Cancer Prevention Knowledge of People with Profound Hearing Loss

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BACKGROUND: Deaf persons, a documented minority population, have low reading levels and difficulty communicating with physicians. The effect of these on their knowledge of cancer prevention recommendations is unknown.

METHODS: A cross-sectional study of 222 d/Deaf persons in Michigan, age 18 and older, chose one of four ways (voice, video of a certified American Sign Language interpreter, captions, or printed English) to complete a self-administered computer video questionnaire about demographics, hearing loss, language history, health-care utilization, and health-care information sources, as well as family and social variables. Twelve questions tested their knowledge of cancer prevention recommendations. The outcome measures were the percentage of correct answers to the questions and the association of multiple variables with these responses.

RESULTS: Participants averaged 22.9% correct answers with no gender difference. Univariate analysis revealed that smoking history, types of medical problems, last physician visit, and women having previous cancer preventive tests did not affect scores. Improved scores occurred with computer use ($p=0.05$), higher education ($p<0.01$) and income ($p=0.01$), hearing spouses ($p<0.01$), speaking English in multiple situations ($p<0.001$), and in men with previous prostate cancer testing ($p=0.04$). Obtaining health information from books ($p=0.05$), physicians ($p=0.008$), nurses ($p=0.03$) or the internet ($p=0.02$), and believing that smoking is bad ($p<0.001$) also improved scores. Multivariate analysis revealed that English use ($p=0.01$) and believing that smoking was bad ($p=0.05$) were associated with improved scores.

CONCLUSION: Persons with profound hearing loss have poor knowledge of recommended cancer prevention interventions. English use in multiple settings was strongly associated with increased knowledge.

KEY WORDS: deaf; prevention; cancer.

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INTRODUCTION

Hearing loss is the country's second most common disability, affecting 10% of Americans, of whom 1% have a profound loss.¹ Deaf and hard of hearing (D&HH) persons, as a group, have lower socioeconomic status,² altered health-care utilization patterns,^{3,4} and significant communication difficulties with health-care workers.^{5,6}

Some D&HH persons belong to the Deaf community, a well-recognized ethnic minority^{4,7} with its own language (American Sign Language, ASL, in the US), culture and beliefs.^{8–11} ASL is a complete language with unique idioms, syntax, and grammar.^{12,13} Deaf persons see their deafness as desirable^{3,4,14,15} and capitalize the D in deaf to differentiate themselves from deaf people who are not Deaf community members. Deaf persons use certified ASL interpreters, if available, when seeing physicians. Signed English, which uses reduced English syntax with some idiosyncratic constructions, fits neither the ASL nor English grammatical systems, but is easier for English-based people to learn; it is less efficient than ASL. Signed Contact Language is used by some Deaf people when communicating with hearing people.¹⁶

Existing literature suggests that Deaf persons, like other minorities,¹⁷ have unique health and cultural beliefs, and understanding of medical topics.^{14,15,18–20} They have poorer knowledge than hearing persons about preventive interventions,¹⁴ such as AIDS avoidance,¹⁵ and are less likely to understand common medical terms.¹⁹ They also appear to utilize preventive interventions less, but the extent of this is unclear and needs further study.^{14,21} It is more certain that they often experience suboptimal doctor-patient interactions with consequent misunderstandings about their disease or treatment.^{3,6,15} Reasons for this are unclear, but probably involve language barriers and their isolation from the media.^{3,4,14} Deaf persons using interpreters during physician visits comply better with preventive recommendations.²¹ However, unique issues exist with ASL interpreters, including confidentiality concerns, varying interpreter skills, alternative interpretations of English phrases, and frequent unavailability—not to mention the cost.^{2,22}

Deaf persons, like other non-English speaking minorities, have unique perceptions of diseases that influence how they seek treatment.¹⁷ They (vs deaf) see their hearing loss as a positive trait⁴ and generally oppose cochlear implants in children and genetic counseling to prevent pregnancies of deaf babies.^{8–11} Moreover, they have less chance to use their primary language with physicians,²³ less formal education,²⁴ poorer health status,²⁵ and inferior medical care²⁶ compared to English-speaking populations of similar socioeconomic

status. In fact, they are the non-English speaking minority at greatest risk for poor physician communication, being least likely to speak their language, and have difficulty expressing themselves, fewer opportunities to address misunderstandings,²⁶ and unfamiliarity with how to access the health-care system.^{20,27} Therefore, understanding what influences their adherence to preventive health interventions may inform programs for all non-English-speaking Americans.

