Cardiovascular disease knowledge among culturally Deaf patients in Chicago

Helen Margellos-Anast [a,*], Melanie Estarziau [a], Gary Kaufman [b]

[a] *Sinai Urban Health Institute, Sinai Health System, California Avenue at 15th Street, Room K450, Chicago, IL 60608-1797, USA*
[b] *Mount Sinai Hospital Department of Medicine, Sinai Health System, California Avenue at 15th Street, Room F908, Chicago, IL 60608-1797, USA*

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Abstract

Background. Deaf persons experience communication barriers that may impact on their knowledge of cardiovascular disease (CVD); however, data measuring this deficit are limited. A comprehensive health survey of Deaf adults included questions on CVD knowledge.

Methods. Between November 2002 and March 2003, 203 Deaf adults participated in the survey, which was conducted via face-to-face interviews in American Sign Language. Questions assessed knowledge of heart attack and stroke symptoms, risk factors, and emergency response.

Results. Forty percent of respondents could not list any symptoms of a heart attack, while over 60% could not list any symptoms of a stroke. Less than half of respondents identified chest pain/pressure as a symptom of a heart attack. Only 61% reported that they would call 911 in response to cardiovascular disease symptoms. The median number of risk factors correctly identified by respondents was 3 of 6.

Conclusions. Knowledge of cardiovascular disease among Deaf respondents is low, and considerably lower than that of the general hearing population. The need to develop health education materials and programs for Deaf individuals is evident. Health care providers should be educated on Deaf culture and barriers in communication. Finally, efforts need to be made to assure that 911 is deaf-accessible.
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Introduction

Deaf individuals face barriers in communication with the majority culture that may lead to significant deficits in their health knowledge. An estimated 20 million people in the U.S. are deaf or hard of hearing, with approximately 1.2 million reporting profound hearing loss (Ries, 1994). The number of culturally Deaf (Deaf with a capital "D") is more difficult to define. Culturally Deaf individuals are frequently deaf from birth or prelingually (generally defined as before the age of 3), and prefer sign language for communication. Most Deaf Americans identify American Sign Language (ASL) as their native language. ASL is a unique language, with its own grammar and syntax; it is not a gestured representation of the English language (Valli and Lucas, 1995). Many Deaf people are therefore not fluent in English. In fact, the average Deaf high school graduate has English language skills equivalent to those of a fourth grade hearing student (Allen, 1986; Holt, 1993). Consequently, many Deaf individuals do not fully comprehend written health information. Most also face the additional barrier of not being able to communicate directly with their health care provider. Finally, as over 90% of Deaf individuals grow up in hearing families (Schein, 1989; Mitchell and Karchmer, 2004), they miss out on a significant source of incidental learning, overheard conversations, further decreasing what has been referred to as their "fund of information" (Pollard, 1998).

Heart disease and stroke are the number 1 and 3 killers of Americans, respectively (Kochanek et al., 2004). An estimated 1.2 million Americans per year experience heart attack, while 700,000 experience stroke (American Heart Association, 2004). Recent improvements in our understanding of the pathophysiology of both heart disease and stroke have led to significant advances in both prevention and treatment. However, in order for preventive and treatment methods to be effective, the general public must be knowledgeable about cardiovascular disease (CVD), including its risk factors, warning signs, and emergency response.

Little data exist regarding heart attack and stroke knowledge among Deaf individuals. Deaf persons are missed by national and local surveys that rely on phones, are not included in face-to-face interviews administered in spoken English, and only

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* Corresponding author. Fax: +1 773 257 5680.
E-mail address: marhe@sinai.org (H. Margellos-Anast).

participate in written surveys if they are proficient in English. A comprehensive review of the literature revealed no prior surveys conducted with Deaf persons focusing on CVD knowledge. However, as a marginalized population with compromised access to health information, it seems likely that Deaf individuals would be less knowledgeable about CVD risk factors, symptoms, and proper emergency response than the general population.

Thus, we sought to describe the knowledge of heart attack and stroke symptoms, risk factors, and emergency response among a sample of Deaf patients from Chicago.

Methods

A sample of 203 Deaf patients from either of Chicago's two largest Deaf-serving health care systems (Sinai Health System (SHS) and Advocate Health Care (AHC)) participated in a comprehensive, face-to-face health survey conducted between November 2002 and March 2003 in ASL by Deaf interviewers. Participants were generally recruited during a clinic visit. In some instances, appointments were set-up in advance for persons to come in and complete the interview. In order to be eligible, participants had to be adult (≥ 18 years) Deaf clients of either SHS or AHC who make their own health decisions and are proficient in ASL.

