

ETHICS FEATURE

Health Care Interactions with Deaf Culture

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Approximately 9% to 10% of Americans have hearing loss,¹ making it the second most common disability in the United States.² Regardless of hearing loss level, persons who are deaf or hard of hearing (D&HH) have altered health care utilization patterns^{3,4} and significant communication difficulties with physicians,³⁻⁵ often experiencing misunderstandings about their disease or treatment recommendations.⁴⁻⁶ They are a “silent” group to many physicians.

The D&HH population is a heterogeneous group that includes persons who have varying degrees of hearing loss, use multiple languages, and belong to different cultures. Solutions to providing health care to one group from the D&HH population do not necessarily apply to the other groups. Factors that must be considered with this population include degree of hearing loss, age of onset of loss, preferred language, and psychological issues. In this article, D&HH refers to anyone with a hearing loss, ranging from hard of hearing to profoundly deaf. Persons referred to as deaf (lower case d), usually do not consider themselves members of the Deaf Community, although they may be severely or profoundly deaf. These deaf persons may prefer English as their means of communication with physicians, but their usage of English may not be standard. Persons referred to as Deaf (upper case D) typically belong to the Deaf Community,⁷ a minority population with its own culture and social mores,^{3,7,8} use American Sign Language (ASL), and typically have a low English reading level.⁵ ASL differs from English in crucial ways, including its idioms and grammar.^{9,10} Members of the Deaf Community usually prefer certified ASL interpret-

ers when seeing physicians. Deaf persons are the non-English-speaking minority at greatest risk for physician-patient miscommunication.¹¹

When communicating with Deaf persons, physicians should remember that they probably have low reading levels and their writing is usually non-standard English. Two examples of the Deaf Community’s social mores that are relevant to the health care setting are:

1. No secrets—deaf people consider it rude to be excluded from any conversational information. When a Deaf person leaves the room to accept a phone call, s/he is expected to tell the group about the phone call when s/he returns. Deaf people should be informed of the content of any conversation, including that which is not relevant to their immediate situation, eg, personal asides between 2 hearing people. Environmental sounds accessible to a hearing person also should be communicated to the D&HH person by pointing to the locus of the sound and speaking the accompanying word(s). For example, the sound of a knock on the door should be communicated to the D&HH person by pointing to the door and simultaneously speaking the words “knock at the door” as soon as the sound is heard. This eliminates the need for the D&HH person to guess the reason for the hearing person’s looking at or moving toward a specific location. Sign language interpreters are trained to provide this information for D&HH persons.
2. Abrupt beginnings to conversations and “long goodbyes”—English communication works its way up to the main point and then concludes; ASL communication starts with the main point and winds down. Therefore, physicians may believe communications are finished when Deaf patients are still “winding down” the conversation. When physicians give treatment recommendations to Deaf patients, the patient may ask the same questions multiple times.

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The major issue for all D&HH patients is communication with the hearing world. Helen Keller said that being deaf is worse than being blind because being blind isolates one from things, but being deaf isolates one from people. As the non-English-speaking minority at greatest risk for physician-patient miscommunication, Deaf people particularly have problems with common English words; some educated Deaf persons do not understand the words “nausea” and “allergic”¹² or “constipation.” D&HH persons have poorer health care knowledge, including an inferior understanding about current preventive medicine interventions, compared with hearing persons.^{11,13} When seeing D&HH persons, physicians must speak simply, use certified interpreters as indicated, and verify that patients understand all recommendations.

Following is an example of a miscommunication between a physician and his Deaf patient when no interpreter was present and English was used. The physician wrote, “You may need surgery.” The patient understood this to mean, “You need surgery in May.” In ASL, the English sentence, “You may need surgery” would be signed, “You maybe need surgery.” In ASL, the English sentence “You need surgery in May” could be interpreted as “You (in) May need surgery.”

Health Care Services

Research has shown the need to improve health care services for all D&HH groups and that the health care communication needs of D&HH people have been and continue to be neglected.^{2,3,4,14-17} D&HH persons report lower subjective health care status^{2,4} and have inferior knowledge regarding HIV/AIDS^{6,18} and preventive medicine.¹³ Deaf persons visit physicians less frequently.¹⁹ Deaf participants expressed belief that physicians and nurses seemed unprepared to accommodate their communication needs,²⁰ and physicians reported “significantly greater difficulties communicating with (deaf) patients. . . .”²¹

Communication barriers can put these patients at risk in a variety of ways. For example, there may be an inability to interpret written prescriptions.¹² We know of a deaf mother who put liquid oral antibiotics in her daughter’s ear for an ear infection.

