

Improving Access to Health and Mental Health for Chicago's Deaf Community: A Survey of Deaf Adults

A Collaborative Project of the Sinai Health System and
Advocate Health Care

Final Survey Report

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Improving Access and to Health and Mental Health for Chicago's Deaf Community: A Survey of Deaf Adults

Executive Summary

INTRODUCTION

This report presents key findings from what we believe is the most comprehensive health survey ever conducted with Deaf adults. Participants were Deaf patients of two Chicago-based health care systems, both offering special health care programs aimed at deaf and hard of hearing persons. A plethora of useful information pertaining to health status, health care experiences, communication styles, barriers to accessing health care, health knowledge, attitudes and behaviors was collected via standardized, face-to-face interviews conducted in American Sign Language (ASL). The findings presented herein are based on 203 interviews with culturally Deaf adults. A description of the process followed in developing a standardized interview tool to be administered in a visual-manual (i.e., ASL) rather than a written language, and a description of the unique challenges such a process presents are also presented within the report. Finally, the report concludes with recommendations of steps that can be taken to improve health service delivery to Deaf individuals.

BACKGROUND AND SIGNIFICANCE

An estimated 28 million people in the United States (approximately 10% of the population) have some degree of hearing loss and this disability is increasing with the aging of the population. The subgroup of this population that self-identifies as being culturally Deaf is more difficult to define. People who identify themselves as Deaf with a capital "D" consider themselves to be part of a linguistic minority who share a valued cultural connection, not a medical problem. They are more likely to have been deaf from birth or prelingually (generally defined as before the age of 3), and to rely solely upon sign language or manual communication for the input of information. The National Center for Health Statistics estimates that this latter group comprises 0.55% to 0.875% of the population three years and older. For Chicago, this would translate into 15,928-25,340 individuals; for the larger metropolitan area including Cook County, DuPage County and Will County, the Deaf population is estimated to be between 37,307-59,352.

The first language of more than half of all Americans with significant hearing loss and of most culturally Deaf people living in the United States is American Sign Language (ASL), a formal, visual-manual language that has its own grammar and syntax. It requires face-to-face contact to provide full comprehension and is not simply a gestural representation of the English language. ASL does not have its own written component. Most Deaf people are not bilingual and, therefore, are not fluent in English. The average English reading level for an adult who was born deaf or became deaf prelingually is fourth grade. Prelingually deaf persons, therefore, often have significant problems with written language.

The special communication and cultural needs of Deaf individuals may lead to significant gaps in their knowledge of health, healthy living and how to properly act in a patient role within the health care system. The fourth-grade average reading level of these adults may not allow them to fully comprehend the written health information they encounter in their doctor's office, nor the captioning for a health-related program that appears on television. Often times, the communication attempts they have made with their health care providers have proven unproductive and frustrating. A majority of physicians overestimate the percentage of Deaf patients who are proficient in English and do not realize the severe limitations of lip reading. The

most skilled lip readers correctly interpret only 25-30% of the movements they detect on a hearing person's lips. In addition, the limitations in most Deaf persons' English reading and writing skills makes writing back and forth with a health professional highly ineffective. The only way to successfully communicate with a Deaf patient is in their native language. Generally, this means health care providers need an ASL interpreter to be present.

It has been hypothesized that Deaf persons have an increased risk for developing significant deficits in their knowledge of health, healthy living and health care systems. However, a thorough review of the literature revealed that little prior research has focused on documenting whether this is in fact the case. It is for this reason that Sinai Health System (SHS) and Advocate Health Care (AHC), Chicago's two major providers of health and mental health care to Deaf persons have collaborated over the past 18 months to develop, implement and analyze the results of a health survey that is sensitive to the communication and cultural needs of the Deaf Community, and that begins to document these issues. Collecting such information is the first step in improving the health status and knowledge of Deaf individuals.

GOALS AND OBJECTIVES

The goal of the survey was to collect information about the health status, health care experiences, communication styles, barriers to accessing health care, health knowledge and behaviors of a sample of clients who are deaf and for whom American Sign Language is their native language. It was hoped from the beginning that this information would be used to catalyze the development of one or more interventions intended to overcome identified barriers and improve the health knowledge, status and behaviors of Deaf clients of our institutions.

The specific objectives include:

- To develop a collaborative interview tool and process to collect information via standardized face-to-face interviews conducted in ASL;
- To implement the data collection process at multiple sites associated with Sinai Health System and Advocate Health Care;
- To use the data collected to more fully characterize the health and mental health needs, and barriers to addressing those needs amongst Deaf clients;
- Based on the results of the analysis, to identify opportunities for improvements in health and mental health care delivery to this population;
- To use the results of the survey to catalyze the development of one or more interventions intended to overcome identified barriers and improve the health knowledge, status and behaviors of Deaf clients;
- To disseminate findings to appropriate individuals within the Deaf community, the health care system, other researchers and appropriate policy makers.

METHODS

The Project Team was comprised of individuals from both collaborating institutions, many of which had extensive experience working with Deaf patients. This team consisted of health care professionals (mental and general health), researchers, and administrators. Some members of the Project Team were hearing while others were Deaf. This Team was invaluable in guiding the development of the survey instrument and the subsequent analysis.

Given the communication issues inherent when working with a Deaf population, and the low English proficiency of many Deaf individuals, the Project Team decided from the very beginning that the survey instrument would need to be a standardized face-to-face interview conducted in ASL. One of the first steps in its development involved determining the topics that would be included. The 4 main domains of content for inclusion on the survey are as follows:

1. Demographics/General Information (e.g., age, income, insurance status)
2. Access to and Quality of Care (e.g., interpreter use, methods of communication with doctor/counselor)
3. Health Knowledge/Attitudes/Behavior (e.g. smoking, heart attack, HIV)
4. Health Related Quality of Life (SF-12, version 2)

In order to allow for comparisons between the findings of the survey and other populations (i.e., the general hearing population of the United States), as many questions as possible were selected from existing standardized or widely used questionnaires. It is important to point out that this was the first time most of these questions have been used with a Deaf population. Once a good draft of the instrument was developed, it was then translated into ASL. The first step is to create an ASL gloss, which is a written representation of each question as it is to be translated into ASL—in other words a script for sign language. While ASL is a visual-manual language, and cannot be completely captured in a written format, the gloss is important in portraying the essence of the question to the interviewer. It thus serves as a training tool for the interviewers, and assures that questions are asked consistently across subjects and across sites. It is a key step in standardizing the survey instrument.

Another vital step in standardization involved the training of the Research Assistants (RAs) who were to serve as the interviewers. These individuals were native signers, and were themselves members of the Deaf Community. Both RAs participated in a formal training session prior to the pilot testing of the instrument. The purpose of the training was to assure that all of the data was collected and recorded consistently from all survey respondents.

Each site planned to pilot test the informed consent process and survey instrument with 5-10 clients. SHS began pilot interviews in late November and completed 9 interviews. AHC began pilot interviews in early December and completed 5 interviews. The pilot testing proved to be a very useful process and resulted in several changes to the survey instrument.

The final survey instrument consisted of 139 questions and generally took about an hour to complete, although women and people over the age of 50 had more questions to answer and sometimes took slightly longer.

Participants were recruited from Deaf clients seen in either a general or a mental health clinic. A person was invited to participate if he/she expressed an interest in doing so and met the following criteria:

- Adult (18 years of age or older),
- Deaf client of either the SHS or AHC
- Makes own health decisions (i.e., does not reside in a group home or have a legal guardian);
- Relies primarily on ASL for communication;

-OR-

- Is proficient in ASL, and either (1) prelingually deaf (before the age of 3) or (2) self-identifies with the Deaf Community.

Once informed consent was obtained, interviews were conducted or an appointment scheduled to interview the person at a later time. Participants were given \$50 each for completing an interview.

The survey was conducted between November 2002-March 2003. A total of 120 people were screened at SHS and another 106 at AHC. Of those, 102 (85%) people were eligible to participate at SHS and 101 (95%) at AHC. All who were eligible to participate agreed to do so.

RESULTS

The basic demographics of respondents recruited from the two sites differed significantly on many characteristics. For example, over half of SHS respondents were non-Hispanic Black (51%) whereas the majority of AHC respondents were non-Hispanic White (82%). SHS respondents were also more likely to reside in the City of Chicago (86% vs. 30%), to have a lower level of education, a lower income, to be unemployed and to report being Medicaid-insured than were respondents from AHC (Tables 3 and 4, pgs. 14 and 15). Clearly, in terms of race and socioeconomic status respondents from the two sites are very different. The diversity of the surveyed population is an asset of our study, and resulted from the collaboration between SHS and AHC in collecting this data.

With 139 questions on the final survey, it would be impossible to summarize all of our findings in one report. We have thus decided to proceed by presenting the most interesting findings in five specific topic areas. The data presented in this summary of the report is a sampling of the extensive amount of information presented within the report itself.

Topic 1. Access to and Quality of Care

Respondents from both institutions were similar with regards to how long they had been patients at the particular clinic from which they were recruited. Nearly half of respondents (43%) reported they had been patients of that clinic for more than 3 years, where as only about 25% were new patients who had been at that clinic for less than one year. In other words, this was a group that was relatively well connected to the health care system. When asked if they have one person who they think of as their "personal doctor" or primary health provider, all but 8 respondents answered "yes". The proportion that indicate having a primary health provider (99% SHS, 93% AHC) is therefore higher than the average for Chicago residents as a whole (83%), but this is likely due to the manner in which participants were selected for the study. Respondents were also asked how they primarily communicate with their doctor and/or mental health provider. Since both institutions offer specialized services for Deaf persons, it is not surprising that most of the respondents reported that either their provider knows ASL or a professional interpreter is used (Figures 1.4 and 1.5, p.20). However, even considering the unique deaf-services available at both SHS and AHC, 10% of respondents indicated that they rely primarily on an "other" less than adequate method.

Disconcertingly, when the use of interpreters during hospitalizations and Emergency Department (ED) visits was assessed, over one-third of those who had been hospitalized or were seen in an ED indicated they had never had a professional interpreter present to assist them in communicating with the doctor.

Finally, as indicators of the type of health information respondents receive from their physicians, we asked whether a physician had ever spoken to them about various topics. Findings suggest that participants are not receiving adequate information about preventive care topics from their physicians (Figure 1.6, p. 22).

We cannot however accurately conclude from this data whether physicians are not speaking with their Deaf patients about these topics, or are presenting the information in a way that their Deaf patients do not completely comprehend.

Topic 2. Health Knowledge, Attitudes and Behaviors

The level of knowledge of survey respondents about their health and healthy behaviors was generally low across most topic areas. When comparison data was available for hearing populations, survey respondents had lower levels of knowledge than their hearing counterparts. In many instances, the level of knowledge differed significantly by site or by some other demographic characteristic. When this was true, AHC respondents generally had higher levels of knowledge than SHS respondents. With respect to demographics, those who were more educated (more than a HS education), reported a higher household income (>\$20,000 per year), and non-Hispanic white people had higher levels of knowledge than their less educated, poorer and non-white counterparts. The specific findings that follow are a sampling of the most interesting ones presented in the report.

Among the most disturbing findings, nearly half of respondents (40%) could not identify any of the 7 most common warning signs of a heart attack, while 62% could not identify any of the 7 most common warning signs of a stroke. The exhibited insufficiency in knowledge of the symptoms of a heart attack and stroke are especially disconcerting given the known benefit associated with early treatment. Of course there is no benefit associated with reacting early, if one does not react correctly. We asked respondents what they would do if they thought they were having a heart attack or a stroke. The most imperative response according to the American Heart Association is to call 911. About half (61%) of our respondents indicated that they would call 911. Finally, we asked respondents to identify the factors that increase one's risk for having a heart attack or a stroke. Approximately one-third of respondents (32%) could not identify any risk factors for a heart attack or stroke, with statistically significant differences in knowledge by site (47% of SHS respondents could not identify any risk factors vs. 16% of AHC respondents, $p < 0.0001$).

As elevated blood cholesterol is a major risk factor for cardiovascular disease, we would like people to be familiar with ways to manage their cholesterol levels. However, approximately 1 in 4 respondents (27%) could not identify any ways to control blood cholesterol levels, with statistically significant differences in knowledge by site (42% of SHS vs. 12% of AHC could not identify any methods, $p < 0.0001$).

One positive finding was that the majority of respondents at both sites (94% overall; 99% at SHS and 90% at AHC) were familiar with the terms HIV and AIDS. However, when their knowledge in this area was further assessed the findings revealed a general lack of knowledge of the transmission of HIV/AIDS. For example, approximately 40% of respondents did not realize that using intravenous drugs is a major risk factor for transmission of the virus, and one in three believed that using a public restroom would put them at risk. Also, over half of respondents (51%) did not know that there are drugs available to help a person with HIV live longer.

One of our hypotheses when the study was initiated was that Deaf patients may not understand common English medical terms and therefore may miss important health information based simply on that fact. We sought to test this hypothesis by asking respondents to tell us what certain medical terms mean. The terms were finger spelled to the respondents, and four possible definitions were read. Findings suggest that 1 in 3 respondents could not correctly define the term "cancer", and that even fewer could correctly define the term "cholesterol" (38%). Also, less than half of women surveyed correctly defined the term

“pap smear”. Clearly, these results are indicative of a great shortfall in the knowledge of English medical terms.

When the proportion of individuals undergoing routine cancer screening was assessed, findings were similar to reported rates in the general U.S. population. For example, a little more than half (52% of SHS and 58% of AHC respondents) of the respondents 50 years of age and older indicated they had EVER been screened via sigmoidoscopy or colonoscopy. These numbers are about the same as the 48% of the general U.S. population 50 years of age and older who indicated they had ever received one of these screening tests on the 2002 Behavior Risk Factor Surveillance Survey (BRFSS). Also, the proportion of women over 50 indicating that they had ever had a mammogram was quite high: 91% at SHS and 95% at AHC (Table 2.7, p. 38). This compares well with the 89% of women between the ages of 50-59 nationwide who reported EVER having had a mammogram (BRFSS, 1997).

Topic 3. Prevalence of Risk Factors

If we are to develop steps to be undertaken to improve the health status of Deaf persons locally and regionally, we need to have a sense of how this population compares to the general population in the prevalence of risk factors. Fortunately, the survey included a number of questions intended to get a better sense of the general health status of respondents.

Many of the risk factors for cardiovascular disease (CVD) are rooted in modifiable behavior, and data was collected on some of these behaviors. With regards to smoking, 1 in 4 SHS respondents reported being current smokers, compared to only 1 in 10 AHC respondents ($p < 0.0001$). In other words, Deaf clients of SHS have smoking rates similar to those for the nation (23% according to BRFSS 2000), while AHC Deaf clients have significantly lower rates. Interestingly, the prevalence of former smokers at AHC was quite high (57%), implying a large proportion had successfully quit (Figure 3.1, p. 39)

Overall, 31% of those surveyed reported having high cholesterol (another risk factor for CVD), with no statistically significant differences by site (25% at SHS and 37% at AHC). The prevalence of elevated cholesterol among our survey respondents was therefore comparable to the 30% of the general U.S. population who report having high cholesterol (BRFSS 2001). With regards to high blood pressure, 43% of respondents reported that they had ever been told that they have high blood pressure, with no statistically significant differences by site (42% at SHS and 45% at AHC). This figure is considerably higher than the 26% of people from the general U.S. population who have hypertension (BRFSS 2001).

Interestingly, respondents at SHS were significantly more likely to report that they fell into a “high risk” category for becoming infected with HIV than were respondents at AHC. At SHS, 53% of respondents fell into the “high risk” category, compared to only 16% at AHC (Table 3.1, p. 41). The question used to assess whether someone was at “high risk” was adapted from BRFSS 2002.

Topic 4. Sources of Health Information and Relationship with Health Knowledge

The relationship between sources of information about health and level of knowledge was explored. Preliminary analysis findings suggest that those reporting multiple sources of information about their health have a greater level of knowledge, even after controlling for level of education. When looking at the individual sources of information, only Internet access was statistically related to knowledge. For example, the 48% of respondents with Internet access on the average reported more of the 7 most common warning signs of a heart attack (1.4 vs. < 1 ; $p < 0.005$), were more likely to call 911 if they thought they were having a

heart attack or stroke (70% vs. 53%; $p < 0.05$), and were more likely to correctly define the term “cholesterol” (55% vs. 24%; $p < 0.0001$) than were those without Internet access.

Topic 5. Health-Related Quality of Life (SF-12, version 2)

In recent years the concept of Health-Related Quality of Life (HRQOL) has been extensively examined in many populations including the general U.S. population, different racial and ethnic groups, people from different countries and disease-specific groups. It has been established that people assess their own physical, mental and social well being relatively well. While several inventories that measure HRQOL (e.g., SF-36, SF-12) have been developed and studied in different populations, we were unable to identify any which had been used with Deaf persons. We therefore felt it important to measure HRQOL as a part of our survey.

The instrument we used to assess HRQOL was the SF-12, version 2. The translation of the SF-12, version 2 into ASL and its use with a Deaf population is in and of itself a major contribution of this research effort. This instrument consists of 12 items, and yields an 8-scale health profile and 2 summary scores, a Physical Composite Score (PCS) and a Mental Composite Score (MCS). Norm-based scoring was used, which means that a score of 50 corresponds with the average score for the general U.S. population, while a score below 50 indicates below average health, and a score above 50, above average health.

Respondents at AHC had significantly higher PCS than those at SHS (52.9 vs. 44.7, $p < 0.0001$) (Figure 5.3, p. 50). In other words, our findings suggest that Deaf clients at SHS have worse physical health than the majority of the U.S. population, whereas the opposite is true at AHC. Given the demographic characteristics of the two groups (Tables 3 and 4, pgs. 14 and 15) suggesting that SHS respondents were generally of a lower socioeconomic status than AHC respondents, this is not surprising. In terms of their MCS, the two groups were nearly identical.

While it will be necessary to undertake additional analyses to further and more completely validate the use of this instrument with a Deaf population, preliminary results suggest that SF-12 scores correlate well with other measures of physical and mental health status.

CHALLENGES AND LESSONS LEARNED

We recognized from the beginning that there would be unique challenges involved in conducting research with Deaf individuals. The extensive amount of experience of several Project Team members with Deaf patients allowed us to anticipate many challenges prior to initiating the project. We were thus able to take them into consideration in our planning phase. Other unanticipated challenges presented themselves later in the process. Throughout, numerous lessons were learned that will assist us and others with future research efforts, program development and service delivery.

The greatest challenge involved the standardization of the survey instrument, which was to be administered in a visual-manual rather than a written language. Extensive efforts were made to assure that questions were asked consistently across respondents and across sites, so as to minimize bias. These efforts have been described in the “Methods” section. However, interviewers needed to be allowed some flexibility in their technique in order to account for the variations in the fluency and signing style of the person being interviewed. The results of our data analysis have lead us to believe that despite the extensive efforts expended in standardizing the instrument, certain questions were not asked consistently across sites. However, as there was only concern about 4 of the 139 questions, it seems that generally the standardization was successful.

Another challenge concerned the lack of familiarity of most participants with research and research methods. Some of this was anticipated and the pilot testing of the survey instrument helped us to work through certain assumptions we have about the way data should be collected or the way questions should be asked that might not be ideal for use with our Deaf clients. Some of these issues concerned certain types of questions that did not translate well into ASL (e.g., true/false questions), while others concerned a lack of familiarity by participants of common research questions and categories (e.g., excellent/very good/good/fair/poor). The fact that a fair number of clients were recruited from mental health clinics further complicated data collection, as persons with certain mental health conditions sometimes experienced difficulty in answering the questions asked.

It must also be kept in mind that the fact that these surveys were conducted face-to-face may hinder the credibility of the more sensitive data. Participants may not have been completely honest with some of their answers if they feared those answers might affect their services or otherwise incriminate them. In addition, the research assistants administering the survey were members of the Deaf Community and sometimes knew the participant personally. Although it was stressed that responses would be kept confidential, it is not fully known if this affected responses to more sensitive questions.

A final challenge concerns the time required to conduct the interview. It was felt that it would be unrealistic to expect people to participate in an interview much longer than an hour. We were therefore limited in the amount of data we could collect and had to prioritize the information we were most interested in obtaining. Even an hour seems like a large time commitment, and we were concerned that the time might be a deterrent to some people. However, this concern turned out to be unwarranted. Most respondents were very enthusiastic about participating and were excited about the opportunity to express their views and opinions. Socialization within a deaf-friendly environment is highly valued within Deaf culture and this value appears to have extended into an interview situation with a native signer.

The general willingness and enthusiasm displayed by Deaf patients at each of our institutions was likely the most positive lesson learned as a result of this research effort. However, it is important to reiterate that both of these institutions have strong deaf-services and an existing rapport with their patients. It is unclear how well such a survey would be received in the general Deaf community. Another important lesson concerns the validity of the SF-12 when used with a Deaf population. While it will be necessary to undertake additional analyses to further and more completely validate the use of this instrument with a Deaf population, preliminary results suggest that SF-12 scores correlate well with other measures of physical and mental health status.

RECOMMENDATIONS

Over the last 18 months, Michael Reese Health Trust (MRHT) support has provided an opportunity to bring together the staff of Sinai Health System and Advocate Health Care's Deaf programs, the largest deaf-serving programs in the Chicago area. It has given us an opportunity to share information and ideas, as well as to conduct research and network with others working in the field at the national level. The following recommendations represent many hours of dialogue over the length of the project. Some of the recommendations stem directly from our survey results, while others represent our broader experiences working with and serving the Deaf community.

For Providers of Health Care Services:

While our institutions have made considerable efforts to accommodate our Deaf patients, many health care providers lack familiarity with Deaf individuals and the knowledge necessary to effectively serve them. For one, providers need to be aware that many Deaf patients do not really know how to be a “patient”. They may not know how to communicate effectively with a health care professional. They may not have knowledge of their family medical history, especially if their parents were hearing and did not sign. This knowledge deficit requires the provider to be more proactive in eliciting information and feedback from the patient than is the norm for the hearing population. As demonstrated in our survey, an additional concern in serving Deaf patients is their lack of familiarity with medical terminology and basic health information. Therefore, the provider must take extra care to explain things and to elicit feedback to ensure that understanding has been achieved. The development of more Deaf-friendly health education materials would further facilitate the communication of health information to a Deaf patient.

For Public Policy:

The material resources necessary to provide quality health care services to a Deaf population exceed those needed to provide the same level of care to the hearing population. For one, a Deaf person’s medical encounter takes longer. This is partly a factor of the extra time involved in ASL interpretation. However, even a provider fluent in ASL requires more time with a Deaf patient given the general deficit in health knowledge, a deficit demonstrated by our survey results. The need for an ASL interpreter is an additional cost. The Americans with Disabilities Act requires health care institutions to make “every reasonable effort” to make the accommodations noted above for Deaf patients. Neither Medicare nor Medicaid provides sufficient remuneration to cover these extra costs however, putting health care institutions in a difficult spot. There are also no additional reimbursements for interpreter time. We recommend the exploration of methods of payment for the additional services and time needed to provide quality care to Deaf patients.

Since the language of most Deaf persons (ASL) is a visual-manual one, the opportunities for the use of “telemedicine” with this population are intriguing. Funding to test effective uses of these and other technologies is recommended.

For Further Research:

Our survey was conducted among our own patients who, by definition, are well connected to health care. The results of the survey therefore cannot be generalized to all Deaf persons. We would therefore like to see the survey replicated within a randomly selected sample of the Deaf population and those results compared to ours. The contribution to our knowledge of the unique health-related issues faced by the Deaf community would be well worth the effort. Also, our survey demonstrated a health knowledge deficit among our Deaf patients. We along with some others in the field are in the process of developing health information materials and health education programs aimed specifically at Deaf individuals. These materials and programs need to be evaluated to determine what works best in increasing the health knowledge of Deaf persons. Finally, in our survey we used many questions from validated health surveys commonly used in the hearing population, but which had not previously been used with Deaf respondents. The SF-12 is one prime example. There is much work to do in testing these research instruments for validity and reliability with Deaf persons, so as to enable comparison studies of Deaf and general populations. Research into the development of effective, standardized screening tools for use with a Deaf population is also warranted. These standardized screening tools could then be disseminated to all providers for use with their Deaf patients.

