Individual and Community Determinants of Calling 911 for Stroke Among African Americans in an Urban Community

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Background—African Americans receive acute stroke treatment less often than non-Hispanic whites. Interventions to increase stroke preparedness (recognizing stroke warning signs and calling 911) may decrease the devastating effects of stroke by allowing more patients to be candidates for acute stroke therapy. In preparation for such an intervention, we used a community-based participatory research approach to conduct a qualitative study exploring perceptions of emergency medical care and stroke among urban African American youth and adults.

Methods and Results—Community partners, church health teams, and church leaders identified and recruited focus group participants from 3 black churches in Flint, MI. We conducted 5 youth (11–16 years) and 4 adult focus groups from November 2011 to March 2012. A content analysis approach was taken for analysis. Thirty-nine youth and 38 adults participated. Women comprised 64% of youth and 90% of adult focus group participants. All participants were black. Three themes emerged from the adult and youth data: (1) recognition that stroke is a medical emergency; (2) perceptions of difficulties within the medical system in an under-resourced community, and; (3) need for greater stroke education in the community.

Conclusions—Black adults and youth have a strong interest in stroke preparedness. Designs of behavioral interventions to increase stroke preparedness should be sensitive to both individual and community factors contributing to the likelihood of seeking emergency care for stroke. (Circ Cardiovasc Qual Outcomes. 2013;6:00-00.)

Key Words: blacks ■ emergency ■ stroke

Underuse of tissue-type plasminogen activator is a major missed opportunity to reduce disability among stroke survivors. Blacks are less likely to receive tissue-type plasminogen activator than non-Hispanic whites largely because of greater prehospital delay among blacks. In addition, blacks are more likely to have a stroke and suffer greater post-stroke disability after stroke than non-Hispanic whites.

Survey research makes up much of the previous work exploring timely hospital presentation for acute stroke among community-dwelling adults. One study found that women were more likely to report they would call 911 for an acute stroke than men, whereas another study found no sex difference. Two studies found little endorsement of barriers to calling 911, such as the beliefs that there is no effective acute stroke treatment, witnesses could get their loved one to the hospital faster, or the cost of the ambulance was too expensive. Other factors such as the appreciation of how religion, family, community, structural organization, and economics may influence individual behavioral intent to call 911 are difficult to assess in surveys. However, these concepts are ideally suited for qualitative research, which is increasingly valued in cardiovascular outcomes research. Yet a systematic review of qualitative research in stroke found a paucity of qualitative research on delays in acute stroke hospital presentation. Focus groups allow interactions among participants and are ideal for exploring complex relationships and decisions that may be difficult to measure quantitatively. Focus group methodology encourages participants to explore concepts developed by researchers as well as spontaneous issues of importance to participants. The discussions are inclusive of illiterate people and do not depend on individual question interpretation. Focus groups also foster participation from those reluctant to interview alone or who remain wary of research studies. This may be especially true among blacks, given the long history of research-related abuse in this population. For these reasons, we conducted focus groups with black adults and youth to explore: knowledge and perceptions of calling 911 for acute stroke, perceptions of medical care in the community, personal experiences with stroke, and preferences for stroke education. Designing interventions to increase appropriate acute stroke 911 calls in urban black populations depends on our clear understanding of greater prehospital delay among blacks. In addition, blacks are more likely to have a stroke and suffer greater post-stroke disability after stroke than non-Hispanic whites.5,6

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WHAT IS KNOWN

- African Americans receive acute stroke treatment less often than non-Hispanic whites partially because of greater prehospital delays.
- Interventions to increase stroke preparedness (recognizing stroke warning signs and calling 911) may allow more patients to be candidates for acute stroke therapy.

WHAT THE STUDY ADDS

- Adult and youth African American focus group participants recognized that stroke is an emergency.
- Future interventions to increase stroke preparedness should consider addressing personal cost, witnesses’ emotional state, perceptions about the medical community, and community factors such as perceived delays in emergency medical services arrival.

