Stroke literacy in Central Harlem

A high-risk stroke population

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ABSTRACT

Background: Awareness of stroke warning symptoms and risk factors (stroke literacy), as well as knowledge of available treatment options, may be poor in high-risk populations. We sought to evaluate stroke literacy among residents of Central Harlem, a predominantly African American population, in a cross-sectional study.

Methods: Ten community-based sites in Central Harlem were identified between 2005 and 2006 for administration of a stroke knowledge survey. Trained volunteers administered in-person closed-ended questionnaires focused on stroke symptoms and risk factors.

Results: A total of 1,023 respondents completed the survey. African Americans comprised 65.7% (n = 672) of the survey cohort. The brain was correctly identified as the site where a stroke occurs by 53.7% of respondents, whereas the heart was incorrectly identified by 20.8%. Chest pain was identified as a symptom of stroke by 39.7%. In multivariable analyses, African Americans (odds ratio [OR] 2.20, 95% confidence interval [CI] 1.09–4.45) and Hispanics (OR 5.27, 95% CI 2.46–11.30) were less likely to identify the brain as the damaged organ in stroke. Hispanics were more likely to incorrectly identify chest pain as a stroke symptom, compared with whites (OR 3.40, 95% CI 1.49–7.77). No associations were found between calling 911 and race/ethnicity and stroke knowledge, although women were more likely than men to call 911 (OR 0.50, 95% CI 0.30–0.80).

Conclusion: Significant deficiencies in stroke literacy exist in this high-risk population, especially when compared with national means. Culturally tailored and sustainable educational campaigns should be tested in high-risk populations as part of stroke public health initiatives. *Neurology*® 2009; 73:1950–1956

GLOSSARY

BRFSS = Behavioral Risk Factor Surveillance Survey; **CI** = confidence interval; **DASH II** = Second Delay in Accessing Stroke Healthcare; **EMS** = emergency medical services; **FAST** = face, arm, speech, time; **OR** = odds ratio.

Prehospital delays remain the major rate-limiting step for acute thrombolytic therapy for stroke.¹ Awareness of stroke symptoms and the need to immediately call 911 by patients, families, and bystanders may significantly reduce prehospital delays. Healthy People 2010 has outlined a revised goal to increase awareness of warning symptoms of stroke and calling 911 to 83%.² Knowledge of stroke symptoms and risk factors, which we will name *stroke literacy*, may reduce prehospital delay, increase the proportion of patients receiving acute thrombolytic therapy,³ and potentially increase early detection of risk factors and the frequency of preventive care that patients seek.

Knowledge of stroke symptoms and risk factors in the general population remains poor, with estimates differing based on the means of assessing stroke literacy (open-ended vs closed-ended questionnaires), as well as the populations sampled. Prior surveys have shown that between 39% and 61% of individuals are able to name at least 1 stroke symptom, whereas 57% to 76% of individuals are able to name at least 1 risk factor for stroke.⁴ A recent analysis of the

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data from the Behavioral Risk Factor Surveillance Survey (BRFSS) in 2005 indicated that only 16.4% of individuals could correctly identify all stroke symptoms and call 911 in case of a stroke.⁵ Analyses from the BRFSS in men and women from 2003 to 2005 have identified Hispanic ethnicity, being uninsured, earning less than \$35,000 per year, and not completing high school as associated with poor stroke and heart disease literacy.⁶⁻⁸

In our study we aimed to explore stroke literacy in Central Harlem, a predominantly African American (two-thirds of all residents) urban population with a high proportion of the population living under the federal poverty level (New York City Department of Health, 2000). We further aimed to delineate whether there were any differences based on race/ethnicity or gender. The total population in Central Harlem was 151,113 in the year 2001. Stroke and heart disease accounted for approximately 15% of years of potential life lost in the year 2001 in Central Harlem, which was higher than HIV/AIDS, cancer, or trauma. The stroke death rate in Central Harlem is 45 per 100,000 residents, which is almost double that of New York City as a whole.⁹