Much progress has been made toward developing effective, available health education for hearing persons. One example is the University of Michigan's award-winning, computer-based, cancer prevention video.²⁸ Unfortunately, this education is mostly transmitted by voice, and the written words require a high literacy level, making it unlikely to work for d/Deaf persons, whose average reading level is at 4th–6th grade.^{4,29} We amended this program to include a real-time video of an ASL interpreter communicating the information and appropriate reading level captions, then tested this in Michigan's Deaf community to evaluate its effectiveness for conveying recommended cancer prevention information to that population.

This report focuses on our subjects' baseline knowledge of cancer screening recommendations, as documented by a survey given before the video was shown; we are not reporting on the results of our intervention to improve the baseline knowledge. What makes this unique is our extensive database, which allows evaluation for associations of baseline scores with variables unique to this population, such as language, hearing loss, and cultural variables.

METHODS

Video Development

The University of Michigan Cancer Center's award-winning Michigan Interactive Health Kiosk was amended as follows. First, the content was updated to reflect then current recommendations by a physician (PZ) with expertise in this area. Next, a questionnaire was added to the beginning, to gather baseline information from participants, including demographics, hearing loss variables (e.g., age of onset), family hearing loss history, language history (e.g., language used in school), health-care history, sources of health-care information, and cultural identity (e.g., if Deaf community member). Third, 12 questions based on the video content were completed by subjects before (baseline knowledge), immediately after (looking for improvement in baseline knowledge), 1 month later, and 6 months after viewing the video (long-term information retention). Only the responses to the baseline survey are reported in this paper.

A certified ASL interpreter was videotaped signing the entire program, including the questionnaire and test questions. This was inserted as a box covering 1/5 of the video screen (Fig. 1). A Deaf leader in the Deaf Community watched the videotape to ensure that the interpreter used accurate ASL and that the captions, developed by a deaf communications expert (HM) and placed on the screen below the interpreter, were intelligible.

Two focus groups of Deaf individuals viewed the questionnaire, the information program, and the test questions to suggest changes to maximize the clarity of the information. The first group suggested several improvements. These were made, and the second group found that these changes resulted in both the captions and interpreter being clear and intelligible.

Figure 1. Computer program: cancer screening.

Recruitment

The study, after approval by the University of Michigan's IRB, was conducted in Michigan's lower peninsula, focusing on individuals with profound hearing losses. We contacted every club/organization in our target area that serves D&HH persons to discuss the study. If club members were interested, a second visit was arranged to begin the program. We also used our extensive contacts among Michigan's D&HH population, as well as attended conferences, conventions, and picnics, to recruit additional subjects. The director of Michigan's Division on Deaf and Hard of Hearing, which advocates for all individuals with hearing loss, helped publicize the study.

All contacts age 18 and over with a hearing loss who were present at club meetings were offered the opportunity to participate. Approximately 20% of those offered agreed (low participation is common with this population due to their mistrust of society and health-care institutions)^{30,31}. These persons completed the Gallaudet Hearing Loss Scale.¹ If they had a profound hearing loss (i.e., answered "no" to the first five questions), they were enrolled in the study after signing the consent form.

Data Collection

Respondents completed the on-line questionnaire followed by the survey assessing their knowledge of cancer screening recommendations for their gender and age group (see Appendix). Eight of the 12 survey questions (the "common cancer scale") were asked of all participants. Three of the remaining four questions related to female cancer screening (cervical, breast cancer) and one to males (prostate cancer); gender-specific questions were asked only of appropriate participants. Thus, females had 11 questions (8 "common scale" plus 3 female specific—the "female cancer scale"), and males had 9 questions (8 "common scale" plus one male specific—the "male cancer scale"). This report focuses on how subjects performed on the initial survey before viewing the educational video; thus, details about their response to the intervention part of the study are not described here.

The time required to complete the questionnaire and initial survey ranged from 25 to 120 min; the mean was 45 min.

