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Original article

Cancer screening knowledge, attitudes, and behaviors among culturally Deaf adults: Implications for informed decision making

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Abstract

Background: Previous studies show that Deaf persons tend to have lower health status, lack health knowledge, have differing health attitudes, and decreased health care utilization when compared to the general population. The authors sought to examine knowledge, attitudes, and behaviors surrounding age- and gender-specific cancer screening tests amongst a sample of Deaf adults who were patients of Deaf-friendly medical organizations. The authors also sought to compare age- and gender-specific cancer screening rates amongst this sample to that of the general US population. **Methods:** A sample of 203 adult Deaf patients participated in a comprehensive, face-to-face health survey conducted between November 2002 and March 2003. The survey was administered in American Sign Language by Deaf interviewers and included age- and gender-specific cancer knowledge, attitude, and behavior questions. **Results:** Knowledge pertaining to Pap smear among females was low, while the proportion having ever had a Pap smear was comparable to the general population. Mammography knowledge amongst females age 50 and older was comparatively higher, although it remained lower than the proportion of females in this age group who reported ever receiving a mammogram. Overall, screening rates for breast, cervical, and colorectal cancer were similar to rates in the general US population. Attitudes toward specific cancer screening tests were also favorable. **Conclusions:** Persons within the Deaf community can have cancer screening rates similar to those of the general US population. However, utilization in the absence of knowledge regarding these tests is worrisome and brings about ethical, health care quality and health education concerns.

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1. Introduction

Approximately 20 million people in the United States have some form of hearing loss with about 1.2 million people being deaf [1]. It is more difficult to ascertain the number of persons who are culturally Deaf (“Deaf” with a capital “D”). Generally persons who self-identify as culturally Deaf experienced hearing loss before the age of three and use American Sign Language (ASL) as their primary form of communication. ASL is a unique language, with its own grammar and syntax; it is not a gestured representation of the English language [2]. Many Deaf

people are 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 [3,4]. The Deaf community is a cultural and linguistic minority [5], which means Deaf individuals experience unique challenges and barriers, especially when it comes to health care [6,7].

Previous studies show that Deaf persons tend to have lower health status, lack health knowledge, have differing health attitudes, and decreased health care utilization when compared to the general population [5,6,8–11,13,15]. For example, in a nationally representative sample of non-institutionalized US adults, Deaf adults had lower health status as compared to their hearing counterparts [8]. Other studies, which did not gather data regarding age at onset of deafness or use of ASL, have also found that persons with

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significant hearing loss had poorer health compared to their hearing counterparts [9,10].

Studies have also shown that health-related knowledge among Deaf persons is low [6,11]. The communication barriers that Deaf people face likely contribute to their lack of health knowledge [12]. For example, communication between a hearing physician and a Deaf patient is often limited because of the language barrier and lack of trust between the Deaf patient and the physician [13,14]; exchanging written notes and reading lips often lead to minimal comprehension.

There has not been much research conducted on the attitudes of Deaf adults toward health and health care, but the limited data that does exist is not encouraging. A qualitative study of women with significant hearing loss, most of who identified with the Deaf community, found that many did not understand the importance of preventive care measures [6]. A study of mostly Deaf adults revealed that many were wary of the healthcare system as a result of prior negative health care experiences [5]. Another study has suggested that people with significant hearing loss rate the importance of certain health maintenance behaviors lower than their hearing counterparts [13].

Finally, research suggests that health care utilization is lower amongst those who are Deaf as compared to hearing persons. In a nationally representative study of non-institutionalized adults, it was shown that pre-lingually deafened adults had fewer doctor visits than those in the hearing population [15]. The communication barriers Deaf people face when trying to access the healthcare system likely underlie this lack of utilization [5,13,16,17]. In addition, even when healthcare is utilized, such as preventive screening procedures, knowledge and attitudes toward these measures may still be lacking [5].