METHODS A convenience sample of 10 community-based sites in Central Harlem, including houses of faith, senior citizen centers, and organized community health fairs, were identified between 2005 and 2006 for administration of a stroke knowledge survey. The survey was adapted from questions administered in the BRFSS to assess stroke literacy. Trained bilingual (Spanish and English) volunteers administered face-to-face interviews to self-selecting respondents at these sites. Only those who acknowledged that their primary residence was in Central Harlem were asked to complete the survey. Structured multiple-choice closed-ended questionnaires were administered, and answers were recorded. Questions were focused on the following stroke symptoms: hemiparesis, hemisensory loss, difficulty speaking, blurred vision, and worst headache of life. Additional questions focused on where in the body a stroke occurs, correct and incorrect stroke risk factors, whether chest pain was a stroke symptom, and course of action in case of stroke symptoms (including calling 911).

A composite score of number of correct responses for stroke risk factors was constructed, with respondents obtaining a 1 when identifying a stroke risk factor correctly (age, hypertension, diabetes, obesity, cocaine abuse, tobacco use, and family history) and 0 when there was no response or when identifying an incorrect stroke risk factors (pneumonia, arthritis, car accident). Respondents were also asked to rate their trust in the health care system from 1 (no trust) to 5 (complete trust), and to self-identify their race/ethnicity, age, and gender. For the purposes of analysis, trust was defined as more than moderate trust. The

Table 1 Baseline demographics (n = 1,023)

Mean age, y	51.6
Gender, %	
Men (n = 328)	32
Women (n = 695)	68
Race/ethnicity, %	
African American (n = 672)	65.7
Hispanic (n = 164)	16
White (n = 44)	4.3
Other (n = 143)	14

questions asked as part of the questionnaire are available in appendix e-1 on the *Neurology*[®] Web site at www.neurology.org. The study was approved by the Harlem Hospital Institutional Review Board.

Our outcomes of interest included the following dichotomous variables: not identifying the brain as where stroke occurs, identifying the heart as where stroke occurs, answering incorrectly to each of the stroke symptoms (including saying "yes" to chest pain being a stroke symptom), scoring less than 6 on the composite stroke risk factor score, identifying all 5 stroke symptoms, identifying all 5 stroke symptoms and chest pain not being a stroke symptom, and not calling 911 in case of stroke symptoms.

Descriptive and comparative statistics were computed to identify differences in stroke literacy, with outcomes of interest including location in the body where a stroke occurs (stroke location), stroke symptoms and risk factors, and appropriate course of action in the event of stroke warning signs. Univariate analyses using the χ^2 test were performed to examine the association between the outcomes of interest and explanatory variables, such as age, race/ethnicity, gender, and trust. The effect of demographic factors and stroke location on the outcomes of interest was analyzed with multivariable logistic regression models with race/ethnicity (reference white) and gender (reference men) as the primary explanatory variables. We included correctly identifying the brain as the organ affected in stroke, trust in the health care system, gender, race/ethnicity, and age as continuous variables in all models because they were possible confounders. We performed univariate analyses and then calculated the models including all possible confounders of interest. Results were considered significant at the $p < 0.05$ level, and model fit adequacy was assessed using the Hosmer-Lemeshow statistic for $p > 0.05$. All analyses were performed using SAS version 9.1 (SAS Institute Inc., Cary, NC).

