Understanding Reasons for Delay in Seeking Acute Stroke Care in an Underserved Urban Population

Amie W. Hsia, MD; Amanda Castle, BA; Jeffrey J. Wing, MPH*; Dorothy F. Edwards, PhD; Nina C. Brown, MPH; Tara M. Higgins, BA; Jasmine L. Wallace, MPH; Sara S. Koslosky, MPH; M. Chris Gibbons, MD, MPH; Brisa N. Sánchez, PhD*; Ali Fokar, MPH; Nawar Shara, PhD; Lewis B. Morgenstern, MD; Chelsea S. Kidwell, MD

Background and Purpose—Few patients arrive early enough at hospitals to be eligible for emergent stroke treatment. There may be barriers specific to underserved, urban populations that need to be identified before effective educational interventions to reduce delay times can be developed.

Methods—A survey of respondents’ likely action in a hypothetical stroke situation was given to 253 community volunteers in the catchment areas of a large urban community hospital. Concurrently, 100 structured interviews were conducted in the same hospital with patients with acute stroke or a proxy.

Results—In this predominantly urban, black population, if faced with a hypothetical stroke, 89% of community volunteers surveyed said they would call 911 first, and few felt any of the suggested potential barriers applied to them. However, only 12% of patients with stroke interviewed actually called 911 first (OR, 63.9; 95% CI, 29.5 to 138.2). Instead, 75% called a relative/friend. Eighty-nine percent of patients with stroke reported significant delay in seeking medical attention, and almost half said the reason for the delay was thinking the symptoms were not serious and/or they would self-resolve. For those arriving by ambulance, only 25% did so because they thought it would be faster, whereas 35% cited having no other transportation options.

Conclusions—In this predominantly black urban population, although 89% of community volunteers report the intent of calling 911 during a stroke, only 12% of actual patients with stroke did so. Further research is needed to determine and conquer the barriers between behavioral intent and actual behavior to call 911 for witnessed stroke. (Stroke. 2011;42:00-00.)

Key Words: acute stroke ■ African American ■ barriers ■ disparities ■ education ■ emergency medical services ■ survey

Stroke has a disproportionate impact on blacks compared with whites reflected in higher incidence and mortality rates.1-5 Time from stroke onset to hospital presentation is a critical factor in acute stroke care because eligibility for thrombolytic therapy requires early arrival. Some studies have found significant racial differences in this delay time.6,7 which likely contributes to the differences in tissue plasminogen activator treatment rates by race that have been demonstrated in some studies.8,9

Previous work has identified factors that may contribute to delay in seeking stroke treatment and has reinforced the complexity of this decision-making process. These include cognitive factors such as considering the symptoms as not being serious,10,11 and social factors such as calling a relative or physician instead of calling 911.12 Additional racial and cultural factors, including embarrassment and perceived control/self-efficacy, have not been fully explored.12 Understanding why people make certain decisions during an acute event is crucial for developing effective education interventions to reduce time to hospital arrival. This study surveyed a primarily medically underserved black urban population about stroke knowledge and beliefs that may be barriers to seeking urgent medical attention. Healthy volunteers and hospitalized patients with acute stroke or proxies in the same community were interviewed concurrently to compare behavioral intent versus actual behavior and gain insight into reasons for delay. We hypothesized that there are barriers to seeking acute stroke care that are specific to an urban population about stroke knowledge and beliefs that may be barriers to seeking urgent medical attention. Healthy volunteers and hospitalized patients with acute stroke or proxies in the same community were interviewed concurrently to compare behavioral intent versus actual behavior and gain insight into reasons for delay. We hypothesized that there are barriers to seeking acute stroke care that are specific to an urban population.
underserved population. These may include (1) informational barriers (knowledge of treatment and recognition of warning signs); (2) attitudinal barriers (mistrust of healthcare system and providers); and (3) institutional barriers (preparedness for acute treatment in a high-risk population).