SUMMARY

The main goal of this project was to gather useful information in order to better understand the special health-related needs of Deaf persons. The survey demonstrated a general lack of health knowledge among Deaf respondents who were generally well connected to the health care system. Even among this group of well connected individuals, respondents did indicate some barriers to quality health care, some of which might be explained by a lack of knowledge of how to function in the patient role. Also, respondents were found to be at equal risk for several health outcomes as the general population. It was anticipated from the beginning that our findings would be used to implement an intervention aimed at improving the health knowledge, status and behavior of Deaf patients at both institutions. We are currently preparing to initiate a second phase of research intended to evaluate the effectiveness of two health education interventions on health knowledge, self-efficacy, self-management and patient role behaviors. Finally, we believe that the information gathered in the survey will be indispensable in instigating further research, interventions, and policy implications for Deaf persons.

SECTION 1. BACKGROUND AND SIGNIFICANCE

The special communication and cultural needs of people with hearing loss are often unrecognized, dismissed, and/or ignored by the mainstream hearing population. An estimated 28 million people in the United States are deaf or hard of hearing and this disability is increasing with the aging of the population. This comprises approximately 10% of people living in the United States. There are several common causes for hearing loss including genetics, noise or trauma, disease, premature birth, sensitivity to certain drugs or medications, viral or bacterial infections, and aging. The subgroup of this population that self-identifies as being culturally Deaf is more difficult to define. People who identify themselves as Deaf with a capital "D" consider themselves to be part of a linguistic minority who share a valued cultural connection, not a medical problem.¹ They are more likely to have been deaf from birth or prelingually (generally defined as before the age of 3), and they rely solely upon sign language or visual-manual communication for the input of information. The National Center for Health Statistics estimates that this latter group comprises 0.55% to 0.875% of the population three years and older. For Chicago, this would translate into 15,928-25,340 individuals; for the larger metropolitan area including Cook County, DuPage County and Will County, the Deaf population is estimated to be between 37,307-59,352.^{2,3}

The extent of a person's hearing loss, the age at which hearing loss occurred, and the communication environment to which the person with a hearing loss has been exposed throughout his or her life at home and school help determine which mode of communication he/she will utilize. The first language of more than half of all Americans with significant hearing loss and of most culturally Deaf people living in the United States is American Sign Language (ASL), a formal, visual-manual language that has its own grammar and syntax. ASL is the third most commonly used language in the United States. It requires face-to-face contact to provide full comprehension and is not simply a gestural representation of the English language. ASL does not have its own written component. As is true within the hearing population, most culturally Deaf people are not bilingual and, therefore, are not fluent in English. The average English reading level for an adult who was born deaf or became deaf prelingually is fourth grade. Prelingually deaf persons, therefore, often have significant problems with written language.^{1,4}

The fact that 90% of deaf children are born into families with hearing parents further complicates the manner in which many Deaf persons acquire knowledge either directly or incidentally. Many hearing parents of deaf children never become fluent in ASL. Deaf children living in hearing families in which no one is fluent in ASL experience the unique circumstance of not sharing a common language with their parents and siblings. The absence of clear understanding of what is happening around or to the deaf child living in a non-signing home environment impedes that child's ability to learn to communicate his or her needs clearly to another person, to anticipate other people's interpersonal expectations, and to acquire the incidental learning that occurs around the dinner table or while riding a car or bus with one's family. Deaf children living within a non-signing environment are a linguistic minority even in their own home. These children are born no less intelligent than their hearing counterparts but many grow up in inaccessible, under-stimulating environments that create significant barriers to acquiring knowledge and life skills. In fact, some deaf people never learn a formal language. They rely on idiosyncratic gestures developed within their home environment (i.e., "home signs") to communicate.

Once parents have established a certain communication mode with their child, that choice will affect their decision regarding the type of educational setting they feel is best for their child. There are several educational settings for deaf and hard of hearing children across the country. Most states have at least one state-funded residential school for the deaf, with dormitories for children to stay in while receiving an

education from teachers who are fluent in ASL. The children can go home on the weekends to spend time with their families. At these schools, the children have opportunities to participate in sports, organizations, and clubs. Residential schools play an instrumental role in the preservation of the Deaf Community because that is where future generations of deaf children are exposed to Deaf role models, native signers and Deaf Culture, all of which helps them to develop their identity as a culturally Deaf person.

Some parents prefer to put their children in their local school district as opposed to sending them to a residential school that may be far away from home. To ensure that the child is placed in the least restrictive environment, several school districts allocate funds to a "central school" for a mainstreamed program. These programs have teachers who are fluent in ASL in self-contained classes, and interpreters for classes the child takes with hearing peers. In these mainstreamed programs, students still do have the opportunity to socialize with each other and to participate in after-school activities with an interpreter. Their exposure to Deaf role models and sign language at home and in their neighborhood, however, often is very limited.

Sometimes, parents do not wish to expose their children to the "Deaf world" so they place their child in their home school district with the hope that the child will learn to integrate with other students who speak. Depending on which school district and the child's needs, a sign language interpreter or a signing itinerant teacher may be involved. Frequently, the child is the only deaf student in school. The child may feel isolated if he or she cannot communicate with other students.

All of these factors combined frequently result in deaf children who have been born into hearing families growing into adults who experience significant gaps in their knowledge of health, healthy living and a patient's role within the health care system. The fourth-grade average reading level of these adults may not allow them to fully comprehend the written health information they encounter in their doctor's office, nor the captioning for a health-related program that appears on television. Often times, the communication attempts they have made with their health care providers have proven unproductive and frustrating. A majority of physicians overestimate the percentage of Deaf patients who are proficient in English and do not realize the severe limitations of lip reading. Approximately 40% to 60% of sounds appear similar on the lips. The most skilled lip readers, therefore, correctly interpret only 25-30% of the movements they detect on a hearing person's lips.¹

MacKinney and his colleagues were able to show that culturally Deaf persons enrolled in a primary care program that included full time ASL interpreters were more satisfied with physician communication and had improved preventive care outcomes when compared to culturally Deaf friends who served as controls.⁵ Time, resources, availability of interpreters, and the infrequency of seeing Deaf patients all contribute to a failure to regularly use interpreters in many health care settings.^{5,6} It is rare for a Deaf patient to meet with a physician who is fluent in ASL. However, even with a certified sign language interpreter or a bilingual physician, comprehension is not guaranteed. Many English medical terms and concepts are not commonly understood among Deaf patients. To explain them in a culturally and linguistically sensitive manner within a physician's office involves extended amounts of time to expand the meaning of those terms and concepts. For those patients with a significant gap in their knowledge of basic health care issues, this educational process may require multiple explanations over time.

A review of approximately 660 brief abstracts of articles, books, and other publications addressing deafness and deaf and hard of hearing issues published during the period 1995-2000 and available through the National Rehabilitation Information Center, revealed little professional literature (focused on deaf and hard of hearing populations) documenting the relationships among health education, attitudes and

behavior, and risk factors; tools for measuring health/quality of life; strategies to influence prevalence/incidence of chronic and other illnesses; or variations in outcomes of interventions among persons with differing degrees of deafness. Most of the literature focuses instead on: deafness and children, including shortcomings in their education and socialization; parenting challenges and the value of networks and extended families; employment/vocational issues; programs and services for the deaf/hard of hearing; technologies related to hearing impairment including cochlear implants, hearing aids; and public policy issues related to deafness.

Therefore, the first step towards improving the health status and health knowledge of Deaf individuals is to document the current deficit by collecting hard data about the health status, health care experiences, communication styles, health knowledge, risk factors and barriers to accessing health care. Sinai Health System and Advocate Health Care both offer special health care programs aimed at deaf and hard of hearing persons in the Chicago area. Over the past 18 months, we have worked together to develop, implement and analyze the results of a health care survey that is sensitive to the communication and cultural needs of the Deaf Community.

Partner Descriptions

Sinai Health System (SHS) and Advocate Health Care (AHC) both have designed programs to address the physical and mental health needs of a large group of deaf and hard of hearing (DHOH) adults and children and their hearing family members. These programs are unique in Chicago and serve as models for many other areas of the country. Both programs have been found to be 100% culturally competent by the Illinois Department of Human Services, Division of Mental Health to serve the Deaf population. Together, these patient populations represent a wide range of ethnic, socio-economic and educational backgrounds.

Sinai Health System:

The Sinai Deaf Access Program offers a broad range of medical, mental health, and support services to DHOH patients at several locations. The most extensive array of services—including primary and specialty care for DHOH adults and children—can be found on the main system campus at Mount Sinai Hospital as well as at several other clinics throughout the city of Chicago. Three of the primary care physicians and three behavioral health clinicians are proficient in ASL and are aware of important dimensions of Deaf culture. Sign language interpreters are readily available to assist with needed specialty services. Medical and referral services for DHOH clients are also available at three Access Community Health Network clinics on Chicago's North and South sides—Schwab at Anixter Center and Grand Boulevard Family Health Center, and a new Sinai Health First Clinic on Peterson Avenue.

During 2003, 843 non-duplicated DHOH clients were seen for a total of 5,723 medical visits; approximately 10% of the DHOH clients are children. Ethnically, African Americans represent 50.1%, Caucasian 20.7%, Latino 15.3% and Other/Unknown 13.1% of the population served.

Sign language interpreters play an important role in the Deaf Access Program by helping patients communicate with other physicians and health professionals in their native language. Interpreters work closely with the system's administration to assure the quality of interpreting services in all settings. In addition, the Program has a contractual agreement with an external interpreting referral service for emergencies outside of normal business hours. Public TTY's are located in the hospital's emergency department and lobby. All televisions in the medical center are quipped with closed captioning and portable TTYs, telephone amplifiers, and other assistive listening devices are available on request.

Advocate Health Center:

Advocate-Metro Outreach provides comprehensive mental health care in ASL to persons who are deaf, hard of hearing and deaf-blind children, adolescents and adults and their families in the six county area of metropolitan Chicago. The program began in 1981 on the north side of Chicago at Advocate Ravenswood Hospital. Its main office is now located at Advocate Illinois Masonic Medical Center on the north side of Chicago. Satellite offices currently are located at four suburban sites: Advocate Lutheran General Hospital in Park Ridge, Advocate Christ Hospital in Oak Lawn, Metropolitan Family Services in Palos Hills and Advocate Good Samaritan Hospital in Downers Grove. The continuum of care includes clinical assessments (for adults and children), individual, family and group therapy, psychiatric evaluations and medication monitoring, case management, and crisis intervention with a 24-hour phone line connected to a TTY. In 2003, 195 unduplicated clients were seen through this program for a total of 3,523 visits.

The continuum of care also includes a Psychiatric Deaf Clinical Liaison who collaborates with Advocate Illinois Masonic Medical Center and other community hospitals to provide assessment, treatment, discharge planning and aftercare linkage to Deaf persons who are hospitalized on psychiatric units within Chicago's community hospitals. A videoconference network now links the four Advocate sites and enables a psychiatrist (one of two in the Chicago metro area who is proficient in ASL) to provide telepsychiatry and consultation to Deaf patients from a distance. Deaf Chicagoland AIDS Network (Deaf CAN) is a new program of Advocate Metro Outreach that provides prevention education to the Deaf Community and patient education, counseling, and other support services to Deaf persons who are HIV+.

In addition to Advocate Metro Outreach, the Arlington Heights office of Advocate Medical Group (affiliated with Advocate Lutheran General Hospital) includes 6 family practice physicians and two pediatricians who are familiar with the needs of the DHOH population. They offer comprehensive primary care services along with routine ASL interpretation and a 24-hour answering service that is TTY accessible. The population served encompasses 230 DHOH adults and children; during 2001 there were 668 visits by this client group.

Goal and Objectives

The goal of the survey was to collect information about the health status, health care experiences, communication styles, barriers to accessing health care, health knowledge and behaviors of a sample of clients who are deaf and for whom American Sign Language is their native language. It was hoped from the beginning that this information would be used to catalyze the development of one or more interventions intended to overcome identified barriers and improve the health knowledge, status and behaviors of Deaf clients of our institutions.

The specific objectives include:

- To develop a collaborative interview tool and process to collect information via standardized face-to-face interviews conducted in ASL;
- To implement the data collection process at multiple sites associated with Sinai Health System and Advocate Health Care;
- To use the data collected to more fully characterize the health and mental health needs, and barriers to addressing those needs amongst Deaf clients;
- Based on the results of the analysis, to identify opportunities for improvements in health and mental health care delivery to this population;

- To use the results of the survey to catalyze the development of one or more interventions intended to overcome identified barriers and improve the health knowledge, status and behaviors of Deaf clients;
- To disseminate findings to appropriate individuals within the Deaf community, the health care system, other researchers and appropriate policy makers.

¹ Phillips BA. Bringing culture to the forefrom: formulating diagnostic impressions of deaf and hard of hearing people at times of medical crisis. *Professional Psychology: Research and Practice* 1996; 27(2): 137-144.

² *Healthy People 2010, Conference Edition*. Washington DC: US Department of Health and Human Services, 2000.

³ Munroe-Ludders B. Personal communication to Toby Perlman, August 1, 2001.

⁴ McEwen E and Anton-Culver H. The medical communication of deaf patients. *The Journal of Family Practice* 1988; 26(3):289-291.

⁵ MacKinney, TG, Walters D, Bird G, Nattinger A. Improvements in preventive care and communication for deaf patients. *Journal of General Internal Medicine* 1995; 10:133-137

⁶ Ebert DA, Heckerling PS. Communication with deaf patients: knowledge, beliefs, and practices of physicians. *JAMA* 1995; 271(3): 227-229.

SECTION 2. METHODS

Developing the Survey Instrument

Given the communication issues inherent when working with a Deaf population (outlined above), and the low English proficiency of many Deaf individuals, the Project Team decided from the very beginning that the survey instrument would need to be a standardized face-to-face interview conducted in ASL. The interview would need to be conducted in an hour or less in order to be feasible. As translation from English to ASL increases the administration time of a survey, the instrument would need to consist of 150 questions or less.

A review of the literature and discussion amongst Project Team members revealed survey tools that were examined as starting points during survey development. During this initial literature review, the Project Team looked for tools that had previously been used with a Deaf population. As little published research has been conducted with Deaf individuals, only a few relevant instruments emerged as starting points.^{1,2} The literature review also revealed areas in need of additional research. Again, little published research was found documenting the health status, knowledge and behaviors of the Deaf population. Evidently, there is a need for additional research in most areas. As one specific example, in recent years the concept of Health Related Quality of Life (HRQOL) has been extensively examined in many populations including the general U.S. population, different racial and ethnic groups, people from different countries and disease-specific groups. It has been established that people assess their own physical, mental and social well-being relatively well. In fact, numerous studies have shown that people's own perception of their overall health is remarkably accurate and can be used to predict future health care needs, as well as, five and ten year mortality.^{3,4,5,6} While several inventories that measure HRQOL (e.g., SF-36, SF-12) have been developed and studied in several different populations, we were unable to identify any which had been used with Deaf persons. We therefore felt it imperative to measure HRQOL as a part of our survey.

The Project Team was invaluable in the development of the survey instrument. Several members of the Project Team have extensive experience working with Deaf patients, and provided insight into topics for inclusion on the survey, as well as issues to consider during question selection and instrument development. The Project Team met frequently during the instrument development process. The members of the Project Team are described in Table 1.

Table 1. Project Team Members

Advocate Health Care		Sinai Health System	
Name	Title	Name	Title
Dorothea DeGutis, MD	Consulting Psychiatrist	David Ebert, MD	Medical Director, Sinai Deaf Access
Carroll Cradock, PhD	Director, Behavioral Health	Teri Hedding, MA	Manager, Sinai Deaf Access
Barbara Giloth, DrPH	Director, Program Development	Gary Kaufman, MD	Internal Medicine/Pediatrics, Sinai Deaf Access
Lisa Kivland, IC/TC	Certified Sign Language Interpreter	Lewis Lummer	Research Assistant
Melvin Patterson	Research Assistant	Helen Margellos-Anast, MPH	Epidemiologist, Sinai Urban Health Institute
Toby Perlman, PhD	Manager, Advocate Metro Outreach	Linda Miller	Vice President, Care Management
Raymond Rodgers, MSW	Research Assistant	Steve Whitman, PhD	Director, Sinai Urban Health Institute

At the completion of this process, the Project Team identified the following 4 domains of content for inclusion in the survey:

1. Demographics/General Information
2. Access to and Quality of Care (including physical and mental health care services)
3. Health Knowledge/Attitudes/Behavior (with a focus on disease prevention rather than on disease management issues)
4. Health Related Quality of Life (SF-12, version 2)

The 4 domains and all relevant sub-topics included on the final instrument are presented in Table 2.

Table 2. Survey Domains and Subtopics

Survey Domains and Sub-Topics
1. Demographics
2. Access to Care/Quality of Care
3. Health Knowledge, Attitudes and Behaviors
Exercise
Nutrition/Eating Habits
Weight Status
Cancer Screening
Recognition of Medical Terminology
Cholesterol
Blood Pressure
Cardiovascular Disease
Alcohol/Drugs
Smoking
HIV/AIDS
Mental Health
Medication Use
4. Health-Related Quality of Life (SF-12v2)

The next step was to identify specific questions by which to obtain the information of interest. Many of the questions included on the survey instrument were drawn from national standardized questionnaires such as the National Health Interview Survey (NHIS) and the Behavioral Risk Factor Surveillance System (BRFSS). Including at least some questions from existing standardized and widely used questionnaires was viewed as important as it allows for valuable comparisons between the findings of our study and those of other populations (i.e., with regards to NHIS, the comparison group would be the general hearing population of the U.S.). It is important to point out that this was the first time most of these questions have been used with a Deaf population. The Sinai Urban Health Institute had recently been through a similar process in constructing a Community Survey to assess the health needs and health status of 6 Chicago neighborhoods.⁷ That survey served as a valuable starting point, and alleviated some of the groundwork. Once the topics and inventories were assembled, a draft of the interview instrument was constructed, reviewed multiple times over the course of several months, and revised.

The instrument then needed to be translated into ASL. The Research Assistants (RAs), who also served as the interviewers, were primarily responsible for this task. The RAs were native signers, who are themselves members of the Deaf community. They took the completed survey and created a gloss for all questions. A gloss is a written representation of each question as it is to be translated into ASL—in other words a script for sign language. The gloss was then thoroughly reviewed by the other members of the Project Team proficient in ASL. It is important to remember that ASL is a visual, not a written language, and cannot be completely captured in a written format. Nonetheless, the gloss is important in portraying the essence of the question to the interviewer, thus serving as a training tool for the interviewers, and assuring that questions are asked consistently across subjects and across sites. An excerpt from the survey, including questions in English and ASL gloss can be found in Appendix 1.

To our knowledge, the SF-12 has never been used with a Deaf population. Therefore, the translation of the instrument into ASL also included the translating of the SF-12. A copy of the SF-12 in ASL gloss is attached in Appendix 4.

Finally, the Research Coordinator formatted the ASL gloss version of the survey instrument to facilitate data collection and data entry. Formatting included the addition of interviewer instructions, skip patterns, prompts and data entry codes.

Study Process and Protocol

Prior to applying for IRB approval of the study and initiating the pilot testing of the instrument, the specifics of the study process and protocol had to be settled on. Specifically, the Project Team needed to decide on the study inclusion/exclusion criteria, recruitment process, and informed consent process. More information on each of these components can be found below under "Recruitment of Participants".

IRB Submission

Before beginning the pilot test of the survey instrument, it was necessary to apply for IRB approval at both sites. SHS received IRB approval in early November; AHC in early December.

Training the Research Assistants

Both RAs participated in a formal training session with the project's Research Coordinator (Helen Margellos-Anast) prior to the pilot testing of the instrument. The purpose of the training was to assure that all of the data was collected and recorded consistently from all survey respondents. The training session was about 2 hours in length and covered the following areas: recruitment, screening, informed consent, interview techniques and rules, an orientation to the survey (formatting, instructions, skip patterns, etc.), recording of responses and data editing. The RAs also videotaped themselves going through the interview, critiqued one another, and worked collectively to further standardize their approach. Finally, each RA also went through a mock interview with Project Team member Lisa Kivland (ASL Interpreter for Advocate Medical Group), for further practice.

Pilot Testing the Instrument

Each site planned to test the informed consent process and survey instrument with 5-10 clients. SHS began pilot interviews in late November and completed 9 interviews. AHC began pilot interviews in early December and completed 5 interviews. The pilot testing proved to be a very useful process and resulted in several changes to the survey. Some examples of resulting changes to the survey instrument included:

- Changing the order of the questions so more sensitive questions (e.g., HIV, alcohol use) are asked towards the end, after a rapport has been established between the interviewer and the respondent;
- Establishing consistent response categories across similar questions;
- Adding a "No Coded Response Applicable" (NCRA) category to certain questions where respondents did not always fit into one of the pre-defined groups;
- Revising questions that were confusing to some respondents;
- Replacing ambiguous categories with numeric scales, as it was found that respondents had a hard time placing themselves into these categories. For example, the question "How important is getting exercise to you personally? {very important, important, somewhat important, not very important}" was revised to read, "On a scale from 1 to 10, where 1 is 'not at all important' and 10 is 'very important', how important is getting exercise to you personally?";

- Using flash cards with numeric scales to serve as visual aids, thereby clearly orienting the respondent towards a negative vs. a positive response;
- Changing True/False questions to Yes/No questions, as the concepts of True/False do not translate well into ASL; and,
- Clarifying interviewer instructions that were not conveying the intended message.

The Final Survey Instrument

The final survey instrument consisted of 139 questions. Interviews generally took about an hour to complete, although women and people over the age of 50 had more questions to answer and sometimes took slightly longer. An excerpt from the final version of the survey instrument, along with the corresponding ASL gloss, is attached in Appendix 1. For the complete instrument, please contact: *Helen Margellos-Anast, Sinai Health System, California Avenue at 15th Street, Chicago, IL 60608; phone:773-257-5259, fax:773-257-5680, e-mail:marhe@sinai.org*

The Target Population

Adult (18 years of age or older), Deaf clients of either the SHS or AHC who met the following criteria were eligible to participate:

- Make their own health decisions (i.e., do not reside in a group home or have a legal guardian);
 - Rely on ASL as their primary mode of communication;
- OR-
- Are proficient in ASL, and either (1) prelingually deaf (before the age of 3) or (2) self-identify with the Deaf Community.

Recruitment of Participants

Participants were recruited slightly differently at each of the institutions. In both instances, they were recruited from amongst Deaf clients seen in either a general or a mental health clinic. At SHS, recruitment was primarily face-to-face. The RA screened appointment records for potential participants. When the person came in for a scheduled appointment, the RA would approach the patient, briefly introduce himself and the study (using the Recruitment Script in Appendix 2), and would determine whether the person was potentially interested in participating. If the person did express an interest in participating, then the RA would determine his/her eligibility for the study using the top half of the Screening Form (Appendix 3). This process worked well at SHS, as all clients were recruited from either the main campus or the Peterson clinic. The RA therefore was easily able to get to where he needed to be whenever a Deaf client came in for an appointment.

