POPULATIONS AT RISK

Health Care System Accessibility

Experiences and Perceptions of Deaf People

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BACKGROUND: People who are deaf use health care services differently than the general population; little research has been carried out to understand the reasons.

OBJECTIVE: To better understand the health care experiences of deaf people who communicate in American Sign Language.

DESIGN: Qualitative analyses of focus group discussions in 3 U.S. cities.

PARTICIPANTS: Ninety-one deaf adults who communicate primarily in American Sign Language.

MEASUREMENTS: We collected information about health care communication and perceptions of clinicians' attitudes. We elicited stories of both positive and negative encounters, as well as recommendations for improving health care.

RESULTS: Communication difficulties were ubiquitous. Fear, mistrust, and frustration were prominent in participants' descriptions of health care encounters. Positive experiences were characterized by the presence of medically experienced certified interpreters, health care practitioners with sign language skills, and practitioners who made an effort to improve communication. Many participants acknowledged limited knowledge of their legal rights and did not advocate for themselves. Some participants believed that health care practitioners should learn more about sociocultural aspects of deafness.

CONCLUSIONS: Deaf people report difficulties using health care services. Physicians can facilitate change to improve this. Future research should explore the perspective of clinicians when working with deaf people, ways to improve communication, and the impact of programs that teach deaf people self-advocacy skills and about their legal rights.

Deaf people have poorer health and use health care services differently than do hearing people.[1,2] The reasons for this are unclear. Deaf people continue to report difficulties accessing health care even in the years since the passage of the Americans with Disabilities Act of 1990 (ADA).[3,4]

People who are deaf and use American Sign Language (ASL) have much in common with members of other linguistic and cultural minority groups.[5] These similarities include limited access to English language-based communication, infrequent contact with clinicians familiar with their language and culture, and the challenging experience of working with family members and friends as interpreters. Not all deaf people are members of the cultural minority group that uses ASL. This community is commonly distinguished with an upper-case "D" in "Deaf," while "deaf," with a lower-case "d," refers to the audiologic lack of hearing.[6] The size of this community is not known since the U.S. Census and other national surveys do not ask about ASL use; estimates range from 100,000 to 1 million.[5] Most adults who communicate with ASL became deaf in childhood; of all deaf adults, 8% became deaf prelingually (before age 3) and another 11% became deaf between the ages of 3 and 19.[1]

In this study, we explore experiences with health care in the Deaf community. We gathered information using focus group interviews conducted in ASL because of the English literacy limitations of deaf adults[7] and because ASL is the preferred language for members of the Deaf community.

METHODS

Four semi-structured focus group meetings, approximately 2 hours each, were conducted in each of 3 cities (Philadelphia, PA, Ann Arbor, MI, and Rochester, NY). We recruited participants from the local Deaf communities through direct face-to-face interactions at Deaf community events, through collaboration with Deaf community organizations, and through distribution of large-print colored flyers with graphics to facilitate communication with individuals with low literacy. Our inclusion criteria were: deafness, communication preference for ASL, and willingness to share health care experiences. We did not specifically recruit people with negative health care experiences. Some focus groups were organized in conjunction with Deaf community organizations; we did not otherwise purposely group participants. Participants were unpaid but we provided refreshments during the focus groups.

At the time of the focus group meetings, we collected some sociodemographic and health information from participants using a written questionnaire (1 two-sided page; Appendix A). For participants who had difficulty reading or understanding the questionnaire, interpreters were available to translate the questions into ASL.

The research team developed a focus group facilitator guide that included sample questions and discussion topics (Appendix B). Deaf and hearing research staff facilitated the focus groups in ASL. Certified interpreters, some with native ASL skills (i.e., hearing children of Deaf adults), attended the focus groups and voiced the ASL discussions into a tape-recorder. Researchers present at the focus group reviewed the typed transcripts for accuracy.

Hearing and deaf researchers on the analyses team each reviewed the transcripts and identified key reoccurring concepts, ideas, and incidents. Researchers discussed these themes during face-to-face meetings and over email to further refine the themes. We developed a coding system based on those themes and used the text-based qualitative research software package Folio VIEWS[8] to help manage the data. The few coding disagreements were reviewed and discussed by members of the analysis team until consensus was reached.