RESULTS A total of 1,023 respondents completed the survey. Baseline demographics of the sample are included in table 1. Sixty-eight percent of the respondents were women; the mean age was 51.6 years, with a range between 13 and 94 years. African Americans comprised 65.7% (n = 672) of the survey cohort, whereas 16% (n = 164) were Hispanic, 14% (n = 143) were other, and 4.3% (n = 44) were white. The figure includes a sample of the baseline responses; the full responses are available in table e-1. Only 53.7% of respondents correctly identified the brain as being the site in the body where a stroke occurs; 72.7% of whites identified the brain as the

Figure Responses to a sample of stroke literacy questions for each race/ethnicity

affected organ, whereas 56.3% of African Americans and 35.4% of Hispanics did so. The heart was incorrectly identified as the involved organ by 20.8% of respondents, but 45.2% of Hispanics indicated it was the affected organ, compared with 15.3% of African Americans and 15.9% of whites. Hemiparesis was the best-recognized stroke symptom (68.6% of respondents), followed by speech disturbance (59.2%), worst headache of life (54.4%), and blurred vision (43.7%). Chest pain was incorrectly identified as a symptom of stroke by 39.7% of respondents; it was identified as a stroke symptom by 59.1% of Hispanics, compared with 36.5% of African Americans and 22.2% of whites. Hypertension was the best-recognized risk factor (86%), followed by family history of stroke (66.7%), obesity (59.1%), diabetes (52%), smoking (44%), and cocaine abuse (37.4%). The risk factor scores ranged from 0 to 7, with a mean of 3.8, a median of 4, and an SD of 2.1. A low score was defined as less than 6 points and was present in 73.2%. All 5 stroke symptoms were identified by 22.4% of the sample, whereas 10.7% identified all 5 stroke symptoms and identified chest pain as not being a stroke symptom. Only 2.8% of Hispanics were able to identify all 5 stroke symptoms and chest pain not being a stroke symptom. In case of stroke symptoms, 89.8% of the sample would call 911.

Univariate and multivariable analyses for identifying the organ affected in stroke are included in table 2. African Americans and Hispanics were more likely

to not identify the brain as the organ where stroke occurs, an association that remained in multivariable models (adjusted odds ratio [OR] 2.20, 95% confidence interval [CI] 1.09–4.45 for African Americans; adjusted OR 5.27, 95% CI 2.46–11.30 for Hispanics). Hispanics were significantly less likely than whites to identify that chest pain is not a stroke symptoms (adjusted OR 0.19, 95% CI 0.08–0.49), whereas African Americans were not (adjusted OR 1.71, 95% CI 0.78–3.71). Table 3 includes analyses examining each individual stroke symptom. In multivariable models, women were less likely than men to fail to identify hemiparesis and hemisensory loss as stroke symptoms (adjusted OR for hemiparesis 0.71, 95% CI 0.52–0.97). Hispanics were more likely to not be able to identify hemiparesis, difficulty speaking, and worst headache of life as stroke symptoms, and they were more likely to incorrectly identify chest pain as a warning symptom of stroke, compared with whites (adjusted OR 3.40, 95% CI 1.49–7.77). These observations were not noted among African Americans.

Table 4 outlines the results of analyses on composite scores. When examining the odds of not identifying all 5 stroke symptoms, African Americans and Hispanics were more likely to not be able to identify all 5 stroke symptoms in univariate analyses and multivariable models (adjusted OR for Hispanics 3.58, 95% CI 1.62–7.9; adjusted OR for African Americans 2.73, 95% CI 1.39–5.38). Multivariable

Table 2 Univariate and multivariable analyses of answering to the organ affected

	Univariate odds ratio	95% Confidence interval	Multivariable odds ratio*	95% Confidence interval*
Brain affected in stroke (odds of replying "no")				
Women vs men	0.82	0.61-1.09	0.84	0.64-1.11
Race/ethnicity (reference white)				
African American	2.11	1.03-4.33	2.20	1.09-4.45
Hispanic	4.99	2.31-10.8	5.27	2.46-11.3
Other	2.07	0.94-4.54	2.15	1.00-4.65
Heart affected in stroke (odds of replying "no")				
Women vs men	1.35	0.95-1.92	1.32	0.94-1.84
Race/ethnicity (reference white)				
African American	0.77	0.31-1.9	0.86	0.35-2.08
Hispanic	0.2	0.08-0.5	0.19	0.08-0.49
Other	0.54	0.2-1.42	0.54	0.21-1.41

*Adjusted for age, race/ethnicity, gender, trust in the health care system, and knowledge of the brain as the organ affected in stroke.

analyses revealed that African Americans were more likely than whites to have a risk factor score lower than 6 (OR 2.12, 95% CI 1.10–4.12). No associations were found between calling 911 and race/ethnicity and stroke knowledge, although women were more likely than men to call 911 (adjusted OR 0.50, 95% CI 0.30–0.80).