The current study set out to examine the cancer screening knowledge, attitudes, and behaviors amongst a socially and economically diverse group of culturally Deaf adults. The authors developed several research questions to drive their analyses. First, the authors wanted to determine the level of knowledge that Deaf persons have about specific cancer screenings. Second, the authors wanted to assess the proportion of Deaf respondents who receive age and gender appropriate cancer screening tests and compare those rates to those within the general United States population. Finally, the authors set out to explore Deaf patients' attitudes toward specific cancer screening measures.

2. Methods

The details of designing and standardizing the survey instrument and the rationale of the survey are described in detail elsewhere [18]. In brief, Deaf patients were recruited from amongst Deaf clients seen in a general or mental health clinic at either of Chicago's two largest Deaf-serving health care systems (Sinai Health System (SHS) and Advocate

Table 1
Demographic and other characteristics among Deaf survey respondents ($n = 203$)

Characteristics	<i>n</i>	Percent ^a /median
Gender		
Female	110	54%
Male	93	46%
Age (median) ^b	192	43
Age ^b		
18–39	80	42%
40–49	57	30%
50+	55	29%
Race/ethnicity		
Non-Hispanic White	113	56%
Non-Hispanic Black	58	29%
Hispanic	20	10%
Other	12	6%
Education level		
≤High school	101	50%
>High school	92	45%
NCRA	10	5%
School		
Residential	68	34%
Mainstream ^c	118	58%
Other	17	8%
Income		
≤\$20,000	104	51%
>\$20,000	66	33%
Do not know/refused	33	16%
Insurance type ^d		
Public ^e	104	54%
Private ^f	74	38%
Self-pay	15	8%
Site		
Sinai Health System	102	50%
Advocate Health Care	101	50%
Primary source of health information ^g		
Media	53	28%
Interpersonal	55	29%
Health care sector	58	31%
Other	22	12%
Do not know/refused	2	1%
No. of times see Dr. in past 12 months		
Zero to two times	53	26%
Three to five times	46	23%
Six or more times	104	51%
Method of communication with physician ^h		
Professional interpreter	92	48%
Physician that knows ASL	68	35%
Other ⁱ	32	17%

NCRA: no coded response applicable.

^a Totals may not add up to 100% due to rounding.

^b Due to missing data, $n = 192$.

^c "Mainstream" includes schools with and without specialized programs for deaf children.

^d Excluded from analysis are respondents who selected "other" or "do not know/not sure" $n = 10$.

^e Includes Medicaid and Medicare.

^f Employer sponsored and other private insurance.

^g Due to missing data, $n = 190$.

^h $n = 192$.

ⁱ Other includes lip reading, using notes, speaking, gesturing/acting, family/friend interpreters.

Health Care (AHC)). In order to be eligible, a participant had to be an adult (≥ 18 years) and a Deaf client of either SHS or AHC who makes his/her own health care decisions. Overall, 203 Deaf patients participated in a comprehensive, face-to-face health survey conducted between November 2002 and March 2003 in ASL by Deaf interviewers.

The survey instrument included 139 questions measuring access to and quality of care, as well as health-related knowledge, attitudes, and behaviors for a variety of health topics. Respondents were asked a series of yes/no questions to determine whether respondents had discussed preventive medicine topics with a physician. To assess respondents' knowledge of screening tests, an interviewer spelled out the name of the screening test in sign language and asked the respondent if he/she knew the test. If the respondent signed "yes" then he/she was asked to select, amongst a list of choices, the one correct definition. Respondents were also asked to rate the importance of specific screening tests on a scale from 1 (not at all important) to 10 (very important). Respondents were asked if they had received preventive screenings by first being given the definition of the screening test, (if he/she had not already chosen the correct definition), and then asking if he/she had ever had that test. Those who said 'yes' to having ever been screened were asked when they most recently received the screening, and were then categorized according to test-specific recommendations.

