

Clinical and Cultural Issues in Caring for Deaf People

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Background and Objectives: *The clinical practice of family medicine is increasingly cross-cultural. Promoting culturally sensitive and competent health care is one of the goals of medical educators in guiding medical students and residents, as well as designing continuing education for family physicians. Working with minority communities is essential to meet that goal. The Deaf community is a linguistic and cultural minority group that is often overlooked. Working with the Deaf community to help develop cultural competency and sensitivity has potential benefits. This article introduces some of the sociocultural experiences of deafness and their relevance in health care settings.*

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The US Deaf community is not commonly identified as a minority population despite many similarities to other cultural minority groups (Table 1). People with hearing loss represent approximately 10% of the US population,¹ but the size of the US Deaf community is difficult to measure. Estimates range between 100,000 and 1 million.²⁻⁴ Their language, American Sign Language (ASL), is quite different from English and is the third most commonly used language in the United States.⁵

Compared with the general population, members of the Deaf community have lower socioeconomic, education, and literacy levels.^{1,4,6} Language barriers frequently prevent the acquisition of information,^{3,6,7} which further disempowers Deaf people. In their interactions with members of the majority culture, Deaf people often encounter biases and prejudices that can limit their educational and employment options. Members of the Deaf community tend to socialize among themselves and have limited social interactions with people from the majority culture. Differences in perspectives and social norms between members of the majority culture and the Deaf community can lead to misunderstand-

ings during social encounters. As with other minority communities, all of the above factors have a significant effect on interactions with the health care system.

Understanding the sociocultural aspects of deafness is important to primary care clinicians for a number of reasons. Deaf people comprise a significant portion of the US population and can be found in virtually all communities. With the passage of the Americans With Disabilities Act of 1990 (ADA), Deaf people will have improved access to the health care system and may appear more frequently in our practices and in those of our medical trainees. Deaf patients may also present for medical care more frequently because of population demographics; a large portion of the Deaf population was deafened in utero as a result of the rubella pandemic of 1964, and they, like all adults their age, will have increasing age-appropriate health care needs as they enter middle and late life. Another result of the ADA is that Deaf people will more often be employees in our practices, medical students and residents in our programs, and professional colleagues in our institutions. Medical education guidelines for culturally competent and sensitive health care clearly state that the concept of cultural diversity is not limited to ethnicity.^{8,9} By learning about the sociocultural aspects of deafness, residents, medical students, and practicing physicians gain a broader appreciation of human diversity and will be better prepared to meet the needs of their diverse patients (Table 2). In addition, the discomfort that physicians report when working with patients who have hearing loss may be reduced.¹⁰

Deaf Community

The word *Deaf*, with an upper-case “D,” refers to the culture and community of Deaf people, while the word *deaf*, with a lower-case “d,” refers to the audiologic lack of hearing.¹¹ Not all people who are deaf are members of the Deaf community. Use of ASL is more important for membership in the Deaf community than is the inability to hear. People who are deaf but who communicate primarily orally, through voicing and speech reading, are not usually members of the Deaf community. Children of Deaf parents usually have learned ASL as their first language and are members of the Deaf community, even if they have normal hearing.¹²

Membership in the Deaf community can often be predicted by knowing at what age a person became deaf. People deafened earlier in life are more likely to use ASL than English. This is particularly true of people who have never heard English, those who were deafened before the acquisition of language at around age 3 (prelingually). These people tend to become members of the Deaf community.

People deafened in adulthood are more likely to have good English skills, as well as hearing friends and a hearing spouse or partner. Having heard English before, communication through English speaking and speech reading is somewhat easier than for prelingually deafened adults. In addition, learning a new language, including ASL, is more difficult for adults than it is for children. Thus, these deaf people are less likely to become members of the Deaf community.

Most Deaf people partner with other Deaf people; 95% of Deaf marriages involve two deaf people.¹³ More than 90% of their children are hearing people.^{4,12} Some Deaf people have a hearing spouse or partner. If these hearing partners are fluent in ASL, often they, like hearing children of Deaf parents, are also part of the Deaf community.

