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High tech and high touch: Recruitment strategies for enrolling African American stroke survivors in Community Based Intervention under Nurse Guidance after stroke (CINGS) trial☆

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ABSTRACT

Background: Substantial effort has been undertaken to improve the recruitment and retention of participants in stroke trials. African Americans are disproportionately under-represented in stroke clinical trials as well as clinical trials for other chronic disease conditions. To circumvent barriers to recruitment, clinical trial recruitment strategies used to recruit African Americans have focused on different aspects of community engagement.
Purpose: This study examined a community-engaged, multi-phased tailored approach to recruiting African Americans with stroke. The recruitment approach described was designed to support the Community Based Intervention under Nurse Guidance after Stroke (CINGS) trial, part of the Wide Spectrum Investigation of Stroke Outcome Disparities on Multiple Levels (WISSDOM) Center established to explore stroke disparities.
Methods: A multiple-phased recruitment approach was undertaken and involved a recruitment planning phase and a recruitment phase. The recruitment planning phase involved the use of focus groups designed to explore barriers and facilitators of stroke recovery. The active recruitment phase included multiple strategies with ongoing evaluation.
Results: Information gained from focus groups offered insights into strategies critical to recruiting African Americans with stroke for behavioral research during the early recovery period. Strategies to enhance the identification of and recruitment of potential participants included use of: a) a hospital system stroke database, b) system-wide friendly visits/warm handoff approaches, c) electronic health record, d) associated external sites and e) protocol adjustments.
Conclusions: Developing tailored approaches to curtail barriers to research participation is critical for increasing the probability of reaching African American study participant recruitment and retention goals. Research teams may require training in community-engagement research strategies essential for obtaining achieving target recruitment goals.

1. Introduction

To date substantial effort has been undertaken to improve the recruitment and retention of participants in stroke trials [1–3]. A comprehensive review of recruitment approaches completed by Berge and colleagues [1] highlighted a complexity of barriers to recruitment

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which include: a) investigator overload, b) lack of clear research agenda and research infrastructure, c) narrow inclusion criteria and d) complex and lengthy procedures that limit some stroke survivor's ability to provide informed consent. Berge and colleagues [1] also noted strategies known to improve the enrollment process such as: a) regular contacts with eligible study participants, b) simple informed consenting procedures, c) dedicated and experienced research staff and d) adequate project research funding. Conclusions drawn from Berge et al. [1] suggest that successful recruitment efforts are oftentimes limited by multiple factors related to: a) the stroke survivor such as limited knowledge of research, b) the investigator such as limited research experience or time devoted to the project and c) health systems that have limited infrastructure to complete the research and manage complex regulations associated with stroke trials.

Substantial unique challenges also exist in the recruitment of racial-ethnic minorities for stroke-related research. Inclusion of racial-ethnic minorities is critical to understanding the negative racial-ethnic disparities that currently exist in stroke outcomes [4]. African Americans have been substantially under-represented in stroke clinical trials as well as clinical trials for other chronic disease conditions where African Americans suffer a great a greater burden compared to their white counterparts [2,5,6]. Multiple factors contribute to low clinical research enrollment among African Americans including higher levels of distrust for healthcare providers compared to other populations, lack of awareness of clinical research, poor patient-provider communication and exclusion based on severity of the disease condition [6–10]. Unfortunately, this lack of participation in stroke-related research limits the ability of African Americans with stroke to achieve equity in outcomes while also decreasing the burden of the condition [11].

To circumvent barriers to recruitment, clinical trial recruitment strategies used to recruit African Americans have focused on different aspects of community engagement. For example, the church represents a trusted institution in African American communities across the US. Clergy members within the church serve as "gatekeepers" to and within the community by virtue of established trust with parishioners [12]. Over the past decade, the medical research community has focused on developing partnerships with clergy who actively advocate and collaborate for clinical research participation [12].