We chose not to video-record the focus groups because of the difficulty in clearly capturing the ASL of each focus group participant and facilitator. Researchers were cognizant of the limitations of analyzing the English translations. For example, personal pronouns in ASL are not gender specific but the transcripts all used gender-specific pronouns since English does not use the pronoun "it" to refer to people. Sometimes, the focus group discussion preceding the pronoun indicated to the interpreter which English gender pronoun to use; other times, the interpreter had to choose a gender pronoun. Quotes in the transcripts (and this article) that use the words "his" and "he" do not necessarily mean that the physician (person) referred to is a man.

The study was approved by the institutional review boards of the 3 participating universities. All volunteers were informed about the study prior to the focus group meetings and consented to participate.

RESULTS

Sociodemographic and Health Characteristics

Sociodemographic information describing focus group participants is given in Table 1. Focus group size varied from 2 to 21; those held in Philadelphia had the largest attendance. Study participants ranged in age from 24 to 83 (median age 51 years). Of the 69 (75%) participants who reported their family income, the median was $25,000 (range $5,000 to $100,000). Many participants (80%) reported losing their hearing before 3 years of age (i.e., prelingually). ASL was the primary language of 78% of participants (88% of prelingually deafened participants).

Health-related information from the written questionnaire is shown in Table 2. Most (94%) had some form of health insurance and many had accessed the health care system within the previous year.

Quality of Health Care Communication

Participants reported having a poor understanding of their clinicians' instructions because of difficulty with health care

Table 1. Demographic Characteristics of Participating Deaf Adults (n=91)

Characteristic	Number of Subjects	Percent
Gender		
Male	45	49.5
Female	46	50.5
Location		
Philadelphia, Pennsylvania	56	61.5
Rochester, New York	19	20.9
Ann Arbor, Michigan	16	17.6
Race		
White	81	89.0
African American	10	11.0
Other	0	0
Marital status		
Single	28	30.8
Married/Partnered	42	46.1
Widowed	8	8.8
Divorced	12	13.2
Separated	1	1.1
Deaf identity		
Deaf and part of deaf culture (Deaf)	76	83.5
Deaf but not part of deaf culture (deaf)	4	4.4
Hard of hearing	9	9.9
Late-deafened	1	1.1
No response	1	1.1
Education		
Did not finish high school	12	13.2
High school diploma or GED	39	42.9
Some college education or 2-y degree	21	23.0
Bachelor degree and higher	17	18.7
No response	2	2.2
Hearing loss levels of subjects		
Profound hearing loss	57	62.6
Severe hearing loss	21	23.1
Moderate-severe hearing loss	5	5.5
Moderate hearing loss	5	5.5
No response	3	3.3

GED, General Educational Development.

communication. Although many participants reported that communication was best with medically experienced certified interpreters, they were infrequently available to help facilitate communication. Alternatives to the use of interpreter services were often inadequate.

Speechreading. Speechreading, sometimes referred to as lip reading, was considered inadequate for many reasons, although it appeared to be a common method of trying to communicate. Sometimes, there were physical barriers to conveying any information through speechreading, such as surgical masks (Table 3). Sometimes, the physical barriers to speechreading could not be changed: "My primary care doctor . . . his lips are very small. Even when he looks at me, it's hard for me to understand . . . "

Generally, even without identified physical barriers, speechreading was an unsatisfactory way to try to communicate: "I was so shocked when they had 5 people, doctors and aides . . . All these people came towards me . . . I wondered what was going on. So I started writing notes to them . . . I could see they were talking, . . . I had no idea why there were 5 people there looking at me . . . "

Written Communication. For many, note-writing was inadequate for communication because of the vocabulary used

Table 2. Health Characteristics of Participating Deaf Adults (*n*=91)

