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# The Use of Qualitative Methods in Developing Implementation Strategies in Prevention Research for Stroke Survivors in Nigeria

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Implementing complex clinical interventions is a key challenge in many global regions. Local communities play a necessary role in enhancing feasibility and strengthening adaptive issues in the design and implementation of stroke interventions in developing countries. Drawing on the knowledge of physicians, patients, and caregivers, the authors employed qualitative methods as a phase 1 strategy to explore the challenges of stroke management and improve the adaptability and efficient delivery of a multimodal preventive intervention for secondary stroke disease

in Nigeria. A total of 22 individual interviews were conducted with healthcare professionals, as well as 12 focus groups with patients and caregivers. Findings revealed four operational domains to improve strategies for phase 2 implementation and intervention: (1) barriers influencing optimal adherence in stroke survivors, (2) patient health beliefs and perceptions of patient health beliefs by others, (3) adoption of the “patient report card,” and (4) “medical action plan” and family management strategies. *J Clin Hypertens (Greenwich)*. 2016;18:1015–1021. © 2016 Wiley Periodicals, Inc.

Stroke is the second leading cause of death worldwide, with low- and middle-income countries accounting for more than 85% of stroke mortality globally.<sup>1</sup> In Africa specifically, where access to primary care services and resources is generally limited and poorly funded, the burden of stroke has become a challenging public health issue.<sup>2–4</sup> The World Health Organization reported in 2005 that 6 million persons die from stroke each year, which accounts for 11 persons every minute.<sup>5</sup> Moreover, high morbidity rates are known to affect up to 50% of survivors who will experience long-term disability.<sup>6</sup> Given the role of hypertension as the leading modifiable risk factor for stroke, the high proportion of undiagnosed or uncontrolled hypertension especially among younger African adults is also cause for concern. A young and healthy adult workforce is the key to future prosperity in the region.<sup>7,8</sup>

While the overwhelming majority of strokes are eminently preventable, the primary care management of people with or at risk for stroke in many African countries and developing nations remains lacking.<sup>9</sup> This is largely the result of all available data being primarily hospital-based, combined with limited community awareness of hypertension and its prevention, treatment, and control.<sup>10,11</sup> The Nigerian healthcare system operates at a three-tier system: the primary, secondary, and tertiary levels. Primary healthcare has its sublevel at the

village and district levels. The secondary healthcare system is managed by the ministry of health at the state level, which is the first level for which specialty services are available at different divisions of the state. The tertiary level is essentially referral and specialized care.<sup>12</sup> Thus, in countries such as Nigeria with high stroke mortality rates, there is a critical need to assess the human experience of the disease at all healthcare system levels and identify prevailing challenges affecting best-quality care for everyone affected by stroke. Until now, qualitative studies have not been widely included as foundational to the implementation process for examining complex healthcare interventions in stroke-preventive care in sub-Saharan Africa.

The current study presents the empirical use of qualitative methods during phase 1 of the Tailored Hospital-Based Risk Reduction to Impede Vascular Events Study (THRIVES). The objectives of the study were twofold: (1) to gather information from physicians, stroke survivors, and their caregivers about the challenges of living with stroke disease; and (2) to capture feedback from this community to adapt the design of the THRIVES multimodal intervention for testing in a phase 2 randomized controlled clinical trial of secondary stroke risk reduction.

## METHODOLOGY

A detailed description of the THRIVES study design and phase 1 protocol has been previously published. Below we present a concise overview of the resulting qualitative methodology and procedures.

## Study Setting and Participant Enrollment

Interviews were conducted at four hospital sites in southwest Nigeria. Study sites included The University

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College Hospital Ibadan (governmental tertiary care referral center) and The Blossom Center for Neurorehabilitation (nongovernmental neurorehabilitation center) located in Ibadan, Nigeria, and The Federal Medical Center (tertiary care referral center), and Sacred Heart Hospital (community-level hospital) situated in Abeokuta, Nigeria.

All interview participants were “purposively” recruited and selected locally from the four study sites. Patients were identified from existing stroke registries and enrollment was guided by individuals currently receiving medical care who met the following criteria: adults (18 years and older), no aphasic condition, dementia (Community Screening Interview for Dementia  $\geq 20$ ), or disability (modified Rankin Scale  $< 3$ ). Caregivers were identified based on personal experiences of providing home care for stroke patients, regardless of whether the patients they served were enrolled in the patient focus groups or had been excluded based on severe cognitive impairments. Healthcare professionals were chosen by invitation from each of the study sites and included departmental representatives that were knowledgeable as either supervising or providing clinical care for stroke patients (ambulatory care, neurology, social work, nursing administration, diet and nutrition, information technology, primary care, speech therapy, physiotherapy, pharmacy, and clinical psychology).