Some evidence suggest that African American millennial church attendance falls below that of their white counterparts [13]. Moreover, amongst older church goers, church attendance has rapidly declined over the past decade. Thus, a high reliance on the church as a primary source of recruitment may prove problematic in the future. Consequently, novel strategies may be needed that consider recruitment issues in totality and are designed to use multi-level approaches that extend even beyond the African American community. The current literature related to the recruitment of African Americans for clinical studies suggests that the development of tailored approaches which curtail barriers to research participation [14,15] is critical for increasing the probability of reaching African American study participant recruitment goals.

Known barriers to research participation that are not specific to stroke but have clear implications include: a) fear and mistrust of research due to lack of information and knowledge of historical injustices [16], b) power differences between patient/participant and health provider/researcher that reflect unequal authority [17], c) researchers poor understanding of African Americans in general. More importantly, when the aforementioned barriers are strategically addressed using tailored recruitment approaches are utilized, levels of research participation among African Americans are higher [14,18].

In this paper we describe a tailored and multilevel approach to recruiting African Americans with stroke. The recruitment approach described here was designed to support the Community Based Intervention under Nurse Guidance after Stroke (CINGS) project which is a mixed methods clinical trial designed to explore racial differences in stroke recovery patterns between African Americans and Whites. The CINGS trial is part of the Wide Spectrum Investigation of Stroke Outcome Disparities on Multiple Levels (WISSDOM) Center which was developed to examine stroke recovery by bringing together scientists from multiple disciplines such as nursing, medicine, regenerative medicine and rehabilitation [20]. The WISSDOM Center is organized around three unique but collaborative basic science, clinical science and population science projects designed to explore stroke disparities.

2. Methods

2.1. Recruitment planning phase

2.1.1. Setting and sample

A purposive sample of individuals from 4 neighboring counties in the lowcountry coastal region of South Carolina (Charleston, Berkeley Dorchester, and Georgetown) were recruited from existing grassroots patient advocacy groups, community advisory boards, and the Medical University of South Carolina (MUSC) stroke center referral network. The goal was to obtain a representation of: Black/African American adults post stroke; family members and informal caregivers; and professionals that work with adult stroke survivors in either healthcare or community milieu. The key informant interview participants (n = 14) included stroke survivors, family members/informal caregivers, and healthcare representatives from medicine, nursing, rehabilitation specialist, public health practitioners and other allied health professions with expertise in stroke care. The focus group participants (n = 43) included 20 stroke survivors, 19 family members/informal caregivers and 4 community advisory board members representing faith-based, social services, and community advocacy organizations. Inclusion criteria included: African American adults with a previous diagnosis of an ischemic stroke within the last 5 years; adult family member/informal caregivers of a stroke survivor and reside in either Charleston, Berkeley, Dorchester, or Georgetown counties. Individuals were excluded if they could not communicate in English language. Interviews and focus groups were held in various locations across the 4 neighboring counties to facilitate access from rural areas and to encourage participation from those who preferred not to travel to the academic medical center area. This study was approved by the MUSC Institutional Review Board.

2.2. Recruitment phase

2.2.1. Eligible sample

Stroke survivors residing in the Charleston, SC and surrounding counties were potentially eligible to participate in the CINGS trial. The recruitment area included Charleston, Dorchester, Berkeley, Colleton and Georgetown counties which is a region of over 2500 square miles and has an average population density of 260/sq. mi [19]. Georgetown and Colleton counties were included because of their location as rural boundary counties within the tri-county area. Eligible participates were primarily patients admitted to the Medical University of South Carolina (MUSC) Medical Center Comprehensive Stroke for stroke care.

2.3. Study inclusion/exclusion criteria

Inclusion criteria: diagnosis of initial ischemic stroke; ischemic stroke of mild-moderate stroke severity measured by the NIH Stroke scale (5–15 and some level of motor deficit but not complete paralysis); ages 30-75 years-of-age, resident of Charleston, Berkeley, Dorchester, Colleton, and Georgetown counties in South Carolina; able to communicate in English; and discharged to home care within 30 days. Participants could also have aphasia if no more than mild form and depression if being treated.

