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Health Care Access Behaviors in the Deaf Community of Connecticut

Peter S. Khang

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**HEALTH CARE ACCESS BEHAVIORS
IN THE DEAF COMMUNITY OF CONNECTICUT**

Peter S. Khang

B.A., Tufts University, 1993

A Thesis

Submitted in Partial Fulfillment of the

Requirements for the Degree of

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at the

University of Connecticut

2000

APPROVAL PAGE


Master of Public Health Thesis

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IN THE DEAF COMMUNITY OF CONNECTICUT**

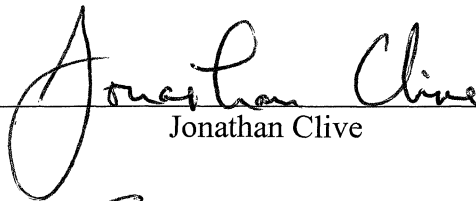
Presented by

Peter S. Khang, B.A.

Major Advisor


Holger Hansen

Associate Advisor


Jonathan Clive

Associate Advisor


Stacie Mawson

University of Connecticut

2000

Acknowledgements

I would first like to thank my mother and sister for ably supporting me in all of my endeavors. Without your love I would not be where I am today. I would like to thank my thesis committee for their guidance and direction during my research and writing of my project. Individually, Holger, thanks for your wise guidance and even-keeled demeanor. Jonathan, thanks for your upbeat sharing of your statistical knowledge. Stacie, thanks for being so generous with your time and for all the wonderful feedback and direction you provided.

I extend a warmhearted thanks to the CDHI who has supported this project and embraced me into the Deaf community. A special thanks to Sue Pederson, teacher and friend, who has taught me so much about the Deaf community. Finally, of course, I humbly thank all of the members of the Deaf and hearing-impaired community who took the time to complete the survey. It is my hope that the medical profession can do a better job at providing adequate and appropriate health care to your respective communities.

About the Author

Peter first became interested in ASL and the Deaf community while taking an ASL course at Wesleyan university his senior year of high school. Though he took more ASL courses in college and became involved in the Deaf community, his interest had to take a back seat to his pre-medical studies.

As a third-year medical student, after fortuitously meeting Stacie Mawson, the executive director of the CDHI, he became very interested in health care issues in the Deaf community. After deciding to conduct this thesis research, he knew that he needed to experience firsthand the community. The CDHI and especially Stacie Mawson and Sue Pederson welcomed and introduced him to the Deaf community. For public education, he started a health education seminar series (H.E.S.S.) in which medical students give talks on various health-related topics to the Deaf community. In hopes of improving the provision of health care here in Connecticut, he established an “ASL for health care professionals” course here at the medical school. The class has been a great success, piquing the interest of many a student, and looks to become a mainstay in the elective curriculum here at UConn Medical School.

Peter starts his Kaiser Permanente Family Medicine residency in Los Angeles, California this July, 2000. He hopes to continue with his involvement in the Deaf community out there.

Table of Contents

Title Page.....	i
Approval Page.....	ii
Acknowledgements.....	iii
About the Author.....	iv
List of Tables.....	vii

PART 1.

Introduction.....	1
Epidemiology.....	2
<i>Gender and Race</i>	5
<i>Family Income</i>	6
<i>Employment</i>	6
<i>Education</i>	7
<i>Limitation of Activity</i>	7
Etiology.....	8
Deaf Culture.....	10
<i>Age of Hearing Loss</i>	11
<i>Differences in Perspective</i>	12
<i>American Sign Language</i>	13
<i>Families</i>	14
Modes of Communication.....	14
<i>Speech and Lip-reading</i>	15
<i>Writing</i>	16
<i>Professional Interpreters</i>	16
<i>Family Member Interpreters</i>	17
Legal Issues.....	18
Health-Care Related Issues.....	20
<i>Patient Knowledge/Literacy</i>	21
<i>Provider Perspective</i>	24
<i>Patient Experiences</i>	25

PART 2.

Study Rationale/Specific Aims.....	28
Materials and Methods.....	29

<i>Questionnaire Development</i>	29
<i>Definitions</i>	31
Data Analysis.....	32
Results.....	33
Discussion.....	40
<i>Response Rate/Demographics</i>	40
<i>Hearing Status</i>	40
<i>Health Care Access Behaviors</i>	41
<i>Understanding/Satisfaction</i>	48
<i>Limitations</i>	49
Conclusion.....	50
Recommendations.....	51
<i>Institutions</i>	51
<i>Community Efforts</i>	52
<i>Future Research</i>	54
Appendix A: Survey instrument.....	55
References.....	60

List of Tables

Table 1. Prevalence of hearing impairment by rating scale.....	4
Table 2. Causes of Hearing Loss.....	8
Table 3. Sample Demographics.....	33
Table 4. Patients' Hearing Status.....	34
Table 5. With whom respondents visited the doctor.....	35
Table 6. Modes of Communication.....	35
Table 7. Reasons why did not use a professional interpreter.....	36
Table 8. Understanding, by Groups.....	37
Table 9. How Hard to Get Interpreter, Deaf Group.....	38
Table 10. Levels of Understanding by Hearing Status.....	39

PART 1.

Introduction

Hearing loss is one of the most prevalent chronic physical conditions in the United States.^{1,2} According to the most recent Health Interview Survey from the National Center for Health Statistics (NCHS) of the U.S. Department of Health and Human Services, approximately 20 millions persons, or 8.6% of the population, were reported to have hearing problems. Of this population with reported hearing troubles, it is estimated that 550,000 persons are deaf, (0.49% of the population).²

Deaf and hearing-impaired persons must deal with extraordinary communication barriers when accessing the health care system.³ Studies have found that even well educated Deaf persons failed to understand almost one-third of what the hospital staff tried to tell them.⁴ Further, compared to other immigrant populations, Deaf patients are less likely to find physicians who can use American Sign Language (ASL) than other immigrant groups are to find a physician who speaks their native language.⁵ According to the literature, only between 6% and 33% of Deaf patients utilized professional interpreters, and in one study, over 50% of Deaf people reported difficulty in obtaining an interpreter when needed.⁶ Deaf patients often receive health care that is inadequate and inappropriate for their needs as a result of individual, interpersonal, and systemic factors.³

In part 1 of my paper, I will review the epidemiology and etiology of hearing loss and deafness. Then, I will discuss features of the Deaf culture, such as American Sign Language, community values and social rules, that are important to understand and appreciate in order to critically examine the interaction between Deaf patient and the

health care system. I will remark upon the various modes of communication available to the Deaf and hearing-impaired patient and health care provider and then review the legal context within which these interactions take place. Finally, a review of the health care-related issues will examine patients' health care knowledge base and literacy, their experiences with the health care system, and providers perspectives and experiences.

In part 2, I will present the finding of my research and then discuss their significance. The paper concludes with a conclusion and recommendations for the next steps.

As far as terminology is concerned, Deaf, with a capital D, will refer to the culturally deaf, those who experienced their hearing loss before the age of three and/or consider themselves a part of the Deaf community. In contrast, deaf will refer strictly to the audiologic aspects of hearing loss.

Epidemiology

What is deafness? Unlike blindness, for which there exists a legal definition, “deaf” and “deafness” have no unanimously agreed upon definition. Prevalence data for hearing impairment may vary widely across studies for several reasons. One reason for this variability is different data collection methods-- self-report versus audiometric testing. Another reason is the use of different criteria for defining hearing impairment-- fence (“the level in decibels above which a significant hearing loss is said to exist”), ear (whether one or both ears are used in the definition), and audiometric test stimuli (speech or pure tones.)⁷

The estimates of prevalence of deafness and hearing trouble vary by data collection method. Using a self-rating scale (SRS), there were 421,000 persons who were “deaf, both ears,” and 2,562,000 who were “at best, a lot of trouble hearing in both ears.”²

For those who received a positive response to one of the screening question in the survey, the Gallaudet Hearing Scale (GHS) was administered to all people over 3 years of age. The GHS has the advantage of shedding light on the important question of how a hearing loss affects a person’s ability to hear and understand speech. By the GHS, of the 20,295,000 persons who had hearing trouble, 552,000 “could not hear and understand any speech,” 726,000 “could hear and understand words shouted in ear,” and 4,920,000 “could hear and understand words shouted across the room.”²

The results of the National Health Interview Survey (NHIS) are reported in terms of a cross-classification of the SRS and GHS scales. There is a potential of inconsistent classification from using two scales with overlapping meaning to classify subjects. These are addressed in the data analysis and the results in terms of all of the categories of hearing trouble are shown in Table 1.² The groups those with *hearing trouble* and those who *cannot hear and understand normal speech* from this cross classification table are used for analysis and comparison in the NHIS. In the following paragraphs, those with *hearing trouble* (20.3 million) includes all levels of severity of hearing loss, whereas those who *cannot hear and understand normal speech* (4.8 million) denotes a subset with more severe hearing loss.

Table 1. Prevalence of hearing impairment by rating scale

Rating Scale	Total (in thousands)	% of those with hearing trouble*	% of total population
SRS			
Hearing trouble	20,295		8.8%
Deaf, both ears	421	2.2%	0.18%
At best, a lot of trouble hearing in both ears	2,562	13.1%	1.1%
GHS			
Hearing trouble	20,295		8.8%
Cannot hear and understand any speech	552	2.8%	0.23%
Cannot hear and understand words shouted in ear	726	3.6%	0.3%
Cannot hear and understand words shouted across a room	4,920	24.7%	2.1%
Cross-Classification			
Hearing trouble	20,295 ^a		8.8%
Cannot hear and understand normal speech	4,811	23.7%	2%
Can hear words shouted across the room	3,659	18%	1.6%
None or at best words shouted in ear	1,152	5.7%	0.49%

*percent distributions exclude frequencies of unknowns of SRS and GHS.

