

Profound Hearing Loss: Addressing Barriers to Hearing Healthcare

Sheila R. Pratt, Ph.D.^{1,2}

ABSTRACT

The impact of profound hearing loss on infants and adults is variable and greatly influenced by improved audition derived from hearing aids and cochlear implants. However, barriers to healthcare, hearing healthcare in particular, can offset the benefits provided by these sensory devices. Common barriers include cost, location, availability of trained professionals, acceptance of the hearing loss, language and cultural differences, secondary disabilities, and mental health issues. These barriers and their distinct presentations vary somewhat by age, language, and where people live (urban vs. rural), and can interfere with receiving testing and devices in a timely manner. They also can limit auditory, speech and language therapies, and interfere with acceptance of the hearing loss and devices. Rehabilitation should focus on eliminating or reducing the adverse impact of these barriers on patients and their families. Some of which can be done through professional training and multidisciplinary activities, counseling, and community outreach.

KEYWORDS: hearing loss, barriers, healthcare, rehabilitation

Learning Outcomes: As a result of this activity, the participant will be able to identify the barriers to appropriate hearing healthcare for people with profound hearing loss.

HETEROGENEITY

It has been estimated that 3.4% of people with hearing loss in the United States have a severe-to-profound hearing loss (pure-tone average = 71 to +90 dB HL) with 8% of those being younger than 18 years.¹ This statistic does little,

however, to capture the nature and magnitude of deficits resulting from profound hearing loss because people with hearing loss, regardless of severity, are incredibly heterogeneous in their histories, background, and presentations of impairment, and therefore their restrictions

¹Geriatric Research and Clinical Education Center, VA Pittsburgh Healthcare System, Pittsburgh, Pennsylvania; ²Department of Communication Science and Disorders, University of Pittsburgh, Pittsburgh, Pennsylvania.

Address for correspondence: Sheila R. Pratt, Ph.D., Department of Communication Science and Disorder, University of Pittsburgh, Pittsburgh, PA 15260 (e-mail: spratt@pitt.edu).

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on activities and participation within their environments. They also vary with respect to the barriers that interfere with receiving appropriate services and making progress.

The implementation of universal newborn hearing screening and the advances in auditory sensory technologies have increased outcome variability and reduced the predictive power of the audiogram. As such, the distinctions between profound hearing impairment, disability, and handicap have become pronounced. For example, as recently as 30 to 40 years ago, an infant born with a profound hearing loss was often not identified until approximately 18 to 24 months of age and had a very low likelihood of acquiring intelligible speech (<20%), even with appropriately fitted hearing aids and enrollment in speech and auditory therapies.²⁻⁴ These children rarely developed normal speech production skills. In contrast, most children born with congenital hearing loss today are identified shortly after birth, diagnosed within a few months and fitted with hearing aids by 6 months, and in cases of profound hearing loss, often implanted with cochlear implants between 12 and 24 months of age.^{5,6} Consequently, many of these infants develop intelligible speech—some acoustically normal speech.⁷⁻⁹ The data from studies looking at the impact of early identification, diagnosis, and intervention on communication skill development reflect these advances, but also show that not all infants and children demonstrate substantive benefits. Despite lags in group means for speech perception, speech production, as well as language and cognitive outcomes compared with normal hearing peers, some children perform at normal or near-normal levels, whereas other children demonstrate profound deficits that show little change with age. Moreover, variability is high, especially for those children with more severe hearing losses.¹⁰

In adults, distinctions remain between communication skills and needs of people with prelingual hearing loss and those with adventitious loss, as well with individuals who opt to sign and function within the Deaf community. Age also continues to be a factor, with many elders suffering from auditory system deterioration along with other health conditions such as cardiovascular disease, diabetes,

arthritis, vision loss, motor impairment, depression, and cognitive decline.^{11,12} As such, standard audiometric test results, as well as hearing aid and cochlear implant performance, fail to adequately represent the extent to which hearing loss restricts activities and participation within their environment. This variability and heterogeneity argues for diversity of assessment approaches, individualized treatment, and increased documentation of treatment effectiveness and efficiency across various populations and settings. It also argues for patient access to professionals trained to the top of their profession—professionals with the training and skills to identify and respond to individual patient needs. Some of the barriers experienced by patients that interfere with this approach to rehabilitation relate to healthcare systems more generally, whereas other barriers are specific to hearing healthcare.