Families

Families with Deaf adults and hearing children have similarities to families in other cultural minority communities. Although the parents communicate within the family mostly using ASL and socialize within the Deaf community, hearing children become fluent in English and have better integration with the majority culture. Like the assimilating children of immigrant families, hearing children in Deaf families have an ability to interact both in their parents’ culture and in the majority community. Often these children will act as interpreters between their parents and people in the mainstream culture. This bicultural/bilingual role continues into adulthood, and it is not uncommon for hearing children of Deaf parents to continue in this fashion as a cultural bridge by working in a deafness-related field.¹¹

Table 1

Similarities Between the Deaf Community and Some Other Minority Groups

Social

- Use of a non-English language
- Socialize and partner/marry within community
- Cultural norms different than those of the majority community
- Children often become bicultural/bilingual

Power

- Lower education level, socioeconomic status, and literacy than the general population
- Often encounter prejudices that limit opportunities
- Limited access to English language-based information

Health care

- Infrequently encounter a doctor from their own cultural group
- Language differences and health knowledge limitations are often barriers to appropriate health care.

The experience of deaf children with hearing parents is quite different from children in most other minority groups. Approximately 90% of deaf children have hearing parents.¹² Communication between deaf children and hearing family members is often quite limited. Most families do not learn ASL. Rather than learning ASL and other aspects of the Deaf community from their parents and families, deaf children learn them from deaf peers, often at residential schools for deaf children. The experience of residential schools is of easy, visually oriented communication with others who are similar. Often there is a feeling of finally fitting in. Visiting home can mean feeling different and isolated, such as being excluded from family dinner table conversations that are not being signed.¹⁴ “My family never discussed anything important at dinner,” a deaf man recalls. “Whenever they would laugh at the table, I would ask what had happened, and they would say, ‘Oh, it’s not important’.”¹⁴ Residential schools and deaf peers play an important role in culture transmission in addition to becoming surrogate families for many Deaf people. Deaf people have limited access to their parents’ culture, and their parents often have limited understanding of their children’s culture.

The Deaf experience of culture transmission—horizontal (from peers) rather than vertical (from parents)—is different from that of many cultural groups, but it is similar to one cultural minority group in the United States: the homosexual community.¹⁵ Both Deaf adults and homosexual adults can feel isolated from their parents and their parents’ culture and community. Both may feel rejected by their parents for being different from their parents, a difference over which they have no control. Both homosexuals and Deaf people may find that their “difference” is often viewed from a

medical pathology perspective rather than a sociocultural perspective. For both groups, parents may mourn the loss of the “perfect child,” the idea that their child will not grow up to meet their expectations. Although both homosexual adults and Deaf adults may have some connection to their family’s culture and ethnicity, they also may have a strong bond to a community in which their parents are not members.

Deaf Culture

As with other cultural minority groups, the Deaf community has its own theater, poetry, literature, and humor. There are also social rules that differ from those of the majority culture, and these differences sometimes result in confused interactions between hearing and Deaf people.

Attention-getting behavior in the Deaf community cannot depend on an auditory signal. Clearing one’s throat or politely saying “excuse me” will not attract a deaf person’s attention. Acceptable methods to get someone’s attention in the Deaf community rely on the senses of touch and vision rather than hearing. Touching someone who is close by to get their attention is acceptable. Stomping one’s foot or banging on a table, ways of communicating through vibrations, are also acceptable, as is waving a hand within a person’s visual field. For the uninitiated hearing person, waving, stomping, and banging can seem socially inappropriate. Because the Deaf community has different rules about touching, touching considered appropriate for a Deaf person may seem overly forward to a hearing person.

A typical example of differences in social rules involves a Deaf man who describes an experience of a cross-cultural miscommunication. He and his Deaf wife are called in for a parent-teacher conference because their hearing first-grader has been behaving inappropriately in school. They are surprised that their son’s teacher is concerned that he does not know the difference between “good touch” and “bad touch.” At the parent-teacher conference, the teacher describes the boy’s behavior. When their son wants to get his teacher’s attention, he taps her on the thigh. The parents are relieved. Viewed in a Deaf cultural context, this first-grader’s behavior is appropriate. The best way for this child to get the attention of his Deaf parents or their Deaf adult friends is to touch them. At his age and height, the closest place to touch happens to be the adult’s thigh. In this case, the misunderstanding is explained, and the son receives a lesson on the different social rules at home and school.

