

The Deaf Disadvantage:
Addressing Gaps in Healthcare Access within the Deaf Patient Population

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The Deaf and Hard-of-Hearing Patient Population

For years, disadvantaged populations have been at the forefront of efforts to rectify gaps in healthcare access. The main drawback with these deliberations is that they fail to differentiate the needs of the many within the whole. We tend to group disadvantaged populations together as though they can all be tailored to with the same solution. It is vital to acknowledge the varying needs required by each subgroup to establish equal access within the healthcare field. One of these subgroups is the Deaf and hard-of-hearing (HH) population. This accounts for around 11 million US individuals that report a hearing disability with an estimated 1 million being functionally Deaf.^{1,2} The greatest predictors of poor health outcomes in this community are barriers in communication, health literacy, and health education.³ Because of these deficits in access, Deaf and HH patients are more frequently seen to struggle with obesity, intimate partner violence, and mental health issues.^{4,5} By uncovering the challenges and obstacles faced by this specific patient population, the healthcare field can better tailor its efforts to achieve equity for Deaf and HH individuals.

Incidental Learning

An estimate from the National Institute on Deafness and Other Communication Disorders reports that 90% of Deaf children are born into hearing families.⁶ Because Deaf and HH children are often raised and immersed in a hearing world, they fail to benefit from the incidental learning that their hearing counterparts tend to take for granted. Incidental learning refers to the passive acquisition of information that is achieved through casual conversation with family and friends.^{4,7} This is often referred to as the “dinner table syndrome” and is experienced by Deaf/HH individuals in a variety of ways. They may miss large chunks of conversation which leads to confusion and frustration. They may then ask for clarification on said missed

information and family or peers will fail to take the time to reiterate ideas or expand on gaps in the individuals' understanding.⁸ Regardless of the manner in which they encounter this, it is commonplace for Deaf/HH individuals to experience this deficit in socialization. Without this natural absorption of knowledge, Deaf individuals miss out on vital familial medical history and fail to create a foundation of health awareness. In contrast, their hearing peers have “greater social access...[and] redundant access to multiple alternative sources of common health information” leading to a greater advantage of naturally obtained knowledge that will shape their future health outcomes.⁵

Having proper access to medical topics that are presented in conversations throughout the home has a significant impact on one's general health knowledge. In a study performed with Deaf high school students from New York, researchers found that those who were included and engaged in health-related discussions at home had a greater likelihood of demonstrating cardiovascular knowledge.⁹ Without proper channels to learn and socialize regarding medical information, Deaf children become Deaf adolescents and on to Deaf adults lacking basic knowledge of how to care for their health. This leads to significant gaps in health literacy which Deaf/HH individuals have the burden of compensating for later in life.

Health Literacy

In recent years, health literacy has come to light as a significant barrier to medical access and improved health outcomes. Health literacy is divided into three main delineations. Functional health literacy refers to the application of one's literacy skills to obtain materials and information related to his or her health. Interactive health literacy involves the utilization of one's communication skills to acquire new and ever-changing health information from social interactions. Critical health literacy then relies on one's evaluation and discernment skills to

apply this acquired knowledge to his/her own life.^{5,9} In a systematic review of 96 studies, it was determined that “low health literacy was consistently associated with more hospitalizations, greater use of emergency care, lower receipt of mammography screening and influenza vaccine, poorer ability to demonstrate taking medications appropriately, [and] poorer ability to interpret labels and health messages.”¹⁰

Deaf and HH individuals face challenges at every level of health literacy. In a study that further evaluated these inequalities, researchers designed their own assessment which controlled for discrepancies in functional health literacy. This allowed the examiners to evaluate Deaf/HH participants’ lack of understanding of the health content rather than that of the English language. Despite correcting for this confounding variable, results still pointed to significant “disparities between Deaf/HH and hearing adolescents on general health literacy.”⁵ This obstacle, in addition to those faced at each step of the healthcare experience, place Deaf/HH patients at an amplified disadvantage in health outcomes compared to other limited English proficiency (LEP) populations facing similar issues with language and communication.⁷ Most patient populations that do not employ English as their primary language still have family, peers, and a community that can rectify the discrepancies in health knowledge through socialization. Unfortunately, a large majority of Deaf and HH individuals are not afforded this same advantage and continue to build their personal health experience on an extremely rocky foundation.