Methods

We conducted focus group research from November 2011 to March 2012 within Preparing to React Immediately to Stroke through Education, a collaboration between the University of Michigan Stroke Program and Department of Health Behavior and Health Education (academic partners), and Bridges Into the Future, a faith-based community organization in Flint, MI (community partner). Using a community-based participatory research approach, the Preparing to React Immediately to Stroke through Education team is working with 3 predominantly African American churches in Flint to design and test a faith-based, peer-led intervention to increase appropriate 911 calls for acute stroke among youth and adults. Focus group results will directly inform the intervention. We enrolled youth because of the prevalence of multigenerational families among African Americans and the views of Bridges Into the Future that resources should be directed toward youth who represent the future of the city and often have contact with their grandparents.

Genesee County, where Flint is the largest city, has one of the highest age-adjusted stroke hospitalization rates in MI. Of the 102,434 people in Flint, 57% are African Americans and 37% live below the poverty level. The greater Flint population has the highest rate of uninsured adults (22.9%) of all MI metropolitan areas. The Genesee Health Plan is a healthcare safety net for this population but does not cover emergency medical services (EMSs) for most recipients.

According to Federal Bureau of Investigation data, Flint also remains one of the most violent cities in the United States. Because of its severe budget deficit, Flint is now (for the second time) under the control of a state-appointed Emergency City Manager.

Participant Recruitment

Community partners led focus group recruitment, providing each church with a bulletin announcement, flyers, and a verbal announcement read aloud by pastors. Church health teams also helped identify adult (≥18 years old) and youth (11–16 years old) potential participants whom they felt were representative of the church population. Specifically, the church health team was asked to recruit participants representative of the age, gender, and socioeconomic status of the church population. They were also asked to recruit at least some adults whom they knew had a personal history of stroke or knew someone who had a stroke. The community partners then contacted these potential participants to discuss details of focus group participation. Those who agreed to participate received a reminder phone call from the academic partners 2 to 4 days before the focus group session. Our predefined goal was to recruit 10 youth and 10 adults from each of the 3 churches to allow for diversity of opinions without overtaxing the community. However, we ended up recruiting more participants than was our goal because of the strong community commitment to the project and the researcher team’s commitment to not turn away any community member who was interested in participating. We felt that saturation had been achieved after the completion of the final focus groups.

Data Collection

Academic and community partners moderated each focus group session (L.E.S., J.B.M., S.B., S.F.). Each focus group session also included a community member note taker. Youth and adults were divided into separate groups of 4 to 15 people. Each focus group session lasted between 105 and 120 minutes. Focus groups sessions were held on Saturdays at each church, and the participants were offered a boxed lunch in addition to a $20 participation incentive.

Academic and community partners created the focus group guide consisting of 4 sets of open-ended questions, with probes for further explanation. First we probed recognition of stroke warning signs and individual thresholds for calling 911 by presenting increasingly alarming health scenarios: (1) Your friend begins to feel lightheaded, she eats a candy bar and feels better; (2) Your friend is walking down the street and tells you she can’t feel her right hand; and (3) Your friend suddenly develops right arm and leg weakness and does not seem to understand what you are saying. For each scenario, the moderator asked what is happening and what would you do? Moderators probed responses to the friend refusing 911: Your friend tells you “no, no, don’t call 911, it doesn’t even hurt. I just need to rest.” We probed social norms by asking how would your family and friends react if you called 911? We explored perceptions of medical care in the community with questions of: How long does it take an ambulance to come if you call 911? Which hospital do people go to if they have a medical emergency?; and On arrival to the hospital, your friend is left in the corner of the waiting room. What would you do? Moderators also encouraged individuals to share any prior experience with stroke: Can anybody tell us a story of someone you know who has had a stroke? They included follow-up questions: Were you there? How did you know it was a stroke? How confident were you that it was a stroke? What did other people do? How did they react? Did anyone call for an ambulance? How did this person get to the hospital? Finally, we probed how people best learn about stroke and how we can help people to call 911 for stroke and other emergencies. Moderators queried each topic until all participants had the opportunity to speak. The focus group discussions were recorded and transcribed verbatim by a professional transcriptionist.

