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EXAMINING THE EFFECT OF LONGSTANDING DEAFNESS ON HEALTH LITERACY:
A SYSTEMATIC REVIEW

By:

SARA PAYAMI

A capstone research project submitted to the Graduate Faculty in Audiology in partial fulfillment
of the requirements for the degree of Doctor of Audiology, The City University of New York

2021

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This manuscript has been read and accepted for the Graduate Faculty in Audiology in satisfaction of the capstone project requirement for the degree of Au.D.

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ABSTRACT

EXAMINING THE EFFECT OF LONGSTANDING DEAFNESS ON HEALTH LITERACY: A SYSTEMATIC REVIEW

By:

SARA PAYAMI

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Objective: This systematic review aims to evaluate whether deafness has a significant effect on one's health literacy (HLit) skills, and, if there is a difference between HLit of a normal hearing individual compared to that of a Deaf individual. Disparities in HLit unique to the Deaf experience are identified.

Methods: A comprehensive search utilizing various peer-reviewed databases was conducted via the City University of New York's (CUNY) Graduate Center Library to identify relevant studies published after 2009. Inclusion criteria incorporated quantified studies which commented on the HLit of d/Deaf communities in the U.S. published from 2009 to present day.

Results: Although additional studies focusing on the HLit of the d/Deaf population are needed, the 9 studies discussed within the scope of this systematic review were able to adequately demonstrate the poor HLit levels of d/Deaf Americans. The studies that included normal hearing and d/Deaf participants illustrated the presence of poorer HLit skills of the d/Deaf population, in relation to the normal hearing population.

Discussion: Deaf individuals do not have the exposure to incidental learning opportunities that normal hearing individuals take for granted, such as family history or caregiving, thus leading to the prevalence of inadequate HLit among them. Without access to information such as familial

histories, medical processes and procedures, Deaf individuals are unable to equip themselves to face all types of health conditions. As the results demonstrated, d/Deaf participants consistently have poorer HLit in comparison to their normal hearing counterparts. Therefore, the d/Deaf population faces an even poorer position in terms of HLit. Additionally, communication barriers between the d/Deaf and medical professionals leave this demographic unsatisfied with the level of care experienced, thus leading them to avoid healthcare settings. Improper access to healthcare puts all individuals at risk for untreated conditions, reduced quality of life, and increased risk of fatalities. Health outcomes are likely to be worse in d/Deaf people compared to those who are normal hearing because of imbalances in access to health care, health info, education, and economic resources.

Conclusion: Closing the gap in the HLit status of d/Deaf Americans is a goal that needs to be addressed within the public health sphere. Ignoring this problem serves to exacerbate existing healthcare disparities. Adverse health outcomes can best be prevented when more research is performed and initiatives are taken to give support to the d/Deaf, young, and elderly alike.

Key words: *hearing loss, deaf, Deafness, Deaf community, health literacy, healthcare literacy, hard of hearing, health disparities, healthcare, access to healthcare, primary care, sign language, American Sign Language, communication, barriers to healthcare, healthcare accessibility, public health, medical expenses, adolescents, adults, older adults, and United States.*

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INTRODUCTION

For the average American, circumnavigating the realm of healthcare often proves to be a challenge due to the system's complexities of options, medical terms, and vastness. Although most of the U.S. population typically understands the English language and does not necessarily have disabilities, there exists no general preparation or standardized instruction to navigate through healthcare. The system in its current form fails to equip or prepare users with the skills and information necessary to understand its structure, which would otherwise help to adequately address the public's medical needs. The scope of understanding these needs is generally defined as *health literacy* (HLit), which is the ability by which individuals can obtain, process, and understand basic health information and services needed to make suitable decisions regarding theirs and individuals they care for (Cornett, 2009). Although the literature sometimes refers to HLit and *healthcare literacy* as slightly different terms, for the purposes of this study, they will be used interchangeably.

An emerging concern about this topic is that this spectrum of general knowledge is meant for all users, despite differences in socioeconomic status, education level or cultural background. Prior research has shown that even when doctor and patient share the same language, miscommunication and misinformation increase as the patient does not always understand medical terminology (Thompson & Pledger, 1993). Not surprisingly, this leads to obstacles for the patient to meet end-goals of successful diagnoses, treatments and even education.

The Evolution of the Health Literacy Concept and Terms

Traditionally, the term literacy is defined as a person's ability to read and write in their first language. However, health and healthcare literacy are different in that content and concepts specific to the medical industry elevate the tradition term, thus requiring increased thought and

process for all involved parties. To further understand HLit, the following perspective allows for an understanding of how the model evolved into what it is today.

Starting in 2003, several surveys were conducted by the National Center for Education Statistic (NCES), which helped define and clarify the status of HLit in the United States (U.S). Then, as is now, NCES was mandated by the U.S. Congress to collect, analyze, and report findings related to the status of education within the U.S. The NCES is typically tasked with addressing high priority education data needs, assessing rate indicators of education status and trends, and providing this information to the U.S. Department of Education, U.S. Congress, education policymakers, practitioners, data users, and the general public. As it relates to the topic of HLit, the NCES collected and analyzed data that was later published in the National Assessment of Adult Literacy (NAAL) (Kutner et al., 2007). Similarly, the Educational Testing Service (ETS) worked with the publishers of the NAAL to establish another body of evidence called the Health Activities Literacy Scale (HALS). The findings in HALS were used to make important contributions to the field of HLit in the U.S. (Sum et al., 2002).

The NAAL survey established various levels of HLit in American adults. The study's goals were to illustrate how HLit differs within targeted populations, and, where these Americans obtain information about health issues. In order to qualify and standardize the concepts, the NAAL study utilized HLit scales and tasks as outlined by the Institute of Medicine and its publication, *Healthy People 2010*. An analysis of the NAAL study's results revealed differences among the public in HLit based on self-reported background characteristics. Following the publication of the NAAL, it became clear that there exists a link between general literacy, health, and education. Extrapolated survey results revealed that poor HLit skills can be contributing factors to wide disparities often seen in types of healthcare individuals receive. The

survey further defined HLit as, “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Kutner et al., 2007). Indeed, it was noted that having adequate HLit is important for all adults to be able to satisfactorily manage their healthcare needs.

In 2004, ETS published a Policy Information Report by Rudd, Kirsch, & Yamamoto called *Literacy and Health in America*, which focused on health and investigated the issues surrounding language-literacy and health outcomes. Other parts of the series concentrated on the inequalities of healthcare literacy between adults in the U.S. as compared to those in other high-income countries, and, of native born versus foreign born individuals in the U.S. and in other high-income countries. *Literacy and Health in America* highlighted issues such as drug and alcohol use, disease prevention, first aid care, emergencies, and health promotion as they related to traditional literacy and health. The authors’ goal was to help broaden the scope of research performed in HLit beyond that which occurs in the traditional medical office and hospital setting. Other goals included emphasis on the importance of an individual’s ability to understand complex health materials and demonstrate HLit disparities that exist within at-risk and vulnerable members of the U.S. population.

As previously mentioned, the HALS was formulated as a means to collect and condense relevant information that can be used to effect change within the sphere of HLit. The framework for HALS was adapted from the NAAL and are representative of the processes associated with healthcare activities as related to adults. These processes included, *health promotion, health protection, disease prevention, healthcare and maintenance, and systems navigation*. The following describes each of the four healthcare activities which can be used as descriptors for segments of HLit:

Health promotion referred to events that individuals commit to performing for the own health benefit. The term relates to nutrition, physical activity, and other healthy habits.

Health protection focused on undertakings that preserve and protect the health of individuals and communities. Such activities include learning about the changes in products, improving designs of structures or systems, and, in rules governing details or procedures.

Disease prevention activities involved behaviors that are adopted to help prevent the onset of an illness or a disease or to detect diseases at earlier stages. These accomplishments require individuals to take preventative measures and engage in early detection. They include activities such as getting a flu vaccination for those in a vulnerable population, screening programs for vision or hearing loss, and prostate or breast cancer screening tests.

Healthcare and maintenance required individuals to seek proper care in a timely manner and form a strong partnership with a healthcare provider, such as regularly complying with prescribed treatment regimen or engaging in a dialogue with their doctors or pharmacists.

Systems navigation required individuals to properly navigate the health system by knowing their rights and responsibilities, properly applying for insurance benefits, and verifying their coverage, and giving informed consent for procedures and studies (Rudd et al., 2004).

In addition, the health tasks included in the NAAL were also representative of several domains in the healthcare system: *clinical*, *prevention*, and *navigation*. *Clinical domains* included activities between the healthcare provider and patient such as clinical encounters, diagnosis and treatment of illness, and medications. Examples of tasks that are needed within clinical areas are submitting office visit patient information forms, understanding of pharmaceutical dosing instructions, and following healthcare provider recommendations to prepare for or complete diagnostic tests.

Activities related to maintaining and improving health, preventing disease, intervening early in emergency problems, and initiating self-care and self-management of illness comprises the *prevention domain*. Examples of the prevention domain include following age- and gender-appropriate guidelines for preventative health services, identifying signs and symptoms of health problems, seeking proper treatment in a timely manner, and understanding how balanced eating and exercise habits can decrease risks for health complications.

The *navigation domain* highlights activities related to understanding how the healthcare system works and individuals' rights and responsibilities. Examples include understanding health insurance coverage, determining eligibility for public insurance or assistance programs, and being able to give informed consent for a healthcare service (Kutner et al., 2007).

To further understand this research, the HALS generated scores which corresponded to the respondent's level of HLit. The range of scores designated a value to one of five different HLit levels: Level 1 indicating the lowest proficiency to Level 5 as the most proficient (Rudd et al., 2004). Notably, deficits within the areas of healthcare activities and their domains indicate a need for improvement of healthcare literacy.

