The Challenges of Community-Based Research
The Beauty Shop Stroke Education Project

Dawn Kleindorfer, MD; Rosie Miller, RN; Sharion Sailor-Smith, RN; Charles J. Moomaw, PhD; Jane Khoury, PhD; Michael Frankel, MD

Background and Purpose—Public knowledge of stroke warning signs and risk factors is poor, especially in higher risk groups such as blacks. We sought to design a creative new way to educate black women by working through local beauty salons and measuring the results of the intervention.

Methods—Thirty black beauticians were educated about stroke warning signs and risk factors in 2 large urban areas in the US. The beauticians then educated their clientele during appointments. Stroke knowledge gained was measured via de-identified pre- and post-intervention (at 6 weeks and 5 months) surveys that included open-ended questions. Stroke warning signs were taught using the “FAST” (Face, Arm, Speech, Time) method.

Results—There were 383 completed baseline surveys, and 318 surveys were completed at 5 months. Of the 383 women, 78% were <60 years old, 69% had some college education, 41% had hypertension, and 12% had diabetes. The percentage of women who knew 3 warning signs significantly improved from the baseline survey (40.7%) to the final survey (50.6%), and similar improvements in knowledge were seen in both study regions. There was no improvement in knowledge of 3 risk factors (16.5% versus 18.2%). After our educational intervention, 94% knew to call 911 for stroke symptoms, an 8% improvement over baseline (P=0.002).

Conclusions—Despite the challenges of community-based research encountered within our project, we found that stroke education in the beauty shop significantly improved knowledge regarding stroke warning signs and calling 911 among a group of black women. This improvement in knowledge was sustained for at least 5 months. Knowledge of stroke risk factors, however, did not improve. The use of the beauty shop as an educational site is a novel approach to stroke education for women that can be practically applied in the community. Education regarding stroke risk factors remains a challenge that warrants further study. (Stroke. 2008;39:2331-2335.)

Key Words: educational campaigns ▪ women & minorities ▪ intervention ▪ public knowledge ▪ racial disparity

More strokes and stroke-related deaths occur in women than in men,1 and black women bear an even larger burden. Compared to white women, black women have almost twice the risk of stroke, and their risk is close to 4 times higher in the younger age groups.2,3

The only FDA-approved treatment for acute ischemic stroke, recombinant tissue plasminogen activator (rt-PA), can reduce disability in stroke patients who receive it, but this treatment can be given only within 3 hours of symptom onset.4 Rapid delivery of rt-PA requires prompt recognition of stroke symptoms and quick action by the patient, family, or witnesses. Patient delays in arrival to medical care may be the most important reason for underuse of rt-PA.5

Unfortunately, previous studies have found that public awareness of stroke warning signs is poor in the United States and in other countries.6–15 Persons at highest risk for stroke, including the elderly and blacks, have the least knowledge.7,8,10,16 Consequently, many patients seek medical attention well after the 3-hour window allowed for rt-PA administration.17–19 Therefore, there is a clear need for new creative strategies for educating the public, particularly black women. We present the results from a stroke public awareness project in a new locale: the black beauty shop.

Methods
This project was carried out in two major metropolitan areas with large black communities: Cincinnati and Atlanta. Using community contacts, study coordinators in both cities invited beauticians who primarily serve the black community to participate in the project. Beauticians who agreed attended a “Beauty Shop Training Luncheon” at a location within the community, where the principal investigator made a brief presentation about stroke warning signs and risk factors, a stroke survivor discussed her experiences, and the study coordinator described the details of the project. Beauticians were surveyed about their knowledge of stroke risk factors and warning signs both pre- and postluncheon.