Participants received \$10 for participation in this part of the study.

Analysis

Frequency analysis of all data was performed. Chi-square tests were performed for categorical data, and t-tests were performed for continuous data to assess univariate associations between variables. Spearman's rho was calculated to assess correlation between pairs of non-normal data. Multivariate analyses were performed as appropriate to assess possible confounders, such as age, education, age at loss of hearing, and use of ASL.

We analyzed the data in three ways: for the entire group, males alone, and females alone, adjusting for the number of questions answered by each gender. For the entire group, we assessed scores on the eight common cancer-screening questions and evaluated whether these varied among respondents with different demographic or hearing/communication characteristics. Analysis was similarly performed for the male and female cohorts separately; adjustments were made for age (correct answer varied by subject age). The percentage correct was calculated by dividing correct answers by the total number of questions asked of each participant.

Multivariate analysis was performed using two different models. One was a gamma regression model of the proportion of correct responses (due to the skewness of the data), expressed as percentages. Since gamma distribution is appropriate for positive data, we offset zeros appearing in the data by adding 0.01 to all the data points; the link function is assumed to be logarithmic. We also analyzed the response data using a Poisson model with a logarithmic link, which allows for the direct interpretation of zeros appearing in the data. For each subject, the number of correct responses is viewed as a Poisson random variable with the log number of questions used as offset. This modeling structure allows one to interpret the parameters as change in rate of correct responses. We also applied a binomial model to the number of correct responses, but the Poisson model gave a better fit to the data. Association of competing predictors was checked by correlation coefficient or by other appropriate tests of association, and only the most significant predictor was retained in the model to avoid the effect of masking. For example, the yearly income variable was strongly associated with college degree. Only college degree was retained in the multivariate regression model, however, since it had a much smaller p-value for association with response rate in univariate analysis. Both the gamma and the Poisson models were fit and analyzed using PROC GENMOD in SAS 9.1.

RESULTS

Baseline Data on Participants

Two hundred twenty-two participants completed the questionnaire and survey; demographic information is summarized in [Table 1]. Participants were primarily Caucasian, Deaf community members, lost hearing at a young age, had a d/Deaf spouse, and had low household incomes. They use multiple means to communicate; Table 2 indicates languages used in different situations. In sum, ASL was preferred by 70% of the

Table 1. Demographic Characteristics of Participants (p>0.05 for All Except Where Indicated Otherwise)

	Total group	Men	Women
Age in years (mean + SD)	54.5±16.6	54.3±16.1	54.6±16.9
Ethnic background (%)			
Caucasian	77.9	76.7	78.8
African American	16.2	15.6	16.7
Hispanic	0.5	1.1	0
Native American	2.7	3.3	2.3
Asian American	0.5	1.1	0
Other	2.3	2.2	2.3
Employed (%)	45.9	42.2	48.5
College degree (%)	21.2	22.2	20.5
Married (%)	57.7	61.1	55.3
Income (mean $\pm$ SD)*	21,922±21,702	25,482±24,158	19,539±19,636
Median (\$)	16,000		
Spouse %			
Deaf	75.8	80.0	72.6
Hard of hearing	8.6	9.1	8.2
Hearing	15.6	10.9	19.2
Member Deaf community*	78.8	72.2	83.3
Age lost hearing			
<1 year	47.7	51.1	45.5
1–4	36.0	35.6	36.4
5–19	11.3	10.0	12.1
>20	5.0	3.3	6.1
Reason lost hearing			
Meningitis	12.2	13.3	11.4
Rubella	13.1	12.2	13.6
Birth complications	12.6	14.4	11.4
Heredity	11.7	11.1	12.1
Other	50.5	48.9	51.5
Types of medical conditions			
Hypertension	34%		
Arthritis	29%		
Depression	24%		
Heart condition	12%		
Diabetes	10%		
Cancer	7%		

* $p=0.07$

subjects, though English was preferred with hearing people (42% spoken, 16% signed English) and interpreters with physicians/nurses (41%). English was the language most commonly used at home as a child (59%) and at school with teachers (56%).

