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The Deficits in Health Literacy and Inadequacies of Specialized Health Care in the South for Deaf and Hard of Hearing Patients

By

Kaleb Kittrell

A thesis submitted in partial fulfillment of the requirements of the Honors College at the University of South Alabama and the Bachelor of Sciences in the Mathematics and Statistics department

University of South Alabama

Mobile, AL

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Committee Member: Dr. Drew Lewis

Douglas Marshall

Interim Dean, Honors College

DEDICATION

I dedicate this research primarily to those who are Deaf or Hard of Hearing, but also to all others who are underserved in healthcare. Through my passion for healthcare and advocacy for those underrepresented, this research has been a true honor to undertake these past four years. Every patient is important, regardless of who they are.

Additionally, I dedicate this work to my partner, Cameron Swann, and my supportive family members, Monica Swann, Lillian Snow, and Chandler Kittrell. I'd also like to thank my two cats, Misty and Ash, even though you'll never be able to read this. Thank you all, sincerely, for the patient and unwavering support, compassion, and love. I could not, in any other circumstance, have done it without y'all. I love you all so very much!

Lastly, I'd like to dedicate this to my late cousin, Lexy Ann Deese. I love and miss you so dearly. It's been a long couple of years since I've last heard your voice, but somehow, I can hear you cheering for me close by.

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I would also like to thank the Honors College for funding my transportation, lodging, and attendance to the Southern Regional Honors Conference 2022. It was a wonderful experience filled with captivating and thoughtful research from other undergraduate students, and I am thankful I was able to attend. A special thanks to Dr. Kathy Cooke for your kindness and dedication to the Conference and your South students, and to Dr. Chrystal Lewis for making sure all of us South kids were travelling safely and accounted for.

I express tremendous gratitude to Dr. Chrystal Lewis for being such a patient and flexible research mentor. Your kindness and willingness to undertake this research with me will forever be the highlight of my experience here at South. Thank you, from the bottom of my heart, for caring about me not only as an undergraduate Honors student, but also as a young kid discovering his future and learning how to serve others through research. Additionally, I thank Dr. Drew Lewis and Dr. Ashley Flagge for serving as committee members. You both have been so helpful and willing to work with me. I appreciate you both!

ABSTRACT

Health literacy is a constantly evolving concept that requires similarly evolving adaptation and specialization of health care to increase the quality of life for all. One demographic that is largely ignored when it comes to research in health literacy, specifically in the traditional South, is the d/Deaf and hard of hearing/Hard of Hearing (DHH) population. The purpose of this study is to determine the general health literacy of this specific demographic and compare results with that of other demographics to highlight the anticipated deficit in health literacy levels and emphasize the critical need for specialized care.

This prospective, non-experimental, descriptive study utilized online survey software to gather anonymous general health literacy levels of those that self-identify as DHH. This survey consisted of the Short Assessment of Health Literacy – English (SAHL-E) to determine health literacy level and follow-up questions based on trauma in healthcare. Out of 10 participants, all scored greater than or equal to 14, demonstrating good health literacy. Eight of these participants provided thoughtful responses to the questions about trauma and healthcare. Upon analysis, the data shows that regardless of socio-economic status, those who are DHH are in need of accommodations that allow for consistent, high quality health care. This data contributes not only to the realization of reality for the DHH in health care settings, but also the nationwide goal of increasing general health literacy and thus the quality of life.

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LIST OF ABBREVIATIONS

ASL – American Sign Language

CDC – Centers for Disease Control and Prevention

DHH – d/Deaf and hard of hearing/Hard of Hearing

REALM – Rapid Assessment of Adult Literacy in Medicine

SAHL-E – Short Assessment of Health Literacy – English

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CHAPTER I

INTRODUCTION, REVIEW OF LITERATURE, AND THEORETICAL FRAMEWORK

INTRODUCTION

The South, more formally known as the "Deep South" to some, is a geographical region of the United States with a distinct, recognizable culture. Primarily, the South as we know it today consists of Alabama, Mississippi, Georgia, South Carolina, Louisiana, and the surrounding states. The South in general lacks literacy, which is commonly known by those that live in the South and those that do not. According to the National Center for Education Statistics from the U.S. Department of Education (2003), using estimates of low reading literacy from the National Assessment of Adult Literacy (NAAL), around 15% of the population of Alabama lack the most basic of prose literacy skills with a 95% confidence interval that this estimation is between 11.8% and 19.4%. In comparison to the other Southern states, the low literacy levels of this geographical area are quite high, with South Carolina ranking Alabama at 15%, Mississippi and Louisiana at 16%, and Georgia at 17% (U.S. Department of Education). Due to this lack of general literacy, it can also be extrapolated that other forms of literacy may be lacking, including health literacy.