2.1. Data analysis

Data were analyzed using SAS statistical software, version 9.1 (SAS Institute, Cary, NC, 2004). Chi-square and Fisher Exact tests, as appropriate, assessed the relationship between categorical variables. Knowledge and behavior measures were adjusted for demographic factors, frequency of seeing doctor in the past 12 months, primary method of

communication with a doctor, and source of most health information with significant associations reported. A p -value of <0.05 was considered statistically significant for all analyses. To assess the importance of receiving screening tests on a scale from 1 to 10, authors used the median score due to the non-normal distribution of respondents' scores.

3. Results

As can be seen in Table 1, just over half of the respondents were female. The median age was 43 years, with 42% of respondents being between the ages of 18–39 years. Fifty-six percent of the respondents were non-Hispanic White, 29% were African American, and 10% were Hispanic. The majority of the respondents reported having gone to a mainstream school, half reported that their annual household income was \$20,000 or less, and 54% of the respondents received some form of public insurance. Almost one-third of respondents relied upon the healthcare sector as their primary source of health information, followed by interpersonal sources (29%) and the media (28%). Furthermore, the majority of respondents (74%) had seen a doctor three or more times within the past 12 months (Table 1). Among respondents who had seen a doctor within the past 12 months ($n = 192$), 48% reported their primary method of communication with a doctor was via a professional interpreter, followed by having a doctor that knew ASL (35%), and 17% relying primarily on some other form of communication.

3.1. Cervical cancer

Among the 110 female respondents, only 48% were able to correctly define Pap smear (Table 2). This ability varied

Table 2

Percent of Deaf survey respondents correctly defining and receiving screening tests by test type and recency of test

Test type	Population	Percent correctly defining screening test	Recency of test	Percent receiving screening test	
				Culturally Deaf patients	US ^a
Pap Smear	Females ≥ 18 years ($n = 110$)	48	Ever received Pap Smear	90	92
			Received Pap Smear within preceding 3 years	86	79
Mammogram	Females ≥ 50 years ($n = 30$)	77	Ever received Mammogram	90	89
			Received Mammogram within preceding 2 years	80	78
Sigmoidoscopy/ Colonoscopy	≥ 50 years ($n = 55$)	N/A	Ever received Sigmoidoscopy/Colonoscopy	51	48
Digital Rectal Exam	Males > 50 years ($n = 25$)	N/A	Ever received Digital Rectal Exam	76	55
			Received Digital Rectal Exam within preceding year	52	22

N/A: not available.

^a Mammogram data is from the Behavior Risk Factor Surveillance System (BRFSS), 1997, and is limited to women aged 50–59 years. Sigmoidoscopy/Colonoscopy data is from the Behavior Risk Factor Surveillance System (BRFSS), 2002 Digital Rectal Exam data is from the National Health Interview Survey (NHIS), 1992, and is limited to men aged 50–59 years. Pap smear data is from the National Health Interview Survey (NHIS), 1998.

significantly by race/ethnicity, age, education level, and household income. Specifically, non-Hispanic White women, those aged 50 years or greater, those with more than a high school education and those with a higher household income were more likely to correctly define Pap smear (supplementary data).

Despite this inability to define the test, 90% of female respondents reported ever having a Pap smear with 86% having one within the past 3 years. These numbers are comparable to the 92% of US women who reported ever having a Pap smear and the 79% who reported receiving one in the past 3 years [19] (Table 2). Furthermore, the proportion of female respondents in the study who reported ever having a Pap smear varied significantly by the frequency of seeing a physician in the past 12 months (supplementary data). Eighty-five percent of the women who had seen a doctor zero to two times in the past 12 months had ever received a Pap smear, while almost all (97%) of the women who had been to the doctor six or more times in the past 12 months reported having ever received a Pap smear. In addition, the proportion of females in this study who received a Pap smear in the past 3 years varied significantly by method of communication with a doctor. Females who reported primarily using a professional interpreter to communicate with a physician were significantly more likely to have had a Pap smear within the past 3 years when compared to females who reported “Other” as their main form of communication (supplementary data).