Specific Clinical/Research Issues with Deaf Persons

During the past 15 years, we have conducted multiple research studies with D&HH persons. These have involved the entire hearing loss range of D&HH persons (from hard of hearing to d/Deaf) in multiple health care areas (prevention, depression, health care access, etc) and in multiple populations (Medicaid to upper class and racially diverse groups). As a result, we have encountered many issues and barriers. Five that are germane to the Deaf Community are: linguistic accommodations, lack of trust of the “hearing world,” the need for confidentiality, respect for intelligence, and dissemination of information

Linguistic Accommodations

Researchers and clinicians must always remember that the main issue for D&HH persons is communication with the hearing world. Therefore, informed consent forms (ICF) and any other written or oral communication must be configured to be intelligible to D&HH persons. To insure that truly informed consent would be obtained from participants, we have amended the standard consent form so that it would be intelligible to D&HH persons with substandard reading levels. We also presented the information in sign language and gave participants the opportunity to ask questions before they provided their signature. We believe the informed consent process has been improved by these measures.

Although we have previously used modified ICFs, we continue to have problems with the University of Michigan’s Institutional Review Board (IRB). For example, in a study that began in 2003, the IRB insisted that we prepare the ICF in standard, nonmodified form, to “protect the University of Michigan legally and to establish patient confidence and safety.” Despite previously approving the modified forms, the IRB twice returned the ICF to us, insisting that we use standard language to ensure “adequate consent.” It took several months to resolve this issue.

In the clinical setting, patient education handouts are often unintelligible to Deaf persons whose reading level may not exceed that of sixth grade and who may not understand such words as “nausea” and “constipation.” Handouts for non-English-speaking populations are printed in their native

language. Handouts for Deaf patients should be tailored to their linguistic needs as well. If they are not, they will fail to communicate important information.

Lack of Trust of the "Hearing World"

There seems to be a general mistrust of society at large, including researchers, which may manifest itself in a number of ways. For effective relationships with D&HH persons, it is critical to establish trust with them. Lack of trust seemed to be involved in the research setting for a variety of reasons.

Researchers' Motives and Physician Care

Our initial visits to a Deaf Club for Senior Citizens were enthusiastically received, but the club members subsequently refused to participate in the research. We later learned that club members thought we were exploiting Deaf people for financial gain. The support of our Deaf colleagues was crucial to us in overcoming this obstacle.

Deaf persons may be aware that a visit to a physician is necessary, but they are reluctant to do so.¹⁹ They may feel their treatment is inferior to that of hearing persons. Physicians can provide better care for Deaf persons by meeting their communication needs.

Payment of Participants

Although deaf club members were informed that each participant would be paid for participating, there were misconceptions about who pays whom and skepticism about whether or not payment would be made. Repetitious explanations and the act of paying participants convinced some persons to become involved. Reasons for the false perceptions are unclear. Deaf colleagues made the following suggestions: (1) when promising to pay Deaf research participants, have the money in hand to reinforce concretely what is being communicated in ASL and (2) pay participants as soon as possible after the completion of any segment of the research. Implementation of these changes improved participant recruitment and trust, but some confusion remained regarding who pays whom.

Researchers' and Physicians' Claims

One person refused to sign the ICF after the researchers explained it in ASL and responded to the ensuing questions. This resulted in all potential

participants withdrawing from the study. The person referred to an experience some 20 years earlier, when mistakenly signing a document thinking that it was for a free issue of a magazine and later learning that the signature was for a paid subscription.

Additional participants were recruited later that day by the interpreter who was a regular at the club and a trusted person among the Deaf Community. The interpreter reassured the club members regarding the researchers' claims and explanation of the ICF, and the recruitment process was ultimately successful.

In the clinical setting, we have seen Deaf patients refuse to sign the general forms required of all new patients for release of information to insurance companies. These patients seemed concerned that the forms would be used for other purposes. They probably did not understand the printed forms. Forms designed to accommodate lower literacy levels may help reduce misunderstandings and misgivings.

The Need for Confidentiality

Recruitment problems can arise from the issue of participant confidentiality. The Deaf community is small, and members are concerned about confidential information being available to others. Although we explained the methods for maintaining confidentiality in a variety of ways, some Deaf people remained skeptical. We received feedback from a Deaf colleague that some Deaf people were not interested in participating in our research because they "did not want everyone to know their business." Emphasizing the confidentiality of participants' names and information is crucial to the recruitment process.

Involving Deaf colleagues with our research planning and implementation further increased the confidence of the Deaf community and ensured that our materials were appropriately structured. It was also suggested that we add the phrase "No Names" to written recruitment communications.

