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Perceptions of Cardiovascular Health in an Underserved Community of Deaf Adults Using American Sign Language

Michael McKee, MD,MPH[1,3], **Deirdre Schlehofer, MPhil, EdD**[2], **Jessica Cuculick, MS.SEd**[2], **Matthew Starr, MPH**[1], **Scott Smith, MD, MPH**[1], and **Nancy P. Chin, PhD, MPH**[1]

[1]National Center for Deaf Health Research, Department of Community and Preventive Medicine, University of Rochester School of Medicine and Dentistry, Rochester, NY, USA

[2]Department of Liberal Studies, National Technical Institute for the Deaf, Rochester Institute of Technology, Rochester, NY, USA

[3]Family Medicine Research Programs, Department of Family Medicine, University of Rochester School of Medicine and Dentistry, Rochester, NY

Abstract

Background—Cardiovascular disease leads in overall mortality and morbidity in the United States. Cardiovascular disparities remain high among minority and underserved groups. Deaf American Sign Language (ASL) users are an underserved and understudied group that receives little attention from researchers due to language and communication barriers. A recent ASL survey in Rochester, NY, indicated greater cardiovascular risk among Deaf participants.

Objective—To investigate risk perceptions of cardiovascular disease among Deaf ASL users, linking perceptions to features of Deaf culture and communication. This information will be used to inform future strategies to promote cardiovascular health among Deaf adults.

Methods and Participants—Four focus groups were conducted in Rochester, New York, with 22 Deaf participants in ASL. Videotaped sessions were translated and transcribed by a bilingual researcher. A team of investigators coded, analyzed and identified key themes from the data.

Main Results—Themes centered on five major domains: knowledge, barriers, facilitators, practices, and dissemination. The majority of themes focused on barriers and knowledge. Barriers included lack of health care information access due to language and communication challenges, financial constraints, and stress. Inconsistent knowledge emerged from many key areas of cardiovascular health.

Conclusions—The study outlines key themes for improving cardiovascular health knowledge and perceptions among Deaf ASL users. Findings suggest the importance of providing health educational programs and information in ASL to maximize understanding and minimize misconceptions. When caring for Deaf ASL users, providers should take extra effort to ask about cardiovascular risk factors and confirm patients' understanding of these factors.

Corresponding Author: Michael M. McKee, MD, MPH Assistant Professor Department of Family Medicine Family Medicine Research Programs 1381 South Avenue, Rochester, NY michael_mckee@urmc.rochester.edu Phone 585-506-9484 × 124 Fax 585-473-2245 .

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Keywords

ASL; Deaf; Deaf culture; cardiovascular health; risk perceptions

Introduction

Cardiovascular disease (CVD) leads in overall morbidity and mortality in the United States; the American Heart Association estimates that starting at age 40 the lifetime risk of CVD is 2 in 3 for men and more than 1 in 2 for women.[1] Disparities in CVD prevalence persist in underserved groups, indicating that social factors impact disease risk.[2-5] At the national level, Bryant, Chin and colleagues found that among native English speakers, knowledge about heart disease risk factors was high yet they struggled to apply their knowledge into practice. Among non-English speakers, however, knowledge was incomplete, suggesting communication and language barriers confer additional risk. Individuals with limited English proficiency or reduced communication abilities are at particularly high risk for health disparities.[6-7]

Deaf Minority

Deaf ASL users are individuals who identify themselves as a linguistic minority community, with their own unique language and culture.[89] Deaf ASL users through their language differences and hearing loss often struggle to understand spoken English and may lack proficiency in written English.[10-12] Deaf ASL users historically have been unable to access health education programs and health research studies. Communication and language barriers isolate this group from mass media and health care messages.[13-15] As a result, health disparities for deaf ASL users appear in cardiovascular disease.[16]

The goal of this study was to explore the perceptions of CVD risk in an understudied linguistic minority population of Deaf American Sign Language (ASL) users. This study was part of a Centers for Disease Control-funded study of CVD risk perceptions in underserved hearing populations across the US.[17] We were interested to see if Deaf ASL users conformed to the pattern of partial or incomplete knowledge, similar to what was seen in other non-English speaking populations.

