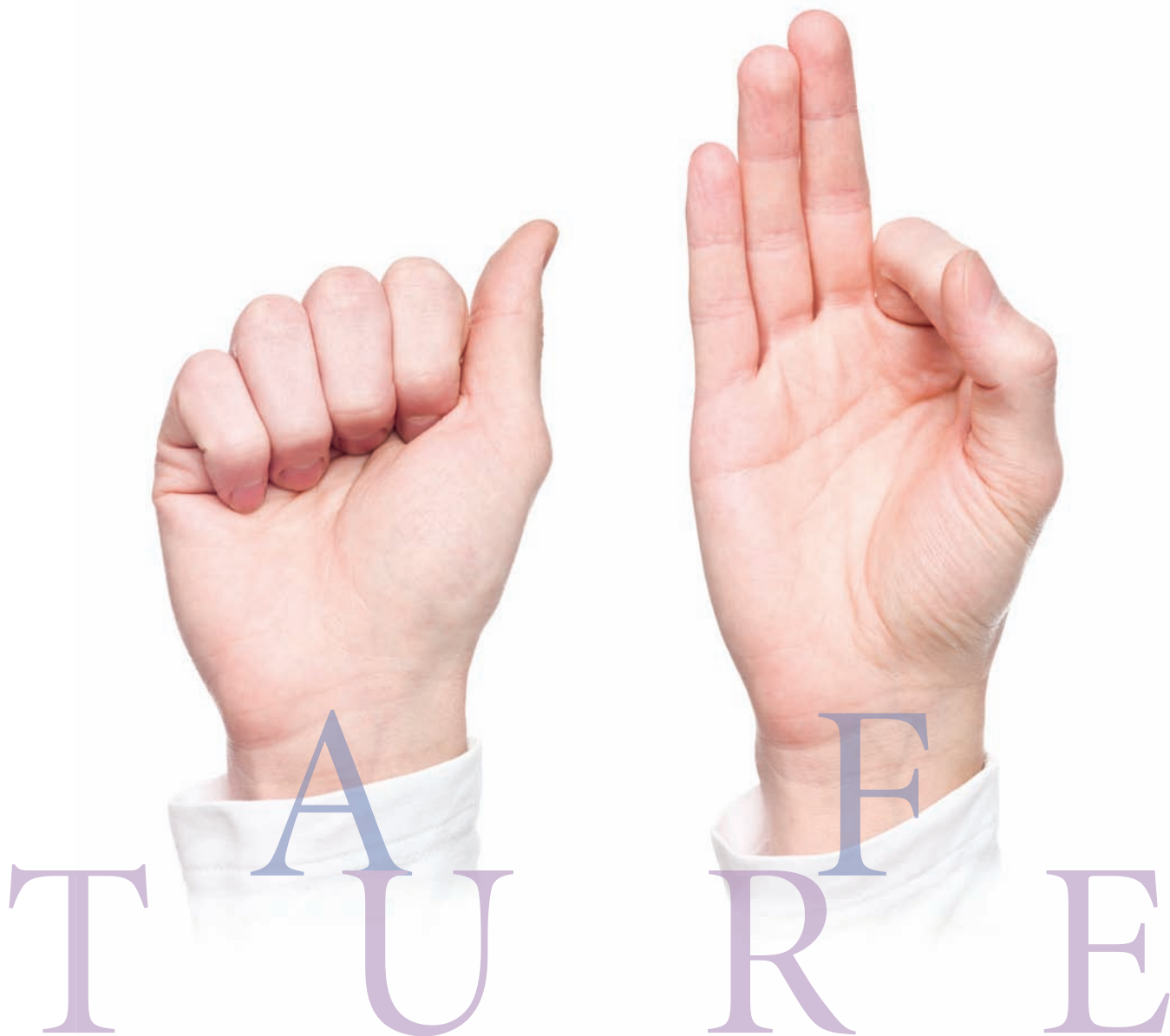




Abstract: To successfully navigate in the hearing world, deaf individuals must be able to read and write to bridge the gap when others do not know American Sign Language. Unfortunately, 90% of deaf children are born to hearing parents and do not develop language skills early on, which negatively impacts their ability to access health information and healthcare. Healthcare providers must ensure they provide culturally competent care and their practices accommodate the needs of deaf patients to mitigate communication barriers and ensure equitable care with positive health outcomes.