### Data Collection

Phase 1 qualitative interviews for THRIVES study were carried out in January and February 2014. Prior to administering the phase 1 interviews, two pretest trials were conducted to practice with data collection materials and validate protocols for delivering the interview guide content and informed consent process.<sup>13</sup> Approval was obtained via the Ministry of Health in the Oyo State, Nigeria, to contact a separate state hospital facility to conduct a series of practice pretest interviews and thus avoid contamination of the main sampling pool of participants to be drawn for the randomized clinical trial.

All procedures for data collection and analysis for phase 1 of the project were reviewed and approved by institutional review boards in both Nigeria and the United States: the University of Ibadan, Ibadan, Nigeria, the Federal Medical Center, Abeokuta, Nigeria, the Medical University of South Carolina, Charleston, South Carolina, and the University of California, San Diego. Informed consent was secured from every participant, both in the pretest and in the main study, prior to the interview process.

A total of 22 individual interviews and six patient and caregiver focus groups were conducted. Each focus group included six to eight participants. Characteristics of all participants are listed in Table. Interview guides for both the individual interviews and focus group discussions were designed in a semistructured open-ended format<sup>14,15</sup> to increase potential for exploring

**TABLE.** Characteristics of Interview Participants

	Number
Hospital administrators	3
Healthcare providers	19
Average age of all health professionals, y	~43
Time in practice of all healthcare professionals	
1–5 y	7
6–10 y	7
11–19 y	4
30–31 y	7
Patients	44
Female	20
Male	24
Average age of all patients, y	~59
Caregivers	39
Female	24
Male	25
Average age of all caregivers, y	~40

participant viewpoints and personal experiences with the management of hypertension and other secondary stroke risk factors. Trained staff from the Faculty of Public Health at the University of Ibadan conducted study interviews in English and in Yoruba (the local language), and facilitated in the process of translation and transcription of interview texts. The average individual interview was 60 minutes, and 90 minutes for the focus group discussion.

### Qualitative Data Analysis

A directed content analysis approach<sup>16</sup> was employed to provide a more structured process and the interview transcripts were reviewed in the following manner. Two of the research investigators began an initial cycle of open coding based on preexisting theory within the interview guide to identify contextualized segments of data from the targeted questions.<sup>17</sup> Data that could not be assigned using the question-based coding schema were labeled as new and emerging coding categories or in some cases resulted in a subcategory of an already existing exemplar.<sup>18</sup> Disagreements in assignment or description of codes were resolved through discussion and consensus among the lead qualitative research investigators. A second and third cycle of reviewing the transcripts assisted in refining the number of overall codes by grouping them into descriptive categories<sup>19,20</sup> deemed appropriate for analysis.

All interview transcripts were uploaded by the first author, along with the codebook, to a web-based qualitative analysis program known as Dedoose (version 6.1.18, 2015).<sup>21</sup> Dedoose allows for a number of flexible features to facilitate organizing and sorting the volume of interview transcripts, as well excerpting quotes, and locating key words, phrases, and data responding to the original interview guide. In some instances, codes were eventually merged because of conceptual similarity or redundancy, while in other

examples codes were dropped from the schema because of lack of utility to the specific aims of the study.

## FINDINGS

Our results present four operational domains relating to factors that influence medical adherence for stroke survivors, physician perceptions of patient and caregiver behaviors and beliefs, challenges for implementation of primary intervention components, and finally the benefits for increased family management strategies:

- Barriers influencing optimal adherence in stroke survivors
- Patient health beliefs and perceptions of patient health beliefs by others
- Adoption of the patient report card
- Medical action plan and family management strategies

Each domain area is described with supporting quotes chosen on the basis of presenting a salient example of the opinions expressed by the interviewees. Quotes are verbatim unless indicated by authors' edits such as an ellipsis (...) to signal that text has been removed for the sake of brevity.