Methods

Community Survey

A convenience sample of 20 community-based sites in the high-stroke-risk catchment area of a large urban community hospital, Washington Hospital Center in Washington, DC, was identified between 2007 and 2008 for administration of a stroke knowledge and hypothetical action survey. These sites included churches, senior citizen centers, men’s groups, and community health fairs. This survey was modified from 1 developed by the TLL Temple Project to assess community knowledge before educational interventions in East Texas. The community survey was administered by trained members of the research team who performed face-to-face interviews with community volunteers. It consisted of open-ended and multiple option questions regarding stroke symptom identification and 5-point Likert scale ratings for attitudinal and self-efficacy statements (Figure S1, http://stroke.ahajournals.org). Respondents were also presented with a hypothetical situation of a relative experiencing a possible stroke and asked how likely they would be to take certain actions. This design has been found reliable in studies of health interventions with low-literate adults.

In-Hospital Stroke Survey

Concurrently, 100 structured interviews were conducted by a single interviewer with patients with acute stroke in the same hospital (Washington Hospital Center) within 48 hours of admission and consisted of socioeconomic items, initial impression, first action, transport mode, and open-ended questions regarding reasons for transport mode and delay to hospital arrival (Figure S2). Reasons for delay were further explored with multiple option questions. To include mild and severe strokes, if the patient could not be interviewed because of aphasia, severe dysarthria, or altered mental status, then a relative or friend (proxy) who was with the patient at the time of presentation was interviewed.

Statistical Approach

Participant characteristics were summarized as percents. For variables collected in both surveys, we compared frequencies using χ² and Fisher exact test. Among community participants, stroke symptom recognition from open and multiple option questions were summarized as percents. Among patients with stroke, emergency medical services (EMS) use was summarized as percents. Among those arriving by EMS, reasons for use were applied to them. Among those arriving by EMS, reasons for use were summarized as percents. All analyses were performed in SAS Version 9.1.3.

This study was approved by the local Institutional Review Board. Written informed consent was obtained from the community volunteers and a $5 gift card was provided after the survey. Waiver of written informed consent was obtained for the patient/proxy interview.

Results

Community Survey

A total of 253 community volunteers from Washington, DC, participated in the survey (Table 1). Two thirds recalling being exposed to stroke information in the previous year with television news, newspapers/magazines, and doctors cited as common sources. Ten percent of respondents had a stroke themselves, 49% had a relative with stroke, and only 14% had no experience with stroke.

Despite the exposure to stroke information reported by the community volunteers from both public education and personal experience, on open-ended questioning, only 15% to 48% of respondents were able to cite the classic stroke symptoms (“sudden trouble speaking” and “numbness or weakness of the face”) were most frequently cited: 36% and 48% of respondents, respectively). Stroke symptom recognition increased to 62% to 82% of respondents with multiple option questions. However, 69% of respondents also incorrectly identified chest pain as a stroke symptom based on their answers to the open-ended and multiple option questions (18% cited chest pain as a symptom in the open-ended question, 54% on the multiple option question, and 69% on either or both questions).

In-Hospital Survey

There was a total of 100 respondents for the patient/proxy interview (Table 1): 82 were patients themselves, 13 were a
Table 1. Participant Characteristics