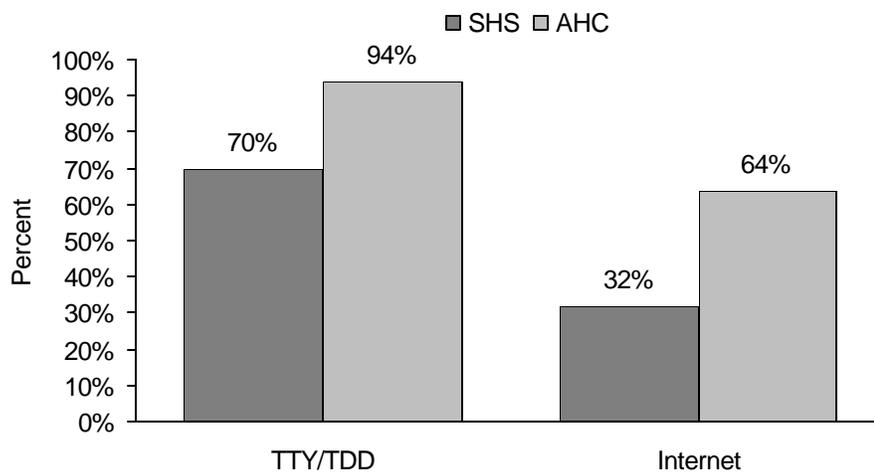
At AHC, the clinics from which we recruited were spread out throughout the city and suburbs (see Figure 1), making it unrealistic for the RA to recruit each and every subject via face-to-face contact. Therefore, while some clients were recruited face-to-face, more often, clients of AHC were contacted either via TTY, e-mail or fax and an appointment specifically set-up for them to come in for an interview. The study was introduced to them during this initial contact.

While the Project Team members most familiar with each site intuitively developed the model for recruitment at each of the sites, the data collected in our survey reinforced the utility of the methods employed. As Figure 2 shows, a greater proportion of respondents from AHC had access to TTY and/or the Internet than at SHS.

Figure 1. Locations of AHC Recruitment Sites



Figure 2. Proportion of Respondents Reporting TTY and Internet Access by Site



The Informed Consent Process

The prior experiences of Project Team members working with Deaf clients and recommendations from other researchers, especially at Gallaudet University, led to the informed consent process being set-up with three dimensions: 1) a consent form in English for potential participants to read and sign; 2) a brief video pamphlet translating the English form into ASL; and 3) an ASL version of the form presented to the potential participant by the RA. Respondents were given the option of choosing any of these methods. Regardless of the method selected, the participant had the opportunity to ask the RA questions before signing the paper version of the consent form. Interestingly, no one opted for the videotape version of the

consent form. Rather, about one-third of participants chose the paper version while two-thirds chose to have the RA present the form to them in ASL.

Administering the Survey/Data Collection

Once informed consent was obtained, the RA collected demographics and some general information from the participant (bottom of the Screening Form, Appendix 3). The interview was then conducted or an appointment scheduled to interview the person at a later time. Interviews generally took about an hour to complete, although women and people over the age of 50 had more questions to answer and sometimes took slightly longer. Participants were given \$50 each for completing an interview.

Participation Rates

The first survey was administered on 11/21/2002 and the last on 3/22/2003. During that time period, 120 people were screened at SHS, and another 106 at AHC. Of those, 102 (85%) people were eligible to participate at SHS and 101 (95%) at AHC. All who were eligible to participate agreed to do so.

Data Entry

The project database was constructed using Microsoft Access. The electronic data entry forms were created with pre-programmed skip patterns and other quality checks to minimize the potential for data entry errors. The RAs were responsible for entering the data from each of their interviews into the database. Periodically, the RAs would transfer both the electronic and paper versions of the survey files to the Research Coordinator. The Research Coordinator monitored the database periodically to assure the integrity of the data.

Data Cleaning and Analysis

Once all the data had been collected and entered into the computer, we turned our attention to the data analysis. Data was transferred to SAS⁸ statistical software, version 8.2 for analysis. The first step involved assessing the demographic characteristics of our study population, and the differences between those recruited from each site. Next, basic frequency tables of each question were generated and reviewed. Unusual or inconsistent data values were researched, and the data cleaned accordingly. Some back coding of "other" or "no coded response applicable" responses was also carried out at this time. Given the breadth of information collected on the survey and the multitude of more detailed analyses that could be undertaken, the Project Team guided the initiation of higher-level analyses. The first priority was to focus on analyses that would be useful in guiding the planning of an intervention stemming from the survey findings (Phase II, submitted to the MRHT 9/15/03, funded 12/04/03). More detailed analyses included the creation of new variables when indicated (e.g., knowledge scores), stratification by demographic characteristics, and other stratified analyses as directed by the Project Team. As one example, the association between sources of information about health and level of knowledge was further assessed.

Scoring the SF-12, version 2

Norm-based scoring was used for the SF-12, version 2. First, certain items need to be recoded into categories appropriate for calculating the score. Then, responses were summed across the 8 subscales. In all cases, a higher score is indicative of better functioning. The next step involved a linear transformation of the scores to achieve a mean of 50 and a standard deviation of 10 in the general U.S. population. In the end, there is an SF-12 profile consisting of 8 subscale scores, along with 2 summary measures, one focused on physical (Physical Composite Score) and one on mental (Mental Composite Score) functioning. All scores range from 0-100, with a higher score being indicative of a higher level of functioning in that area. A score of 50 indicates that the person has a level of functioning similar to that of the general U.S.

population, whereas a score above 50 implies better than average health status, and a score below 50, worse than average health status. Further information on the scoring of the SF-12, version 2, can be found in the manual.⁹

Statistical Analysis

In most instances, simple frequencies were compared for statistical significance between sites, or across respondents differing on some other characteristic (e.g., race), using a Chi-Square test. Continuous variables were assessed for significance via t-test (comparing 2 groups) or Analysis of Variance (3 or more groups). For all statistical tests, a p-value of .05 or less was considered statistically significant. Two-sided tests of hypothesis were used.

¹ MacKinney TG, Walters D, Bird G, Nattinger A. Improvements in preventive care and communication for deaf patients. *Journal of General Internal Medicine* 1995; 10: 133-137.

² Zazove P, Niemann LC, Gorenflo DW et.al. The health status and health care utilization of deaf and hard-of-hearing persons. *Archives of Family Medicine* 1993; 2:745-752.

³ Idler EL, Russell LB, and Davis D. Survival, Functional Limitations, and Self-rated Health in the NHANES I Epidemiologic Follow-up Study, 1992. *Am J Epidemiology* 2000; 152:874-83

⁴ McGee DL, Liao Y, Cao G, and Cooper RS. Self-reported Health Status and Mortality in a Multiethnic US Cohort. *Am J Epidemiology* 1999; 149:41-6

⁵ Idler EL and Benyamini Y. Self-rated Health and Mortality: A Review of Twenty -Seven Community Studies. *J of Health and Social Behavior* 1997; 38(March):21-37

⁶ Idler EL and Ronald JA. Self-rated Health and Mortality in the NHANES-I Epidemiologic Follow-up Study. *Am J Public Health* 1990; 80:446-452

⁷ Whitman S, Williams C, Shah AM. Sinai Health System's Community Health Survey: Report 1. Chicago, Illinois: Sinai Health System, 2004.

⁸ SAS Institute, Inc. Window Based SAS and Window Based SAS/STAT. Cary, North Carolina, 2003.

⁹ Ware JE, Kosinski M, Turner-Bowker DM, Gandek B. *How to Score Version 2 of the SF-12 Health Survey (With a Supplement Documenting Version 1)*. Lincoln, RI: QualityMetric Incorporated, 2002.

SECTION 3. POPULATION CHARACTERISTICS

Demographics

Overall, 203 Deaf clients (102 at SHS and 101 at AHC) completed the survey. The resulting survey population is very diverse. As evident in Tables 3 and 4, participants recruited from the two sites differed significantly in many of their characteristics. The diversity of the surveyed population is an asset of our study, and resulted from the collaboration between SHS and AHC in collecting this data.

Table 3: Demographic Characteristics of Survey Respondents by Site and for the Total Sample

		SHS (n=102)	AHC (n=101)	Total Sample (n=203)	p-value*
Gender	% Female	55%	53%	54%	NS
Race/Ethnicity	NH Black	51%	6%	29%	< 0.0001
	NH White	29%	82%	56%	
	Hispanic	13%	7%	10%	
	Other	7%	5%	6%	
Age	Mean Age (yrs)	44	46	45	NS
Residence	Chicago	86%	30%	58%	< 0.0001
	Suburbs	14%	70%	42%	
Level of Education**	< HS	19%	14%	16%	< 0.0001
	HS Grad	47%	20%	34%	
	More than HS	20%	43%	31%	
	College Grad	11%	18%	14%	
Type of School	Residential	33%	34%	34%	NS
	Mainstream [^]	63%	53%	58%	
	Other	4%	13%	8%	
Income	≤ \$20,000	60%	46%	53%	< 0.0001
	\$20,001-\$40,000	7%	38%	23%	
	>\$40,000	9%	12%	11%	
	Don't Know	24%	4%	14%	
Employment Status	Employed	29%	63%	46%	< 0.0001
	Laid off/Unemployed	23%	14%	19%	
	Retired	10%	10%	10%	
	Other ^{^^}	39%	12%	26%	

*p-value of characteristics between SHS and AHC. Chi-Square/Fisher as appropriate was used to assess significance of categorical variables; t-test for continuous variables. NS="not significant" (p>0.05).

** Some responses were not codable and are not presented, so percents do not add up to 100%.

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

^{^^} At SHS, the most commonly written in "other" response was SSI/SSDI (21% of SHS respondents).

Table 4. Sources of Health Insurance Among Survey Respondents by Site and Total Sample[^]

	SHS (n=102)	AHC (n=101)	Total Sample (n=203)	p-value*
Medicaid	49%	18%	34%	< 0.0001
Medicare	43%	15%	29%	< 0.0001
Employer Sponsored	18%	60%	39%	< 0.0001
Other Private	1%	6%	3%	NS
No Insurance	9%	6%	7%	NS

[^] Respondents could indicate more than one source of insurance.

* p-value of characteristics between SHS and AHC. Chi-Square/Fisher as appropriate was used to assess significance of categorical variables.

NS="not significant" (p>0.05).

Specifically, the two groups differed significantly with respect to:

- race/ethnicity- SHS respondents were predominately non-Hispanic black (51%), whereas AHC respondents were predominately non-Hispanic white (82%);
- urban/suburban residence-SHS respondents resided primarily in the city of Chicago (86%), whereas AHC respondents resided primarily in the suburbs (70%);
- level of education-61% of AHC respondents reported some education beyond high school compared to only 31% of SHS respondents;
- employment status-63% of AHC respondents reported they were employed versus only 29% of SHS respondents;
- insurance status-nearly 50% of SHS respondents reported being insured by Medicaid compared to only 18% of AHC respondents. Conversely, 66% of AHC respondents reported either employer sponsored or private insurance versus only 19% of SHS respondents.

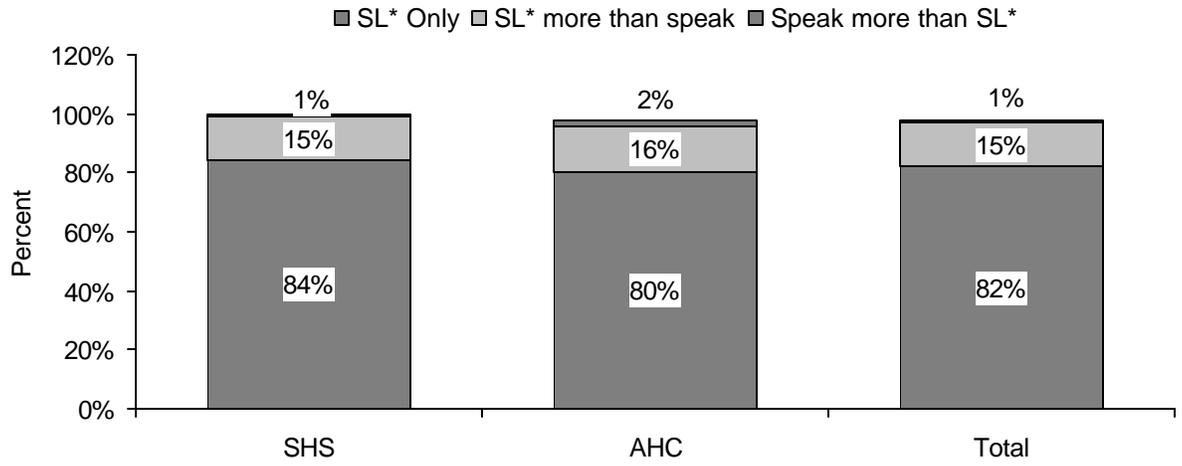
All of the above data collectively makes it clear that in terms of socioeconomic status and race/ethnicity, the two groups are very different.

It is also important to note that many of the demographic characteristics are related to one another (e.g., education is related to income, race to education, etc.) making it difficult to use a single characteristic to fully account for site differences in survey findings (see "Key Survey Findings" for some examples). The true indicator responsible for some of these differences may be socioeconomic status, which is appreciably more difficult to fully capture in a single measurement. As a result of the statistically significant differences between sites in their characteristics, and the association of some of these characteristics both with survey findings and with one another, in most instances we will present our results by site.

Communication Issues

Given the inclusion criteria, it is not surprising that the majority of respondents were prelingually deaf (before the age of 3), with 90% of respondents (89% at SHS and 91% at AHC) falling into this category. It is also not unanticipated that when asked about their usual and preferred method of communication, the majority indicated primarily relying on a method of sign language, with or without another method (Figure 3). In fact, 99% and 96% respectively of SHS and AHC respondents rely primarily on a form of sign language for effective communication (Figure 3).

Figure 3. Usual and Preferred Method of Communication by Site and Overall^



^ Numbers do not add up to 100%, as category "Another Method" is not included in the graph
*SL=form of sign language

SECTION 4. KEY SURVEY FINDINGS

With 139 questions on the final survey, it would be impossible to summarize all of our findings in one report. We have thus decided to proceed by presenting the most interesting findings in five specific areas. The areas included are:

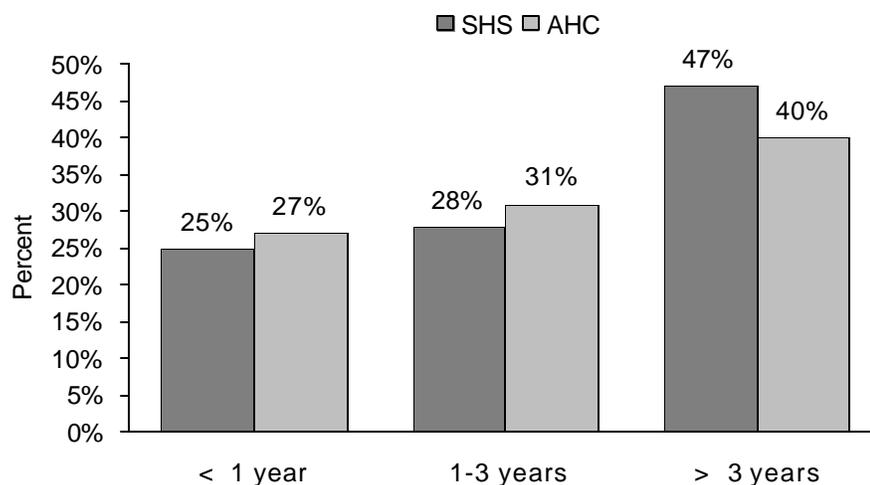
1. Access to and Quality of Care
2. Health Knowledge, Attitudes and Behaviors
3. Prevalence of Risk Factors
4. Relationship Between Sources of Health Information and Health Knowledge
5. Health-Related Quality of Life (SF-12, version 2)

Topic 1. Access to and Quality of Care

Access to Care

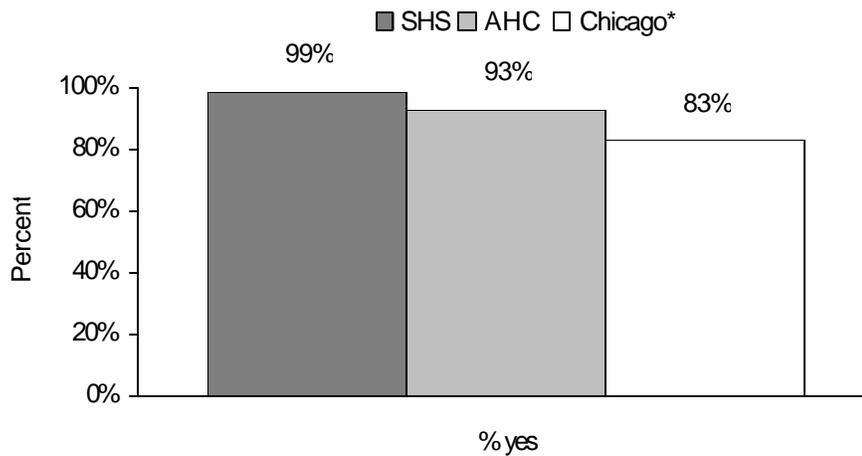
As our participants were recruited from clients at one of two health care systems, it is not surprising that they comprise a sample of Deaf individuals who are well connected to the health care system. This is evident when examining some of the resulting survey data. Respondents were asked how long they had been patients at the particular clinic from which they were recruited. Respondents from both sites were strikingly similar in this regard. As shown in Figure 1.1, nearly half of respondents (43%) reported they had been patients of that clinic for more than 3 years, where as only about 25% were new patients who had been at that clinic for less than one year.

Figure 1.1 Length of Time Respondent had been a Patient of the Clinic from which Recruited



We also asked respondents if they have one person who they think of as their “personal doctor” or primary health provider. All but 8 respondents answered “yes” to this question (Figure 1.2). National data from the 2000 Behavioral Risk Factor Surveillance System Survey (BRFSS) revealed that only 83% of Chicago residents report having a primary health provider, suggesting that survey respondents were better connected to the health care system than the general population. As stated previously, this is an artifact of the way in which respondents were recruited. Nonetheless, it is important to keep this connectedness with the health care system in mind as subsequent data is examined. Our data is not reflective of the general Deaf population, but rather of Deaf patients of SHS and AHC.

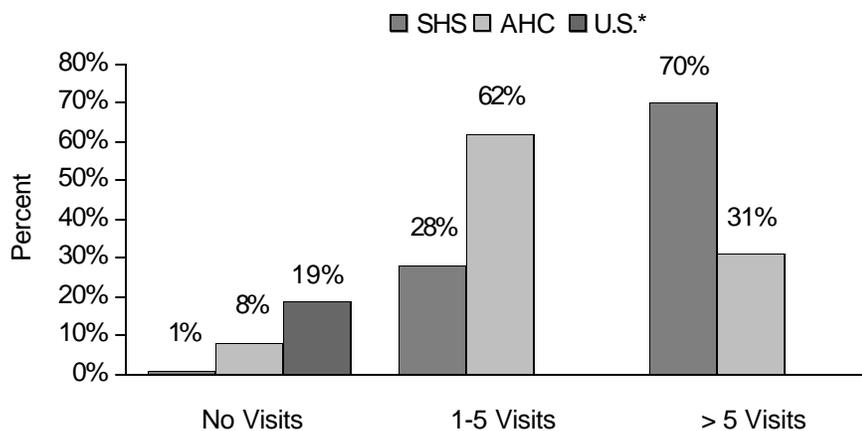
Figure 1.2. Proportion of Respondents with a Primary Health Provider



* BRFSS, 2000

Survey respondents reported seeing a physician regularly. As shown in Figure 1.3, all but 1% of SHS respondents and 8% of AHC respondents had seen a physician in a clinic or office setting within the past year. These percentages are low when compared to the 19% of U.S. adults reporting that they had not seen a physician in the past year (NHIS, 1998). Also, more SHS respondents (70%) than AHC respondents (31%) reported that they had seen a physician more than five times in the past year. This data suggests that SHS respondents may have been in poorer physical health than AHC respondents, a fact that is substantiated by the Physical Composite Score of the SF-12 and other survey data (see Topic 5: Health Related Quality of Life).

Figure 1.3 Number of Visits to a Doctor's Office in the Past 12 Months



* NHIS, 1998

Communication Issues and Quality of Care

Respondents were asked how they primarily communicate with their doctor. As shown above, most had been patients of one of the two participating institutions for some time. As both institutions offer specialized services for Deaf patients, it is not surprising that the most common response at both sites was that either their doctor knows ASL or a professional interpreter is used (Figure 1.4). However, even amongst patients of these two facilities, over 10% indicated that they rely primarily on an “other”, less than adequate method. The same sort of information was solicited from those respondents who reported ever having seen a mental health counselor or psychiatrist (n=108). Again, the majority of respondents reported having had a counselor fluent in ASL or using a professional interpreter (Figure 1.5).

Figure 1.4 Primary Mode of Communication with Doctor

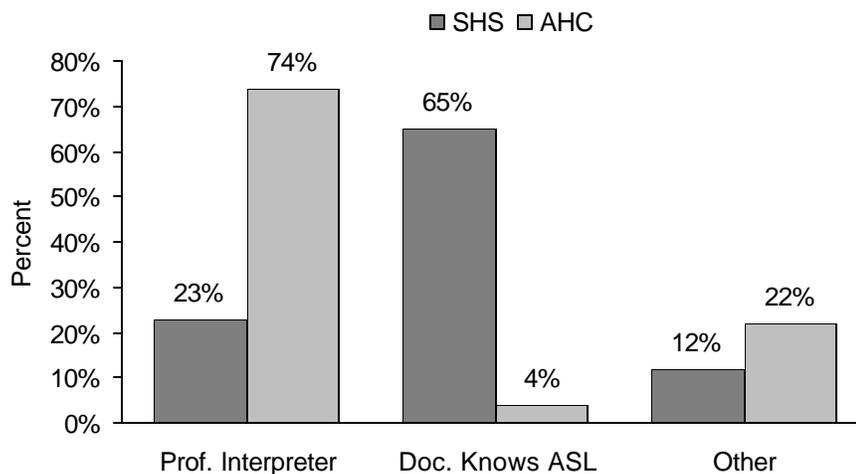
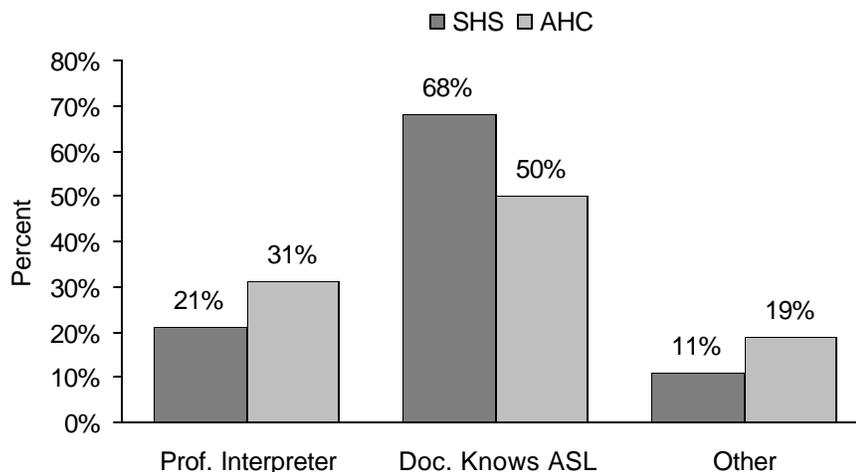


Figure 1.5 Primary Mode of Communication with Counselor or Psychiatrist



We were also interested in assessing the use of interpreters with Deaf patients during hospitalizations and Emergency Department (ED) visits. We therefore asked respondents who indicated that they had been hospitalized at least once in the past 5 years (n=86) about the frequency of interpreter availability during

their most recent hospitalization. We asked the same of respondents who indicated that they had been to the ED within the past year (n=97). The findings are in Tables 1.1 and 1.2.

