context of the THRIVES study. Discussion on type of message took into account the needs of each patient. After much deliberation, it was agreed that there would be personalized messages as well as generic messages for dissemination to the study subjects. The generic messages would target key behavioral outcomes such as adherence to medication and keeping a scheduled appointment while the personalized messages would target expected outcomes such as issues related to dietary choices, weight control and other behavioral and systemic issues as they relate to individual patients. These stereotyped individualized messages would be prescribed by physicians and disseminated by the trained nurses. Four categories of stereotyped messages were reviewed: 1) pre/post clinic appointment reminder text messages, 2) generalized messages on lifestyle modifications that apply to all stroke patients, 3) feedback messages based on the PRC score, and 4) personalized messages centered around adherence to medications to control blood pressure, blood glucose and blood cholesterol as well as blood thinners. Communication experts revised these messages along with senior physicians on the THRIVES team to ensure that the subjects could understand the messages specifically revised for individualization. The messages were pretested among patients after translation. All the text messages were within 160 characters in length, which is the maximum for most mobile phones in Nigeria.

#### 3.2.3. Personalized text message feedback

The feedback mechanism was important to carrying out an effective impact assessment. This was incorporated in the third category of the messages developed for feedback based on the PRC score for each visit. Such feedback would promote an interactive engagement with the study subjects to improve adherence and learn from mistakes. Feedback messages were tailored at providing comments to the study subjects based on the PRC score. Stereotyped messages included phrases such as: *Excellent! Keep up the good work; Very Good! Almost there; Slight room for improvement; Good. Moderate room for improvement; and Fair Considerable room for improvement.* This feedback is to be provided within 24 h. Ethical issues involved in the process of feedback were also discussed. The principle of confidentiality was emphasized.

#### 3.2.4. Logistics of text messaging

Logistical issues related to the text messaging looked at frequency of the text messaging, when to send the messages and allocation of human resource to manage the SMS activities. After weighing all the available options with sustainability in mind, a consensus was formed to keep a laptop, containing all clinical details in electronic format at each site. A one-way automated text messaging was adopted as compared to two-way text messaging, which has the potential to alter the cycle of engagement between the physician and subjects. In terms of when to send the messages, the TTF decided text messages should not be sent at inconvenient times such as late at night and early in the morning, when they are not likely to be read, appreciated and acted upon. Also, the TTF agreed that text messages could be sent once or twice before a subjects visit. A guide was therefore designed for the scheduling and delivery of the messages. Finally, the TTF members felt it was important to incorporate medication reminders.

### 3.2.5. Language of dissemination

Reviewing the language in the disseminated text messages is imperative as one of the overarching goal of THRIVES is to deliver an intervention that is culturally appropriate. Discussions arose as to whether the messages would be in the English language or Yoruba, the indigenous language of the study sites bearing in mind the subjects' proficiency level and linguistic preference. This would inform which language form would be used for each subject. This would be addressed through the standard procedure for translation of scripts from English to other languages. In this case, the English versions were translated to Yoruba and back-translated to English to ensure consistency.

### 3.3. Stroke video documentary

In order to address the need for improving the stroke literacy of the lay community and health workers [19], a multi-chapter, 90-min stroke documentary video was originally conceptualized and developed in the English language over a 24 month period between May 2010 and April 2012. The key message was to improve the knowledge and awareness of stroke among different segments of the society including men, women, children, health workers, people at risk of cardiovascular disease and stroke, stroke survivors and their families, religious leaders, teachers, lawmakers, the press, policy makers and political leaders. With the commencement of the THRIVES Study in 2013, the stroke documentary was further upgraded and adapted into an in-clinic stroke educational video, one of the intervention tools administered to the experimental group of the THRIVES Clinical Trial [20].

The review of the stroke documentary video took into consideration the content, delivery, duration, language and frequency of viewing session logistics.

#### 3.3.1. Content

The content of the video included the description of the stroke signs and symptoms, risk factors, cost of prevention, the patient report card, the text messaging intervention, physical activities, diet, the role of policy and an interview with a stroke patient to discuss life after stroke. The critique of the video upheld the existing content and highlighted the need to edit out repetitive epidemiological information and replace it with a brief statement on the epidemiology as well as contain clear simple messages that would be easily comprehended by the stroke patients. Additionally, it was suggested that the viewing session should be followed by a short question and answer session to improve clarity. The need to incorporate cultural relevance and creativity into the stroke video as well as the translation of the video into local languages to ensure comprehension was emphasized. To accomplish this, a plan was designed to involve popular actors and musicians that study subjects can relate with in order to drive home the messages.