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Competencies and best practices

By Kathleen J. Richardson, DNP, ARNP, NP-C, CEN

Three factors affect health behaviors: health literacy, culture/cultural barriers, and language proficiency.¹ Attempts to overcome all three barriers for the deaf have been inconsistent along with the results. To successfully navigate in an unaccommodating hearing world, deaf individuals must acquire the ability to read and write to bridge the gap when others do not know American Sign Language (ASL). Unfortunately, 90% of deaf children are born to hearing parents but do not develop language skills early on in life. With English as a second language, deaf individuals tend to

have low-status jobs, limited education, higher unemployment, and face cultural and linguistic challenges in accessing healthcare. All of these factors result in poorer health and decreased utilization of preventive services.^{2,3}

Legislative measures ensuring equitable access and protecting vulnerable populations exist. However, the healthcare system does not always adhere to these laws. All providers are responsible to ensure patients are well-informed active partners in healthcare. Providers espousing to “do no harm” are ethically bound to provide culturally competent care.

Keywords: communication, deaf, healthcare, improving healthcare outcomes, patient and provider communication

However, the majority of providers do not understand the deaf community and do not accommodate cultural and linguistic requirements.⁴

Providers with cultural competence pursue a holistic approach to patient care in context with the patient sense of self.² Cultural Diversity training and references provide an opportunity to understand individuals within the context of their culture. However, these efforts focus on racial and geographic cultures, such as Hispanic, Asian, Black, and American Indian cultures. The deaf culture is rarely mentioned, resulting in an uninformed and ill-prepared healthcare system with substandard care outcomes.

■ Method

An exhaustive search was conducted utilizing electronic databases and the Boolean phrases “deaf and healthcare” and “deaf and culture.” Literature regarding the deaf population is not robust, and all articles relating to deaf individuals, communication, and culture were included.

■ Theoretical framework

Leininger’s theory of culture care diversity and universality was utilized as the guiding theoretical framework for evaluation of articles and development of recommendations. Leininger’s theory states that people solve problems about the human condition based on their perceived cultural frameworks. If care is not congruent with cultural/personal beliefs, stress levels increase, and health behaviors and overall health decreases.⁵

■ Total deaf population

A true accounting for the deaf population is difficult to determine. The last federal government census asking about deafness was conducted in 1930. Current U.S. Census Bureau calculations estimate the deaf population to be over 10 million.⁶ The survey of Income and Program Participation estimates that approximately 1 out of every 20 Americans are deaf or hard of hearing, 2 to 3 of every 1,000 children are born deaf, and 90% of deaf children are born to hearing parents.^{7,8}

■ Social theories

Throughout history, people who are deaf have been referred to as having a medical condition, being disabled, and, more recently, having a distinct culture. Historically, deaf persons were isolated and unable to connect with other deaf individuals. As such, they were marginalized and thought to be inferior. Early in the 19th century, this perception changed as deaf schools opened. Deaf individuals were able to gather, share common experiences and thoughts, and develop a community. These schools provided a better sense of identity, role models, and self-worth, and facilitated the

development of deaf communities where the deaf could be with similar persons, communicate, and develop a “family.” However, this environment was short lived.⁹

The late 1800s saw extensive emigration and evolution of the “melting pot” concept, which propagated the belief that deaf persons should assimilate into the speaking/hearing culture, and “oralism” became enforced. In the hearing world, deaf participation was limited because the hearing culture became the standard by which persons and abilities were measured. Since the deaf community could not equally participate with the hearing, they were again marginalized. The deaf were perceived as a minority group, which created barriers to upward mobility, access to services, and acceptance.⁹

Presently, social theorists consider the deaf community a subculture of the larger hearing population that developed in response to marginalization from the hearing population. The deaf culture developed and continues to evolve through common experiences and a sense of belonging. This evolution differs from most cultures, since membership does not happen at birth.⁹