Table 1.1. Availability of a Professional Interpreter During Most Recent Hospitalization (Among Those Hospitalized in Past 5 Years, n=86)*

	SHS (n=47)	AHC (n=39)	Total Sample (n=86)
Always	32%	51%	41%
Most of the time	0%	0%	0%
Sometimes	11%	13%	12%
Never	47%	26%	37%

*Some responses were not codable and are not presented, so percents do not add up to 100%

Table 1.2. Availability of a Professional Interpreter During Most Recent Emergency Department Visit (Among Those With ED Visit in Past Year, n=97)*

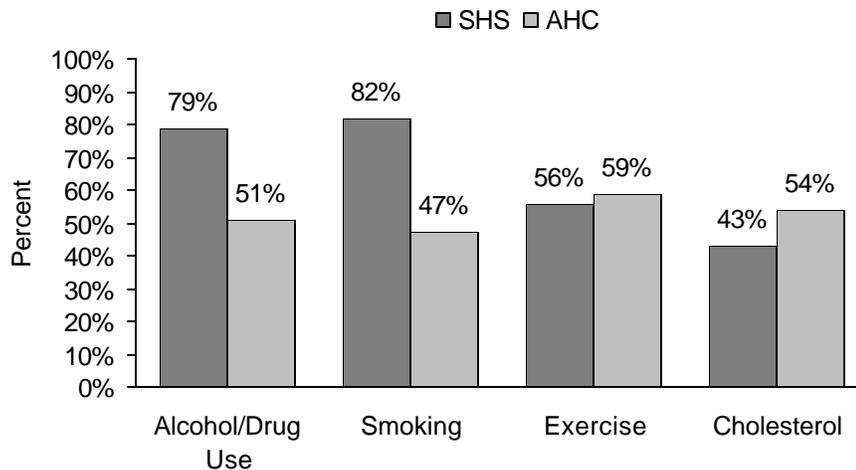
	SHS (n=61)	AHC (n=36)	Total Sample (n=97)
Always	49%	39%	45%
Most of the time	2%	8%	4%
Sometimes	3%	8%	5%
Never	34%	33%	34%

*Some responses were not codable and are not presented, so percents do not add up to 100%

It is certainly disconcerting that over one-third of those who had been hospitalized or were seen in an ED indicated never having a professional interpreter present to assist them in communicating with the doctor. One shortcoming of our data collection is that we did not ask respondents where they had been hospitalized or which ED they had visited. As a result, we are unable to use this data to assess our own services or those of other hospitals in the Chicago area. However, we did request information on the site of service from approximately the last quarter of respondents interviewed at SHS. Consequently, we have a sub-sample of 10 respondents who had been hospitalized and indicated that they had never been presented with an interpreter for whom we do know the location of service; none of these respondents indicated either SHS or AHC as the location of service. The same was true for the sub-sample of 10 respondents indicating having been seen in an ED and not being provided with an interpreter; none indicated either SHS or AHC as the ED visited. Of course, only about 10% of respondents were asked about location. Therefore, all we can confidently say is that our data suggests that the availability of interpreters to Deaf patients in the Chicago area is less than ideal.

Finally, as indicators of the type of health information respondents receive from their physicians, we asked whether a physician had ever spoken to them about various topics such as smoking, exercise and cholesterol screening. These topics are preventive health standards of care for primary care providers, so in theory all of the numbers should be 100%. As evident in Figure 1.6, that is not the case.

Figure 1.6 Proportion of Respondents Indicating a Doctor Had Ever Asked or Spoken to Them About Certain Topics



So, although the majority of respondents interviewed indicated being able to communicate well with their physician (data not shown), they were still not receiving some vital information about their health from that physician. There are many constraints that limit the time physicians have with patients, and therefore many are forced to cut corners. The increased time it takes to communicate with a Deaf patient likely exacerbates the issue. We cannot however accurately conclude from this data whether physicians are not speaking with their Deaf patients about these topics, or are in fact presenting the information to their Deaf patients, but in a way that the patients do not fully comprehend.

Topic 2. Health Knowledge, Attitudes and Behaviors

The level of knowledge of survey respondents about their health and healthy behaviors was generally low across most topic areas. When comparison data was available for hearing populations, survey respondents had lower levels of knowledge than their hearing counterparts. The most compelling of the data is presented as illustrative of this trend.

In many instances, the level of knowledge differed significantly by site or by some other demographic characteristic. When this was true, AHC respondents generally had higher levels of knowledge than SHS respondents. With respect to demographics, those who were more educated (more than a HS education), reported a higher household income (>\$20,000 per year), and non-Hispanic white people had higher levels of knowledge than their less educated, poorer and non-white counterparts. A few examples of such differences are presented in the findings herein (see Tables 2.1, 2.2, 2.3 and 2.6). In most cases, adjusting for a single demographic characteristic did not account for the entire site difference. Often times, demographics were found to explain some of the difference at one site, but not at the other. Alternatively, knowledge was sometimes found to differ by site in one demographic group but not in another. Examples of this phenomenon can also be found in the findings presented below (see Figures 2.1, 2.2, and 2.3).

Regardless, this difficulty to explain site differences completely by demographic differences suggests that there is something inherently different about patients served by each of our institutions. Perhaps this difference has to do with socioeconomic status, which cannot easily be captured by a single demographic characteristic. Alternatively, it is possible that there is a difference between the urban and suburban Deaf, which might be related to social connectedness with the Deaf community. The resolution of this issue will require further, higher-level analyses.

Cardiovascular Disease and Cardiac Risk Factors

Warning Signs of a Heart Attack or Stroke:

As a part of the survey, respondents were asked to relate to the interviewer the warning signs of a heart attack, and in a subsequent question, the warning signs of a stroke. Respondents were not provided with response categories, but were simply asked to name as many warning signs as they could.

Nearly half of respondents (40%) could not identify any of the 7 most common warning signs of a heart attack. There were no statistically significant differences by site or any other demographic characteristic. The most common warning sign of a heart attack identified was chest pressure/pain, but even this seemingly obvious warning sign was identified by less than half of respondents (49%). In comparison, in a recent random digit dial survey of 1294 hearing adult respondents in 20 study communities, 90% identified chest pressure/pain as a symptom of a heart attack.¹ Also, in the same study, the median number of warning signs reported was 3, while in our survey the median was 1.¹

With regards to stroke, 62% of respondents could not identify any of the 7 most common warning signs, with no statistically significant differences by site or any other demographic characteristic. The most common warning sign of a stroke identified was sudden numbness of face, arm, leg, or one side of body, but even this warning sign was identified by only 29% of respondents. Evidence suggests that even in the hearing population, the warning signs of a stroke are not as well known as those of a heart attack. For example, a recent random digit dial telephone survey in the Cincinnati Metropolitan area of 1880 hearing adults found that 43% of those interviewed were not able to identify any of the warning signs of a stroke.²

The authors of the article concluded that considerable education is needed to increase the public's awareness of stroke warning signs and risk factors. Obviously, while there is a deficit in knowledge in the general population regarding stroke symptoms, our survey suggests that the deficit is even greater among our Deaf respondents.

The exhibited insufficiency in knowledge of the symptoms of a heart attack and stroke are especially disconcerting given the known benefit associated with early treatment.

Responding to a Heart Attack or Stroke:

Of course there is no benefit associated with reacting early to a heart attack or stroke, if one does not react correctly. We asked respondents what they would do if they thought they were having a heart attack or a stroke. The most imperative response to a heart attack or a stroke according to the American Heart Association is to call 911. Just over half (61%) of our respondents indicated that they would call 911 if they thought they were having a heart attack or a stroke. Stratification revealed no statistically significant differences by site or any other characteristic. These results are disappointing given the benefit of getting treated immediately and correctly.

Risk Factors for a Heart Attack or Stroke:

As important as it is to recognize one is having a heart attack or a stroke and to react promptly and correctly, it is equally, if not more important to take steps towards preventing their occurrence. We asked respondents to identify the factors that increase one's risk for having a heart attack or a stroke. In this case, the list of possible responses was read to the respondent and he/she was asked to identify those that are risk factors. Approximately one-third of respondents (32%) could not identify any risk factors for a heart attack or stroke. There were statistically significant differences in knowledge by site, with nearly half of respondents at SHS (47%) being unable to identify even one risk factor compared to 16% at AHC ($p < 0.0001$).

To further assess the level of knowledge around the risk factors of a heart attack or stroke and its association with the characteristics of the respondent, a knowledge score was created. This was done by summing the number of correctly identified risk factors and dividing by 6 (the maximum possible). The score is then displayed as the percent correct out of 6. For example, if a person correctly identified 3 of the 6, his/her score would be 50%. The average respondent had a score of 47%, with respondents at AHC having a higher average knowledge score than respondents at SHS (70% vs. 23%, Table 2.1). There were also statistically significant differences in knowledge score by race, the type of school attended as a deaf child, highest level of education received and income. These are all presented in Table 2.1. Adjustment for demographic characteristics did not eliminate site differences (Figures 2.1a-2.1c), implying knowledge is associated with a combination of factors (e.g., SES, environment), and cannot be explained by a single thing.

Table 2.1. Statistically Significant Differences in the Knowledge of Risk Factors for Heart Attack/Stroke by Site and Respondent Characteristics (using Knowledge Score[^])

		Average Knowledge Score [^]	p-value*
Site	SHS	23%	< 0.0001
	AHC	70%	
Race/Ethnicity**	NH White	62%	< 0.0001
	Other	29%	
Level of Education	HS or less	37%	0.0001
	More than HS	59%	
Type of School	Residential	41%	< 0.05
	Mainstream ^{^^}	53%	
	Other	66%	
Income	≤ \$20,000	41%	< 0.0001
	> \$20,000	71%	

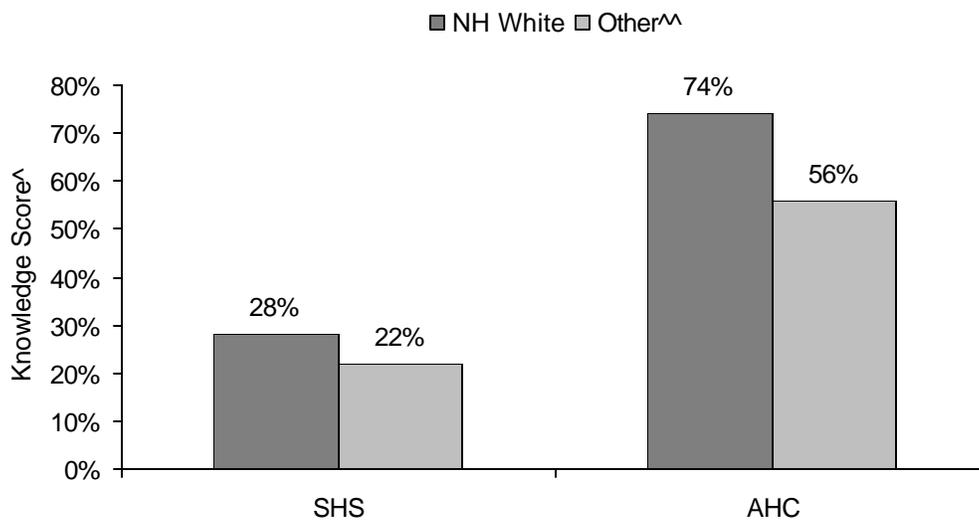
*T-test/ANOVA as appropriate was used to assess significance (p<0.05)

**Only NH White and Other could be used as there were not enough NH Black respondents (n=5) at AHC to use this third category

[^]Knowledge Score was calculated by dividing the number of correct responses by the total possible

^{^^}Mainstream includes schools with and without specialized programs for deaf children

Figure 2.1a. Differences in the Knowledge of the Risk Factors for Heart Attack/Stroke by Site and Race (using Knowledge Score[^])

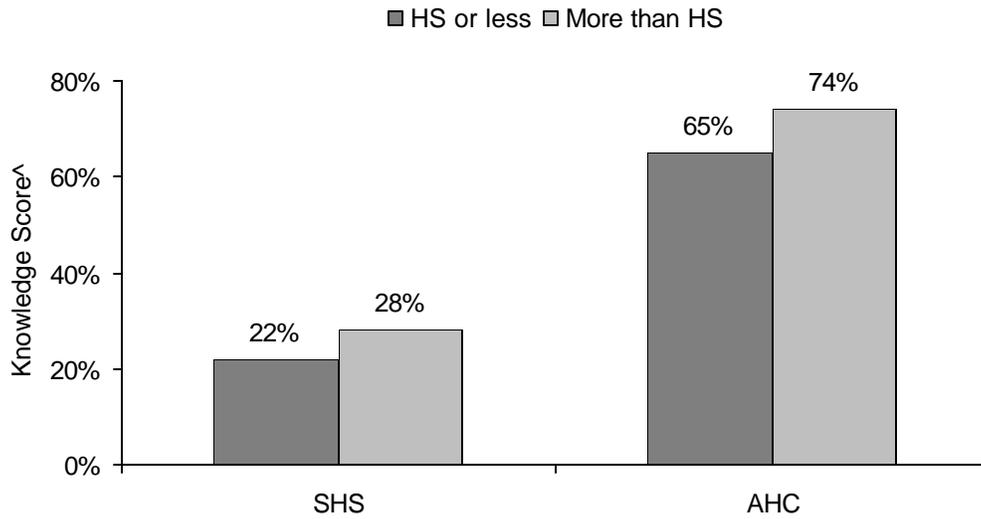


Multiple regression models with Site and Race as independent factors were used to generate p-values. Site (p<0.0001) and Race (p<0.05) both remained significant predictors of Knowledge

[^]Knowledge Score was calculated by dividing the number of correct responses by the total possible

^{^^}Only NH White and Other could be used as there were not enough NH Black respondents (n=5) at AHC to use this third category

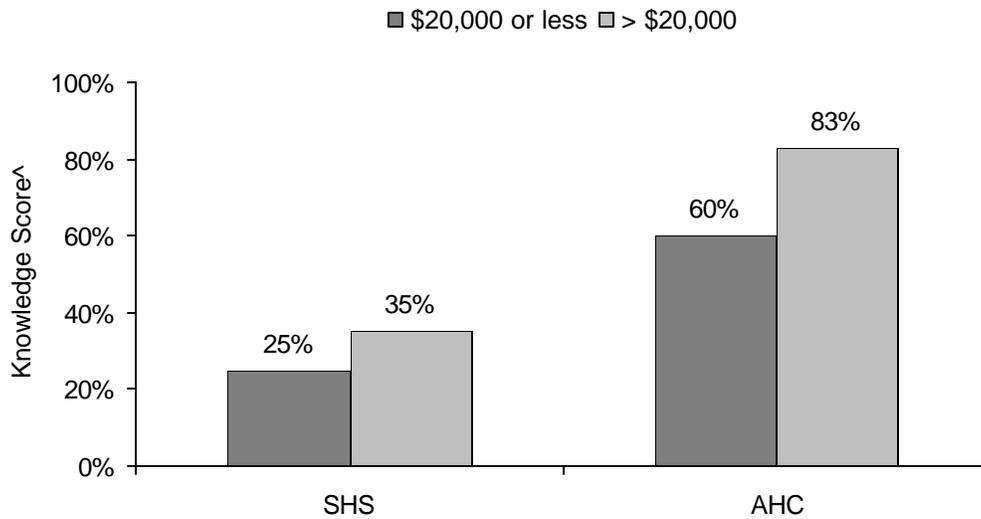
Figure 2.1b. Differences in the Knowledge of the Risk Factors for Heart Attack/Stroke by Site and Level of Education (using Knowledge Score[^])



Multiple regression models with Site and Education as independent factors were used to generate p-values. Site ($p < 0.0001$) remained a significant predictor, where as Education did not ($p > 0.05$)

[^]Knowledge Score was calculated by dividing the number of correct responses by the total possible

Figure 2.1c. Differences in the Knowledge of the Risk Factors for Heart Attack/Stroke by Site and Income (using Knowledge Score[^])



Multiple regression models with Site and Income as independent factors were used to generate p-values. Both Site ($p < 0.0001$) and Income ($p < 0.0005$) remained significant predictors of knowledge

[^]Knowledge Score was calculated by dividing the number of correct responses by the total possible

Cholesterol

Recognition of Term "Cholesterol":

In order to assess familiarity of Deaf respondents with the English medical term "cholesterol", the word was finger spelled to respondents, four possible definitions read, and respondents were asked to identify the correct definition. Only about one-quarter of SHS respondents and one-half of AHC respondents were able to correctly define the term (Table 2.2), with respondents at AHC being significantly more likely to do so ($p < 0.0001$).

Table 2.2 and Figures 2.2a-2.2c present findings on the relationship between demographics and the ability to correctly define the term "cholesterol". Table 2.2 shows that statistically significant differences exist by race, level of education and income, with non-Hispanic White respondents, those who are more educated and those with a higher income being more likely to correctly define the term. However, Figures 2.2a-2.2c show that demographic differences between the sites do not completely explain differences in knowledge by site, implying level of knowledge is rooted in a combination of factors.

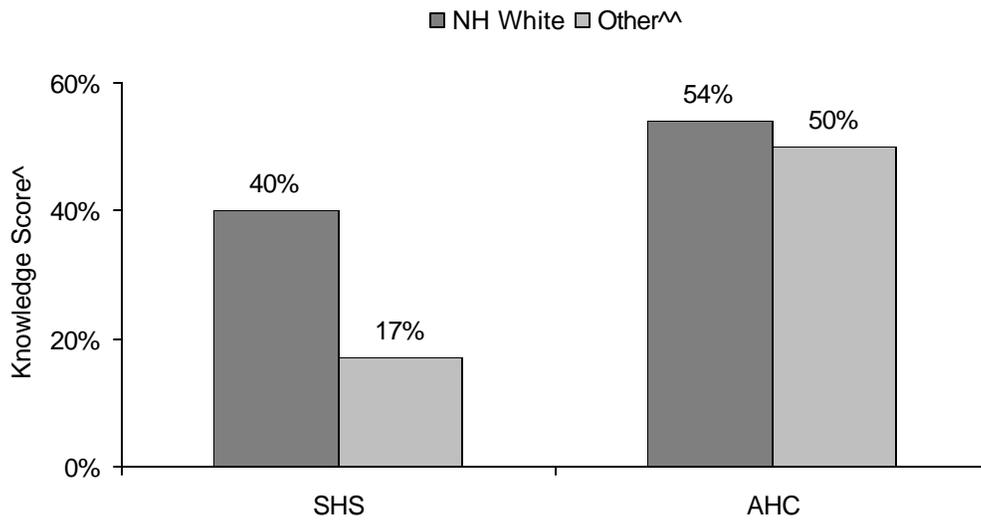
Table 2.2. Statistically Significant Differences in the Proportion Correctly Defining the Term "Cholesterol" by Site and Respondent Characteristics

		Correctly Define (%)	p-value*
Site	SHS	24%	< 0.0001
	AHC	53%	
Race/Ethnicity**	NH White	50%	< 0.0001
	Other	23%	
Level of Education	HS or less	21%	0.0001
	More than HS	58%	
Income	≤ \$20,000	32%	<0.0005
	>\$20,000	61%	

*Chi-Square/Fisher as appropriate was used to assess significance ($p < 0.05$) of categorical variables

**Only NH White and Other could be used, as there were not enough NH Black respondents ($n=5$) at AHC to use this third category

Figure 2.2a. Differences in the Proportion of Respondents Correctly Defining the Term "Cholesterol" by Site and Race (using Knowledge Score[^])

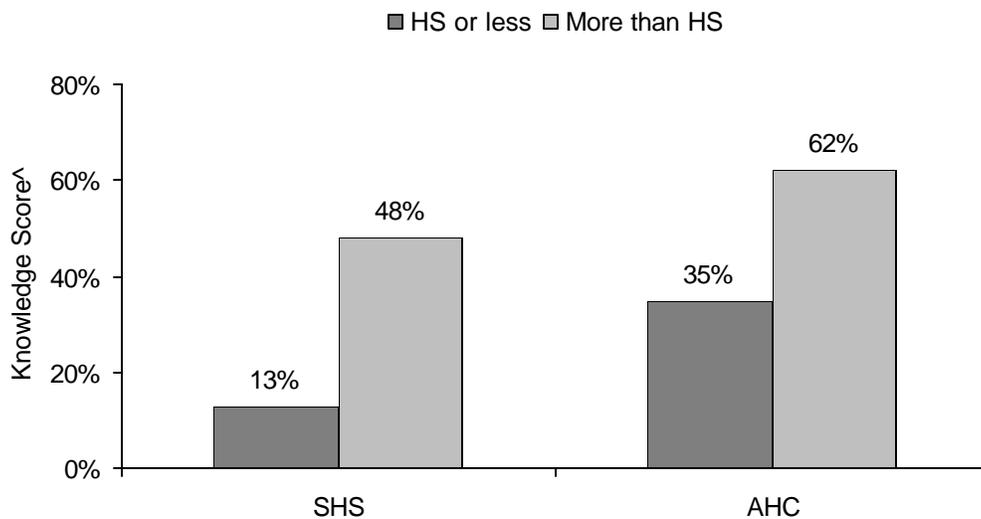


Cochran-Mantel-Haenszel, stratifying by Site and Race was used to generate p-values. Site was a significant predictor only among those of "other" race, while Race was a significant predictor at SHS but not at AHC

[^]Knowledge Score was calculated by dividing the number of correct responses by the total possible

^{^^}Only NH White and Other could be used as there were not enough NH Black respondents (n=5) at AHC to use this third category

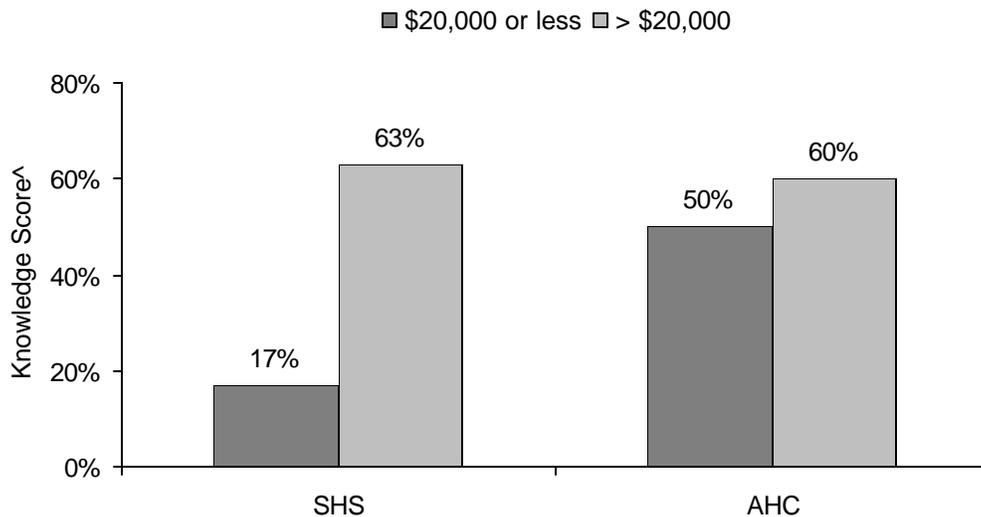
Figure 2.2b. Differences in the Proportion of Respondents Correctly Defining the Term "Cholesterol" by Site and Level of Education (using Knowledge Score[^])



Cochran-Mantel-Haenszel, stratifying by Site and Education was used to generate p-values. Site was a significant predictor only among "HS or less", while Education was a significant predictor at both sites.

[^]Knowledge Score was calculated by dividing the number of correct responses by the total possible

Figure 2.2c. Differences in the Proportion of Respondents Correctly Defining the Term "Cholesterol" by Site and Income (using Knowledge Score[^])



Cochran-Mantel-Haenszel, stratifying by Site and Income was used to generate p-values. Site was a significant predictor only among "\$20,000 or less", while Income was a significant predictor only at SHS.

[^]Knowledge Score was calculated by dividing the number of correct responses by the total possible

Knowledge:

As elevated blood cholesterol is a major risk factor for cardiovascular disease, it is imperative that people be familiar with ways to manage or lower it. To assess this knowledge, we asked respondents to identify the steps one can take to control cholesterol. In this case, the list of possible responses was read to the respondent and he/she was asked to identify those things that would be useful in managing blood cholesterol levels. Approximately 1 in 4 respondents (27%) could not identify any ways to lower or manage blood cholesterol levels. There were statistically significant differences in knowledge by site, with 42% of respondents at SHS being unable to identify even one way to improve blood cholesterol compared to only 12% at AHC ($p < 0.0001$).