Methods and Participants

The institutional review board at the University of Rochester approved the study. All volunteering subjects provided written informed consent to participate in the study. Twenty-two participants aged 40 years and older took part in four 90 minute long focus groups consisting of three to eight individuals each during the Fall of 2008. The group sessions held in Rochester, New York were guided by a set of open-ended, semi-structured questions regarding cardiovascular health, preventive behaviors, health information sources as well as methods of disseminating health information. Prior to the start of the focus groups, a short demographic survey was completed by all participants.

Recruitment for the focus groups was done through a local electronic newsletter (*DeafTimes*), an email listserve maintained by the Prevention Research Center: National Center for Deaf Health Research (NCDHR) at the University of Rochester, and flyers. Interested subjects were included on the basis of ASL communication preference, age (40 years and older), and willingness to participate in a group session format.

The investigative team used a number of novel approaches in conducting the focus groups intended to maximize participants' sense of belonging and minimize mistrust and language

barriers. Two Deaf researchers fluent in ASL moderated each group. Prior to the start of the focus groups, the facilitators conversed with the participants to ensure ASL fluency. Video recording was utilized to provide us the ability to not only record signs but also to follow the participants' expressions and body language, both of which contribute to meaning in ASL. The focus groups were limited in size to allow for better interaction and participation among the participants. Two of the focus groups were held in a conference room at the offices of the Prevention Research Center: NCDHR. Two other focus groups were completed at a local Deaf club.

A bilingual Deaf research assistant translated and transcribed the focus groups into written English. The research team reviewed the videotapes to verify the accuracy of the translation and transcription of the data. The six members of the research team (five Deaf and one hearing) identified recurring themes under five domains (knowledge, barriers, facilitators, practices, and sources of health information) drawn a priori from past focus groups involving the national study of underserved hearing groups.[17]

The team developed a code book from an extensive review of the first focus group transcript. There were few coding disputes, and these were discussed in detail and resolved to the team's satisfaction. Two team members (Chin and McKee) coded the remaining three focus groups using ATALS.ti software and the code book. They reviewed the data fully to ensure that the previously established domains were still appropriate for the Deaf ASL group. To ensure coding accuracy, quality checks were randomly conducted.

Findings

The average age of the focus group participants was 55 years old (range was 41-69 years old). The Rochester sample was a fairly educated group (59.1% had college degrees or higher), yet there were a fair number of participants who lacked any knowledge of family history (22.7%). Slightly more women (59.1%) participated. Most respondents were overweight or obese according to body mass index (BMI) status (72.7%) (Table 1).

Through the Atlas coding software, themes in the domains of knowledge and barriers were coded most frequently at 196, and 171 times respectively, while themes related to facilitators (90), practices (50) and dissemination (49) were coded less frequently.

Knowledge

Cardiovascular health knowledge varied widely among the participants. There were several areas of general knowledge strengths among the participants. These topics included common heart disease symptoms, the dangers of cigarette smoking, the basic benefits of exercise and the importance of reducing dietary salt and personal stress. As found in the national study of underserved hearing populations, poorer awareness and knowledge on stroke appeared to create fear and confusion among the participants (Table 2).

There were several other areas of knowledge inconsistency or misinformation including the dangers of illegal drugs, heart and brain anatomy and medications (Table 2). Most concerning was the confusion over medications. Many participants confused Tylenol as being cardioprotective medication rather than aspirin. One participant with a cardiac valve replacement mistook her blood draws for anticoagulation monitoring for injections of blood thinning medication.

Barriers

Many of the barriers shared by the participants appear to be commonly shared societal barriers cited by other populations: adverse weather (e.g. unable to exercise due to weather),

hectic schedules resulting in little free time, fast food temptations and especially, inadequate finances. Poor finances were mentioned frequently by participants as a barrier to affording healthy produce, accessing a fitness club or financing health care programs. Many participants resorted to fast foods or processed foods due to their lower cost.