The authors of *Literacy and Health in America* used the HALS scale to estimate the distribution of HLit skills of vulnerable and at-risk groups, and, evaluated how health related literacy is connected to health status, socioeconomics, and civic engagement. Findings indicated that of the total population, about 20% of the U.S. adults are estimated to have skills at or below the lowest level on the HALS. In the study, these adults were performing below the average proficiencies of adults who graduated from high school. Interestingly, U.S. national and state organizations, such as the National Governor's Association, have stated that a HLit score of Level 3 would be the minimum necessary as a standard for success within the current labor

market (Rudd et al., 2004). As one fifth of the surveyed population fell within this category the implications related to poor HLit and the impact that it has on individuals within this population reveal a significant deficit.

Performance levels in the NAAL study were also used to categorize and identify the strengths and weakness of adults within various ranges of HLit abilities. Four competency levels were identified to reference the HLit skillsets: *below basic*, *basic*, *intermediate*, and *proficient*. These skill levels established by the NAAL study were attributed to three different types of literacies that can relate to health: *prose*, *document*, and *quantity*.

Prose literacy is the knowledge and skills needed to understand and use information from sources such as news stories, brochures, and instructional videos.

Document literacy is the knowledge and skills required to perform tasks that require locating and extrapolating information found in various sources. This may include knowing how to read a street map to find a particular location, reading a schedule to correctly utilize transportation, or fill out information on a job application.

Finally, *quantitative literacy* is the knowledge and skills required to perform tasks relating to numbers embedded in printed materials such as balancing a checkbook, calculating a restaurant service tip, determining the amount of interest on a loan, or even reading numerical values related to clinical information (Kutner, 2006; Rudd, 2004).

The correlation between HLit, race, and education

The NAAL results revealed that 53% of the participants had an intermediate level of HLit, 12% were classified as proficient, and the remaining third of the population had basic or below basic HLit skills. The study by Cutilli and Bennett in 2010 gave insight to the findings published in the NAAL in 2003 and provided a glimpse into the HLit of adults of different

socioeconomic, educational, racial backgrounds from the U.S. As the NAAL highlights, the individuals that tend to have the worst HLit/poorest understand of healthcare information includes those who are 65 years of age or older, male, and Black or Hispanic, non-native English speaker, have less than a high school diploma, live at or below the poverty line, rate their overall health as poor, have Medicare, Medicaid, or no insurance, and are not seekers of print or non-print sources of healthcare information.

Similar to findings from the NAAL, responses to the HALS varied based on patients' level of education, race or ethnicity, country of origin, and birth. Health literacy proficiencies are strongly tied to social, educational, and economic outcomes in society. As an example, HLit has been found to correlate to levels of education. While education increases literacy skills, it is true that the same skills impact the level of education attainment. Deficiency in literacy places adults at a significantly higher risk for poverty, which in turn can lead to adverse living situations putting them at a disadvantage for adequate learning environments or labor markets (Sum et al., 2002).

The highest HLit scores on the HALs were attained by younger adults who had above a high school diploma, were Caucasian, and born within the U.S. The differences noted between the racial groups reveal the impact of many variables such as education, resources, and immigrant status on an individual's ability to thrive. In terms of analysis of HLit proficiencies in related to participants' access to these resources, the general trend revealed that adults who had better financial resources, health status, reading practices, and civic engagement, had better HALs scores than those who had worse access. In conjunction to the NAAL findings, the HALS conclusions revealed that social factors have a powerful impact on HLit and in turn, health outcomes. As highlighted above, there are distinguishable differences in the HLit skills of adults

with varying educational attainment, health status, socioeconomic status, and reading practices (Rudd et al., 2004).

Other factors affecting HLit

It can be assumed that the foundation of functional HLit is to have adequate language-literacy skills. For example, adults need to be able to read articles or brochures about preventative health measures, buy over-the-counter medications, and understand insurance forms. Often, adults have to make healthcare decisions for the needs of their children or parents, which requires them to make decisions about insurance enrollment, scheduling various doctors' appointments, ensuring that physicals are completed in a timely manner, and receiving treatment for their illnesses (Kutner et al., 2007). In order to analyze and successfully complete these tasks, the patient is required to not only be health literate, but also understand the written complexities of information.

Patients obtain health information from a variety of sources which can impact their HLit levels. Adults with below basic scores were more likely to not seek any health information from printed sources, such as newspapers, magazines, books, and brochures. Individuals with basic, intermediate, or proficient HLit were more likely to use printed sources of health information. Further, the use of the internet had dramatic effects on scores as well: of adults with below basic HLit scores, 80% reported not using the internet, while 15% of those with proficient HLit reported no internet use. Although the barriers to internet use are not fully known, it can be inferred that those who do not utilize the internet do not do so because they either cannot afford the technological equipment, are not literate enough to understand what they read online, or unaware of using the internet as a source of information. Even though not all information on the

internet is reliable, those who have so-called “web surfing” skills know how to navigate search engines to obtain the information that they are looking for from reliable sites.

Part of the Cutilli and Bennet study required participants to self-assess their perception of their health as compared to the results of their HLit assessment. Interestingly, there was a direct relationship between self-assessment of overall health and HLit scores: those adults who perceived themselves to have overall better health, such as excellent or very good, had proficient or intermediate HLit scores as compared to adults who reported poor, fair, or good overall health. Additionally, the survey examined the relationship between HLit scores and sources of health insurance. Those who belonged to the group who attained their insurance through their employer, military, or third party had the highest percentage of adults with intermediate or proficient HLit. Individuals who relied on Medicare, Medicaid, or had no insurance had the greatest percentage of below basic HLit (Cutilli & Bennett, 2010). As noted within the study, many adults lack the HLit skills needed to navigate the U.S. health system thus impeding the ability to obtain proper care. Cutilli and Bennett (2010) cited the need for the healthcare system to re-evaluate the HLit abilities of the populations they serve and provide materials and information at a HLit level that can be understood by the general population and used to make informed decisions.

The data revealed that the highest percentage of individuals falling within and below-basic HLit did not seek information from families, friends, or coworkers. Those who had intermediate or proficient scores did seek information from their families, friends, and coworkers. In terms of obtaining healthcare information from healthcare professionals, those whose HLit levels that fell in the below-basic to basic levels either did not seek any help, or were completely reliant on healthcare individuals as their main source of information. Those who

scored within the intermediate and proficient levels did not rely on healthcare professionals as their main source of information and referred to them in moderation (Cutilli & Bennett, 2010). Thus, it can be concluded that those with better HLit levels have an appropriate understanding and skill level of when to ask for healthcare information from healthcare professionals and family members. Additionally, healthcare information should be presented at a literacy level that is understood by all patients, with a focus on individuals with the poorest HLit.

Health Literacy, Hearing Loss and the Deaf

In view of the barriers to HLit that the average American faces, it becomes a further concern that there are additional obstacles for individual with hearing loss. While various factors such as degree of hearing loss, age of onset, and educational/cultural background affect communication, the Deaf community in particular may be at further risk in terms of HLit function.

According to the National Association of the Deaf, the term deaf (lower case “d”) is associated with individuals who have the audiological condition of not hearing due to illness, trauma, or age. The term Deaf, with an uppercase “D”, is used to refer to the group of deaf people who share a language, such as ASL, and a corresponding culture. The members of the Deaf community do not see their hearing loss as a disability, rather membership in a community that utilizes sign language as their primary source of communication. These individuals have their own code of conduct and personal beliefs about the topic of Deafness and interactions with the hearing world. Relative to this issue are two terms that need to be differentiated in order to highlight the specific communication difficulties the community members face: *pre-lingual* and *post-lingual deaf*.

The term *pre-lingually deaf* refers to a child who is either born deaf or who lost his or her hearing early in childhood, prior to acquiring language. The pre-lingual hearing loss can be of genetic origin or caused and acquired secondary to disease or trauma. Interestingly, these individuals are most often children born to parents who have no prior knowledge of deafness (Jallu et al., 2019). Before the implementation of the universal newborn hearing screening protocols by U.S. federal agencies in the late twentieth and early twenty-first centuries, children born with hearing impairments were not diagnosed or identified until two to three years of age (The Joint Commission on Infant Hearing [JCIH], 2019). At this age, which is after the most critical period of speech and language acquisition, delayed speech development becomes apparent, and parents would have to quickly advocate to have their child receive the interventions needed to assist in adequate language development and progress in school (Wrightson, 2007).

Related to this area is the term *post-lingual deafness* which refers to those who acquired language prior to the onset of the hearing loss (Scheier, 2009). Post-lingually deafened individuals not only had the exposure to the phonemes that compose the words in their spoken language, but they were also able to develop much or all of their own speech and language skills before the onset of hearing loss. Depending on the individual's age, they were most often shielded from the negative effects of pre-lingual deafness such as poor literacy development, poor development of sense of self, difficulty relating to and communicating with their peers, poor social-emotional development and other delays that would affect them for a lifetime (JCIH, 2019). These individuals are known to have greater success utilizing amplification devices such as hearing aids and cochlear implants, which can help restore them to their pre-deafened stages of functionality and communication abilities.

The Deaf Community and the Medical Community

Considering that spoken English and American Sign Language (ASL) are two separate and distinct languages due to syntax, semantic, and pragmatic differences, communication between a hearing healthcare provider and a deaf patient may be at an imbalance. Unless a provider can fluently converse in ASL or offer an ASL interpreter, the average patient from the Deaf community may have reduced oral communication skills. Deaf patients often avoid interactions with the healthcare system because they are left feeling ashamed, embarrassed, and do not get the answers that they need. Deaf patients have been known to leave their appointments not understanding their diagnoses or their treatment plans, medication use or sides effects, thus requiring the patient to resolve questions for themselves, which can lead to unsuccessful results (Sheppard, 2014). Deafness by culture is not considered to be a disability by its own community. By virtue of its varying characteristics, deafness distances the individual from the majority of the hearing population's communicating sphere. To the hearing community, deafness is not a disability likened to losing a limb or requiring the use of a wheelchair. Yet, it is the role of the healthcare provider to take the necessary steps to ensure a provision of care is adequate for all individuals, no matter what form of communication the patient utilizes.

