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;39:000-000.)

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

More strokes and stroke-related deaths occur in women than in men, 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.

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. 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.

Unfortunately, previous studies have found that public awareness of stroke warning signs is poor in the United States and in other countries. Persons at highest risk for stroke, including the elderly and blacks, have the least knowledge. Consequently, many patients seek medical attention well after the 3-hour window allowed for rt-PA administration. 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...
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, ie, 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
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% \((P = 0.53; \text{Table 2})\). 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>(n) (% of (n))</th>
</tr>
</thead>
<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>(n) (% of (n))</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>(n) (% of (n))</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 1 2 3</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>Baseline survey ((n = 383))</td>
<td>13.3 15.9 30.0 40.7%</td>
<td>7.6 14.1 31.6 46.7%</td>
</tr>
<tr>
<td>6-week survey ((n = 354))</td>
<td>7.6 13.3 28.3 50.8%</td>
<td>6.5 11.3 28.2 54.0%</td>
</tr>
<tr>
<td>5-month survey ((n = 318))</td>
<td>5.7 12.0 31.8 50.6%</td>
<td>7.9 15.4 28.0 48.7%</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 those 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-nomographic 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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This study was funded by a grant from the Hazel K. Goddess Fund for Stroke Research in Women.

Disclosures
None.

References


Beautyshop Stroke Program Survey

For our records, please answer the following questions about yourself:

1. How old are you?  CIRCLE ONE ONLY
   a. 18-39
   b. 40-59
   c. 60-75
   d. 75+

2. Are you: FEMALE or MALE? (circle one)

3. What is your race?  CIRCLE ONE ONLY
   a. African-American
   b. Caucasian
   c. Asian
   d. Other __________

4. How far did you go in school?  CIRCLE ONE
   a. did not complete high school
   b. high school diploma or GED
   c. some college
   d. college degree

Now, please turn the page and answer our questions about stroke and heart attack.

1. Please list three risk factors for stroke:
   (Risk factors are things that make it more likely for somebody to have a stroke)
   1. ________________________________________________
   2. ________________________________________________
   3. ________________________________________________

2. Please list three warning signs of stroke:
   (Warning signs are symptoms that a person has that a stroke is happening)
   1. ________________________________________________
   2. ________________________________________________
   3. ________________________________________________

3. What is the first thing you should do when you, or someone else, has stroke warning signs?  CIRCLE ONE ONLY
   a. call a friend for help
   b. wait and see if they get better
   c. take them to emergency room
   d. call 911
   e. call a doctor

4. Where did you learn about stroke? CIRCLE ANY THAT APPLY!
   a. in school
   b. on TV
   c. from a family member/friend
   d. doctor’s office
   e. newspaper/magazine

5. Your 70 year old family member suddenly says she can’t use her arm, and that she doesn’t feel good. When you look at her, she seems confused and her face looks funny, and she isn’t moving her right arm. She says not to worry, she just wants to lie down. What should you do?
   a. Call a friend and ask them about it
   b. Let her rest for a while and see if it passes
   c. Call 911
   d. Call her doctor

What do you think is going on?
   a. she’s just tired
   b. she’s having a heart attack
   c. she’s got a bad case of flu
   d. she’s having a stroke

6. Your 45 year old family member says that he is having pain in his chest. He looks sweaty and he keeps rubbing his left arm. What should you do?
   a. Call a friend and ask them about it
   b. Let him rest for a while and see if it passes
   c. Call 911
   d. Call his doctor

What do you think is going on?
   a. he’s just tired
   b. he’s having a heart attack
   c. he’s got a bad case of flu
   d. he’s having a stroke

1. What are your medical problems?  Circle any of the following:
   a. high blood pressure
   b. diabetes
   c. cancer
   d. lung disease (emphysema, for example)
   e. heart attacks or angina (chest pain)
   f. peripheral vascular disease (poor circulation in the legs)
   g. high cholesterol
   h. arrhythmias (heart beating irregularly/too fast, atrial fibrillation)
   i. history of a stroke or transient ischemic attack (a “mini-stroke”)
   j. carotid artery stenosis (blocked arteries in the neck)
   k. history of a heart bypass surgery? (open-heart surgery)
   l. none of the above

2. List your medicines, if you can remember them:

   ______________________________________________________
   ______________________________________________________
   ______________________________________________________
   ______________________________________________________
   ______________________________________________________

3. Do you smoke?  YES or NO
   If yes, how many packs of cigarettes per day?
   a. less than a 1/2 pack/day
   b. 1 pack/day
   c. 2 packs/day
   d. 3 packs/day
   e. more than 3 packs per day

THANK YOU VERY MUCH!!!

Figure I. Survey questions given to Beautyshop Project participants.
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