ACCESS TO HEALTHCARE

Older Adults with Hearing Loss

Adults who are hard-of-hearing or have a profound loss report more difficulties and delays accessing healthcare, especially if they are older males who are separated or divorced and have other chronic health conditions.^{11,13} Limited financial means, living in a rural area, and depression further contribute to reduced access by patients.^{13,14} In addition, adults with hearing loss often are reluctant to access healthcare due to potential communication breakdowns and the rapid pace of medical delivery. Physicians and nursing staff can be unaware of these breakdowns because people with substantive hearing loss often compensate with nonverbal gestures consistent with comprehension (e.g., head nodding). The result is poor understanding of their health conditions and information, noncompliance with prescribed or recommended treatments, and overall dissatisfaction with the healthcare delivery system. Pandhi et al¹¹ argued that hearing loss heightens barriers to healthcare with long-term negative consequences. As such, it is not surprising that adults with hearing loss tend to be less healthy and die earlier than their normal hearing counterparts.¹⁵

Deaf Individuals

Barriers to healthcare are magnified for Deaf adults who utilize healthcare less than postlingually hearing-impaired adults, but at a level similarly to other language minority groups.¹⁶ Deaf patients typically require certified interpreters and lack adequate health literacy due to limited experience with the healthcare system and reduced oral and written language proficiency. In the United States, Deaf people use American Sign Language (ASL) to communicate and they learn English as a second language, often through the process of learning to read and write. Consequently, their reading and writing skills can be compromised and interfere with access to written health information and the ability to clearly communicate through text. Limited health literacy and lack of access to health information via ASL further reduce understanding of preventative health information and existing conditions and treatments.^{17,18} Certified interpreters are usually available in large healthcare networks in metropolitan areas but commonly are lacking in independent clinics and smaller hospitals in rural areas because of cost and limited numbers of available interpreters, even though the provision of interpreters is legally obligated by federal law. Healthcare workers who sign proficiently are quite rare and those with less proficient ASL skills assume liability risks when they sign with patients about critical health issues. Some Deaf patients prefer to not use an interpreter, friends, or family members for reasons of confidentiality, and many friends and family members are unfamiliar with ASL medical terminology, as are many Deaf individuals.^{19–21}

Deaf adults with oral skills may rely on their limited auditory skills and speechreading, but oral/visual-aural communication can require substantive mental effort and increase stress and anxiety, especially in the presence of noise and visual distractors.²² Trauma and emergency situations are particularly problematic for Deaf individuals.^{23,24} A study in Israel found that relying on informal interpreters, such as family members, friends, and neighbors, can be problematic for Deaf people in those situations and accessibility to certified interpreters is preferable.²⁴ Various types of communication technologies have been developed for emergencies, but many lack effectiveness and are not trusted by Deaf people.

Differences in culture and assumptions about social interaction also can be a healthcare barrier for some Deaf patients. Deaf society tends to be more collectivist than the general hearing population in the United States, which values the individual and competition over cooperation within society. As evidenced by its emphasis on profits, the healthcare system in the United States reflects this competitive bias, which some Deaf individuals find uncomfortable. There also has been a history of medicalization of deafness that many in Deaf society do not accept, and which they consider to be an outgrowth of an oppression of Deaf people by the larger hearing society.²⁵ They hold the belief that their deafness is not an illness or a defect that needs to be fixed;^{25–27} so, receiving medical or rehabilitation services, especially otology and audiology services, can be sociologically and emotionally problematic. As a result, some Deaf people avoid or delay needed services.