Perhaps most salient, communication and language barriers posed a major challenge, which in turn, reduced access to health information among the Deaf participants. For example, one participant indicated confusion about hypertension due to not having been provided an interpreter during the medical office visit (Table 2). Due to poor communication at the medical visit, his understanding of how blood pressure is diagnosed appeared distorted. Other participants also reported experiences in which language barriers reduced access to health education and/or support programs. One participant expressed wanting to join a weight support group but felt a language-inaccessible environment prohibited him from joining (Table 2).

Practices

There were several reported strengths in cardiovascular health practices among the participants. Participants expressed confidence in their efforts to reduce dietary salt intake, avoid cigarette smoking and second hand smoke, attempting to avoid stress and to exercise. The focus groups revealed strategies in reducing dietary salt (i.e. use of fresh or frozen vegetables instead of canned vegetables; avoidance of adding salt to one's foods, and use of reduced sodium foods).

Facilitators

Participants at the four focus groups valued group and community support to promote and encourage physical activity. Participants commented that they were more likely to maintain a walking or fitness program when done with friends rather than alone. Interpreters and ASL-fluent medical professionals provided valuable access to health information and motivation (Table 3). Several individuals provided examples of creative strategies to overcome challenging language barriers and confusing medical terminology including medical websites (Table 3).

Good knowledge of family history and personal experiences with medical issues appear to be strong facilitators for many of the participants in seeking appropriate medical help or making healthy lifestyle changes (Table 3).

Dissemination

Among the participants, there were several apparent information sources for health knowledge acquisition. Deaths of famous celebrities (e.g. Tim Russert's heart attack and Peter Jenning's lung cancer from smoking) from diseases appeared to be an effective dissemination tool to increase health knowledge. Participants were able to provide great details on what occurred including risk factors involved with the celebrities' death.

Several medical workshops being offered in the Rochester area were conducted in ASL. These ASL-accessible workshops provided a popular means of disseminating information about cardiovascular disease and general health (Table 3). Captioned TV shows provided another popular source of health information for some of the participants. Although captioned TV was identified as a facilitator of health knowledge, several participants stated that the captioning can be challenging to understand especially if medical or complex terminology was used.

Other important dissemination tools that participants claimed were effective were ASL accessible health videos and medical websites including www.deafmd.org and www.deafdoc.org. These websites offer videos in which an individual can observe and learn about health or medical terminology in ASL. Lastly, Rochester, NY, has several ASL fluent medical professionals who were reported to be a major source of health information for the participants.

Discussion

Deaf ASL users are an understudied and underserved linguistic minority population who are in need of cardiovascular health research and education. This study provided further information on cardiovascular perceptions which can be useful in guiding future projects to help improve understanding of cardiovascular health.

Health information access posed a challenge for many of the participants in the focus groups. As a result, much of the knowledge Deaf individuals acquired was obtained through personal experiences and/or shared experiences of spouses, family members, and Deaf friends. This limited the opportunity to correct inaccurate health information or to deepen an understanding of a health concept. Many of the participants, as a result, had superficial cardiovascular health knowledge that was easily distorted.

Margellos-Anast et al.(2006) showed similar findings with dismal awareness of cardiovascular disease among Deaf ASL adult users residing in Chicago; 40% of respondents were unable to list any symptoms of a heart attack, over 60% could not do the same for stroke, and only 61% reported that they would call 911 if they had any acute cardiovascular symptoms.[16]

Furthermore, communication and language barriers can affect how Deaf individuals acquire information through incidental learning opportunities. Poor knowledge of family history was evident among the discussions in our focus groups (five out of 22 participants). Many Deaf individuals are familiar with the “dinner table syndrome”, where they have consciously or subconsciously experienced years at the dinner table and other social situations watching close family members and friends converse with each other but are unable to decipher what is being said.[18] Poor intra-family communication can reduce knowledge of family history, making it problematic for health care providers who screen and care for Deaf individuals. Worse yet, many other sources of information and communication technologies such as the telephone, radio, and television historically isolated Deaf individuals from information in mainstream society.[19] Without the ability to hear spoken language, Deaf ASL users may be impeded in their ability to benefit from auditory reinforcement to clarify and expand their vocabulary, including health terminology and concepts.