^aExcludes unknowns due to cross-classification.

In terms of age of onset, among those with *hearing trouble*, 5.6% experienced the problem before 3 years of age, 14.7% between the ages of 3 and 18, and 79.1% at age 19

or older. For the subgroup of persons with hearing trouble *who could not hear and understand normal speech*, the corresponding estimates are 6.6% before the age of 3 years, 9.4% between 3 and 18 years, and 83.4% at age 19 or older.²

The prevalence rate of hearing impairment is age-dependent, with the rate increasing with advancing age. Approximately 0.1% of the population under 45 years of age is deaf, compared to 2.5% of the population over 65 years of age.⁷ From 1971 to 1991, the United States' aging population has seen its incidence of hearing loss increase by 53%.³ This trend is not likely to reverse or slow down as the baby boomers continue to age. Most persons (60.9%) who could *not hear and understand normal speech* were in the "over 65 years" group, compared to only 9.3% of those with normal hearing being over 65 years of age.² In fact, greater than half of people over the age of 80 years have significant hearing loss.³

There were differences according to socio-demographic variables. Each demographic variable will be discussed.

Gender and Race

The prevalence of deafness varies according to gender and ethnicity. Although the female population is larger and older than the male population, there were more males (12 million, 10.5% prevalence) than females (8.3 million, 6.8% prevalence) with hearing trouble. Within each age group, white males are more likely than females to be deaf or hearing-impaired, and the gap increases after the age 18 years. The prevalence rates of males who could not hear and understand normal speech for the age ranges 18-44 years and 45-64 years approximately doubled between 1971 and 1991.²

Ethnically, whites are twice as likely as Blacks to be deaf or hearing-impaired, with an overall prevalence of 9.4% for whites and 4.2% for Blacks. Non-Hispanics are also more than twice as likely as Hispanics to be deaf or hearing-impaired with a prevalence of 9.1% for non-Hispanics and 4.2% for Hispanics.²

Family Income

Persons with *hearing trouble* are proportionately over-represented in low income families (less than \$10,000 annually) and under-represented in high income families (over \$50,000 annually.) Age-adjusted estimates of members of families earning \$10,000 or less were 14.4% for persons with *hearing trouble* and 18.6% for those *who cannot hear and understand normal speech*, compared to only 11.1% of those *with no hearing trouble*. At the high end of the income spectrum, 24.9% of persons *with no hearing trouble* were in the greater than \$50,000 income bracket compared to only 16% of those with *hearing trouble* being in the greater than \$50,000 income bracket.²

Employment

In terms of employment, the proportions of persons not in the labor force increases with increasing level of severity of hearing loss. There is virtually no difference in rates of employment status between those with *no trouble hearing* (29.4%) and the age-adjusted rate of those with *hearing trouble* (29.9%) However, the subset that *cannot hear or understand normal speech* has a noticeably higher rate (38.2%) of not being in the labor force.²

In terms of types of occupations, the main distributional difference between those with *normal hearing* and the two hearing trouble groups relates to the blue-collar and service occupations (service, farming, forestry, fishing, precision production, craft and repair occupations.) Approximately 27.1% of those with *normal hearing* were in the blue-collar and service industries compared to 37% of those with *trouble hearing* and 40.2% of those who *cannot not hear and understand normal speech*.²

Education

The proportion of persons over 18 years old and with less than 12 years of education increases as the level of hearing ability decreases. It ranges from 19.7% of those with *no trouble hearing* to 33.1% of those with *trouble hearing* to 44.1% of those who *cannot hear and understand normal speech*. The pattern is in the opposite direction for proportions of persons with greater than 12 years of education, i.e. increasing levels of hearing loss are associated with smaller proportions of persons attending college.²

Limitation of Activity

Differences exist in levels of limitation of activity due to chronic conditions. The NCHS definition reads as follows: “limitation of activity refers to any long term reduction of activity resulting from chronic disease or impairment.” It should be noted that the relationship between chronic limitation and hearing ability is one of association, not necessarily one of causality. The proportion of persons with limited activity increases with decreasing hearing ability. It ranges from 12.3% for those with *normal hearing* to

29.3% (age-adjusted) for those with *trouble hearing* and 49.7% (age-adjusted) for those *who cannot hear and understand normal speech*.²

Summarizing the socio-demographic characteristics mentioned above, the 1991 National Health Interview Survey showed that people who identified themselves as having *trouble hearing* also identified themselves as having a lower income, a greater level of unemployment, less education and more careers in blue collar and service industry jobs than the general population.

Etiology

Hearing loss is a multifactorial disorder caused by genetic and environmental factors.⁸ The incidence of congenital severe to profound deafness in the United States is approximately 1 in 1,000 births, which represents between 2,000 to 4,000 infants born each year. Estimates have it that at least 50% of congenital or early onset deafness has a genetic etiology.⁹ In the past several years, several genes have been identified as being responsible in congenital hearing loss.⁸

Table 2. Causes of Hearing Loss

Cause of Hearing Loss	Percent due to cause (%)
At birth	4.4
Ear injury	4.9
Ear infection	12.2
Loud brief noise	10.3
Other noise	23.4
Getting older	28
Other	16.8
Total	100.0

Adapted from National Center for Health Statistics National Health Interview Survey, Series 101, number 188, table 16, 1994.

However, of the estimated 20 million deaf and hearing-impaired adults in the United States, only 5.6% report the presence of hearing loss before the age of 3 years. Almost 4 out of 5 persons had onset of hearing loss after age 18 years.² Approximately 33.7% report that their loss is due to some sort of noise, (“noise from machinery, aircraft, power tools loud music, appliances, walkman personal stereos, hair dryers, etc.”) 28% that their loss is due to age or “getting older,” while 17.1% report that it is due to infection or injury.¹⁰

Etiology information on Deaf and hearing-impaired *students* is available from the Annual Survey of Hearing Impaired Children and Youth. This survey represents an estimated 60-65% of Deaf and hearing-impaired students who receive special education services.¹⁰ This study revealed that about half (47.4%) of the students had the onset of deafness at birth while a quarter (23.2%) had the onset after birth, with 29.4% with an onset not known/unreported. Of the causes of deafness at birth, heredity tops the list at 13%, while maternal rubella, cytomegalovirus, other pregnancy/birth complications (Rh incompatibility, prematurity, and birth trauma) round out the list. Of the causes of deafness after birth, meningitis is the leading known cause at 8.1%, with otitis media (3.7%), other infections/fever (4.0%), and trauma (0.6%) rounding out the list.¹⁰

Over the past 10-15 years, the incidence of hearing loss due to maternal rubella has decreased significantly, while other reductions are seen for Rh incompatibility, measles, mumps, infections, high fever and trauma. However, the incidence of hearing loss due to meningitis has changed very little, staying at 8.1% of all causes.¹⁰

Deaf Culture

There is a unique Deaf culture in the United States.³ Deafness has a culture-based definition and is differentiated from “hard of hearing” or hearing-impaired.” While the deaf population includes those with any amount of functional hearing loss, the Deaf community (indicated by Deaf with a capital D) refers to a group of individuals that shares a common language (ASL) and a set of beliefs that differs from the white, hearing middle-class norm.³ Simply having hearing impairment does not automatically gain one acceptance into the Deaf community.¹¹ The Deaf community is a “rich and complex social system whose member have common values and shared experiences,”¹ and has “developed and supports its own traditions, values, behavioral expectations and definitions of politeness, social and political organizations, arts, churches, recreational centers, print and electronic publications, and sporting events.”³

As the Deaf culture differs from the mainstream, it has its own unique set of social rules, which sometimes are a source of cross-cultural misunderstanding. As Steinberg (1991) noted, “Non-manual behaviors, such as use of eye contact and physical proximity, attention getting maneuvers, greeting and parting rituals, and concepts of privacy and confidentiality may differ significantly from behaviors in mainstream American culture.”¹

For example, a person signing commonly maintains intense and continual eye contact or may touch a nearby listener.¹ In the Deaf community, acceptable ways of getting another’s attention include touching someone who is close by, stomping one’s foot or banging on a table (ways of communicating through vibrations) and waving a

hand through one's visual field.¹¹ For an unknowing hearing person, these methods may seem inappropriate.

By hearing community standards, conversation-closing in the Deaf community is a prolonged process.¹¹ Because ASL requires face-to-face interactions, which is valued by the Deaf community, the relatively terse "good-bye" used by hearing people, including physicians, may be considered rude by Deaf people.¹¹ Because the Deaf culture emphasizes visual aspects of the world, cultural etiquette is more accepting of physical descriptions of personal characteristics as a means of identifying a person. Aspects such as weight ("overweight," "big,") shape of the nose ("large", "small,") or receding hairline¹¹ are not considered shallow or demeaning when used to identify someone. However, this can be considered rude in the hearing world.

Age of hearing loss

The age of loss of hearing is a reliable predictor for membership in the Deaf community.¹¹ Children who are born deaf or become deaf before the age of language development (about 3 years) usually have difficulty with spoken and written language. They usually learn ASL as their first language.¹² Thus, this group generally becomes members of the Deaf community.