Study packets were delivered to the participating beauticians, who were to distribute them to women at their hairstyling appointments. Beauticians were instructed to select 10 to 20 women who kept

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2331
When grading the open-ended responses for the warning signs, we used a template for deciding whether or not a written response was considered a correct answer.8,9 The responses were grouped into categories. Warning sign categories considered correct were numbness/tingling, slurred speech, weakness, headache, confusion, problems with vision, dizziness, loss of balance, and difficulty walking. Risk factor categories considered correct were those listed in the materials distributed: increasing age, male sex, black race, family history, heart disease medical history, hypertension, smoking, heavy alcohol use, high cholesterol, physical inactivity, obesity, or stroke patients with a population.20 We planned to evaluate how those symptoms contained within the FAST message were remembered.

The data were analyzed using SAS version 9.1. The \( \chi^2 \) statistic was used to examine overall change from baseline to 6 weeks and baseline to 5 months for the client’s knowledge. A Bonferroni correction was not applied, as these were a priori hypotheses. To look at the changes over time, a general estimating equations approach was used. To account for the ordinal nature of the response, variable analysis was based on a multinomial logistic model. This approach allowed inclusion of covariates to account for baseline differences in client levels at the different salons (age and education level), and differences between the beauticians.

Results

Study coordinators contacted 80 beauticians, and 30 agreed to participate in the project. At the training session, 22 completed both pre- and posttest surveys. The 8 who arrived too late to take the pretest still received the education. Eighteen of the 22 (82%) had attended some college, and 15 (68%) were above age 40. After the training session, 17 (77%) beauticians improved in their knowledge by at least 1 risk factor, and 18 (82%) beauticians improved by at least 1 warning sign.

A total of 383 surveys from black women clients were obtained at baseline, 354 were completed at the 6-week follow-up, and 318 were completed at the follow-up 5 months after the intervention. The demographics and stroke risk factors of the initial 383 participants are presented in Table 1.

Because the surveys were deidentified, the only way for the study investigators to verify that sequential surveys with the same identification number were in fact from the same person was to cross-check the demographic information (age range, race, gender, and educational level) across the surveys. Only 145 IDs had matching demographics at all 3 time points. We were able to identify several potential sources of error, including beauticians giving clients survey forms with someone else’s identification number, clients filling out the survey carelessly with regard to demographics, and beauticians distributing 6-week and 5-month surveys to new women, i.e., women who had not received the original educational intervention.

The group of 145 women with matching surveys was similar to the larger initial group of 383 in terms of age (\( P = 0.35 \)), education (\( P = 0.12 \)), medical history (probability values range from 0.13 to 0.91), baseline knowledge of...
warning signs ($P=0.88$), and baseline knowledge of risk factors ($P=0.22$). In addition, knowledge of 3 risk factors and warning signs over time were similar between the overall group and the set of surveys with matching demographics (data not shown) suggesting that the entire group has many more than 145 women in common. Thus, we suspect that the errors of mismatched identification numbers and careless demographics were considerably more prevalent than the error of introducing new women into the study. Therefore, we have reported results for the 383/354/318 women at each time point, as representative of the group of women who completed all 3 surveys. The results described below were not significantly different between the 2 study sites: Atlanta and Cincinnati (data not shown).

**Warning Sign Knowledge**

The percentage of women who knew 3 warning signs significantly improved ($P=0.006$) from the baseline survey (40.7%) to the 6-week survey (50.8%; Table 2). This improvement was still apparent at 5 months (50.6%). The number of women who knew no warning signs significantly decreased over time, from 13.3% at baseline to 5.7% at 5 months ($P=0.0007$). After adjustment for the client’s educational level and age and for the beautician who performed the education, the odds ratio (95% CI) for knowing at least 1 stroke warning sign at 5 months after the intervention compared to baseline (preintervention) was 1.78 (1.36, 2.33; $P<0.0001$).

The percentage of women who knew all 3 symptom components of the FAST message improved from 5.0% at baseline to 22.6% at the 5-month survey ($P<0.0001$). Each component was cited more frequently at the 5-month survey than at baseline: face 19.8% versus 36.8% ($P<0.0001$); arm 41.3% versus 54.4% ($P=0.0005$); and speech 41.8% versus 58.2% ($P<0.0001$).