Access Within the Healthcare Setting

While Deaf and HH individuals face significant and consistent barriers within the home, they continue to experience disparities when interacting in healthcare settings. Language barriers within the healthcare field are commonly associated with decreased patient compliance, increased medical costs, and poorer outcomes overall.¹¹ There are multiple ways a medical

professional can address the communication barriers presented when interacting with a Deaf or HH patient: in-person interpreting, ad hoc interpreting, VRI, written conversation, or lipreading. Each of these options has its unique limitations that are dependent upon the setting and scenario.

According to most Deaf/HH patients, in-person interpreting is the preferred modality to bridge the communication gap.¹² However, depending on the setting and availability, this is not always a viable option. In a study that evaluated 108 complaints regarding healthcare interpreting services for the Deaf/HH community, approximately half of the patients were informed the day of their appointment of there being no interpreter available while 28.7% were paired with an interpreter that was not adequately qualified.¹³ These hindrances are amplified in an emergency or urgent setting. Few hospitals have the capacity to employ around-the-clock interpreting services and the ones that do will cater to the largest population of LEP patients in that given area.¹¹ With all of these factors working against a Deaf/HH patient benefiting from an in-person interpreter, alternative measures must be secured.

Video remote interpreting (VRI) is the best subsequent option for patients within the Deaf and HH population. With its low cost, broad flexibility, and strong professionalism, VRI is the mode of facilitating communication that is extremely favored by healthcare personnel.¹⁴ Nevertheless, this form of interpreting is not without its drawbacks. In a survey of 555 Deaf adults who had used VRI in a healthcare setting within the last year, 59% of participants reported their experience to be unsatisfactory due to multiple aggravating features.¹⁵ One major frustration was regarding technical difficulties which were exasperated by staff unfamiliar with the technology and how to resolve its recurring issues. Another frequent disappointment was with the fluidity of the service. When having to be examined, patients are often required to move around and face varying directions of the room. This consistent repositioning interrupts the flow

of communication occurring between all parties. It lengthens interactions that are dependent on gathering vital health information and ones that are already strained on time.¹⁵ While this service is a viable alternative, it ultimately fails to equalize the hurdles Deaf/HH patients face when attempting to receive adequate healthcare access.

Ad hoc interpreting is the following alternative and refers to the use of individuals who are not professionally trained in medical interpretations, but can function as intermediaries due to their familiarity with the language. These individuals can be healthcare personnel, family members, or friends that facilitate communication between the Deaf/HH patient and his or her provider. Regardless of language fluency, “professional medical interpretation...is a specialized skill...[and] even if the interpretation by non-professional interpreters is linguistically perfect, misleading information still may be transmitted.”¹¹ This is frequently due to the complex nature of medical topics, the tendencies to oversimplify a concept based on one’s discretion, and the sensitive nature of personal information that must be provided.¹¹ Ad hoc interpreting is rarely reliable and is always a liability.

When all preferred methods fail, medical personnel frequently resign to passing written notes or combining lip reading with gestures. The former requires fluency in the written English language and the latter only provides slim access to any conversation given that less than 30 percent of the English language can be discerned from lip reading.¹² American sign language (ASL) is the native language of Deaf and HH individuals. The syntax, grammar, and structure of ASL is entirely different from English with “documented evidence of the nonequivalency of some spoken and signed concepts that may be used in health care assessment.”¹⁴ The detriment in using either of these mechanisms starts with a misunderstood interaction and ends at a wrong diagnosis. In a case where a Deaf patient’s exaggerated signing was interpreted as “psychosis”

and another patient’s notes written in ASL grammar were interpreted as “dysfluency”, both were admitted for psychiatric observation that did not reveal any evidence of the proposed diagnoses.¹⁶ While these cases did not lead to any further harm, they do highlight the potential dangers that can result from these rudimentary methods.