One or more medical problems were reported for 64% of respondents (most common conditions are listed in Table 1); no significant gender difference existed. Nineteen percent of subjects reported having smoked during their lifetime; males tended to be more likely to have smoked ($p=0.06$). Subjects averaged 5.5 visits to a physician in 2000 (range 0–50). The most common reason(s) for their last visit were: regular check-up (48%), illness (21%), unspecified tests (22%), consultation (26%), and other (24%). Many reported prior cancer prevention interventions: 81% of females had had a mammogram and 88% a Pap smear, while 55% of males previously had a prostate exam. The majority of subjects were satisfied (42%) or very much satisfied (27%) with their last physician visit. Similarly, 35% were comfortable and 21% very much comfortable with their doctor; 71% had very good (29%) or good (42%) communication.

Table 2. Language Used to Communicate in Different Settings (%)*

	ASL	English spoken	English signed language	Contact sign language	English written	Interpreters	Other
At home	59	25	22	27	12	0	3
With hearing persons	22	42	16	25	31	23	5
With d/Deaf	70	12	26	30	8	0	4
M.D.s/R.N.s	7	36	9	9	44	41	2
As child at home	10	59	9	15	18	0	9
Teacher used in school	19	56	24	19	11	0	2

*Respondents could choose more than one answer for each question

Most subjects (86%) believe that smoking is bad for one's health; smaller percentages knew it causes lung disease (68%), cancer (66%), premature death (37%), dirty teeth (35%), and heart attacks (32%). Respondents reported getting health-care information from many sources, including physicians (61%), family (38%), books (36%), friends (30%), Internet (27%), TV (22%), newspapers (20%), nurses (19%), Deaf clubs (4%), and other (8%).

A small number (15) of Deaf persons who declined participation completed a written survey soliciting key demographic variables (age, income, education, marital status). There was no difference between their responses and those of our subjects.

Cancer Screening Survey Data

Overall Performance. Our participants answered 22.9%±17.6% of the cancer screening survey questions correctly: 22.1%±16.6% for males and 23.4%±17.6% for females (NS). Table 3 shows the percentage correct for each question; no gender differences existed for questions that both answered (i.e., questions 5–12). No question had an average percentage correct over 50%.

Statistical Analyses

Demographic Variables. Demographic variables associated with an increased percentage correct were computer use (24.3% vs 19.3, $p=0.05$), a college degree (33.1% vs 20.2%, $p<0.001$), and higher income (Spearman's $\rho=0.18$, $p=0.01$). Caucasians tended to score higher (24.1% vs 18.7%, $p=0.06$). No association existed between the total score and age, gender, marital or employment status, and whether a Deaf community member.

Hearing Loss Variables. No association existed between the cancer survey score and hearing loss age of onset or etiology. Subjects with hearing spouses did better (38.8% correct) than those with hard of hearing (20.8%, $p=0.009$) or d/Deaf (21.0%; $p<0.001$) spouses. Parent or sibling hearing status did not affect respondent scores.

Language Use. Language use had numerous significant associations with the common cancer scale results. Higher scores were found with English spoken at home (33.1% vs 19.5%, $p<0.001$), with hearing persons (28.4% vs 18.9%, $p<0.001$), and with physicians/nurses (30.0% vs 19.0%, $p<0.001$). These remained significant when controlled for

gender. Lower scores occurred when participants used ASL (20.9% vs 25.8%, $p=0.04$) or another language at home (8.7% vs 23.4%, $p=0.02$), or wrote notes to communicate with physicians/nurses (20.2% vs 24.8%, $p=0.05$). Lower score trends occurred when participants used another language (not ASL or English) with hearing persons, as well as an interpreter, ASL, or Signed Contact Language with physicians/nurses.

Health-care Status, Knowledge, and Utilization. There were no differences in scores when women had previous preventive tests. Men with previous prostate checks did better (26% vs 18.2%, $p=0.04$). No significant difference existed between smoking at least 100 cigarettes during their lifetime or not, but those who agreed that smoking is bad for one's health had higher scores (24.4% vs 12.6%, $p<0.001$). There was no association with presence of various medical problems or reason for seeing the physician on their last visit; there was a