Stress, from a number of factors: unemployment/low income, language barriers, low education, poor knowledge of family history, poor health care access and/or public insurance, was considered to be a major contributor to cardiovascular disease by many of the participants. Chronic stress from these factors can lead to health disparities for many individuals in marginalized groups.[20] Yet, it is unclear if the dangers from stress were perceived or real. Further research is needed to explore the relationship with chronic stress and cardiovascular risk.

Many Deaf ASL users struggle with poor communication with their health care providers, which may reduce their fund of knowledge about multiple health issues and may decrease the quality of their health care visit. Despite the passage of the Americans with Disabilities Act (1990), accessible communication at health care settings occurred irregularly for many of the participants in the focus groups. Due to poorer communication with their providers,

Deaf ASL users seek health care less often compared to other Deaf individuals who lose their hearing after the acquisition of spoken language.[21]

As compared to the national study of CVD perceptions among underserved hearing people, our Deaf study participants shared characteristics of both the non-English speaking groups and the underserved English speakers.[17] Communication and language barriers prevented access to critical health information from educational health programs, the Internet, as well as health care visits for many of the Deaf ASL users in the study. Deaf ASL users also struggled with structural constraints of too little money, difficult to understand federal support systems, easily accessed fast foods, and too little time which frustrated their ability to put what knowledge they did have into daily practice, similar to underserved English-speaking groups.

To the best of our knowledge, this is the first published study to examine Deaf ASL individual's cardiovascular perceptions yet there are certain limitations with the study. The data was obtained from a relatively small sample size. The data was also gathered in Rochester, NY which may not be generalized to other Deaf communities in the United States. Rochester differs from a number of other Deaf communities across the United States in regards to its higher rate of accessible health centers, programs and interpreters for the Deaf. It has been reported that Rochester has one of the highest per capita of Deaf individuals in the United States. Thus, the study's findings may not be fully generalizable to other Deaf communities in the United States.

Conclusion

The study outlines key themes for improving cardiovascular health knowledge and perceptions among Deaf ASL users. Findings suggest the importance of providing health educational programs and information in ASL to maximize understanding and minimize misconceptions. When caring for Deaf ASL users, providers should take extra effort to ask about cardiovascular risk factors and confirm patients' understanding of these factors. Greater access to ASL-fluent medical staff and interpreters can help reduce some of the communication barriers present for many Deaf ASL users. The cohesiveness of the Deaf community would be conducive to the use of trained Deaf health educators as a tool to effectively disseminating accurate cardiovascular health information to this largely socially marginalized community. Deaf health educators may also be able to approach other Deaf ASL users in a more appropriate cultural context that can enhance the receipt of health care information.

ASL accessible web-based health educational videos and programs can increase the cost effectiveness of Deaf friendly programs. They can also provide a tool for non-ASL fluent health educators and providers to better care for Deaf ASL users. Further exploring these options could be instrumental in reducing some of the cardiovascular disparities among Deaf ASL users consistent with the goals of Healthy People 2020.

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Table 1

Participant Characteristics

Characteristics	Number
Gender	
Male	9
Female	13
Education	
College Degree	13
No College Degree	9
Body Mass Index	
≥25	16
<25	6
Knowledge of Family History	
No knowledge	5
Yes knowledge	17