There also is an impression among healthcare workers that Deaf people are difficult to work with at an interpersonal level, which can interfere with the quality of services.^{22,28,29} They have been described as aggressive, immature, impulsive, stubborn, suspicious, and unintelligent.²² These impressions likely come from communication breakdowns and differences in the social rules of communication between hearing clinicians and Deaf patients. For example, Deaf people find it impolite for healthcare workers to not maintain eye contact when communicating with them.²² The social rules surrounding physical touching and pointing for many Deaf people also differ from those of hearing people. Deaf people dislike being left out of conversations, which easily can happen when communicating through a family member or interpreter, and communication breakdowns and misunderstandings can occur because of miscues and misperceptions. As an example, facial expression is linguistic in ASL and conveys critical content and grammatical markers; so, inadvertent facial expressions by hearing healthcare workers can be confusing and easily misconstrued by Deaf patients. An added stressor is that the pragmatics of ASL can be incompatible with the fast pace of many healthcare settings.^{22,28} So, it is not surprising that Deaf people access the healthcare system less

often than normal hearing and postlingually people with hearing loss and have lower satisfaction with the quality of their care.^{30,31}

Infants and Children with Hearing Loss

Many infants and children receive healthcare through private insurances, state Medicaid programs, and the federally funded Children's Health Insurance Program (CHIP). However, many vulnerable populations continue to encounter barriers to adequate healthcare. For example, children from minority and immigrant communities, especially if the immigrant child or a family member is an undocumented alien, may avoid medical facilities. Children who are homeless or in foster care frequently are in poor health but often receive inadequate or inconsistent care.^{32,33} So too for children from poor and/or rural families who may have insurance but lack transportation, parent time off from work, or appropriate medical resources in their communities.³⁴ Adolescent children experience unique barriers to healthcare that put them at higher risk for mortality.³⁵ Of concern is their difficulty obtaining mental healthcare and counseling, particularly for drug and alcohol counselling and suicide prevention.³⁶ Children with disabilities access the medical system far more than nondisabled children and account for a large share of pediatric healthcare costs, but low-income families with disabled children carry a greater financial burden than middle- and high-income families even after accounting for insurance.³⁷ These added economic burdens and inconsistencies in coverage have implications for hearing healthcare and rehabilitation services, because many children with hearing loss have at least one other disabling condition. However, the healthcare system, like many educational systems, does not always view hearing loss as the primary condition.

ACCESS TO HEARING HEALTHCARE

As indicated earlier, universal newborn hearing screening has been highly effective in identifying congenital hearing loss, but concerns remain about delayed diagnostic testing and infants lost to follow-up for diagnostic testing. There

also are problems with the number of diagnosed infants failing to receive early intervention. The 2015 Hearing Screening and Follow-up Survey data reported by the Centers for Disease Control and Prevention indicate that out of the nearly 4 million infants born in the United States in 2015, 98.2% were screened for hearing loss and 1.7% failed the screening.⁵ Of those failing the screening, 9.9% were diagnosed with hearing loss (12.1% of the losses were profound), but 27.9% were lost to follow-up. Of the infants diagnosed with hearing loss, 87.6% were referred for IDEA Part C early intervention services, of which only 66.5% enrolled in some type of early intervention service—65.3% before the recommended age of 6 months. Therefore, despite a largely successful screening process, the goal of diagnosing and enrolling all infants with congenital hearing loss into early intervention programs by 6 months has not been fully actualized.

Barriers to receiving timely and appropriate early hearing healthcare services include location, awareness and availability of resources and appropriately trained professionals, socioeconomic status, insurance coverage, parent concerns, and other health conditions.^{38–40} Infants and children from rural areas of the country tend to be underserved because of these barriers.^{39,41} For example, many rural areas of the United States do not have otologists and audiologists trained to work with infants and young children. This can delay diagnostic testing and treatment and elevate parent concerns about hearing testing procedures and treatment options. Many families from rural areas are required to drive long distances to receive hearing aids and cochlear implants, increasing the likelihood of delayed fittings, inconsistent use of devices, and poor outcomes. Also, families from rural areas experience greater costs associated with travel and time away from work than those from more urban areas.