Characteristic	Number of Subjects	Percent
Health insurance		
Via work*	55	60.4
Medicaid/Medicare	30	33.0
No insurance	5	5.5
No response	1	1.1
Most recent physician visit		
In past year	78	85.7
2 y ago	2	2.2
More than 3 y ago	8	8.8
Not sure	2	2.2
No response	1	1.1
Most recent complete physical exam		
In past year	59	64.8
2 y ago	11	12.1
More than 3 y ago	8	8.8
Never	3	3.3
Not sure	9	9.9
No response	1	1.1
Most recent hospital use		
In past year	32	35.2
2 y ago	11	12.1
3 y ago	5	5.4
More than 3 y ago	25	27.5
Never	8	8.8
Not sure	9	9.9
No response	1	1.1
Most recent emergency department visit		
In past year	25	27.4
2 y ago	12	13.2
3 y ago	7	7.7
More than 3 y ago	19	20.9
Never	14	15.4
Not sure	12	13.2
No response	2	2.2

Includes insurance received via participant's or family member's current or former work.

and handwriting quality (Table 3). Sometimes, writing was ineffective because of syntax differences between ASL and English (Table 3 and see Table 4). "Sometimes they write it in English and sometimes I say, "Please repeat easy, in a different way."

Telephone Communication. For deaf people, telephone-based communication is often written communication using a TTY (Table 4). As with written communication, difficulties with English syntax and vocabulary commonly occurred. Another difficulty reported was health care workers' lack of familiarity with TTYs and telephone relay services (Tables 3 and 4).

Technology has also created difficulties for relay services. Voice mail systems that require pushing a number on the telephone keypad often do not wait long enough for a relay operator to type the information to the deaf caller and wait for the typed response (Table 3).

Difficulty with telephone communication led some participants to go directly to an emergency department, "We just go right to the hospital. I wouldn't call my doctor at all. I just go right to the emergency room."

Sign Language Interpreter Services. Communication improved when facilitated by interpreters. One man described his contrasting experiences with angioplasties, the first without and the second with interpreter services:

Oh my! The first time, . . . I had no idea I was going to be laying there and they were going to stick something in me and they said, "cough." I didn't know when I was supposed to cough . . . . So the second time I had to have this procedure, 2 years ago, I had an interpreter. Oh my gosh! I learned so much. It was like it was the first time!

For most participants, the best communication occurred when working with medically experienced certified interpreters (Table 3). Working with health care staff with some knowledge of sign language was felt to be "better than nothing," although communication was still poor (Table 3).

Although family members were often brought to health care appointments, participants reported that they were frequently inadequate as communication facilitators and participants still felt excluded from the health care conversation (Table 3). Working with family members as interpreters also compromised privacy. One (deaf) woman described how she felt about being expected to interpret for her husband's doctor appointments:

My husband has a right. I felt like his rights were being infringed upon more so than me. He didn't have any privacy apart from me. Suppose, for some reason, he would prefer not to have me involved. Although, he's never said this. On the other hand, he's never had a choice. So, it bothers me that he does not have a choice.

Practitioners with Sign Language Skills

Some participants from Rochester reported experiences communicating directly with clinicians with sign language skills (Table 3). Reports of these encounters were positive, "I was able to have a discussion with my new doctor and we changed some things and I think it's a lot better. . . [T]his new doctor [is] able to sign . . . I'm much healthier, and I feel a lot better about it." One participant summarized, "I was able to explain deeply what was going on with me . . . They asked me questions and I was able to sign back. Having a doctor that signs is a wonderful experience." Rochester has both hearing and deaf clinicians with sign language skills; our analyses did not reveal a consensus from participants' regarding a preference for hearing or deaf clinicians.

Emotions Elicited by Health Care Experiences

Many participants expressed strong emotions about their health care experiences. One recurrent theme from focus group participants was fear. Participants were afraid of the consequences of miscommunication with their health care practitioners, and were often afraid of the consequences of telling their practitioners about inadequate communication: "You know I can't drop this doctor, I am stuck . . . if I drop this doctor and have to find another doctor, he's [the new doctor] going to want to know why I changed doctors and then he's going to find out and he's not going to want to pay for the interpreter." These fears were reinforced by experiences with clinicians, as illustrated by a participant's story of trying to advocate for better communication with her husband's doctor: "OK, the way I see things is he's [my husband] from 'the old school.'" Now he has no expectation for communication. He does the best with what happens. He never makes a request for himself. However, one time I asked the doctor, "I know that you also have other deaf patients as well." So, I said to the doctor, "Have you ever thought of hiring an interpreter?" The