### Barriers Influencing Optimal Adherence in Stroke Survivors

The first and most widely discussed domain addressed barriers that influence optimal medical adherence in stroke victims and focused on four subareas of importance (medical, diet, exercise, smoking). Within each of the four subareas, a common challenge for participants was the issue of "cost." The family system in Africa is generally expected to provide security, self-worth, and a sense of belonging for every member of the family. It is an important locus of social roles and social relations. Studies have demonstrated that strong family and social support appear to have a positive impact on disease control and self-management behavior.<sup>22</sup>

The majority of health professionals stated that for many stroke patients the number of prescribed drugs and frequency of dosing was a key factor in discouraging patient compliance. A substantial number of healthcare providers relayed experiences about patients who acknowledged reducing and dividing the number of pills prescribed and periodically taking a "day off" in order to "stretch out the supply." Other providers noted that if poststroke recovery is slow and treatment duration is thus prolonged, many patients are forced to exhaust all financial resources including supplements from other family support. This is especially burdensome when patients are retirees. A primary care physician explained,

"When they run out of money, they don't take their drugs and sometimes they want to come to the hospital ... often they don't have the money for transportation. Some of them, in a month spend 10,000 Nigerian Naira (\$60 US) or 15,000 Nigerian Naira (\$90 US) on drugs alone."

As a potential solution, healthcare administrators recommended the need for greater interaction "between providers of the same patient who frequent different clinics" to find a single drug that can perform more than one function. This practice would replace the need for too many medications of the same type being prescribed by different providers.

Affordability and accessibility to healthy foods is also a concern among healthcare professionals and patients and caregivers. Food in Nigeria can be expensive based on seasonality and to require a patient to eat five servings of fruit a day was frequently described by providers as "too high an expectation." In addition, providers reported that most families do not have the extended financial means to buy healthy foods exclusively for only the stroke victim. Several patients described challenges with the frequent "intake of more western or junk diets" that were compromised by "excessive salt intake and starchy food that worsens my high blood pressure."

Moreover, some families shared not even owning a refrigerator to keep food and vegetables fresh. One of the physiotherapists stated that for some families, "it is considered a status symbol to buy only the 'finished' food items." Most patients, however, seemed well aware of the necessary diet restrictions for stroke prevention and discussed doing their best to "eat a balanced diet with fruits and vegetables, especially the low cost ones."

With regard to exercise adherence, providers suggested that many patients try to exercise in their home with the aid of a caregiver, physiotherapist, or in some cases on their own if safety is not a factor. One physician noted that many patients were "resistant to be back in the public environment after their stroke because of feeling shy knowing there is distortion in their body, and they are not totally stable and able to balance." Most physiotherapists, however, work mainly in the hospital. Some stroke patients are forced to rely on family members or caregivers to bring them to the hospital for therapy because of paralysis or difficulty in walking. In contrast, patients who have recovered more quickly and are independently back in the work force claim that they do not have the time to exercise 3 days a week and "cannot afford to leave their job during the day to meet with a physiotherapist." Reported resistance to exercise was also based on the extreme expense of exercise therapy. For example, according to one of the neurologists, "The cost would be 15,000 Nigerian Naira (\$90 US) for one session and for those that go outside of the hospital on their own, some people reportedly pay 25,000 to 30,000 Nigerian Naira (\$150–\$180 US) per exercise therapy session. The duration of a session might be only 30 minutes to 1 hour."

Several healthcare professionals suggested that recovery must begin to target physical "effort" rather than physical "activity" to achieve exercise adherence.

In discussing the problem of smoking behaviors, healthcare professionals emphasized the importance of

patients abstaining from tobacco and also for family members and caregivers who may also be contributing to secondhand smoke in the home. Several physicians also pointed out the additional dangers of “combustibles from our cars and pollutants in the environment with no laws regulating them.” Most providers agreed that smoking is challenging to overcome especially when the patient was a habitual smoker prior to the stroke event. Many providers advocated for “greater education and peer support” on smoking activity, while others suggested that the government consider a ban on selling all forms of tobacco, especially given that many stroke patients also report using snuff regularly.

### Patient Health Beliefs and Perceptions of Patient Health Beliefs by Others

The second domain focused on perceptions of patient health beliefs by healthcare professionals and presented an interesting contradiction to actual patient and caregiver discussions regarding patient autonomy, and the explanatory model used by the families<sup>23,24</sup> to describe causes of patient health predicaments.

