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## **Stroke Ready Intervention: Community Engagement to Decrease Pre-Hospital Delay**

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## Abstract

**Background:** Time limited acute stroke treatments are underused primarily due to pre-hospital delay. One approach to decreasing pre-hospital delay is to increase stroke preparedness, the ability to recognize stroke and the intention to immediately call emergency medical services, through community engagement with high risk communities.

**Methods and Results:** Our community-academic partnership developed and tested 'Stroke Ready', a peer-led, workshop-based, health behavior intervention to increase stroke preparedness among African American youth and adults in Flint, Michigan. Outcomes were measured with a series of nine stroke and non-stroke one minute video vignettes; after each video, participants selected their intended response (primary outcome) and symptom recognition (secondary outcome) receiving one point for each appropriate stroke response and recognition. We assessed differences between baseline and post-test appropriate stroke response which was defined as intent to call 911 for stroke vignettes and not calling 911 for non-stroke, non-emergent vignettes and recognition of stroke. Outcomes assessments were performed before workshop one (baseline), at the conclusion of workshop two (immediate post-test) and one month later (delayed post-test). A total of 101 participants completed the baseline assessment (73 adults and 28 youth), 64 completed the immediate post-test and 68 the delayed post-test. All participants were African American. The median age of adults was 56 (IQR 35-65) and youth was 14 (IQR 11-16), 65% of adults were female and 50% of youth were female. Compared to baseline, appropriate stroke response was improved in the immediate post-test (4.4 vs. 5.2,  $p<0.01$ ) and was sustained in the delayed post-test (4.4 vs. 5.2,  $p<0.01$ ). Stroke recognition did not change in the immediate post-test (5.9 vs. 6.0,  $p=0.34$ ), but increased in the delayed post-test (5.9 vs. 6.2,  $p=0.04$ ).

**Conclusion:** Stroke Ready increased stroke preparedness a necessary step toward increasing acute stroke treatment rates.

**Clinical Trial Registration Information:** [www.clinicaltrials.gov](http://www.clinicaltrials.gov). Identifier: NCT01499173.

**Key words:** stroke; community; outcomes research

Acute stroke treatments reduce post-stroke disability and are cost effective.<sup>1-3</sup> Yet, they are dramatically underutilized -- administered to less than 5% of stroke patients in the US.<sup>4</sup> The primary reason that patients do not receive time-dependent, acute stroke treatments is their delay in hospital presentation.<sup>5, 6</sup> Stroke preparedness, the ability to recognize stroke and the intention to respond immediately by calling emergency medical services (EMS), is a crucial step to increasing the number of stroke patients who are eligible for acute stroke treatments.<sup>7</sup> With the recent success of acute endovascular stroke treatment,<sup>3</sup> stroke preparedness interventions are needed now more than ever.

The community is vital to any stroke preparedness intervention strategy. For example, stroke patients rarely activate EMS themselves,<sup>8</sup> aphasia, dysarthria and hemiparesis make getting to the phone and communicating difficult. Furthermore, witnesses may be better able to recognize stroke symptoms in someone else.<sup>9</sup> Thus, bystanders are most likely to call for EMS.<sup>8</sup> Community Based Participatory Research (CBPR), a form of community engagement, is a collaborative approach to research where community and academic partners share responsibility in conceiving, designing, testing and disseminating interventions to improve the health of the community.<sup>10</sup> Novel approaches such as this may be needed to reach the ultimate goal of increased acute stroke treatments.

Stroke preparedness interventions may prove particularly valuable for African Americans, who experience greater stroke incidence, pre-hospital delay and are less likely to receive acute stroke treatments than non-Hispanic whites.<sup>4, 11-14</sup> Overall stroke preparedness interventions have been shown to decrease pre-hospital delay and increase acute stroke treatment rates.<sup>15</sup> Yet, many of these studies have not included African Americans<sup>16</sup> or have had less success in African Americans compared to non-Hispanic whites.<sup>17</sup> Thus, for the development and pilot testing of stroke preparedness interventions, engaging African American communities is important. Within the context of a CBPR approach, we present the development and results of pilot testing of a theory-based, peer-led intervention to increase stroke preparedness among African American youth and adults in an urban, underserved, predominately African American community.