DISCUSSION Significant deficiencies in stroke literacy were observed in this cohort. Moreover, the correct response rates were lower for almost all stroke symptoms compared with a recent analysis of an optional stroke survey component of the BRFSS conducted in 13 US states and the District of Columbia.⁵ The national survey found 92.6% of respondents correctly identifying hemiparesis and 68.8% identifying visual difficulties as stroke symptoms, compared with 68.6% and 43.7%, respectively, in our participants. The identification of correct responses may be more in keeping with results obtained in the Beauty Shop Stroke Education Project, where at baseline only 40.7% of women were able to identify all 3 stroke warning signs in the face, arm, speech, time (FAST) mnemonic.¹⁰ The reasons for the high proportion of participants who identified cocaine use as a stroke risk factor are not clear, but may be related to high rates of use in this and surrounding communities and the high proportion of individuals who live below the poverty line.¹¹ Our results are in keeping with other analyses of the BRFSS data where Hispanics had lower overall stroke literacy,^{6-8,12} though we did not collect data on

household income or educational achievement to correct for these important covariates. The differences noted between Hispanics and African Americans are interesting given the similar burden of risk factors and stroke incidence in both groups at younger ages and reflect an important need to understand how to best educate these at-risk patients.

Associations between stroke literacy and activation of emergency medical services (EMS) have varied. Reports from the Czech Republic and Brazil indicated an association between stroke literacy and a higher probability of activating EMS in case of a stroke.^{13,14} One report from the Second Delay in Accessing Stroke Healthcare (DASH II) found no association between knowledge of stroke symptoms and activation of the EMS for stroke.¹⁵ In DASH II, activation of EMS was more likely when someone other than the patient identified the stroke with associated faster arrival times. In our study, poor stroke literacy was not associated with activating EMS, although this may be confounded by the closed-ended multiple-choice format of questionnaires. The use of open-ended questions and hypothetical scenarios may yield lower response rates that are more in keeping with observed behavior. Interventions aimed at educating family members may be one strategy that could be effective in decreasing arrival times. The reasons for differences between these studies remain unclear, but may be related to the means by which different countries educate the public about stroke symptoms or confidence in EMS and the health care system.

The proportion of participants who incorrectly identified chest pain as a warning symptom of stroke and incorrectly named the heart as the organ involved in a stroke was of particular interest and suggests that stroke is still being confused with heart attacks. Our results regarding knowledge of the brain as the affected organ in stroke were similar to a hospital-based sample in India, where 45% did not identify the correct organ.¹⁶ This remains despite the introduction of the term "brain attack." Hispanics, compared with African Americans and whites, were significantly more likely to misclassify cardiac symptoms as stroke related. In our study, the number of respondents who incorrectly identified chest pain as a stroke symptom is similar to findings in the BRFSS 2005 survey,⁵ although Hispanics were significantly higher than the national mean in misclassifying cardiac symptoms as stroke related, despite language concordant interviews. Whether this reflects a paucity of public stroke education for Hispanics, language barriers in health care encounters, or other factors is unknown; one prior study found that Hispanics who spoke English were more likely to be aware of stroke symptoms and the appropriate action to take in the event of those symptoms.¹⁷ Further