A majority of healthcare professionals shared stories referencing patients who use metaphysical powers and local herbalists to find cures for their physical health symptoms. Like in many African countries, patients may underutilize biomedical health services and maintain a different understanding of various ailments due to limited knowledge of western medical care, poverty, and remnant beliefs in the supernatural causation of diseases.<sup>25</sup> One clinical psychologist shared a story about a woman who was convinced her stroke was caused by not following God’s instructions:

“It took me the whole 6 months to work with a woman and explain to her every time that her symptoms were not the result of a curse set upon her. I think Africans generally, not just Yorubas attribute our illness to God. Anything we can’t explain, we justify quickly and say ‘this is God.’”

Several physicians explained that aside from taking western medicine, many Yoruba families attribute a stroke event to a “spirit from another world” and most patients will continue to look out for herbal medicine and spiritual aides to combat their disease. A physiotherapist described a patient, who confided to him,

“I am a Yoruba man and if they say that a witch cries yesterday and a child dies this morning, who would not believe that it is the witch that cries and causes the child to die.” “In our culture,” the physiotherapist continued, “people prefer spending money on the burial ceremony, on big clothes because we believe big clothes means big man. So if we can break away from that system, the level of compliance will increase.”

In contrast to the expectations of our health professionals, our sample of patients and caregivers spoke

instead about prioritizing clinical instructions they receive from their medical doctors. While many patients talked about the significance of “God” and “prayer” in their life, they repeatedly spoke about following biomedical guidance provided by their doctors. “One should obey all the rules and suggestions given so that one can be in total health,” said one patient. “We must take our drugs regularly” and “eat the right things we’ve been directed to.” Several hypertensive and diabetic patients cautiously described the hazards of “slothfulness” and “negligent attitudes” toward health and warned about the dangers of “excessive thinking.” “Whenever we are supposed to rest, we do not rest,” said one patient. A caregiver offered, “Our doctor said we must not bother our minds with anything. We must not get angry too much and we must not undergo too much stress or we will not have the right mind to support the patient.”

### Adoption of the Patient Report Card

The third domain addressed the primary component of the poststroke intervention, known as the patient report card, which was well received in introduction by all participants. The card is to be used by physicians during hospital visits to record current patient status and progress toward optimal control of stroke risk factor recommendations. Most providers believed the patient report card could greatly facilitate acquiring health histories and also serve to be valuable quality improvement tool. Others viewed the patient report card as a way to build rapport with patients and families and to easily pinpoint the changes in health behaviors that are required in the management of their disease. One of the hospital administrators went so far as to suggest the potential for offering a free drug sample or incentive that could be rewarded just to encourage the patient and make them feel happy for achieving a high score on the report card. Another recommendation offered by a clinical psychologist urged the inclusion of a section in the report card for the patient to self-assess their engagement in the treatment and how well they feel they are complying with the goals of the card.

This will make the patient feel that they are doing something about their health. This gives patients a level of control that they are part of this process and not simply drawn into the plan but actively involved in getting better.

Nearly all providers felt that the implementation of the card should begin with robust training for all healthcare providers explaining how the card is to be administered and discussed with the patient, family, and caregiver so that it will be integrated and practiced in a standardized manner in each department at all site locations.

Conversely, healthcare providers were also quick to express hesitation over the prospects of having to

manage an additional assignment in an already over-laden patient schedule.

“We already sometimes see about 250 patients daily in the ambulatory care clinic and we don’t have nearly enough staff. It is going to be a great challenge to use the card because of this, unless we can request for more staff.”

One of the hospital administrators cautioned that economic resources for the production of the report card might be more challenging in some locations than others. A clinical psychologist advised, “If you look at it, the benefit will outweigh the (economic) burden that it would be.”

Patients and caregivers alike responded with great interest in the patient report card. Many expressed “relief” in being offered a documented list of items to improve upon rather than to try and remember the verbal advice given during a healthcare provider visit. “I will bring it because of the drugs written on it, I will take my drugs regularly, I will obey whatever instruction the doctor writes on it,” commented one patient. “It is just like a performance evaluation sheet. It helps our caregivers, doctors, and physiotherapist to know what is left for them to do and makes it easy to monitor the health condition of our body.”

### Medical Action Plan and Family Management Strategies

The fourth and final domain focused on the critical need for patient and family education on the cause of stroke, effects of the drugs, and target and goals of a successful recovery plan. One provider described the necessity for an action plan this way:

“Too often when the patients come to the hospital, they see the doctors and buy their drugs, but the doctors hardly have time to counsel them because of the large number of patients that they have to attend to. No time and staff strength is low in the hospital. Patients and their families can leave clinic feeling ill-informed.”