**Risk Factor Knowledge**

The percentage of women who knew 3 risk factors did not significantly increase between the first and third surveys; 16.4% versus 18.2% ($P=0.53$; Table 2). Similarly, the percentage who knew no risk factors did not significantly decrease (12.5% versus 13.8%; $P=0.61$). After adjustment for the client’s educational level and age and for the beautician who performed the education, there was still no significant difference between the baseline and 5-month group.

**Clinical Scenarios**

When presented with clinical scenarios of stroke, a large majority of the women knew to call 911 for stroke symptoms. After the educational intervention, the response to “call 911” for stroke symptoms significantly improved from 85.9% at the baseline survey to 94.1% at 6 weeks ($P=0.002$). The improvement was still apparent at 5 months (94.3%).

**Discussion**

Despite the challenges of community-based research encountered within our project, we demonstrated sustained improvement in knowledge of stroke warning signs by educating women in black beauty shops. The intervention also appeared to impact women’s plan of action if symptoms of stroke were to occur, because they indicated that they were more likely to call 911 in response to symptoms and signs of a stroke after the intervention.

The beauty shop is an excellent locale for medical education, especially within the black community, because women tend to know and trust their beauticians and have regular appointments that are often quite extended. In other words, the beauty shop is the ideal combination of a “captive audience” and a trusted educator. Our data support the concept that using the beauty shop for medical education is feasible and worthwhile. Several medical education projects using beauty and barber shops for other diseases have now begun, such as hypertension, prostate cancer, and breast cancer awareness (personal communication with public health officials in several states).

**Table 1. Demographics and Stroke Risk Factors Among the Black Women Beauty Shop Project Participants (n=383)**

<table>
<thead>
<tr>
<th>Age group</th>
<th>Number (Percentage)</th>
</tr>
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<tbody>
<tr>
<td>18 to 39 years</td>
<td>116 (30.3%)</td>
</tr>
<tr>
<td>40 to 59</td>
<td>182 (47.5%)</td>
</tr>
<tr>
<td>60 to 75</td>
<td>74 (19.3%)</td>
</tr>
<tr>
<td>75+</td>
<td>11 (2.9%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th>Number (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High school or less</td>
<td>119 (31.1%)</td>
</tr>
<tr>
<td>Some college or college degree</td>
<td>264 (68.9%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Risk factors*</th>
<th>Number (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>157 (41.0%)</td>
</tr>
<tr>
<td>High cholesterol</td>
<td>71 (18.5%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>46 (12.0%)</td>
</tr>
<tr>
<td>Current smoker</td>
<td>43 (11.2%)</td>
</tr>
<tr>
<td>Heart disease</td>
<td>18 (4.7%)</td>
</tr>
<tr>
<td>Arrhythmia</td>
<td>14 (3.7%)</td>
</tr>
<tr>
<td>Prior stroke or TIA</td>
<td>13 (3.4%)</td>
</tr>
<tr>
<td>Peripheral vascular disease</td>
<td>11 (2.9%)</td>
</tr>
<tr>
<td>Carotid stenosis</td>
<td>4 (1.0%)</td>
</tr>
</tbody>
</table>

*Survey stated “check all that apply.”

**Table 2. Warning Sign and Risk Factor Knowledge**

<table>
<thead>
<tr>
<th>No. of Correct Responses</th>
<th>Warning Sign Knowledge</th>
<th>Risk Factor Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Baseline survey (n=383)</td>
<td>13.3%</td>
<td>15.9%</td>
</tr>
<tr>
<td>6-week survey (n=354)</td>
<td>7.6%</td>
<td>13.3%</td>
</tr>
<tr>
<td>5-month survey (n=318)</td>
<td>5.7%</td>
<td>12.0%</td>
</tr>
</tbody>
</table>
Unfortunately, knowledge of stroke risk factors in this study did not improve, which is similar to studies within our own community and in other areas. Perhaps this is because we did not have a mnemonic for remembering stroke risk factors, as we did for stroke warning signs (FAST). This lack of improvement may also be related to the topic itself: remembering risk factors requires more abstract thinking, and modifying some of the risk factors requires behavior changes that are notoriously difficult to achieve (such as smoking cessation, healthy lifestyle, etc.). However, education regarding risk factors should not be abandoned: the Health Belief Model of social theory suggests that knowledge of risk factors, and in particular, the person’s own perceived “vulnerability” to stroke, are important in changing behavior.