Data Analysis

Strict principles of qualitative data analysis were followed to deduce themes and report results. Because little is known about barriers and facilitators to calling 911 in an underserved community, conventional content analysis was used to guide the analysis. Qualitative content analysis, as defined by Hsieh et al., is a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns. In this process, the researcher immerses herself in uncoded data and categorizes it through close examination of the transcripts. We supplemented this approach by anticipating potential codes, which comprised knowledge of stroke and recognizing symptoms, based on prior research of decision making in acute stroke and our experiences, although no existing theory guided the analysis. To minimize individual bias tainting the qualitative analysis, both academic and community partners (L.E.S., J.B.M., S.B.) with diverging areas of expertise (health education, stroke neurology, community organization) and backgrounds conducted the analysis. Each coder independently analyzed 3 transcripts and developed an initial codebook to categorize transcript data. The codes were then compared among the 3 coders, and a final codebook was agreed on. Each coder then coded the remaining transcripts and recoded the 3 original transcripts. The coders then met as a group and reconciled
the coded transcripts. We then imported the transcripts into NVivo and aggregated codes into broader themes that were representative of the transcripts. The coders then compared and discussed the themes until a final set was agreed on. Code development was performed independently of NVivo because our community partner had no access, and we did not want to sacrifice her analytic input. For the purpose of reporting the results, each quote was assigned a letter representing the focus group, whether it was an adult or a youth group and a participant identifier. This study was approved by the University of Michigan Institutional Board, and informed consent was obtained.

Results
We conducted 5 youth and 4 adult focus groups, with a total of 39 youth and 38 adult participants. Women comprised 64% of the youth and 90% of the adult focus group participants. The median age of adults was 51 years (interquartile range, 43–60; 4 missing) and of youth was 13 years (interquartile range, 12–15; 9 missing). Forty percent of the adults were college graduates or had an advanced degree (3 missing). All participants were African American. We identified 3 themes in the adult and youth focus groups.

Stroke Is an Emergency
Both adult and youth participants overwhelmingly recognized stroke symptoms and felt that stroke was a medical emergency (see Table for prototypic quotes). As one adult (A, adult 1) noted, “They call them [strokes] the silent killer. They can come up on you.” Another (A, adult 2) took this knowledge a step further: “I would probably call an ambulance for her because, by me going through slow traffic, you think she could get worse, and [with an ambulance] they could take her right in. If you get her in there in a certain time, within a couple hours or two, there is a condition … they can help it faster.” They also affirmed the social acceptability of calling 911 for acute stroke. Although noting that the potential stroke victim may be upset with the person who calls 911, they were confident that they would be happy with the decision later.

Adult and youth groups endorsed different barriers to calling 911 for stroke. Adults identified individual cost as prohibitive because when I went in, what my doctor told me was just … I told her about some things that are going on in my body, and she said well welcome to old age. You see, I didn’t want to hear that. I wanted to know what can I do.” Youth discussions were more centered on emergency medical situations. Adult and youth groups discussed the relationship between community infrastructure and medical services, with youth placing greater importance on this relationship, particularly in relation to calling 911. All participants reported wide variation in EMSs response times, ranging from minutes to nearly an hour. Although adults reasoned that delays likely result from factors such as time of day and competing emergencies, youth vocalized the resigned attitude that EMSs respond slowly to calls from more stigmatized and violent neighborhoods. One youth (C, youth 2) reported, “Police probably better than calling 911, because sometimes, when you call 911, they don’t come (laughing),” whereas another youth (C, youth 3) stated, “If you get sick, you might as well walk … no wasting gas (laughing).” Many youth had called 911 for altercations, shootings, and arson; a minority had called 911 for a medical emergency. The experience of calling 911 and emergency department visits were viewed with frustration and anxiety. Youth reported confusion with standard EMS procedures and the need to complete seemingly irrelevant forms in the emergency department.

Approaches to Learning About Stroke
Nearly all participants endorsed a need for more information about stroke preparedness (recognizing stroke warning signs and calling 911). Two youth noted (I, youth 1), “I think that … like everyone should know about strokes … and sometimes it is not available to everybody” and (I, youth 2), “like I learn from different ways, but I feel that everyone should like know about this and be able to know what to do.” In this same vein, there was agreement about the value of conducting workshops at the churches and enrolling adults and youth together; as 1 youth (B, youth 1) put it, “like your parents might want to come, then again, the schools might not allow the parents to come, but at church, they allow the parents to come and the children.” Adults and youth suggested that stroke survivors share their stories and workshops simulate actual stroke scenes through videos and presentations. Several adults also requested that workshops provide participants with informational pamphlets that they can share throughout the community (including at church services, local beauty/barber salons, and senior events). The adults also noted that accommodating busy schedules (ie, having nonwork day sessions) and serving a meal will help attendance.
Table. Quotations Illustrating Key Themes and Categories Identified From African American Adult and Youth Focus Groups (n=77)