Exclusion criteria: Patients with acute or critical or surgical illness expected to require admission or currently in ICU; hemorrhagic stroke; planned discharge to skilled health care facility; terminal illness with life expectancy <1 year; undergoing transplant surgery; substance addiction

(alcohol abuse or illicit drugs use); a prisoner at the time of stroke; pregnant at the time of stroke; unable to commit to the study protocol including the outpatient follow-up at 3, 6, and 12 months; unable or unwilling to provide informed consent in English.

3. Approaches to recruitment

Recruitment of participants for CINGS involved both a formative "recruitment planning phase" and a "recruitment phase". The recruitment planning phase involved the use of key informant interviews (KII), focus groups and feedback from the study's Community Advisory Board (CAB) to: 1) explore barriers and facilitators of stroke recovery and 2) identify potential challenges, opportunities, and acceptable approaches for recruiting African American stroke survivors into a clinical trial. These examinations of stroke recovery emphasized patient, provider and healthcare system perspectives about the early stroke treatment and recovery process. Information gained from the interviews and focus groups offered important insights into strategies critical to recruiting AAs with stroke for behavioral research during the early recovery period. The recruitment phase emphasized the use of a) a hospital system stroke database, b) system-wide friendly visits/warm handoff approaches, c) use of the electronic health record, d) associated external sites and e) protocol adjustments. To offer the most complete overview of the recruitment planning phase and recruitment we detail each strategy, offer an assessment of strengths and weaknesses of each strategy and provide a brief summary of lessons learned.

3.1. Recruitment planning phase

Strategy (Utilization of Key Informant and Focus Group Information): The interviews and focus groups provided detailed information about the process of care for stroke and how that process creates barriers and facilitators to recruitment of stroke survivors for behavioral research.

The primary goals and objectives of the focus groups were to explore perceived barriers and facilitators to stroke recovery, expectations for recovery, and potential targets or strategies to maximize stroke recovery and research participation among Black/African American stroke survivors.

Findings: Key findings of the focus group interviews showed that barriers and facilitators of stroke recovery emerge from the beliefs, attitudes, and actions of the patient with stroke, their family members/caregivers, their stroke care providers, and the healthcare systems where they receive care [21]. The process of care for stroke inherently involves a high number of individuals involved in stroke care. Stroke survivors report constant interaction with healthcare and community resource providers including physicians, nurses, therapists that worked collaboratively throughout their hospital stay to help them reach stability and subsequently, hospital discharge. The number of healthcare providers can be overwhelming and stroke survivors oftentimes become disoriented and question the specific role of each provider in their healthcare which in turn creates some level of trepidation when approached about research participation. Many stroke survivors and families wonder if this "new person", who may be the research coordinator, if they are part of the healthcare team and thus there to provide 'medical' treatment. More importantly, does this "new person" have their best interest in mind, should this person, who may or may not be part of their stroke care, even be approaching them about research which has no direct bearing on their stroke recovery. For others, there may be a perception that research has negative consequences. For example, one patient noted "a neighbor had participated in previous research and died so she wouldn't be interested in participated in research". The patient declined despite hearing an overview of the research and the minimal risk of involvement. For others, it's simply that research is of low priority and even investing the time in hearing about the project during hospitalization, is not worthwhile at this early/acute stage in their recovery.

Lessons learned: Hospitalization for stroke is at best "chaotic" and adds to the feeling of being overwhelmed in the eyes of stroke survivors. Understanding the constant flow of people and information is critical to determine the correct timing and approach for recruitment. Many stroke survivors are experiencing cognitive, motor and sensory loss which limits their ability to process information carefully and correctly. Consequently, some are not at the point in their recovery to make decisions about research which, in the perceptions of many, has no bearing on their recovery. Some are not at the point of "readiness to take on one more thing" particularly when the explanation of the research may not have clear "meaningfulness" to the stroke survivor or to their care partner or immediate support system.

3.1.1. Recruitment phase

A. Strategy (Stroke Database/Stroke Lists): An IRB approved hospital system database and stroke list of patients admitted to MUSC with a diagnosis of stroke was utilized as part of the recruitment process.