Table 3. Percentage Correct of Pretest Questions

	N	% Correct
1. Pap smear frequency at their age?*		
a. Age 50 and older	73	32
b. Age 18–49 years	57	12
2. Mammogram frequency at their age?*		
a. Age <40 years	27	15
b. Age 40–49 years	73	49
c. Age 50 and older	30	20
3. What is the goal of a mammogram?*	130	27
4. Prostate exam frequency at their age?^		
a. Age <40 years	21	14
b. Age 40–49 years	16	0
c. Age 50 and older	53	41
5. What are skin cancer signs?	221	11
6. Which types of cancer can smoking cause?	221	14
7. What are current exercise frequency recommendations?	221	28
8. Fecal occult blood test frequency for their age?		
a. Age <50 years	94	8
b. Age 50 and older	126	29
9. Sigmoidoscopy frequency at their age?		
a. Age <50 years	94	12
b. Age 50 and older	125	15
10. Digital rectal exam detects what kinds of cancer?	221	25
11. The biggest cause of cancer in America?	220	43
12. The biggest cause of heart attacks in America?	220	17
Females overall	138	23
Males overall	97	22
All respondents overall	235	23

*Asked only of females

^Asked only of males

positive association with increased comfort level ($p=0.001$; $r=0.2$) and with good communication with the physician ($p=0.01$; $r=0.16$).

Health-care Information Source. Respondents had higher scores when health information was obtained from books (26.0% vs 21.0%, $p=0.05$), physicians (25.3% vs 18.8%, $p=0.008$), nurses (29.1% vs 21.4%, $p=0.03$), or the Internet (29.7% vs 20.2%, $p=0.002$). There was no significant association of scores with getting health-care information from TV, newspapers, friends, family members, Deaf club members, or other sources.

Multivariate Analysis. Multiple concomitant variables (e.g., sex, age, educational status, financial status, speaking English) were explored in search of predictors that explained the variation in frequency of correct responses. Using the gamma model, one variable was associated with higher scores: believing that smoking is bad ($p=0.05$); speaking English at home showed a trend at $p=0.06$. The Poisson model results are similar, with both speaking English at home ($p=0.01$) and believing smoking is bad ($p=0.04$) turning out to be significantly associated with a higher score.

DISCUSSION

Our findings mirror our previous reports that D&HH persons have lesser knowledge of preventive recommendations than hearing persons.^{14,15} This finding is not surprising considering most subjects identified themselves as a Deaf community member, a group with known low English literacy²⁹ and the non-English speaking minority at greatest risk for miscommunication with the health-care system.²⁶

This report is the first to our knowledge to evaluate multiple factors that might explain the low preventive knowledge base of Deaf persons. The significant and persistent association of English (spoken, signed, or print) in multiple areas of communication with higher scores should be highlighted, especially since using ASL and other languages was associated with lower scores. We only cited results that were statistically significant at the 0.05 level, but multiple other language questions showed a trend ($p=0.06$ – 0.10) between the use of spoken English and higher scores. We suspect the reason for this association is simple. Our society dispenses health-care information primarily through the English language, whether face-to-face, in print, on the radio or via TV. Respondents familiar with English are able to receive this information, whereas the others are not. Similarly, the higher scores of respondents with a hearing spouse or who were not part of the Deaf community most likely reflect the ability of hearing spouses to receive prevention messages in English and transmit them to their partners, and for non-Deaf community members who are more likely to have exposure to hearing society. Most Deaf persons associate mainly with each other, reducing the likelihood of information exposure from multiple media sources. Future studies are needed to clarify the importance of English familiarity with health-care knowledge in this population, as well as whether other non-English-speaking minorities have comparable findings.

Multivariate analysis demonstrated two variables associated with higher scores: speaking English at home and believing that smoking is bad for one's health. The probable reasons for the former have been outlined above. The association between believing that smoking is bad for one's health and higher scores may also be an indirect measure of greater exposure to media information (among those who believe smoking is bad).^{3,14}

A comment is indicated about the relatively low smoking prevalence in our respondents (19% vs 28% in the general population). This has been reported previously in Deaf populations;^{3,32} other minority populations likewise have unique smoking levels, both increased and decreased, compared to the general population.^{33,34} Reasons for the lower smoking rates in Deaf persons are believed to include both communication barriers, i.e., the lack of mass media access, and cultural preferences. Whether the decreased smoking is related to the level of hearing loss is unknown, as is the difference in use between Deaf vs. deaf vs. hard-of-hearing persons. This highlights the complexity of studying D&HH populations. The level of hearing loss, type of hearing loss, culture, and communication history/barriers may all contribute to lifestyle preferences.