|                  | Survey Respondents (n=253) | Stroke Patient/Proxy Respondents (n=100) | \(P\)  
|------------------|-----------------------------|------------------------------------------|-------
| **Race**         |                             |                                          |       
| Black/African American | 91.3 (231)                  | 80*                                      |       
| White/non-Hispanic  | 2.37 (6)                    | 7.2*                                     |       
| Multi             | 2.8 (7)                     |                                          |       
| Other             | 2.0 (5)                     | 9.6*                                     |       
| Missing           | 0.8 (2)                     |                                          |       
| **Gender**        |                             |                                          |       
| Male              | 58.1 (147)                  |                                          |       
| Female            | 41.1 (104)                  |                                          |       
| Missing           | 0.8 (2)                     |                                          |       
| **Education**     |                             |                                          |       
| Less than high school graduate | 24.9 (63)                  | 27.0 (27)                                | 0.786 
| High school graduate/GED | 41.1 (104)                  | 31.0 (31)                                | 0.101 
| Some college      | 19.0 (48)                   | 4.0 (4)                                  | <0.001 
| College graduate  | 9.1 (23)                    | 29.0 (29)                                | <0.001 
| Postcollege       | 5.9 (15)                    | 9.0 (9)                                  | 0.425 
| **Health insurance** |                         |                                          |       
| Private PPO/HMO/other | 29.7 (75)                  | 65.0 (65)                                | <0.001 
| Medicare          | 23.7 (60)                   | 43.0 (43)                                | <0.001 
| Medicaid          | 32.8 (83)                   | 25.0 (25)                                | 0.192 
| DC Alliance       | 19.0 (48)                   |                                          |       
| Insurance type unknown | 4.0 (10)                   |                                          |       
| No insurance      | 7.5 (19)                    | 9.0 (9)                                  | 0.804 
| Do not know       | 2.0 (5)                     |                                          |       
| Refused           | 0.4 (1)                     |                                          |       

*Based on confirmed ischemic strokes hospitalized at Washington Hospital Center in 2008 (individual demographic data were not collected).

Table 2. Intended Versus Actual Responses to Stroke Symptoms

| Stroke Action         | Survey Respondents (n=253) | Stroke Patient/Proxy Respondents (n=100) | \(OR^* (95\% CI)\)  
|-----------------------|-----------------------------|------------------------------------------|----------------------
| Call 911              | 89.3 (226)                  | 12 (12)                                  | 63.9 (29.5–138.2)    
| Call relative/friend  | 6.3 (16)                    | 75 (75)                                  | 0.02 (0.01–0.04)     
| Call doctor           | 0.8 (2)                     | 1 (1)                                    | 0.4 (0.04–4.8)       
| Call no one/drive to hospital | 3.2 (8)                     | 2 (2)                                    | 1.9 (0.4–9.4)        
| Other                 | 10 (10)                     |                                          |                      

*Comparisons were made using logistic regression models controlling for insurance differences.

Discussion

In a high-risk, predominantly black medically, underserved urban population, significant discrepancies exist between

combination of patient and a relative/friend, and 5 were a relative/friend only. Half of the patients failed to use EMS and instead reached the hospital by car or public transportation. There was no difference in patients’ use of EMS for those whose interviews were completed by a proxy or a combination of patient and proxy compared with the patients themselves. There was no significant association between level of education and use of EMS. In fact, the trend favored more frequent use of EMS by those with less education (56.9% of those with a high school diploma or less used EMS versus 38.1% of those with more than a high school diploma, \(P=0.063\)), a finding consistent with the responses from our healthy volunteers. There was also no difference in EMS use between those who lived alone and those who did not.

Comparison of Community Versus In-Hospital Survey Responses

If faced with a hypothetical stroke, of community volunteers surveyed, 89% said they would call 911 first. In contrast, only 12% of patients with stroke interviewed in fact called 911 first (Table 2). This was highly significant even when controlling for differences between the 2 groups in insurance (OR, 63.9; 95% CI, 29.5 to 138.2). The first action of stroke patients interviewed was more likely instead to call a relative/friend (Table 2).

Barriers for Calling 911

Few community volunteers felt any of the suggested barriers applied to them. Those with lower education were actually more likely to plan to call 911 (93% versus 83%, \(P=0.012\)). Meanwhile, 89% of patients with stroke felt there was a significant delay in seeking medical attention, and in response to open-ended questions, almost half cited thinking the symptoms were not serious and/or the symptoms would resolve as reasons for delay (data not shown). The multiple option format revealed an even higher frequency of these and other barriers (Figure). Of those with actual and/or perceived delay in hospital arrival, all attested that ≥1 of the listed reasons for delay applied to them, including almost one fourth who thought there was nothing that could be done to help.