Table 3. Examples of Communication Experiences by Communication Mode

Speechreading (physical barriers)
 Facilitator: " . . . how did you communicate for your surgery?"
 Participant 1: "There was no communication."
 Participant 2: "They wear the masks. How can you talk to them?"
 Participant 3: " . . . It's not possible to talk to them through the mask."
Written Communication (handwriting and vocabulary)
 "When we write, sometimes the doctor writes too fast and I can't read what they've written. Sometimes the doctor uses these long words, so the doctor
   has to write it all over again so that it is clear for me."
Written Communication (syntax)
 " . . . when I try to write back and forth, it's very difficult for me because I use ASL."
Telephone Communication (telephone relay service)
 " . . . the nurse is usually afraid because she has no experience with relay service . . . I've gotten so many . . . [telephone] hang-ups [when I] get the
   [relay] operator to call them. 'I want to talk to the doctor,' I'll tell them, and I get this blank, no sound for a while. The doctors' offices don't know what
   the relay service is."
Telephone Communication (automated message systems)
 "I'll call through relay and get the machine that says, 'If you want this, press number 1, press number 2, press number 3.' . . . Press number
   1 if you want this, press number 2 if you [want this]. I hate that."
Sign Language Interpreter Services (medically experienced interpreters)
 " . . . for surgery, I asked for an interpreter who had a medical background . . . when I had an interpreter who had no medical background, she signed
   beautifully, . . . but in the medical area, you know, she didn't understand and . . . [our communication] broke down."
Sign Language Interpreter Services (unskilled interpreters)
 "It happened that she knew how to sign but not like an interpreter. She wasn't skilled like an interpreter, but I did need her to tell me what the doctor
   says . . . so it made me feel more comfortable. She was not a professional interpreter, but she just came from a deaf family and she helped me. She
   gave me some relief . . . "
Interpreter Services (family member as interpreter)
 Participant (age 29): " . . . If I was with my mother, my mother would communicate to them and tell them, and she was always there to help. My mother
   would go with me to help."
 Facilitator: "And you communicate pretty well with your mother?"
 Participant: "Okay. Not great. Okay."
Sign language skilled clinician
 Participant (age 41): " . . . they have a doctor who can sign . . . I went there for the first time . . . and when we sat down and chatted for 30 minutes
   about my health, I was very surprised, and when I went home, I told my wife, I said, 'Wow! That was the first time that you know, when I've ever been
   to the doctor, that they talked with me.'"

physician was very nice and both my husband and I like him very much. We very much liked his services, but he said, "The day I have to hire an interpreter is the day that I stop having deaf patients."

Poor communication, lack of information, and fear also seemed to contribute to feelings of mistrust, "I was still awake and the doctor kept . . . pushing me down to make me lay down. I just said 'I want to know what you're doing,' and he would say, 'Don't worry. You're fine. Lay down.'"

Participants also felt that some health care workers disliked working with deaf people:

> Participant: Doctors are patient with people who are blind or in wheelchairs, but they are not as patient with us deaf people.
> Facilitator: Why do you think that is?
> Participant: Well, maybe it's because we can't [read and] write [well]. The people in wheelchairs and [those who] are blind can speak, but we can't, and we have to write back and forth with the doctors.