People deafened in adulthood (Late-Deafened Adults, LDA) are more likely to have good English skills and hearing friends. This group is less likely to use ASL and therefore is less likely to belong to the Deaf community.¹¹

Differences in Perspective

While the majority of mainstream America may view deafness as a disability, even as a pathology, the Deaf perspective is that it is a connection to their cultural community,³ “another realization of the human condition.”¹³ As Barnett explains, “Deaf people do not define themselves as having less hearing than the majority, any more than African Americans define themselves as having more pigment than the Caucasian majority.”¹¹

The medical perspective that deafness is a pathologic entity to be corrected may be viewed by the Deaf community as a prejudice,¹³ or a manifestation of paternalism. Because of these opposing views, the issue of cochlear implants is a very controversial one. Some medical professionals see it as a way of “making a child normal” by restoring use of some hearing. However the fact that current implant technology has not been shown to be successful in language acquisition, and for other attitudinal and logistical reasons, the Deaf have opposed cochlear implantation in children.¹³ In fact, it is seen by some as the latest effort by the hearing medical community to eradicate Deaf culture and hearing loss.³

Many Deaf adults have felt oppressed by the hearing community. This perspective has grown from a “lifetime exposure to hearing people who perceive deaf individuals as disabled, impaired, and otherwise undesirable and health care providers who typically focus on the pathology of hearing loss.”³

American Sign Language

American Sign Language (ASL) is the third most common language in the United States.¹¹ It is the primary language of the Deaf community and is recognized by linguists as a proper language.¹¹ Created by Deaf people, it is a linguistically rich visual and gestural, three-dimensional language that relies on facial expressions, body posture, and the space around the signer. This expressive use of body and face, this hyper-affectiveness, can sometimes lead to health care professionals misdiagnosing the Deaf person as having an inappropriate affect, even a mood or personality disorder.¹¹

ASL structure differs so greatly from English that it would be impossible for a person to simultaneously speak English and sign the same content in ASL.⁹ Taken from “Learning ASL” by Padden and Humphries,¹⁴ an example of a conversation in ASL and English is provided below. (The capitalized words in the ASL section indicate a specific sign in ASL.)

ASL:

Alan: HEAR YOU HOSPITAL. HAPPEN?

Dave: YES, I ALMOST HEART ATTACK I. NOT BAD. FINE.

English:

Alan: I heard you were in the hospital. What happened?

Dave: Yes. I almost had a heart attack. It wasn't that bad. I'm fine now.

This vibrant language is inextricably linked to the development and the very fabric of Deaf culture.¹ Indeed, the use of ASL is more important for membership in the Deaf community than the inability to hear.¹¹

Families

Most (approximately 95%) of Deaf marriages involve 2 Deaf people, and 90% of their children are hearing people. If a Deaf person has a hearing spouse or partner, it is likely that that person is fluent in ASL and is a part of the Deaf community.¹¹

Hearing children of Deaf adults often play a bridging role between Deaf and hearing cultures. While the parents use ASL at home with the family and socialize within the Deaf community, the hearing children become fluent in English and have better integration with the hearing culture. As a result, these children often act as interpreters for their families. This bicultural role often continues into adulthood, as it is not uncommon for them to work in a deafness-related field.¹¹

Deaf children of hearing parents face a uniquely different set of challenges. Approximately 90% of deaf children have hearing parents. Since most families do not learn ASL, communication between deaf children and hearing family members is rather limited. Deaf children often learn ASL and about aspects of the deaf community from their peers, often at residential schools instead of from their families. Thus, residential schools and deaf peers play an important role in the culture transmission. Deaf children, while having some connection to their families' culture, often have strong bonds to the Deaf community.¹¹

Modes of Communication

Successful communication with the Deaf patient requires an understanding of the patients' choice of language. Communication options include speech, lip-reading,

writing and sign language, and the optimal mode may be one or a combination of several. I will discuss the merits and limitations of each modality.

Speech and Lip-reading

It is commonly assumed that Deaf persons can understand speech through lip-reading. However, lip-reading is a very difficult skill upon which few Deaf persons can safely rely, especially in the medical setting.¹⁵ Only 30%-40% of English sounds is visible on the lips,^{11,15} and the rest are either invisible or indistinguishable from other sounds. Examples of indistinguishable sounds are “*chew-shoe-Jew-choose-juice-two.*”¹⁵ Obviously, the potential for misunderstanding is great.

Moreover, lip-reading can be extremely tiring as it requires constant, intense monitoring of small, rapidly changing lip patterns and continual guesswork of what is being said. Even the most proficient lip-readers find their effectiveness deteriorate when they are tired or anxious, when the lighting is poor, or when the speaker’s lip patterns are not clear.¹⁵

Some Deaf people communicate by speaking, especially if they received an oral education (which teaches speech.) However, learning to create sounds without ever having heard them is difficult for a Deaf person. While a hearing person can hear sounds and then imitate them and make adjustments, there are no sounds for Deaf people to imitate and thus they lack any immediate feedback of hearing one’s own voice. As a result, their voices may be unmodulated, to which hearing people often react with a surprised and somewhat disapproving look on their faces. This makes some Deaf persons reluctant to use their voices.¹¹

Writing

Writing, though it seems to be a logical and readily accessible alternative for communication, is not without its drawbacks. Because it is a slow and time-consuming process, busy providers are tempted to abbreviate or make fewer comments using pen and paper than when interacting verbally with patients. This can lead to incomplete communication for the patient. A critical limiting factor to the usefulness of writing is that the literacy level of the average Deaf adult is at the 4th or 5th grade.^{11, 15} This decidedly limits the amount of information that can be transferred through writing. Further, it is not uncommon for physicians' handwriting to be illegible. In addition, Deaf patients may feign understanding communication through written notes rather than reveal their deficiencies in English.¹² Clearly, writing is not a perfect mode of communication for Deaf persons.

Professional Interpreters

Serious barriers to effective communication can be overcome by the use of a professional interpreter who can ensure good communication between patients and health care professionals.¹⁶ For Deaf persons who know American Sign Language (ASL), it is the most effective, efficient, and comfortable mode of communication.¹⁵ Therefore, the use of professional interpreters is a highly effective modality. The role of the interpreter is to interpret everything that is said in the Deaf person's presence and does not include editing, counseling, or participating in the conversation. The interpreter may depart from the exact words when using ASL to convey concepts and idioms more accurately and descriptively. Their goal is to convey as accurately as possible the speaker's thoughts, feelings and attitudes, so that the overall message is retained.⁹

Professional interpreters receive certification from either the Registry of Interpreters (RID) or the National Association of the Deaf (NAD), the two major national interpreting certification organizations. The level of certification depends on the interpreter's skill in both ASL and English. Both the NAD and the RID have incorporated into the certification process training of ethics and professional behaviors of interpreters, including confidentiality.⁹ There is additional training in specialized areas for which interpreters may receive a certificate, such as law, performance (arts), and education. Although there is no official certificate for medical interpreting currently, there exists health care-related training for interpreters, such as emergency room procedures and protocol, pharmacology, anatomy and physiology, mental health interpreting, and HIV awareness, to name a few.

Family Member Interpreter

Though it may be tempting to take advantage of a family member, relatives of Deaf persons may not be reliable as interpreters. Confidentiality issues and emotional involvement (lack of objectivity) would mandate caution in such situations. Further, family members may act as information filters, by intentionally or unintentionally omitting, reframing, or rephrasing which results in a poor level of communication.³

Hearing children are often called upon to serve as interpreter for their Deaf parents. It can be difficult to convey information that is beyond their comprehension, particularly if the child is under stress.¹⁷ Here is an illustrative example of the potential dangers of using a child interpreter to convey important information.

“So there I was. I don’t know. Probably five or six. And the doctor is saying “Tell you mother she needs a mastectomy.” I didn’t know how to spell it. [Starts to cry.] And I didn’t even know what it meant. And my mother is looking at me like, “What? What did he say?””³

Legal Issues

Over the past 30 years, there have been two federal laws that have had a profound impact on the Deaf and hearing-impaired community: the Rehabilitation Act of 1973 and the American with Disabilities Act (ADA) of 1990. The Rehabilitation Act of 1973 prohibited discrimination on the basis of disability and required most federally assisted institutions to make their programs and services accessible to people with handicaps, including providing “effective communication” for people with hearing loss.³ The ADA of 1990 extended this prohibition of discrimination to include all services, programs and activities provided or made available by state and local governments, regardless of their receipt of federal financial assistance. It included a section guaranteeing equal access to health care and health education. Health care providers are required to provide aids to the Deaf and hearing-impaired patient, which may include qualified ASL interpreters, note-takers, transcription services, written materials, assistive listening devices, and other services. In terms of expenses, the costs of these accommodations are to be viewed as the general cost of doing business and are not to be billed to the patient.³ The effect of this has been to shift the burden of payment for interpreting and other services to the health care provider.

Specific to Connecticut, the U.S. Department of Justice issued in 1998 a consent decree (consent decrees are monitored and enforced by the Federal court in which they are entered) on the case of the Connecticut Association of the Deaf v. Middlesex

Memorial Hospital. A lawsuit on behalf of several Deaf individuals was brought against 10 acute care hospitals for failing to provide sign language and oral interpreters for persons who are deaf or hearing-impaired. In the end, all of the state's 32 acute care hospitals entered into an agreement with the federal government and with a broad class of deaf and hard-of-hearing individuals to improve hospitals' communication services to deaf patients and the deaf companions of hearing patients. The following guidelines were set forth by the consent decree. The hospitals will:¹⁸

- set up a state-wide on-call system to provide interpreters 24 hours a day, seven days a week, for persons who are deaf or hearing-impaired (the system will respond to most requests in urban areas within an hour, and in rural areas within one hour and fifteen minutes);
- use sign language pictogram flash cards that will be developed by the Department of Justice to assist in communication when sign language interpreters are not available;
- provide TTY s throughout the hospitals public areas and in patient rooms, when requested;
- install visual alarms where audible alarms are provided;
- provide other auxiliary aids and services when necessary for effective communication, including computer assisted real-time transcription services, closed caption decoders for televisions, captioning of hospital-generated videos, qualified notetakers, assistive listening devices and systems, and written materials;
- train employees and volunteers about issues relating to communication with persons who are deaf or hearing-impaired, including special training for emergency department personnel, psychiatric personnel, social workers, and other key personnel;
- offer training to all affiliated physicians; and
- pay \$333,000 in compensation to the named plaintiffs and individuals who filed complaints with the Department of Justice.