Deaf individuals are known to have difficulties and delays in accessing healthcare, though the extent to which they and their health suffers due to these disparities is unknown because of the lack of research in this field. Obtaining this information would be especially helpful in order to better anticipate the needs of the aging population, who are already more predisposed to an increased burden of disease than their younger counterparts (Niccoli & Partridge, 2012) and higher rates of morbidity due to having a compromised and weakened immune system at their age (Pandhi et al., 2011). Many Deaf individuals associate the healthcare

system with fear, mistrust, and frustration due experiences with healthcare providers as young children (Kuenburg et al., 2016). By failing to communicate and even address the emotional needs of the Deaf patient with hearing loss, providers are left to probe and evaluate on their own, leaving the Deaf patient uninformed and fearful. Children who experience this are especially vulnerable to developing fear and frustration of the healthcare system, maintaining these notions as adults through suspicions of substandard treatment by way of a lack of communication. So too, the Deaf may feel that healthcare provides are lacking compassion and ignorant to the needs of Deaf culture (Sheppard, 2014). The privilege of healthcare access should be extended to all individuals, regardless of their communication status.

Barriers to Entry for the d/Deaf Community

Patients within the Deaf community face barriers to healthcare and have negative experiences, many of which stem from lack of a communication (Kuenburg, 2016; Sheppard, 2014). Healthcare providers typically do not have the training to adequately communicate with the average individual from the Deaf community. Although using “broken” ASL, exchanging notes, or lip reading can facilitate some degree of communication, these strategies are often impractical, and may lead to misunderstandings due to improper translations. In addition, this can lessen the patient’s confidence in the provider and make them reluctant to receive the care that they desire (Sheppard, 2014). As reported in the literature, often times, providers who attempted use these methods became frustrated with the level of effort needed to communicate with Deaf patients, which made the Deaf individual feel resentful and unwanted (Sheppard, 2014). Prior research has shown that full medical histories of Deaf patients have been left significantly incomplete due to the providers inability to communicate with the patient (Alexander et al., 2012). This is a dilemma for both the patient, whose medical needs are at risk

for being overlooked due to the incomplete history, and, for the provider who is providing care to an individual who is unsure of the patient's full medical background.

Deaf patients who do not utilize cochlear implants typically have no access to auditory stimulation, unlike patients who have hearing loss or those who are considered to be "hard of hearing" (HOH). Deaf individuals rely on an ASL interpreter who uses their facial expressions and body language to add meaning and context to their language interpretations (Middleton et al., 2010). So too, individuals who are HOH also struggle to communicate with their providers, although perhaps not to the same degree as a deaf patient. Due to the degrees and types of hearing losses involved, even individuals with mild to moderate hearing losses who do not routinely use amplification are at risk for reduced clarity of information from a provider unfamiliar with audition as it relates to meaningful communication. Those individuals with such a hearing loss can use hearing aids to amplify sounds around them and benefit from these devices, however relative to the Deaf patient, hearing aids offer limited assistance. Studies have found that adults who are HOH are more likely to experience difficulties and delays in accessing healthcare as compared to adults who have normal hearing (Pandhi, 2011). For Deaf patients, the only devices that can start to approximate an experience even remotely comparable to normal hearing are cochlear implants. However, historically the Deaf community has maintained a negative perception to utilization of such technology and has yet to become common enough to be a viable hearing health option.

A British study completed by Emond et al, (2015a) found that Deaf adults tend to visit their general practitioner more frequent than the general population does, most likely because they do not feel adequately informed by their providers after a single appointment. However, 44% of Deaf adults found their last visit with their general practitioner to be difficult or very

difficult compared to 17% of adults in the general population in that survey. Additionally, about 40% of Deaf patients found the receptionist to be unhelpful compared to only 8% of the general population. Although receptionists are not medical providers *per se*, their role in getting the patient to the appointment, working out details with insurance and payments, and paperwork is crucial support in these processes. If Deaf patients cannot communicate with this front-line service, it becomes the first of other barriers they will face when trying to receive access to healthcare.

Healthcare settings are seen as uncomfortable and stressful environments for d/Deaf patients because of the general anxieties associated with the implications of illness, and the fear of what they will have to understand. Walking into the office and seeing a friendly face who wants to help is very important and necessary, but when it is lacking this situation becomes one of the first reasons why a patient might not return. Another notable problem is the fact that most appointments are made over the phone, which Deaf patients cannot use in its most common form. If the healthcare practice is not available or easily accessible through other media such as emails or text messages, then the only option for the Deaf person is to go to the office in person, which can be logistically inconvenient. This poses yet another barrier to entry, especially if the patients have other physical disabilities that prevent them from travelling, lack of funds to pay for transportation, or inability to travel alone due to cognitive decline. Moreover, when the Deaf patients were able to see their providers, 53% of the surveyed population had to rely on lip-reading and 15% had to rely on writing notes. Of these patients, 23% felt that explanations they received were very poor, compared to only 3% of the general population who felt similarly. This explains why 67% of the general population felt that they have trust and confidence in their doctor, while only 25% of the Deaf population shared the same sentiment (Emond et al, 2015a).

If patients cannot hear or understand what their doctor is saying to them about their health, it makes it virtually impossible to trust the Doctors, especially if patients feel that providers are not doing all that they can in order to accommodate their needs.

Technology Services for the Deaf

Arguments can be made for the use of the services such as telecommunication device for the Deaf (TDD), teletypewriter (TTY), and relay calling available to the Deaf. The TDD is a general term for devices used by the d/Deaf and HOH to communicate through a phone and the TTY allows users to type out their message using a keyboard of a text telephone. The device converts the message to a code that is transmitted through the telephone line to another TTY device that decodes the message and displays the text to the other user on their screen. Similarly, the TTY device can be used in conjunction with a communication assistant (CA), who receives a call from a TTY user, then calls the person that the user is trying to communicate with. The CA relays the messages from the TTY user to the non-user as an intermediary in the conversation.

Although these services are theoretically effective for communication, they are not necessarily practical as users must be in possession of the TTY device as well as understand how to operate it. Users report that the TTY conversation can be frustrating as they can only communicate in a single direction at a time, which lengthens conversations. As advancements are made in personal technology such as smartphones, TDD users have turned to using text messages to communicate with others, thus reducing the need for the TDD devices and relay services. Due to the decrease in demand, the supply of CAs decreased thus making it difficult for those who still rely on these services to use them (Telecommunication Recommendations, 2015).

Mobile phone applications are also available for use by the d/Deaf and HOH in addition to the technologies discussed above. Smartphone applications require the user to have a device

and download specific talk-to-text phone software for private use based on the mobile carrier's allowances. To use them, the smartphone microphone has to be pointed or held close to the speaker's mouth so their voice can be adequately accessed. The application transcribes the spoken word for the user to read. Although this application is advantageous for those who cannot hear, there are barriers to its use as well. Similar to the less advanced technology of the TTY and TDD, smartphone solutions require the user to have and operate the device. Often these applications are free for users, however, some versions require payment after a limited trial use or have unwanted advertisements. Additionally, this poses a problem for users who have visual disabilities in addition to hearing loss and cannot read the words easily. Moreover, these applications are not monitored by government agencies, meaning that the accuracy of the transcriptions are unknown and may lead to misinterpretations by the user (Maiorana-Basas & Pagliaro, 2014).

An additional consideration to make is the availability and the associated cost of these devices and ASL interpreters within a healthcare setting. The Americans with Disabilities Act (ADA) mandates that hospitals must provide effective means of communication for patients, family members, and hospital visitors who are Deaf or HOH (ADA Business Brief, 2003). Sign language interpreters, cued speech interpreters, and TTD devices are covered under this act and must be provided to patients who request them. Yet, there are instances of scheduling and other errors that can temporarily leave the patient without an interpreter. Patients may be forced to make decisions without understanding all information due to lack of proper communication especially in cases of emergency where time becomes critically relevant. Additionally, even though the ADA requires all providers to ensure effective communication for individuals with hearing disabilities no matter the setting (U.S. Department of Justice, 2020), it is difficult to

ensure compliance to these regulations in a private office setting versus a medical center. Private healthcare providers find the cost expensive to retain interpreters for the services of only a few patients, thus forcing Deaf patients to choose to receive services from a setting or practitioner with inadequate Deaf communication skills, or choose a different provider, which risks further delays in access to healthcare.

While the patient can bring a family member or friend fluent in sign language to attend an appointment, this solution poses other problems as relating to privacy as the patient might feel uncomfortable with a relative present to translate intimate or sensitive details of their health. So too, under these circumstances, patients may not fully disclose information to the provider, thus compromising the exchange of relevant details. For example, an adolescent Deaf patient might not ask their provider to perform a test to check for transmission of sexually transmitted diseases (STDs) in front of an immediate family member who is providing translations due to fear of backlash when home. Further, while family members can translate everyday words, medical terminology may be complex and increase the potential for an incorrect translation (Scheier, 2009).

Even when an interpreter is available to attend an appointment, sign language is not necessarily consistent in terms of language use. Depending on where the person is native, signed language interpretation is not a guarantee of understanding as there are regional, dialectical and language differences. Meaning, American Sign Language is not the same as British or Australian sign language or finger spelling and is in fact, closely related to French Sign Language. Providers may believe diagnoses and treatment plans are understood by the patient however, even with sign language interpreters present, patients might make medication errors, miss

appointments, misunderstand diagnoses, or undergo incorrect procedures due to communication errors.

The sum of the outlined issues regarding communication barriers, feelings of shame and frustration, and maltreatment by providers, is the risk of avoidance to healthcare. It is not a rare occurrence for Deaf patients to undergo examinations or procedures without understanding why. One patient described an experience in which she approached her provider for acne treatment, yet for reasons that she did not understand, underwent a pelvic examination. This experience was later described as frightening, confusing, and traumatic, resulting in the patient not seeking treatment for 25 years (Sheppard, 2014). The patient's discomfort precluded her from seeking routine medical care and thus at risk for other health issues. Another study corroborated the idea that many participants accept a medication or agree to a procedure without completely understanding the purpose behind it. One patient admitted that she just agrees to everything the provider discusses despite not understanding cause and consequence in order to feel less ignorant (Kritzinger et al., 2014).