Table 4. Deaf-Related Abbreviations and Their Meanings

ADA The Americans with Disabilities Act of 1990 (ADA) came into effect in 1992. The ADA was written broadly and many aspects of the law are still
     being interpreted by the court system. The ADA states that all physicians' offices are public accommodations and therefore subject to the
     provisions of the ADA. Physicians' offices must ensure "effective communication" with deaf patients and deaf family members of patients.
     Physicians should consult with deaf patients (family members) as to how to ensure "effective communication." The cost of adhering to the ADA
     cannot be passed on to the patient.
ASL American Sign Language (ASL) is the primary language of the U.S. Deaf community. Like many of the world's languages, ASL has no written form.
     Written communication with Deaf people is necessary in a second language. English and ASL have different syntax, another reason why written
     English may be unclear to a Deaf person. For example, ASL sentences do not necessarily follow subject-verb-object word order.
TRS Telephone relay service (TRS) is designed to facilitate telephone communication between someone without a TTY and someone with a TTY. The
     telephone call is made to a relay service operator who can hear and has a TTY; the operator makes the telephone call to the second person and
     types whatever is being said for the TTY user to read. The operator also speaks whatever is being typed for the person without a TTY to hear.
TTY A TTY, also known as a TDD, is a device used for telephone communication via typewriting. A basic TTY consists of a keyboard, a screen, and a
     coupler or jack that allows connection to a telephone line. A person with a TTY calls another person with a TTY on the telephone; the characters
     typed by one person also appear on the screen of the other person's TTY.
VRI Video remote interpreting (VRI) uses video conferencing technology to bring interpreter services to places and times when there is no local
     interpreter available. With health care VRI, the doctor and patient are in the same room and the interpreter is at a remote site. The interpreter and
     the deaf person communicate in ASL via video while communication between the interpreter and hearing physician is audio. Health care VRI is
     best with high bandwidth connections (a minimum of 384 kbs, such as 3 ISDN lines) to ensure clear video in both directions that avoids frame-
     drops and permits clear images, including numbers and fingerspelling. Health care VRI is increasingly available.
VRS Video relay service (VRS) is similar in structure to TRS. VRS is designed to facilitate communication between someone with a standard telephone
     and someone who communicates in ASL with a "videophone." The VRS operator is fluent in ASL and can speak. An advantage of VRS is that Deaf
     people can communicate in their primary language (ASL), rather than type in English on a TTY.

Participants expressed frustration with the health care system. Sometimes, this frustration was related to the perception that they are cared for differently than hearing people:

"...All I want is to be able to go to the emergency room and please, them knowing what to do. Take care of me like anybody else. I have to go in and they don't communicate with me and they start touching me all over my body, it's very distressing."

Participants were frustrated in their efforts advocating for good communication:

"I find out if there is an interpreter provided and if there's none there, then I leave ... I don't want to struggle with them."

Frustration was sometimes related to feeling stuck with poor communication,

"Some doctors refuse to pay ... I request an interpreter and they refuse. They say writing is good enough, writing will do, but sometimes I get stuck and I'm uncomfortable with writing."

Participants also experienced frustration with the perspective that the interpreter was only for them, rather than for facilitating communication among all parties,

"I don't like doctors' attitudes when they say that I need an interpreter, [saying] "Do you need an interpreter?" You know, I don't need an interpreter, but if they can't sign, then WE [emphasis added] need an interpreter."

Knowledge of the Americans with Disabilities Act

Most participants were aware that the ADA existed and is related to access, but few knew specific information about this legislation: "... I don't remember what's involved with interpreters there or not, but deaf people should not have to pay for the interpreters. I don't remember for sure if that's in the rules or not about who pays for the interpreter. Do you know what the ADA says about paying for interpreters?"

Suggestions for Improvement

Participants were motivated to help health care practitioners work better with Deaf patients. "I'm going to teach him, the doctor, how much I'm missing without an interpreter, how much information I'm missing. I want him to know how much information I'm missing." Some thought practitioners should learn some basic sign language in addition to learning about sociocultural aspects of deafness. One participant suggested a "hands-on experience with maybe like a half-day activity designed to simulate what it's like to be deaf." Many participants reported that the one thing to teach their doctors is that they must work with interpreters.

Other Positive Experiences

In addition to use of ASL by health care practitioners, participants stated when health care practitioners took time to explain and use visual aids, and when interpreter services were provided, many had successful health care experiences, "... it got confusing, so I asked for an interpreter, and I got one amazingly, oh my gosh! I got lots of information, it felt spontaneous, even the nurse told me information that was useful; when writing before, [I] never got that information. I realized doctors are complicated, but by forcing doctors to write, it made the doctor limited in the information that was given to me."

DISCUSSION

This is one of the few published studies to explore Deaf adults' experiences in the health care system. The use of focus groups allowed us to learn about the breadth and depth of participants' perspectives and experiences. This methodology is consonant with Deaf culture; gatherings are considered opportunities for sharing information and topics often considered private to hearing individuals are openly discussed by Deaf individuals in moderately large groups.