To facilitate such communication, Connecticut Hospital Association, representing the 32 hospitals, entered into a contract with Family Services Woodfield (FSW), a Bridgeport family services agency with experience in providing services to the deaf community, to establish a statewide sign language interpreter system. Under the FSW-CHA system, qualified interpreters will be available to hospitals twenty-four hours a day, seven days a week.¹⁹ This consent decree is expected to serve as a model for other states.

Health Care-Related Issues

Illustrative Case (taken from Issues to Consider in Deaf and Hard-of-Hearing Patients)

“A 60-year old deaf woman, a native user of American Sign Language, presented as a new referral. During visits with her previous physician, she had always communicated by using her daughter as an interpreter. The referral physician arranged for a certified interpreter and then called the new patients (using the state’s relay service) to inform her that an interpreter would be present during the office visit. The patient expressed her relief. For the interview, the physician chose a well-lit room and allowed the interpreter and the patient to arranged the seating. The patients appeared to be comfortable and stated her sense of ease with the environment. She then asked her daughter to leave the room. Her chief complaint was rectal bleeding, a symptom that had been present for several months. The patients had not previously discussed the complaint because of embarrassment in the presence of her daughter.”¹³

Despite our powerful technological capability to identify and diagnose deafness, to offer advanced digital hearing aids, and even cochlear implants, to systematize special education and rehabilitation, the health care system is most frequently called upon to provide care for the deaf patient when the patient’s complaint is unrelated to deafness.¹⁵ The doctor-patient relationship is the foundation for high quality health care. As this coveted relationship is based on bilateral communication, the barrier to communication presented by deafness is the single most critical factor affecting health care delivery.¹⁵

This fault rests largely on the poor patient knowledge base, grossly inadequate communication, and provider attitudes and beliefs, and the limitations of our current system.

Patient Knowledge/Literacy

Deaf patients' low level of literacy and relatively small health-related knowledge base presents challenges to the provision of adequate and effective health care. The average deaf high school graduate has a literacy level at the 4th to 5th grade.^{11, 3, 15} In comparison, 15-year-old hearing students have a median literacy level at the 10th grade.⁹ The reasons for this low level of literacy are multifactorial. First, since most hearing parents do not know ASL, deaf children of hearing parents have a delayed language acquisition which profoundly hinders the development of the child. Second, for many Deaf people, English is a second language to American Sign Language, and therefore it can be expected that it would be more difficult to "master" English.

This low level of literacy and poor English skills have a profound effect on an individual's fund of health related knowledge. Low literacy levels preclude acquisition of knowledge from health education publications and from daily newspaper articles.³ This results in a significant decrease in "incidental" gain of health information.

While literacy levels contribute to the low fund of health-related knowledge, there are other reasons as well. One is the relatively decreased quantity of time devoted to health education in residential schooling. Because deaf students often begin elementary school with fewer language skills and a smaller basic knowledge base,⁹ more of the class time is devoted to learning lip-reading, proper voicing and ASL at the sacrifice, of among

other things, reading. Further, students in residential schools tend to receive little or no education in the basic sciences (i.e. biology and anatomy) or general health education.³

A study done by Getch, Young and Denny in 1998 revealed that 13% of respondents (deaf schools) had no formal or established curricula that addressed sexuality education, including sexually transmitted diseases, birth control, substance abuse and appropriate relationships.³

The relative paucity of health information among Deaf students has been studied formally. In one study, age-, gender-, and ability- matched children ages 5 to 15 took the “inside the body” test which was designed to measure children’s perceptions of their internal body. Deaf children at every age named fewer internal body parts than did their hearing counterparts and were less likely to name such large organs as liver or kidney, and other gastrointestinal organs such as intestines.²⁰

In another study, Gibbons used the Goodenough-Harris “Draw a Person” test to compare twenty 8- to 10- year old hearing and congenitally deaf students with regard to their perception of internal body parts. The mean number of body parts named by the hearing group was 9.3 versus 3.0 for the deaf group. ($p < .05$) Hearing children were better than deaf children at identifying bones (100% v. 40%), the brain (100% v. 40%), and the heart (90% v. 70%).²¹

In 1990, Kleinig and Mohay administered a health knowledge questionnaire to 139 hearing and 66 hearing-impaired high school students ages 12 to 18. The areas of knowledge covered included recognition of adverse health-related consequences of behavior, factual health knowledge, awareness of preventative health behavior, response to ill health, drug usage, and knowledge of internal body parts. The results showed that

at all grade levels, hearing students obtained higher scores than hearing-impaired students. However, this difference between the two groups decreased with increasing grade as the hearing-impaired students showed a marked improvement in questionnaire scores.²²

A study of 36 Deaf adults revealed that the vast majority of respondents have a lower health information knowledge base than the hearing population. When asked about personal health facts, only 24% knew the normal body temperature, and 6% knew when it was easiest to get pregnant. When asked about vocabulary words commonly used in health care, words that only a minority of respondents knew include pediatrician (6%), nausea (29%), allergic (50%).²³ Knowledge of medical terminology is thus limited for Deaf persons, and is at a comparable level to non-English speaking immigrants.⁵

Thus, low literacy levels are a concern for Deaf patient for many reasons. It may hinder or preclude understanding printed materials and make it more difficult to communicate with the physician. These poor English skills also make it difficult to write and understand notes between patient and provider, to read and understand prescription instructions, and to read and understand other health related documents.³ This literacy limitation takes on a greater significance in light of the fact that numerous studies have shown that written material presented to hospitalized patients require an average literacy level of at least the 11th grade level.³

Deaf persons' knowledge of their own medical history may also be limited. The health care discussions between parent and physician may occur in the presence of the deaf child, but the child may not understand or have explained the meaning. As adults, it is not unusual for them to have to write their parents or a school official for their past

medical history.¹⁵ This limited knowledge base has serious impact on provider information gathering.

Provider Perspective

Even if the deaf patient finds the wherewithal to access the physician's office, there will still be obstacles to face. Most of the education and training a medical physician receives focuses on the audiologic and pathologic aspects of hearing loss – etiology, detection, treatment. Little attention is given to the cultural and developmental aspects of deafness, knowledge that would facilitate successful communication.¹³ As a result, most providers do not appreciate the communication needs and preferences of Deaf individuals and tend to make assumptions about lip-reading, the efficacy of written notes, and English literacy levels.³

In a recent survey study of physicians regarding their experiences with deaf patients, Ebert and Heckerling found that writing was the most common form of communication with deaf patients (34%). Though almost two-thirds (63%) of physicians knew that signing should be the initial form of communication, less than a quarter (22%) used ASL interpreters. Usage of ASL interpreters was associated with a belief that signing should be the initial method of communication with deaf patients ($p=0.04$) and knowledge that lip-reading has limited effectiveness ($p=0.04$). The authors of this study comment that their study provides evidence that physicians' knowledge and beliefs regarding deaf people may influence their patterns of communication with deaf patients.²⁴ This study suggests that a deaf patient may have sub-optimal communication and consequently care in a significant percentage of their encounters with physicians.

Another survey study investigated physician's attitudes, communication techniques, and knowledge of deaf patients. Survey questionnaires were distributed to physicians; one version asked about patients in general and the other asked specifically about deaf patients. It was found that physicians reported significantly greater difficulties communicating with and different attitudes toward deaf patients compared to physicians surveyed about their patients in general. Specifically, physicians completing the questionnaire focusing on deaf patients reported greater difficulty in understanding their deaf patients and that these patients had more difficulty in understanding them ($p < .001$), trusted them less ($p < .001$), and were less likely to understand the diagnosis and treatments ($p < .001$). Further, physicians themselves reported feeling less comfortable with deaf patients ($p < .001$) and that their deaf patients asked fewer questions (than their hearing counterparts.)²⁵

Patient Experiences

Several studies have shed some light on the experiences of Deaf persons and the health care system. In a 1980 survey of health problems and experiences of Deaf people, Schein and Delk found that patients reported that they fail to understand almost 1/3 of what the hospital staff try to convey to them. The most common form of communication was writing, in both the inpatient and outpatient setting.⁴

The two most common problems noted by the Deaf respondents regarding their health care experiences were that writing back and forth became tiring and that they did not understand what was being said. These numbers take on more significance given that greater than 60% of the respondents had attended at least one year of college.⁴ Given that

this level of education is not representative of the Deaf population at large, it is logical to assume that less-educated persons would have poorer communication.

In a 1988 study, McEwen compared age- and education level- matched ESL (English as a second language) students with Deaf participants in terms of their communication patterns with health professionals. Compared to the ESL subjects, Deaf subjects were less likely to be able to speak to a physician in their language of greatest fluency. Further, though there was no significant difference between the Deaf and ESL students in terms of their knowledge of commonly used medical terms, the results indicate that the knowledge is limited. For example, fewer than 50% could identify the meaning of gallbladder, stools, sober, anxiety, erection, or nausea. Another key finding was that Deaf test participants more frequently felt that their physician did not understand them and they less frequently tried to re-explain themselves compared to the ESL participants.⁵ The authors proposed the following reasoning: “if a deaf patient must rely on English more often, because few physicians know how to use sign language, it is reasonable that deaf patients should feel there is a greater problem in communication.”⁵

A study by Lass, Bertrand and Baker examined the level of health knowledge, attitudes and practices of a Deaf population. When tests on words routinely asked in a medical history, the average respondent was unable to give a correct definition for six out of sixteen vocabulary words (i.e. pediatrician, surgeon, psychiatrist, nausea, allergic, fever, dizzy, etc.) The study also asked about knowledge of proper responses to medical conditions and the answers were evaluated by trained medical personnel to determine which responses were appropriate. Less than half of the respondents were able to give the appropriate response to “experience hallucinations” and “experiencing chest pain.”²³

A study by Zazove, et al. found that, compared to hearing persons, Deaf and hearing-impaired have more difficulties communicating with physicians, have trouble understanding physicians, and feel less comfortable with physicians.⁶ This study's rate of professional interpreters utilization was 18%, even though most subjects had profound hearing loss. It was postulated that the low usage was due to the unavailability of interpreters.