3.2. Breast cancer

Among female respondents aged 50 years and older, 77% were able to correctly define a mammogram (Table 2) with no significant differences by demographic or other respondent characteristics. When respondents in this group were asked to rate the importance of receiving a mammogram regularly to maintaining good health on a scale from 1 to 10 (with 10 being high) the median score for the importance of getting a mammogram was 10, with 80% answering a “10”. Furthermore, 90% of female respondents aged 50 and older reported ever having a mammogram, and 80% had one within the preceding 2 years [20], which was similar to the US estimates of 89% and 78%, respectively [21] (Table 2).

3.3. Colorectal cancer

Sixty percent of respondents aged 50 years and older reported that a doctor had ever talked to them about colorectal cancer screening. There was a significant difference in whether a doctor had ever talked to respondents by frequency of seeing a doctor in the past 12 months. Those who reported having seen a doctor three to five times in the past 12 months were more likely to report that a doctor had ever talked to them about colon cancer screening as compared to those who reported seeing

a doctor zero to two times in the past 12 months (93% vs. 44%, p -value <0.05).

This group of respondents was also asked to rate the importance of being screened for colon cancer in maintaining their health on a scale from 1 to 10 (10 being high). The median score for the importance of being screened for colon cancer was 10, with 69% of respondents answering a “10”. Furthermore, about half of respondents aged 50 years and older reported ever having a sigmoidoscopy or colonoscopy, which is similar to national estimates (48%) [22] (Table 2).

3.4. Prostate cancer

Among male respondents aged 50 years and older, 60% reported that a doctor had ever talked to them about prostate cancer screening. Amongst this same group, 76% of respondents reported ever having a digital rectal exam (DRE) with 52% receiving one within the preceding year. These proportions are higher than those for the United States where 55% of men 50–59 years reported ever having a DRE with 22% having done so within the year prior [19] (Table 2).

4. Discussion

This study addressed the cancer screening knowledge, attitudes, and behaviors among culturally Deaf adults. The setting in which this study took place is unique as both SHS and AHC see many Deaf patients and offer special programs for this community including access to mental health professionals/doctors who are fluent in American Sign Language as well as interpreter services. The availability of such services for Deaf patients is rare and is in contrast to a study that cited very few Deaf patients being offered these services [23,24].

Overall, knowledge of medical tests and their purpose among study respondents was low. For example, only 48% of female respondents could define the term “Pap smear” and accurately report its purpose. There may be several explanations for these findings. First, patient knowledge requires access to information. Hearing individuals can receive such information via media, by overhearing information from conversations, or from healthcare providers. These methods are not always realistic ways in which a Deaf person could obtain the same information [6]. For one, research suggests that printed health education materials are written at high reading levels [25]. In fact, one study found that the reading level of cancer education materials ranged from 9th grade to a 15th grade reading level [26], however over half of Deaf adults read at a 4th grade level or less [3,4]. In addition, over 90% of people who are Deaf grow up in hearing families [27,28] and therefore miss out on overhearing health-related conversations [7,29]. Furthermore, as evidenced from the low proportion of respondents reporting that a doctor had explained specific screening tests

to them, there may be an issue with patient education during doctor visits. Physicians may not be educating Deaf patients at a level that meets the patient's expectations, messages may be getting lost in the translation, or patients may not be able to retain the information after it is given [30].

However, a higher proportion (77%) of female respondents aged 50 years or older were able to accurately define the term "mammogram" with no significant differences by socioeconomic characteristics. This higher proportion may be due to the small sample size of females 50 years or older in this study ($n = 30$). It may also be associated with the fact that a mammogram is an observable test whereas a Pap smear is not. Furthermore, these results may also be reflective of the comparatively large amount of societal attention given to this health issue within the United States.