■ Culture and ethnicity

Culture is a set of shared values, practices, conventions, and attitudes.¹⁰ Culture is learned through interaction and strengthened as individuals with shared experiences connect and further refine their values, practices, conventions, and attitudes. Traditionally, culture is learned from parents. However, deaf persons are typically born to hearing parents unknowledgeable of deaf culture.¹¹ Most parents do not know ASL or learn to communicate with their children, and a language delay develops. The deaf child may not be able to socialize and develop friendships.¹¹ A lack of communication is a common shared experience for deaf individuals. This communication void and inability to communicate with the world is the first of many cultural experiences demonstrating that the individual is different and belongs to the deaf culture. As deaf individuals become exposed to sign language and other deaf persons, the enculturation process becomes complete, and deaf persons identify themselves as ethnically deaf.¹²

Ethnicity is a product of situational and strategic adaptive processes, which develop identity boundaries and cultural content and context. Belonging to an ethnic group is a rational decision. It is not a matter of shared genetics or ancestry. Instead, ethnic groups share commonality. The ethnically deaf have similar physical abilities, customs, and shared experiences. Discrimination for inability and resistance to assimilate fully into the greater hearing culture creates a “sense of Peoplehood” among the deaf and defines their shared ethnicity (see *Ethnic components of deaf culture*).¹³

Ethnic components of deaf culture¹⁴

Utilizing the distinct properties of ethnic group categories, this table describes deaf cultural and ethnic norms.

Ethnic component	Deaf cultural/ethnic norms
Collective name	Deaf-World (Capital "D" [Deaf] indicates deaf culture. Lower case "d" [deaf] indicates the condition of deafness).
Feeling of community	Self-recognition, strongly identify with each other because of communication ease, feeling of being welcome, and deaf marry other members of the Deaf-World (99%).
Behavioral norms	Decisions are consensus based; all information is shared.
Distinct values	Allegiance to Deaf-World culture; belonging is important, endogamous marriage, commitment to contributing to the DeafWorld and treasuring the contributions.
Knowledge	Know important events in deaf history; understand when it is best to use ASL versus English.
Customs	Methods of introductions, taking turns, polite, frank speaking, sharing of information (no secret conversations).
Social structure	Organizations specifically for the deaf, endogamous marriage, tendency to live in proximity to each other.
Language	Visually-based communication and language, ASL competence—not sound. ASL-specific narratives, humor, poetry, and visual arts.
History	Know and share history, territory, and genealogy through stories, books, movies, and commonality (shared experiences).
Kinship	Strong immediate connection to other deaf persons and Deaf-World when introduced, regardless of geographics. All are a part of a larger family defined by deafness not genealogy. Biologic similarities of deafness provide the biologic resemblance across generations. Strong attachment to residential schools and vacation travel includes visiting these schools. Culture knowledge, norms, language, and values are shared and learned through socialization into deaf culture typically after having similar experiences in a nondeaf world that does not embrace the deaf child into its culture.
Ethnic boundaries	The Deaf-World has distinct boundaries specific to the culture (sign language, social activities, ASL teaching, political issues and activities, athletics, arts and leisure, employment, and publishing); they are fluent in the visual world and their activities flourish in these media. The Deaf population faces discrimination. Society does not accommodate their "natural variance." Use of a different language than spoken English (much like immigrants who do not do well in school and society related to communication barriers) emphasizes similarities with other minority groups requiring understanding and each can learn and support each other, but specific issues and agendas are different for each minority and cannot be lumped together.

■ Perceptions

Perceptions of deafness differ. Webster's Dictionary defines deafness as "lacking or deficient in the sense of hearing" or "not able to hear."¹⁰ These definitions reflect the medical model perception that deafness is a disability requiring cure.⁹

The hearing population views deafness as a medical condition/disability that requires treatment and reflects hearing persons' expectations that deaf persons should learn to navigate without accommodation.¹⁴ The majority of deaf persons come from a hearing family (greater than 90%), and most families expect deaf family members to assimilate into the speaking/hearing culture and do not become fluent in ASL to communicate with their deaf children.³

The western medical model focuses on curing illness or deviation from the norm. Deafness is considered an abnormal finding and therefore must be cured. This perspective

results in promotion of invasive procedures and anti-deaf culture policy. Providers practicing "good" western medicine may discourage parents and children from learning sign language or embracing deaf culture practices. Cochlear implants and surgeries are espoused as the only options to cure the disability of deafness, and to not do so would be a disservice.¹⁴