Table 3 Univariate and multivariable analyses of stroke symptoms responses

	Univariate odds ratio	95% Confidence interval	Multivariable odds ratio*	95% Confidence interval*
Hemiparesis (odds of replying "no")				
Women vs men	0.71	0.53-0.94	0.71	0.52-0.97
Race/ethnicity (reference white)				
African American	1.85	0.84-4.07	1.7	0.75-3.85
Hispanic	3.48	1.51-8.00	2.53	1.07-5.97
Other	1.94	0.82-4.56	1.56	0.65-3.87
Hemisensory loss (odds of replying "no")				
Women vs men	0.63	0.48-0.83	0.62	0.46-0.83
Race/ethnicity (reference white)				
African American	0.87	0.46-1.66	0.71	0.36-1.40
Hispanic	1.27	0.63-2.55	0.83	0.40-1.74
Other	1.21	0.59-2.46	0.96	0.45-2.04
Difficulty speaking (odds of replying "no")				
Women vs men	0.96	0.73-1.26	1.04	0.77-1.41
Race/ethnicity (reference white)				
African American	1.66	0.83-3.29	1.75	0.85-3.63
Hispanic	2.91	1.39-6.11	2.00	0.92-4.37
Other	2.30	1.09-4.90	2.06	0.93-4.60
Blurred vision (odds of replying "no")				
Women vs men	0.87	0.67-1.14	0.81	0.61-1.09
Race/ethnicity (reference white)				
African American	4.93	2.32-10.4	4.55	2.10-9.85
Hispanic	7.05	3.14-15.8	5.41	2.37-12.4
Other	5.45	2.41-12.3	4.88	2.12-11.3
Worst headache of life (odds of replying "no")				
Women vs men	0.9	0.68-1.2	0.91	0.67-1.22
Race/ethnicity (reference white)				
African American	1.19	0.62-2.28	1.35	0.69-2.63
Hispanic	2.64	1.30-5.38	2.17	1.06-4.46
Other	2.76	1.33-5.72	2.66	1.26-5.58
Chest pain (odds of replying "no")				
Women vs men	1.04	0.78-1.38	1.05	0.78-1.42
Race/ethnicity (reference white)				
African American	2.08	0.98-4.42	1.71	0.78-3.71
Hispanic	4.88	2.19-10.9	3.40	1.49-7.77
Other	2.15	0.95-4.87	1.82	0.78-4.23

*Adjusted for age, race/ethnicity, gender, trust in the health care system, and knowledge of the brain as the organ affected in stroke.

studies into understanding health literacy gaps in Hispanics in the United States may well shed light on the reasons.

Differences found by race/ethnicity and gender in this study may have important public health implications. Educational campaigns are most effective when they are tailored to an individual's cultural heritage.¹⁸ When using community-based interventions delivered through non-health care providers, improvements have been noted in knowledge of stroke symptoms, though in the Beauty Shop Stroke Education Project there were no effects on stroke risk factor knowledge.¹⁰ In one study performed in our same community, elementary school-age children were educable about stroke symptoms using "Hip-Hop Stroke," and were able to retain this knowledge.¹⁹ This type of educational intervention illustrates that more innovative strategies in these high-risk communities are necessary. In this case, part of the success stemmed from using hip-hop music and a well-known artist to deliver culturally relevant stroke education.

Stroke literacy may be beneficial outside of its possible effect on rates of thrombolysis in vulnerable populations. Certain patients will never be eligible for IV thrombolysis, and knowledge about risk factors for stroke remains poor. Prevention remains the most effective strategy to reduce morbidity and mortality associated with stroke. Informed patients are more likely to have improved emotional well-being and reduced use of health care services without affecting quality.²⁰ Whether more stroke-literate patients can be more proactive in risk factor control or report TIA symptoms to their physician is not known, but should be examined.