<table>
<thead>
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<th>Theme 1: stroke is an emergency</th>
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<tbody>
<tr>
<td>Adult</td>
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<td><strong>Decision making in an emergency:</strong> “If you said [to the 911 responder] like somebody is having a stroke or something like that, they will probably rush, but if you just lack… somebody’s hurt and don’t know what is happening, they probably just take their time.” (A, adult 3)</td>
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<td><strong>Social norms:</strong> “They be angry [stroke victim], right then… then thank you later. They might be mad at first, but they will thank you later.” (A, adult 4)</td>
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<td><strong>Individual cost:</strong> “And this person that was telling me … was telling me no [to call 911], they called an ambulance before and it was $900, and they did not want me to call and they refused to get into the ambulance.”</td>
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<td>“So the ambulance came.”</td>
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<td>“Yeah … because we were at an event, and they did call it, but they don’t charge you if you don’t get in, and she refused to get into the ambulance.” (E, adult 3)</td>
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<td><strong>Youth</strong></td>
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<td><strong>Decision making in an emergency:</strong> “You have to call real fast or you might lose your brains.” (C, youth 4)</td>
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<td>“I was lying in the bed and she came in the room. She said, ‘XXX, I’m having a stroke.’ And she was talking to me. She started slurring, so I got up and I called, and I told her I was … you need to go to the hospital. She said, ‘No, I’m alright,’ but I called my mother and my mama finally got her to go.” (D, youth 1)</td>
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<td><strong>Emotional state:</strong> “I know, at that point in time, when I am really starting towards panicking, like all right, I just need to really take you somewhere that they can take care of you because I really won’t be knowing what is going on.” (I, youth 1)</td>
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<td><strong>Liability:</strong> “Still call or leave her because I can’t be responsible. That’s reckless … that’s like killing somebody. You gotta leave her [to go call 911 even if she does not want you to call 911].” (B, youth 3)</td>
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<td><strong>Theme 2: perceptions of medical services in an under-resourced community</strong></td>
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<td><strong>Adult</strong></td>
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<td><strong>Distrust of the medical community:</strong> “I understand that because I am a retiree from General Motors and I never said I am gonna fix anything because God is my fix, but what I am saying, when it comes to my health, I know my doctor doesn’t know everything about what he needs to know.” (E, adult 4)</td>
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<td><strong>Fatalism:</strong> “They are not going to the doctor. They are not going to waste their money on a bill when, you know, a lot of people, especially men … they know they have high blood pressure and cholesterol, but they still gonna eat what they want because they figure they gonna die anyway.” (E, adult 5)</td>
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<td><strong>Doctor–patient communication:</strong> “All kinds of side effects, but nothing that has helped me to understand what is going on with my body.” (E, adult 6)</td>
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<td><strong>Community resources:</strong> “I don’t know if this is right or not, but within an inner city, I don’t know if days have anything to do with it … how long it take them [EMS] to get there, but it depends on the activities that are going on too. Because like on a Thursday night, Friday night, Saturday night … I mean it is going down … you know what I’m saying? They are very busy, you know, so it would take them a long time for to get to … it would take longer to get there than I suppose like a Sunday or a Monday. You know?” (H, adult 1)</td>
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<td><strong>Youth</strong></td>