Another situation in which differences in social norms can lead to cross-cultural miscommunication is conversation closing. Leave-taking in the Deaf community is usually a prolonged process by hearing-

community standards.¹⁶ This is probably because communication in ASL requires face-to-face interactions. Telephone conversations for Deaf people, using telephone teletypes (called TTYs or TDDs), require typing in English and are not a satisfying way to communicate for many people. Because face-to-face communication is valued, the relatively short “goodbye” typical of conversation closing by hearing people, including physicians, can be considered rude by Deaf people.

Because Deaf people have a community that emphasizes visual aspects of the world, cultural etiquette allows a person to be described by physical characteristics, such as their weight, the shape of their nose, or their receding hairline. Descriptions such as these are often felt to be rude in hearing culture. Within the Deaf community, there is also an emphasis on information access. When a hearing physician tries to deliver news in a way that is intended to be gentle, it may be perceived as offensive to a Deaf person who feels that the physician is trying to withhold information.

American Sign Language

ASL is a source of pride in the Deaf community and is an important aspect of Deaf culture. ASL was not recognized as a proper language by linguists until the 1960s¹⁷ and differs from other sign systems used in the United States in that it is a natural language that has evolved with the community over time. Other sign systems, such as Signed Exact English and Cued Speech, are artificial coding systems created by educators and linguists, and these systems are often more difficult to use than naturally occurring languages. Like Morse code, these other sign systems are alternative ways to communicate using the English language. ASL, however, is not manually coded English or finger-spelled English words. Although ASL is quite different from English, it does share features with other languages: there is no present tense of the verb “to be,” as in Hebrew; adjectives follow nouns, similar to the Romance languages; and the pronoun system, like Cherokee,¹⁸ is more complex than English. Because English and ASL are so different, it is difficult to speak English and sign ASL simultaneously, as it would be if one were trying to speak English while simultaneously writing in French. Unlike spoken languages, ASL takes advantage of three-dimensional space to express thoughts. Unlike English, but similar to many of the world’s spoken languages, ASL does not have a written form.¹⁹

ASL is not solely a manual language. In addition to the hands, ASL uses facial expression, body posture, and space around the signer. Sometimes this use of body and face to communicate can result in health care professionals misdiagnosing an expressive Deaf person as having tics, inappropriate affect, and personality and mood disorders.²⁰⁻²²

Oral Communication

The preferred mode of communication within the Deaf community is ASL. The visual nature of ASL allows for accurate transmission of information to and from people who cannot hear. There are deaf people who communicate orally by voicing in English and speech reading. However, the reason why some deaf people do not communicate orally is sometimes unclear to hearing people.

In oral communication, receptive language usually consists of speech reading, which involves watching lip shapes and nonverbal clues to determine what is being said. Speech reading is a difficult skill. Only 30%–40% of English is distinguishable on the lips.^{6,20,23} The remainder of the sounds are ambiguous, requiring guesswork. The difficulty of reading lip shapes has been compared to reading the whorls of fingerprints.¹⁴ Because of the guesswork involved and the resulting decrease in communication accuracy, speech reading can be an unsatisfying way to communicate.

To express themselves orally, deaf people voice in English. For hearing people, learning how to speak a language involves trying to copy the sounds heard spoken by others. Hearing persons listen to the sounds they make themselves and can then make adjustments until the sounds coming from their own mouths match the words they hear spoken by others. For deaf children, there are no heard sounds to copy. There are also no sounds that can be heard coming from their own mouths, so there is no easy way to correct their own pronunciation. This makes learning to speak difficult. Voice modulation is also difficult for deaf people. The response of many hearing people to the unmodulated voice of a deaf person is often negative, such as a shocked facial expression or teasing by children. Attempts to avoid these negative reactions, in addition to the difficulty of learning to speak a language that they cannot hear themselves, are reasons why many Deaf people do not often voice for themselves.