Findings: Stroke databases offer great insights into the number of patients admitted to the healthcare system with a diagnosis of stroke. The database associated with this project was administered by a team of independent healthcare providers, coordinators and researchers not associated with the CINGS project. Thus, CINGS personnel required a second level of permissions to access this information. Throughout the duration of the CINGS trial, multiple research teams within the healthcare institution were attempting to recruit stroke patients from the same stroke database. This resulted in research staff members across the hospital enterprise approaching the same stroke patient about multiple clinical research project opportunities. Stroke survivors often qualified for multiple research projects but found it challenging to determine the research project priority due to information overload and a lack of clarity regarding the benefit of participation. Another challenge with database-based recruitment efforts are personnel limitations. Due to high database management personnel attrition rates and administrative personnel with part-time employment, hospital databases became vulnerable to inaccurate or delayed information input. This in turn impacted database-focused recruitment efforts.

Stroke lists generated from hospital discharge and outpatient appointment schedules offer opportunities to identify stroke survivors who may be eligible for research. These lists can be generated from appointment schedules across clinical departments including neurology, primary care, and internal medicine. The unique generation of stroke patient lists from "work plans" rather than EHRs provides a rich data source that is dependent upon the healthcare provider/discipline and unit scheduled to see the patient. Still, one caveat is the high variability that may exist among units regarding how this information processed and disseminated.

Lessons learned: Stroke databases are only as good as the dedicated personnel and processes established and maintained for accuracy and efficiency of information. Stroke databases have limitations and may be hard to access. Stroke databases are excellent for the identification of stroke survivors who have experienced excellent recovery and/or are absent of cognitive or communication issues. Those individuals early in the recovery process are oftentimes overwhelmed by the high number of contacts from individuals accessing the database for research participants. Investigators should be cognizant of the limitations of these databases and the potential impact patient contact has on the same individuals they are hoping to recruit. To help mitigate patients from being overburdened with research participation request, database information fields should include dates of contact and enrollment status (declined, pending, or active). Additionally, health systems should consider improving coordination across studies by identifying database gatekeepers. These strategies can assist in ensuring investigators and research coordinators awareness about the number of times a patient has been approached to participate in research studies. Ultimately, establishing these strategies and procedures can protect patients from

excessive contact for research participation.

Similarly, stroke lists can be utilized for research recruitment purposes however, their primary purpose is clinical work related. Recruitment via stroke lists is limited by time limits of clinic visit appointment, appointment cancellations and other factors related to the clinical practice environment. Finally, stroke list change frequently and require the research team to check/recheck daily for changes in scheduling.

B. Strategy (System-wide warm handoffs): A key approach to recruitment of the CINGS Trial was the use of "warm handoffs". Warm handoffs are an in-person referral to another healthcare provider and are believed to build trust and improve attendance to subsequent appointments [22,23]. Warm handoff contacts occur between hospital personnel (unit coordinators, nurses, etc.) and CINGS study personnel (study coordinators, nurses, physicians, fellows) to facilitate initial contact. Similarly, warm handoffs can occur between study personnel and other units when stroke survivors or their families have relevant stroke-related questions rather than questions regarding research study participation. Because CINGS personnel consist of healthcare providers, they often helped stroke survivors make direct contact for other issues unrelated to the study rather than simply providing a name and number for them to make their own contact. Warm handoffs and "friendly visits" by CINGS' personnel offered an opportunity to carefully evaluate the responses of stroke survivors who either responded "maybe" or "not right now" when asked to participate in the CINGS trial. The friendly visits were characterized by a) offering a safe place to discuss stroke related issues and b) the study personnel not making any assumptions about the stroke survivor or their family while at the same time building the rapport for future recruitment opportunities. CINGS friendly visits offered study personnel evidence that a "not right now" may not be permanent "no" and may indeed simply indicate an opportunity to recruit later. For patients who did not fully decline i.e., indicated "not right now", study personnel would ask if the patient would like to be recontacted at a later time. However, if a patient stated "no" or otherwise fully declined, no further contact was made.