The 3 study sites permitted us to explore a variety of Deaf experiences. We conducted focus groups in a medium, large, and very large city. Since the U.S. Census does not collect information about ASL, it is difficult to compare the 3 Deaf communities. Rochester is thought to have a high per capita Deaf population with a higher median education level, partially because of the presence of National Technical Institute for the Deaf. We did not compare focus group results between cities; the only difference that emerged during analyses was the mention of ASL-skilled clinicians in Rochester. This may be an artifact of the samples; at the time of the study, all 3 cities had at least 1 clinician with ASL skills and at least 2 cities (Ann Arbor and Rochester) had a deaf family physician (birth or childhood onset).

Participants' reports of difficulties with written communication are not surprising; the median reading level of deaf high school graduates in the United States is fourth to fifth grade[7] and the medical vocabulary knowledge of U.S. Deaf adults is similar to that of non-English language immigrants to the United States.[9] Difficulties with speechreading are also not surprising; only 30% to 40% of spoken English is visible on the lips.[10,11] Despite these difficulties, some participants used these modalities to communicate about their own and their families' health. We suspect that because health is so important, and because interpreters were infrequently available, participants felt pressured to try any method in an effort to communicate. In 1 study U.S. Deaf adults were less likely than non-English language immigrants to communicate with their physician in their primary language[9] (Table 5).

Participants' reports that interpreter services were infrequently available are consistent with the findings of Ebert and Heckerling.[10] Physicians surveyed in their study reported that they worked infrequently with interpreters even though they recognized that communication was best via interpreter services. Some of our participants thought that interpreter services would be used more frequently if there were wider recognition that all parties involved, and not just Deaf people, benefit from improved communication. In our focus groups and in those conducted by Witte and Kuzel,[4] deaf participants suggested that the expense of interpreter services may account for its infrequent use. Some physicians have cited the unreimbursed cost of interpreter services as a barrier to working with interpreters.[12–14]

Participants preferred working with medically experienced interpreters or with health care practitioners with sign language skills. This is consistent with the findings of MacKinney et al.,[15] who found that deaf adults seeking care at a clinic with easy access to interpreter services reported higher satisfaction with health care communication, and were more adherent with some preventive health recommendations than deaf adults who sought care elsewhere. For mental health settings, Steinberg et al.[3] found a preference for practitioners who

Table 5. Comparison of the Deaf Community and Some Other Language Minority Groups

Similarities

Social
  Use of a non-English language
  Socialize and partner/marry within community
  Sociocultural norms different than those of the majority community
  Children often become bicultural/bilingual
Health care
  Infrequently encounter a doctor from their own cultural group
  Language differences and health knowledge limitations are often barriers to appropriate health care
  Poorer health than the general population
  Less likely to visit a physician than the general population
Opportunity
  Lower education level, socioeconomic status, and literacy than the general population
  Often encounter prejudices that limit opportunities
  Limited access to English language-based information

Differences

Expectations
  Unlike members of other language minorities:
    Deaf people are expected to have fluency in written English
    Deaf people are expected to communicate with their physicians by note-writing in English
    Deaf people are expected to communicate with their physicians by speechreading in English
Cultural transmission
  American Sign Language (ASL) and Deaf culture are usually transmitted horizontally (from peers) rather than vertically (from parents)
Legal
  Guidelines for health care communication with Deaf people come from the Department of Justice
  Guidelines for health care communication with others who have low English proficiency come from the Department of Health & Human Services

Adapted from Barnett, Family Medicine 1999.[5]

are fluent in ASL and for practitioners who are deaf. We did not ask specific questions comparing hearing and deaf clinicians in our focus groups and cannot draw any conclusions on this issue as a consequence.

Participants perceived their practitioners to have insufficient knowledge regarding deafness and suggested medical education programs as a potential solution. Ebert and Heckerling[10] asked physicians 5 questions regarding deafness; most physicians overestimated the accuracy of speechreading but answered the other 4 questions correctly. A more thorough analysis of practitioners' knowledge regarding deafness may help to identify areas to focus educational efforts. Participants' perception of prejudice in the health care system is consistent with reports of deaf people in another study[4] and findings about physicians' attitudes toward working with deaf patients.[16] Although there are a few publications regarding medical education and deafness,[5,17–22] the impact of these programs on the attitudes and experiences of deaf patients, their families, and their health care practitioners has not been examined.