PART 2.

Study Rationale/Specific Aims

Hearing loss is one of the most prevalent chronic physical conditions in the United States. According to several studies, the rate of professional sign language interpreter utilization ranges from 6.3% to 33%.^{4, 6, 23} While one study posited access barriers as contributing to the low rate, there has not been a report of the reasons accounting for this low rate of utilization of professional interpreters.

In this study, I will examine the health care access behaviors of the Deaf and hearing-impaired community in Connecticut. With whom do the patients visit the doctor? What modes of communication do they use? From the results of my pilot study, I learned that most Deaf respondents visited the doctor alone and only a small minority used a professional interpreter. Thus, I explore the explanations for this. Why don't all Deaf patients use professional interpreters? Is it a matter of personal preference or are there systemic barriers or other factors? Is it a function of the Deaf culture? How much of what the doctor says do they understand? How satisfied are they with their care?

Additionally, there has not been a formal collection of data on Connecticut's Deaf and hearing-impaired community. Thus, I tightly collaborate with the Commission for the Deaf and Hearing Impaired (CDHI) in this project and intend to present the findings to directly inform CDHI policy.

Materials and Methods

Questionnaire Development

A review of the medical, health care professions, and deaf establishment literature was conducted on the current health services utilization characteristics of the Deaf and hearing-impaired community, with particular attention to the utilization of professional American Sign Language (ASL) interpreters.

University of Connecticut Health Center IRB approval for the study was obtained. A survey instrument was developed that contained 19 questions that mirrored those in the literature. A draft was presented to both hearing and Deaf officials at the Connecticut Commission for the Deaf and Hearing Impaired (CDHI) and, based on feedback, modifications were made to the survey instrument to improve wording and grouping of questions for clarity. This pilot survey instrument was mailed to 36 addresses systematically selected (every 5th name, starting with names beginning with the letter “A”) from the Connecticut Text Telephone Directory, 1999 Edition, published yearly by Converse Communication Corporation. Converse Communications is a private company that loans telecommunication devices for the deaf (TDD’s) to Deaf and hearing-impaired persons at no cost and sells various models of TDD’s to others who are interested in having one (i.e. family members, friends, co-workers.) Anyone who borrows or buys a TDD is listed in this directory, and they are given the option at the time of initially borrowing or buying to have their name be unlisted. This TDD directory is free of charge and, as the only such directory in the state, is considered the most comprehensive list of names and addresses of (TDD) users in Connecticut.

The pilot study response rate was 33% (12/36). Initial data from the pilot study indicated that most Deaf respondents visited the doctor alone, a minority of them utilized a professional interpreter and a majority found it difficult to get an interpreter. Revisions to the survey instrument included creating a question that addressed reasons for not using a professional interpreter, rearranging the order of the questions to lessen apparent confusion and deleting a question that was redundant, and adding two questions to assess awareness of legal rights. These revisions were made in consultation with officials at the CDHI.

The final survey instrument asked respondents about their demographics, characteristics of their hearing loss (questions [q.] 4, 5), health care experiences (q. 8, 9, 10, 11), health care access behaviors (q. 12, 13, 14, 15, 16), level of satisfaction with health care (q. 17), rating of communication abilities (q 20), and amount of understanding (q 21). The final survey instrument was sent by mail to a systematic sample of 600 entries from the directory, starting from where the pilot study ended and selecting every 5th name. Each survey instrument was accompanied by a cover letter introducing myself and explaining the purpose of the study. An addressed, stamped envelope for response was included.

Consideration was given to the option of conducting the survey in ASL, either through the usage of trained ASL-competent interviewers or the interactive video questionnaire (IVQ).²⁶ However, financial and logistical constraints dictated the usage of a mailed, written, English survey. The final survey instrument was 5 pages long and was expected to take 5 to 10 minutes to complete. (see appendix A)

Definitions

Responses to the question regarding age of onset of hearing loss were used to classify respondents as either culturally Deaf or late-deafened adults (LDA), as membership in the Deaf community can usually be predicted by this variable.¹¹

The Deaf group is comprised of those who reported losing their hearing either at birth or before the age of three. They can be considered pre-lingually deaf, and are very likely to belong to the Deaf community. As members of the Deaf community, it is likely this group uses American Sign Language as its primary language, socializes mainly among the Deaf community, and has its own unique cultural traditions, values and social rules.

The LDA group is a distinctly different cohort and is comprised of respondents who reported losing their hearing after the age of 18 years. They can be considered post-vocationally deaf and are very likely to have identified with hearing society through upbringing, schooling and social connections. They are more likely to have good English skills, speaking ability, and more likely to have hearing friends and a hearing spouse or partner.¹¹ As “late deafened adults,” they are usually unable to understand speech without visual aids such as speech-reading, sign language, and/or Computer Aided Real-time Transcription (CART). LDAs also can share in the common experience of having been raised in the hearing world and having become deaf rather than having been born deaf.²⁷

These two groups, the culturally Deaf group and the late deafened adult group, are the two groups that I will use for most comparisons in this paper. The 35 respondents who reported losing their hearing between the ages of 4 to 11 and 12 to 18 were not

included in the data analysis of comparisons as their community membership is unclear. These children may have been “mainstreamed,” in which case they would have been educated in local public schools and not in Deaf residential schools. Persons with residual hearing and those who lost their hearing in childhood may have received an “oral” education, which teaches English, reading, writing, lip-reading and speech *without* using American Sign Language. Lastly, they may have received a “bilingual, bicultural” education, in which ASL and English are taught as first and second languages respectively.¹³ Thus, because of the potential for various types of schooling, one can not be certain of these respondents’ cultural membership.

The inclusion criteria were as follows: the participant must be a) Deaf or hearing-impaired, b) over 18 years of age and c) a resident of Connecticut at the time of survey. The exclusion criteria were as follows: the participant must not be a) hearing and b) less than 18 years of age.

Data Analysis

After an initial descriptive analysis, differences between culturally Deaf and “late deafened adults” (LDAs) regarding health care access behaviors, modes of communication, levels of understanding were tested using chi-square analysis and Fisher’s exact test where appropriate for differences in proportions. A two-sided level of $p < 0.05$ was considered significant.

Results

A total of 600 survey instruments were mailed in conjunction with the Connecticut Commission for the Deaf and Hearing Impaired. Six (6) were returned due to delivery to the wrong address. 207 (207/594 = 34.8%) questionnaires were returned, and 190 satisfied the inclusion criteria (190/594 = 32.0%).

Table 3. Sample Demographics

Variable	All (n=190)	Culturally Deaf ^a (n=127)	LDA ^b (n=28)	P
Average Age (s.d.)	50 (16.4)	47.4 (15.1)	55.4 (17.0)	
Male, %	40.5%	43.3%	21.4%	0.032
Caucasian*, %	91.6%	92.1%	92.9%	0.887
Marital Status				
Single	28.4%	32.3%	17.9%	0.011
Married	45.8%	50.4%	39.3%	
Divorced/Widowed	25.3%	17.3%	42.9%	
Education				
Less than 9 th grade	7.4%	7.9%	7.4%	0.385
Some high school	12.7%	11.8%	11.1%	
High school graduate	29.1%	33.1%	14.8%	
Some college	22.8%	23.6%	33.3%	
College graduate	28.0%	23.6%	33.3%	

*African American 2.6%, American Indian 1.1%, Asian American 0.6%, Hispanic/Puerto Rican 3.7% (for all)

^a reported loss of hearing at birth or before the age of 3 years.

^b reported loss of hearing after age of 18 years.

Table 3 shows the demographic characteristics of the respondents. The average age of the Deaf respondents was 8 years less than that of the LDAs and they were more likely to be male. In terms of marital status, over one-half of the Deaf respondents were married, and approximately a third were single compared to almost 40% of the LDA respondents being married and only 17.9% being single. It is noteworthy that, overall, 69.9% of the respondents reported having at least a high school diploma. There was no statistically significant difference in the education levels between groups.

There were *no statistically significant differences* between Deaf and LDA groups in the following categories: type of physician visited, last visit to physician, number of visits in past year, setting of visit, levels of satisfaction.

Table 4. Patients' Hearing Status

Age of hearing loss	Number (%)
At birth	90 (47.4)
Under 3 years of age	37 (19.5)
Between 4 and 11 years of age	25 (13.2)
Between 12 and 18 years of age	10 (5.3)
19 or older	28 (14.7)
Total	190 (100.1)

Percentage exceeds 100 due to rounding.

Table 4 summarizes patients' hearing status. Approximately 2/3 (66.9%) of the respondents reported having lost their hearing before the age of 3 years, and thus can be considered "pre-lingually deaf"¹¹ and will be referred to as "Culturally Deaf". Almost 15% of the respondents reported losing their hearing after the age of 19, and thus can be considered "post-lingually deaf" or "post-vocationally deaf" and will be referred to as the Late Deafened Adult (LDA) group. Those reporting onset of hearing loss between the ages of 4 to 11 years and 12 to 18 years will not be included in either subgroup for reasons described in the data management section.

Table 5. With whom respondents visited the doctor

All (n=190)		Culturally Deaf (n=127)	LDA (n=28)	P*
Alone	61.1%	57.5%	64.3%	0.048
With Professional Interpreter	12.1%	17.3%	0%	
With Family Member	23.2%	22%	32.1%	
With Hearing Friend/Other	3.7%	3.2%	3.6%	

*Fisher's exact test.