While the finding of relatively low levels of health knowledge in this population was not surprising, it was surprising to find such high levels of perceived importance and utilization of screening measures in the absence of knowledge. This is contrary to the idea that health knowledge is a necessary precursor to health attitudes and behaviors (i.e. utilization).

While it is unlikely that knowledge drove behaviors in this study, it is possible that behaviors may be associated with the seemingly high positive attitude. A study by Tamaskar and colleagues found a positive association between the importance that a sample of respondents with significant hearing loss gave to a specific screening test and whether respondents had received the screening test [14]. In the current study, the large proportion of individuals reporting that they had received these tests coupled with the small sample size made it impossible for us to assess this relationship more completely. In addition, the high importance associated with a mammogram by the majority of females aged 50 years and older in this study is in contrast to the findings of a qualitative study by Steinberg et al. [5]. One possible explanation for this difference is the relatively high rate of females aged 50 years and above knowing the definition and receiving a mammogram as compared to the Steinberg study. Finally, Social Desirability Bias may have lead to respondents overstating the importance they place on the test.

Overall, the relatively high rates of cancer screening tests given a general lack of knowledge regarding these tests is of concern, especially since the majority of the respondents reported using either a professional interpreter or having a physician that knows ASL. One can conclude that informed decision making by Deaf patients regarding cancer screening most likely did not occur. Informed decision making requires that a patient first understand the disease or condition for which the screening is available and being offered. Second, the patient must understand the test used to screen for the condition or disease, as well as the risks, benefits, alternatives and limitations of the test. Finally, informed decision making requires that a patient is able to

weigh the information provided and make a decision based upon his/her preferences [31].

From a health care perspective, patient knowledge is also a measure of quality. Rimer and colleagues sum up the Institute of Medicine's position on quality health care as follows: "quality health care should be patient centered—that is, it should provide care that is respectful of and responsive to patient preferences, needs, and values, and it should ensure that patients' values guide all clinical decisions." [31, p. 1215]. It is difficult for patients to feel empowered and advocate for their health when they do not understand the options they have and the decisions they can make regarding their health care.

There is some evidence that Deaf persons may not be the only group utilizing health-screening services without sufficient knowledge surrounding them. A study by Breitkopf and others found insufficient knowledge of Pap smears among a sample of poor minority women who received Pap smears on a routine basis [32].

4.1. Limitations

The cross-sectional nature of this study makes it impossible to examine directional relationships between health knowledge, attitudes, and behaviors. However, it seems plausible that health knowledge, overall, may have failed to drive cancer screening attitudes and testing behaviors. For each instance in which knowledge of a health test was measured, the overall rate of respondents knowing the definition for the screening test was considerably lower than the proportion reporting having received the respective screening test. Since all data was self-reported this opens up the possibility for recall bias. Moreover, given that respondents of this study were recruited through health care systems with an unusually high prevalence of Deaf patients and specialized services for this population, including access to an interpreter or physician that knows ASL, these findings cannot be generalized to the entire Deaf community. However, the presence of this limitation also offers us the opportunity to showcase the possibilities that arise among a sample of Deaf adults linked to a health care system that provides culturally competent care. Namely, that health care utilization can be relatively high and that utilization of cancer screening tests can reach rates similar to that of the general United States population.

5. Conclusion

This study shows that persons within the Deaf community can have cancer screening rates similar to those of the US population. However, even in the presence of similar cancer screening rates and access to appropriate, quality care, Deaf persons may still be greatly lacking in their knowledge and purpose of these tests thus hindering their ability and right to make informed decisions about their body and their health.

This finding is very worrisome and brings about ethical, health care quality and health education concerns that must be addressed.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at [doi:10.1016/j.cdp.2007.10.008](https://doi.org/10.1016/j.cdp.2007.10.008).

Conflict of interest

None declared.

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