Health literacy is an ever-changing concept, and thus requires a definition that is just as flexible to keep up with new findings and rationales. According to the Centers for Disease Control and Prevention (CDC) (2021), there are multiple ways to define health literacy for its applications. One particular definition pertains to "personal health literacy," which means "the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (CDC, 2021). Another definition is that of "organizational health literacy," which is "the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (CDC, 2021). These two definitions, amongst others for health literacy, are encompassing and describe both an individual and group that serves said individual.

It can be reasonably inferred that if a certain region struggles with general literacy, there may be an equal, if not higher, percentage of deficit in the health literacy of that same population. The University of North Caroline at Chapel Hill highlights this relationship. This map is a predictive model that utilizes data from the 2010 U.S. Census and the 2011 5-year American Community Surveys (ACS) files (National Health Literacy Mapping to Inform Health Care Policy, 2014). When looking at the interactive map from the National Health Literacy Mapping to Inform Health Care Policy (2014) website, it is seen that the states of Mississippi, Alabama, Georgia, and South Carolina have a speckling of red when looking at the NAAL Categories, which define counties in each state to be red when at or below the NAAL standard for basic literacy and green when above the standard. When compared to other North, Northeastern, or Northwestern states, it is seen that the estimated health literacy levels of those in the South are most definitely below par. However, there is something to consider when looking at the U.S. Department of Education's data, the CDC's definitions, and UNC's maps: this is the general population. What about when the data is split up based on income? What about class? Race, ethnicity, gender? Many studies recognize the shortcomings of health literacy in these groups in the South, but there is one group that is largely ignored and little thought of that is present everywhere in our country: the d/Deaf and hard of hearing/Hard of Hearing population.

The term “deaf,” as defined by Merriam-Webster (n.d.), is “having total or partial hearing loss.” Additionally, the term “hard of hearing” means “relating to or having partial hearing loss, once again defined by Merriam Webster (n.d.). In short, the lowercase terms refer to the audiological status of a person. Alternatively, the uppercase terms “Deaf” and “Hard of Hearing” refer to the culture and identity of Deaf and Hard of Hearing people (Rkanigel, 2016). Ultimately, it is up to personal preference when a person decides which term to use to describe themselves, although each term tends to denote a particular meaning. As learned through the course of this research, it is important to note that the term “hearing impaired,” generally used as a catch-all phrase to denote d/Deaf and hard of hearing/Hard of Hearing people, can be considered an offensive term to those in the Deaf community as the word “impaired” connotes an inability. Some do not believe that hearing loss is an “impairment.” Thus, out of respect, this work will avoid the use of the term “hearing impaired,” and suggest the reader should as well in future conversation.

REVIEW OF LITERATURE

POPULATION STATISTICS

The d/Deaf and hard of hearing/Hard of Hearing (DHH) population is huge. Ross Mitchell (2005) from the Gallaudet Research Institute at Gallaudet University found that there are approximately 11,000,000 people (10,688,525 ± 491,406) in the U.S. over the age of 5 that are deaf or hard of hearing, which is around 4.1% of the population (p. 115). However, that number decreases as you remove those that do not have issues with conversations, then remove those that have some difficulty with a hearing aid, until you have those that cannot hear a normal conversation with a hearing aid at around 1,000,000 people (993,499 ± 152,421) (p. 115). However, a million people is still a substantial amount. Why is it that people who are DHH not considered in the hearing person's world so often, although there are so many who communicate through ASL or other forms of sign language? For instance, the most recent hot-button topic in today's world, COVID-19, has impacted everyone, but very particularly those who are DHH. Garg et al. (2021) very plainly describe the impact of facial masks on the DHH, although necessary for reduced transmission efforts around the globe (p. 12). "As a result of this preventive measure, the deaf and hearing-impaired people feel excluded from the world," states Garg et al (p. 12). This is just a small example compared to the many occasions that those with hearing impairments have been looked over or ignored.