Table 5 summarizes the health care access behaviors of the respondents. The “hearing friend” and “other” cells were collapsed due to low frequencies. Fisher's exact test was used for analysis due to low expected cell counts. Overall, 61.1% of the respondents reported visiting the doctor alone for more than half of their visits. Significant differences existed between Culturally Deaf and LDA respondents with regard to their health care access behaviors. Notably, 17.3% of the Deaf respondents reported using a professional interpreter compared to no LDAs. This difference in professional interpreter utilization is likely to account for the statistical significance, as the differences in the other categories are lower. Overall and within groups, more persons used family members as interpreters than professional interpreters.

Table 6. Modes of Communication.

Modes of communication	Culturally Deaf (n=127)	LDA (n=27)	P
Professional interpreter	22.0%	3.7%	.027
Family member interpreter	21.3%	22.2%	.912
Friend interpreter	2.4%	3.7%	.691
Writing	51.2%	25.9%	.017
Lip-reading	54.3%	55.6%	.908
Gestures	22.6%	14.8%	.826

Percentages exceed 100 as multiple responses were allowed.

Table 6 summarizes the usage of modes of communication. (See question 13 in appendix A.) Among all respondents, writing and lip-reading were the two most commonly used modes of communication. In comparing the Deaf and LDA groups, there were statistically significant different rates of usage of professional interpreters (22% v. 3.7%, $p < .027$) and writing (51.2% v. 25.9%, $p < .0017$). There was no statistical difference in usage of family member interpreters, friend interpreters and gestures between the two groups.

Table 7. Reasons why did not use a professional interpreter

Reason	Number (%)
Prefer to go alone	43 (24.9)
Don't have money for interpreter	30 (16.4)
Too much hassle to get interpreter	24 (12.7)
Dr. won't provide interpreter	22 (11.6)
Don't feel comfortable with interpreter	19 (10.1)
Prefer to write	18 (9.5)
Don't know how to get interpreter	14 (7.4)
Don't trust an interpreter	5 (2.6)
Other	42 (22.2)

Percentages exceed 100 as multiple responses were allowed.

Table 7 summarizes the reasons why deaf persons did not utilize a professional interpreter. Respondents were allowed to mark more than one response. Approximately one quarter (24.9%) of the respondents reported that they prefer to go alone as the primary reason they chose not to use a professional interpreter. Significant percentages of respondents indicated “not having enough money to pay for interpreter” (16.4%), “too much hassle getting interpreter” (12.7%) and “doctor won't provide interpreter” (11.6%) as their main reasons. Almost 10% reported a preference of writing as their reason.

There were no statistically significant differences in responses between Deaf and LDA groups. (Data not shown.)

More than one tenth (12.7%) of the respondents indicated personal reasons for not utilizing an interpreter. About 10% (10.1%) reported “not feeling comfortable with an interpreter” and a small percentage (2.6%) indicated “not trusting an interpreter.”

Table 8. Understanding, by Groups

	Culturally Deaf (n=126)	LDA (n=27)	P
Understands doctor			.102
High level	53.2%	70.4%	
Low level	46.8%	29.6%	
Doctor understands			.034
High level	44.4%	77.8%	
Low level	55.6%	22.2%	

Table 8 summarizes the differences between the Deaf and LDA respondents in terms of their understanding of what their doctor says and their doctor’s understanding of what they try to communicate. Due to low frequencies, two intervals (high and low) were created for “understanding the doctor” and “doctor understands you.” There is a statistically significant difference in the doctors’ levels of understanding between the Deaf and LDA groups. Almost four-fifths (77.8%) of the LDA respondents reported high levels of understanding as compared to less than half (44.4%) of the Deaf group ($p<.034$). However, there was only a non-significant trend between groups in how much they understood the doctors. (70.4% v. 53.2%, $p<.102$)

Table 9. How Hard to Get Interpreter, Deaf Group

Response	Number (%) (n=71)*
Very difficult	16 (22.5)
Difficult	22 (31.3)
Okay	21 (30.0)
Easy	6 (8.9)
Very Easy	6 (8.9)

*Percentages reflect only those who chose to answer this question.

Table 9 summarizes the level of difficulty in obtaining the services of a professional interpreter for Deaf respondents. Over half of the respondents (53.8%) rated it “very difficult” or “difficult” to get an interpreter, while only 17.8% rated it “easy “ or “very easy.” It is of note that 80 of the 155 persons responded that the question did not apply to them. Thus, this subset of respondents includes only those Deaf respondents who did indeed report trying to utilize a professional interpreter.

Table 10. Levels of Understanding by Hearing Status

	Culturally Deaf		LDA		P*
	High Understander (n=59)	Low Understander (n=65)	High Understander (n=7)	Low Understander (n=19)	
Lipreading					.0019
High	66.2%	33.9%	52.6%	28.6%	
Low	33.8%	66.1%	47.4%	71.4%	
Speech					.0006
High	53.8%	32.2%	83.3%	62.5%	
Low	46.2%	67.8%	16.7%	37.5%	
Writing English					.0063
High	86.3%	64.4%	94.4%	71.4%	
Low	13.8%	35.6%	5.6%	28.6%	
Satisfaction					.0001
High	88.1%	42.4%	72.2%	50.0%	
Low	11.9%	57.6%	27.8%	50.0%	

*Fisher's exact test

Table 10 shows the differences in proficiency of communication and satisfaction between groups by understanding levels. Due to low frequencies, cells were collapsed to create two intervals in understanding and communication abilities, high and low. Significant differences between Deaf high and low understanders exist with regard to their self-rating of communication abilities. Deaf high understanders were more likely than Deaf low understanders to highly rate their ability to lip-read (66.2% v. 33.9%, $p=.0019$), to speak (53.8% v. 32.2%, $p=.0006$), and write English (86.3% v. 64.4%, $p=.0063$).

Regarding satisfaction levels with the health care they received, Deaf respondents with high levels of understanding were more likely to be highly satisfied than those with low understanding. (88.1% v. 42.4%, $p=0.001$).

There were no statistically significant differences for comparison of professional interpreter, family member interpreter, visiting the doctor, education level and gesturing.

Discussion

Response rate/Demographics

The 34.5% response rate is in line with what the pilot study suggested. Data was not collected on non-responders. A second mailing was not employed. The response rate may have been somewhat low due to the fact that the questionnaire was written in English, which some culturally Deaf persons may not have been able to read. Several agencies for the deaf contacted the investigator indicating that they assisted several deaf clients in filling out the survey instrument.

Compared to the U.S Department of Health and Human Services 1991 census report, our respondent group had a lower proportion of persons with less than 12 years of education (19.7% v. 44.1%).² This indicates a more highly educated respondent group. According to the NHIS, persons with early onset hearing trouble are more likely to have never been married than are those with later onset.² Our marital status data reflect similar trends.

Hearing Status

The proportions of hearing status are not surprising given that our sample was drawn from a publicly available directory of those who have tele communication devices for the Deaf (TDDs). The deaf community commonly uses TDDs as an effective means

of communicating. The self-reported age of hearing loss was consistent with self-reported ratings of proficiency in American Sign Language (ASL), which suggests that the questions accurately reflected “hearing status.” (data not shown)

Based on the literature,¹¹ those who lose their hearing prelingually (i.e. before the age of 3) are more likely to be culturally deaf than those who lose their hearing after the acquisition of language. Thus, approximately 2/3 of the respondents can be considered culturally deaf. 14.7% of the respondents can be considered “late-deafened adults” (LDAs) by virtue of the age of onset of deafness and are predicted to have a “hearing” identity, few ASL skills and little affiliation with the deaf community.¹¹

Health Care Access Behaviors

The Deaf community exists as a separate minority culture in America, a fact that is rarely appreciated by the majority of hearing persons.^{6, 11} The health care system is most frequently called upon to provide care for the deaf patient when the patient’s complaint is unrelated to deafness.¹⁵ Thus, the barrier to communication presented by deafness is the single most critical factor affecting health care delivery.¹⁵

According to the U.S. Department of Health and Human Services 1991 Census report, “persons with trouble hearing had proportionately more annual bed days because of health problems, more annual doctor visits, and greater limitation of activity due to chronic conditions, than persons with normal hearing had.”³

Connecticut has a unique cultural and political landscape in terms of services for the Deaf and hearing impaired. In 1974, the Connecticut Commission for the Deaf and Hearing Impaired (CDHI) was established by state law and became the first successful

commission on the deaf in the nation. It has since served as a model for other states due to its unique services.²⁸ Family Services Woodfield (FSW), a community-based human services agency that has a community Sign Language Service, is the state's largest provider of medical sign language interpreting services. The 1998 Consent Decree has mandated that all designated hospitals need to contact FSW when they need an interpreter for scheduled outpatient appointments, hospital stays, and emergencies. Thus, Connecticut has institutional support services for the Deaf and hard-of-hearing community.

Further, the presence of the preeminent American School for the Deaf (ASD) also serves to attract a sizeable Deaf community and to raise the local and state community's awareness of deafness. Founded in 1817 by Thomas Hopkins Gallaudet and Laurent Clerc, two icons of Deaf education and culture, the American School for the Deaf is the oldest school for the deaf in the United States, and the oldest special education institution of any kind in the Western Hemisphere.²⁹

A growing number of recent legislative rulings have supported the rights of some deaf patients to be provided with a professional interpreter in both the inpatient and outpatient settings.³ Specific to Connecticut, the U.S. Department of Justice instituted the "Consent Decree" that mandates designated hospitals in Connecticut to provide interpreters in medical situations.

Against this cultural and political landscape of an established Deaf community and state-supported services, it was hypothesized that the rate of professional interpreter utilization would be higher than that previously reported in the literature.

In this study, the majority of Deaf patients visited the doctor alone (57.5%) and less than one-fifth (17.3%) of Deaf patients utilized a professional interpreter for most of their appointments. This number is consistent with previous studies that indicated between 6.3% and 33% of Deaf patients utilized a professional interpreter.^{4, 6, 23} In one study by Zazove et al., the study's 18% utilization rate of professional interpreters was postulated to be due to their unavailability, based on a report by the Division of Deafness of the Michigan Department of Labor that 50% of deaf people in that state have trouble getting an interpreter when needed.⁶ However, no questions were included in the survey instrument that directly asked about the reasons for not using an interpreter.