Participants' experiences of the health care system were often associated with stress and strong negative emotions. This may partially explain the research that indicates that prelingually deafened adults are less likely to visit a physician than adults in the general population.[1]

Findings from this study suggest areas for research. The knowledge and experiences of clinicians regarding deaf patients should be further explored, including the reasons for not arranging for interpreter services. Advanced education programs in health care interpreting should be offered, and their impact on health outcomes studied. Deaf people sometimes reported not requesting interpreter services from their clinicians. Self-advocacy educational programs should be tested to see how they impact frequency of use, satisfaction, and outcomes of care. Programs that teach health care students and professionals about deafness should also be studied. National surveys of health and health care experiences should include individuals who are deaf,[23,24] and information regarding the nature of the hearing loss and preferred language should be included in the data collection. This will facilitate accurate assessments of the impact of technical innovations such as see-through surgical masks, computer software that converts spoken language to written text, video relay service (VRS, see Table 4), and remote sign language interpreter services using videoconferencing equipment with high bandwidth connections (VRI, see Table 4). Finally, programs that help interested deaf people to enter careers in the health professions should be examined to see their effect on health care system access for deaf people and their families.

Physicians can take steps now that may improve the health care experiences of Deaf people and their families. Clinicians should ask patients if communication is effective and how it could be improved. Physicians and physician organizations should lobby government agencies and insurers to create a system whereby physicians are reimbursed for interpreter expenses, or professional interpreters could bill third-party payers directly for their services. To facilitate telephone communication, physicians' offices could establish a separate number for TTY and relay service callers (TRS or VRS) that avoids the automated menu system or permits them to exit the automated system quickly (e.g., "If this is a relay service call, press 1 now to speak with a receptionist.").

Limitations

This study was designed to learn about the health care experiences of deaf people who communicate primarily in ASL. Participants in our study are not representative of the entire U.S. deaf population as the majority of deaf people lose their hearing later in life and often do not learn ASL; the health care experiences of these people may be different than those of the participants in this study.[25]

In addition, Deaf people who elected to participate in the study may have had different health care experiences than those who decided not to participate. Our study participants were more highly educated and more likely to have seen a physician in the preceding 2 years than a national sample of prelingually deafened adults;[1] perhaps participants' recent experiences in the health care system contributed to their motivation to be involved in the study. Although we suspect that many of the experiences described in the focus groups are common in the U.S. Deaf population, the prevalence of each type of experience may be different and some other experiences common in the U.S. Deaf population may not have been identified by focus group participants. Given the limitations of our sampling design, our results do not generalize beyond the focus groups we conducted.

Our study was not designed to compare health care experiences in different cities. The 3 cities and their health care systems are quite different. We do not have information that describes the Deaf community in each city, so we could not recruit participants to reflect the sociodemographic characteristics of the local Deaf community. The Deaf community organizations that helped recruit focus group participants were different in each city (examples include a gay/lesbian Deaf organization and an organization of older Deaf adults). Given these differences, subgroup analysis, based on geography or other sociodemographic characteristics, would be difficult to interpret.

Participants described both positive and negative communication experiences with health care, although there were more categories of negative experiences. Our focus groups were conducted in ASL, so the reported challenges with English language health care communication (via reading/writing or speechreading) are not surprising. We asked about good and bad experiences (Appendix B), but did not specifically ask about good English language experiences. It is possible that social pressures during ASL focus groups inhibited participants from sharing positive experiences with English communication. More likely, participants took advantage of the rare opportunity to speak with researchers and described their most pressing health care issues, mainly the limited access to fluent communication in their primary language. This process is consistent with typical discourse in the Deaf community, in which the most important topics are discussed early in the conversation.[20]

CONCLUSION

Deaf people report positive experiences and difficulties using health care services. More research in larger more representative populations of deaf people and their families is necessary to make the health care system more accessible and communication with health care providers more satisfying and effective.

Supplementary Material

The following supplementary material is available for this article online:

Appendix A. Demographic Questionnaire

Appendix B. Facilitator Guide

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