To further assess the level of knowledge around steps that will help one to lower or prevent elevated cholesterol and the association of this knowledge with respondent characteristics, a knowledge score was created. This was done by summing the number of correctly identified steps and dividing by 5 (the maximum possible). The score is then displayed as the percent correct out of 5. For example, if a person correctly identified 3 of the 5, his/her score would be 60%. The average respondent had a score of 51%, with respondents at AHC having a higher average knowledge score than respondents at SHS (72% vs. 30%, Table 2.3). There were also statistically significant differences in knowledge score by race, the type of school attended as a deaf child, highest level of education received and income. These are all presented in Table 2.3. Adjustment for demographic characteristics did not eliminate site differences (Figures 2.3a-2.3c), implying knowledge is associated with a combination of factors (e.g., SES, environment), and cannot be explained by one factor alone.

Table 2.3. Statistically Significant Differences in the Knowledge of Steps to Lower or Prevent Elevated Cholesterol by Site and Respondent Characteristics (using Knowledge Score[^])

		Average Knowledge Score [^]	p-value [*]
Site	SHS	30%	< 0.0001
	AHC	72%	
Race/Ethnicity ^{**}	NH White	61%	< 0.0001
	Other	38%	
Level of Education	HS or less	39%	< 0.0001
	More than HS	64%	
Type of School	Residential	44%	< 0.01
	Mainstream ^{^^}	57%	
	Other	71%	
Income	≤ \$20,000	47%	< 0.0001
	>\$20,000	71%	

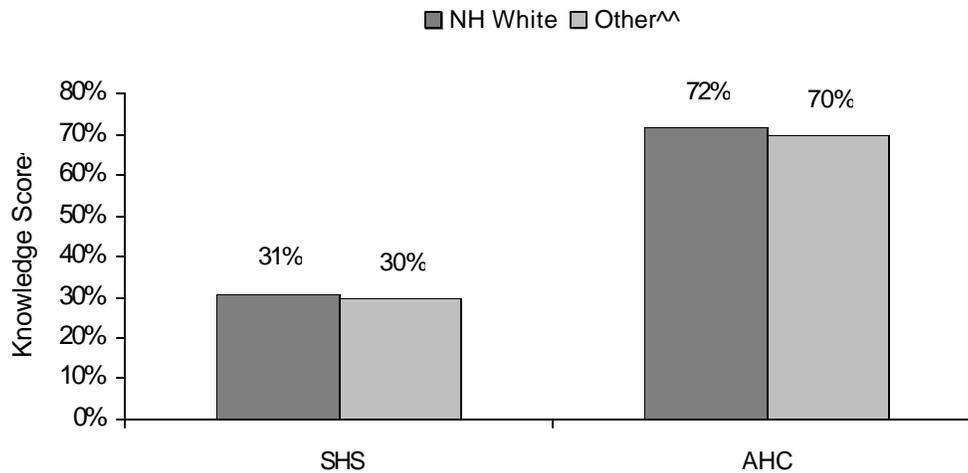
*T-test/ANOVA as appropriate was used to assess significance (p<0.05)

**Only NH White and Other could be used as there were not enough NH Black respondents (n=5) at AHC to use this third category

[^]Knowledge Score was calculated by dividing the number of correct responses by the total possible

^{^^}Mainstream includes schools with and without specialized programs for deaf children

Figure 2.3a. Differences in the Knowledge of the Steps to Lower Cholesterol by Site and Race (using Knowledge Score[^])

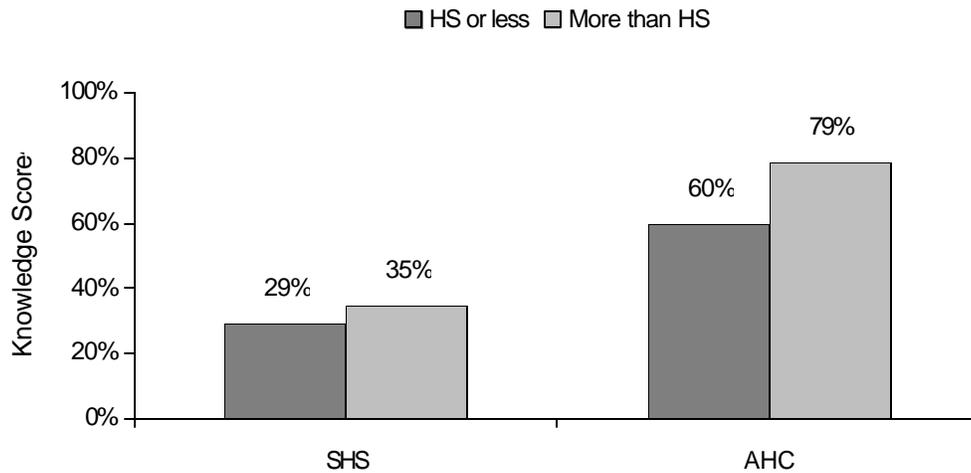


Multiple regression models with Site and Race as independent factors were used to generate p-values. Site (p<0.0001) remained a significant predictor of Knowledge, but Race did not (p>0.05).

[^]Knowledge Score was calculated by dividing the number of correct responses by the total possible

^{^^}Only NH White and Other could be used as there were not enough NH Black respondents (n=5) at AHC to use this third category

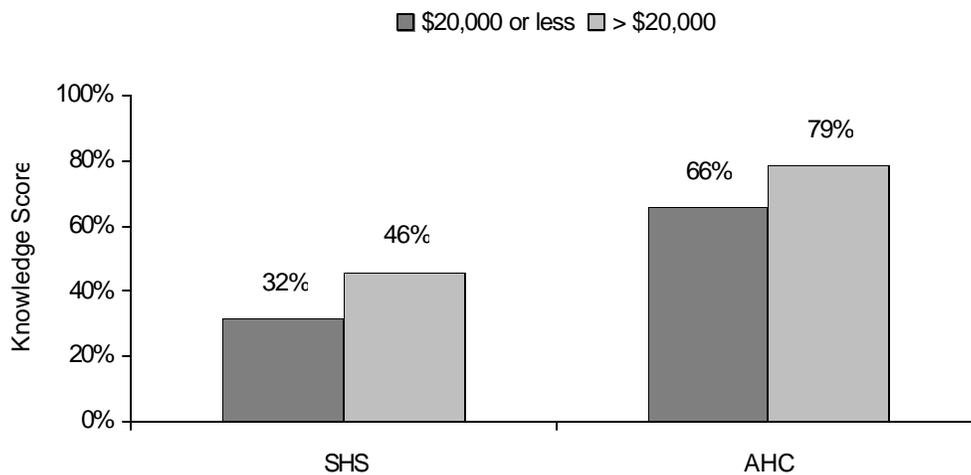
Figure 2.3b. Differences in the Knowledge of the Steps to Lower Cholesterol by Site and Education (using Knowledge Score[^])



Multiple regression models with Site and Education as independent factors were used to generate p-values. Site ($p < 0.0001$) and Education ($p < 0.05$) both remained significant predictors of Knowledge.

[^]Knowledge Score was calculated by dividing the number of correct responses by the total possible

Figure 2.3c. Differences in the Knowledge of the Steps to Lower Cholesterol by Site and Income (using Knowledge Score[^])



Multiple regression models with Site and Income as independent factors were used to generate p-values. Site ($p < 0.0001$) and Income ($p < 0.05$) both remained significant predictors of Knowledge.

[^]Knowledge Score was calculated by dividing the number of correct responses by the total possible

HIV/AIDS

Knowledge:

The majority of respondents at both sites (94% overall; 99% at SHS and 90% at AHC) indicated they were familiar with the terms HIV and AIDS. Amongst those familiar with the terms, knowledge of HIV/AIDS was further assessed in a couple of ways. First, we asked respondents, "Which of the following do you believe increases a person's risk of contracting HIV, the virus which causes AIDS?". This question was followed by a list of behaviors, some of them valid risk factors for acquiring HIV, and some of them not. The proportions indicating that different behaviors would put them at an increased risk are shown in Table 2.4.

There were some promising findings:

- 84% of respondents realized that having multiple sex partners would put them at an increased risk;
- Nearly 70% responded that not using a condom when having sex with someone they did not know would put them at risk.

However, more findings were disappointing than promising. For example:

- Approximately 40% of respondents did not realize that using IV drugs is a major risk factor for transmission of the virus;
- Nearly 60% thought that donating or receiving blood would place them at an increased risk of contracting the virus;
- One in three believed that using a public restroom would put them at risk.

Table 2.4. Proportion Indicating Each is a Risk Factor for HIV/AIDS[^]

Risk Factor for HIV/AIDS (% Yes)?	SHS (n=101)	AHC (n=91)	Total Sample (n=192)	p-value*
Having more than one sex partner	88%	80%	84%	NS
Not using a condom when having sex with someone you don't know**	69%	67%	68%	NS
Sharing needles when using IV drugs	53%	65%	59%	NS
Anal sex without a condom	42%	47%	44%	NS
Oral sex without a condom	38%	49%	43%	NS
Donating/Receiving blood***	58%	57%	58%	NS
Using public restrooms!	41%	24%	33%	< 0.05
Visiting the home of someone with HIV/AIDS#	32%	9%	21%	< 0.0001
Kissing someone with HIV/AIDS	33%	24%	29%	NS
Not using birth control pills	8%	8%	8%	NS

Not really a risk factor

*Chi-Square/Fisher as appropriate was used to assess statistical significance between site. NS="not significant" (p>0.05)

[^]Limited to those who had heard of HIV/AIDS

** Statistically significant differences by Income (< \$20,000=61%, > \$20,000=81%)

*** Statistically significant differences by race (NH White=64%, Other=50%)

! Statistically significant differences by race (NHW=25%, Other=42%) and level of education (< HS=42%, >HS=23%)

Statistically significant differences by race (NH White=13%, Other=31%) and Income (< \$20,000=27%, >\$20,000=13%)

The knowledge of risk factors between sites was pretty consistent with a couple of exceptions. Respondents at SHS were more likely to believe that using a public restroom would increase their

likelihood of acquiring HIV. They were also more likely to believe that visiting the home of someone with HIV/AIDS would pose a risk to their health. Table 2.4 also summarizes differences in knowledge that are significantly associated with demographics such as income, race and level of education. As with knowledge about cardiovascular disease, generally, those who were more educated (more than a HS education), reported a higher household income (>\$20,000 per year), and non-Hispanic white people had better knowledge about HIV risk factors than their less educated, poorer and non-white counterparts.

We further assessed knowledge about HIV/AIDS by asking four True/False questions. As indicated in the Methods section, these questions were actually asked as yes/no questions as the pilot testing of the instrument revealed that the concepts of "true" and "false" do not translate well into ASL. The four statements and the proportion responding correctly are summarized in Table 2.5. It was encouraging to see that 92% of respondents realized that there is not a cure for AIDS. However, findings around the other three statements were indicative of poor knowledge. For example, over half of respondents (51%) did not realize that there are drugs available to help a person with HIV live longer. Knowledge in this regard differed significantly by site, race, level of education and income (Table 2.5).

Table 2.5. Proportion Responding Correctly to True/False Questions about HIV/AIDS[^]

Statement	Correct Response	SHS (n=101)	AHC (n=91)	Total Sample (n=192)	p-value*
There are drugs available that are intended to help a person who is infected with HIV live longer.**	TRUE	30%	75%	51%	< 0.0001
There is a cure for AIDS.	FALSE	93%	90%	92%	NS
A pregnant woman with HIV can get treatment to help reduce the chances that she will pass the virus on to her baby.	TRUE	21%	44%	32%	< 0.001
Only homosexual people can get HIV and develop AIDS.	FALSE	85%	56%	71%	< 0.0001

*Chi-Square/Fisher as appropriate was used to assess statistical significance between site. NS="not significant" (p>0.05)

[^]Limited to those who had heard of HIV/AIDS

** Statistically significant differences by race (NH White=62%, Other=39%), Education (< HS=34%, > HS=70%) and Income (< \$20,000=34%, > \$20,000=78%)

Behavior:

A significantly larger number of respondents at SHS reported that they had ever been tested for HIV as compared with respondents at AHC (71% vs. 34%, p< 0.0001) (Table 2.6). In the year 2000, 46% of the general U.S. population had ever been tested for HIV (BRFSS 2000). Respondents at SHS were therefore more likely than the general U.S. population to be tested, whereas respondents at AHC were less likely to be tested. A portion of this difference is likely due to variation in the demographics of respondents at the two sites. Nationally, non-Hispanic Black people are the most likely to be tested (63%) followed by Hispanic (48%) and NH White (43%) people (BRFSS 2000). Our findings suggest that Deaf respondents are as likely to be tested for HIV as hearing people from similar socioeconomic backgrounds. However, further analyses are necessary to definitively make such a statement.

Table 2.6. Statistically Significant Differences in the Proportion of Respondents Indicating Ever Being Tested for HIV[^]

		% Ever Tested	p-value*
Site	SHS	71%	< 0.0001
	AHC	34%	
Age	18 to 44 years	68%	< 0.0001
	45 to 64 years	35%	
	65 and up	22%	
Race/Ethnicity**	NH White	45%	< 0.05
	Other	63%	
Type of School	Residential	38%	< 0.0001
	Mainstream ^{^^}	66%	
	Other	24%	
Income	≤ \$20,000	65%	0.0001
	>\$20,000	33%	

*Chi-Square/Fisher as appropriate was used to assess significance (p<0.05) of categorical variables

**Only NH White and Other could be used as there were not enough NH Black respondents (n=5) at AHC to use this third category.

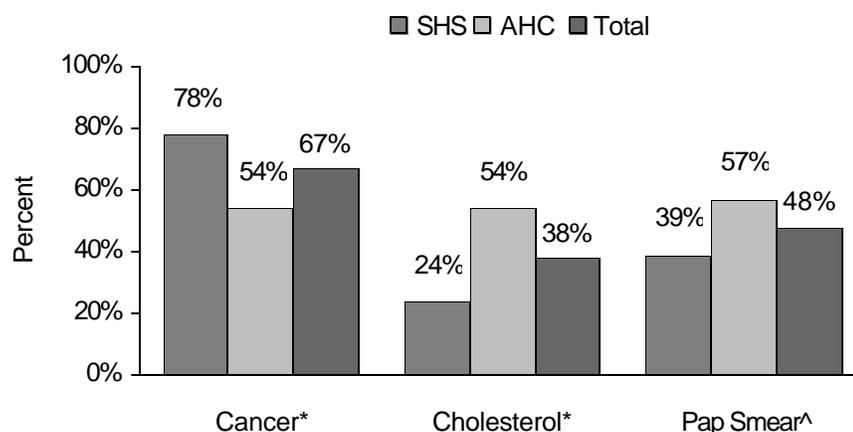
[^]Limited to those who had heard of HIV/AIDS

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

Knowledge of English Medical Terms

It might be possible to explain part of the deficit in general health-related knowledge among Deaf respondents through a lack of knowledge of English medical terms. One of our hypotheses when the study was initiated was that Deaf patients may not understand common English medical terms and therefore may miss important health information based simply on that fact. We sought to test this hypothesis by asking respondents to tell us what certain medical terms mean. The terms were finger spelled to the respondents, and four possible definitions were read. The respondent was then asked to select the correct definition. Figure 2.4 shows the likelihood of correctly defining three terms (including "cholesterol", previously discussed) by site. Clearly, the results presented are indicative of a great shortfall in the knowledge of common English medical terms among Deaf clients of SHS and AHC. For example, 1 in 3 respondents could not correctly define the term "cancer". Even fewer could correctly define the term "cholesterol" (38% of all respondents), and less than half of women surveyed correctly defined the term "pap smear".

Figure 2.4. Proportion Correctly Defining Medical Terms



^Only women asked to define the term "pap smear"; n=110

*Statistically significant difference between SHS and AHC ($p < 0.05$). Chi-Square was used to assess significance of categorical variables.

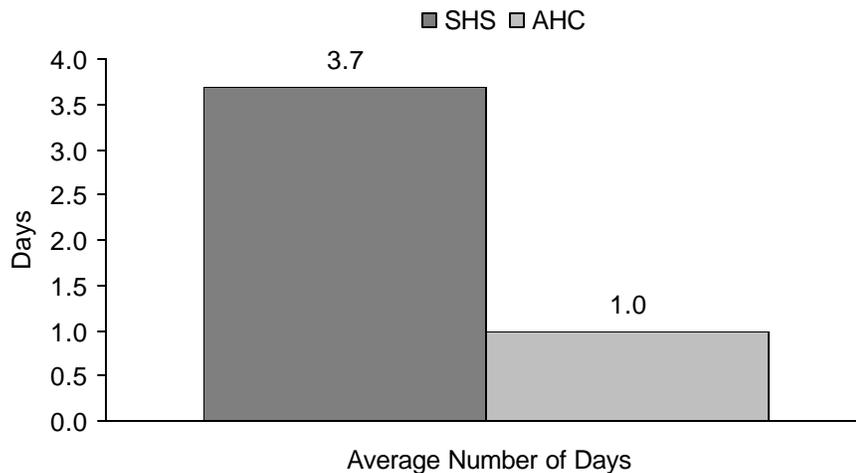
Exercise

The benefits of regular physical activity have been clearly established and extensive efforts have been made to convey them to the general population. We were interested in whether that message had reached Deaf patients at our facilities, and if so, whether it had impacted on their behavior.

The average respondent indicated that getting exercise was very important to them personally. In fact, when asked to rate the importance of getting exercise on a scale from 1 to 10, where 1 is "not at all important" and 10 is "very important", the average score was 8.5. More than half the respondents rated this a 10. There were no significant differences by site or any other characteristic.

We then asked respondents how much exercise they get in a typical week. The question read, "We are interested in how much exercise you get. By exercise, we mean activities that make you breathe harder and make your heart beat faster. Examples of exercise activities include running, brisk walking, lap swimming, aerobics, bicycling, playing basketball, and tennis, among others. In a typical week, on how many days do you exercise for at least 20 minutes?" Figure 2.5 shows the average number of days of exercise reported by site. We were surprised to find that respondents at SHS reported significantly more days of exercise in a typical week than did respondents at AHC (3.4 days vs. 1.0 days, $p < 0.0001$). It was originally hypothesized that this might result from the fact that a greater proportion of SHS respondents reside in the City as opposed to the suburbs. It seems plausible (and has in fact been shown) that people residing in a City would be more likely to walk on an everyday basis as a means of transportation, and that if they interpreted this walking as exercise, then this might explain the difference by site. To check this hypothesis, we stratified respondents by site and by whether they lived in the City or in a suburb, and assessed the average number of days of exercise reported. The results are shown in Figure 2.6. Clearly, the average number of days of exercise is consistent by site, regardless of place of residence. In other words, our hypothesis does not seem to account for the difference.

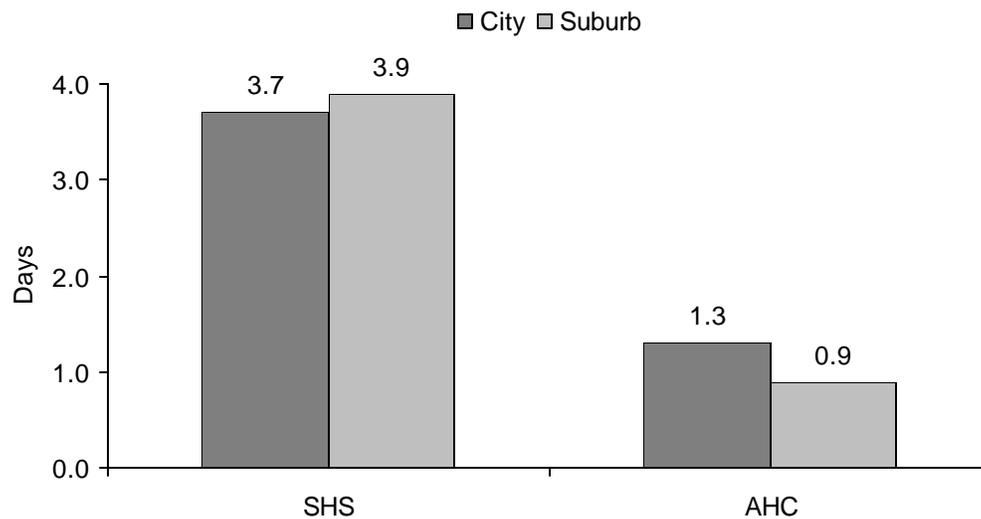
Figure 2.5. Average Number of Days of Exercise[^] in a Typical Week



p-value < 0.0001; Assessed via t-test.

[^] Moderate activity of 20 minutes or more in a typical week

Figure 2.6. Average Number of Days of Exercise[^] in a Typical Week by Site and City or Suburban Residence



[^] Moderate activity of 20 minutes or more in a typical week

We were left to believe that there might have been a discrepancy in the way the question was asked at each of the two sites, and therefore this data might be unreliable. At the completion of the study, the interviewers were debriefed about this question and a few others for which the data revealed unanticipated and unexplainable trends. The results of the debriefing suggest that this question was asked slightly differently by each of the interviewers. Interestingly however, the true explanation may be in the reason behind the question being asked differently at each site. It seems that the AHC interviewer had to define the term "exercise" for most respondents, while SHS respondents generally understood the term. The SHS interviewer revealed that several of his interviewees mentioned that their doctor had spoken to them about

getting more exercise, and had suggested walking as a means of exercise. Therefore, the site differences may be real, but an understanding of how the question was asked is beneficial in the interpretation of the data.

Finally, we asked respondents to identify some benefits of regular exercise. Response choices were not read to respondents. The majority of respondents were able to identify at least one benefit of exercise (92% of SHS and 85% of AHC respondents). The most frequently identified benefits were that:

- Exercise improves mental health and psychological well-being (55%);
- Exercise helps to build and maintain bones and muscles (33%);
- Exercise helps to control weight (33%).

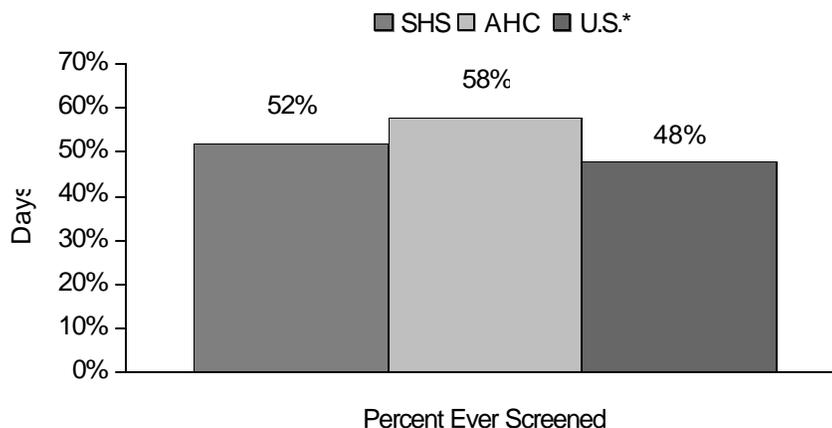
Only 17% of respondents mentioned that regular exercise reduces the risk of a heart attack or stroke.

Cancer Screening

Colorectal Cancer Screening:

It has been recommended that persons 50 years of age and older should be routinely screened for colorectal cancer. A number of screening methods exist, and some combination of them is recommended on a routine basis. The U.S. Preventive Services Task Force (USPSTF) recommends the use of sigmoidoscopy every 5 years in those 50 years and older. We asked survey respondents 50 years of age and older (n=57) whether they had ever had a sigmoidoscopy or a colonoscopy. As seen in Figure 2.7, only about half of respondents meeting this age criterion (52% of SHS and 58% of AHC respondents) reported that they had EVER been screened via sigmoidoscopy or colonoscopy. These numbers are about the same as the 48% of the general U.S. population 50 years of age and older who indicated they had ever received one of these screening tests on the 2002 BRFSS (Figure 2.7). We were also interested in how likely respondents were to have received their test within the past 5 years (i.e., according to the recommendations). It was found that 43% of SHS and 53% of AHC respondents reported having been screened according to the recommendations.