Literacy, Education, and Fund of Knowledge

The average literacy level of a deaf high school graduate in the United States is 4th–5th grade.^{6,17} Many hearing people are surprised by this, but imagine learning to read when you are unable to sound out unfamiliar words. It has been suggested that the low English literacy of the US Deaf community is related to the fact that ASL has no written form,²⁴ but historical events suggest otherwise.^{25,26} More likely, the reasons for the low literacy level of Deaf adults are multifactorial, with delayed language acquisition by deaf children with hearing parents as one contributor.

Low literacy in English is probably also related to the fact that for many Deaf people, English is a second language (ie, second to ASL). Knowledge of medical vocabulary is limited for US Deaf people, similar to

non-English speaking immigrants to the United States.⁷ This is important to consider when using printed health education materials or written instructions with Deaf patients.

Another contributor to the low literacy level for Deaf adults may be the lack of consensus on the methods and content of education for a deaf child. Class time spent learning speech reading and proper voicing is time spent not learning other subjects, including reading. One deaf woman describes learning in school about the French Revolution:

We spent 2 weeks learning to say 'guillotine' . . . Then you go out and say 'guillotine' with your deaf voice, and they haven't the slightest idea what you are talking about—usually they can't tell what you're trying to pronounce when you say 'Coke' at McDonald's.²⁷

Limited exposure to some topics in school for deaf children contributes to the limited fund of knowledge often experienced by Deaf adults, but low literacy is also a factor. Information from newspapers, magazines, and television captioning is less accessible than it is for hearing people. Deaf people also do not have access to "ambient information." They do not overhear conversations or hear radio and television announcements. Thus, Deaf adults have limited access to information that many hearing adults would consider common knowledge.

For these reasons, health care messages delivered through print, radio, and television may not be effective with the Deaf community; this has been demonstrated regarding their knowledge about and attitudes toward HIV.^{3,28,29} Health education videotapes and presentations in ASL may be more effective ways to reach this population.

Health knowledge limitations also affect provider information gathering during a patient encounter. Most hearing adults learn about their medical family history and their own early childhood illnesses by overhearing family conversations or their parents answering questions posed by their physician. Deaf children cannot overhear these conversations and later, as adults, may not know the answers to these questions.³⁰ They also may not even know that this information is important to their physician.

Doctor-Patient Communication

Determining the best strategies for communication between doctor and patient is ideally a mutual decision. When the patient is Deaf and the physician is not fluent in ASL, working with an interpreter can facilitate communication. Unlike other people for whom English is a second language, Deaf people are often expected to communicate with physicians via speech reading and note-writing in English.^{7,23,31–33} Deaf people

are the only non-English speaking group that may be judged to be mentally retarded if they are incapable of composing a grammatically correct English sentence.⁷ Deaf people frequently report that physicians do not understand them,^{7,33} and they are less likely to try to explain themselves again than are non-English-speaking immigrants.⁷ Although physicians and patients report that sign language interpreters would facilitate communication, interpreters are infrequently used.^{23,33} Lack of reimbursement for physicians' costs for interpreter services has been reported as one difficulty of working with Deaf patients.³⁴

The guidelines for working with ASL interpreters are similar to those for working with other language interpreters. It is best to work with trained interpreters and to avoid family members and other nonprofessional interpreters because of the potential negative effect on patient care.^{35,36} Whereas many languages are interpreted consecutively, so that only one person is speaking at a time, ASL is usually interpreted simultaneously. The ASL interpreter will often sit to the side and a bit behind the physician. This allows the Deaf person to see both the interpreter's signing and the physician's nonverbal expressions. During family meetings or other situations where there is not one-to-one communication, it is usually best to allow the Deaf people and interpreters to determine a seating arrangement that allows for good communication. A Deaf person watching an interpreter rather than the person speaking is sometimes distracting,⁵ particularly for the hearing person who is speaking. It is important to remember, however, that without watching the interpreter, the Deaf person cannot know what is being said.

Medical interventions sometimes limit doctor-patient communication, particularly in inpatient settings. Whether through ASL or writing, use of one's arms is important for a Deaf person's communication. Thinking about this can be helpful when choosing an intravenous site or using an arm board or arm restraints.

