Community-Based Participatory Research
A New Approach to Engaging Community Members to Rapidly Call 911 for Stroke
Lesli E. Skolarus, MD; Marc A. Zimmerman, PhD; Jillian Murphy, MPH; Devin L. Brown, MD; Kevin A. Kerber, MD; Sarah Bailey, MA; Sophronia Fowlkes, BA; Lewis B. Morgenstern, MD

Background and Purpose—Acute stroke treatments are underutilized primarily because of delayed hospital arrival. Using a community-based participatory research approach, we explored stroke self-efficacy, knowledge, and perceptions of stroke among a predominately African American population in Flint, Michigan.

Methods—In March 2010, a survey was administered to youth and adults after religious services at 3 churches and during 1 church health day. The survey consisted of vignettes (12 stroke, 4 nonstroke) to assess knowledge of stroke warning signs and behavioral intent to call 911. The survey also assessed stroke self-efficacy, personal knowledge of someone who had experienced a stroke, personal history of stroke, and barriers to calling 911. Linear regression models explored the association of stroke self-efficacy with behavioral intent to call 911 among adults.

Results—Two hundred forty-two adults and 90 youths completed the survey. Ninety-two percent of adults and 90% of youth respondents were African American. Responding to 12 stroke vignettes, adults would call 911 in 72% (SD, 0.26) of the vignettes, whereas youths would call 911 in 54% (SD, 0.29; P<0.001) of the stroke vignettes. Adults correctly identified stroke in 51% (SD, 0.32) of the stroke vignettes and youth correctly identified stroke in 46% (SD, 0.28) of the stroke vignettes (P=0.28). Stroke self-efficacy predicted behavioral intent to call 911 (P=0.046).

Conclusions—In addition to knowledge of stroke warning signs, behavioral interventions to increase both stroke self-efficacy and behavioral intent may be useful for helping people make appropriate 911 calls for stroke. A community-based participatory research approach may be effective in reducing stroke disparities. (Stroke. 2011;42:00-00.)

Key Words: community-based participatory research ■ stroke

A
cute stroke treatments are underutilized. Some studies have found that African Americans are less likely to receive acute stroke treatments than whites.1,2 The primary reason patients do not receive acute stroke treatment is hospital arrival outside the treatment window.3 Prehospital delay is greater among African Americans than whites.4 Although prompt 911 calls decrease prehospital delay and hospital triage times,5 emergency medical service is notified in <40% of acute stroke cases.6 Someone other than the patient calls 911 in up to 95% of all acute stroke situations.8

To address the underutilization of acute stroke treatment, behavioral interventions have focused on increasing knowledge of stroke warning signs.7-9 Researchers have consistently found that although knowledge is important, it is not enough to increase health behavior, a finding that is also true for stroke.10,11 Individuals with a previous stroke or more knowledge about stroke warning signs are not more likely to call 911.5,12 Little research has been performed to explore other factors that may influence the decision to call 911, such as self-efficacy. Self-efficacy is a person’s perception of his or her abilities and it is this perception that often influences behavior rather than his or her actual ability.13 Self-efficacy is an important component in both acute and chronic health behaviors. For example, self-efficacy has been associated with greater intent to seek emergency care for acute myocardial infarction.13 Furthermore, baseline self-efficacy and changes in self-efficacy during behavioral interventions are associated with behavior change, such as smoking cessation, improved medication adherence, and diabetes self-management.15-17 Self-efficacy is also associated with decreased health care utilization and improved self-reported health and disability.18,19

To inform future behavioral interventions to increase utilization of acute stroke treatments among African Americans, we conducted a community-based participatory research project in Flint, Michigan. Flint is an ideal population
to study factors related to the behavioral intent to call 911 because of the high age-adjusted stroke hospitalization rate and stroke mortality rate, which is 1.5-times higher than that of the rest of the United States, suggesting a great need for stroke education.\(^{20}\) The purpose of this study was to assess knowledge of stroke warning signs, behavioral intent to call 911, and barriers to calling 911 among a high-risk population of African American adults and youth. We also sought to determine whether respondents with high levels of stroke-self-efficacy had higher behavioral intent to call 911 compared to respondents with low levels of stroke self-efficacy.