This study has several limitations. Respondents were self-selected, which introduces selection bias, and information on survey response rates was not available. In addition, low educational achievement has been associated with poor awareness of stroke warning symptoms.⁵ We did not collect information regarding maximum years of school achieved, where school was attended, or socioeconomic status, and this could be the main explanation for our findings of differences in stroke literacy between Hispanics and African Americans. Our use of knowledge of the correct organ damaged in stroke as a proxy for stroke literacy has not been validated. Comparisons between groups may also be difficult to interpret because of the smaller numbers of whites sampled. Additionally, we have little information to make comments on the category "other." In our analyses, we made multiple comparisons, and it is possible that at least some of our findings are due to chance. The

Table 4 Univariate and multivariable analyses of composite score responses for stroke symptoms and risk factors

	Univariate odds ratio	95% Confidence interval	Multivariable odds ratio*	95% Confidence interval*
Not identifying all 5 stroke symptoms				
Women vs men	0.73	0.52-1.03	0.72	0.50-1.04
Race/ethnicity (reference white)				
African American	2.60	1.39-4.86	2.73	1.39-5.38
Hispanic	5.02	2.37-10.6	3.58	1.62-7.90
Other	5.63	2.56-12.37	5.00	2.17-11.6
Risk factor score response <6*				
Women vs men	1.12	0.81-1.55	1.09	0.8-1.49
Race/ethnicity (reference white)				
African American	2.12	1.10-4.12	2.21	1.18-4.14
Hispanic	1.56	0.75-3.25	2.09	1.04-4.21
Other	2.05	0.96-4.37	2.35	1.14-4.85

*Adjusted for age, race/ethnicity, gender, trust in the health care system, and knowledge of the brain as the organ affected in stroke.

*Composite score of number of correct responses for stroke risk factors (age, hypertension, diabetes, obesity, cocaine abuse, tobacco use, and family history).

structure of questionnaires (closed-ended multiple-choice format) may have been leading, giving rise to higher rates of correct responses than open-ended, hypothetical scenario questions.²¹

Despite these limitations, this study reveals significant deficiencies in stroke literacy in this high-risk community, which is worse than a selected sample of national means. Our sample had a larger proportion of Hispanics and African Americans than the BRFSS national sample. This study finds similar results to prior studies in overall stroke literacy, including those in developing countries,^{5,14,16,21,22} again highlighting the need to improve stroke literacy. The optimal method for improving stroke literacy, as well as whether it leads to a reduced burden of cerebrovascular disease, is yet to be determined. It will likely involve both individual and community-based strategies that are culturally relevant, such as Hip-Hop Stroke, and that can be tested in prospective studies and clinical trials.

DISCLOSURE

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Classification scheme requirements for therapeutic questions

Class I. A randomized, controlled clinical trial of the intervention of interest with masked or objective outcome assessment, in a representative population. Relevant baseline characteristics are presented and substantially equivalent among treatment groups or there is appropriate statistical adjustment for differences.

Class II. A randomized, controlled clinical trial of the intervention of interest in a representative population with masked or objective outcome assessment that lacks one criterion a-e in Class I or a prospective matched cohort study with masked or objective outcome assessment in a representative population that meets b-e in Class I. Relevant baseline characteristics are presented and substantially equivalent among treatment groups or there is appropriate statistical adjustment for differences.

Class III. All other controlled trials (including well-defined natural history controls or patients serving as their own controls) in a representative population, where outcome is independently assessed, or independently derived by objective outcome measurements.

Class IV. Studies not meeting Class I, II, or III criteria including consensus or expert opinion.

AAN classification of recommendations

A = Established as effective, ineffective, or harmful (or established as useful/predictive or not useful/predictive) for the given condition in the specified population. (Level A rating requires at least two consistent Class I studies.)

B = Probably effective, ineffective, or harmful (or probably useful/predictive or not useful/predictive) for the given condition in the specified population. (Level B rating requires at least one Class I study or two consistent Class II studies.)

C = Possibly effective, ineffective, or harmful (or possibly useful/predictive or not useful/predictive) for the given condition in the specified population. (Level C rating requires at least one Class II study or two consistent Class III studies.)

U = Data inadequate or conflicting; given current knowledge, treatment (test, predictor) is unproven.