A study conducted in the United Kingdom in 2015 highlighted the effects of the health disparities between the general population and the Deaf community and assessed the different pathologies that arose as a result. The information on Deaf British Sign Language (BSL) patients was collected and compared to the responses of a sample of adults who responded to the Health Survey for England from 2009, 2010, and 2011. Results of the study revealed that the Deaf participants' health was poorer than that of the general population and there was likelihood that they suffered from under diagnosis and undertreatment of chronic conditions, which put them at risk of preventable illnesses. Within the Deaf population, the rates of being overweight were 72% for men and 71% for women, compared to rates of 65% and 58% observed in the general

population, respectively. In the Deaf sample, 90% of participants who were over the age of 65 were overweight or obese. There was a higher incidence of raised blood pressure in the Deaf sample as well; 37% compared to 21% in the general population (Emond et al, 2015b). Additionally, the members of the Deaf sample had worse rates of awareness and detection of their hypertension, and of the ones who were aware of their condition, only half were following the correct treatment protocol to address their condition. The members of the Deaf sample were also determined to have higher rates of diabetes and depression, but surprisingly had lower rates of alcohol consumption and smoking (Emond et al, 2015b). These results highlight the fact that the BSL Deaf population sample is likely to have poorer awareness, detection, and maintenance of their medical conditions, which will put them at a greater risk for preventable diseases and inadvertently potentially reduce life expectancy.

Research question

The NAAL research supports claims that one third of the American adult population has below basic or basic healthcare proficiency, yet the results of the HALS study states that 20% of participants fell at or below level 1 on their HLit scale. Many U.S. national and state organizations have stated that a proficiency level 3 score would be the minimum necessary as a standard for success within the current labor market, which demonstrates the need for improved English and healthcare literacy within this country. Although both studies attempted to collect responses from a sample that is representative of the U.S. population, they both failed to record responses from individuals with impairments such as Deafness, as part of the representative population. As discussed, the Deaf population is vulnerable to miscommunications that can lead to feelings of frustration, mistrust, and embarrassment in the healthcare setting. These are errors that can negatively impact the health of these Deaf individuals.

The current paper aims to further evaluate through a literature review if Deafness has a significant effect on an individual's HLit skills, and whether there is a difference between the HLit of a normal hearing individual compared to that of a Deaf individual. Further, the author seeks to reveal how Deaf patients address any disparities within their level of HLit, as compared to that of normal hearing individuals.

METHODS

This systematic review examined the difference of HLit in normal hearing versus d/Deaf Americans. The author included data collected from research about specific health care issues that can be affected by the HLit proficiency of the Deaf population. Specific topics included but were not limited to, knowledge of cancer, HIV, and Medicare enrollment. Relevant studies for the data search required articles to be in English, published in a textbook or peer reviewed journals between 2009 through present day, and, be related to individuals who are part of the normal hearing and/or d/Deaf communities. Omitted were articles that discussed the HLit of individuals outside of the U.S. The inclusion and exclusion of the published studies discussed in this systematic review was guided by and outlined by the PRISMA (Preferred Reported Items for Systematic Reviews and Meta-Analyses) checklist and flow diagram (The PRISMA group, 2009). Application of these criteria resulted in 9 articles being chosen for this review.

Search databases: PubMed, Medline, CINAHL, EBSCO, Cochrane, and Google Scholar.

Search terms included: *hearing loss, deaf, Deafness, Deaf community, HLit, healthcare literacy, hard of hearing, health disparities, healthcare, access to healthcare, primary care, sign language, American Sign Language, communication, barriers to healthcare, healthcare accessibility, public health, medical expenses, adolescents, adults, older adults, and United States.*

RESULTS

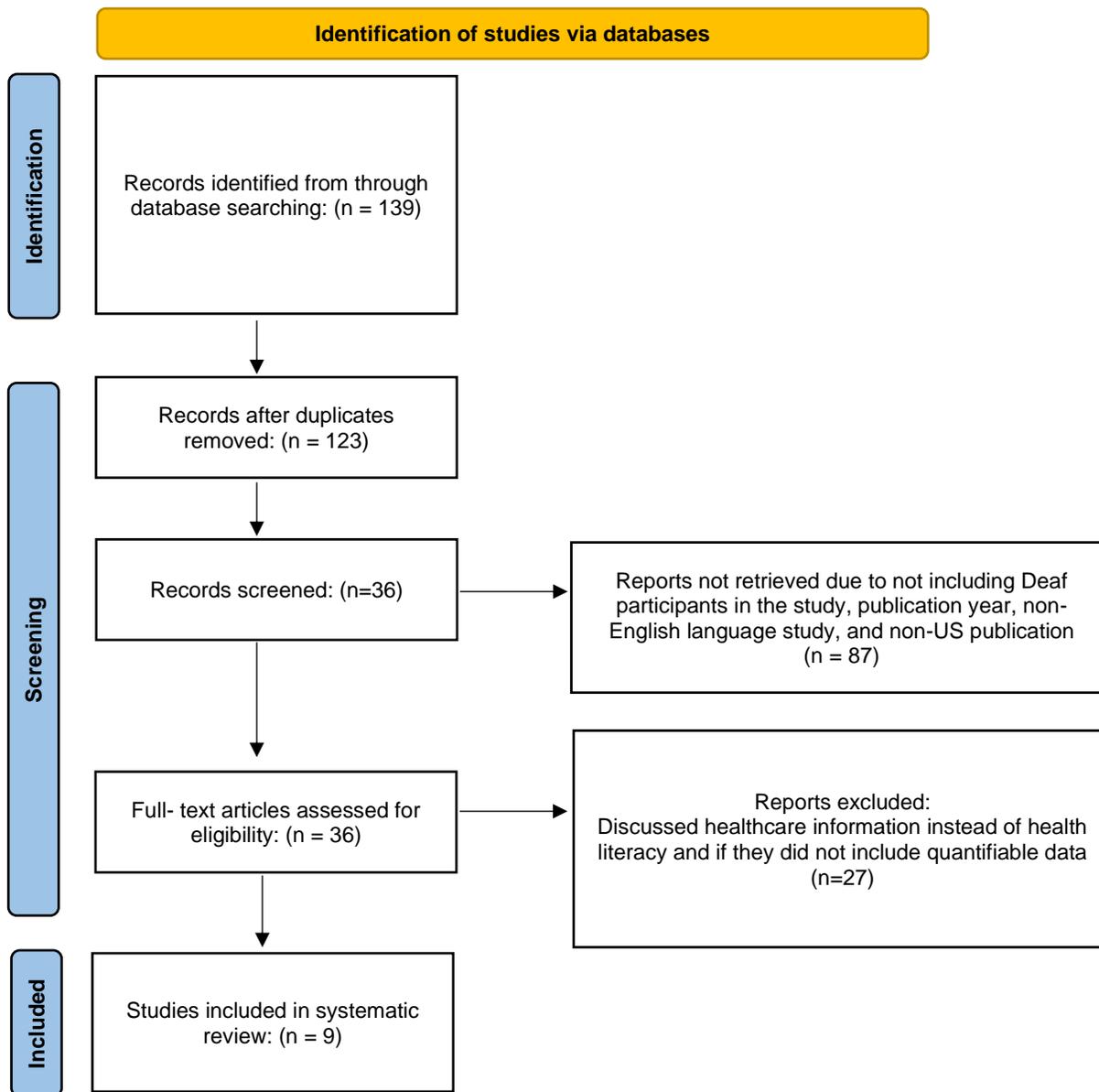


Figure 1. PRISMA flowchart of the literature search, retrieval process and selection of studies for this systematic review (The PRISMA group, 2020).

Study Characteristics

Figure 1 shows a PRISMA flowchart of the literature search and retrieval process for this systematic review. A comprehensive search utilizing various peer-reviewed databases, was conducted via the City University of New York's (CUNY) Graduate Center Library to identify the relevant studies published after 2009 to present day. The initial database search yielded a total of 139 relevant studies. Deletion of replicate articles resulted in a remaining 123 studies. Examination of the retrieved articles, elimination of articles that did not mention Deaf individuals, elimination of articles outside of specified range of publication year, articles that were not in English, and articles that were not published in the U.S. resulted in the elimination of 87 studies. The remaining 36 studies were assessed for eligibility in this research. Studies were further excluded if they discussed health information instead of healthcare literacy and if they did not include any quantified data. After excluding studies that did not meet the criteria, 9 studies were discussed in this research. Those studies were able to address the effect of d/Deafness in regard to the HLit of adolescent and adult Americans.

Each study had varying population sizes, ranging from 38 to 19,233 participants. Six out of the eight studies that included both male and female participants received more responses from female participants. Five out of the seven studies that provided racial demographics primarily received responses from white participants. A total of 11 different HLit assessments were utilized between the 9 studies discussed in this research (table 1). In the realm of HLit assessments, the Short form of the Test of Functional Health Literacy (S-TOFHLA) is considered a gold standard test of functional HLit, but this assessment was only utilized in two of the studies; Kushalnagar et al., 2017 and Smith et al, 2016. The remaining studies utilized and modified other general HLit assessments such as the Rapid Estimate of Adult Literacy in

Medicine (REALM) and Newest Vital Signs (NVS) or specified assessments focused on HIV knowledge or cardiovascular health as they pertained to that specific body of research. In terms of assessment administration, Goldstein et al., 2010 and McKee et al., 2015 both utilized pre-recorded videos and a computer survey to record survey responses, while Smith et al., 2016 only used a computer to record responses and Kushalnagar et al., 2017 and Sacks et al., 2013 used a pre-recorded video to administer the survey and accepted responses through live ASL translations. Only one study utilized a phone survey as a means to collect data, a method which they later noted to be a large limitation of their study because it made it difficult for participants with a severe hearing loss to participate (Wells et al., 2020) (table 3).