Fewer than half of patients reporting each of the most common barriers ultimately arrived by EMS except for those who cited no transportation or calling a friend/relative first (Figure).

Thirty-two percent of patients/proxies reported initially recognizing that the patient may be having a stroke with no association with level of education (25.9% of those with lower education recognized the stroke symptoms versus 40.5% of those with higher education, \(P=0.122\)). Still only 56.3% of these patients arrived by ambulance compared with 45.6% of those who did not suspect stroke (\(P=0.320\)). Despite suspecting stroke, more than two thirds of these patients cited thinking the symptoms were not serious or that the symptoms would resolve as reasons for delay, a similar frequency compared with those who did not suspect stroke.

Of those who arrived by ambulance, only one fourth did so out of belief that using EMS would be the fastest method of transportation to the hospital, whereas 35% cited not being able to drive or having no other transportation options.

Discussion

In a high-risk, predominantly black medically, underserved urban population, significant discrepancies exist between

comparing the suggested barriers ultimately arrived by EMS except for those who cited no transportation or calling a friend/relative first (Figure). Thirty-two percent of patients/proxies reported initially recognizing that the patient may be having a stroke with no association with level of education (25.9% of those with lower education recognized the stroke symptoms versus 40.5% of those with higher education, \(P=0.122\)). Still only 56.3% of these patients arrived by ambulance compared with 45.6% of those who did not suspect stroke (\(P=0.320\)). Despite suspecting stroke, more than two thirds of these patients cited thinking the symptoms were not serious or that the symptoms would resolve as reasons for delay, a similar frequency compared with those who did not suspect stroke.

Of those who arrived by ambulance, only one fourth did so out of belief that using EMS would be the fastest method of transportation to the hospital, whereas 35% cited not being able to drive or having no other transportation options.
how healthy volunteers say they would behave during a hypothetical stroke compared with how hospitalized patients with stroke actually behaved at the time of their stroke. Whereas most healthy volunteers say they would call 911 immediately, most patients with stroke delay taking this action. This paradoxical failure to act promptly contributes to delayed presentation, reduced opportunity for acute therapy, and greater stroke morbidity.

A potential explanation for the observed paradox or disconnect between behavioral intent versus actual behavior is that patients or witnesses may not recognize stroke signs and symptoms when they occur and, therefore, not trigger a call for EMS. Although the Delay in Accessing Stroke Healthcare (DASH) II study did not find an association between stroke knowledge and EMS use (in fact, those with greater knowledge were less likely to use EMS), perhaps lay people have difficulty translating this knowledge to accurately identify a stroke as it is happening. However, in our study, even among those who suspected stroke, only approximately half used EMS. Therefore, being able to recognize stroke is not sufficient. The action a patient takes in the acute stroke setting may depend on multiple factors, including depth of stroke knowledge; presence of social, cultural, or behavioral barriers; and ability to translate knowledge into appropriate action.15

One factor frequently cited by patients as a contributor to delay was the belief that no medical intervention could help them. That observation underscores the importance of educating the public on not only the availability of a time-sensitive therapy, but also motivating the public to use it. Although current stroke education campaigns focus on symptom recognition and calling 911, most do not explicitly state that calling 911 can result in treatment to improve outcome. If people are taught that prompt treatment of stroke is not just limited to standard supportive care, that knowledge could provide motivation that may overcome social and attitudinal barriers found here and reported in other studies.15,17

Additional misperceptions appear to contribute to delay. Despite the exposure of the study community to national stroke education campaigns, two thirds of the patients did not recognize they were having a stroke. In addition, the community often believed chest pain to be a common stroke symptom, which may have contributed to patients’ failure to recognize stroke.