A total of 120 people were screened at SHS and 106 at AHC. Of those, 102 (85%) people were eligible to participate at SHS and 101 (95%) at AHC. All of those who were eligible to participate agreed to do so. Participants were given $50 for completing the interview. This study received approval from both hospitals' Institutional Review Boards.

Measures

The details of designing and standardizing the survey instrument have been published elsewhere (Margellos-Anast et al., in press). Briefly, the survey instrument included 139 questions aimed at measuring access to and quality of care, and health-related knowledge, attitudes, and behaviors for a variety of health topics. Knowledge of heart attack and stroke symptoms was assessed by asking the open-ended questions: "What are some warning signs of a heart attack/stroke?" (2 separate questions). Respondents were encouraged to name as many symptoms as they could. Correct symptoms were those consistent with the American Heart Association's published list (American Heart Association, 2004). Respondents were prompted to list as many symptoms as they could. Knowledge of CVD risk factors was assessed by asking, "Which of the following increase your risk of having a heart attack or stroke?" The list of possible responses included both correct and incorrect responses. Additionally, we sought to determine how respondents would react in an emergency by asking the open-ended question, "What should you do if you think you are having a heart attack or stroke?" Those who did not indicate that they would call 911 were also asked, "Why would you not call 911?"

Information was also solicited on the presence of CVD risk factors including: current and past cigarette smoking, diagnosed high blood pressure, and diagnosed elevated cholesterol. Respondents were considered to be at risk for CVD if they reported any one of these risk factors. The risk factors were analyzed individually and in combination (having at least one of the three) for their association with knowledge of CVD. The method used to assign CVD risk status is a variant of the one used by the Centers for Disease Control and Prevention (CDC, 2004).

Data analysis

Data were analyzed using SAS statistical software, version 8.2 (SAS Institute, Cary, NC). The association between respondent characteristics and knowledge of CVD symptoms, risk factors, and response was assessed by chi-square and Fisher's Exact Tests for categorical variables and t tests for continuous variables. In cases where the data were not normally distributed, non-parametric tests (Mann–Whitney for comparing two groups and Kruskal–

Wallis for comparing three groups) were utilized. A P value of < 0.05 was considered statistically significant.

Results

The sociodemographic characteristics of respondents and the prevalence of self-reported risk factors for CVD are presented in Table 1. In terms of race/ethnicity and socioeconomic status, respondents from the two sites were very different. Whereas the SHS respondents were primarily non-Hispanic Black (51.0%), AHC respondents were predominantly non-Hispanic White (82.2%). Also, respondents from SHS were less likely to have an education beyond high school, more likely to report a household income of less than $20,000 a year, more likely to indicate having no health insurance or being insured by Medicaid, and more likely to reside in the City of Chicago as opposed to a suburb than were their AHC counterparts. Of the 203 respondents, 171 (84.2%) reported at least one risk factor for CVD.

Symptoms

Nearly half of respondents (40.4%) could not list any of the most common symptoms of a heart attack, while 62.6% could

Table 1
Characteristics of survey respondents, Chicago, IL, 2002–2003

		Total sample ($n = 203$)	Sinai Health System ($n = 102$)	Advocate Health Care ($n = 101$)
Gender	Female (%)	54.2	54.9	53.5
Race/ethnicity *	NH Black (%)	28.6	51.0	5.9
	NH White (%)	55.7	29.4	82.2
	Other (%)	15.8	19.6	11.9
Age*, a	>40 years old (%)	55.2	47.4	62.9
Age	Mean age (years)	44.8	43.5	46.1
Level of education*, b	>High school (%)	47.7	31.6	64.2
Income*, c	<$20,000 (%)	61.2	78.4	47.9
Insurance*, d	Medicaid/no insurance (%)	41.1	57.8	24.0
Residence*	Urban (%)	58.1	86.3	29.7
	Suburban (%)	41.9	13.7	70.3
Self-reported risk factors	High blood pressure (%)	43.4	41.8	44.9
	High cholesterol (%)	30.8	25.0	37.1
	Current/former smokers (%)*	58.1	48.0	68.3
	One or more risk factors (%)	84.2	75.5	93.1

not list a single stroke symptom. When a heart attack symptom was identified, the most commonly mentioned was chest pain/pressure (49.3% of respondents), followed by shortness of breath (24.1%), and arm/neck pain (14.8%). With regard to stroke, the most commonly identified symptom was sudden numbness of the face, arm, leg, or side of the body (28.6%). There were no significant differences in knowledge of heart attack or stroke symptoms by site or any demographic characteristic (data not shown).

