Expanding Stroke Preparedness to Vulnerable Populations: A Music Video for the Deaf Community

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BACKGROUND: Acute stroke treatments reduce disability after stroke, but eligibility for these treatments depends on rapid hospital arrival after symptom onset. Stroke preparedness interventions teach stroke symptoms and the importance of calling 911, thereby increasing patient eligibility for stroke treatments. Stroke preparedness interventions for the Deaf community are lacking. We sought to adapt a stroke preparedness music video, which was initially created for the hearing, for the Deaf community.

METHODS AND RESULTS: We used a community-engaged approach, partnering with members of the Deaf community, to adapt the video over 4 months. Adaptation involved assessing the comprehensibility and appropriateness of the video and interpreting the song lyrics into American Sign Language.

CONCLUSIONS: We collaborated with the Deaf community to create a stroke preparedness video for the Deaf. Future research will involve refining the video and testing its efficacy to increase stroke symptom recognition and intent to call 911.

Key Words: acute stroke, behavior modification, behavioral intervention, cerebrovascular disease, stroke, stroke ischemic, stroke preparedness

Stroke preparedness is the ability to recognize stroke symptoms and the intention to respond by calling 911. Stroke is a leading cause of disability. Treatments for stroke such as tissue plasminogen activator and mechanical thrombectomy reduce disability after stroke, but are time-sensitive. Delay in hospital arrival after onset of stroke symptoms is one reason why acute stroke treatments are underutilized. Increasing stroke preparedness may overcome prehospital delay. Some stroke preparedness interventions have successfully increased stroke symptom knowledge and intent to call 911 using mass media, music, peer education, video, and written materials.

To reduce prehospital delay nationwide, however, stroke preparedness must reach vulnerable populations. While interventions have targeted vulnerable populations such as race/ethnic minorities, little work has been done to address the needs of the Deaf community, a segment of the population with unique communication needs.

The Deaf, with a capital D, refers to deaf individuals who use American Sign Language (ASL) as their primary mode of communication and embrace Deaf culture. There are ≈500 000 deaf ASL users in the United States. The Deaf community has low health literacy and poor knowledge of stroke symptoms. A survey of 203 Deaf patients attending routine medical clinical visits showed that >60% of Deaf people could not name a single stroke symptom and only 61% would call 911 if they thought they were having a heart attack or stroke. In comparison, in the national Behavioral Risk Factor Surveillance System telephone survey, ≈88% of hearing participants reported they would call 911 in the same situations. Deaf people make calls via telecommunications relay services.

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service. Therefore, their optimal stroke response, call 911, is the same as that of a hearing person.

Educational videos are an effective means of educating Deaf people about health-related topics. ASL is a visual language with its own syntax and language structure. The Deaf may not be proficient in written English. Therefore, pamphlets with written health information may not be the optimal means of communicating with the Deaf. Randomized controlled trial data have shown that videos can be successfully used to educate the Deaf about health-related topics such as cancer. In partnership with the Deaf community, we therefore sought to adapt a stroke preparedness video for the Deaf community.

METHODS

The data that support the findings of this study are available from the corresponding author upon reasonable request. Our research was conducted in Flint, Michigan, home to >3000 Deaf and hard-of-hearing individuals and the Michigan School for the Deaf. Through a community-based participatory research approach, we are currently testing a community-wide stroke preparedness intervention in Flint. One of the core components is a community-created stroke preparedness music video. The lyrics in the video focus on the National Stroke Association’s stroke symptom acronym FAST (e.g., F—face drooping, A—arm weakness, S—speech difficulty, and T—time to call 911) and the importance of calling 911 upon symptom onset. Our community partners noted we were excluding the Deaf and hard of hearing and challenged us to adapt the video to include ASL and captioning. In response, we created a community advisory board, which included a hearing public health graduate student fluent in ASL, the director of the Flint Canaan Baptist Church Deaf choir/Deaf Ministry (a church choir comprising both hearing and Deaf members), and 2 Deaf community members. Together with our community advisory board, we adapted the stroke preparedness video for the Deaf. This study fell under the University of Michigan Institutional Review Board’s approval for our community-wide stroke preparedness intervention study. Informed consent was not required.

RESULTS

Adaptation took place from December 2018 to April 2019. To start, 2 Deaf members of the Deaf choir reviewed the video and lyrics with the bilingual research team member (B.M.) and an expert in the stroke preparedness intervention (C.C.) to ensure understanding of the video, and to discuss any questions particularly around any stroke content. The Deaf choir members who reviewed the video did not have any specific expertise in stroke or emergency response. The role of the Deaf reviewers was to provide initial feedback about their ability to comprehend the stroke educational content of the lyrics. Three (hearing) interpreters/choir members then interpreted the song into ASL and taught the remaining 12 choir members the ASL interpretation. One choir member was chosen to conduct the choir during practice sessions and for filming. The choir’s performance of the ASL interpretation took place at a local church and was recorded (https://www.youtube.com/watch?v=1yYNMzcn5BA). Two members of the Deaf choir reviewed the final video and provided feedback for future video iterations, which included editing scenes to focus more on choir members’ hands while signing and including scenes filmed in community settings besides the church.

DISCUSSION

We are the first to adapt a stroke preparedness intervention for the Deaf, a population that traditionally has low health literacy and poor access to health information. The major strength of the current intervention is that it was created using a community-engaged research approach in partnership with the Deaf community. Collaborating with the Deaf to adapt health interventions increases the likelihood that the intervention will meet their unique communication and cultural needs. Open communication between academic researchers and the Deaf about their health builds trust, increases transparency, and empowers the Deaf to engage in health research and interventions directed towards their community.

CONCLUSIONS

Stroke preparedness materials for the Deaf can be created using a community-engaged approach. Future work will involve refining the video to improve the cinematography including lighting, focus, and camera placement. Next steps would then include determining the acceptability and appropriateness of the video in a larger representative sample of the Deaf and testing the efficacy of the video to increase stroke preparedness. Continued collaboration with the Deaf community will inform the optimal way to implement the video to maximize its reach to the Deaf. Stroke preparedness is a public health message that should be accessible to all populations.

ARTICLE INFORMATION

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