The most frequently cited factors for delay included patients’ initial belief that their symptoms were not serious and/or did not require treatment. Even among the one third of patients who recognized they were experiencing a stroke, use of 911 was lower than might be expected given the responses of healthy volunteers to questions about a hypothetical stroke. Some patients may decide to call 911 only if they feel their symptoms are severe.11,15 Future studies should explore community members’ thresholds for calling 911 depending on hypothetical symptom severity and should examine the correlation between patients’ tendency to call 911 and their stroke severity.

Nevertheless, such findings taken in aggregate indicate that current education campaigns are not achieving their goal in this target community; similar findings might be expected in other urban, underserved communities. Therefore, new approaches to public education about stroke symptoms may be necessary. These might include (1) culturally appropriate descriptions of stroke signs and symptoms with a distinction from cardiac signs and symptoms; (2) education campaigns targeted at audiences other than the potential stroke patient, for example, children16,17; (3) an emphasis on the fact that a treatment exists that can improve outcomes and minimize disability; and (4) an emphasis on the fact that stroke symptoms, even when not outwardly severe or dramatic, can be manifestations of a serious disease process requiring immediate medical attention.

The current findings indicate that surveying community volunteers does not provide reliable data on what barriers exist in that community to seeking acute stroke care. It was difficult to establish in a hypothetical scenario addressed to community volunteers why patients might delay calling 911 in the setting of an acute stroke.

This study has several limitations regarding participant selection. First, the respondents for both the community survey and patient/proxy interview were self-selected, which introduces selection bias, and the number of refusals was not collected, thus preventing the calculation of response rates. Second, some characteristics such as medical history other than stroke were not collected for the community volunteers limiting our ability to ensure the 2 groups are comparable, and there were socioeconomic differences between the survey and patient respondents. Still, the community participants were recruited at organizations in the catchment area of the hospital, chosen specifically because they serve disproportionately black, lower-income, and/or elderly populations, similar to the population of patients with stroke at this particular hospital. To attempt to mitigate for some of these differences, we evaluated the effects of education and adjusted for insurance type when conducting comparisons between groups. Third, it is possible that the recruited patients had less severe strokes than the hospital population, because the majority of interviews in this study were completed by the patients with stroke themselves instead of by proxy. Milder stroke severity may have contributed to their decision not to use EMS. However, our finding that there was no greater use of EMS for those patients who could not complete the interview themselves suggests that stroke severity does not fully account for whether a patient will arrive by ambulance. This is an important topic for future investigation.

Conclusions

This study illustrates that although most in this high-risk community can correctly answer a survey question to call 911 immediately in case of “stroke,” patients tend to not take this action when faced with the actual situation. Additional studies are needed to explore reluctance to call 911 so that educational interventions can be developed to address these reasons for delay.

Acknowledgments

The investigators thank the Acute Stroke Program of Interventions addressing Racial and Ethnic disparities (ASPIRE) community...
survey and patient/proxy interview respondents for their time and insights.

**Sources of Funding**
Supported by the National Institute of Neurological Disorders and Stroke (NINDS) and the National Center on Minority Health and Health Disparities (NCMHD) (U54NS057405).

**Disclosures**
None.

**References**
Understanding Reasons for Delay in Seeking Acute Stroke Care in an Underserved Urban Population


Stroke. published online May 5, 2011;

Stroke is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
Copyright © 2011 American Heart Association, Inc. All rights reserved.
Print ISSN: 0039-2499. Online ISSN: 1524-4628

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://stroke.ahajournals.org/content/early/2011/05/05/STROKEAHA.110.604736

Data Supplement (unedited) at:
http://stroke.ahajournals.org/content/suppl/2011/06/01/STROKEAHA.110.604736.DC1

Permissions: Requests for permissions to reproduce figures, tables, or portions of articles originally published in Stroke can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office. Once the online version of the published article for which permission is being requested is located, click Request Permissions in the middle column of the Web page under Services. Further information about this process is available in the Permissions and Rights Question and Answer document.