A lack of routine screening programs across the lifespan also acts as a barrier. Between the neonatal period and school-entry, additional children develop or acquire hearing loss. By 9 years of age, it is estimated that the prevalence of hearing loss at least doubles that found during the neonatal period.⁴² In a study by Watkin and Baldwin,⁴³ children originally screened as neonates were retested at school entry and the rate of moderate or worse hearing

loss was 1.5 per 1,000, whereas the neonatal rate was only 0.9 per 1,000. Furthermore, in a chart review study looking at progressive loss in early childhood, Barreira-Nielsen et al⁴⁴ found that about one-third of their progressive cases had passed their newborn hearing screen, although many were at risk for hearing loss and met the criteria for hearing loss surveillance.⁶ Without screening or surveillance measures, many of these children are missed until they participate in preschool child-find and school-based hearing screening programs.⁴⁵ Walker et al⁴⁶ found that later identified infants and children take longer to be diagnosed after identification and have substantial delays in receiving rehabilitation services when compared with infants identified through newborn screening programs. Compounding the problem is that these later identified children can manifest notable communication, cognitive, and learning deficits that parents and professionals fail to associate with hearing loss, especially when children have a unilateral and mild loss. Children who acquired a profound hearing loss are more quickly identified because of the pronounced impact on communication. With increased age, the onset of profound loss can be traumatic, which also tends to hasten access to services.

Routine screening for hearing loss in adults is lacking in the United States despite hearing healthcare being targeted for adults in the Healthy People 2020 recommendations,⁴⁷ and routine screening being recommended by professional health organizations.^{48,49} In 1996, the U.S. Preventive Services Task Force⁵⁰ endorsed the screening of asymptomatic adults aged 50 years and older for hearing loss in primary care settings. In 2009, it reviewed the current evidence for screening hearing loss in older adults^{51,52} and found that hearing screening was related to increased hearing aid use 1 year later, and that fitting hearing aids subsequent to screenings produced positive results. However, no improvements were seen in functional auditory performance. The screening programs benefited adults at risk for hearing loss and no direct evidence of harm was found. However, the cost of implementing large-scale screening programs remains prohibitive in the United States; yet Morris⁵³ modeled a program in the United Kingdom that was economically feasible.

With adults, the most common barriers to hearing healthcare are financial limitations and costs, stigma associated with wearing hearing aids and cochlear implants, inconvenience, and disappointment due to unrealistic expectations.⁵⁴ Lack of awareness of their hearing loss and limited access and treatment options can further interfere with getting appropriate services.⁵⁵ Adults living in rural areas tend to be more reluctant to receive hearing healthcare than adults in urban areas. Hearing loss severity, however, is a clear motivating factor. Adults who experience difficulties and frustrations during daily listening activities have an increased likelihood of seeking services, and those who recognize and accept their hearing problems are more willing to use hearing aids and cochlear implants. Yet, many adults wait 7 or more years before seeking hearing aids even in the face of notable communication difficulties.⁵⁶ Because of the severity of their losses, adults with profound hearing losses tend to engage relatively early with the hearing healthcare system.

Hearing healthcare use by Deaf adults is extremely low. Many Deaf adults remain skeptical of hearing healthcare professionals because of past experiences and the medicalization of deafness. Although increasing numbers of young Deaf adults wear hearing aids and cochlear implants, those who communicate through ASL align themselves most readily with the Deaf community and will have more communication barriers when receiving services.⁵⁷ There also remains a stigma associated with wearing hearing aids and cochlear implants; so, social constraints can be particularly difficult for adolescents and young adults, resulting in rejection or situational use of devices. Young Deaf individuals tend to be quite technologically sophisticated and readily communicate through computers, smart video, and text. However, the field of audiology has yet to interface with the Deaf community and offer them services through these types of media.