The deaf do not believe themselves to be disabled and do not perceive their existence as disabled persons do. Typically, disabled individuals hope their children are not born with a disability. Instead of hoping that their children are not born deaf, deaf persons tend to hope that their children are born deaf but do not mind if they are hearing. The deaf welcome deaf spouses, family, friends, and value their differences from hearing society.¹⁴

The deaf community does not see value in surgeries for cochlear implants, since deafness is not a disability, and sur-

gery has too many risks. Cochlear implants do not make the person exactly the same as hearing individuals and impede communication and socialization. Children with cochlear implants do not learn ASL and have no language or way to communicate for several years, causing a diminished quality of life.^{13,14} The deaf community believes that hearing parents of deaf children are not provided comprehensive information from medical providers when considering surgical or alternative options, and parents may not consider the child's wishes—just their own. The deaf view surgical procedures and genetic counseling/manipulation as forms of eugenics to eradicate deafness.¹⁴ Advocates for the deaf community suggest that parents should become fully engaged in the deaf culture to understand their child and his or her wishes before any procedures.¹⁴

The deaf community is different than deaf culture. Those affiliated with deaf persons help form the deaf community and include deaf, SL interpreters, hearing parents, siblings or children, ex-oralists, and signing deaf.^{9,13} This community is composed of persons with varying levels of hearing and identify themselves differently. When referring to deaf culture, a capital letter “D” is used (Deaf). A lower case “d” (deaf) is used when discussing the condition of deafness (hearing loss).¹³

Deaf persons are culturally deaf and exhibit deaf behaviors (language, norms, values, beliefs, spatial territory, and traditions). A person can be deaf but culturally hearing. These individuals typically do not associate with deaf communities. Hard of hearing individuals normally have already acquired English speech and writing. They have hearing spouses and consider deafness as a medical condition.^{13,14} However, all have differing perceptions regarding capabilities of the deaf.

One study investigated perceptions of deaf capabilities by comparing four groups: two hearing, one with exposure to sign language ($n = 35$), and one without ($n = 24$); two deaf, one raised in and identifying with the deaf culture ($n = 22$) and one raised in and identifying with hearing culture ($n = 19$). Although an overall positive perception of deaf capabilities was identified, perceptions varied significantly between those exposed to deaf culture and sign language and those not exposed ($F = 4.042, P < 0.05$). Deaf and hearing persons exposed to ASL and deaf culture perceived deaf persons as very capable and were not significantly different in perception scores, whereas deaf individuals raised in a hearing culture and hearing persons not exposed to deaf culture perceived deaf persons to be less capable. Most notable is that unexposed deaf individuals had the least positive perceptions of all four groups. Additionally, deaf adults raised in hearing culture had the least positive perceptions about sign language being a true language ($F = 6.302, P < 0.01$).¹⁵

■ Accessing healthcare

Deaf persons often avoid healthcare because of communication issues and distrust of healthcare providers' intentions and behaviors.⁴ They leave appointments with doubts about their experience and question whether they received appropriate care. In an attempt to mitigate these misgivings, they may go to multiple providers before finding someone who can communicate even minimally.¹⁶

The deaf experience illness and depression with similar symptoms as the hearing. However, communication barriers preclude diagnosis and treatment of depression resulting in negative outcomes. Providers both inpatient and outpatient do not have the skills to communicate effectively with deaf patients, and pressing health issues may not be identified or discussed.¹⁷ Presence of deafness can obscure other genetic problems or illness. Providers tend to focus on curing the deafness or, because of communication issues, fail to ask the right questions or provide comprehensive care.^{18,19}

Approximately 40% of deaf people have mental health problems compared with 25% in the hearing population.¹⁹ Depression can be exacerbated through misdiagnosis, remaining undiagnosed, a lack of communication or understanding of feelings/symptoms, or the inability to ask questions or seek help and familial dynamics. Current screening methods for depression are inadequate for deaf individuals. Written tools are not understood, providers typically do not screen for depression symptoms, and interpreters intrude on privacy. Even when patients want help, they do not know what to ask for and choose to remain silent rather than appear “stupid.”^{4,19}