Reprints: Information about reprints can be found online at:
http://www.lww.com/reprints

Subscriptions: Information about subscribing to Stroke is online at:
http://stroke.ahajournals.org/subscriptions/
ONLINE SUPPLEMENT

Understanding Reasons for Delay in Seeking Acute Stroke Care in an Underserved Urban Population

Figure S1. Community Survey
Figure S2. Patient/Proxy Interview
We are conducting a study sponsored by Georgetown University. We would like a few minutes of your time to help us discover community awareness of strokes and related health issues. Please participate in the survey even if you do not know much about this topic because we are trying discover exactly what people like yourself actually know about this serious medical problem. Your input will be very helpful in developing community awareness of a serious problem. I also want to assure you that your answers will remain anonymous.

1. Have you seen, heard, or read anything about strokes in the last year or so?  
   □ Yes  □ No → #3  □ Don’t Know → #3  □ Refused → #3

2. Which of the following were the sources of your information on strokes? **Mark All That Apply.**
   □ Billboards  □ Doctor  □ Newspaper / Magazine  □ Radio News
   □ Radio PSA*  □ TV News  □ TV PSA*  □ Work / Organization Presentation
   □ Other: ____________________________________________
   *Public Service Announcement

3. Have you known anyone who has had a stroke? If so, who?  
   □ Acquaintance  □ Close Friend  □ Family Member  □ Spouse / Partner
   □ No Personal Experience  □ Self  □ Don’t Know  □ Refused

4. How would you rate your ability to recognize the symptoms of a stroke?  
   □ Excellent  □ Good  □ Fair  □ Poor

5. Suppose you are visiting a friend who begins to feel unwell. Neither of you knows exactly what is wrong. Can you tell me any symptoms your friend would have that might be a sign that he/she is having a stroke? **Mark All That Apply.**
   □ Sudden Confusion  □ Sudden Chest Pain
   □ Sudden Trouble Speaking  □ Sudden Dizziness or Loss of Balance
   □ Numbness or Weakness of Face  □ Sudden Problems Walking
   □ Abdominal Pain  □ Sudden Trouble Seeing in One or Both Eyes
   □ Tingling of Both Hands  □ Shortness of Breath or Difficulty Breathing
   □ Numbness or Weakness of Arms or Legs  □ Severe Headache with No Known Cause
   Additional Symptoms: ____________________________________________
6. Now I am going to read a list of additional symptoms. Please answer Yes or No if you think each is a possible symptom of a stroke.

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Sudden Confusion</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>b. Sudden Trouble Speaking</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>c. Numbness or Weakness of Face</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>d. Tingling of Both Hands</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>e. Numbness or Weakness of Arms or Legs</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>f. Abdominal Pain</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>g. Sudden Chest Pain</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>h. Sudden Problems Walking</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>i. Sudden Dizziness or Loss of Balance</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>j. Sudden Trouble Seeing in One or Both Eyes</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>k. Shortness of Breath or Difficulty Breathing</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>l. Severe Headache with No Known Cause</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
</tbody>
</table>

7. Again, suppose you are at your friend’s house and you think your friend might be having a stroke. Please tell me exactly what the first thing is you would do at this point.

- □ Call or Go to Doctor.
- □ Wait, i.e. Call friend’s nearest family member, have friend lie down to rest, wait and see if symptoms resolve.
- □ Take Friend to Emergency Room Yourself.
- □ Call 911.