Out of the nine studies reviewed, all but three studies specifically modified their assessment in order to make it accessible for the participants based on their communication requirements (Tolisano et al., 2020, Wells et al., 2020, and Willink & Reed, 2020). McKee et al., 2015 commented that the use of the *PIAT-R* literacy measure for criterion validity of the ASL-NVS (NVS modified for ASL users) is limited because it was not meant to be used on a modified version of the assessment. Pollard Jr et al., 2009 reported that modifying the REALM instructions may have led to an overestimate in actual participant comprehension of the test terms because they misunderstood the instructions. Of the 9 studies, three (Kushalnagar et al. 2017, Pollard Jr et al., 2009, and Sacks et al., 2013) reported that small sample groups posed as limitations for their ability to generalize their results to a broader population and three (Goldstein et al., 2010, Kushalnagar et al., 2017, and Smith et al., 2016) reported that a small age range of participants were a limit of their studies. McKee et al., 2015 and Pollard Jr et al., 2009 and both reported that high educational attainment of their study population sample is unlikely to be representative of the general Deaf population in the U.S., while McKee et al., 2015 also found

that the low racial and ethnic diversity of their participants was a considerable limitation in the generalizability of their results to the general Deaf population in the U.S.

Study Outcomes

Although these studies each approached the topic of HLit by employing varying assessment protocols, focusing on different populations, and, concentrating on diverse areas of health, all 9 studies concluded that hearing loss is a contributing factor for poorer HLit (Table 2). In addition, of the groups studied, Deaf individuals with poorer HLit were more susceptible to negative health events related to having poorer HLit, as compared to individuals with normal hearing.

In 2020, Willink and Reed set out to find the association between 1) self-reported hearing loss, 2) the ability of the insured to understand Medicare, 3) the availability of information, and 4) the patients' satisfaction with the information at their disposal. So too, Medicare enrollment is not a simple process as beneficiaries are confronted with numerous choices related to their supplementary insurance plans, various levels of financial protection, and prescription drug coverage. Notwithstanding, beneficiaries also have to navigate the system to find alternatives for services not covered by Medicare (Willink & Reed, 2020).

Currently, The Centers for Medicare and Medicaid Services (CMS) support beneficiaries through several mediums such as the *Medicare and You* book, the 1-800-MEDICARE phone hotline, the Medicare.gov website, and closed-captioned YouTube videos (Willink & Reed, 2020). Steps taken by the Medicare agency to improve navigation of the program and understanding of options for beneficiaries are ongoing and aim to address concerns of low HLit in among older adults. These efforts include using simplified language across various mediums and ensuring linguistic and culturally competent messages, but do not address challenges faced

by beneficiaries with hearing loss, which affects two-thirds of Medicare beneficiaries who are 70 and older (Willink & Reed, 2020). Hearing loss not only affects the way beneficiaries obtain information, but also how they process and understand it. In addition to limiting access to auditory information that is necessary for communication, hearing loss is associated with cognitive impairments which overextends the brain's resources and increase fatigue due to extended listening effort (Willink & Reed, 2020). Even though CMS has taken steps to reach the d/Deaf population with information about their Medicare benefits and programs, this population still faces HLit related barriers to accessing this necessary information.

Using the Medicare Current Beneficiary Survey (MCBS), Willink and Reed examined the self-reported understanding of the Medicare program by analyzing responses of 10,510 Medicare users. Notably, the study excluded responses from 22 individuals because they were deaf. The survey relied on self-reported hearing loss and asked respondents if they had significant difficulty hearing. Further, from the perspective of the patient, roughly one-third of respondents stated that Medicare was difficult to understand. Of those reporting that Medicare was very difficult to understand, 42% were likely to have a little trouble hearing and 7% were likely to have a lot of trouble hearing. Forty-nine percent of the total respondents said that they had trouble finding Medicare information secondary to their hearing loss (Willink & Reed, 2020).

When controlling for covariates associated with HLit, respondents who self-reported having a little trouble hearing and a lot of trouble hearing had 18% and 25% higher odds, respectively, of reporting greater difficulty understanding Medicare. In regard to difficulty finding Medicare information, those with a little trouble hearing 85% reportedly had no trouble, 12% reportedly had a little trouble, and 3% reportedly had a lot of trouble. Of those with a lot of

trouble hearing, hearing 51% reportedly had no trouble, 21% reportedly had a little trouble, and 28% reportedly had a lot of trouble. There was no difference in the odds of calling the Medicare hotline among those with a little or a lot of trouble hearing. However, those with a lot of trouble hearing were more likely to visit the Medicare website for information compared to those with no trouble hearing, indicating that a visual display of the information was more preferable for individuals with more hearing loss.

Results of this study reveal that the primary barrier to Medicare information is that existing tools that facilitate understanding of the program are not designed to be accessible to those with hearing loss. The changes made to address the poor HLit of Medicare beneficiaries are focused on making the language more accessible but are not addressing barriers associated with receiving and processing information for those with hearing loss. As previously mentioned, these recipients who have hearing loss are more likely to search for coverage options online but are left dissatisfied with the available information. Further, the inconsistency of hearing loss treatment coverage within the programs adds to the difficulty of navigating the treatment options for those who do have hearing loss, leaving beneficiaries confused as to what they have access to (Willink & Reed, 2020).

Wells et.al., (2020) studied 19,233 adults ages 65 and over and found that lower healthcare literacy is correlated with older age and hearing loss. Additional contributors included being male, coming from a lower income household, having a number of health conditions, and not using hearing aids. These findings were also substantiated by Tolisano et al. (2020), who concluded that being a female and having better hearing were predictors of improved HLit scores. Further, Wells et al., (2020) found that individuals with lower HLit and hearing loss also had higher medical costs, often associated with results of individuals not utilizing preventative

medical services in a timely manner, and due to gaps in care because of lack of patient comprehension of follow up instructions from poor HLit. Further, this association of high medical costs can also be attributed to avoidance of medical care due to lack of trust and difficulty understand what they are told, leaving patients to address their health needs at a point when an extreme and costly intervention is needed. As a result of the late care, the study suggests that health issues may not be completely resolved, leading to even greater dissatisfaction, disappointment, and suspicion within this population of future medical care. Unfortunately, the health system's design creates an atmosphere where the individuals who need the most health-related attention, such as senior citizens who are unable to navigate their Medicare benefits, end up isolated and left ill-equipped to handle their healthcare needs (Willink & Reed, 2020).

McKee et al. conducted a study in 2015 which utilized a HLit assessment adapted for use in ASL as a means to test the HLit of Deaf ASL users in comparison to English speakers. Pre-existing HLit assessments were not suitable for use with Deaf ASL users because they relied on pronunciation and reading comprehension skills. The authors of this study adapted the Newest Vital Signs (NVS) assessment due to the ease of its adaptation and validation in ASL. This test, called the ASL-NVS, integrates aspects of numeracy, document literacy, and reading literacy, which are critical to understanding the provided health information and making proper health related decisions based on that information. The survey also used an adapted heart disease fact questionnaire to check the basic cardiovascular knowledge of the participants (McKee, et.al. 2015).

Data for the study was collected from 405 participants ages 40-70. Of those participants, 239 were normal hearing English speakers. The study found that the healthcare literacy of Deaf participants was statistically significant poorer than that of normal hearing adults. In fact, about

half of the Deaf respondents had inadequate HLit compared to the rest of their group. Additionally, the overall cardiovascular knowledge of the Deaf population was significantly lower, and the correlation between the HLit and cardiovascular health knowledge for Deaf population was significantly higher than that of the normal hearing population. Deaf participants who were older, had lower education attainment, had a lower income, and had poorer English reading literacy had the poorest HLit scores of the Deaf respondents (McKee et al., 2015). Another study utilized the Rapid Estimate of Adult Literacy in Medicine (REALM) assessment but had similar findings. The REALM is an assessment that requires respondents to pronounce 66 English words which are gathered from patient education materials and intake forms from primary care settings. Although this is a test that reveals a correlation between accurate word pronunciation in relation to reading comprehension in normal hearing individuals, this is not the case with pre-lingually deafened individuals. Their word pronunciation ability is affected by general difficulties with speech articulation and phonetic decoding strategies. Therefore, it would be unfair to utilize this test in its current form and make assumptions that correct pronunciation of REALM terms predicts reading comprehension in Deaf ASL users.

The authors modified the REALM assessment in order to accurately test the Deaf participants in their study. The REALM was adapted to be a test of self-reported comprehension of the test words instead of a word-pronunciation task. This study surveyed 57 Deaf adults ages 21-67 and found that the Deaf population is at risk for health consequences due to having poor HLit, regardless of their level of educational attainment (Pollard Jr et al., 2009). While most participants suggested that they understood more than 90% of REALM terms, one third of participants earned scores that were equivalent to below a ninth-grade level, which is indicative of low HLit. Within this group, 30% had at least a high school education, and 22% had college

degrees. Terms that were understood by all participants included, but were not limited to, *pill*, *eye*, *stress*, and *germs*. The words that were least frequently understood included, but were not limited to, *impetigo*, *colitis*, *potassium*, *obesity*, *rectal*, and *osteoporosis* (Pollard Jr & Barnett, 2009). It is noteworthy that the words that were understood by all respondents were mainly monosyllabic, while the words that were least frequently understood were all multisyllabic. This finding suggests that regardless of educational attainment within Deaf individuals, English and HLit disparities are present within this population that are not exhibited in hearing individuals.

Furthermore, the study did not measure actual comprehension of the terms, meaning, it is possible that some participants indicated comprehension of terms that they did not truly understand. Thus, it is possible that the results of the study overestimated the actual comprehension of terms, which reveals that the HLit status of the participants is even poorer than reflected in the results discussed above (Pollard Jr & Barnett, 2009). It is possible to conclude that the HLit comprehension status of this group is even poorer than detected, placing Deaf even further at risk for having poorer HLit than normal hearing individuals.