## **Methods**

### *Setting and partnership*

Flint, Michigan, the birthplace of General Motors, was once a thriving industrial city. Today, the majority of the population is African American (60%), and over 40% of the population

live below the poverty level. Genesee County, where Flint is the largest city, has one of the highest age-adjusted stroke hospitalization rates in Michigan<sup>18</sup> Furthermore, Flint has the lowest acute stroke treatment rate of any community of its size in the US,<sup>4</sup> suggesting a substantial community need for increasing stroke preparedness.

Our community-academic partnership was established in 2009 to improve the cardiovascular health of Flint. Our partnership is composed of academic partners from the University of Michigan, including stroke neurologists and experts in health behavior and health education, and community partners from Bridges into the Future, a faith-based organization dedicated to improving the health of Flint. By means of a CBPR approach, we developed and tested a theory-based, peer led intervention, 'Stroke Ready' between September 2010 and August 2015. Our purpose was to increase stroke preparedness among adults and youth in three African American churches.

#### *Stroke Ready health behavior theory*

While educational levels are associated with acute stroke treatment rates, previous stroke and stroke knowledge are not associated with stroke preparedness suggesting that knowledge is likely necessary but not sufficient to decrease pre-hospital delay.<sup>19, 20</sup> Thus, interventions based on behavioral theory are needed. Constructs from the Theory of Planned Behavior were used to guide Stroke Ready development and assessments.<sup>21</sup> According to the Theory of Planned Behavior, the most immediate predictor of behavior is intention, which in turn is best predicted by an individual's attitude toward the behavior, perceived subjective norms around the behavior, and perceived self-efficacy with regard to the behavior.<sup>22</sup> For example, individuals with greater intent to call EMS for stroke will be more likely to actually do so when an acute stroke situation arises.<sup>23</sup> An individual's intention can be enhanced by increasing self-efficacy (one's perceived confidence in her ability to recognize and react to stroke symptoms), improving attitudes (one's negative or positive feelings toward the behavior), and reshaping subjective norms (one's perception about how others will judge the behavior). Stroke Ready materials and workshops focused on augmenting self-efficacy, attitude and subjective norms around calling 911 as well as providing education in stroke recognition and response.

#### *Stroke Ready development and testing*

##### *Phase 1: Development of Culturally Sensitive Stroke Ready materials*

Stroke Ready materials consisted of 5 main components: 1) Participant workbook, 2) Peer leader manual, 3) Workshop PowerPoint slides, 4) Stroke video vignettes and 5) Stroke Ready music video. The 41-page Stroke Ready participant workbook was conceptualized and drafted by the community-academic partners, reviewed by the community advisory boards and designed by a local Flint graphic designer. It emphasized community members' description of stroke symptoms and community relevant stroke statistics (Figure 1). The 97-page peer leader manual was constructed with one page for the PowerPoint slide and the opposing page with peer leader instructions for the delivery of the slide. The Stroke Ready PowerPoint presentation topics are outlined in Table 1. Stroke video vignettes were embedded into the PowerPoint to show stroke symptoms. Previous interventions have had success incorporating music, particularly hip-hop, into stroke education.<sup>24</sup> While community partners were enthusiastic about including music, they felt that hip-hop would not be appropriate for older adult church members and instead suggested Gospel music. Thus, we collaborated with a Flint church music director to create an original score and lyrics incorporating the National Stroke Association's FAST stroke symptoms mnemonic (e.g., F—facial droop, A—arm weakness, S—slurred speech, T—time to call 911). This original gospel music score and video (<https://www.youtube.com/watch?v=VIPZ4h-e2nQ>) was performed by local youth and adults and featured dancing by the academic and community partners. The music video included a strong focus on self-efficacy by asking viewers to participate in demonstrating stroke signs. All materials were reviewed by community focus groups<sup>25</sup> and our adult and youth community advisory board to ensure cultural sensitivity.

### *Phase 2: Peer leader training*

To increase community capacity and promote sustainability of the intervention,<sup>10</sup> Stroke Ready was delivered by peer leaders. We recruited and trained youth (ages 10-18) and adult peer-leaders from three Flint churches. Peer leaders were selected based on their previous participation or leadership roles within the church. We exceeded our goal of 12 peer leaders by recruiting and training 27 peer leaders, including 11 youth.