8. I am going to read you some statements about what a person might do if he or she thinks a friend is having a stroke. In this situation, the friend says, “Oh, I’ll be okay. You don’t need to do anything”. For each action I read, please tell me, on a scale of 1 to 5 with one being not at all likely, and five being very likely, how likely you would be to take that action. How likely are you to…

<table>
<thead>
<tr>
<th></th>
<th>Not At All Likely</th>
<th>Very Likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Write down the time symptoms began?</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>b. Ask ER doctor if your friend qualifies for immediate treatment with a “clot buster” or “tPA” for stroke?</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>c. Ask the ER doctor to evaluate your friend for a stroke?</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>
9. Some people may for different reasons delay or avoid calling 911 if they have symptoms of a stroke. I would like to find out if you feel that any of these reasons apply to you. I am going to read you a list of reasons; please rate how much each reason might contribute to you delaying or avoiding calling 911.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not At All Likely</th>
<th>Very Likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. You would be embarrassed to have an ambulance come to your house</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>b. You think the symptoms will go away without treatment.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>c. You would worry about missing work if you ended up admitted to the hospital.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>d. You are afraid of doctors, medical tests and treatments</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>e. You would worry about the cost of the ambulance ride and how to pay for it.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>f. You would worry about the cost of being hospitalized and how to pay the bills.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>g. You think that it would take too long for Emergency Medical Services (EMS) to come pick you up and it would be faster to find your own way to the hospital.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>h. Are there other reasons I have not mentioned that might make you delay or avoid calling 911?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Those are all the questions related to stroke that I have for you. I just need to get some basic demographics information and we will be done.

10. Gender:    □ Male        □ Female

11. I would like to ask you about your living arrangements. Would you say are: **Mark All That Apply.**

- □ Married or Living with Partner    □ Living with Children Under 18 Years of Age
- □ Living Alone                   □ Don’t Know
- □ Living with Adult Family / Friends □ Refused

12. With what race or ethnicity do you identify? **Mark All That Apply**

- □ White / Non-Hispanic            □ Other: ________________________________
- □ Hispanic                        □ Don’t Know
- □ Black / African American        □ Refused
- □ Asian / Pacific Islander

13. Age: ________    □ Don’t Know    □ Refused

14. What is the highest grade of school that you’ve completed?

- □ Less Than High School Grad    □ High School Graduate / GED    □ Some College
- □ College Graduate              □ Post College                 □ Don’t Know
- □ Refused

15. What type of health insurance or coverage do you now have? **Mark all that apply.**

- □ No Insurance                  □ Medicare                    □ Medicaid
- □ Private PPO / HMO*             □ Private, not PPO / HMO*     □ DC Alliance
- □ Insurance, Type Unknown       □ Don’t Know                  □ Refused

*HMO: Requires a primary care doctor to authorize all services.
*PPO: Has a preferred group of physicians from who to obtain services.

Zip Code: __________

Staff’s Initials: _____ _____ _____    Completion Date: ____________________________
Interview Introduction

Hello, my name is [ ] and I am a member of the Washington Hospital Center and Georgetown stroke team. I would like to invite you to participate in a research study looking at how people learn about stroke. We hope to help people in the future by improving the way we teach the Public about stroke. This questionnaire will only take a few minutes and all your answers will be kept confidential and anonymous. Are you willing to participate in our study?

☐ Yes  \( \Rightarrow \) CONTINUE WITH QUESTIONNAIRE
☐ No \( \Rightarrow \) THANK PATIENT AND STOP HERE

Thank you for agreeing to participate in this study.

Before we begin, can you tell me your age?

☐ Check if correct age is given

I am going to ask you a series of questions that relate to the symptoms that brought you to the hospital and how you arrived at the hospital.
1. When you developed the symptoms that brought you to the hospital, what did you FIRST think was wrong (record patient response without prompting)?

(1) ☐ Heart attack ➔ GO TO #6
(2) ☐ Stroke
(3) ☐ TIA
(4) ☐ Other - Please specify: ________________________ ➔ GO TO #6
(5) ☐ Didn’t know ➔ GO TO #6

2. Where did you learn about the warning signs of stroke . . . anywhere else . . . anywhere else . . . ?" (Record as many as the patient states; do not prompt.)