Findings: Warm handoffs and friendly visits facilitate an increase in recruitment over the longer term, even though initial contacts may not result in immediate enrollment. These visits offer an opportunity for the study personnel to "stay in contact with the stroke survivor during their journey", "assist and support" them through the healthcare system and "build relationships" critical to study enrollment at a later date. There is evidence that this increased amount of time devoted to the potential participant is critical to building feelings of altruism as a motivation for study participation [14,24]. These visits also have an impact on reducing study drop-outs as individuals with established relationships with the study team were less likely to drop out after study enrollment. The friendly visits also offered the study team an opportunity to refine the enrollment approach over time by utilizing learned information to better target, communicate and build relationships with potential study participants.

Lessons Learned: Stroke survivors and families see the healthcare system as one uniform entity consisting of healthcare personnel and researchers. Consequently, it is important for study personnel to distinguish themselves and study from healthcare providers and the system as a whole. Although the study is completed within the healthcare system, it is part of a complexity of people (healthcare providers), clinics and hospital units where the unique divisions (medical vs research) are not clear. Consequently, the goals and objectives of the many individuals engaging the stroke survivor and their families are not clear. When interactions lack clarity, the likelihood of research enrollment and participation will decline.

C. Strategy (Use of Electronic Health Record [EHR]): Electronic health record usage has offered substantial advantages for initial screening and recruitment of individuals with a specific diagnosis such as stroke in clinical trials. Identification of potential participants is possible by IRB approved strategies to collect ICD-9/10 codes that are generated during the admissions process. Such approaches are efficient for cost effective identification of individuals with stroke [25–27].

Findings: Over a 2.5-year period, 4461 individuals identified through the EHR for potential participation in the CINGS trial. Among those 4200 (94%) were deemed ineligible for participating in CINGS with the most common reasons being: residency or residing outside of the defined recruitment area (32.9%), ages outside of the target age range (28.6%), having diagnoses other than stroke (18.5%) and having a type of stroke that did not meet inclusion criteria (10.7%) [28].

Lessons Learned: When utilizing the EHR as a primary source, many individuals who appear to meet inclusion criteria will ultimately be excluded. The EHR can generate reports for research purposes based on ICD-9/10 code diagnoses. However, these reports frequently overestimate the true number of individuals available. Such processes cannot always account for every inclusion/exclusion criterion and offer a broad stroke of potential participants. An interesting finding was 15% of those identified with a suspected stroke were later determined to not to have a final diagnosis of stroke [28]. This may be explained by patients upon arrival to the emergency department may receive a preliminary diagnosis of "potential stroke" based on symptomology, but this is later ruled out and determined to be a "stroke mimic" which accounts for more than a third of all emergency department admissions [29]. The limitations of the EHR should be carefully considered when estimating the recruitment pool and likelihood of enrolling stroke survivors in research studies [28].

D. Strategy (Use of External Research Sites): The primary research site of CINGS was MUSC in Charleston, SC. Charleston, SC is within 23 miles of both the Dorchester and Berkeley County sites. Whereas many individuals in the region who experience a stroke come to MUSC for their primary stroke care, they oftentimes return to their communities for post-stroke primary care even those who return to MUSC for stroke follow-up care. Thus, sites in Berkeley (17 miles) and Dorchester (23 miles) counties serve as excellent potential recruitment sites given their close proximity to the MUSC campus.

Findings: Recruitment of stroke survivors at external sites to the MUSC campus pose novel challenges. We refer to them as "external sites" because they are external to the main campus, yet the research organization would traditionally be considered "multi-site. We observed that the external sites had different cultures and work-flow patterns/strategies. Some were in line with the primary research site approaches and others slowed or delayed recruitment.

Lessons Learned: Recruitment of research participants at external sites requires a full consideration of factors that are beyond the control of the research study team and the primary healthcare system research site. External sites can experience attrition in study-designated personnel that has a greater impact on recruitment and retention compared to personnel changes at the primary site since primary sites implement succession plans where personnel are cross-trained and cultivated to fulfill the needs of the study upon study personnel attrition.

Changes in external site personnel often require re-establishing cohesion between primary and external sites. Moreover, external personnel must undergo training to understand efficient processes for recruitment/retention which becomes even more challenging when they are required to simultaneously complete training for their primary duties at the external site. External sites are also less likely to have the same volume of stroke survivors as the primary site, thereby limiting the day-to-day focus on the study. Collectively, additional onboarding and training time at the external site can delay identification and enrollment of individuals for the study.