Each peer leader attended a 3 hour training focused on three core areas: stroke preparedness, skills-based knowledge (communication, technology, leading activities), and research implementation (basic understanding of program planning including monitoring and evaluation).<sup>26</sup> We utilized a teach-back model for training peer leaders, whereby workshops were first taught by stroke neurologists and community partners and then later presented back

to the research team by the peer leaders.<sup>27</sup> Peer-leaders received t-shirts to wear during the workshops, monetary compensation for their time, and certificates of training completion.

### *Phase 3: Intervention recruitment and delivery*

Community partners and peer-leaders recruited workshop participants through word-of-mouth, church bulletins, flyers, text messaging and church service announcements; each church recruited 20 adult and 20 youth ages 10 and above. The workshops were delivered one week apart and were led by at least 2 peer-leaders using the peer leader manual and PowerPoint presentations. The multi-media workshops included PowerPoint slides that were read aloud, videos showing stroke symptoms, facilitated discussions, and audio recording for more medically based information (Table 1).

The first workshop included sections on: 1) stroke recognition and the importance of calling 911; 2) stroke burden in the Flint African American community; 3) improving outcome expectations (i.e. stroke is treatable); and 4) an interactive demonstration using straws for arteries with play dough for clots and pipe cleaners for acute stroke treatment. This demonstration showed the value of the acute stroke treatment and encouraged positive attitudes toward securing this outcome.<sup>28</sup> The second session focused on subjective norms and self-efficacy to call 911 through stroke role-play scenarios. Scripts were provided for characters including stroke victim, family member and 911 operators to allow participants to practice the desired behavior (i.e. self-efficacy). Workshop two also contained a discussion of barriers to calling EMS and how to overcome these barriers that were identified during community focus groups (i.e. subjective norms).<sup>25</sup> Participants received certificates, bags, pens, and a small monetary compensation for their involvement.

### *Outcome assessment*

We created an outcome measure to assess stroke recognition and response using video vignettes. While previous stroke preparedness assessments included written vignettes, health video vignettes were created to provide a more realistic experience for the viewer.<sup>29</sup> The stroke preparedness outcome measure included nine, 45 second video vignettes (5 acute stroke, 2 non-acute stroke (strokes that occurred weeks or months ago) and 2 non-stroke (peripheral neuropathy, myocardial infarction); participants selected the diagnosis and their intended response after each video. Each video had a unique set of answer choices that were determined from cognitive interviews with community members. Stroke recognition answer choices included 4 unique diagnoses and 'don't know'; stroke response options included 5

unique choices and 'don't know'. For acute stroke scenarios, one point was awarded for the appropriate responses of recognizing stroke and calling 911. For non-acute stroke and non-stroke scenarios, one point was awarded for each appropriate response which was defined as any response other than stroke and calling 911. By including non-acute stroke and non-stroke scenarios, the instrument selected against participants calling 911 for all scenarios. Stroke recognition (score 0-9) and response (score 0-8) were scored independently. One of the vignettes was an acute myocardial infarction, which did not fit the response scoring, leaving 8 response vignettes. Assessments were completed before the first workshop (baseline), at the conclusion of workshop two (immediate post-test) and one month later (delayed post-test). Our primary outcome was the change in appropriate response to call 911 between the baseline and the immediate post-test and the secondary outcome was the change in appropriate stroke recognition between the baseline and the immediate post-test. We also measured stroke attitude, self-efficacy, subjective norms using a 5 point Likert scale (Table 2). Process measures assessed Stroke Ready quality, comprehension and satisfaction using a Likert scale.

### *Analysis*

Sociodemographics were described using descriptive statistics. Multilevel linear regression models with a fixed church-level intercept and a random participant level intercept to account for the times series analysis were used to explore the change in stroke response and recognition. Average marginal effects were used to report the change in appropriate stroke response and recognition after completing the immediate post-test and delayed post-test. We determined the intraclass coefficient (ICC) to estimate the impact of clustering at the church level on intervention efficacy. The majority of the missing data were for one video and rather than drop these participants from the primary analysis, we used the conservative approach of including them in the analysis with missing data recoded as 'don't know'. We explored differences in the effect of the intervention based on whether the participant was a youth or an adult by including interaction terms of outcome assessment and age group (youth vs. adult) into the multi-level linear regression models assessing stroke response and recognition. Multilevel mixed-effects ordered logistic regression models with a fixed church-level intercept and a random participant level intercept were used to explore change between baseline and immediate post-test and baseline and delayed post-test in stroke attitude, self-efficacy, subjective norms after accounting for the participants' church.