(1) ☐ I had a stroke/TIA before
(2) ☐ Relative/friend had a stroke
(3) ☐ TV
(4) ☐ Radio
(5) ☐ Newspaper or magazine advertisement
(6) ☐ Newspaper or magazine article
(7) ☐ Health fair
(8) ☐ Lecture at Church
(9) ☐ Lecture at Community group
(10) ☐ Lecture at Employer
(11) ☐ Lecture at Nursing home
(12) ☐ Lecture at Health clinic
(13) ☐ Doctor
(14) ☐ Don’t remember (PROBE: “Any idea where…”)
(15) ☐ Other – Specify:

3. Whom did you first call or speak with after your symptoms started?

(1) ☐ No one/drove to hospital
(2) ☐ 911
(3) ☐ Primary Care Provider
(4) ☐ Relative/Friend
(5) ☐ Other Please specify:
4. What was the reaction of the person you first called or spoke with after your symptoms started?

(1)  Encouraged me to call 911
(2)  Encouraged me to call my PCP
(3)  Encouraged me to go to the hospital
(4)  Drove me to the hospital
(5)  Drove me to a local clinic
(6)  Recommended that I wait to see if my symptoms improved
(7)  Other – Please specify: ____________

5. How did you arrive at the emergency department/hospital (If patient was transferred from another hospital, record the means by which they first arrived for medical attention)?

(1)  Ambulance
(2)  Personal car
(3)  Relative’s/Friend’s car
(4)  Taxi
(5)  Public transportation (e.g. bus, subway)
(6)  Other - Please specify: ____________________________

6. Why did you choose to travel to the hospital that way?

Write in response:

___________________________________________________________
POTENTIAL BARRIERS

For patients presenting >3 hours after symptom onset:

7. What was the reason for delay in coming to the hospital:

(1st ask open ended and write in response(s)):

_________________________________________
________________________________________________________________________

Then ask specifically if each of the following was a factor and check all that apply:

(1) [ ] Didn’t believe there was anything that could be done to help
(2) [ ] Concerned about cost
(3) [ ] Don’t have medical insurance
(4) [ ] Embarrassed to have ambulance come to the house
(5) [ ] Don’t trust hospitals/doctor
(6) [ ] Religious beliefs
(7) [ ] Bad prior experience with hospitals/doctor
(8) [ ] Didn’t think symptoms were serious
(9) [ ] Thought symptoms would get better on their own
(10) [ ] Don’t have a phone
(11) [ ] Tried to reach my doctor first
(12) [ ] Tried to reach a friend/relative first
(13) [ ] Afraid of hospitals/doctor/tests
(14) [ ] Worried about missing time from work
(15) [ ] No transportation
PATIENT DEMOGRAPHICS

8. What is the highest grade of education you completed? ___ ___

No formal education = 00
Elementary = 01 02 03 04 05 06 07 08
Some High School = 09 10 11
High School = 12 → GO TO #13
Skill or Trade School = 13 → GO TO #13
College = 14 15 16 17 → GO TO #13
Graduate Education = 18 → GO TO #13
Refused = 99 → GO TO #13

9. What type of health care insurance do you have (Check all that apply)?

(1) □ None
(2) □ Medicare
(3) □ Medicaid
(4) □ Private/HMO/PPO
(5) □ Don’t Know
(99) □ Refused

10. Do you live alone?

(1) □ Yes
(2) □ No
(99) □ Refused

*That's all the questions I have -- You've been very helpful. Thank you for your cooperation.*

COMPLETE SURVEY ON NEXT PAGE
11. Record the source for this case.

(1) ☐ Patient
(2) ☐ Relative/Friend
(3) ☐ Combination of above

12. Did respondent request additional health information during this survey?

(1) ☐ Yes
(2) ☐ No

Record respondent questions about survey:

________________________________________________________________________
________________________________________________________________________

13. Interviewer __________________________

14. Date/Time of Interview: __/__/__  @  _____ : _____ (AM/PM)

14. Duration of Interview: ________________ minutes