Three studies focused specifically on the Deaf adolescent population and demonstrated the effect of Deafness on their HLit. Smith and Samar (2016) aimed to find the disparities of HLit skills between Deaf and normal hearing participants while controlling for the potential influence of English print literacy on the measures that they used. This study recruited 187 Deaf/Hard of Hearing (D/HOH) and 94 normal hearing high school student who were all college bound and had to demonstrate satisfactory performances in their core academics subject classes. The demographics of the D/HOH individuals who completed the survey revealed that they were significantly older, more often male, had higher grades, but from lower childhood socioeconomic homes and tended to be more frequently white non-Hispanic in comparison to the hearing

participants. About 80% of the D/HOH participants reported an onset of hearing loss prior to the age of 3 and most of them reported having normal hearing parents and family members. The D/HOH participants reported a very broad range of hearing loss, with varying usage of amplification devices. Approximately two-thirds of the group reported having hearing aids and one-third reported having cochlear implants. D/HOH participants described a wide range of cultural identities including individuals who described themselves as “culturally deaf” or “hard-of-hearing”, “hearing impaired”, or “hearing”. They also reported a range of best languages ranging from ASL, to equivalent competence in ASL and English, and to English (Smith & Samar, 2016).

Smith and Samar performed a comprehensive review of available HLit measures, assessments, and tools that were appropriate to use with D/HOH adolescents and chose to use the Health Literacy Skills Instrument-Short Form (HLSI-SF), the Short Form of the Test of Functional Health Literacy (S-TOFHLA), and the Comprehensive Heart Disease Knowledge Questionnaire (CHDKQ). The CHDKQ tested the participants’ knowledge of cardiovascular health, independent of their reading skills. This topic is of importance because cardiovascular disease is a critical concern for the D/HOH population.

While all of the hearing participants completed the survey, only 61% of the D/HOH completed the survey. When controlling for general demographics, results of the survey revealed that the D/HOH participants had significantly lower scores on all three assessments compared to the normal hearing participants. D/HOH participants who reported having more frequent family discussions about their family health history had higher HLSI-SF and S-TOFHLA scores than D/HOH adolescents who had fewer discussions. D/HOH adolescents who reported being able to appropriately choose proper timing for seeing a doctor had higher HLSI, S-TOFHLA, and

CHDKQ scores. D/HOH adolescents who reported having an easier time determining the truth of printed health information had higher HLSI-SF and CHDKQ scores than those who reported having trouble making these decisions. In addition, those who reported an easier time determining the accuracy of health information obtained from other people had higher CHDKQ scores. These relationships were not significant for hearing adolescents. Participants who reported having an easier time deciding when they needed to talk to their doctors about their family medical history, how much exercise they need to stay healthy, and which foods are healthy to eat had higher CHDKQ scores. Those who reported having an easier time deciding how much exercise they need to stay healthy and which foods are healthy to eat had higher HLSI scores. Hearing adolescents generally demonstrated similar patterns in these relationships (Smith & Samar, 2016).

Overall, D/HOH who achieved the highest scores on the S-TOFHLA were those who described themselves as being hearing/hearing impaired/hard-of-hearing instead of d/Deaf, those who reported having better hearing with assistive devices, those who reported having hearing aids and used them frequently, those who described English as their best language, those who reported a good quality of communication with their parents, and those who reported attending hearing schools at least half of the time. D/HOH adolescents who had higher cardiovascular health knowledge scores included those who reported wearing their hearing aids frequently, described English as their best language, and reported attending hearing schools at least half of the time. Even though having a cochlear implant was not related to the scores on any of the assessments, a notable trend revealed that those who used their CI more frequently, compared to participants who did not, received higher HLSI scores (Smith & Samar, 2016).

While the prior study revealed that D/HOH high school students demonstrated poorer functional and general HLit and cardiovascular knowledge, another study pointed out that Deaf high school students also have knowledge gaps when it pertains to their knowledge of HIV. Previous studies on Deaf adolescents and young adults revealed inconsistencies in their HIV knowledge base due to lack of access to information (Goldstein et al., 2010). Messages that targeted this age range are typically transmitted through 3 vehicles of delivery: television, radio, and print media. These are not typical means of communication for the Deaf who primarily communicate through ASL.

For this study, 700 students from 15 high schools for the Deaf in the U.S. were recruited and surveyed using a recorded video with standardized questions delivered in ASL. Of the respondents, 70% self-reported as being Deaf and the remaining self-reported as hard-of-hearing. About one third of respondents admitted being comfortable speaking to at least one adult about problems like drugs or sex, and 53% stated that they feel comfortable speaking to another adult about these topics. In terms of HIV sources of information, 70% reported receiving information from school while only 44% reported receiving information from their families (Goldstein et al., 2010).

Some Deaf students did attain the highest scores possible, however, the mean for the entire survey was 7.2 points, revealing inconsistent knowledge between the students. Further, school means ranged from 5.9 to 10.3, further illustrating the variation between each school's instruction on this topic (Goldstein et al., 2010). For example, while most school discussed HIV transmission with students, not all school reviewed HIV testing or the effects of drugs and alcohol on decreasing sexual inhibitions. This suggested that students are at greater risk depending on their school curriculum, which is out of the students' control, even though it

greatly impacts their knowledge base. Though there were no hearing students who participated in this survey, six out of the fourteen questions on this survey were taken from a HIV knowledge survey administered to two groups of high-risk adolescents. In 1997, the 410 at risk normal hearing respondents correctly answered 90% of those questions, while the Deaf/hard-of-hearing respondents who took this survey in 2008 gave responses that were between 33-70% correct to the same questions. The implications of this study reveal that Deaf high school students know less about HIV than their normal hearing counterparts and in need of a standardized and comprehensive HIV education that is adapted for their needs (Goldstein et al., 2010).

The above studies revealed that Deaf adolescents have poorer HLit and are at a greater risk for health-related knowledge gaps, but Kushalnagar et al., (2018) aimed to obtain a better understanding of the critical HLit of Deaf college students who use ASL. This study found focused on 38 adolescents who have reduced access to health information discussions at home due to communication barriers. They reported that these students were more likely to rely on peers to acquire the critical health information that they need to develop their HLit skills. While it is preferred that these adolescents have someone to fill in their knowledge gaps, rather than have no information, if their peers are unknowingly relaying inaccurate healthcare related information to them, then this will cause them further harm. Instead, adolescents need a reliable source to obtain information from, such as a knowledgeable family member or trusted healthcare provider.

Although this population is at a disadvantage, the adolescents in this study demonstrated that they could still strengthen their critical HLit skills by improving their interactive HLit, even if their functional HLit remained the same. These adolescents might not have access to the same incidental learning opportunities as their normal hearing counterparts, but they still have access

to health literate friends who can compensate for the missed information and help them address gaps in their health-related knowledge base.

In 2013, Sacks et al., published a study that clearly demonstrated the ability for Deaf men to comprehend and apply healthcare information once it was presented in their preferred communication model. This study aimed to establish that Deaf and normal hearing individuals had differing levels of general cancer and testicular cancer knowledge by assessing their knowledge before and after the presentation of an educational video related to the topic (Sacks et al., 2013). One hundred seventy-five males between the ages of 18 to 40 were recruited for this study. In this population, 85 Deaf men primarily spoke ASL, and the remaining participants were normal hearing English speakers. The males completed a general and testicular cancer knowledge assessment prior to watching an educational video which explained how prostate and testicular cancer develop, the risk factors, diagnosis and treatment courses, and importance of participation in clinical trials. The video was in English with closed captioning and included ASL signers. The same pretest assessment was taken at the conclusion of the educational video (Sacks et al., 2013).

Results revealed that at pretest, the Deaf men had significantly poorer general and testicular cancer knowledge compared to normal hearing men. After viewing the educational video, both groups of men significantly increased their general and testicular cancer knowledge. Further analysis displayed that Deaf men's post-test knowledge surpassed the pre-test knowledge of the normal hearing male. The results of the assessment reveal that if healthcare information is presented to Deaf men through their preferred mode of communication, they can retain and apply the information in a manner that is comparable to a normal hearing male. Given this data and knowing that early detection and treatment is crucial for testicular cancer survival, it is clear that

public health officials need to improve provision of healthcare information in a mode of communication that is preferable for ASL users to allow them to access information as readily as normal hearing individuals are able to (Sacks et al., 2013).

Table 1. Demographics of Deaf and hearing participants.

Author	Sample Size	Age	Gender (Male/Female)	Race (White/other)	Education Level
Goldstein et al., 2010 (U.S.)	700 Deaf High School Students	14-18 years of age	371/329	259/441	Various levels of high school education
Kushalnagar et al., 2017 (U.S.)	38 Deaf undergraduate college students	College aged adolescents	17/20	17/20	At least some college education
McKee et al., 2015 (U.S.)	405 participants; 166 Deaf	40-70 years of age	174/231	295/106	Less than high school through completed college and more
Pollard Jr et al., 2009 (U.S.)	57 Deaf Adults	21- 67 years of age	29/27	Unknown	12th grader through Doctoral Degree in addition to one individual who did not indicate education level
Sacks et al., 2013 (U.S.)	175 males; 85 Deaf	18-40 years of age	100/0	89/86	High school through more than college degree
Smith et al., 2016 (U.S.)	281 adolescents; 187 D/HOH	High school aged adolescents	113/168	142/139	Various levels of high school education
Tolisano et al., 2020 (U.S.)	300 Adults	18-91 years of age	140/160	241/59	Unknown
Wells et.al., 2020 (U.S.)	19, 223 adults	65 years of age and older	6855/12368	Unknown	Unknown
Willink et al., 2020 (U.S.)	10,510 Medicare enrollees	65 year of age and older	4747/5763	8578/1932	Less than high school through completed college

Table 2. Research study parameters and criterion.

S-TOFHLA: Short form of the Test of Functional Health Literacy, DHS: Deaf Health Survey (DHS), ASL-NVS: ASL version of Newest Vital Sign, REALM: Rapid Estimate of Adult Literacy in Medicine, HLSI: Health Literacy Skills Instrument-Short form, CHDKQ: Comprehensive Heart Disease Knowledge Questionnaire, BHLS: Brief Health Literacy Screen, IVR: Interactive Voice Response.

