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The difficulty of studying race-ethnic stroke rehabilitation disparities in a community

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Abstract

Objective: Minority populations have worse stroke outcomes compared with non-Hispanic whites (NHWs). One possible explanation for this outcome disparity is differential allocation of stroke rehabilitation. We utilized a population-based stroke surveillance project to determine the feasibility of studying Mexican American (MA)-NHW differences in stroke rehabilitation in a

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population-based design including identification of community partners, development of standardized data collection instruments, and collection of pilot data.

Methods: As part of the Brain Attack Surveillance in Corpus Christi (BASIC) project, we followed 48 patients for the first 90 days after stroke, and attempted to work with community partners to garner information on ethnic-specific rehabilitation modalities used. With input from local occupational and physical therapists and speech language pathologists, we created data collection forms to capture specific rehabilitation activities and time spent on these activities and conducted a three month data collection pilot.

Results: Of the rehabilitation venues in the community (n=79), 63 (80%) agreed to partner in our pilot project. During the three month pilot, 545 data forms from 20 stroke patients were collected. This corresponds to approximately 18% of the stroke patients during this time. Forms were used by 13 of the 63 partners during the pilot. Those using the forms included 3 of 4 inpatient rehabilitation facilities, 4 of 13 skilled nursing facilities, 4 of 26 home health agencies, and 2 of 36 outpatient rehabilitation providers.

Conclusions: Initial agreement from rehabilitation providers to participate in research was excellent, but completion of study related data collection forms was sub-optimal suggesting this approach is not feasible for a future population-based stroke rehabilitation study. Further methods to study post-stroke rehabilitation disparities in communities is needed.

Keywords

stroke; rehabilitation; ethnicity; outcomes

Introduction

The National Institute on Minority Health and Health Disparities defines health disparities as “differences in the health status of different groups of people”¹. Race-ethnic disparities in stroke outcomes have been documented². One possible but little studied contributor to these disparities is race-ethnic differences in access to post-stroke rehabilitation or in the utilization and/or effectiveness of rehabilitation³. Remarkably, little published data exist on race-ethnic disparities in stroke rehabilitation from any study design or data source. Some studies have attempted to compare race-ethnic differences in rehabilitation with a focus on the inpatient rehabilitation setting^{4, 5}. These studies ask the question of whether race-ethnic differences in rehabilitation provision or outcomes exist among those admitted to inpatient rehabilitation. Importantly, this work has demonstrated that race-ethnic differences in the provision of specific rehabilitation activities may exist⁶. This approach, however, is limited in addressing the question of the existence of race-ethnic disparities in allocation of stroke rehabilitation and the possible impact on outcomes for several reasons. First, only a small proportion of stroke patients receive rehabilitation in the inpatient setting⁷. Second, there are race-ethnic differences in the utilization of inpatient rehabilitation, with minorities less likely to receive rehabilitation in this setting, which could be the result of structural barriers, such as insurance coverage, patient and family preferences, or other factors³. Therefore, the inpatient rehabilitation population is highly select and does not reflect the broader stroke population and disproportionately excludes minorities. To answer the question of whether

race-ethnic disparities in stroke rehabilitation exist, population-based epidemiologic studies that encompass the full spectrum of stroke patients and rehabilitation settings are urgently needed.

Given there is some evidence that race-ethnic disparities in post-stroke rehabilitation exist and that stronger evidence of such disparities would result in a clear target for intervention to improve outcomes in minority stroke patients, why have population-based stroke rehabilitation studies not been undertaken? The answer may lie in the logistical challenges to doing this research, including the measurement of rehabilitation treatments across sites, which is particularly challenging with the many therapy-specific interventions employed in stroke rehabilitation⁸. In our population-based stroke study, the Brain Attack Surveillance in Corpus Christi (BASIC) Project, we conducted a pilot study to build the needed infrastructure to conduct a population-based stroke rehabilitation study with a focus on the Mexican American population. We have documented clear stroke outcome disparities in this population including worse neurologic, functional and cognitive outcomes in Mexican Americans compared with non-Hispanic whites after accounting for a host of confounding factors⁹. In our pilot study, we aimed to see if we could extend BASIC to include the collection of detailed rehabilitation data in stroke patients. Specifically, we aimed to identify the necessary community partners, develop data collection instruments that could be used across rehabilitation settings, and collect pilot data to plan for a larger study focused on ethnic disparities in post-stroke rehabilitation and the impact on outcomes.

Methods

The BASIC Rehabilitation methods were previously reported³. Briefly, during Fall 2015, we used active and passive stroke surveillance as part of BASIC to find 72 (48 of which got any rehabilitation service) consecutive patients who agreed to participate in the pilot study, and were followed prospectively for 90 days. Stroke cases were validated by stroke trained physicians using source documentation. BASIC, a rigorous population-based stroke surveillance system, is conducted in one county in south Texas and aims to identify all strokes in the county¹⁰. The population of the county was 361,221 in 2016, 63% of which was Mexican American¹¹. Roughly 450 strokes occur annually in the community.