Educational Materials

As mentioned previously, ASL is a language all on its own. While it may rely on the same vocabulary as the English language, ASL focuses on emphasizing the main topic of a sentence first and utilizes facial expressions and body movement to exhibit grammar. These differences are among many when comparing ASL and English.¹⁷ Most health resources made available to Deaf/HH patients also include sociocultural metaphors and idioms that are only relevant to the hearing population but do not translate in ASL or to Deaf/HH culture. Finally, many organizations adapt their educational materials to be accessible by merely decreasing the reading level to a lower grade. This surface-level change does not benefit individuals who use ASL for their primary language and who may have little to no English literacy. Hence, these same institutions should not only take reading level into account, but also “ASL usage, Deaf sociocultural characteristics,

and fund of information deficits” in order to modify health resources to be truly accessible to the Deaf/HH patient population.¹⁸ This process, which is illustrated in Figure 1, is an exhaustive

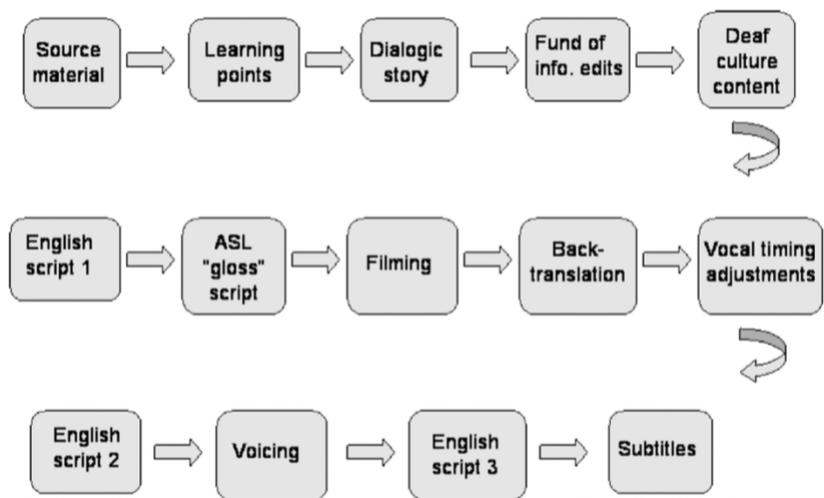


Figure 1. Process of Adapting Health Education Material¹⁸

one that, when implemented appropriately, creates materials that “maximize comprehension and engagement for the deaf and HH audience.”¹⁸

In this digital age, it is imperative to utilize any possible advantage that would aid in a Deaf/HH patient’s understanding of their health. A new study introduced gaze tracking as a method to determine how Deaf/HH patients interact with online health resources. Because humans are not equipped to process large amounts of visual stimuli all at once, researchers were interested in devising a system that would evaluate how individuals selectively engage with certain health resources.¹⁹ In the future, this system could be an invaluable asset in determining the most optimal way of providing the best access, comprehension, and retention of health resources.

Bridging the Gap

It is apparent that the Deaf and HH patient population face disadvantages and inequalities at each step of attempting to obtain proper health knowledge and care. Starting at home and extending all the way to follow-up health materials and resources, these patients have a great need for improvements in their accessibility to the healthcare field and the information it supplies. Developing outreach events that are catered to the Deaf/HH population helps children living in a predominantly hearing world to socialize with those from the same community regarding topics that will enrich their health literacy.⁹ Improving access to interpreters, enhancing the limitations of VRI, and guaranteeing individualized access to communication with healthcare personnel will limit the risks, harms, and deficits that this population faces each time it seeks medical attention.^{12,13} Ensuring that healthcare staff is trained on the notion of deafness as a culture rather than a disability is imperative to elevating these patients’ interactions with the field of medicine. Finally, making the effort to truly cater health resources and educational

materials to the unique sociocultural and linguistic needs of the Deaf/HH population will drastically improve their health outcomes.³ Each of these considerations has the power to encourage a Deaf child to learn their family's medical history, ensure a HH adult leaves the emergency room and follows up with their cardiologist, teach a patient the proper instruction to take their new medication, and, ultimately, save a life.

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