**Subjects and Methods**

**Setting and Research Team**

Flint has a population of 117,068 people, of which 53% are African Americans and 41% are whites.\(^{21}\) It is the birthplace of General Motors and, like many cities in the industrial Midwest United States, has seen the decline of its manufacturing industry, leaving many of its residents unemployed. Today, \(^{2}\) in 4 people in Flint live in poverty.\(^{21}\)

One of the foundations of a community-based participatory research approach is the establishment of a team of community and academic partners who collaboratively design a study that produces outcomes that will benefit the community.\(^{22}\) For this research, the team consisted of academic partners (University of Michigan stroke neurologists and experts in Health Behavior and Health Education) and community partners (founders of Bridges into the Future, a faith-based African American community organization). Input and approval were also obtained from the Community-Based Organization Partners of Flint. This is an alliance of community-based organizations that was established to strengthen the influence of community partners involved in community-based participatory research projects in Flint.\(^{23}\)

**Design of Stroke Vignettes**

Members of the research team, particularly the community partners, felt that the validated stroke action test\(^{24}\) was not suitable for their community. The community partners felt that because of its length and situations that are not customary in their community (eg, going to the gym), respondents would have difficulty relating to and completing the stroke action test. Thus, the academic–community partnership collaboratively developed a series of new stroke vignettes to evaluate knowledge of stroke warning signs and behavioral intent to call 911. The intent of each vignette was to describe a person’s symptoms either in a manner highly suggestive of an acute stroke or in a manner not suggestive of an acute stroke. The vignettes underwent content validation by a team of stroke experts. Next, a stroke neurologist (L.S.), health behavior and health education expert (J.M.), and the community partners (S.B., S.F.) conducted a focus group with African American youths to evaluate the vignettes. Vignettes then underwent a series of individual cognitive interviews with African American youths and adults to assess their readability and interpretation.

**Population**

The sample of 4 predominately African American churches represented various geographical locations of Flint. Members of the research team met individually with each church pastor to introduce themselves and the project goals. Each church’s Senior Pastor reviewed and approved the surveys. In March 2010, the written survey was administered to youths (target age, 11–14 years) and adults at 4 sites after religious services at 3 churches and, by community partner request, at a church health seminar. Youths were included based on the recommendation of the community partners who identified that youths have a key role in community sustainability and frequently spend time with their grandparents who are at risk for stroke. At least 1 academic partner and 1 community partner were present for every survey administration. Five dollars was given to each participant after survey completion. Approval was obtained from the University of Michigan’s Institutional Review Board.

**Survey Instrument**

First, previous experience with stroke was queried via the following questions: (1) Have you ever had a stroke? (asked to adults) and (2) Do you personally know someone who has had a stroke? (asked to youths and adults). To investigate behavioral intent to call 911 when the diagnosis of stroke was provided, respondents were asked, if you think someone is having a stroke, who is the first person you would call? Response options included spouse/partner, pastor, parent, child, neighbor, friend, doctor, ambulance, or other. Next, a series of 16 vignettes (12 stroke vignettes and 4 nonstroke vignettes) were queried. The stroke vignettes included common stroke symptoms, such as hemiparesis, dysarthria, aphasia, visual changes, dizziness/imbalance, and severe headache.\(^{23,26}\) The 4 nonstroke vignettes were chest pain, musculoskeletal pain, orthostatic hypotension, and epistaxis. For each vignette, respondents selected 1 option out of the following: “stroke,” “no stroke,” and “do not know.” A follow-up question accompanied each vignette: “If this happened, what would you do first?” Response options included: (1) call doctor’s office immediately; (2) wait a couple of hours, then decide; (3) call a family member or friend immediately; and (4) call 911 immediately. Identifying stroke and behavioral intent to call 911 were scored separately, with 1 point given for identifying stroke and behavioral intent to call 911. Vignettes with missing responses were scored as incorrect (range, \(^{2}\)–\(^{10}\)).

Additionally, adult respondents were queried on self-efficacy and barriers to calling 911. Stroke self-efficacy was assessed using 2 statements: (1) I would not be able to tell if someone is having a stroke; and (2) I don’t know what to do. Statements were assessed on a Likert scale ranging from 1 (strongly agree) to 4 (strongly disagree). The inter-item correlation was 0.43, so the scores were combined to form a stroke self-efficacy scale (mean, 5.3; SD, 1.6). Scores ranged from 2 (low self-efficacy) to 8 (high self-efficacy).