This concern about confidentiality has a parallel with the use of interpreters in the clinical setting. The Americans with Disabilities Act mandates that physicians provide interpreters, at the physician's expense, if the patient requests one before a scheduled visit.

Although the skill of the interpreter is one issue that physicians must consider (some interpreters do

not do well with the complexity of medical interpreting), another major issue is the reputation of the interpreter for maintaining confidentiality. Before providing an oral or sign interpreter, one can increase the effectiveness of the communication by asking the patient if the interpreter being provided by the clinic is acceptable. If the patient does not trust the interpreter, he or she may withhold information or not ask pertinent questions of the physician.

Respect for Intelligence

Concern for being perceived as “dumb,” associated with a lack of intelligence, is a notable issue among Deaf people. Historically, schools for deaf children have been labeled as schools for “the deaf and dumb.” Currently this is not the case, but D&HH people (including those with mild hearing losses) are still often treated as if they are of inferior intelligence.

During data collection sessions, some participants refused to complete the post-test, believing there was no need to respond to the same (pretest) questions again and that this was an insult to their intelligence. Although any research participant may have this misconception, this has special significance for the D&HH population. One participant approached us claiming the research program is “not nice”—it asks the same questions twice. This person then said, “I’m not an imbecile—I-M-B-E-C-I-L-E.”

Unfortunately, the “deaf = dumb” phenomenon still exists. A recent e-mail from a late-deafened research participant attached communications from other late-deafened friends who lamented that since they became deaf, hearing people act as though they have also become stupid and were treating them as if they had lost their cognitive as well as their hearing ability. A recent conversation with a physician revealed a concern about a Deaf patient’s intelligence, based on written English language use. This physician had no understanding that Deaf patients’ intelligence is not reflected in their written English, because English is their second language. This misunderstanding can result in misplaced concern and effort with any D&HH patients who use nonstandard English.

Dissemination of Information

Informing Deaf participants of research results seems to be a necessary accommodation.²² They

regularly inquired about the dissemination of research results. Participants were particularly concerned that physicians and other health care professionals were being informed regarding how to best care for D&HH patients. This may be related to a deep mistrust for hearing society, as well as negative experiences many of them have had interacting with physicians.

We now offer to send copies of our publications to our participants, often through their clubs, to assure them that their participation did provide information for health care professionals. Although the publications may not be entirely understood by most of our participants, the fact that we have published the results has seemed to create positive feelings regarding research involvement. We have also offered to provide question-and-answer sessions regarding these results at the clubs.

Discussion

One only need remember Helen Keller’s comment that being deaf is worse than being blind to be reminded of the importance of communication to Deaf (and to all D&HH) persons. Awareness of this and the other issues regarding the various D&HH groups can facilitate better health care provision and successful interaction with these persons. The use of contemporary cross-cultural ethical practices when conducting deafness research will increase the likelihood of success with research²² and improve the likelihood of successful clinical encounters.

Considerations for clinicians and researchers to remember when communicating with D&HH patients include:

1. We should assure that the D&HH person has a clear visual field when possible. For example, we should not be in front of a bright window when asking the D&HH person if he or she understood what was being communicated.
2. We should face D&HH persons when talking to them without overenunciating, which makes speech-reading difficult.
3. We should face D&HH persons, not the interpreter, when communicating through an interpreter.

There is a high prevalence of hearing loss and many clinicians will probably care for D&HH per-

sons unknowingly, because some hard-of-hearing and deaf patients try to conceal their hearing loss. Deaf and deaf persons are more readily recognized because of the severity of their hearing loss. In any case, physicians should be aware that these are patients at high risk for miscommunication. In addition, physicians should remember the requirements of the Americans with Disabilities Act to provide interpreters and other support according to patient requirements. This awareness, along with the use of the strategies discussed in this article, should help to improve health care interactions.

Future research on health care for D&HH persons is critically needed with each group within this population. Research is needed to evaluate how best to train physicians to care for these patients, improving patient trust, and providing physicians with better tools to identify those who are hard of hearing but do not openly recognize their hearing loss. Other areas that need further investigation include the effectiveness of the use of video/computers rather than live interpreters with Deaf patients, reasons for non-Deaf persons having more frequent physician visits than hearing persons, and the optimal method of disseminating health care information among the various subgroups of D&HH persons.

The importance of health communication research and the need to educate clinicians regarding appropriate ways to care for the entire spectrum of D&HH persons is underscored when one considers that their numbers will increase as our population ages. Physicians have a moral obligation to conduct this research so that we can be sure this "silent" minority gets quality health care equal to that of hearing patients.

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