#### 3.3.2. Delivery

The plan for video delivery specified the stroke documentary video would be played during pre-appointment waiting time to inform the patients about the stroke experience, why strokes occur, the use of the patient report card, the importance of the text messages, and how patients can track their progress in stroke prevention. The delivery mode would be interactive, as the public health nurses will facilitate it by providing a brief introduction to the viewing session and after the viewing would anchor question and answer session. The video would be replayed many times to reinforce salient contents.

#### 3.3.3. Duration and language

Further TTF member critiques led to suggesting that the duration of the video be reduced to a maximum of 15 min because of possible shortened attention span of stroke survivors who might have varying degrees of post-stroke cognitive dysfunction. In addition, to enhance the cultural relevance and full comprehension of the message of the stroke video,

the TTF members suggested that translations of the video in the local language be produced.

## 4. Impact of the THRIVES task force involvement

This involvement of the TTF in the development and implementation of culturally sensitive intervention had several impacts on the THRIVES project. A key impact of this involvement was the bridging of the gap between the research team and the beneficiaries who do not usually interact in similar interventions. It also fostered a working synergy between the Task force members and the research team. This is evident in the total overhaul of the three interventions. Also it reinforced a role reversal where the TTF assigns tasks to the research team (which previously was the other way around).

The assigned tasks the research team was requested to do were to:

- a) Redesign the constraint section of the PRC in a semi-structured way to enable elaborate capturing of constraints including those mentioned above and many more by the qualitative experts in the research team.
- b) Liaise with the dietician to simplify the diet variables for its adoption and inclusion on the PRC.
- c) Liaise with the physiotherapists to review and simplify the phrase 'physical activity'. Standardize the instructions relating to diet and physical activity by the dietician and physiotherapists. In addition, intensity, type and duration of physical activity would need to be incorporated into the physical activity index options as the options in the original version of the PRC were dominated by duration.
- d) Create and present a simple scoring procedure and column on the PRC as well as modalities for comparing patient target levels including percentiles, percentages and raw scores, with the help of a biostatistician.
- e) Repackage the text messages.
- f) Edit the video to reflect the suggestions and comments given.

The TTF involvement produced more effective and efficient interventions with indicators such as the tracking of progress to which the patients and their caregivers could relate. This ultimately would improve patient and caregiver self-efficacy to seek services and act as key decision makers in matters relating to their health and management of stroke.

This innovative approach provided a platform that would ensure ownership of the intervention by the beneficiaries, thereby improving compliance and adherence to management options in the card.

Involvement of the TTF in driving the intervention has supported that community members can provide technical advice, as well as intensive and rigorous intervention validations, thereby constituting a resource for effective health interventions that is often not recognized or used.

## 5. Conclusion

The involvement of TTF in the shaping of culturally sensitive intervention is a key strategy for improving the utilization and dissemination of the research interventions and findings. The THRIVES study demonstrated that following the community participation process involving relevant disciplines, staff, and key stakeholders, the contribution of the TTF from the beginning of the intervention can be the liaison between researchers, institutions, and those that benefit from the interventions. This dynamic begs to be explored further if research findings are to have a place in informing policy for a paradigm shift in stroke management and acceptance of interventions by the beneficiaries.

Enlisting the resources of the TTF to drive the intervention illustrated that the approach could improve the management of stroke patients in

an effective and efficient manner. This was especially true since the TTF members were appropriately selected with the community input, were willing to generously donate their time, knowledge and skill, maintained a high perception of self-efficacy to disseminate research information to the communities.

### Conflict of interest statement

Oyedunni S. Arulogun declares that she has no conflict of interest.  
Samantha Hurst declares that she has no conflict of interest.  
Mayowa O. Owolabi declares that he has no conflict of interest.  
Rufus O. Akinyemi declares that he has no conflict of interest.  
Ezinne Uvere, declares that she has no conflict of interest.  
Raelle Saulson declares that she has no conflict of interest.  
Bruce Ovbiagele, declares that he has no conflict of interest.

### Authors' contribution

OSA takes a leading role in writing and finalizing of the manuscript. MOO and BO conceptualized and supervised the THRIVES study, contributed to the study design, made substantial contributions to quality assurance.

All authors have made substantial contributions to conception and design of the study protocol. All authors have given final approval of the version to be published. All authors read and approved the final manuscript.

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