Respondents were also asked their level of agreement on a Likert scale from 1 (strongly agree) to 4 (strongly disagree) regarding statements querying barriers to calling 911. Barriers included mode of transportation, cost, religious beliefs, embarrassment, access to ambulance, and knowing someone with a previous bad hospital experience. All responses were analyzed as agree (strongly agree and agree) versus disagree (strongly disagree and disagree). The survey had a Flesch-Kincaid reading grade level of 5.

**Statistical Analysis**

Descriptive statistics were used to summarize demographics of respondents, previous stroke experience, behavioral intent to call 911 when diagnosis of stroke was provided, and barriers to calling 911. The mean of the percent of correct responses for the 12 stroke vignettes and mean of the percent of incorrect responses for the 4 nonstroke vignettes were calculated separately for the youths and adults. Adult and youth knowledge of stroke warning signs and behavioral intent to call 911 were compared using \(t\) tests or \(X^2\) tests. Reliability of the novel vignettes was evaluated using Cronbach’s \(\alpha\). Among adults, linear regression was then used to evaluate the association between stroke self-efficacy (continuous) and behavioral intent to call 911 (continuous), the dependent variable. Linear regression models were performed unadjusted and adjusted for gender, age (continuous), education (some college versus no college), personal history of stroke (yes versus no), and personal knowledge of someone who had experienced a stroke (yes versus no). Regression diagnostic procedures yielded evidence of a skewed distribution of model residuals. Thus, robust standard errors were used to compute confidence intervals and probability values. All tests were 2-tailed and the probability of type 1 error was set at 0.05. Statistical analysis was performed using Stata 11.0 (StataCorp).
Table 1. Demographics and Stroke Experience Among Adult and Youth Respondents in Flint, Michigan

<table>
<thead>
<tr>
<th>Variable</th>
<th>Adult Respondents (n=242)</th>
<th>Youth Respondents (n=90)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, median (IQR)</td>
<td>47 (33–54)</td>
<td>13 (11–14)</td>
</tr>
<tr>
<td>Female</td>
<td>170 (71)</td>
<td>48 (55)</td>
</tr>
<tr>
<td>African American</td>
<td>218 (92)</td>
<td>77 (90)</td>
</tr>
<tr>
<td>Not Hispanic</td>
<td>204 (88)</td>
<td>68 (82)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>7 (3)</td>
<td></td>
</tr>
<tr>
<td>GED</td>
<td>11 (5)</td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td>66 (28)</td>
<td></td>
</tr>
<tr>
<td>Trade school</td>
<td>10 (4)</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>71 (30)</td>
<td></td>
</tr>
<tr>
<td>College graduate</td>
<td>52 (22)</td>
<td></td>
</tr>
<tr>
<td>Advanced degree</td>
<td>16 (7)</td>
<td></td>
</tr>
<tr>
<td>Stroke experience</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal history of stroke</td>
<td>12 (5)</td>
<td></td>
</tr>
<tr>
<td>Personal knowledge of someone who had experienced a stroke</td>
<td>199 (84)</td>
<td>55 (61)</td>
</tr>
</tbody>
</table>

GED indicates general educational development; IQR, interquartile range.

Results

A total of 332 individuals participated in the survey. Two hundred forty-two were adults and 90 were youths. Demographics, education, and previous stroke experience are presented in Table 1. The majority of respondents were African American (92% adults, 90% youths). The median age of adult respondents was 47 years (interquartile range, 33–54 years) and that of youth respondents was 13 years (interquartile range, 11–14 years). The majority of respondents knew someone who had experienced a stroke (84% adults, 61% youth).