The deaf experience negative outcomes because of poor communication. Deaf individuals are ill informed about healthcare issues and do not seek care unless sick. Fears of receiving bad or incorrect treatment inhibit willingness to seek healthcare. No accessible source of clear information creates misinformation, and deaf patients will opt for less effective treatments if they cannot understand something new.¹⁶ Most concerning is the potential for procedures being conducted without the patients being truly informed. Patients may miss crucial pieces of conversation because they could not hear the words, see the speaker's face, or understand the written words. Not wanting to appear stupid, patients may nod and pretend they understand.^{4,19,20}

Steinberg et al. identified multiple factors negatively impacting deaf health and health-seeking behaviors.³ Factors include the following: information deficit (lack of health knowledge and information, desire for information directly from the provider, knowing what to ask, inaccessible information methods); poor communication (lack of direct and clear communication, conveyance of negative

or extreme scenarios); uninformed consent and unethical behavior (fear of procedures or procedures completed without understanding, rough treatment); treatment avoidance (medical decisions avoided due to lack of information); and inadequate appointment considerations (delays, lack of time to conduct appointment, unaccommodated communication). These factors all lead to misperceptions, misdiagnoses, and stereotypes, creating suboptimal healthcare and negative outcomes.³

■ Communication barriers

Providers who do not speak ASL, negative healthcare urban legends, lack of interpreters, decreased privacy, and rough treatment all negatively impact the healthcare experience. Deaf Americans are unable to access healthcare information as readily as hearing equivalents.³ Providers are not familiar with deaf culture and are unable to communicate effectively. Current appointment and office practices are not conducive to accommodating deaf patients. Deaf patients perceive healthcare providers as unwilling to understand their needs and are frustrated with ineffective communication. They will not always be forthcoming with information or be able to adequately describe pertinent health concerns.²¹

Functional literacy, social skills, and communication abilities are directly related to the onset of language acquisition.²² Deaf children of hearing parents have delayed language acquisition and are expected to learn written and spoken English, which has dramatically different sentence structure and vernacular.²⁰ Deaf children of deaf parents who learn to communicate early and have ongoing communication and interaction with parents and family tend to have a higher intellect, a greater ability to use their intellect, and are more mature than children of hearing patients. Deaf children of deaf parents score significantly higher on intellectual functioning tests ($N = 118$, $P < 0.01$) than those with hearing parents, and social adjustment scores also show deaf children of deaf parents score higher in maturity (70%), responsibility (69%), independence (75%), and social (greater than 65%).²²

■ Methods of communication

ASL. The deaf may prefer to speak for themselves, write, or use interpreters, and this typically depends upon the particular reason for the healthcare visit.¹⁷ Deaf individuals learn and communicate visually relying on peers, family, and interpreters to provide information through ASL. ASL is the sixth most common non-English language in United States and is a combination of American Indian and French signs.^{4,23} It does not have a written form. Sign language uses

signs, body language, and facial expression, which all combine to provide a high-context method of communication.⁴

Written English. English is a second language for the deaf, and written literacy is at the second grade level. English is a low-context language with cumbersome descriptors, syntax, and vernacular. English is difficult to learn, since not every word translates well. Misunderstandings can easily occur, and patients “hear” something completely different than what is being spoken. Handwritten conversations and patient information are often illegible, and printed patient materials are not easily understood or provide limited accessible information.^{4,16,20}

Lip reading. Lip reading abilities vary and have limited application even for the most skilled lip readers. Many sounds look the same, and lip reading only yields a 30% to 40% understanding under the best conditions. Poor lighting, facial hair, indirect line of sight, and masks can obscure lips and make lip reading less effective.^{17,20} Hearing people expect deaf persons to lip read, and deaf people may fake

Deaf persons often avoid healthcare because of communication issues and distrust of healthcare providers.



understanding to avoid embarrassment and/or the stigma of “being stupid.”^{19,21}