Author/Article	Survey Used	Communication Method Used	Exclusion Criteria	Conclusion based on HL
Goldstein et al., 2010 (U.S.), “What Do Deaf High School Students Know About HIV”	Adapted from The Deaf Adolescent HIV knowledge and Risk Survey	Videotaped English and ASL translations	Inability to communicate through ASL, not completing informed consent paperwork for students over the age of 18, having major developmental disabilities, and being out of the 14-18-year-old age range	Variation of HIV education in school led to knowledge gaps among Deaf students
Kushalnagar et al., 2017 (U.S.) “Critical Health Literacy in American Deaf College Students”	S-TOFHLA	Written English and captioned video	Non-consenting non-Deaf college students	A strong positive relationship exists between discussion of health-related information with friends and critical HLit among Deaf college students
McKee et al., 2015 (U.S.), “Assessing Health Literacy in Deaf American Sign Language Users”	DHS and ASL-NVS computer-based questionnaires	Spoken English and ASL translation	Individuals with developmental delays, cognitive issues, those unable and unwilling to provide written informed consent, and those who were unable to see and interact with computer-based questionnaires	48 % of Deaf participants had inadequate HLit and were 7 times more likely to have inadequate HLit compared to NH participants
Pollard Jr et al., 2009 (U.S.), “Health- Related Vocabulary	REALM	Written English and ASL translation	Non-consenting non-Deaf adults	Scores of about 31% of Deaf participants indicated low HLit and findings suggest Deaf population is at risk for health consequences

Knowledge Among Deaf Adults”				associate with low HLit, regardless of education level
Sacks et al., 2013 (U.S.), “Testicular Cancer Knowledge Among Deaf and Hearing Men”	Total cancer knowledge survey and educational video	English for NH, English and ASL for Deaf men	Deaf man who had previously participated in the prior study	HLit of Deaf men was worse than NH men prior to video, but improved to be better than HLit of NH men prior to video
Smith et al., 2016 (U.S.), “Dimensions of Deaf/Hard-of-Hearing Adolescents’ Health Literacy and Health Knowledge”	HLSI-SF, S-TOFHLA, CHDKQ	Written English, ASL translations, and Conceptually Accurate Sign English (CASE), video narrations	Students who were not enrolled in the Summer career orientation programs and those who did not display academic excellence	D/HOH adolescents had weaker general and functional HLit and cardiovascular knowledge compared to NH adolescents. D/HOH adolescents who had greater hearing culture identity, consistent and beneficial HA use, good quality communication with their parents, and attended hearing schools had better functional HLit
Tolisano et al., 2020 (U.S.) “Can You Hear Me Now? The Impact of Hearing Loss on Patient Health Literacy”	BHLS	Written and spoken English	Non- English speakers and pediatric patients	About 10% of participants had inadequate HLit, and HLit of men was poorer than women. Hearing loss is an independent risk factor for inadequate HLit
Wells et.al., 2020 (U.S.), “Limited Health Literacy and Hearing loss Among Older Adults”	Telephonic IVR	Spoken English	Individuals who are not enrolled in the AARP Medicare Supplement plan insured by UnitedHealthcare Insurance company, individuals below the age of 65, and individuals who had not has at least 12 months of continuous plan coverage in the year prior to the survey	Individuals with unaided mild, aided severe, and unaided severe hearing losses had a positive association with lower HLit

<p>Willink et al., 2020 (U.S.), “Understanding Medicare: Hearing loss and Health Literacy”</p>	<p>Medicare Current Beneficiary Survey</p>	<p>English (unknown)</p>	<p>Deaf individuals (n=22), those who did not answer the primary outcome of understanding Medicare (n=450), and individuals living in a facility or those who were not enrolled in Medicare in 2017 (n=419)</p>	<p>One third of Medicare, many of whom have hearing loss, have difficulty understanding and navigating their policy to their benefit</p>
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Table 3. Characteristics of Health literacy assessments used.

S-TOFHLA: Short form of the Test of Functional Health Literacy, DHS: Deaf Health Survey (DHS), ASL-NVS: ASL version of Newest Vital Sign, REALM: Rapid Estimate of Adult Literacy in Medicine, HLSI: Health Literacy Skills Instrument-Short form, CHDKQ: Comprehensive Heart Disease Knowledge Questionnaire, BHLS: Brief Health Literacy Screen, IVR: Interactive Voice Response.

Author	Health Literacy Assessment	Type of Assessment	Number of Questions	Type of Answers	Specifically adapted for study	Limitations
Goldstein et al., 2010 (U.S.)	Adapted from The Deaf Adolescent HIV knowledge and Risk Survey	Pre-recorded video and computer response survey	14	Yes or No	Yes: Survey was pilot tested on separate respondents prior to survey use in study. Recorded instructions and questions in ASL were delivered from a screen and respondents answered questions by choosing response on the computer screen.	Small participant age range
Kushalnagar et al., 2017 (U.S.)	S-TOFHLA	Pre-recorded video with ASL translated survey response	38	Qualitative responses rated on level of appropriateness	Yes: a recorded movie with ASL translated dialogue was used	Small sample size, lack of inclusion of other age groups
McKee et al., 2015 (U.S.)	DHS and ASL-NVS computer-based questionnaires	Pre-recorded video survey and computer response	Unspecified	Unspecified	Yes: Selection, translation, adaptation, and validation of BHS and NVS assessment with English closed	Limited use of <i>PIAT-R</i> literacy measure for criterion validity of ASL-NSV, higher than anticipated educational attainment for Deaf

					captioning, English audio, and signed ASL video	participants, subjectively assessed ASL fluency, low racial and ethnic diversity
Pollard Jr et al., 2009 (U.S.)	REALM	Self-administered written survey	66	Circle the word if you comprehend it, leave it blank if you do not comprehend the word	Yes: modified instructions from original	Small sample size, highly educated sample of Deaf participants, modified REALM instructions and lack of measuring actual comprehension of REALM, and modification of tasks prevents the results from being compared to original REALM norms
Sacks et al., 2013 (U.S.)	Total cancer knowledge survey and educational video	Self-administered survey taken twice: once prior to the video and again after watching the video	21	True or False	Yes: video with ASL interpretation and questions in written English or with ASL translations which were pilot tested on separate respondents prior to the survey	Small sample size chosen from a limited geographical area and lack of follow-up after the study to assess long term retention of information
Smith et al., 2016 (U.S.)	HLSI-SF, S-TOFHFLA, CHDKQ	Computer survey	Unspecified	Unspecified	Yes: All assessments were pilot tested on separate respondents prior to the survey. The HLSI-SF and CHDKQ were adapted by translating the instructions, questions, answers, and menu into ASL	Survey time limit prevented some respondents from completing their survey, small survey population, and the limited ability of D/HOH participants' ability to process English content could have lowered HLSI-SF scores even when they

						were statistically controlled for
Tolisano et al., 2020 (U.S.)	BHLS	Self-administered survey	3	Rate from 1-5, 1= not at all, 5= extremely	No	Relied on self-reported English language proficiency, classification of hearing loss based on WRS and PTA of better hearing ear which fails to completely capture the patient's total hearing loss bilaterally, survey fatigue experienced by respondents who have previously filled out many long intake forms, and the responses were obtained from participants between a short time period and limits responses
Wells et.al., 2020 (U.S.)	Telephonic IVR	Telephone survey	Unspecified	Rate level of hearing loss, level of amplification use, level of trouble hearing, level of confidence while filling out medical forms, level of physical activity, level of memory loss,	No	Low survey response rate, not enough questions pertaining to low HLit on survey, and use of telephone to administer survey made it difficult for those with severe hearing loss to participate

				and number of prescription drugs taken daily		
Willink et al., 2020 (U.S.)	Medicare Current Beneficiary Survey	Unspecified survey method	8	Yes or No, rate from 1-5: 1= very satisfied, 5= very dissatisfied	No	Relies on self-reported hearing loss, inability to determine whether hearing aids would assist in better understanding of the Medicare program in unaided individuals with hearing aids, lack of validated instrument that can measure hearing literacy among older adults, and inability to completely account for impact of cognitive impairment on the understanding of Medicare

DISCUSSION

The HLit of the American public is an essential element for individual and community health and wellness. Inadequate language-literacy, which can be described as a person's inability to read, write, speak, compute, and solve problems using coded language, is a current crisis in the U.S. The NAAL and HALS data highlighted that those with the poorest HLit were individuals who are who are 65 years of age or older, male, and Black or Hispanic, non-native English speaker, have less than a high school diploma, live at or below the poverty line, rate their overall health as poor, have Medicare, Medicaid, or no insurance, and are not seekers of print or non-print sources of healthcare information. The data published by the NAAL indicated that only 12% of the population was classified as having proficient HLit. This reveals that the remainder of the population is at risk for having poor understanding of HLit, which impacts their ability to access and function in healthcare settings (Gazmararian et al., 2005).

The U.S. is considered to be one of the most desired places to live, home of the American dream and a land of opportunity. Although Americans are afforded many privileges that individuals in other countries are not privy to, there is an imbalance in the access to healthcare, especially when it comes to individuals with disabilities such as d/Deafness. Although multiple factors can impact access to healthcare, poor HLit has been documented as a large contributor to this problem placing patients at risk for inadequate health and medical management.

When considering the implications of the data collected on the d/Deaf and HOH population, it is important to keep in mind the sample of people that this research impacts. According to Gallaudet University's research institute, 35 million Americans self-report that they have some degree of hearing impairment. Data collected in 2011 by the American Community survey revealed that about 3.6% of the U.S. population, or 11 million Americans, consider themselves to be deaf or have serious difficulty hearing. These rates are self-reported and

therefore may not truly reflect the correct actual quantity of d/Deaf Americans, which may be higher than reported. Additionally, many of these statistics are recorded from telephone surveys, many of which d/Deaf individuals cannot participate in, which yield a population might be excluded from responding due to data collection method.