Table 2

Comments Concerning Knowledge and Barrier Issues

Stroke Knowledge
Example 1: "As for a heart attack, I can tell who is at high risk… I can't tell with a stroke." Example 2: "It's very rare to hear about people who have a stroke… for me, anyway. I believe that it happens to many other people but I only hear about a few in my lifetime."
Finances
Example 1: "I'm a little worried about [my] health because I haven't had Medicaid for two years. I'm too young to get Medicare. I worry if I'm making the right choices in health care. Can I afford it? Will I be able to afford it? Will I lose my home if something happens? It makes me nervous. Nobody has really told me about the choices. I need to do research on the Internet and buy from a private health insurance company. I'm not sure if that's the right choice." Example 2: "Money. Fruits and vegetables cost more and it's cheaper to buy junk food. There's also the issue of insurance to consider." Example 3: "Back then I didn't know about food stamps, so when I got hungry I would smoke so I wouldn't be hungry anymore."
Stress
Example 1: "…Work is a lot of stress. I have a lot of stress. I worry about getting paid. I get paid under the table… I worry because if I get paid like with a real job and paychecks, my social security benefits would be cut. Social security is strict about their rules. I had to have a MRI to prove my health reasons for getting social security. I prefer to keep my work from them. It's sad but the rules that they have are too strict. I would like to work but I get dizzy and it's easy to get fired."
Insurance Access
Example 1: "… Some companies such as Preferred Care [private health insurance] will provide coverage for going to the gym, but for those on Medicare, they don't have this coverage. It's not fair. The better insurance plans will cover the cost of the gym, while others don't." Example 2: "I just joined an exercise clinic for heart tuning. I've been going for six months. The doctor ordered me to after my heart operation. I made improvements and lost some weight but when I saw the bill, I was aghast. I still owe over a thousand dollars. I talked with them and was able to reduce the bill by half, but I still owe so much. I can't pay for all of it. I have to keep paying for it for the rest of my life. I was disgruntled. I made the wrong medical choice."
Communication Due to Lack of Interpreters
Example 1: "I see them [Weight Watchers] meeting and sometimes I wish I could join but it might be hard for me to communicate with them if I'm the only deaf one there." Example 2: "I wouldn't know who will get high blood pressure. A lot of people tell me I will get it. I don't know if I will because I like to eat a lot of salt. One time, the doctor took my blood pressure and said it was a little high… He took my blood pressure and saw it was a little bit high so he pricked my finger and sent a blood test through the mail. It said that I didn't have high blood pressure."
Misinformation on Illicit Drugs, Medications and Anatomy
Example 1: "[Crack] affects you physically and mentally but I don't think it affects the heart unless it's an overdose." Example 2: "I get injections every month to thin my blood [for my cardiac valve replacement]… When I moved here, I got a new doctor and now I get the medication every month up to nine months." Example 3: "… They surgically removed half of his heart… Anyway, he still plays golf to this day with half of a heart."

Table 3

Healthy Practices and Facilitators

Smoking Avoidance
Example 1: "My family smokes. Before I married my husband, he smoked. If they're smoking and I go into the house, I start coughing. It's hard to breathe so I go outside and I feel better. It's like I'm smoking. Second-hand. If they're smoking, I will go outside and tell them to stop smoking so I can come back inside or to open all the windows so I can feel better."
Accessible Health Information
Example 1: "I read a lot online from WebMD for more information. I also read Kid Scholar, which is a book that is simple enough for me to understand and sign out to myself." Example 2: "… I don't need the advanced vocabulary. I like the kids' books, which are easy to understand." Example 3: "There was the DEAR (Deaf Elders Around Rochester) picnic where they talked about the heart. I knew most of the things said, but it was really nice having someone sign it out as well as seeing PowerPoint slides with pictures than having to assume these things myself…"
Personal Experience and Knowledge of Family History
Example 1: "My family has a history of problems with the heart before the age of 75. One was at 77, but that's the only one. I expect I will go the same way. I have had a heart catheter two times and three stents within the past year so now I'm worrying a lot about it. I'm trying to eat right and and slim down again. It's tough." Example 2: "Exercise is important for me because my father had a heart bypass when he was young; he was 58 years old… I exercise because that could happen to me."
Health Care Provider
Example 1: "Well, I guess for heart, cholesterol, and blood pressure reasons. He [ASL fluent primary care physician] encouraged me to start walking so I'm walking now… a week or two ago, three women who work at the Deaf Wellness Center wanted to start walking three times a week right by where I live so I joined them. The four of us go walking for an hour at noon on Mondays, Wednesdays, and Fridays."