Health Care Experiences

For Deaf adults, memories of childhood health care experiences are often negative. They may involve tests of hearing, fitting for hearing aids, and even ear surgery. These interventions may all seem to be attempts to make the deaf child become a hearing individual. Many Deaf adults, however, view their deafness as an essential part of their person and as a connection to their cultural community. Medical interventions to cure or limit their deafness may be viewed as rejection.³⁷ This reaction is often confusing to well-intentioned hearing physicians. This confusion may be rooted in the physicians' medical model of deafness as pathology.

Differences Versus Pathology

Recognizing that physical differences do not define members of a population is important to the apprecia-

Table 2

Recommended Initial Reading About Sociocultural Aspects of Deafness

- Cohen LH. *Train go, sorry: inside a deaf world*. New York: Houghton Mifflin Co, 1994
 - Dolnick E. Deafness as culture. *Atlantic Monthly* 1993;Sept: 272(3)37-40,43,46-8,50-3
 - Sacks O. *Seeing voices: a journey into the world of the deaf*. Los Angeles: University of California Press, 1989
 - Wilcox S, ed. *American deaf culture, an anthology*. Burtonsville, Md: Linstok Press, 1989
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tion of human diversity. 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. Communities often define themselves by who they are and what they do and not by how they compare to an outside reference group. Although hearing levels and melanin levels are pertinent features of members of the respective minority populations, they are not the defining feature.

The pertinence of deafness to the Deaf community can be seen in the discussion of cures for deafness. It is sometimes surprising to hearing people that some Deaf people do not want their deafness cured and that some Deaf couples prefer to have deaf children.³⁸ If hearing would make life easier, why would a Deaf person decline to become hearing? It is often easier to be Caucasian or male in our society, yet many women would not become male and many African-Americans would not become Caucasian to gain the benefit of that ease. Although the physical feature is not the defining feature for members of the community, it is pertinent to individual identity and a connection to others in the group.

Limitations

This article is a hearing family physician's perspectives on the US Deaf community. Information presented here is not generalizable to all people with hearing loss, since not all people who are deaf or hard of hearing are members of the Deaf community. Many Deaf communities elsewhere have similar issues but may not use ASL and may have different cultural rules. Statements made about the US Deaf community in this article generally refer to the majority of the US Deaf population who are Caucasian. There are some regional variations in language and culture within the US Deaf community just as there are in the hearing community. There are also racial differences, including an African-

American variant of ASL analogous to the relationship between the English language dialects of Black English Vernacular and Standard American English.

Conclusions

The Deaf community is a linguistic and sociocultural minority group, although it is not often recognized as such. Information learned from working with Deaf people is often generalizable to members of other minority populations. Teaching about the Deaf community as a linguistic and sociocultural minority group may help current and future physicians think more broadly about issues of culture and human diversity, as well as help them to be more culturally sensitive physicians.