Several factors may explain this relatively low rate of 17.3%. First, this rate may reflect the response bias of the study. In lieu of the 4th grade reading level of the survey and of the 4th or 5th grade reading level of the average Deaf adult,^{30, 6} there may have been persons who read below this level and therefore were not able to complete the questionnaire. Our respondent group may have over-representation of Deaf persons who were more highly educated and more highly functional in the hearing world than the Deaf non-responders. This group may be more independent and less inclined to use interpreters. This may be reflected by the data that show that a quarter of those who did not use an interpreter (24.9%) cited that they "preferred to go alone" as their reason for not utilizing one and another 9.5% cited that they "preferred to write."

As indicated in table 9, of those who actually tried to get an interpreter, over half (53.8%) said that it was difficult to get an interpreter. This may represent general systemic barriers to access such as lack of public knowledge, provider refusal to request an interpreter, scheduling difficulties or limited interpreter availability. In any case it

paints the picture that there may be some degree of difficulty inherent in the interpreter-requesting process.

Several specific systemic barriers may also contribute to the relatively low levels of professional interpreter usage. Four responses that accounted for about one-half (48.1%) of the responses can be grouped as systemic barriers. The responses are “doctor won’t provide interpreter” (11.6%), “don’t have money to pay for an interpreter” (16.4%), “too much hassle to get interpreter” (12.7%), and “don’t know how to get interpreter” (7.4%). Each response will be discussed.

The response “Dr. won’t provide interpreter” may reflect actual practice, even though there may be legal reason to address Deaf health care. The Americans with Disabilities Act states that the service provider is responsible for the provision of accessibility, which, in the case of a Deaf or hearing-impaired person, means accessible communication. It does not specifically state an American Sign Language interpreter, but does state auxiliary aids (i.e. laptops, assistive listening devices, computer-assisted real time transcription services.)

However, several factors may play a role in the physicians’ reluctance to utilize a professional interpreter. Many physicians do not know how to access or hire an appropriate and qualified interpreter.³ Moreover, the health care providers’ ignorance or prejudice may play a role. Providers may not understand the extent of the communication barriers and therefore not perceive a true need for a professional interpreter.³ They may think that writing and lip-reading are equally effective modes of communication. A study by Ebert, et al. showed that a belief that communication by signing was the best means of communication and knowledge of the inefficiency of lip-

reading were significant predictors of the use of sign language interpreters for Deaf patients.²⁴ However, just knowing that signing should be the initial form of communication does not ensure usage of an interpreter. That same study showed that although 63% of physicians knew that signing should be the initial form of communication, only 22% used sign language interpreters more frequently than other modes.²⁴

Expense may be another important factor in deterring physicians from using interpreters.²⁵ In Connecticut, the FSW interpreting services charges \$41 per hour with a minimum of 2 hours to be scheduled for a normal visit and \$60 per hour for emergency visits (less than one business day's notice.) The CDHI interpreters are paid approximately \$28 per hour with a 2-hour minimum. The rate is contingent upon type of certification held and length of employment. CDHI interpreters are paid on a portal to portal basis, for both time and mileage.³¹ Clearly, it is not an insignificant expense to the provider, and may discourage the physician from requesting an interpreter.

An effect of the ADA has been to shift the burden of paying for the interpreter from the state-supported agencies to the checkbooks of providers, some physicians may feel that hiring an interpreter is an expensive luxury.³ Indeed, 9.7% of the respondents cited “doctor won’t provide interpreter” as their reason for not utilizing one.

The two responses “don’t have money to pay for an interpreter” and “don’t know how to get an interpreter” may reflect the interaction of a paucity of public knowledge and providers’ attitudes and practices. Not knowing how to get an interpreter may simply reflect a lack of public knowledge of how to access one. It is possible that the respondents do not know if they are supposed to call, if the doctor will, or even that they

don't know the TDD number to call. Those who reported not having enough money to pay for an interpreter may not be aware of their rights under the ADA to free access to interpreting services. To what degree the responsibility for educating the public and providers lies on the CDHI and other such agencies is a matter of debate. What is known is that almost a quarter (23.8%) of the respondents who did not use a professional interpreter reported a lack of knowledge availability of free services or how to access these services.

More than one tenth (12.7%) of the respondents indicated interpreter-related reasons for not utilizing an interpreter. About 10% (10.1%) reported “not feeling comfortable with an interpreter” and a small percentage (2.6%) indicated “not trusting an interpreter.” As the Deaf community is close with frequent social interaction, it is expected that it would have a strong grapevine. Concern about the confidentiality and privacy of family and emotional problems may make some Deaf patients reluctant to “expose their problems to an interpreter.” Although the interpreters are trained to maintain confidentiality, many interpreters are well known and a part of the Deaf community.¹⁷ This dynamic is likely to be responsible for these 12.7% of the responses.

The wording of the question (for more than 50% of your visits) allowed for the possibility that some patients did indeed use an interpreter some times, as in emergencies or very important visits. This may have led to an under-reporting of actual professional interpreter utilization rates. Several respondents comment on the survey that if it were really serious and they had to understand every detail, they would get an interpreter. The following are examples:

“I can understand the doctor, but will call if I knew there will be difficulty lip-reading.”

“I’d request one if medical problem is serious.”

“Will use an interpreter if I were to need a serious surgery. In that case, I’d need 100% understanding of the procedure.”

This low rate of professional interpreter usage may play a role in the communication barrier,^{32, 6} though this remains controversial. Also, the effect of using a professional interpreter on health care outcomes is not clear. However, if it is the patient’s preferred mode of communication, then an ASL interpreter is likely to enhance the quality of care, if not for the patient, at least for the doctor, who would be able to take a better history, explain diagnoses and answer questions.

A recent study by MacKinney, et al. lends credence to the hypothesis that use of ASL interpreters is a major factor contributing to improved subjective and objective health care outcomes. A case-cohort study of 90 cases and 85 controls was drawn from the Deaf Services Program (DSP) in Baltimore. Cases were Deaf patients enrolled in the DSP and controls were case-referred Deaf friends living in the community but not receiving services at DSP. The DSP, which serves more than 800 of the estimated 10,000 deaf persons in Baltimore, provides full time professional interpreters for participating patients and offices.¹²

For the preventative care outcomes, the results showed that Deaf female cases were more likely to have received Pap tests (cervical cancer screening, OR=3.5, C.I. 1.0-13) and mammography (breast cancer screening, OR= 6.0, C.I. 1.1-37) within the prior three years than the female controls and Deaf male cases were more likely to have received rectal exams (colon cancer screening, OR=7.6, C.I., 1.4-48) than the male controls.¹²

As far as communication outcomes, the cases were much more likely to use a professional interpreter as their primary means of communication for ambulatory visits. While 84% of the cases primarily used an interpreter and only 6% used note writing, only 20% of the controls used interpreters while 67% used note writing. Not surprisingly, the cases reported much greater satisfaction with their communication with their physicians. (92% v. 42%, $p < .0001$.)¹²

In sum, the rate of professional interpreters was lower than expected. Respondent reasons for not utilizing an interpreter shed light on the patterns of health care access behaviors. The reasons included systemic barriers, provider reluctance, personal preferences and limited availability. The 2 most commonly used modes of communication were writing and lip-reading.

Understanding/Satisfaction

Significant differences in communication abilities exist between Deaf high understanders and Deaf low understanders. High understanders were more likely to report high abilities in lip-reading, speech, and writing English. As writing is the most common form of communication between Deaf patients and physicians in medical encounters,²⁴ it is not surprising that those who are proficient with written English would understand more of what their doctors tell them. It makes sense that better communication results in higher levels of understanding.

A study by Alice Nemon examined characteristics of the relationship between Deaf patients and their doctors. Those with good English language skills often brought written prepared lists of symptoms and questions to save time and prevent

misunderstanding, and preferred that the doctor write answers and instructions. This may help explain higher levels of understanding. Deaf patients like to use written notes as their personal record. Persons with minimal language skills are frequently embarrassed to reveal their deficiencies in written English,¹⁷ which may further hinder communication for those with poor communication abilities.

High understanders were also more likely than low understanders to be highly satisfied with their health care. Satisfaction and dissatisfaction usually center around sufficiency of information received.¹⁷ In one study, participants who had more health problems and believed that they received sufficient information felt more satisfaction and less worried than those who felt they received insufficient information.¹⁷ In this study, it may be that those with superior communication modalities can understand more and therefore report being more satisfied.

Compared to LDAs, culturally Deaf respondents had lower levels of understanding overall. They reported lower levels of understanding of what the doctor told them (53.2% v. 70.4%, $p < .102$) and reported that their doctors understood less of what they tried to communicate (44.4% v. 77.8%, $p < .034$). This difference may be due to the fact that LDAs are more likely to have speaking ability and good literacy and English skills.

Limitations

This study has several limitations. As with any mailed survey instrument, there can be a tendency to provide the normative answer. Thus, levels of satisfaction and understanding may be falsely elevated, which means that the Deaf and hearing-impaired

population may actually have lower levels of understanding and satisfaction than this study suggests.

Since data were not collected on non-responders, we do not know with what population we are dealing. The survey literature indicates that, in mail surveys, Deaf respondents are socio-economically better off than are non-responders³³ and are better educated than the average Deaf individual.³ Because our results are not readily generalizable, a major implication is that the lower socio-economic classes of Deaf persons may face even more barriers to access of health care. Further, as most of the respondents in the study were white, these results may not be applicable to persons of color.