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<td><strong>Community resources:</strong> “Yeah … than the police, … because that don’t make no sense that you all live out in xxxx and you can come all the way back to Flint [15 minutes apart], and the police ain’t there. What are you doing that is more important than somebody getting shot? It kind of makes you irritated if you can’t get the help you need. You’re already feeling bad because a person isn’t there … they need help and you just feel helpless.” (G, youth 3)</td>
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<td><strong>Navigating the health system:</strong> “Cause like, say somebody got shot and then you rush them to the hospital. And you get there and they are like you gotta sign all this paperwork. Like, no, I can’t sign paperwork right now when he is losing like half of the blood in his body … like I need help now!” (G, youth 4)</td>
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<td><strong>Theme 3: approaches to learning about stroke</strong></td>
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<td><strong>Adult</strong></td>
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<td><strong>Need for more information:</strong> “I think it takes mouth-to-mouth as well as spreading it like that … bringing people together … so we need to do this as a family because we are concerned … and I am concerned about my family and I want them to stay healthy, so I think that one thing is to begin it, I think we should make a commitment that every one of my family members will hear about stroke workshop or conference or whatever is going on at church.” (E, adult 5)</td>
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<td><strong>Need for more information:</strong> “But … I mean we get the overall picture … even if you are a doctor or whatever … we need to know where we can get the information. We need to know how we can get that information, and then filter it down … because we got a lot of people sitting up in here at XXXXX that could possibly be on the verge of a stroke right now.” (E, adult 6)</td>
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<td><strong>Church as setting to learn about stroke:</strong> “I think church … like what you are starting right here. Because a lot of black people do attend churches, and I think that would be a way to inform a lot.” (E, adult 7)</td>
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<td><strong>Family learning about stroke:</strong> “it doesn’t necessarily have to be something paid, but it involves the whole family, where you can bring your kids … you know, where they get … they can learn on their level and the adults can learn on another level … it helps.” (E, adult 1)</td>
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<td><strong>Youth</strong></td>
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<td><strong>Fun and interesting:</strong> “They are gonna … sooner or later, they are gonna end up liking [stroke workshops]. They will be like, alright, well I’m having fun with my family, so I might as well do it. But not all teens have the thought that just doing family fun things … so it might just be something where they are with their friends too, so now they are just learning with their friends and having fun.” (I, youth 3)</td>
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<td><strong>Stroke survivor:</strong> “I would like to see a stroke.” (C, youth 5)</td>
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<td><strong>Church as setting to learn about stroke:</strong> “Really from the church because people love not having to go to the schools as much as they do coming to their church.” (B, youth 1)</td>
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<td><strong>Family learning about stroke:</strong> “It can be same or different, but it is like, if you teach the adults and the youth, you can have a lot of people that know so that maybe it is happening to that adult and the youth knows because there is always a lot of youth around, the youth can help instead of just all adults panicking and trying to find out what is going on, we have the youth that can help and the adults.” (I, youth 4)</td>
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Youth expressed strong preference for a peer instructor. Youth would also like to perform group presentations, skits, or role-playing—activity ideas likely stemming from frequent appeals that workshops be fun and not boring. One youth (G, youth 5) explained, “I think it is fun being in a role play, acting,” and another (I, youth 3) suggested the importance of family-friendly fun: “I mean if they take it with like their parents, their parents are gonna bring them. If you kind of make like fun to learn about it, kind of make it interesting.” One youth (G, youth 6) raised a simple preference: “Gonna have fun and we gonna eat.” Youth also voiced the importance of a Website and social networking components as a way to share workshop content with friends and family.