Providers across the board asserted that “family members and caregivers of stroke patients must be directly involved in treatment management from the very beginning to ensure that patients after discharge from the hospital will keep their upcoming clinic appointments.” “It is part of our Nigerian culture to take care of one another when you know you are sick,” a speech therapist offered. “If the patient is aware of the action plan and then the family is there to give the care and moral support, then definitely the two approaches will work together hand in hand.”

Although all providers agreed that having an action plan and developed family management strategies would enhance patient recovery, providers as well as caregivers worry about the substantial amount of effort and time needed in properly educating family members about the details of stroke management. Many of the families also

expressed concern regarding the time expected from them for transporting patients to fixed appointments with healthcare clinicians. Providers also questioned the ability to provide consultation above the amount of time that is already spent between a physician and patient. When asked about the potential substitution of using nurses to teach the action plans and family-management strategies one provider eagerly replied,

“Sometimes especially on the wards... nurses are there 24/7 with the patients, they interact, they relate more with the nurses than the doctors. Doctors come, do ward round, go out, go to the clinics. So if nurses are involved, they will impact a lot of knowledge... and they know these patients one-on-one and discuss one-on-one; you will be surprised how much patients are willing to discuss if they have a listening ear, so it will be a nice idea.”

### LIMITATIONS AND STRENGTHS OF THE STUDY

Limitations of this study acknowledge that information produced from our interview data is most relevant to the communities and medical institutions from which we sampled and therefore may not be representative of medical care conditions for other stroke survivors in other regions of Nigeria or the continent of Africa as a whole. In addition, because our sample of patients and caregivers were individuals in current or past care for vascular risk management, we recognize they may be more exposed and informed in their health beliefs and medical knowledge than the general population who do not typically make use of medical care until crisis conditions arise.

We believe the findings demonstrate support for the practical benefits of using qualitative research to identify, explore, and characterize many of the contextual factors that influence the process and potential effectiveness of an intervention, not to mention the related patient experience with respect to healthcare provision and improved access to medical care.

### CONCLUSIONS

In this article, we describe a number of findings that we believe substantiate the use of qualitative methods for researchers who are engaged in hypertension and stroke prevention research in an international setting. The use of qualitative methods to understand stroke patient experiences and affect implementation and intervention development in secondary stroke care prevention research has not previously been widely employed or reported in sub-Saharan Africa until now. Our analysis of 34 interviews (22 individual interviews and 12 focus groups) identified four operational domains that speak to the need for greater assistance, education, and support of stroke patient and caregiver needs, as well as issues influencing medical provision and uptake of secondary prevention methods to be tested in our intervention study. We believe our findings highly

suggest the value of establishing independent health support groups for stroke victims and their caregivers to share knowledge on the importance of medication adherence, diet modification, smoking and alcohol abstinence, and self-management of exercise activity. The findings also point out potential intervention and implementation modifications for consideration during the phase 2 clinical trial of the multimodal THRIVES preventive intervention for stroke survivors.

Another particular strength in our findings results from identifying potential differences in perception about health beliefs and attitudes held by patients and caregivers in contrast to their healthcare providers. These findings also reveal insightful transactional input for patient and provider relationships and the important role of the physician in health promotion and more patient-centered care that has been noted in the United States.<sup>26,27</sup> While patients and their caregivers clearly depend on their physicians for guidance and all decision-making, our findings submit that most patients desired to be more independent and requested increased opportunities to “negotiate” with medical staff. Patients and caregivers frequently stated the appeal for greater flexibility in personal goal setting (using the patient report card and action plan). Many were also eager to contribute their perceptions to the summary report of progress with a rating of their perceived provider engagement.

Lessons learned from the study call attention to the need for strengthening preintervention provider training on administrative elements of conducting and managing the THRIVES stroke prevention tools for each patient. This includes the concerns of clinical time management and task-shifting by healthcare providers. Even with the added responsibility burden, the majority of healthcare professionals remained supportive of the intervention patient report card as a means to document health history and improve rapport and information exchange with patients and their caregivers.

Moreover, results from the phase 1 interviews encouraged the development of a THRIVES Task Force of local and regional Nigerian medical professionals to further explore the need for any additional modifications and adaptations to the study model to increase the feasibility and success of the phase 2 clinical study. In addition to the qualitative data collected during phase 1, we are looking to include a future postintervention qualitative study for the purpose of reflecting on patient experience at different milestones of the study timeline and physical improvements noted by patients and caregivers at the conclusion of the clinical trial study period.

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