When provided the diagnosis of stroke, 89% of adult and 78% of youth respondents would first call 911 (P=0.001). Among adult respondents, the reliability of the 12-item stroke vignettes was good (Cronbach α=0.88 for stroke warning signs and Cronbach α=0.83 for behavioral intent to call 911). Similarly good reliability was found among the youth respondents (Cronbach α=0.82 for stroke warning signs and Cronbach α=0.84 for behavioral intent to call 911). Stroke vignettes were correctly identified as stroke in 51% (SD, 0.32) of the vignettes by adults and in 46% (SD, 0.28) by youths (P=0.28). Adults indicated that they would call 911 in 72% (SD, 0.26) of the stroke vignettes; however, youths would call 911 in 54% of the stroke vignettes (SD, 0.29; P<0.001). Respondents were least likely to call 911 for sudden headache (51% adult, 31% youths) and were most likely to call 911 for dysarthria (91% adult, 63% youths). However, adult respondents identified a stroke in 25% (SD, 0.28) and youths identified a stroke in 28% (SD, 0.27) of the nonstroke vignettes (chest pain, orthostatic hypotension, epistaxis, and musculoskeletal pain; P=0.33). Similarly, among the nonemergent vignettes (orthostatic hypotension, epistaxis, and musculoskeletal pain), adult respondents would call 911 for 38% (SD, 0.39) and youth respondents would call 911 for 27% (SD, 0.33; P=0.01) of the vignettes.

Adult respondents had limited stroke self-efficacy. Thirty-eight percent of adults either strongly agreed or agreed that they would not be able to tell if someone were having a stroke. In addition, 43% of adult respondents strongly agreed or agreed that they would not know what to do if they witnessed someone having a stroke. Few barriers to calling 911 were endorsed by adult respondents. However, 17% of adult respondents believed that they could transport their loved one to the hospital faster than using an ambulance (Table 2).

In the unadjusted model, stroke self-efficacy was associated with behavioral intent to call 911 (β=0.020; SE, 0.010; P=0.046). After adjustment for demographics, history of stroke and knowing someone who had experienced a stroke, age (β=0.004; SE, 0.001; P=0.001), and stroke self-efficacy (β=0.022; SE, 0.011; P=0.034) predicted behavioral intent to call 911 (Table 3).

Discussion

Stroke was correctly identified by adult and youth respondents in approximately half of the stroke vignettes. Behavioral intent to call 911 was high when the diagnosis of stroke was provided, a result that is consistent with respondents in Harlem and central Massachusetts. Yet, behavioral intent

Table 2. Percent Agreement With Potential Barriers to Calling 911 for a Witnessed Stroke Among Adults Respondents (n=242) in Flint, Michigan

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Agree n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could get my loved one to the hospital faster than an ambulance</td>
<td>40 (17)</td>
</tr>
<tr>
<td>The ambulance costs too much</td>
<td>14 (6)</td>
</tr>
<tr>
<td>My personal religious beliefs prevent me from calling</td>
<td>8 (3)</td>
</tr>
<tr>
<td>I am embarrassed to have my neighbors see an ambulance at my house</td>
<td>3 (1)</td>
</tr>
<tr>
<td>An ambulance would not come to my house</td>
<td>8 (3)</td>
</tr>
<tr>
<td>I believe that divine healing is more important than medical care provided by physicians</td>
<td>10 (4)</td>
</tr>
<tr>
<td>I know someone who had a previous bad experience at a hospital</td>
<td>8 (3)</td>
</tr>
</tbody>
</table>

All statements began with the phrase: “I would not call 911 because …”

Table 3. Results of a Multivariable Linear Regression Model Exploring the Association Between Self-Efficacy and Behavioral Intent to Call 911 Among Adults (n=214) in Flint, Michigan

<table>
<thead>
<tr>
<th>Factors</th>
<th>β</th>
<th>SE</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>0.009</td>
<td>0.038</td>
<td>0.823</td>
</tr>
<tr>
<td>Some college education</td>
<td>0.009</td>
<td>0.038</td>
<td>0.806</td>
</tr>
<tr>
<td>Age</td>
<td>0.004</td>
<td>0.001</td>
<td>0.001</td>
</tr>
<tr>
<td>Personal knowledge of someone who had experienced a stroke</td>
<td>-0.013</td>
<td>0.045</td>
<td>0.771</td>
</tr>
<tr>
<td>Personal history of stroke</td>
<td>0.035</td>
<td>0.087</td>
<td>0.685</td>
</tr>
<tr>
<td>Stroke self-efficacy</td>
<td>0.022</td>
<td>0.011</td>
<td>0.034</td>
</tr>
</tbody>
</table>