HABILITATION AND REHABILITATION SERVICES

Habilitation and rehabilitation efforts for people with profound losses should actively work toward removing barriers to healthcare generally, and

hearing healthcare specifically. Sensory devices contribute to the cost of services, although hearing aids typically are provided to pediatric patients by state agencies and insurance programs, and to military veterans through the Veteran's Administration. In recent years, efforts have been made by federal agencies and health-related organization to reduce the cost of hearing aids and increase their availability.^{58,59} In response, self-fitting hearing aids that can be sold directly to the consumer have been developed, although most need refinement before being entirely consumer friendly.⁶⁰ It should be noted, however, that most of these efforts focus on low-cost hearing aids for adults with mild to moderate losses and would be inappropriate options for pediatric patients and listeners with profound hearing loss.

Obtaining cochlear implants also is costly for some patients, and insurance and state programs do not always cover the full cost of the implants and associated medical expenses. They rarely cover travel and housing expenses. The cost of cochlear implants is not likely to drop, but measures can be taken to reduce other types of expenses and access. Telerehabilitation may prove useful in reducing travel costs associated with implant mapping and permit greater access to clinicians who have experience working with adults and children with profound hearing loss.⁶¹ Postimplantation therapies like parent training, auditory training, speech and language therapy, counseling, and communication strategy training have been successfully implemented in rural areas of Australia, but telerehabilitation carries risks associated with confidentiality and security, and concerns about quality and demonstrated effectiveness of services, reimbursement, and maintaining technology infrastructure.⁶²

Early intervention typically is provided in the home or at daycare. Providing home-based services to older children and adults might increase enrollment and compliance with treatments and reduce travel costs by patients. This approach might be particularly beneficial to elderly patients with mobility issues. Allowing access to professionals across state lines could further reduce the financial burdens experienced by some patients and their families. For example, children in eastern Oregon are more likely to

receive consistent and comprehensive services if they work with clinicians from the Boise, Idaho area, than if they must travel to Portland or Eugene, Oregon, for hearing healthcare.

Increasing the number of well-trained professionals to work with patients with hearing loss is an important consideration. Currently, the number of pediatric audiologists is insufficient to provide the hearing services required for infants and children in the United States,³⁴ and the need for audiologists with experience serving geriatric populations will be critical in the coming years. Many pediatricians are unsure of their role in managing infants and children with hearing loss and should be provided with that information through continuing education and professional training programs. Although geriatricians are aware of age-related hearing loss, they often do not make accommodations for patients with hearing loss in the clinical setting or referrals to audiology. There also are an insufficient number of geriatricians and elderly oriented primary care physicians to work with the burgeoning aging population.^{63,64} Audiologists should actively engage these physicians to facilitate communication within the healthcare setting and to streamline referrals for diagnosis and treatment of hearing and other auditory disorders. Social workers are helpful in coordinating patient services, and with other counseling professions, they can support audiologists when working with patients who have depressive symptoms. Depression is a common finding with people who have hearing loss, especially in adolescents and elderly populations. By increasing awareness of the issues surrounding hearing loss and depression, audiologists and counselors can provide better patient support and improve patient health and compliance. Finally, speech-language pathologists are major providers of speech, language, and auditory services to people with hearing loss, but they often lack the specialized training to work with them. This is particularly evident when patients have major communication or cognitive deficits due to their hearing loss or they have comorbid conditions. In addition, speech-language pathologists commonly have excessive caseloads so that the amount of therapy-time per patient can be inappropriately low for working with patients with hearing loss. Children with hearing loss

typically require frequent blocks of intense speech, language, and auditory therapies.

Cultural and linguistic sensitivity training is needed for all healthcare professionals who work with Deaf patients and other linguistic minority groups, and it is not unreasonable to expect some multilingual professionals in clinical settings to accommodate the language of minority communities. Clinicians should make efforts to know the communities that they serve, and understand their needs and how to best communicate with them individually and as a community. Many Deaf and other minority groups may not know or understand what audiology has to offer, which means that culturally, linguistically, and sensory appropriate materials need to be developed to convey that information.³¹ Attending social and civic functions can greatly improve nonexistent, strained, or uncomfortable community relationships. Involvement in community service projects also can be a beneficial means of outreach. Finally, developing functioning multidisciplinary teams that include community members is critical to working with minority communities, becoming responsive to patients and their families, and coordinating services across medical, academic, and personal homes.

CONFLICTS OF INTEREST

None.

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