At its core, functional HLit requires proficient language-literacy. To function in the complex healthcare environment, individuals must possess multiple attributes, including abilities in prose and composition, documentation, quantitative literacy, oral communication, or the ability to engage in two-way conversation, skills in media and computer literacy, motivation to receive health information, freedom impairments, and/or access to communicative assistance from others (Gazmararian et al., 2005). D/HOH individuals' performance on functional HLit measures may not accurately reflect their true functional HLit in specific health contexts. Interactive and critical HLit constructs extend beyond English dependent access because they do not necessarily require English language and reading skills however they do require access to effective communication within the health care system and information environment. Most interactive and critical HLit assessment insurance in the U.S. do not rely on spoken or printed English language test, which is not appropriate for the Deaf or HOH population (Smith & Samar, 2016)

Due to complicated nature of the healthcare system in this country, many individuals with poor HLit are forced to make inappropriate decisions related to their healthcare when they do not properly understand the information provided to them which for obvious reasons, puts them at further risk to mismanagement. Individuals with poor HLit can make more medication errors, are less likely to understand insurance coverage rules, fail to comply with treatments, fail to obtain preventative services in a timely manner, fail to manage their own care effectively, and are more

likely to return for hospitalized care as compared to those with proficient HLit (Gazmararian et al., 2005). A contributor to the gap between those who do and those who do not have adequate skills to process and understand healthcare are the advanced reading levels of health information and the growing role of technology in health communication. The average American reads at an 8th grade level, while most medical information is written at a 12th grade reading level, leaving many people not only unable to read, but also struggle to understand the information provided to them.

Most often, those with the greatest healthcare needs are the ones who struggle the most with comprehending the medical information. Public health initiatives have failed to convey information in a manner that is easily understood by the general public. Information needs to be shared in a manner that is accurate and can reach a broad audience at fast rate. Many individuals are not aware of behaviors that can impact their health in a negative manner. Some were simply never told, some do not want to know, and some do not care. With this type of attitude towards healthcare, the state of public health in the U.S. may never improve. Even if some health literate Americans exist, that will not balance out the members of society who have poor HLit and are unable to navigate the health system, leaving them unable to receive the proper care they need to maintain their physical and mental wellbeing.

Normal hearing individuals are more likely to know their families' medical histories either by having a direct conversation with their families or overhearing family discussions about the state of their health. In the US, Deaf ASL users' knowledge of medical terminology is similar to that of a non-English speaking immigrant to the U.S (Barnett et al., 2011). Deaf individuals often times cannot listen to conversations and are unaware of what they do not know. This is an important consideration to make because family history is a risk factor for many chronic

conditions such as diabetes, cancer, heart disease, etc. Without having access to this information, Deaf individuals are not able to prepare or equip themselves if they too face these conditions in the future.

In comparison to adults who became deaf post-lingually or during adulthood, those who were born Deaf or became Deaf pre-lingually did not have the same exposure to the healthcare system. Deaf adults have low HLit as a result of a lifetime of limited access to information that is considered to be common knowledge for individuals without hearing loss. Even though the ADA provides industry guidelines that can assist organizations to help individuals, it is clear that these guidelines are not being utilized well, as demonstrated by Wells et al. (2020). More research needs to be performed in order to obtain an estimate of how d/Deaf individuals currently receive their healthcare information, such as whether its auditory or visual, and to find out what their preferred method of communication is.

Additionally, American adults who have been Deaf since childhood or birth are less likely to regularly see a physician compared to adults in the general population. Physicians claim that Deaf patients require more time and effort than hearing patients, which is not an effort that every physician is willing to make (Barnett et al., 2011). Deaf individuals feel this resentment, which adds strain to an already complicated relationship with their physician. Furthermore, these individuals have difficulty communicating their needs to their physicians and often have trouble getting their needs tended to. Therefore, due to the barriers in communication, their medical issues are unresolved, and they are left unsatisfied with the care that they received, which leads them to decide to avoid healthcare settings in future instances, regardless of their needs.

A further consideration of note is that Deaf individuals may have a biological basis for their condition via genetic syndrome or disease. Although it may not present itself initially, this

condition may manifest later in their life and they will be unaware of its existence, or of how to treat it. Conditions may also be hereditary, such as Usher's syndrome, which can be passed onto the Deaf individual's child while they are unaware that they even have it. This puts another individual at risk. The potential for an acquired illness such as meningitis also exists. Without proper or consistent access to healthcare, these are conditions which may go untreated, lowering the patient's quality of life and quite possibly being fatal. Health outcomes are likely to be worse in d/Deaf people compared to those who are normal hearing because of imbalances of access to health care, health info, education, and economic resources (Barnett et al., 2011).

It is not surprising that individuals who were pre-lingually deafened struggle with language-literacy. Deaf individuals typically rely on ASL to communicate, yet this language is characterized by its unique abstract phonological organization, plus syntactic, grammatical, and dialogic properties that differ markedly from spoken English (Pollard Jr. & Barnett, 2009). It is estimated that the average normal hearing high school senior reads at a 9th grade level, while the average Deaf high school senior reads at or below a 6th grade reading level (McKee, 2015; Pollard Jr, 2009; Smith, 2012). This suggests that Deaf adolescents are at a higher risk for lower language-literacy, and in turn, lower health terminology recognition and comprehension. The goal is for individuals to establish healthy behaviors during their adolescence, which is a critical time period between childhood and adulthood, that they will continue to maintain throughout their adulthood. At this stage of their lives, adolescents are exposed to risky behaviors such as motor vehicle crashes, unintentional injuries and violence, alcohol, tobacco, and drug use, risky sexual behaviors, unhealthy dietary behaviors, and physical inactivity. If these behaviors continue unchecked by society, they will develop into public health challenges that will later

manifest into leading causes of death during the later stages of adolescence and early adulthood (Smith et al., 2012).

Since many if not most Deaf individuals have family members that are hearing, there is a language barrier that leads to a loss of communication regarding health status, and a loss of family health awareness. Many Deaf individuals have spent years watching interactions and conversations of family members that were not translated for them. They were unable to decipher what was being said, as Deaf individuals only understand what is being said through lipreading 30% of the time (McKee, 2015; McKee, 2019), so they were deprived of the incidental learning opportunities that many normal hearing individuals take for granted (McKee et al., 2015). This loss of incidental learning opportunities can also be described as *dinner table syndrome*, *fund of health knowledge*, and *fund-of-information deficit* (McKee, 2015; McKee, 2019; Pollard, 2009; Smith, 2012).

In comparison to the normal hearing individual, the *fund-of-information deficit* causes a distinct limitation in the Deaf individual's factual knowledge base, even when they have a normal IQ and educational attainment. Family conversations play a crucial role in development of HLit skills, for Deaf children more so than for normal hearing children. The normal hearing child who does not directly talk to their parents about health issues might eventually happen upon a similar conversation which will fill in the gap for them. The Deaf child will not have these incidental opportunities (Smith & Samar, 2016). For these Deaf individuals, not only are they cut off from incidental learning around family, but they also do not have access to auditory sources of information from the radio, television and movies, overheard conversations, and public address announcements (Pollard & Barnett, 2009). This loss of incidental opportunities does not only occur in the home; Deaf individuals miss these learning opportunities at work,

school, around their friends, while browsing social media, and in healthcare contexts (McKee et al., 2015).

Furthermore, though some parents of Deaf children attempt to acquire the skills and signed vocabulary necessary to discuss important health topics such as puberty, human sexuality, and drug use, it can be a challenging task. As a result, the child can misinterpret the provided information or be frustrated by the communication barriers, causing them to further disconnect and isolate themselves from family members (Smith et al., 2012). Moreover, many sources of medical information are written in print, at a reading level appropriate for a 12th grader. As previously established, these Deaf adolescents have poor language-literacy and reading comprehension, which is not conducive for learning based on the method chosen to express the health materials.

As a result of the lack of information and desire to obtain knowledge, these Deaf adolescents are forced to turn to their peers to learn language, cultural norms, and even health information. Often, these individuals struggle to identify and correct misinformation, which leads to the inability to properly manage their healthcare needs. These adolescents are at risk to develop into adults who never establish requisite healthy behaviors, miss sufficient opportunities to obtain reliable information, and are unable to navigate the healthcare system that can provide them with the tools that they lack.

CONCLUSION

Addressing and closing the gap in HLit in both normal hearing and d/Deaf individuals, is a goal that should be addressed within the public health sphere in the U.S. Discounting this problem risks exacerbating difficulties that already exist and further increase health disparities. Although challenging to the healthcare system, results of this systematic review demonstrate how health communication needs to be linguistically and culturally presented at a literacy level accessible to all individuals. Consumers of healthcare require training, education, and empowerment to gain the skills needed for functional HLit. The ability to access and comprehend this information not only aids the underserved communities like the Deaf, but benefits all citizens. When there is more access to healthcare, there are increases in emergency preparedness and disease prevention, and, reduction in health disparities and health promotion inequities. (Gazmararian et al., 2005).

While it is important to implement such changes for adults, further development by government agencies that will evaluate and address knowledge gaps for d/Deaf adolescents will help to advance programs and overall health of these individuals. Adverse health outcomes can be reduced if there exists an increase in research initiatives directed towards this population segment; substantiating health initiatives through research will help to give adolescents the support they need at a time of critical development and maturity. As noted, d/Deaf adolescents do not have the advantage of incidental learning and are therefore at risk for missing conversations about family health history and health status (Smith & Samar, 2016). Interventions aimed to improve the HLit of d/Deaf and HOH adolescents during targeted family-oriented activities will improve mechanisms for healthcare availability. At risk for not addressing these issues are coming of age adolescents who may feel dissatisfied and mistrustful of the healthcare system.

Within this systematic review were limitations consisting of the following; small sample sizes and demographics that were not completely representative of the Deaf American population. It can also be justified that further research needs to focus on increasing and widening the demographic range of the sample population in order to obtain an accurate assessment of the HLit of the Deaf community. As an example, there existed a bias toward the educational attainment level of their Deaf participants which was higher than that of the general Deaf population in the U.S. This created an added concern that suggested the healthcare literacy of the general Deaf population may be even poorer than that of highly educated Deaf population. Inclusion of the Deaf population in major national HLit studies would benefit this demographic as the NAAL and HALS neglected to collect data related to their respondents' disabilities. This information could have provided valuable insight into the needs of the d/Deaf population. Lastly, additional ASL compatible HLit assessments could benefit from standardization for use with this population thus making quantifiable research possible and reducing the effect of language-literacy on measurement outcomes.

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