Discussion

Our findings suggest a complex interface of individual and community factors in the decision to call 911 for stroke among African Americans in an under-resourced urban community. Adult and youth participants overwhelmingly recognized that stroke was an emergency, but to increase 911 calls for stroke, interventions will need to address factors beyond identification of stroke warning signs. Both adults and youth were interested in stroke preparedness, and nearly all participants agreed on the church as a good venue to deliver stroke preparedness information.

Stroke preparedness interventions and the American Heart Association/American Stroke Association’s Power to End Stroke Campaign primarily focus on increasing knowledge of stroke warning signs. Nearly all participants in our study recognized stroke warning signs and that stroke is an emergency, suggesting that existing approaches may only partially increase stroke preparedness. Emergent concepts from our data including personal cost (adults only), emotional state (youth only), individual perceptions on the medical community, and community factors (namely, the perceived delay in EMS arrival) are novel insights that should be considered in interventions to increase stroke preparedness. Our previous work in this community revealed that self-efficacy during stroke should also be considered.7

Adults emphasized the cost of EMS as a major barrier to calling 911. In contrast, our previous work in the community found that when respondents were asked to think of a situation where they witnessed someone who is important to them having a stroke, only 6% agreed with the statement “I would not call 911 because the ambulance costs too much.” This finding highlights the importance of a mixed-methods approach.30 During the focus group sessions, much of the cost discussion was focused on the patient rather than the stroke witness refusing ambulance transport because of the cost. It may be that people would refuse ambulance transport for themselves but would be reluctant to refuse transport because of cost for someone important to them. To encourage 911 calls even if the stroke victim expresses concern about EMS costs, stroke preparedness interventions should consider highlighting the significant reduction in disability after stroke because of timely stroke treatments.1 Furthermore, presenting accurate information about how the Patient Protection and Affordable Care Act will provide many of the uninsured with health insurance that will likely cover EMS may also impact cost perceptions of calling 911.31

Stroke preparedness interventions should also address the stroke bystander’s emotional state, particularly among youth. Many of the youth described feelings of panic or fear surrounding calling 911. Teaching breathing relaxation techniques, positive self-talk, and role-playing stroke and Emergency Room scenarios might boost individual self-efficacy and decrease feelings of panic in both youth and adults. Furthermore, a complex dynamic between competence and control seemed to influence how youth view their potential behavior in an emergency situation, leading us to believe our intervention will need to simultaneously focus on preparing them to recognize stroke, how to stay calm in an emergency, and how to navigate emergency health care.

Strategies to improve individual perceptions of the medical community should be mindful of both community and medical perspectives on emergency care for stroke. When designing stroke preparedness interventions, groups should consider open dialogue among these stakeholders, which may facilitate a better mutual understanding of current systems and identify opportunities for improvement. Additionally, interventions could consider instructing participants on optimal communication with dispatchers and EMS, which may help alleviate some of the frustration expressed especially by youth in this arena. Deconstructing hospital system and staff roles might empower community members who otherwise feel lost navigating the healthcare system. Finally, working with Emergency Department staff and EMS workers to discuss experiences, beliefs, and values of the Flint African American community may also improve communication with the community.

Economics and other social determinants of health play a critical role in explaining and maintaining racial and ethnic health disparities, in the United States and globally.32 Our data support that community-level determinants influence individual behaviors and health. The participants’ perceptions of Flint—a perceived lack of EMS support because of limited city resources and extensive violence—reflect community beliefs and attitudes that may influence the likelihood of them calling 911. Gaining a clear understanding of local EMS resources and the prioritization of 911 stroke calls may help community members contextualize EMSs and surmount their own misgivings. On a community scale, city leadership may decide to subsidize EMSs to the uninsured to encourage EMS use for symptoms suggestive of stroke, whereas the Patient Protection and Affordable Care Act may decrease individual financial costs the uninsured face in calling 911. As the causal pathway to calling 911 for acute stroke grows even more complicated, ignoring community factors may result in a misdirected approach to stroke preparedness.

Our study has several limitations. Women were overrepresented in the adult focus groups. Building trust and fostering participation in research among African American men is necessary, and future efforts to obtain men’s perspectives may benefit from focusing recruitment efforts more directly toward them. Further, a high proportion of our adult participants had graduated college, which does not accurately represent the socioeconomic environment of Flint. However, we note that our findings persist even in this highly educated group; barriers faced by those of lower socioeconomic or educational status may differ and likely prove even more potent.
We only recruited through church venues. Although this limited our sample to those who are religious and mobile enough to attend church, the important role of the church in African American communities cannot be understated.\textsuperscript{33} Notably, churches offer a functional setting with the ability to reach large numbers of African Americans and have a shared mission of improving the health of their members. We cannot exclude that attribution bias or social desirability was present. Nevertheless, we do not think either of these factors diminishes our findings because most participants noted difficulties with EMS, which is not a particularly socially desirable response. Although attribution bias may have occurred in their responses, the fact that participants reported difficulty in using EMS is a significant finding regardless of the accuracy of their perception. This suggests that stroke preparedness interventions may require attention to the issues community members perceive surrounding calling 911.

The use of rigorous qualitative methods has provided a greater understanding of the multilevel factors involving decisions to call 911 for acute stroke in this under-resourced urban community. Future stroke preparedness interventions and educational programs in urban areas may be more effective if they address both individual- and community-level factors to reduce delays to hospital presentation among acute stroke victims. Stroke preparedness is an important issue to the African American community.

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