Technology. Although the deaf community prefers direct, interpersonal communication, this is sometimes unavailable. Technology has advanced and provides options to improve communication and access to information. However, technology can be unreliable and may not convey complete information. Webcams provide real-time interaction but may not convey subtle body language and facial expressions. Prerecorded video can be used for informational purposes such as patient teaching, but they have similar conveyance issues as webcams and do not facilitate question asking for clarification. Teletypewriter/Telecommunications Device for the Deaf (TTY/TDD) can provide real-time interaction but do not provide any facial expressions or body posturing to provide full context. TTY/TDD effectiveness also heavily depends on written communication and may be ineffective due to reading/writing abilities. Additionally, the Internet can serve as a resource for health information. However, Internet effectiveness as an information source is limited by English language reading and writing ability. Furthermore, many websites are not reliable sources for providing accurate health information or guidance.²¹

Professional translators. The Americans with Disabilities Act requires interpreter services be available for all persons to facilitate and accommodate communication and to ensure equitable level of care. Professional translators can translate “on the fly” and are familiar with medical terminology, facilitating efficient and effective communication.^{21,24} However, providers do not always provide access to translators and may expect family members to interpret. Interpreters remove the aspect of patient provider confidentiality and may edit or insert information during translation. Combined, these factors propagate misinformation and a distrust of the healthcare system.^{3,21} Furthermore, ASL translators are members of the deaf community and may already know the patient or their family, which can cause the patient embarrassment and hinder open, honest communication.¹⁸

Family and friends. Family and friends are not effective translators. They usually cannot translate “on the fly” and may be unable to translate medical information. Thinking themselves as helpful, family members and friends may not share complete information and could make decisions for the patient. Additionally, patient provider confidentiality is negated. These factors discourage deaf people from seeking care or using family or friends for translation.^{16,21}

■ Policies

Several policies and laws have been enacted to facilitate equitable access to care and services for minorities, the disabled, vulnerable populations, and many apply to the deaf community. The Americans with Disabilities Act of 1990 and subsequent amendments apply to the right for reasonable accommodation. It mandates that providers have qualified ASL interpreter or other means available to facilitate equal communication.^{4,21,24}

The Joint Commission and Office of Minority Health national standards require culturally and linguistically appropriate services and care. Reasonable accommodations are the responsibility of the provider, and the provider pays for the services, which can include medical ASL interpreters, telecommunication, closed captioning, and real-time video. Unfortunately, little emphasis is placed on deaf accommodations at most hospitals, and providers do not pay for deaf services despite their legal obligation.²¹

Until recently, ASL was not considered a foreign language. It was not taught in schools, and few hearing individuals had exposure. In 2004, the Education Reform and Funding Act “No Child Left Behind” included ASL as a foreign language and declared that ASL meet university acceptance for foreign language requirements.²⁵ ASL is now taught in many high schools across the nation.^{14,21}

Recognition of ASL as a foreign language facilitated application of Congressional statutes pertaining to language and minority students to deaf students. The Bilingual Education Act (P.L. 89-10, Title VII, 1965) provides school minority language program funding, Civil Rights Statutes (P.L. 88-352, Title VI, 1964; P.L. 93-380, 1974) mandate the removal of language barriers, and provision of equal educational opportunities now apply to the deaf population.²⁶⁻²⁸ This means that the curricula, teachers, and institutions must facilitate communication and education for deaf students.

Finally, the United Nations Declaration of Rights of Persons Belonging to National or Ethnic Religious and Linguistic Minorities was enacted in 2003. It states that diminishing minority cultures is a crime against humanity and emphasizes protecting different cultures through education and cultural competency.²⁹

■ Recommendations

The healthcare community can best serve the deaf population through understanding, acceptance, and fostering effective communication. Multiple components of the healthcare environment can be improved upon to facilitate effective patient provider communication and improve health practices/outcomes for the deaf. Identified areas for improvement include the following: the physical environment, provider behavior, use of technology, use of interpreters, patient teaching, patient assessment tools, and provider education (see *Recommendations to improve patient/provider communication*).

■ Recommendations for future study

Future study should focus on identification and development of methods to better facilitate communication between deaf patients and their healthcare providers. Communication methods should include patient health education materials, health screening tools, medical sign language resources, and technologic resources. Additionally, research could focus on provider education to facilitate cultural competency in practice and behavior. Finally, inclusion of deaf persons and advocates in the research process, tool/program development, and subsequent implementation is highly recommended to ensure that the developed tools/programs are not only culturally appropriate but also effective and understood by deaf patients.