Therefore we believe that educational programs need to include more than just stroke warning signs, and risk factor educational programs may in fact need to be taught separately and in different venues from stroke warning signs. Further research is clearly needed to find better ways to educate the public regarding stroke risk factors and to formulate effective methods to teach prevention of vascular disease.

One limitation of our analysis is that we did not have a control group for comparison. When designing the study, we were concerned about the ethical implications of randomizing a difficult to reach high-risk group of subjects to a “no education” group. Therefore, we educated all the subjects that we could, and in fact, hoped that the beauticians would educate many more people than were just enrolled in the study.

There is a potential for selection bias, and our results must be extrapolated with caution. The women in this study were women who kept regular appointments at a beauty shop. It is possible that these women were more knowledgeable and highly educated than the general population. It is also possible that poorer women were more likely to participate because of the financial incentive, which typically has been associated with lower rates of knowledge in other surveys. This study was not intended to be a representative survey of knowledge in black women, but instead a “proof of concept” regarding the use of the beauty shop as an educational locale.

It is also possible that there was a bias introduced by drop-out of subjects. We had an 83% participation rate 5 months after the intervention. Perhaps the 17% who did not complete the third survey were less reliable or less knowledgeable than those who completed the study. However, we note that the follow-up of patients also relied on having a hair appointment within 1 week of the designated 5-month follow-up time point and that these 17% may not have needed a hair appointment at that time or have missed the appointment for some other reason.

Many of the challenges faced by this unique project arose as a by-product of current U.S. HIPAA privacy regulations. In designing the project, we wanted to ensure that it was truly community-based with excellent participation by black women. Within the black community, education through trusted family and friends is extremely important, as mistrust of the medical community is prevalent. According to the Social Cognitive Learning Theory, modeling of others is important for behavioral change, and modeling is considered most effective when those being modeled are similar to the observer. In addition, obtaining HIPAA-compliant investigator-obtained informed consent have previously been shown to introduce significant selection bias into registry studies. For these reasons, we chose to have the surveys and educational message delivered by the beauticians. A letter that described the project and contained an “opt-out” clause was substituted for informed consent documentation (after IRB approval). Because HIPAA regulations do not allow the collection of potentially identifying information without investigator-obtained informed consent, tracking of subsequent surveys became problematic. Suggestions for future community-based projects would include tracking of more specific demographic variables, such as actual age instead of age range, or asking the subjects to list a nonde- mographic nonidentifying question, such as listing a favorite animal. When nonresearch-trained personnel perform education and administer study materials, tracking and rigorous control of the data becomes increasingly difficult.

Another limitation of community-based research is making sure the language is interpreted correctly by adjudicators and investigators outside of the community being studied. Even among English-speaking communities, different words can take on different contextual meanings. For example, many of our participants used the term “sugar” to mean “diabetes” as a risk factor for stroke, which the study investigators had originally counted as incorrect, and later corrected after discussing with our beauticians. This example emphasizes the need for community participation in the project from original study design all the way through data analysis and interpretation, to avoid these kinds of misunderstandings.

Despite the difficulties in accurate tracking of surveys, we were able to show an overall improvement in the knowledge of stroke warning over a 5-month time frame. Our results suggest that the beauty shop is a potentially excellent educational setting for stroke and other health issues for black women and should be used in future studies. Whether changes in current HIPAA regulations could facilitate the process to help improve the quality of community-based research should be explored.

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Disclosures

None.

References


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