We conducted a sensitivity analysis to evaluate the robustness of the findings based on three different approaches to missing data. For participants with missing data from one video,

data was recode as the correct answer and in a second analysis recoded as the incorrect answer. Additionally, we excluded participants with any missing data. All analyses were performed STATA 11 and STATA 14. The research was approved by the University of Michigan Institutional Review Board and all participants signed written informed consent. The trial was registered on [clinicaltrials.gov](https://clinicaltrials.gov).

## Results

A total of 104 participants attended workshop one and 77 attended workshop two. A total of 101 participants (73 adults and 28 youth) completed the baseline assessment, 64 completed the immediate post-test (47 adults and 17 youth) and 68 completed the delayed post-test (53 adults and 15 youth). All participants were African American (Table 3). The median age of the adult participants was 56 (IQR 35-65), 65% were female and 38% had a high school education or less. Forty-nine percent of adult respondents had hypertension and 4% have had a stroke. The median age of the youth participants was 14 (IQR 11-16) and 50% were female. Of the 9 participants in the 16-20 year old age group, 8 were males. We found no difference in age, sex, pre-test stroke recognition or appropriate response between those who completed the immediate and delayed post-test and those lost to follow-up.

### *Stroke Preparedness*

Compared to baseline scores, the appropriate stroke response increased in the immediate post-test (4.4 vs. 5.2,  $p < 0.01$ ) and delayed post-test (4.4 vs. 5.2,  $p < 0.01$ ) (Figure 2). We found no significant increase in stroke recognition when comparing the baseline and immediate post-test (5.9 vs. 6.0,  $p = 0.34$ ), but stroke recognition increased in the delayed post-test (5.9 vs. 6.2,  $p = 0.04$ ). No interaction effects between age group and stroke response ( $p = 0.72$ ) or stroke recognition ( $p = 0.23$ ) were found. The intra-class correlation coefficient (ICC) in an empty model was 0.062, suggesting that church explains about 6% of all variance in stroke action. In the sensitivity analysis, we found no change in the study results under different scenarios of missing data.

### *Stroke attitude, self-efficacy, subjective norms*

We found no difference between baseline and immediate post-test or delayed post-test measures of stroke attitude or family norms (Table 2). Compared to the baseline, self-efficacy for stroke recognition increased in the immediate post-test (OR=1.2, 95% CI 0.5, 2.0,  $p < 0.01$ ) which was sustained in the delayed post-test (OR=0.8, 95% CI 0.07, 1.5,  $p = 0.03$ ). When comparing the baseline to the immediate post-test, self-efficacy for stroke response increased

(OR=0.8, 95% CI 0.03, 1.6, p=0.04) and became non-significant in the delayed post-test (OR=0.3, 95% CI -0.5, 1.0, p=0.51). No change in the community subjective norms between baseline and immediate post-test (OR= -0.5, 95% CI -1.1, 0.09, p=0.09) were found, but community subjective norms decreased in the delayed post-test (OR= -0.9, 95% CI -1.5, -0.2, p<0.01).

#### *Acceptability Measures*

A total of 95% (95% CI, 87-99%) percent of participants felt Stroke Ready was good or excellent quality and 84% (95% CI, 74-92%) reported they understood most or all of the workshop. A total of 80% (95% CI, 70-89%) of participants were very or extremely satisfied with Stroke Ready and 97% (95% CI, 91-99%) would recommend it to a friend.

#### **Discussion**

Stroke Ready is the first stroke preparedness intervention developed and tested through a CBPR approach in collaboration with African American churches. Stroke Ready increased appropriate stroke response immediately after completion of the intervention which was sustained after one month. Stroke recognition increased one month after the intervention. The improvement in stroke self-efficacy, which formed the basis of the behavioral theory for the Stroke Ready intervention, suggest a possible pathway by which appropriate stroke response was increased. Moreover, participants reported high levels of quality, understanding and satisfaction with Stroke Ready. With the promising results of Stroke Ready on the intermediate outcomes of stroke response and recognition, further studies are needed to test clinical outcomes such as decrease pre-hospital delay and increased acute stroke treatments.