Emergency response

Sixty-one percent of our respondents reported they would call 911 if they thought they were having a heart attack or stroke; the next most common response was to call a friend/family member (13.8%), followed by going to the hospital/emergency room (7.4%), with no significant differences by site or any other characteristic. Of the 39% of respondents who did not indicate that they would call 911, the majority stated that they would not think to do so, feel that it is not deaf-accessible, or do not trust 911 to respond properly to their emergency (data not shown). Several responses suggest misinformation about 911, its use and purpose. Also, a sentiment of mistrust for a system designed and primarily

Table 2
Knowledge of CVD risk factors [a] overall, by site and other characteristics, among Deaf adults interviewed in Chicago, IL, 2002–2003

		Mean number identified (range 0–6)	Median number identified (range 0–6)	% unable to correctly identify any risk factors	n
Overall		2.8	3.0	31.5	203
Site *	SHS	1.4	1.0	47.1	102
	AHC	4.2	5.0	15.8	101
Gender	Male	2.5	4.0	31.2	93
	Female	2.2	2.0	31.8	110
Race/ ethnicity *	NH Black[A]	1.5	1.0	46.6	58
	NH White[B]	3.7	5.0	23.0	113
	Other[A]	2.1	1.0	34.4	32
Age	≤40 years	2.7	2.5	31.4	86
	>40 years	3.0	3.0	29.3	106
Level of education *	HS or less	2.2	1.0	39.6	101
	More than HS	3.5	4.5	22.8	92
Income *	≤$20,000	2.4	2.0	37.5	104
	>$20,000	4.3	5.0	10.6	66
Insurance **	Medicaid/ none	2.3	2.0	38.6	83
	Other	3.2	4.0	26.9	119

[a] The following were considered correct responses: high blood pressure, high cholesterol, being overweight, diabetes, cigarette smoking.

* Indicates a statistically significant difference between groups, $P < 0.05$. Mann–Whitney/Kruskal–Wallis as appropriate (non-parametric tests) were utilized for continuous variables, and chi-square/Fisher as appropriate was used for categorical variable. Groups with different letters (when > 2 groups) are significantly different from one another.

** Indicates a statistically significant difference between groups, $P < 0.05$ for median number of risk factors (Mann–Whitney), but not for % unable to correctly identify any symptoms (chi-square).

Table 3
Association between the presence of a CVD risk factor and identifying that risk factor as increasing one's risk for CVD among Deaf adults interviewed in Chicago, IL, 2002–2003

		% identifying as risk factor	P value [a]
Self-reported high blood pressure	Yes	67.1	0.0862
	No	55.0	
Self-reported high cholesterol	Yes	71.9	0.0011
	No	46.1	
Self-reported smoking status	Current/former	52.5	0.0005
	Never	28.2	

[a] Chi-square/Fisher as appropriate was used to assess significance of categorical variables.

utilized by the hearing population was evident in some responses.

Risk factors for CVD

When asked to identify the risk factors for a heart attack or stroke, more than half of respondents identified high blood pressure (58.6%), being overweight (52.7%), and high cholesterol (52.2%). The median number of risk factors correctly identified by respondents was 3 of the 6, with AHC respondents identifying significantly more risk factors on the average than SHS respondents (4.2 vs. 1.4; $P < 0.0001$). Thirty-two percent of respondents could not correctly identify even one risk factor. There was considerable additional evidence of variation in the knowledge of risk factors by socioeconomic status (Table 2).

An association was found between an individual's CVD risk status and his/her knowledge of CVD risk factors. Specifically, respondents with at least one risk factor for CVD correctly identified significantly more risk factors than did those who were not at an increased risk (3.1 vs. 1.6; $P = 0.0012$) (data not shown). Also, respondents with specific risk factors were more likely to correctly identify those particular risk factors (Table 3).

Discussion

To our knowledge, this is the most comprehensive health survey ever conducted with Deaf adults. While we expected to find deficits in knowledge of CVD among this population, the results were more sobering than anticipated. The survey reveals that knowledge of CVD symptoms, risk factors, and emergency response in our population is generally poor and is considerably lower than that of the majority, the hearing population. For example, while 90% of respondents in a U.S. population-based survey listed chest pain/pressure as a heart attack symptom (Goff et al., 1998), only 49% of our respondents did so. Also, over 60% of our respondents could not list a single stroke symptom, which is twice the proportion of hearing adults (30%) that were unable to name any symptoms in response to an open-ended question in separate telephone surveys of Cincinnati, Ohio, and Michigan hearing adults (Schneider et al., 2003; Reeves et al., 2002).