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REFERENCES

- Ries PW. Prevalence and characteristics of persons with hearing trouble: United States, 1990-1991. *Vital Health Stat* 10 1994;188.
- Gentile A. Persons with impaired hearing: United States, 1971. *Vital Health Stat* 10 1975;101.
- Van Biema D. AIDS. *Time* 1994 Apr 4;143:(14)76-7.
- Benderly BL. Dancing without music: deafness in America. Garden City, NY: Anchor Press, 1980.
- Lotke M. She won't look at me. *Ann Intern Med* 1995;123:54-7.
- Davenport SLH. Improving communication with the deaf patient. *J Fam Pract* 1977;4:1065-8.
- McEwen E, Anton-Culver H. The medical communication of deaf patients. *J Fam Pract* 1988;26:289-91.
- Like RC, Steiner RP, Rubel AJ. Recommended core curriculum guidelines on culturally sensitive and competent health care. *Fam Med* 1996;27:291-7.
- Haq C. Does culture matter in health care? Creating a longitudinal multicultural medical school curriculum. *Quarterly, the Wisconsin Medical Alumni Magazine* 1997;37:16-7.
- Ralston E, Zazove P, Gorenflo DW. Physicians' attitudes and beliefs about deaf patients. *J Am Board Fam Pract* 1996;9:167-73.
- Padden C. The deaf community and the culture of deaf people. In: Wilcox S, ed. *American deaf culture: an anthology*. Burtonsville, Md: Linstok Press, 1989:1-16.
- Padden C, Humphries T. *Deaf in America: voices from a culture*. Cambridge, Mass: Harvard University Press, 1988.
- Harvey MA. Psychotherapy with deaf and hard-of-hearing persons: a systemic model. Hillsdale, NJ: Lawrence Erlbaum Associates, 1989.
- Mow S. How do you dance without music? In: Wilcox S, ed. *American deaf culture: an anthology*. Burtonsville, Md: Linstok Press, 1989:33-44.
- Dolnick E. Deafness as culture. *The Atlantic Monthly* 1993; 272:(3)37-40,43,46-8,50-3.
- Hall S. Train-gone-sorry: the etiquette of social conversations in American Sign Language. In: Wilcox S, ed. *American deaf culture: an anthology*. Burtonsville, Md: Linstok Press, 1989:89-102.
- Sacks O. *Seeing voices: a journey into the world of the deaf*, first edition. New York: HarperCollins, 1990.
- Pinker S. *The language instinct*. New York: HarperCollins, 1994.
- Committee on Disabilities of the Group for the Advancement of Psychiatry. Issues to consider in deaf and hard-of-hearing patients. *Am Fam Physician* 1997;56:2057-68.
- Steinberg A. Issues in providing mental health services to hearing-impaired persons. *Hosp Community Psychiatry* 1991;42:380-9.
- Phillips BA. Bringing culture to the forefront: formulating diagnostic impressions of deaf and hard-of-hearing people at times of medical crisis. *Professional Psychology Research and Practice* 1996;2: 137-44.
- Pollard RQ. Psychopathology. In: Marschark M, Clark D, eds. *Psychological perspectives on deafness, volume two*. Mahwah, NJ: Lawrence Erlbaum, Inc, 1998.
- Ebert DA, Heckerling PS. Communication with deaf patients: knowledge, beliefs, and practices of physicians. *JAMA* 1995;273:227-9.
- Balkany T. A brief perspective on cochlear implants. *N Engl J Med* 1993;328:281-2.
- McDermott R, Varenne H. Culture, development, and disability. In: Jessor R, Colby A, Shweder R, eds. *Ethnography and human development: context and meaning in social inquiry*. Chicago: University of Chicago Press, 1997.
- Van Cleve JV, Crouch BA. *A place of their own: creating a deaf community in America*. Washington, DC: Gallaudet University Press, 1989.
- Solomon A. Defiantly deaf. *New York Times Magazine* 1994;Aug 28:38-45,62,65-8.
- Peinkofer JR. HIV education for the deaf, a vulnerable minority. *Public Health Rep* 1994;109:390-6.
- Woodroffe T, Gorenflo DW, Meador HE, Zazove P. Knowledge and attitudes about AIDS among deaf and hard-of-hearing persons. *AIDS Care* 1998;10:377-86.
- DiPietro LJ, Knight CH, Sams JS. Health care delivery for deaf patients: the provider's role. *Am Ann Deaf* 1981;126:106-12.
- MacKinney TG, Walters D, Bird GL, Nattinger AB. Improvements in preventive care and communication for deaf patients: results of a novel primary health care program. *J Gen Intern Med* 1995;10:133-7.
- Zazove P, Niemann LC, Gorenflo DW, et al. The health status and health care utilization of deaf and hard-of-hearing persons. *Arch Fam Med* 1993;2:745-52.
- Schein JD, Delk MT. Survey of health care for deaf people. *The Deaf American* 1980;32:5-6,27.
- Kulback S. Communicating with deaf patients (letter). *JAMA* 1995;274:795.
- Woloshin S, Bickell NA, Schwartz LM, Gany F, Welch G. Language barriers in medicine in the United States. *JAMA* 1995;273:724-8.
- Haffner L. Translation is not enough—interpreting in a medical setting. In: *Cross-cultural medicine—a decade later (special issue)*. *West J Med* 1992;157:255-9.
- Swanson L. Cochlear implants: the head-on collision between medical technology and the right to be deaf. *Can Med Assoc J* 1997;157:929-32.
- Caplan A. Let's listen to arguments about deafness. In: Caplan A, ed. *Moral matters: ethical issues in medicine and the life sciences*. New York: Wiley, 1995:127-8.