To measure improvement in acute treatment rates, large scale interventions such as the acute myocardial infarction study, REACT, or the TLL Temple Foundation Stroke Project are needed.<sup>30, 31</sup> Both trials involved randomization of cities to a multi-level hospital and community intervention compared to usual care. No differences in pre-hospital delay were found in REACT while acute stroke treatment rates increased in the TLL Temple Foundation Stroke Project. Single level interventions have also shown an increase in acute stroke treatments. Community stroke preparedness interventions such as mailings and mass media have decreased pre-hospital delay and increased acute stroke treatments.<sup>32, 33</sup> Similarly randomized, hospital implementation trials of acute stroke practices have resulted in small increases in the number of stroke patients receiving acute stroke treatments.<sup>34, 35</sup> Because both community and hospital level interventions have shown an increase acute stroke treatment rates, determining the

optimal use of resources to increase acute stroke treatments will likely be community specific. Stroke Ready is designed for communities where the largest barrier to acute stroke treatment is pre-hospital delay and is specifically intended for communities with large African American populations. The Stroke Ready's religious content was minimal and found to be acceptable by participants of various religions and levels of religiosity. Thus, we think that Stroke Ready could be widely disseminated in relevant communities.

Stroke Ready highlights the benefits of community engagement. We attribute the excellent recruitment of peer leaders and adult participants to the CBPR approach. The churches were well aware that Stroke Ready was created for them by members of their church and community. We received strong support from church leadership, in part because stroke education is a recognized need in the community and also because of the long-standing relationship between community partners and Flint churches. Stroke Ready enrolled a substantial number of young African American men, a population historically underserved in medical research.<sup>36</sup> This success may be because peer leaders, many of whom were young men, assisted in participant recruitment. The community embraced Stroke Ready and made it their own. A church youth group leader, for example, held additional training sessions for her youth peer leaders.

Stroke Ready exceeded its enrollment goals for peer leaders, met the goals for adult participants but fell short of the youth enrollment goals. Alternate recruitment strategies for youth such as social media could be considered in the future. The intervention evaluation was limited by attrition. Attrition was greater than in some stroke preparedness interventions where testing was performed for all participants simultaneously during school hours.<sup>24, 37</sup> Retention was also higher in other behavioral interventions partnering with African American churches that incorporated strategies such as church incentives for outcome assessment and multiple time options for outcome assessments.<sup>38</sup> These strategies should be considered in the future.

This study has limitations. This was a pre-post design and thus we cannot conclude that Stroke Ready caused an increase in stroke preparedness and psychological variables. However, the short duration between baseline and outcomes and the lack of any known local or national stroke preparedness campaign during the time frame suggest an impact of the intervention. Second, Stroke Ready experienced substantial attrition resulting in missing data. The demographic characteristics of the participants and those lost to follow-up, however, were similar and our primary analyses arrived at similar conclusions using different approaches to missing data. However, we cannot confirm that those lost to follow up were truly missing at

random and thus it is possible that these missing data may contribute subtle biases. Stroke Ready consisted of two sessions and thus it is unknown if fewer workshops would have resulted in improved stroke preparedness. We did not collect data on occupations and thus cannot exclude that many participants may work in the healthcare sector. Finally, our church based educational intervention may limit the generalizability of the study beyond this context. Nevertheless, it is an efficient way to engage African Americans who are more likely to identify themselves as religious and attend church than non-Hispanic whites.<sup>39</sup>

In conclusion, Stroke Ready increased stroke preparedness and stroke self-efficacy; necessary steps toward increasing acute stroke treatment rates. Further study is needed to determine whether Stroke Ready can decrease prehospital delay.