Sixty-one percent of our respondents reported that they would call 911 if they thought that they were having a heart attack or stroke, which is slightly lower than has been found for the majority hearing population using similar open-ended questions (75–79%) (Schneider et al., 2003; Reeves et al., 2002). It has been established that using 911 results in the fastest arrival to the hospital (Williams et al., 1997; Schroeder et al., 2000; Rosamond et al., 1998; Barsan et al., 1993; Kothari et al., 1997). Given clinical outcomes for both heart attack and stroke are greatly improved if treatment is initiated within 3 h of the onset of the event, prompt arrival to the hospital is paramount (The National Institute of Neurological Disorders and Stroke rt-PA Stroke Study Group, 1995; American Stroke Association, 2004; National Heart Attack Alert Program Coordinating Committee EB, 1994).

Nearly 70% of respondents were able to correctly identify at least one risk factor for CVD from a list of potential risk factors. However, when compared to a similar study conducted with a hearing population that also used cued-response, the knowledge exhibited by our respondents is comparably low (Hux et al., 2000). Specifically, a greater proportion of respondents in that study identified hypertension (97% vs. 59%), high cholesterol (92% vs. 52%), and diabetes (75% vs. 40%) as risk factors for CVD (Hux et al., 2000).

One promising finding of our survey is that respondents with a self-reported risk factor for CVD were likely to know that they were at an increased risk for experiencing heart attack or stroke as a result of that factor. This finding is consistent with a study in which respondents with high blood pressure, high cholesterol, diabetes, and current smoking were all significantly more knowledgeable of stroke risk factors than those without those risk factors (Schneider et al., 2003). It is important to note that our respondents were all patients within health care systems that have specialized programs that prioritize effective communication with their Deaf patients. It is unclear whether at risk Deaf patients without the advantage of such specialized programs would be as likely to be aware of their risk status.

In our survey, knowledge of symptoms was ascertained by using open-ended questions, while knowledge of risk factors was assessed via cued response. Thus, while at first glance it appears that knowledge pertaining to CVD risk factors is greater than knowledge of symptoms, these two findings are not directly comparable. It is possible that if our respondents were given a list of symptoms rather than open-ended questions, they would have done better. It can be argued, however, that respondents who can name stroke or heart attack symptoms without being cued may have a deeper understanding of these diseases and therefore may be better prepared in an emergency situation.

Our study population included patients from SHS or AHC who generally reported that they were well connected with those health systems. Therefore, our results represent the knowledge of Deaf patients from either of our two institutions and cannot be extrapolated to the general Deaf population. However, given that our patients are generally well connected to health care systems with specialized Deaf programs, their level of CVD knowledge is likely greater than that of the general Deaf population.

Another limitation of our survey includes the reliance on self-report for CVD risk status. Also, our survey did not include information on the prevalence of two important risk factors for CVD, obesity and diabetes. Thus, it is probable that the true prevalence of at least one risk factor for CVD among our sample may be even higher than the 84.4% we report here. Interestingly, this prevalence is already relatively high when compared to the estimated 64% of U.S. adults that had at least one CVD risk factor in 2001 (CDC, 2004).

Given the language barriers faced by Deaf persons, all the data were collected by Deaf interviewers via face-to-face ASL interviews. The use of interviewers who are native signers and members of the local Deaf Community, along with the rapport that each health care system has with their Deaf patients likely contributed to the survey being so well received.

In summary, CVD knowledge among our respondents was inadequate, and considerably lower than in the majority population. Given that knowledge of CVD risk factors, symptoms, and response are imperative in effectively preventing and treating CVD events, one could conclude that such deficits in knowledge translate into Deaf persons being at an increased risk for CVD morbidity and mortality.

These survey results indicate the need to develop and evaluate health education materials and programs for Deaf individuals. Such resources would give providers more effective means by which to convey information to their Deaf patients. However, it is equally imperative that providers are educated on the unique aspects of Deaf culture and the barriers in communication faced by Deaf patients, otherwise they will fail to understand the necessity of tapping into these resources. Likewise, a true understanding of these issues is vital in making the case for qualified ASL interpreters being used during every medical interaction with a Deaf patient. Similarly, campaigns aimed at the Deaf Community are needed, as are efforts to assure that 911 is deaf-accessible.

One of the overarching goals of Healthy People 2010 is the elimination of health disparities, and one specific objective is to "promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the U.S. population" (U.S. Department of Health and Human Services, 2000). Our data suggest that with regard to the Deaf population, we are far from reaching this objective. If the mentioned objective is to be met, attention and resources need to be focused on this marginalized, neglected, and often misunderstood population.

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