Figure 2.7. Proportion of Respondents 50 Years of Age or Older who had EVER Received a Sigmoidoscopy or a Colonoscopy (n=57)



* BRFSS, 2002

Mammography:

There is some debate in the medical community as to whether routine mammography for women should begin at age 40 or at age 50. In order to be conservative, we limited questions about mammography to women 50 years of age and older. We asked women 50 years of age and older (n=31) if they knew what the term “mammogram” means, if they had ever had a mammogram, and if so, when they last had one. The majority of women did correctly define the term “mammogram” (82% at SHS and 95% at AHC). The proportion of women indicating that they had ever had a mammogram was quite high: 91% at SHS and 95% at AHC (Table 2.7). This compares well with the 89% of women between the ages of 50-59 nationwide who reported EVER having had a mammogram (BRFSS 1997). However, the recommendation is that women 50 years of age and older have a mammogram every year, and only 68% of all female survey respondents asked about mammography indicated that they had been screened in the last year (55% at SHS and 75% at AHC). Nearly 20% had not been screened within the past 3 years (27% at SHS and 15% at AHC) (Table 2.7).

Table 2.7. Proportion of Female Respondents 50 Years of Age or Older[^] who had EVER Received a Mammogram and How Recently (n=31)

	SHS (n=11)	AHC (n=20)	Total Sample (n=31)	U.S.*
EVER Had Mammogram? (% Yes)	91%	95%	94%	89%
Mammogram Within Past Year**	55%	75%	68%	--
Mammogram Within Past 2 Year	73%	85%	81%	78%
No Mammogram Within Past 3 Years***	27%	15%	19%	--

*BRFSS 1997, limited to women 50-59

[^] Recommendations vary on whether annual mammograms should begin at ages 40 or 50. Used 50 to be conservative.

** American Cancer Society recommendation is to be screened every year

*** Includes those who were NEVER screened

Topic 3. Prevalence of Risk Factors

If we are to develop steps to be undertaken to improve the health status of Deaf persons locally and regionally, we need to have a sense of how this population compares to the general population in the prevalence of risk factors. Fortunately, the survey included a number of questions intended to get a better sense of the general health status of respondents. The results around risk factors for cardiovascular disease, HIV and alcohol or drug dependency are presented. Wherever possible, comparison data for the general U.S. population is also presented.

Cardiovascular Disease Risk Factors

Many of the risk factors for cardiovascular disease (CVD) are rooted in modifiable behavior. Below we present findings around the prevalence of CVD risk factors among study participants.

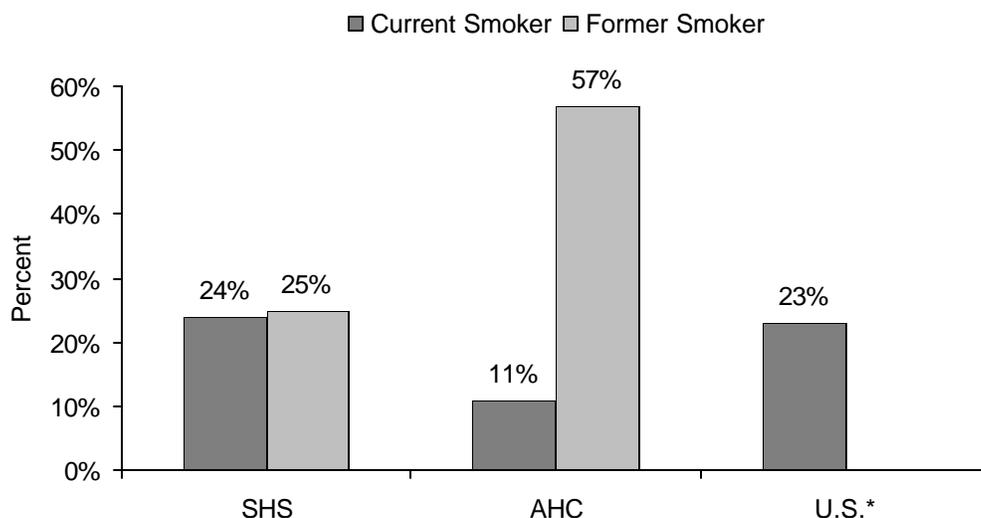
Smoking:

Two questions were asked to assess the prevalence of smoking amongst study respondents:

1. Have you ever smoked at least one cigarette a day for one month or more?
2. Do you currently smoke cigarettes?

Respondents could then be classified into one of three categories based on their responses to these two questions. If they answered “no” to the first question, they would be classified as non-smokers. If they answered “yes” to both questions, they would be classified as current smokers. If they answered “yes” to the first question, but “no” to the second, they would be classified as former smokers. Figure 3.1 presents findings on the prevalence of smoking by site, and comparison data for the U.S. Nearly 1 in 4 SHS respondents reported that they were current smokers, compared to only 1 in 10 AHC respondents ($p < 0.0001$). In other words, Deaf clients of SHS seem to have smoking rates similar to those for the nation (23% per BRFSS 2000), while AHC Deaf clients had significantly lower rates. Interestingly, the prevalence of former smokers at AHC was quite high (57%), implying a large proportion had successfully quit.

Figure 3.1. Prevalence of Smoking by Site



p -value < 0.0001 . Chi-Square/Fisher as appropriate was used to assess statistical significance between sites.

*BRFSS 2000

High Cholesterol:

Respondents were asked whether a doctor, nurse or other health care professional had ever told them they have high cholesterol. Overall, 31% of those surveyed reported having high cholesterol, with no statistically significant differences by site (25% at SHS and 37% at AHC). The prevalence of elevated cholesterol among our survey respondents was therefore comparable to the 30% of the general U.S. population who report having high cholesterol (BRFSS 2001).

High Blood Pressure:

The prevalence of high blood pressure was ascertained similarly to that of high cholesterol. Respondents were asked whether a doctor, nurse or other health care professional had ever told them they have high blood pressure. Overall, 43% of respondents reported that they had ever been told they have high blood pressure, with no statistically significant differences by site (42% at SHS and 45% at AHC). This figure is considerably higher than the 26% of people from the general U.S. population who have hypertension (BRFSS 2001). We are unable to explain this higher than anticipated prevalence of high blood pressure amongst survey respondents at this time.

Weight:

One shortcoming of the survey was that we did not ask respondents for their weight and height. We did, however, ask questions pertaining to perceptions of weight status. For example, we asked respondents whether they think they weigh too much, too little, or the right amount. Overall, about 44% of respondents reported that they weigh too much, with no significant differences by site (44% at SHS, 43% at AHC). Nearly all of those who feel that they are overweight reported that they would like to lose weight. Given people who are slightly overweight are unlikely to report that they are, the true prevalence of overweight among our respondents was likely higher. Among the general U.S. population, two-thirds of adults are overweight (NHANES 1999-2000). The prevalence among our Deaf clients is likely similar.

HIV Risk Factors

Interestingly, respondents at SHS were significantly more likely to report that they fell into a “high risk” category for becoming infected with HIV than respondents at AHC. The question used to assess whether someone was at “high risk” was adapted from BRFSS 2002. Essentially, a list of situations that might put a person at an increased risk for becoming infected with HIV were read, and the respondent was asked to indicate if any of the situations apply to him/her without specifying which one. The “high risk” situations included were:

- You have used intravenous drugs in the past year;
- You have been treated for a sexually transmitted or venereal disease in the past year;
- You have tested positive for having HIV, the virus that causes AIDS;
- You have had anal sex without a condom in the past year;
- You have had sex (even just one time) with someone who would answer “yes” to any of these statements.

At SHS, 53% of respondents fell into the “high risk” category, compared to only 16% at AHC (Table 3.1). As evident in Table 3.1, the same demographic characteristics that were associated with an increased likelihood of being tested for HIV (Table 2.6) are also associated with an increased likelihood of falling into the “high risk” category. Figure 3.2 shows that respondents who fell into the “high risk” category were significantly more likely to have been tested for HIV overall. Interestingly, when assessed by site, the same could be said for SHS but not for AHC.

Table 3.1. Statistically Significant Differences in the Proportion of Respondents Falling Into a "High Risk" Category for HIV Infection[^]

		High Risk [^]	p-value*
Site	SHS	53%	< 0.0001
	AHC	16%	
Age	18 to 44 years	46%	< 0.0001
	45 to 64 years	23%	
	65 and up	5%	
Race/Ethnicity**	NH White	21%	< 0.0001
	Other	52%	
Type of School	Residential	21%	< 0.005
	Mainstream ^{^^}	44%	
	Other	25%	
Income	≤ \$20,000	41%	< 0.01
	>\$20,000	22%	

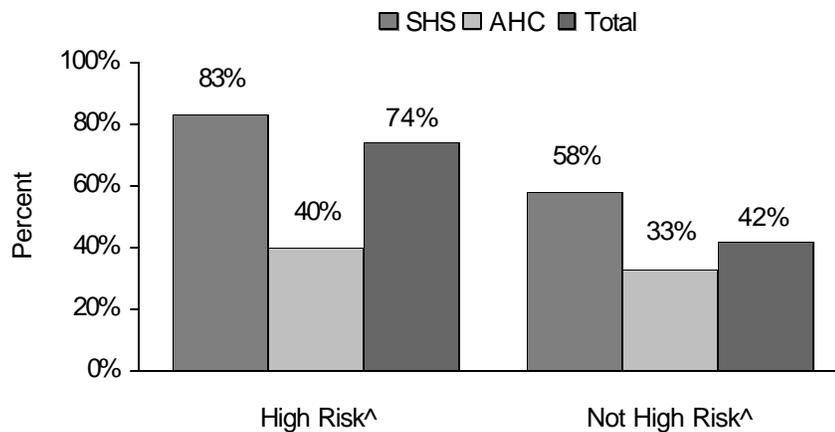
*Chi-Square/Fisher as appropriate was used to assess significance (p<0.05) of categorical variables

**Only NH White and Other could be used as there were not enough NH Black respondents (n=5) at AHC to use this third category.

[^]"High Risk" question adopted for BRFSS 2002.

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

Figure 3.2. Risk[^] for HIV vs. Likelihood of Having Been Tested for HIV by Site and Overall



"High Risk" respondents at SHS were significantly (p<0.05) more likely to report being tested than those not at "High Risk". The differences at AHC were not statistically significant (p>0.05).

[^]"High Risk" question adopted for BRFSS 2002

Possible Alcohol/Drug Dependency

In order to estimate possible alcohol and/or drug dependency, the 4-item CAGE-AID questionnaire was included as a part of the survey. While the original CAGE is concerned with alcohol use only, the CAGE-AID (AID="Adapted to Include Drugs") includes alcohol and drugs. It is a brief, relatively unthreatening questionnaire intended to detect alcohol or drug dependency. Answering "yes" to 2 or more of the questions would indicate a potential problem. The 4 CAGE questions included on the survey are:

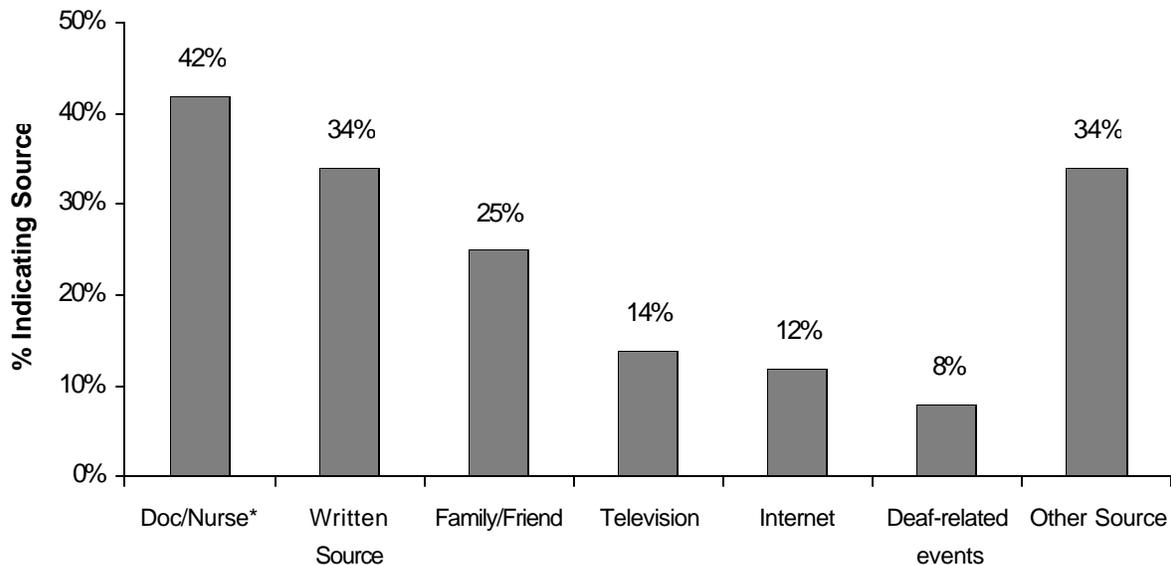
1. Have you ever felt that you should CUT down on your drinking or drug use?
2. Have people ANNOYED you by criticizing or complaining about your drinking or drug use?
3. Have you ever felt bad or GUILTY about your drinking or drug use?
4. Have you ever had a drink or drug in the morning (EYE OPENER) to steady your nerves or to get rid of a hangover?

Significantly more respondents at SHS than at AHC screened positive for possible alcohol/drug dependency via the CAGE-AID (27% at SHS vs. 9% at AHC, $p < 0.005$). To our knowledge, the CAGE-AID has not been standardized or tested for validity and reliability in a Deaf population. It is therefore plausible that it does not screen for alcohol and/or drug dependency as well in a Deaf population as it does in a hearing population. It is also possible that this was one set of questions where the approach used between sites was less than consistent, and that this lead to the discrepancy in results. A third possibility is that respondents at the two site differed in their willingness to reveal such sensitive information. However, it will be necessary to do some more work with Deaf respondents at SHS to determine if there truly is a larger than anticipated drinking and drug problem amongst the Deaf clients.

Topic 4. Sources of Health Information and Relationship with Health Knowledge

We were interested in exploring the relationship between sources of information about health and level of knowledge. As part of the survey, respondents were asked to identify all sources of information about their health and how to stay healthy. A respondent could identify more than one source of information. As displayed in Figure 4.1, the most commonly identified sources of information were: (1) doctor/nurse – 42%, (2) written media (e.g. books, magazine, etc.) – 34%, and (3) family/friends – 25%.

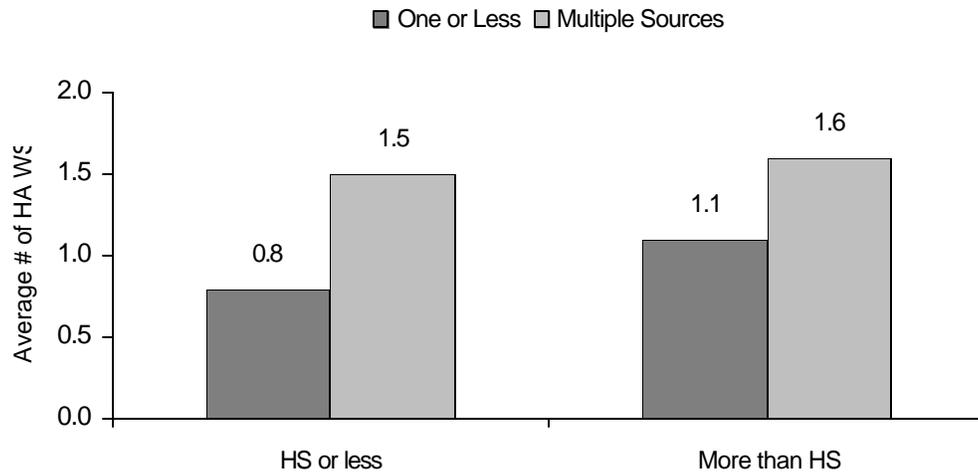
Figure 4.1. Proportion of Respondents Indicating Different Sources of Health Information



* Significant difference in proportion indicating as source by Site (33% at SHS vs. 51% at AHC)

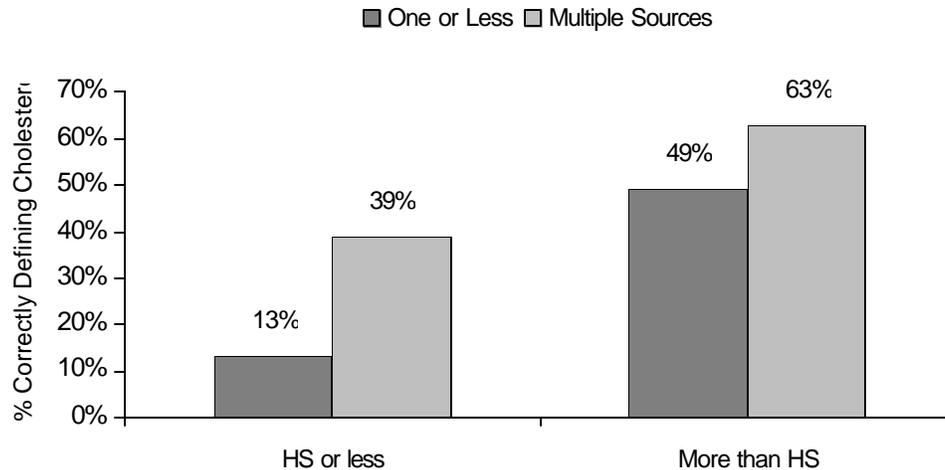
We analyzed the relationship between exposure to multiple sources of information and the level of knowledge about selected issues. Essentially, we were interested in whether exposure to multiple sources of information correlates with better knowledge. The average respondent reported 1.7 sources of information. A new dichotomized variable was created depending on whether the respondent identified multiple sources of information (>1 source) or not (≤ 1 source). We first assessed whether those reporting multiple sources of information differed from those who did not in some way. Not surprisingly, those with a higher level of education were more likely to report multiple sources of information (31% of those with a high school education or less reported receiving information from multiple sources vs. 62% of those with some education beyond high school; p -value < 0.0001). Preliminary findings suggest that those reporting multiple sources of information about their health have a greater level of knowledge, even after controlling for level of education. Examples of this association are included in Figures 4.2 and 4.3. In Figure 4.2 we see that exposure to multiple sources of information is significantly associated with knowledge of heart attack warning signs, even after adjusting for level of education. Among those reporting multiple sources of information, the level of education did not have an additional impact on knowledge. In Figure 4.3 we see that both level of education and multiple sources of information are significantly associated with the ability to correctly define the term “cholesterol”. Among both those with a lower and higher level of education, exposure to multiple sources of information improved the likelihood that the person would correctly define the term “cholesterol”.

Figure 4.2. Average Number of Heart Attack Warning Signs Identified by Number of Sources of Health Information and Level of Education



Multiple regression models with Number of Sources of Info and Level of Education as independent factors were used to test statistical significance. Multiple sources of information remained a significant predictor of knowledge ($p < 0.05$) while Level of Education did not.

Figure 4.3. Proportion Correctly Defining the Term "Cholesterol" by Number of Sources of Health Information and Level of Education



Cochran-Mantel-Haenszel, stratifying by Multiple Sources of Information and Level of Education was used to generate p-values. Both Level of Education and Exposure to Multiple Sources of Info Remain Significant ($p < 0.05$) Predictors.

Finally, we examined the relationship between individual sources of information and knowledge. When this was done, only Internet access was found to be significantly associated. For example, the 48% of respondents with Internet access on the average reported more of the 7 most common warning signs of a heart attack (1.4 vs. < 1 ; $p < 0.005$), were more likely to call 911 if they thought they were having a heart attack or stroke (70% vs. 53%; $p < 0.05$), and were more likely to correctly define the term "cholesterol" (55% vs. 24%; $p < 0.0001$) than those without. As access to the Internet is so clearly associated with

socioeconomic status (see Table 4.1), it is difficult to conclude whether such differences in knowledge are attributable to Internet access itself or to some other factor.

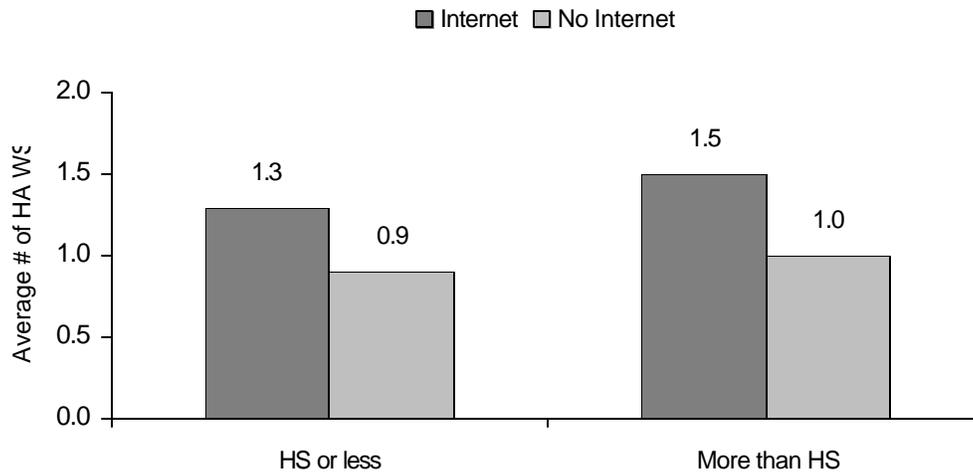
Table 4.1. Statistically Significant Differences in the Proportion of Respondents Reporting Internet Access by Site and Respondent Characteristics

		% with Internet Access	p-value*
Site	SHS	32%	< 0.0001
	AHC	64%	
Age	18-44	55%	< 0.05
	45-64	46%	
	65+	23%	
Race/Ethnicity	NH White	60%	< 0.0001
	NH Black	21%	
	Other	52%	
Level of Education	< HS	15%	< 0.0001
	HS Grad	33%	
	More than HS	60%	
	College +	90%	
Income	≤ \$20,000	38%	< 0.0001
	\$20,001-\$40,000	80%	
	> \$40,000	62%	

*Chi-Square/Fisher as appropriate was used to assess significance ($p < 0.05$) of categorical variables

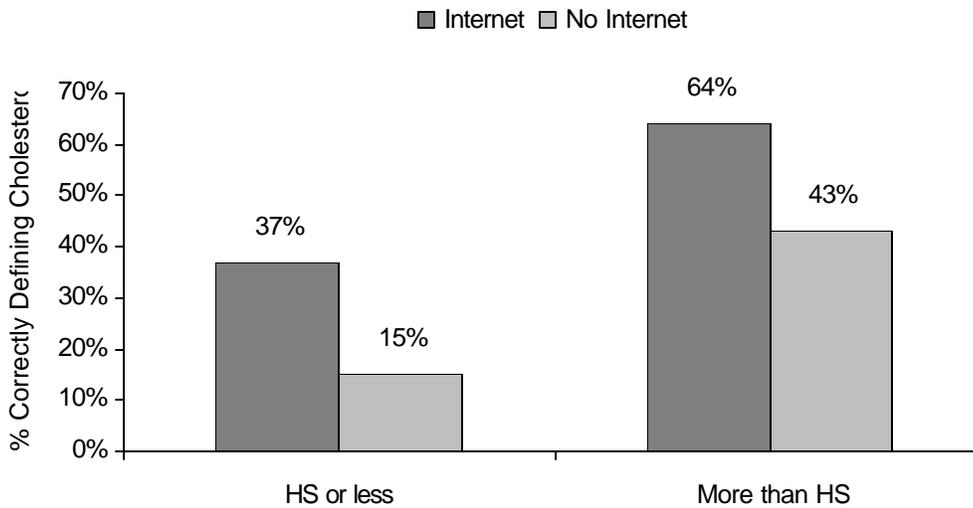
A couple of examples of the association between Internet access and knowledge after adjusting for level of education (one of the factors significantly associated with both Internet access and level of knowledge) are presented in Figures 4.4 and 4.5. Multifactor analyses will be necessary to completely address this issue. Regardless, the fact is that certain ways of presenting information to Deaf persons may be more effective than others. Also, people vary in the likelihood that they will access certain sources of information. This is important to keep in mind in designing methods to effectively educate Deaf individuals.