R²=0.07. SE indicates standard error.
to call 911 was only moderate when assessed using stroke vignettes in which the diagnosis of stroke was not provided. Adult respondents would not call 911 in nearly 1 out of 4 vignettes and youths would not call for nearly 1 out of 2 vignettes. Moreover, the diagnosis of stroke was chosen in ~25% of the nonstroke vignettes, whereas >25% of respondents reported they would call 911 for nonemergent non-stroke vignettes. Youths had lower behavioral intent to call 911, as measured by both providing the diagnosis of stroke and in the stroke vignettes. These results suggest significant need for a community-based intervention targeting youths and adults separately to increase knowledge of stroke warning signs and behavioral intent to call 911. Respondent’s confidence in recognizing stroke and acting appropriately, stroke self-efficacy, were limited. Of interest, after adjusting for sociodemographics, history of stroke, and knowing someone who had experienced a stroke, stroke self-efficacy was associated with behavioral intent to call 911. Our model, however, explained 7% of the variation in behavioral intent to call 911, suggesting that other factors contribute to behavioral intent to call 911. The theory of planned behavior, a health behavioral theory, maintains that the key determinants of behavioral intent to call 911, suggesting that other factors contribute to behavioral intent to call 911. The theory of planned behavior proposes that the key determinants of behavioral intent are attitude toward the behavior (eg, knowledge of stroke warning signs and expected outcome of calling 911), subjective norms (eg, expectations of social network including family and church), and self-efficacy to perform the behavior (Figure). Further exploration of subjective norms and attitude toward calling 911 is needed.

Based on the results of our survey, self-efficacy may be a target to increase 911 calls for acute stroke. Self-efficacy is derived from and modified by personal accomplishments (skills mastery), modeling (vicarious experience), verbal persuasion, and physiological states. Because participants perform tasks (skills mastery), observe others performing the task (vicarious experience), and receive feedback (verbal persuasion), role-playing 911 calls for acute stroke in small groups targets the 3 most relevant means to increase self-efficacy. Role playing has successfully increased self-efficacy and behavior change in other behavioral interventions, especially in the setting of epidodic behaviors when risk to the participant would occur if the behavior is not performed. Additionally, identifying people experiencing an acute stroke in video scenarios and developing an action plan, forms of skills mastery, may also increase self-efficacy.

Engaging African Americans, especially youths, in research is difficult, partly because of the legacy of the Tuskegee study. The community partners helped establish the trust in the Flint community that was needed for this project to take place. Additionally, the community partners were vital in providing insights about measurements to ensure that the survey was appropriate for their community, encouraging data collection from youths, and gaining access to the church populations. For example, the community partners facilitated the introduction of the academic partners and the research project to each church pastor, after which approval was obtained to administer the survey after church services. Finally, both community and academic partners were present at the church services and at the time of survey distribution to demonstrate the partnership to the respondents.

Several limitations of the study warrant attention. First, we used a convenience sample of self-selected church-goers, which introduces selection bias and limits the generalizability of our findings. The population may be younger than the typical audience for stroke messaging and more highly educated than the population of Flint. Nevertheless, the results show deficiencies in knowledge of stroke warning signs and behavioral intent for high probability stroke scenarios and provided an initial test of stroke vignettes that can be used in future studies. Additionally, a church-based cohort may limit the generalizability of the study, but it is an efficient way to sample African Americans who are more likely to identify themselves as religious and attend church than whites. Moreover, although we believe the population of Flint is similar to that of other urban areas, a more broad-based approach for sampling African Americans that includes other urban areas would help address concerns about generalizability. Second, the use of closed-ended questions may overestimate knowledge of stroke warning signs and behavioral intent to call 911 compared to open-ended questions. Finally, although the study relied on self-report, this is the appropriate data source because we were interested in individuals’ perceptions, knowledge, and self-efficacy.

Conclusions

Knowledge of stroke warning signs and behavioral intent to calling 911 for stroke were moderate and stroke self-efficacy was more limited among predominately African American respondents in an urban community. Stroke self-efficacy was associated with behavioral intent to call 911. The results of this survey of church-going African American adults and youths in an urban community suggest the need for further stroke education about stroke warning signs and interventions targeting behavioral intent to call 911 and stroke self-efficacy. Finally, community-based participatory research is an effective approach to developing, administering, and analyzing a community stroke survey and may be a means to reduce stroke disparities.

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Disclosure
None.

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