Consideration must be given to the culture of the external site which may not as research focused as the primary site. Differences in culture may contribute to biases about research participants and impact assessments of research as a valued activity. System culture has a direct impact on recruitment efforts. The team learned that whether at the onset or during changes in research personnel, the team should approach the external site with a focus on determining how the external site "would like to do this" in the context of what has to be accomplished

rather than a heavy handed "this is how you should do this" approach. Ultimately, the burden was on the research team at the primary site to sensitively establish process that worked well for all sites.

E. *Strategy (Protocol Adjustments):* The CINGS project is one of three projects under the umbrella of the WISSDOM Center. A WISSDOM protocol adjustment was made to facilitate more fluid enrollment into the CINGS project.

Findings: Initially, CINGS and the WISSDOM clinical science project operated under the same inclusion/exclusion criteria because both involved human subjects. The clinical science project required a more stringent brain-related criteria to accommodate the diffusion tensor (DT) magnetic resonance imaging (MRI) necessary for mapping a novel structural human brain connectome [30]. The CINGS project did not require the same requirements for inclusion. Inclusion criteria were adjusted to accommodate individuals who were appropriate to enroll in CINGS that would have been excluded otherwise based on the WISSDOM clinical science project [31].

Lessons Learned: Weekly team meetings are needed to understand recruitment issues when multiple projects are enrolling stroke survivors under one stroke research center. The meetings require consistent participation between study coordinators, investigators and any other team members to understand the impact of global inclusion/exclusion criteria on all projects. It is during these team meetings that the complete team can address a diversity of issues and topics that ultimately improve the cohesiveness of the team. For example, not all individuals participating in a grant designed to study disparities related issues are knowledgeable about the complex issues that contribute to disparities or the models used to study them. Team meetings offer opportunities to see the project and disparities issues in general through a wide lens and perspective. Ultimately this broad perspective will improve the global outcomes of the project and offer more tangible information that will reduce the disparity gap that currently exists.

4. Conclusions

Summary General Lessons Learned: Recruitment of racial-ethnic minorities in stroke trials is a complex, but imperative undertaking. A range of factors contribute to the underrepresentation of racial-ethnic minorities in clinical research. Continuous, ongoing assessment to improve efficiency in identifying, enrolling, and engaging racial-ethnic minorities in clinical research focused on stroke outcome disparities is important. The expertise of clinical research coordinators and other key personnel who approached potential participants about CINGS was critical to the success of the interactions. Individuals with the most success were knowledgeable about "lived experience of African Americans" with stroke and such experience wasn't simply a product of racial concordance between the stroke survivor and research team member.

Beyond the factors critical to successful enrollment discussed herein, other factors including lag time between obtaining informed consent and actual enrollment of potential study participants can also serve as a challenge for reaching target enrollment. The lack of communication and miscommunication can frequently exist between study personnel and potential study participants that can have major consequences on recruitment rates. For example, the team documented multiple telephone numbers for future contact as stroke survivors are frequently readmitted, transferred to specialty hospitals/rehabilitation units or experience changes in living arrangements which can subsequently limits contact capabilities. Obtaining permission to call alternative contacts, such as, family members or friends in the event that the study participant cannot be reached offers a solution for maintaining a relationship with the study participant throughout their transition back into the community-at-large.

Finally, the CINGS research team learned that research groups engaged in disparities research require ongoing research training related to disparities in the outcome of interest. Training is required beyond that received from the required Collaborative Institutional Training Initiative [32]. This training is essential because personnel's approaches to recruitment can be biased by past successful experiences with previous projects that may not be applicable to or useful for the current research study. Research teams must clearly understand that recruitment and retention of African Americans in research related to chronic diseases such as stroke is not a one size fit all endeavor. Profoundly, we observed that research teams can be diverse and inclusive but lack understanding about the "lived experience of African Americans" or community-engagement research strategies targeted towards African Americans living with stroke. Thus, personnel training in these areas is essential for obtaining achieving target recruitment goals.

Declaration of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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