Figure 4.4. Average Number of Heart Attack Warning Signs Identified Among Those With Internet Access vs. Those Without, and Stratified by Level of Education



Multiple regression models with Internet Access and Level of Education as independent factors were used to test statistical significance. Internet access remained a significant predictor of knowledge ($p < 0.05$) while Level of Education did not.

Figure 4.5. Proportion Correctly Defining the Term "Cholesterol" Among Those With Internet Access vs. Those Without, and Stratified by Level of Education



Cochran-Mantel-Haenszel, stratifying by Internet Access and Level of Education was used to generate p-values. Internet access remains a significant predictor only in those with "HS or less". Level of Education remains a significant predictor both in those with and those without Internet access.

Topic 5. Health-Related Quality of Life (SF-12, version 2)

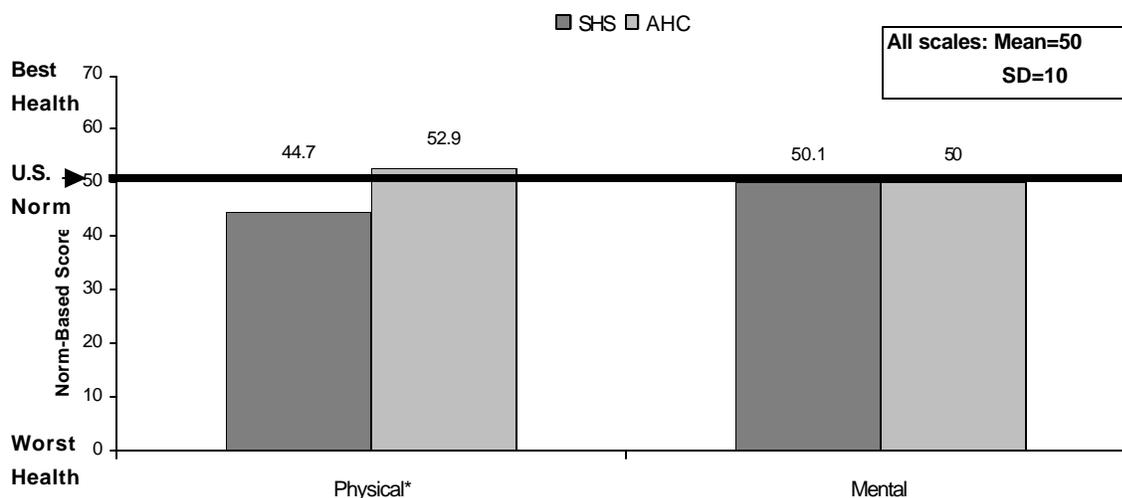
In recent years the concept of Health-Related Quality of Life (HRQOL) has been extensively examined in many populations including the general U.S. population, different racial and ethnic groups, people from different countries and disease-specific groups. It has been established that people assess their own physical, mental and social well-being relatively well. In fact, numerous studies have shown that people's own perception of their overall health is remarkably accurate and can be used to predict future health care needs, as well as, five and ten year mortality.^{3,4,5,6} While several inventories that measure HRQOL (e.g., SF-36, SF-12) have been developed and studied in several different populations, we were unable to identify any which had been used with Deaf persons. We therefore felt it important to measure HRQOL as a part of our survey.

The instrument we used to assess HRQOL was the SF-12, version 2. This instrument consists of 12 items, which yields an 8-scale health profile and 2 summary scores (a Physical Composite Score (PCS) and a Mental Composite Score (MCS)). A copy of the instrument is attached in Appendix 4. Norm-based scoring was used, which means that a score of 50 corresponds with the average score for the general U.S. population, while a score below 50 indicates below average health, and a score above 50, above average health. One definite benefit of using the SF-12 is that it has been so widely used with the general U.S. population, making comparisons between our study respondents and the U.S. population easy and straightforward.

Figure 5.1 shows the average PCS and MCS for respondents at each of the sites. It was not necessary to age-adjust the scores, as respondents from the two sites did not differ in their age distribution. Respondents at AHC had significantly higher PCS than those at SHS (52.9 vs. 44.7, $p < 0.0001$). In other words, our findings suggest that Deaf clients at SHS have worse physical health than the majority of the U.S. population, whereas the opposite is true at AHC. This finding reinforces other survey data suggesting that respondents from SHS were in relatively poorer health. For example, respondents at SHS were significantly more likely to report having seen the doctor more than 5 times in the past year (Figure 1.3). Also, the demographic characteristics of the two groups (Table 3, "Population Characteristics") suggests that SHS respondents were generally of a lower socioeconomic status than AHC respondents. It has been well established that disparities exist in health status by SES, and it seems that this same principle applies to the Deaf population.

Table 5.1 shows that those who reported having seen a physician more than 5 times over the course of a year had, on the average, a lower PCS than those reporting 5 or less office visits. This data represents one validity check of the effectiveness of the SF-12, version 2 when used with a Deaf population.

Figure 5.1. Norm-Based Scoring of SF-12: Summary Measures by Site



*Statistically significant difference between SHS and AHC ($p < 0.0001$). T-test was used to assess statistical significance.

Table 5.1. Differences in SF-12 PCS Between Those with More than 5 Doctor Visits in the Past Year and Those with 5 or Less**

	5 or Less Doc Visits (n=90)	More than 5 Doc Visits (n=101)	p-value*
PCS < 50th Percentile	46%	67%	< 0.005
Mean PCS	51.6	46.6	< 0.005

*Chi-Square was used to assess significance ($p < 0.05$) of categorical variables; t-test for continuous variables.

**One person missing one of SF-12 scores necessary to calculate MCS and therefore missing score.

In terms of their MCS, the two groups were nearly identical. This was not unexpected given about an equal number of respondents at each of the two sites were recruited from a Mental Health rather than a General Health clinic (42% of SHS respondents and 38% of AHC respondents), and we would expect those recruited from a Mental Health clinic to have a lower MCS. In fact, one validity check included assessing whether those recruited from a Mental Health clinic had, on the average, a lower MCS that those recruited from a General Health clinic. The findings are presented in Table 5.2, and clearly show that this was in fact the case, lending confidence to the use of the instrument with a Deaf population.

Table 5.2. SF-12 MCS by Recruitment from Mental or General Health Setting: Proportion Scoring Below the 50th Percentile and Average Score**

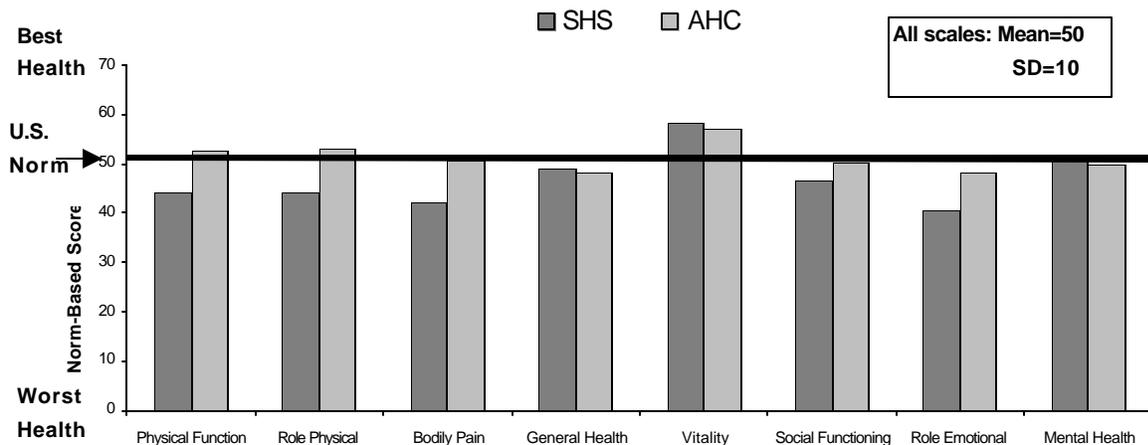
	Recruited from MH (n=81)	Recruited from GH (n=121)	p-value*
MCS < 50th Percentile	57%	42%	< 0.05
Mean MCS	46.8	52.2	< 0.005

*Chi-Square was used to assess significance ($p < 0.05$) of categorical variables; t-test for continuous variables.

**One person missing one of SF-12 scores necessary to calculate MCS and therefore missing score.

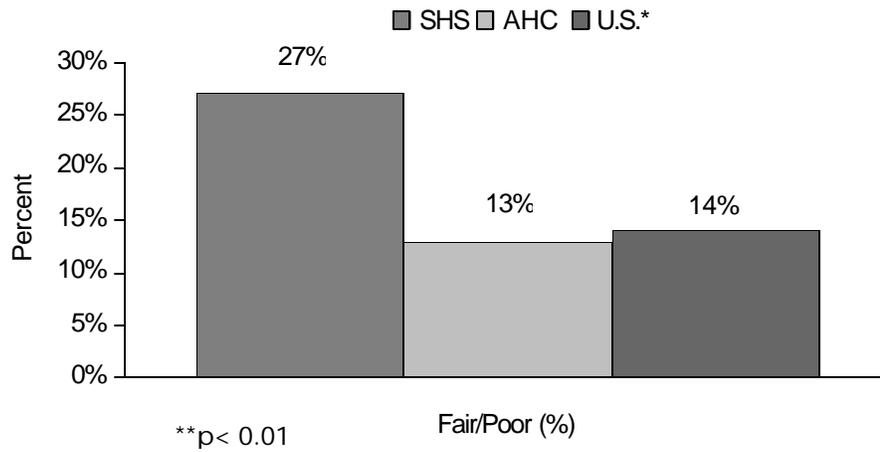
Figure 5.2 shows the 8-scale health profile of respondents at each site. In most cases, AHC respondents scored at or slightly above the U.S. norm, whereas SHS respondents scored below the U.S. norm.

Figure 5.2. Norm-Based Scoring of SF-12: 8-Scale Health Profile by Site



Finally, the first question of the SF-12 asks a person to rate their overall health. Specifically, the question reads, “In general, would you say your health is: {excellent, very good, good, fair, or poor}.” This question in and of itself has been studied and found to be a major predictor of overall health and particularly of 5 and 10 year mortality.^{3,4,5,6} In particular, those who rate their health as “fair” or “poor” have been found to have a worse outlook in terms of future health than those who rate their health as “good” or better. Figure 5.3 shows that respondents at SHS were significantly more likely to rate their health as “fair” or “poor” than respondents at AHC. In fact, twice as many respondents at SHS fell into this category than did respondents at AHC (27% vs. 13%, $p < 0.01$). Again, these findings support the notion that the same sorts of disparities that effect poor, minority communities among the general population seems to be present among the Deaf community as well.

Figure 5.3. Proportion of Respondents with Fair/Poor Self-Rated Health[^] by Site



[^]Self-rated Health was assessed by asking the question, "In general, would you say your health is: (excellent, very good, good, fair, or poor)."

*BRFSS, 2000

**Chi-Square was used to assess significance ($p < 0.05$) of categorical variables

¹ Golf DC, Sellers DE, McGovern PG et al. Knowledge of heart attack symptoms in a population survey in the United States. *Archives of Internal Medicine* (1998); 158:2329-2338.

² Panciali AM, Broderick J, Kothari R, et al. Public perceptions of stroke warning signs and knowledge of potential risk factors. *JAMA* (1998); 279:1288-1292.

³ Idler EL, Russell LB, and Davis D. Survival, Functional Limitations, and Self-rated Health in the NHANES I Epidemiologic Follow-up Study, 1992. *Am J Epidemiology* 2000; 152:874-83

⁴ McGee DL, Liao Y, Cao G, and Cooper RS. Self-reported Health Status and Mortality in a Multiethnic US Cohort. *Am J Epidemiology* 1999; 149:41-6

⁵ Idler EL and Benyamini Y. Self-rated Health and Mortality: A Review of Twenty -Seven Community Studies. *J of Health and Social Behavior* 1997; 38(March):21-37

⁶ Idler EL and Ronald JA. Self-rated Health and Mortality in the NHANES-I Epidemiologic Follow-up Study. *Am J Public Health* 1990; 80:446-452

SECTION 5. CHALLENGES AND LESSONS LEARNED

As far as we can determine, this is the largest health survey ever conducted with Deaf individuals. We recognized from the beginning that there would be unique challenges in conducting research with this population. The extensive amount of experience of several Project Team members with Deaf individuals allowed us to anticipate many challenges prior to initiating the project. We were thus able to take them into consideration as we planned the project. Other unanticipated challenges presented themselves later in the process. Throughout, numerous lessons were learned that will assist us and others with future research efforts, program development and service delivery.

Challenges Encountered

One of the greatest challenges encountered concerned the standardization of the survey instrument, which was to be administered in a visual-manual (i.e., in ASL) rather than a written language. This challenge was partly rooted in the wide variations in sign language style and fluency amongst Deaf patients. As described in the "Methods" section, great efforts were undertaken to assure that all questions were asked consistently of all respondents and across sites. However, the interviewers had to be allowed some flexibility in order to assure that individuals who were not as fluent in ASL could understand the questions. In other words, the interviewers had to be allowed to adjust their interview techniques based on the sign language style and fluency of the individual being interviewed. One of the main purposes of the extensive training that interviewers went through prior to study initiation was to ensure that they were well aware of the information each question was aiming to gather, and as such, to minimize the amount of error introduced into the survey data as a result of this need to accommodate varying communication styles. These substantial efforts expended in the standardization of the survey instrument likely greatly reduced the effect of this obstacle on the survey data.

Nonetheless, the results of our data analysis have lead us to believe that despite these extensive efforts, certain questions were not asked consistently across sites. For example, we asked respondents to tell us how much exercise they get in a typical week. A definition of exercise and some examples of activities that would constitute exercise were included as part of the question. When the data was analyzed, we found that respondents at SHS reported significantly more days of exercise than respondents at AHC. At first we thought such differences might be explained by the fact that SHS respondents were more likely to reside in the City of Chicago, and therefore might rely more on walking as a means of transportation. However, when the data was analyzed by site and by residence in Chicago vs. a suburb, the site differences remained (see Figure 2.6, p. 35). At the completion of the study, the interviewers were debriefed about this question and a few others for which the data revealed unanticipated and unexplainable trends. The results of the debriefing suggest that this question was asked slightly differently by each of the interviewers. Interestingly however, the true explanation may be in the reason behind the question being asked differently at each site. It seems that the AHC interviewer had to define the term "exercise" for most respondents, while SHS respondents generally understood the term. The SHS interviewer revealed that several of his interviewees mentioned that their doctor had spoken to them about getting more exercise, and had suggested walking as a means of exercise. Therefore, the site differences may be real, but an understanding of how the question was asked is beneficial in the interpretation of the data. Given there was only concern about 4 of the 139 questions, it seems that generally the standardization was successful.

Another challenge concerned the lack of familiarity of most participants with research and research methods. Some of this was anticipated and the pilot testing of the survey instrument helped us to work through certain assumptions we have about the way data should be collected or the way questions should

be asked that might not be ideal for use with our Deaf clients. Some of these issues concerned certain types of questions that did not translate well into ASL (e.g., true/false questions), while other concerned a lack of familiarity by participants of common research questions and categories (e.g., excellent/very good/good/fair/poor). When the interviewers were debriefed, one of them mentioned that since most respondents were participating in research for the first time, and were unfamiliar with the process, it might be useful to include more qualitative and open-ended questions. The problem with qualitative data of course is that it is more difficult to analyze. However, this comment is interesting to consider when planning future research. Perhaps it would be helpful and make the process less frustrating for participants if some open-ended questions were included in conjunction with close-ended questions devised with the aforementioned limitations in mind.

Another challenge to data collection had to do with the fact that data needed to be collected via face-to-face interviews. This presented more of a challenge to AHC with their many sites than it did to SHS. At AHC, the interviewer had to set-up appointments and travel to various sites to conduct the interviews. The fact that the interviews had to be conducted in ASL also made it impossible to conduct the survey anonymously, which may have somewhat hindered the credibility of some of the data, particularly around more sensitive topics such as HIV or alcohol use. Questions concerning health care services may also not have been answered completely honestly because respondents may have feared that their services would be affected by their responses. It is important to note however that the consent form specifically stated that responses to survey questions would in no way affect access to or the quality of services received.

Respondents were recruited from both general and mental health clinics. As a result, the mental health status of certain respondents was sometimes an obstacle to data collection. For example, some of our chronically mentally ill respondents, who lacked basic organization skills, missed two or three scheduled appointments before finally completing the interview. It was also a challenge to collect data from some mentally ill participants once they came in for an interview. For example, respondents with significant levels of anxiety tended to worry about answering questions "correctly" and therefore often provided a lot of extenuating and unnecessary information surrounding the actual answer to the question. The interviewers, however, had been prepared on how the more seriously mentally ill participants who had been recruited from our mental health clinics may respond. Also, prior to undertaking the survey the Project Team decided that people living in group homes and those with legal guardians would be excluded from the study. This exclusion criteria had two purposes: on the one hand it assured that the person being interviewed had direct experience with and knowledge of the health care system, and secondly, it assured that people with serious developmental delays or active psychotic features who may not be capable of properly answering the questions, would not be included.

Another unique obstacle to data collection was the dual role of the interviewers as both members of the Deaf community and researchers. Many of those interviewed were well connected to the Deaf community and therefore a fair number knew the interviewer before agreeing to participate. Extensive efforts were undertaken to assure that respondents understood that the interviewer was required to keep all answers confidential. Only one person refused to participate because he/she knew the interviewer, suggesting this might have been less of an issue than we had anticipated. However, we cannot know what effect this unique situation may have had on the credibility of some of the more sensitive data. Alternatively, it is quite possible that the fact that the interviewers are known and respected members of the Deaf community may have increased participation because respondents were more likely to trust the interviewer than if he/she would have been an "outsider". It is well known that there is a general sense of distrust of "outsiders" or non-deaf persons within the Deaf community. Respondents also may have been less sensitive to this issue

than anticipated since many of the providers in both programs also are members of the Deaf community; both programs, therefore, have demonstrated over the years their commitment to confidentiality despite the dual roles their providers play in the Deaf community.

A final challenge concerns the time required to conduct the interview. It was felt that it would be unrealistic to expect people to participate in an interview much longer than an hour. With a hearing population, we could likely have asked 400-500 questions in that amount of time; however, translation of questions into ASL greatly increases the administration time. We were therefore limited in the amount of data we could collect and had to prioritize the information we were most interested in obtaining. Even an hour seems like a large time commitment, and we were concerned that the time might be a deterrent to some people. However, this concern turned out to be unwarranted. Most respondents were very enthusiastic about participating and were excited about the opportunity to express their views and opinions. In fact, participants frequently spent a great deal of time at the end of the interview providing additional thoughts and comments beyond those solicited. Socialization within a deaf-friendly environment is highly valued within Deaf culture and this value appears to have extended into an interview situation with a native signer.

Lessons Learned

The general willingness and enthusiasm displayed by Deaf patients at each of our institutions was likely the most positive lesson learned as a result of this research effort. Not a lot of research has been conducted with Deaf individuals, and so we were not certain what to expect in terms of willingness to participate. While the concept of research was new to the majority of those interviewed (a fact which presented certain challenges, outlined above), people were overwhelmingly cooperative and eager to tell their stories, express their opinions and frustrations, and to provide information that might prove useful in improving health care for the Deaf community. However, it is important to reiterate that both of these institutions have strong Deaf services and an existing rapport with their patients. It is unclear how well such a survey would be received in the general Deaf community although the high value placed on socialization may influence the commitment of respondents to the research process.

Another important lesson concerns the validity of the SF-12 when used with a Deaf population. This measure has recently come into common use in research as a proxy for overall health status and a predictor of five and ten year mortality. Part of its popularity can be attributed to its brevity. It requires asking a series of 12 questions about a person's physical, emotional and mental well-being. To be able to use such a measure with Deaf individuals would make the monitoring of their health status and quality of life both for clinical and research purposes a great deal easier. While it will be necessary to undertake additional analyses to further and more completely validate the use of this instrument with a Deaf population, preliminary results (as described in "Key Survey Findings/Topic 5. Health-Related Quality of Life", p.47) suggest that SF-12 scores correlate well with other measures of physical and mental health status.

Finally, several lessons were learned pertaining to the best way to ask questions of Deaf individuals. A few will be outlined here. First of all, it was found that visual aids greatly facilitate the data collection process. In the current survey, flash cards were used with numeric scales in order to orient the respondent towards a negative vs. a positive response. It was suggested during the debriefing of the interviewers that it would also have been useful to use flash cards with other questions. For example, we asked respondents how many servings of certain foods they eat in a typical day (e.g., dairy products). It would have been useful to have flash cards with pictures of the types of foods that fall into each category to use with those questions. Another lesson is that numeric scales work better with Deaf respondents than do ambiguous categories.

Respondents tended to have a hard time placing themselves into categories such as “very good” vs. “good”. Part of this might be due to a lack of familiarity with research and such scales, and part of it might have to do with the translation of words such as “very” into ASL. Nonetheless, we were fortunate to discover this nuance during the pilot phase of the survey and to adjust our survey instrument accordingly. Similarly we learned that the concepts of True/False do not translate well into ASL, and revised such questions to ask respondents whether or not they agreed with certain statements (yes or no).

SECTION 6. RECOMMENDATIONS

Over the last 18 months, Michael Reese Health Trust (MRHT) support has provided an opportunity to bring together the staff of Sinai Health System and Advocate Health Care's Deaf programs, the largest deaf-serving programs in the Chicago area. It has given us an opportunity to share information and ideas, as well as to conduct research and network with others working in the field at the national level. From these 18 months of intense effort, we have learned a lot and have uncovered gaps in health service provision, potential for public policy changes, and avenues for further research. The following recommendations represent many hours of dialogue over the length of the project. Some of the recommendations stem directly from our survey results, while others represent our broader experiences working with and serving the Deaf community.

For Providers of Health Care Services

While our institutions have made considerable efforts to accommodate our Deaf patients, many health care providers lack familiarity with Deaf individuals and the knowledge necessary to effectively serve them. Beyond the tangible resources necessary to serve Deaf patients, there is a need to train providers on the "how" of serving Deaf patients. Many Deaf persons do not really know how to be a "patient". They often lack the knowledge and instruction on how to communicate effectively with health care professionals. For instance, they may be unaware that they can be assertive in asking questions of the doctor, inquiring about treatment alternatives and asking about side effects of medication. They may not have knowledge of their family medical history, especially if their parents were hearing and did not sign. This knowledge deficit requires the provider to be more proactive in eliciting information and feedback from the patient than is the norm for the hearing population. As demonstrated in our survey, an additional concern in serving Deaf persons is their lack of familiarity with medical terminology and basic health information. Therefore, the provider must take extra care to explain things and to elicit feedback to ensure that understanding has been achieved.

An effort is underway to educate providers on the steps necessary to properly serve their Deaf patients. This effort is being led by Dr. Steven Barnett of the University of Rochester Medical School and the Delmarva Foundation for Medical Care, and is funded by the Centers for Medicaid and Medicare Services (CMS) of the U.S. Department of Health and Human Services. Dr. Barnett is a colleague of Dr. Robert Pollard, the expert panelist at our first MRHT Peer Review last year. The project's efforts have included the identification of model care practices for deaf and hard of hearing individuals which will culminate in a series of documents, intended for both providers and consumers, describing standards of care and offering guidance on providing and receiving quality care. The group also maintains a Web site (www.deafhoh-health.org) with resources for provider and deaf and hard of hearing individuals. We were able to network with both Dr. Barnett and the Delmarva staff at the November 2003 Annual Meeting of the American Public Health Association, where they were presenting their recommendations. At that time, we agreed to continue our dialogue, so we could learn from one another and potentially collaborate on future projects.