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### **Disclosures:**

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Method of Peer Leader Delivery	Workshop one	Workshop two
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<b>Introduction</b>	Recognize that stroke is an emergency and treatable	Recognize that stroke is an emergency and treatable
<b>Psychological Construct</b>	Stroke is common in Flint	Review: F.A.S.T.
<b>Read</b>	Immediate Post-Test	Delayed Post-Test
	P value	P value
	For tPA, the faster you call 911 the better Review: F.A.S.T.	Overcoming barriers to calling 911  Coping with stress  Review: calling 911
<b>Audio</b>	What is a stroke  Stroke is common among African Americans  African Americans have greater post-stroke disability  Stroke is treatable: tPA is a clot buster medicine  Call 911 to get help	What to expect when you call 911  Waiting for help to arrive  Navigating the Emergency Department  Stroke risk factors  Stroke prevention: hypertension
<b>Interactive activities</b>	Think F.A.S.T.  tPA Activity  Workshop review: discussion	What to expect when you call 911: Discussion  Stroke role play  Workshop review: discussion
<b>Video Media</b>	Stroke Clips: F.A.S.T.  Signs of Stroke Music Video	Signs of Stroke Music Video

Table 1: Overview of the Stroke Ready Intervention

	Odds Ratio (OR) 95% CI		Odds Ratio (OR) 95% CI	
<b>Stroke Self-efficacy*</b>				
I would be able to tell if someone is having a stroke	1.2 (0.5, 2.0)	<0.01	0.8 (0.07, 1.5)	0.03
I know what to do if I saw someone having a stroke	0.8 (0.03, 1.6)	0.04	0.3 (-0.5, 1.0)	0.51
<b>Stroke Attitude</b>				
If I were to see signs of a stroke, calling 911 would be†	0.05 (-0.8, 0.9)	0.92	-0.07 (-0.9, 0.8)	0.87
If a person has signs of a stroke, calling 911 right away could be‡	0.3 (-0.8, 1.5)	0.57	-0.5 (-1.6, 0.7)	0.43
<b>Subjective Norms*</b>				
Most people would call 911 if they were to see a stroke	-0.5 (-1.1, 0.09)	0.09	-0.9 (-1.5, -0.2)	<0.01
My family would want me to call 911 if I were to see a stroke	0.2 (-0.7, 1.0)	0.72	0.1 (-0.8, 1.1)	0.75
*Response stems range from strongly agree to strongly disagree				
†Response stems range from : extremely pleasant to very unpleasant				
‡Response stems range from very help to very harmful				

Table 2: Theory of Planned Behavior Psychological Constructs

	Adult N responding (N=73)	Adult % of respondents	Youth N responding (N=28)	Youth % of respondents
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Table 3: Sociodemographics and Medical Conditions of Stroke Ready Participants (N=10)

Age years, median (IQR)	65	56 (35-65)	28	14 (11-16)		
Female	68	65	28	50		
Married	68	37				
Live alone	67	22				
Education	67					
High School Graduate or less		38				
Some College		29				
College graduate		15				
Advanced degree		9				
Medical Condition						
Stroke (including TIA)	55	4				
High blood pressure	61	49				
Heart attack	51	6				
Diabetes	56	34				
Atrial fibrillation	48	2				
Insurance Status	64					
Private		39				
Medicare		30				
Medicaid		20				
Genesee County Health Plan		3				
Uninsured		8				

Figure Legends:

Figure 1: Stroke Ready Workbook

Figure 2: Stroke Response Scores among Stroke Ready Participants

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# Think F.A.S.T.!

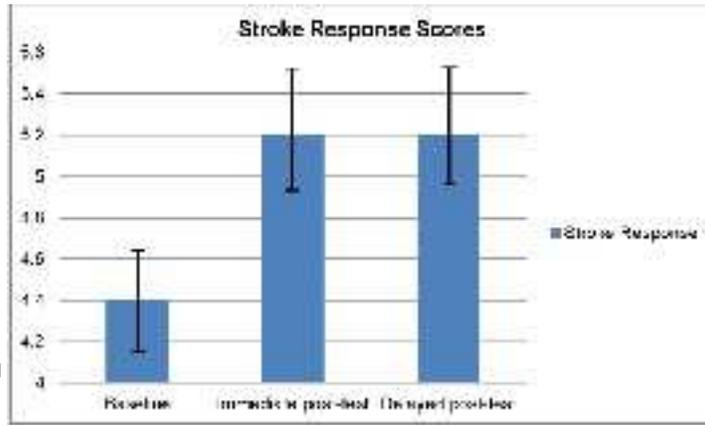
Think F.A.S.T. about the signs of stroke



If the person shows any one of these signs, call 911 as soon as possible!

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