The author is aware of the linguistic/cultural barriers inherent in using an English survey instrument in the deaf community. Consideration was given to the use of an interactive video questionnaire as described in the literature, but time-related, financial and logistical factors dictated the use of a mailed, English survey instrument. Because English may be a second language for some, a written English survey may not have been as effective as an ASL-administered questionnaire at collecting data. The survey may not have tested the respondents on the comprehension of words, but rather on the words themselves, and on their ability to express themselves in English.

Conclusions

This study confirms other reports that deaf and hearing-impaired patients experience barriers to communication in dealing with the health care system. Relative to the author's hypothesis of a professional interpreter utilization rate higher than what has

been reported, Deaf patients had a surprisingly low rate of 17.3%. Personal preference, systemic barriers, interpreter-related reasons may have played a role in limited utilization of interpreters. High levels of understanding seem to be associated with better communication skills and with higher levels of satisfaction.

Thousands of deaf and hearing-impaired individuals lag behind their hearing counterparts in terms of health status, access and utilization of health care services. Connecticut has both the presence of an established Deaf community and the longstanding support of state agencies. Efforts aimed at health care providers, consumers, and advocates should be made to improve the accessibility of professional interpreters.

Recommendations

Institutions

In lieu of the negative impact the ADA seems to have had on the services for the Deaf, especially in regards to the financial “burden” on providers, measures to remedy this should be investigated. It has been proposed that coverage of interpreters’ fees by health insurance companies be negotiated by a state-level committee comprised of Deaf leaders, Registry of the Deaf for deaf interpreter chapters, and other public agencies.²⁴ The state legislature should find ways to address the prohibitively expensive cost of interpreting services for the individual provider, especially for private practices.

A program to address cost to the physician and accessibility of interpreters could be modeled after the Deaf Services Program, a primary health care delivery system for

Deaf patients. Because many physicians may only care for a few Deaf patients, a centralized program may be more cost-effective, convenient, and accountable than attempting to arrange for interpreters on demand. This would minimize the negative effect of cost on interpreter usage and therefore increase accessibility.¹²

To address the systemic barriers, organizations such as the CDHI and the FSW should ensure that the interpreter-requesting process is as simple and uncomplicated as possible. This would benefit both the patient and provider. Efforts should be made to raise public awareness of their right to free interpreting services and provider awareness of their responsibilities under the ADA.

Community Efforts

Physicians and other medical professionals should have an understanding of the cross-cultural and linguistic barriers that may affect the provision of health care. Public education campaigns aimed at providers and providers-in-training and Deaf and hearing-impaired patients should be undertaken. Understanding and learning about the cultural aspects of Deafness is important to primary care clinicians for several reasons. First, as the impact of the ADA and other legal rulings translates into better access to health care for Deaf patients, clinicians will encounter them more frequently. Further, as a substantial portion of the Deaf community that was deafened in utero as the result of the rubella pandemic of 1964, it is likely that they will seek age-related health care as they continue to age. By learning about the Deaf culture, medical professionals can gain cultural awareness and a better appreciation of human diversity.¹¹

As residents and physicians often carry very demanding patient care responsibilities, it makes sense to direct efforts at increasing awareness at medical students. A report of the University of Leeds, U.K. describes an innovative course on deaf awareness and communication skills. The day included hands-on and experiential activities. First, the students partook in a lip-reading exercise in which they paired up and took turns lip-reading (one silently mouthed words while the other wrote them down.) As the authors put it, “The sense of utter incomprehension and bewilderment, failure, powerlessness, and growing frustration included in the ‘lip-reader’ is highly effective for breaking down some of the myths of what deaf people can do and what means can be used to communicate with the, while also giving a powerful introduction to at least some aspects of what it is like to be a deaf person.”³⁴

Later in the course, two Deaf people introduced the students to signing and taught them some basics. The students learned to become more versatile in their approach to communication, particularly in using their body movements and facial expressions.

For the lunch break, students are ‘deafened’ by ear wax and sworn not to speak. Going out to local restaurants and pubs, they stabbed their fingers at the small print of menus, used “thumbs-up” signs, head-shakes, frowns, and other improvised signs. This experience of being deaf had a real profound impact on the students, as they have difficulty communicating, experience the silence of deafness, feel isolated, embarrassed and sometimes angry.³⁴

A course similar to this one could easily be incorporated into the “Introduction to Clinical Medicine” course at medical schools across the country. This would serve as a valuable experience for the doctors-in-training.

Future Research

Further research needs to be conducted to expand the limited knowledge base on health care in the Deaf community. There are several potential avenues for research that arise from my paper. It would be helpful to delineate a typology and characteristic profile of those persons who chose not to use an interpreter. Are there certain predictors of not using an interpreter?

To assess the impact of the Consent Decree, a study should be conducted in Connecticut at various time intervals to monitor changes in interpreting services, health care access behaviors, patients' satisfaction and health outcomes. Information collected could be disseminated to other states as evidence and justification for implementing similar systems in those states. To address the limitations of this study that may have limited the generalizability of the results, the possibility of a questionnaire administered by trained ASL personnel or by a validated interactive video should be explored.

Another avenue for research is to measure the impact of professional interpreters on the Deaf patient and hearing physician encounter in the medical setting. Areas to be investigated include level and degree of general and medical terminology training, differences between male and female interpreters, inpatient and outpatient differences and effect of continuity of interpreter/patient relationship. Are all professional interpreters equally trained in medical-related knowledge? Does gender of interpreter affect satisfaction or health outcome, and how does this vary by visit type (i.e. internal medicine, ob/gyn, etc.). Does utilization of a professional interpreter affect health care outcomes?

Appendix A

Office Use Only: Date Rec.: __, __, __ No. __

Name (optional) : _____

Date: _____

Health Care Survey for the Deaf/Hard of Hearing Population

Instructions:

This survey asks about you and your experience with doctors and hospitals. Please answer each question by circling the appropriate number. If you are unsure about how to answer a question, please give the best answer you can (and write a comment in the left margin.)

Personal Data

1. What is your birthdate? _____
 month day year

2. Are you a: (circle) man woman

3. Which of the following best describes your racial background? (circle one number)
 - 1 American Indian
 - 2 Asian/Oriental
 - 3 Black/African American
 - 4 White/Caucasian
 - 5 Puerto Rican/Hispanic
 - 6 Other: _____

4. What is your hearing status? (circle one number)
 - 1 congenitally deaf
 - 2 late-deafened adult
 - 3 hard of hearing
 - 4 can hear, but only with use of hearing aid
 - 5 other (please describe): _____

5. When did you lose your hearing? (circle one number)

- 1 at birth
- 2 under 3 years of age
- 3 between 4 and 11 years of age
- 4 between 12 and 18 years of age
- 5 19 or older

6. What is your marital status? (circle one number)

- 1 single
- 2 married
- 3 divorced or widowed

7. What is your education level? (circle one number)

- 1 less than 9th grade
- 2 some high school (9th - 12th grade)
- 3 high school graduate
- 4 some college
- 5 college graduate

Health Care Experiences

8. What type of doctor do you mostly see for your health care? (circle one number)

- 1 internal medicine doctor
- 2 family medicine doctor
- 3 OB/GYN (women's doctor)
- 4 Specialist (such as surgeon, heart doctor, cancer doctor, etc.)

9. When did you see your medical doctor last? (circle one number)

- 1 within last month
- 2 between 2 to 6 months ago
- 3 between 6 to 12 months ago
- 4 over one year ago

10. In the past one year, how many times have you seen a doctor for your health? (circle one number)

- 1 0 (zero)
- 2 1 (one)
- 3 2 (two)
- 4 3 (three)
- 5 >4 (more than 4 times)

11. Where do you usually see the doctor? (circle one number)

- 1 private office
- 2 public clinic
- 3 emergency room
- 4 hospital
- 5 other: _____

12. For most (more than 50%) of your appointments do you go with anyone? (circle one number)

- 1 alone
- 2 with a professional interpreter
- 3 with a family member
- 4 with a hearing friend
- 5 other: _____

13. How do you usually communicate with the doctor? (circle **all** that apply)

- 1 professional interpreter
- 2 family member interpreter
- 3 friend interpreter
- 4 writing
- 5 lip-reading
- 6 gestures
- 7 other: _____

14. Why did you not use a professional interpreter? (circle **all** that apply)

- 1 doesn't apply to me
- 2 prefer to go alone
- 3 prefer to write
- 4 don't feel comfortable with interpreter at doctor's office
- 5 too much trouble to get a professional interpreter
- 6 don't trust an interpreter
- 7 don't know how to get a a professional interpreter
- 8 don't have the money to pay for an interpreter
- 9 Dr. won't provide interpreter
- 10 other: _____

15. How difficult is it to get a professional interpreter for medical appointments? (circle one number)

- 1 very difficult
- 2 difficult
- 3 okay
- 4 easy
- 5 very easy
- 6 doesn't apply to me

16. Who paid for the interpreting services? (circle one number)

- 1 the doctor
- 2 the hospital
- 3 CDHI (Commission for the Deaf and Hearing Impaired)
- 4 FSW (Family Services of Woodland)
- 5 you
- 6 don't know
- 7 doesn't apply to me

17. In general, how satisfied do you feel with your medical care? (circle one number)

- 1 very satisfied
- 2 satisfied
- 3 fair
- 4 unhappy
- 5 very unhappy

18. Are you aware of your rights under the American with Disabilities Act? (circle one number)

1 yes

2 no

19. Are you aware of the consent decree (type of law) that requires all hospitals in CT to provide interpreters? (circle one number)

1 yes

2 no

Quality of Communication

Rating of Communication Methods:

Please check the appropriate box for your ability in each of the following:

	excellent	good	fair	poor	none
speech					
speechreading/lipreading					
using sign language					
reading sign language					
fingerspelling					
reading fingerspelling					
writing English					
writing Spanish					

How much do you think the doctor understands you? (circle one box)

everything	almost everything	some	very little	none
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How much do you think you understand what your doctor tells you? (circle one box)

everything	almost everything	some	very little	none
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