Our final recommendation for the provision of health care concerns the need for deaf-friendly health education materials. For many reasons, existing health education materials are not useful in serving Deaf patients. As we have discussed above, ASL is not a written language and consequently Deaf individuals generally have a lower English reading level than their hearing counterparts. Combine this with the lack of health knowledge demonstrated by the survey, and it becomes obvious that health education materials specifically designed for Deaf individuals are necessary. As a part of the next phase of our project (Phase II, submitted to the MRHT 9/15/03, funded 12/04/03), which involves evaluating the effectiveness of two

health education interventions on health knowledge, self-efficacy, self-management and patient role behaviors, we will have developed two video pamphlets that will be available for use by Deaf persons and their providers. However, there is a need for many more such video pamphlets around many health topics.

For Public Policy

Our two institutions are by far the two largest deaf-serving health providers in the Chicago metropolitan area. The service we provide is possible largely because of a dedication on the part of the whole institution. That dedication and expertise is evident in the staff of the deaf program at each site, many of who were involved in this research effort. But it is important to also acknowledge the strong commitment on the part of our institutions' leadership. Without that leadership support, it would not be possible to operate these programs.

In this day of rising health care costs and increased emphasis on provider productivity and the bottom line, offering health care services to a Deaf population takes extra commitment because it requires more resources than similar care for the hearing population. A Deaf person's medical encounter takes longer. This is a factor of the extra time involved in ASL interpretation. Even with a provider fluent in ASL, more time is required because it takes longer to communicate health related information to a population with a "fund of knowledge" deficit, a deficit demonstrated by our survey results. Both our institutions employ full time ASL interpreters for patients and Deaf staff. This too represents an additional cost of doing business. Additional time and resources are also required to ensure that an institution is ready to receive Deaf patients. For example, all staff, from the front door of the clinic or emergency room, to the nurses and ancillary staff serving Deaf patients in the clinic or hospital need to be trained, adding further to the resources necessary to properly serve this population. The Americans with Disabilities Act requires health care institutions to make "every reasonable effort" to make the accommodations noted above for Deaf patients. Neither Medicare nor Medicaid provides sufficient remuneration to cover these extra costs however, putting health care institutions in a difficult spot. There are also no additional reimbursements for interpreter time. We recommend the exploration of methods of payment for the additional services and time needed to provide quality care to Deaf patients.

Since the language of most Deaf individuals (ASL) is a visual-manual one, the opportunities for the use of "telemedicine" with this population are intriguing. The technology involved is expanding at a rapid rate, with new internet-based technologies coming on the market all the time. Advocate has successfully used such a system in their Mental Health program to extend the services of their ASL fluent therapists. Sinai has installed a computer-based phone system that provides easier service to both provider and patient than the TTY. Funding to test effective uses of these and other technologies is recommended.

CMS has been open to the funding of innovative, pilot programs as waivers to the current Medicaid and Medicare funding guidelines. They are to be commended for funding the Delmarva project mentioned above. We would further recommend the funding of projects to demonstrate "best practices" in the provision of services to Deaf patients, as well as cost studies which might lead to higher reimbursement rates for certain services.

A starting point for this public policy work is increasing the awareness of the policy makers in Springfield and Washington about these issues. To that end, we have begun planning with the Public Policy team of the Jewish Federation of Metropolitan Chicago, funded by MRHT and including staff from the Health and Disability Advocates. This effort will continue in parallel with the Phase II Proactive Project.

For Further Research

As noted above, our survey was conducted among our own patients who, by definition, are well connected to health care. The results of the survey therefore cannot be generalized to all Deaf persons. As one example, while the deficits of health knowledge demonstrated amongst our survey participants were large, they are probably only a fraction of what we would see if we surveyed individuals who are not as well connected with the health care system. We would thus like to see the survey replicated within a randomly selected sample of the Deaf population and have those results compared to ours. To locate the Deaf respondents would involve a major effort, but would greatly enhance our understanding of the issues raised in our survey on knowledge deficit, fund of knowledge, health status and access to care.

The survey demonstrated a health knowledge deficit among our Deaf patients. We, along with several others in the field (Dr. Elaine Jones, Associate Professor at the College of Nursing of the University of Arizona and Dr. Pollard of the University of Rochester Medical School in New York), are developing health information materials and health education programs aimed specifically at Deaf persons. These materials and programs need to be evaluated to determine what works best in increasing health knowledge among Deaf individuals.

In our survey we used many questions from validated health surveys commonly used in the hearing population, but which had not previously been used with Deaf respondents. The SF-12 is one prime example, although many of the health knowledge questions also fit this description. Furthermore, in Phase II of the project we plan on using screening tools to recruit individuals for our health education interventions. For example, we plan on using the Beck Depression Inventory, which has been previously used with Deaf individuals but has never been validated within this population. There is much work to do in testing these research instruments for validity and reliability with the Deaf population, so as to enable comparison studies of the Deaf and general populations. Research into the development of effective, standardized screening tools for use with a Deaf population is also necessary. These standardized screening tools could then be disseminated to all providers for use with their Deaf patients.

Conclusion

We are proud of the survey and its findings. To the best of our knowledge, such an extensive survey of Deaf individuals has not previously been attempted. Dissemination of these results is an important next step. We have started this process by presenting our results at the Annual Meeting of the American Public Health Association this past November. Next steps include the submission of abstracts on the results of the survey to other scientific meetings, as well as the preparation of several papers on various aspects of the survey for potential publication. The first of these will concern the process of developing the survey instrument, and will be submitted to the Annals of Deafness.

LIST OF APPENDICES

APPENDIX 1: Excerpt from the Survey Instrument including ASL Gloss

APPENDIX 2: Recruitment Script

APPENDIX 3: Screening Form

APPENDIX 4: ASL Gloss version of SF-12, version 2

APPENDIX 1: EXCERPT FROM THE SURVEY INSTRUMENT INCLUDING ASL GLOSS

**FROM (MONTH) TO (MONTH-TODAY) FINISH DOCTOR, NURSE, OR STAFF
TEACH YOU ABOUT WEIGHT? IF YES, TEACH LOOK LIKE WHAT?**

41. In the past 12 months, has a doctor, nurse or other health professional given you advice about your weight? If yes, what was that advice?

- YES, TO LOSE WEIGHT1 (V41)
- YES, TO GAIN WEIGHT2
- YES, TO MAINTAIN CURRENT WEIGHT3
- NO4
- OTHER5
- SPECIFY: _____ (V41_S)
- DK/NOT SURE.....8
- REFUSED.....9

The next series of questions are about the prevention of disease.

42. C-A-N-C-E-R YOU KNOW WHAT?

Do you know what c-a-n-c-e-r is? **[FINGER SPELL THE WORD]**

- YESASK Q.43, BELOW1 (V42)
- NOREAD EXPLANATION, SKIP TO Q.44, P.172
- REFUSED9

43. YOU UNDERSTAND CANCER WHICH ONE?

Which of the following best fits your understanding of cancer?

- A kind of fat which blocks blood vessels1 (V43)
- A bad growth in the body, that starts small and gets bigger, and can spread throughout the body, making a person dangerously sick2
- Something in food which helps bones become stronger.....3
- A pill which helps the eyes4
- DK/NOT SURE.....8
- REFUSED9

[IF SUBJECT CORRECTLY DEFINES CANCER (RESPONSE #2) THEN MOVE ON WITH THE SURVEY. IF THE SUBJECT INCORRECTLY DEFINES THE TERM, READ THE EXPLANATION BEFORE MOVING ON.]

YOU AGE 50 OR OVER 50?

Are you 50 years old or older?

- YESASK Q.44-46.....1
-[OVER50]
- NOIF MALE, SKIP TO Q.62, P.24.....2
-IF FEMALE, SKIP TO Q.49, P.182

[ASK Q.44-Q.46 ONLY OF PATIENTS 50 YEARS OF AGE AND OLDER.]

44. SIGMOIDOSCOPY OR COLONOSCOPY POOP LOOK FOR CANCER OR OTHER PROBLEM. FINISH YOU EXPERIENCE?

A sigmoidoscopy or colonoscopy is when a tube is inserted into the rectum to look for signs of cancer and other health problems. Have you ever had this exam?

- YES.....1 (V44)
- NOSKIP TO Q.46, BELOW2
- NO CODED RESPONSE APPLICABLE.....7
- SPECIFY:..... (V44_S)
- DK/NOT SURE.....SKIP TO Q.46, BELOW8
- REFUSED.....SKIP TO Q.46, BELOW9

45. BEFORE WHEN YOU FINISH EXPERIENCE SIGMOIDOSCOPY OR COLONOSCOPY??

When did you have your last sigmoidoscopy or colonoscopy? Would you say...

- Within the past year [0 TO 12 MONTHS AGO]1 (V45)
- Within the past 2 years [>1 TO 2 YEARS AGO]2
- Within the past 5 years [>2 TO 5 YEARS AGO]3
- 5 or more years ago5
- NO CODED RESPONSE APPLICABLE.....7
- SPECIFY:..... (V45_S)
- DK/NOT SURE.....8
- REFUSED.....9

46. IMPORTANT WHICH ONE TEST YOUR COLOR CANCER CAREFUL FOR FOR GOOD HEALTH?

On a scale from 1 to 10, where 1 is “not at all important” and 10 is “very important”, how important do you feel that getting screened for colon cancer is in maintaining good health?

[CIRCLE APPROPRIATE NUMBER OR INDICATE NCRA, DK/NS, OR REFUSED]

- | | | | | | | | | | | |
|------------|---|---|---|------------|---|---|---|---|-----------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | (V46) |
| not at all | | | | moderately | | | | | very | |
| important | | | | important | | | | | important | |
- NO CODED RESPONSE APPLICABLE.....7
 - SPECIFY:..... (V46_S)
 - DK/NOT SURE.....8
 - REFUSED.....9

[Q.47-Q.48 APPLY ONLY TO MEN OVER THE AGE OF 50. IF RESPONDENT IS WOMAN, SKIP TO Q.49, BELOW]

47. TEST RECTAL EXAM REQUIRE DOCTOR NURSE HEALTH PROFESSIONAL PUT RUBBER GLOVE FINGER INSIDE RECTUM FEEL PROSTATE GLAND SIZE SHAPE HARD. YOU FINISHED TEST BEFORE?

A digital rectal exam is an exam in which a doctor, nurse, or other health professional places a gloved finger into the rectum to feel the size, shape, and hardness of the prostate gland. Have you ever had a digital rectal exam?

- YES.....1 (V47)
- NO.....SKIP TO Q.62, P.242
- NO CODED RESPONSE APPLICABLE.....7
- SPECIFY:_____ (V47_S)
- DK/NOT SURE.....SKIP TO Q.62, P.248
- REFUSED.....SKIP TO Q.62, P.249

48. WHEN LAST TIME EXAM? WHEN?

How long ago did you have a digital rectal exam? Was it...

- Within the past year [0 TO 12 MONTHS AGO]1 (V48)
- Within the past 2 years [>1 TO 2 YEARS AGO]2
- Within the past 3 years [>2 TO 3 YEARS AGO]3
- Within the past 5 years [>3 TO 5 YEARS AGO]4
- 5 or more years ago5
- NO CODED RESPONSE APPLICABLE.....7
- SPECIFY:_____ (V48_S)
- DK/NOT SURE.....8
- REFUSED.....9

[Q.49-Q.54 APPLY ONLY TO WOMEN. IF RESPONDENT IS A MAN, SKIP TO Q.62, P. 24]

49. YOU KNOW WHAT MEAN (FS) P-A-P-S-M-E-A-R?

Do you know what a P-a-p s-m-e-a-r is? **[FINGER SPELL THE WORD]**

- YES.....ASK Q.50, P.19.....1 (V49)
- NO.....READ EXPLANATION, SKIP TO Q.51, P.192
- REFUSED.....9

APPENDIX 2: RECRUITMENT SCRIPT

**Improving Access to Health and Mental Health Care
for Deaf and Hard of Hearing Populations**

Sinai Recruitment Script

Hello – My name is _____ and I am working with a project here at Mount Sinai to improve health care for deaf and hard of hearing people and I would like to ask you to help us with this project.

We will be interviewing about 100 people here at Mount Sinai and another 100 people at Advocate Illinois Masonic Medical Center. We hope that the answers will allow us to better serve deaf and hard of hearing people in the future and to improve their health. I would like to ask you a few brief questions to see if you are eligible for the study. These questions will only take about 5 minutes, and if you are eligible then I will tell you more about the study. You can then decide if this is something you might be interested in. Can I ask you a few questions?

[IF YES, PROCEED WITH TOP PORTION OF SCREENING FORM. IF NO, THANK PERSON FOR THEIR TIME.]

[IF SCREENING FORM REVEALS THAT THE PERSON IS ELIGIBLE, PROCEED WITH THE FOLLOWING. OTHERWISE, THANK PERSON FOR THEIR TIME.]

You are eligible for the study. We are doing the study to identify the physical and mental health care needs that deaf and hard of hearing people have. We hope to understand the needs of deaf and hard of hearing people better so we can improve services in the future. The interview will take about an hour and we will pay you \$50 for taking the time to answer our questions. You will receive the \$50 when you complete the interview. You can be interviewed today if you have the time, or we can set-up an appointment for the interview on another day.

Is this something you might be interested in?

[IF INTERESTED, PROCEED WITH CONSENT PROCESS, AND FILL OUT THE REST OF THE SCREENING FORM. EITHER INTERVIEW THE SUBJECT OR SCHEDULE AN APPOINTMENT FOR THE INTERVIEW ON ANOTHER DAY.]

[IF NOT INTERESTED]: Thanks for your time.

APPENDIX 3: SCREENING FORM

Improving Access to Health and Mental Health Care for Deaf and Hard of Hearing Populations

Screening Form

Screener (initials only): _____ Date of Screening (mm/dd/yy): _____

1. YOU FINISH JOIN INTERVIEW FOR YOUR HEALTH HERE MT SINAI OR OTHER PLACE NAME IL MASONIC MEDICAL CENTER?

Have you recently participated in an interview about your health at either IL Masonic Medical Center or Mt. Sinai?

- YESREAD PROMPT BELOW1 (S1)
- NOGO TO Q.22

PROMPT: Was the purpose of the interview to identify the physical and mental health care needs of deaf and hard of hearing people?

- YESNOT ELIGIBLE; END HERE.....1 (SP1)
- NOGO TO Q.22

2. YOU AGE 18 OR OVER 18?

Are you 18 years old or older?

- YESGO TO Q.31 (S2)
- NONOT ELIGIBLE; END HERE.....2

3. YOUR HEALTH WHO DECIDE---YOU OR OTHER?

a. Who makes most of the decisions about your health care?

- I DOGO TO Q.41 (S3a)
- A FAMILY MEMBERASK Q.3.B2
- SOMEONE ELSE.....ASK Q.3.B3
- DK/NOT SURE.....READ PROMPT BELOW8

PROMPT: Some people have others who are legally responsible for making health care decisions for them. Other people will consult family or friends to ask their advice when making a health care decision, but still make up their own mind in the end. Who makes the final decision about your health care, you, a family member or someone else?

- I DOGO TO Q.41 (SP3a)
- A FAMILY MEMBERASK Q.3.B2
- SOMEONE ELSE.....ASK Q.3.B3
- DK/NOT SURE.....ASK Q.3.B8

PERSON DECIDE YOUR HEALTH-HE/SHE RESPONSIBLE WATCH?

- b. Is the person who makes your health care decisions your legal guardian?
- YES.....NOT ELIGIBLE; END HERE.....1 (S3b)
 - NO.....READ PROMPT BELOW2
 - DK/NOT SURE.....NOT ELIGIBLE; END HERE.....8

PROMPT: So you are your own legal guardian?

- YES.....GO TO Q.41 (SP3b)
- NO.....NOT ELIGIBLE; END HERE.....2
- DK/NOT SURE.....NOT ELIGIBLE; END HERE.....8

4. YOU LIVE IN HOME GROUP?

Do you live in a group home?

- YES.....NOT ELIGIBLE; END HERE.....1 (S4)
- NO.....GO TO Q.52

5. YOUR EVERYDAY COMMUNICATION YOU PREFER? YOU PICK.

What is your usual and preferred method of communication? Would you say:

- sign language onlyELIGIBLE*1 (S5)
- sign language more than speak...ELIGIBLE*2
- speak/lip read more than sign language..ASK Q.6&7.....3
- speak/lip read only NOT ELIGIBLE4
- another methodSPECIFY**5
- if other, specify:_____ (S5_S)

* IF 1 OR 2, THEN THE PERSON IS ELIGIBLE. STILL COLLECT THE INFORMATION IN Q.6 AND Q.7 FOR OUR RECORDS (NOT TO ASSESS ELIGIBILITY).
 ** ASSESS ELIGIBILITY BASED ON RESPONSE

6. YOU DEAF HAPPEN BEFORE AGE 3?

Were you deaf before the age of 3?

- YES.....ELIGIBLE*1 (S6)
- NO.....ASK Q.7 TO ASSESS IF ELIGIBLE2
- DK/NOT SURE.....ASK Q.7 TO ASSESS IF ELIGIBLE8

*IF 1, THEN THE PERSON IS ELIGIBLE. STILL COLLECT THE INFORMATION IN Q.6 FOR OUR RECORDS, (NOT TO ASSESS ELIGIBILITY).

7. YOU SOCIALIZE DEAF COMMUNITY PEOPLE?

Do you socialize with members of the Deaf Community?

- YES.....ELIGIBLE1 (S7)
- NO.....IF Q.6 IS NO, THEN NOT ELIGIBLE2
- DK/NOT SURE.....IF Q.6 IS NO, THEN NOT ELIGIBLE8

ASSESS ANSWERS TO SCREENING QUESTIONS TO DETERMINE ELIGIBILITY:

PERSON IS ELIGIBLE FOR THE STUDY: ___ YES ___ NO (S_ELIG)

IF ELIGIBLE, DETERMINE IF THE PERSON IS INTERESTED IN PARTICIPATING:

PERSON IS INTERESTED IN PARTICIPATING: ___ YES ___ NO (S_INT)

IF THE PERSON IS ELIGIBLE AND INTERESTED IN PARTICIPATING, COLLECT THE FOLLOWING (NEXT PAGE) IDENTIFYING INFORMATION.

IDENTIFYING INFORMATION

1. NAME FULL FIRST NAME THEN LAST NAME

Name: _____ (SI1)

LIVE WHERE NAME?

2. Street Address: _____ (SI2)

3. City: _____ 4. State: _____ 5. Zip Code: _____ (SI3,SI4, SI5)

6. Phone/TTY: _____ 7. E-mail: _____ (SI6, SI7)

8. Gender:

MALE.....1 (SI8)
FEMALE.....2

9. Date of Birth (mm/dd/yy):_____ (SI9)

10. Race/Ethnicity:

NH BLACK.....1 (SI10)
NH WHITE.....2
HISPANIC.....3
OTHER.....SPECIFY.....7
SPECIFY:_____ (SI10_S)

11. SITE:

SINAI HEALTH SYSTEM.....1 (SI11)
IL MASONIC MENTAL HEALTH.....2
ADVOCATE MEDICAL GROUP (ARLINGTON HEIGHTS).....3

12. YOU JOIN THIS PLACE HOW LONG? YOU PICK?

How long have you been a patient at this clinic? Would you say:

- this is your first visit0 (SI12)
- < 1 year1
- 1-3 years, or.....3
- > 3 years4
- DK/NOT SURE.....8
- REFUSED9

13. METHOD OF CONSENT:

- VIDEOTAPE.....1 (SI13)
- WRITTEN FORM.....2
- ORAL.....3

14. RECRUITED FROM A MENTAL HEALTH SETTING?

- YES (MH PATIENT)1 (SI14)
- NO (NOT MH PATIENT)2

DATE OF SCHEDULED INTERVIEW : _____ (SI_DATE)
[NOTE: PUT IN TODAY'S DATE IF CONDUCTING INTERVIEW IMMEDIATELY].
ASSIGNED STUDY ID #: _____ (SI_ID)

APPENDIX 4: SF-12, VERSION 2 – ASL GLOSS

SF-12 Version 2

1. GENERAL (ABOUT) YOU SEE-MYSELF

In general, would you say your health is:

- Excellent5
- Very good.....4
- Good.....3
- Fair, or2
- Poor1

2. YOU SEE THESE QUESTIONS THAT-THAT FOR ACTIVITIES MEANS YOU DO-DO LIKE MOVING TABLE, PUSH VACUUM, BOWLING, OR PLAY GOLF. TRUE YOU STUCK YOU CAN'T DO-DO BECAUSE YOUR HEALTH? YES? HOW MUCH?

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

a. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.

- Yes, limited a lot1
- Yes, limited a little2
- No, not limited at all3

b. **CLIMBING FEW STAIRS?**

Climbing several flights of stairs

- Yes, limited a lot1
- Yes, limited a little2
- No, not limited at all3

3. 4 WEEKS TOTAL NOW HOW MUCH TIME YOU STRUGGLE PROBLEM WITH YOUR WORK OR EVERYDAY-DO-DO BECAUSE OF YOUR HEALTH?

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

- a. Accomplished less than you would like.
 - All of the time1
 - Most of the time2
 - Some of the time3
 - A little of the time4
 - None of the time.....5

b. AT WORK OR DO-DO YOU FEEL LIMIT?

Were limited in the kind of work or other activities

- All of the time1
- Most of the time2
- Some of the time3
- A little of the time4
- None of the time.....5

4. 4 WEEKS TOTAL NOW, AT WORK OR DO-DO ITSELF YOU EXPERIENCE PROBLEMS THAT CAUSE EMOTIONAL PROBLEM LIKE DEPRESSION OR ANXIOUS?

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

- a. Accomplished less than you would like.
 - All of the time1
 - Most of the time2
 - Some of the time3
 - A little of the time4
 - None of the time.....5

b. WORK ITSELF YOU DO-DO MORE CAREFULLY THAN OTHER JOB-ITSELF MORE?

Did work on other activities less carefully than usual.

- All of the time1
- Most of the time2
- Some of the time3
- A little of the time4
- None of the time.....5

5. 4 WEEKS TOTAL NOW, PAIN ITSELF STOPS YOU FROM DO-DO AT WORK PLUS HOME? HOW MUCH?

During the past 4 weeks, how much did pain interfere with your normal work? Include both work outside the home and housework.

- Not at all.....5
- A little bit4
- Moderately3
- Quite a bit.....2
- Extremely1

6. NOW ASK-ASK YOU ABOUT YOUR FEELING SINCE 4 WEEKS TOTAL NOW. YOU SEE QUESTIONS YOU CHOOSE MORE “MATCH” YOUR FEELING ...ANSWERS THAT QUESTION.

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

a. 4 WEEKS TOTAL NOW YOU FEEL PEACEFUL AND CALM?

Have you felt calm and peaceful?

- All of the time5
- Most of the time4
- Some of the time3
- A little of the time2
- None of the time.....1

b. 4 WEEKS TOTAL NOW YOU FEEL LOT ENERGY?

Did you have a lot of energy?

- All of the time5
- Most of the time4
- Some of the time3
- A little of the time2
- None of the time.....1

c. 4 WEEKS TOTAL NOW YOU FEEL DEPRESSION AND BAD MOOD.

Have you felt downhearted and depressed?

- All of the time5
- Most of the time4
- Some of the time3
- A little of the time2
- None of the time.....1

7. 4 WEEKS TOTAL NOW, YOUR PHYSICAL HEALTH OR EMOTIONAL PROBLEM...ITSELF STOP YOU FROM YOUR WANT SOCIAL LIKE VISIT FRIEND, FAMILY, ETC.

During the past 4 weeks, how much of the time have your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

- All of the time1
- Most of the time2
- Some of the time3
- A little of the time4
- None of the time.....5