Our results need to be interpreted with caution. ASL interactive surveys have inherent barriers, such as the inability to present questions and answers simultaneously (as one can with written English), difficulty translating English into ASL, and longer times to complete surveys.²² We did not test hearing subjects, but have previously shown that D&HH persons have lower health knowledge than hearing persons.³ Our respondents could be a biased Deaf population sample, i.e., members of Deaf organizations willing to use computers. We believe these are unlikely confounders, as reported elsewhere;³⁵ the similarity of demographic data on the small non-participant group supports this concept.

The solution to the poor health-care knowledge demonstrated here is beyond the scope of this paper. Suggested options have included providing interpreters at each visit (problematic due to interpreter unavailability), using VPS telecommunications systems where the Deaf person sees the interpreter on a computer screen (problematic because it would require physician offices to purchase and use them), and developing video educational programs specifically for Deaf persons, thus bypassing potential inherent cultural or other barriers. Other solutions might exist as well, and need to be evaluated.

In summary, we found that persons with profound hearing loss have a low knowledge of recommended cancer preventive interventions. English use was strongly associated with increased knowledge. Further research is needed to better understand the reasons for the decreased health knowledge of this complex minority population, so that appropriate actions can be undertaken to improve their knowledge.

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Conflict of Interest: None disclosed.

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APPENDIX

The set of questions asked

1. How often should you get a Pap smear at your age?
 - I don't know
 - Every year
 - Every 1–3 years, if sexually active, depending on doctor's evaluation
 - Every 1–2 years, depending on doctor's evaluation
 - All of the above
 - None of the above
2. How often should you get a mammogram at your age?
 - I don't know
 - Not recommended at my age
 - Every year
 - Every 3 years
 - Every 1–2 years, depending on doctor's evaluation
 - All of the above
 - None of the above
3. What is the goal of a mammogram?
 - I don't know
 - To find breast cancer after the woman could feel the cancer
 - To find breast cancer after the woman had breast problems
 - To find breast cancer when it is very small
 - To find breast cancer when it is very big
 - All of the above
 - None of the above
4. How often should you get a prostate exam at your age?
 - I don't know
 - Not recommended at my age
 - Depending on how much risk for me, my doctor will recommend
 - Every year

- Every 1–2 years, depending on doctor's evaluation
 - All of the above
 - None of the above
5. What type of cancer testing involves the letters
- A (asymmetry)
B (border)
C (color)
D (diameter)?
- I don't know
 - Lung
 - Stomach
 - Skin
 - Colon
 - All of the above
 - None of the above
6. Which of the following problems can smoking cause?
- I don't know
 - Neck cancer
 - Colon cancer
 - Lung cancer
 - Bladder cancer
 - All of the above
 - None of the above
7. How many minutes a day, most days of the week, should you exercise?
- I don't know
 - Not less than 5
 - Not less than 15
 - Not less than 30
 - Not less than 45
 - All of the above
 - None of the above
8. How often should you get a fecal occult blood test (test bowel movement sample for blood) for colon cancer at your age?
- I don't know
 - Not recommended at my age
 - Every year
 - Every 2 years
 - Every 5 years
 - All of the above
 - None of the above
9. How often should you get a sigmoidoscopy (doctor looks inside rectum with tube) at your age?
- I don't know
 - Not recommended at my age
 - Every year
 - Every 3 years
 - Every 5 years
 - All of the above
 - None of the above
10. Digital rectal exam (doctor checks rectum with fingers) can find which of the following kinds of cancer?
- I don't know
 - Colon
 - Skin
 - Ovary
 - Testicles
 - All of the above
 - None of the above
11. What is the biggest cause of cancer in America?
- I don't know
 - Alcohol and drug abuse
 - Smoking
 - Too many X-rays
 - Not enough exercise
 - All of the above
 - None of the above
12. What is the biggest cause of heart attacks in America?
- I don't know
 - Alcohol and drug abuse
 - Smoking
 - Dangerous chemicals
 - Not enough exercise
 - All of the above
 - None of the above