■ Accommodating deaf patients

Deaf individuals face multiple communication barriers, which place them at high risk for developing preventable disease. Barriers and health risk are related to the degree of hearing loss and communication methods. Current healthcare settings do not adequately accommodate deaf patients,

Recommendations to improve patient/provider communication²¹**Physical environment**

- Good lighting
- Space for an interpreter
- Technology in exam rooms
- Pager or call light to notify patients it is their turn to be seen
- Visual patient education materials in waiting room
- Closed captioning (CC) on TV screens

Provider behavior

- Speak and write clearly, using plain English and clearly identify topic changes
- Congruent facial expressions and message
- Face patient and maintain eye contact
- Keep hands and items away from face
- Tell patient what you are going to do before doing it
- Speak directly to the patient
- Encourage and allow time for questions
- Show genuine interest and respect
- Ask patient and accommodate preferred communication method
- Have patient repeat information to verify understanding
- Do a complete review of systems (ask all questions).
- Become culturally competent and help parents of deaf children become culturally competent.
- Use appropriate (visual) screening and teaching methods.
- Learn ASL alphabet and basic signs.
- Avoid placing I.V.s in patient hands.

Use of technology

- Have technology in working order and readily available.
- Know how to use technology and understand the limitations.
- Use technology if professional medical interpreter not available.
- Facilitate answering questions if standardized ASL or CC video utilized.
- Use high-resolution web cameras and video screens that facilitate visualization of facial and body language along with ASL for both patient and interpreter.
- TTY/TDD phones used as last resort since communication is limited.
- Provide patients reliable and understandable website resources.
- Partner with deaf individuals/advocates to better improve technologic communication resources.
- Payment for technology is the provider responsibility.

Use of interpreters

- Only utilize professional medical interpreters.
- Speak and look at the patient not the interpreter.

- Place interpreter where patient can see him or her and where interpreter can see the patient.
- Use interpreters before procedures to facilitate informed decision making and consent.
- Interpreters can be placed in view of patient but shielded from procedures to facilitate communication during procedures while maintaining patient privacy.
- Payment of interpreters is the provider responsibility.
- Know how to access interpreter services. Two useful websites are the registry for deaf interpreters www.rid.org and www.deaf-interpreter.com, which assists in finding qualified interpreters.

Patient teaching

- Ask patient to identify his or her preferred learning method (doing, seeing, reading) and utilize that method
- Employ visual teaching methods—video with ASL, video with CC, pictures, models
- Utilize medical interpreters and have patient back brief the information to ensure understanding
- Utilize video in conjunction with printed materials and facilitate answering questions
- Online education utilizing ASL websites
- Partner with deaf individuals/advocates to develop new teaching materials appropriate for deaf patients
- Ensure written materials are clear and in plain English
- Small group instruction using peer teaching and ASL

Teaching points for parents of deaf children: Deafness is not a medical condition, parents and family should learn ASL with their deaf child as early as possible, communication is important, provide child with exposure to deaf culture, let child make decisions about cochlear implants when old enough to make an informed decision. (Additionally provide resources for contact and support.)

Patient assessment tools

- Must be in plain, easily understood English, ASL, or pictorial format.
- Partner with deaf individuals/advocates to modify and develop appropriate patient assessment tools.

Provider education

- Cultural competency and deaf culture.
- Health literacy.
- Use of interpreters.
- Use of technology.
- English as a second language.
- Healthcare laws, reasonable access/accommodation, and provider responsibilities.
- Methods of patient teaching.

and methods to disseminate information are not culturally appropriate to ensure understanding. Instead of bridging the communication gap, culturally incompetent healthcare practices propagate health disparities for the deaf. It is imperative that healthcare providers ensure they provide culturally competent care and their practices accommodate for deaf patient needs to ensure equitable care and positive health outcomes. **NP**

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- *Studies about the Deaf Population are not regularly conducted, and information regarding the Deaf population and community is sparse. Thus, to ensure thoroughness, some references cited in this article are older than 5 years.
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