As part of the pilot, physical therapy (PT), occupational therapy (OT), and speech language pathology (SLP) representatives from participating venues collaborated in an iterative process to develop and pilot standardized discipline-specific point-of-care (POC) data collection forms. Examples of POC forms that were used successfully to document PT, OT, and ST therapy sessions in previous inpatient stroke and inpatient traumatic brain injury rehabilitation studies were used as a starting point^{6, 12}. The iterative process involved biweekly meetings via teleconference or in-person with study staff, investigators (SH), and the local PT, OT and SLP representatives to conceptualize, create and refine the POC data collection forms. The iterative process took approximately 7 months because specialty teams learned quickly that what is practiced in one site is often different from other sites. Therapists also realized that definitions of common terms differ from site to site and practitioner to practitioner. The resulting POC forms document therapy-specific interventions that encompass the care provided across different rehabilitation venues in this

community and provide a standardized way to document rehabilitation services across facilities and providers. Because development efforts included representatives from participating sites, the forms contain interventions that may be specific to one or more sites but are not used by all.

Therapists at participating venues were trained to use these forms via discipline-specific train-the-trainer meetings, training videos developed by the project team, and written training materials and asked to prospectively record data using the forms for all stroke patients for three months. The forms were designed to take only a few minutes to complete during or shortly after a therapy session and collected information regarding the specific rehabilitation activities conducted as well as the time spent on each activity. No project-related resources were provided for the pilot data collection, rather we asked the venues and therapists to use the forms as part of the therapy sessions with their stroke patient. Descriptive statistics were used to summarize the data. Due to the small sample, we do not present data on rehabilitation activities.

The University of Michigan IRB and both hospital systems' IRBs in Corpus Christi approved this study. Subjects signed written informed consent.

Results

We identified that 4 inpatient rehabilitation facilities (IRFs), 13 skilled nursing facilities (SNFs), 36 home health agencies (HHAs) and 26 outpatient (OP) venues provide stroke rehabilitation in the study community, of which 63 (80%) agreed to partner in our pilot project (see Figure). During the three month pilot, 545 data collection forms from 20 of the 48 enrolled stroke patients who received rehabilitation were collected. For PT, forms from 19 stroke patients were completed. The number of PT forms per patient ranged from 2 to 41. For OT, forms from 11 stroke patients were completed. The number of OT forms per patient ranged from 5 to 38. For SLP, forms from 9 stroke patients were completed. The number of SLP forms per patient ranged from 1 to 24. Data collection forms were used by 13 of the 63 partners during the pilot. Those using the forms included 3 of 4 IRFs, 4 of 13 SNFs, 4 of 26 HHAs, and 2 of 36 OPs.

Discussion

Although we successfully established community partnerships with 80% of stroke rehabilitation venues in the community and developed data collection forms with input from local therapists, the participation in pilot data collection was low. In particular, uptake of the data collection forms outside of the IRF setting was minimal, which is particularly relevant to the study of disparities given the finding that MAs are less likely to go to an IRF after stroke in this community³. Clearly, alternative methods to collecting detailed stroke rehabilitation data are needed to understand race-ethnic differences in post-stroke rehabilitation at the population level. One possibility includes the addition of project staff versus reliance on therapists to collect prospective rehabilitation data to eliminate the time requirements on already busy clinical therapists. This option, however, would likely be prohibitively expensive given there were 69 rehabilitation venues in this community alone.

A second alternative would be retrospective abstraction of detailed rehabilitation data by project staff. This option would require permission to access patient rehabilitation records, standardized data collection instruments and reliable data collection procedures. Given the variability in documentation that likely exists across the 69 rehabilitation venues, standardized data collection would undoubtedly be difficult. Additional pilot work to understand documentation practices in this and other communities and piloting such alternative data collection methods could identify whether this strategy is viable. Third, alternative data sources, such as publically available administrative data, could be used to measure rehabilitation utilization. Medicare based data are being utilized in currently funded projects¹³; however, stroke disparities are most pronounced in those less than 65 years of age and therefore, Medicare data does not capture the age range most critical for consideration of race-ethnic disparities in outcomes. Other potential data sources that could be utilized include the State Inpatient Databases, the National Inpatient Sample, or use of Optum®, a large data warehouse of privately insured patients supplemented with Medicaid mix data that can be purchased.

Although there are clear challenges to conducting a population-based stroke rehabilitation study, this should be a high priority for stroke disparities research for several reasons. First, race-ethnic disparities in stroke outcomes are apparent and unexplained by clinical factors and other confounders⁹. Second, limited data suggest that race-ethnic differences in post-stroke rehabilitation exist, including our own recent pilot data which demonstrated that Mexican Americans were less likely to receive care in the inpatient rehabilitation setting³. Together, these findings suggest that rehabilitation may be important to stroke outcome disparities but no population-based study has investigated how rehabilitation contributes to worse outcomes in Mexican Americans or other minority groups. Finally, evidence of disparities in access to or effectiveness of stroke rehabilitation would identify a clear target for future interventions to improve stroke outcomes in minorities. The stroke rehabilitation community may help this process by encouraging funders to support the important work of identifying and remedying disparities in stroke rehabilitation care. This may begin with a focus on stroke rehabilitation disparities in guidelines and other priority statements, absent thus far.¹⁴ It is certainly possible that, at least in part, this is some of the solution to the worse stroke outcome in minority populations.

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Figure 1:

Participation by rehabilitation setting

IRF: inpatient rehabilitation facility; SNF: skilled nursing facility; HHA: home health agency; OP: outpatient rehabilitation