This particular demographic is largely impacted when it comes to health literacy. McKee et al. (2015) are one of the first to pioneer a gauging of health literacy in ASL speakers that are DHH. This study was published in 2015, suggesting that even questions about health literacy in DHH patients in general were not really explored or studied until very recently. In this study, two things were established: the selection of a test called the ASL-NVS that was found to be useful in gauging health literacy in DHH ASL speakers and the finding that Deaf ASL users are 6.9 times more likely to have inadequate health literacy than a hearing patient on average (pp. 95-96). There were many other findings, including that Deaf ASL users averaged at a 5.9 grade level for reading, whereas hearing patients averaged around 9.8 grade level for reading (Table 1). Thinking critically, it is clear why DHH ASL users have lower English reading comprehension and thus lower health literacy. If ASL is nothing like English, with its own syntax, grammar, structure, phrases, and much more, there is no reason to expect a native ASL speaker to know English as well as their own mother tongue. Thus, if all the information given to a DHH patient at a doctor's office is either through written English material, lip-reading, online translation, or poor in-person interpreting, it is no surprise that they rank lower in health literacy compared to hearing patients.

Another study done by Gur et al. (2020) focuses on the adolescent side of health literacy in Deaf and Hard of Hearing patients. This study was done to find whether health literacy was lower in the younger Deaf and Hard of Hearing population in comparison to adult patients, in which the previous study by McKee et al. (2015) was only done in patients aging from 40-70 years old as mentioned in Gur et al.'s (2020) research. This study did not use the ASL-NVT, but rather a set of questionnaires, three of which were in-house productions created by Gur et al. (2020) and one called the Turkish Health Literacy Scale-32, which is designed "to assess the level of health literacy of individuals over the age of 15 or those with minimal language literacy" (p. 2). In 88 of the participants, with the oldest participant being no older than 33 years old, it was found that 70.5% displayed inadequate health literacy (p. 3). This is only expected, since it is the same for adolescents as it is for adults: if the literature is not presented in the way the patient can truly understand, there is room for error and thus causes lower understanding when it comes to health issues.

NONVERBAL COMMUNICATION FINDINGS

One study, done by Smith and Samar (2016), aimed to reduce the confounding of English printed literacy on health literacy of Deaf and Hard of Hearing participants. This fixes an issue with McKee et al.'s (2015) original study: although the ASL-NVT was translated into a format that was intended to be better understood by native ASL speakers, it still allowed the option for reading subtitles in English (Deaf, Hard of Hearing, or hearing) and was still designed in mind with the hearing population since they were used as a control. Smith and Samar (2016) designed their questionnaires (none of them being the ASL-NVT) to be fully translated for Deaf and Hard of Hearing patients with no concern for other languages, thus leaving no interpretation responsibility upon the participants of the study, which can cause issues with data collection (p. 143). As expected, the Deaf and Hard of Hearing participants routinely scored lower on the HLSI (General Health Literacy test), S-TOFHLA (Functional Health Literacy test), and the CHDKQ (Comprehensive Heart Disease Knowledge Questionnaire) when compared to their hearing counterparts (p. 151). This, once again, is no surprise. Although the point of Smith and Samar's (2016) study was to reduce the effect of English confounding on health literacy exams and questionnaires when studying this topic, although arguably successful in said task, it falls short when the patients come in with knowledge they gained from English readings, hearing health professionals, and self-reliant lip reading or interpretation. This begs the question: how does a native ASL speaker gain the knowledge they need to make informed decisions and protect themselves from preventable diseases if they cannot learn the material in a language they know?

English has a written and spoken component, but ASL does not have a written language yet. Thus, outside of spoken language, English is the only written way to communicate via paper, screens, and other nonverbal forms of communication. In an article study written by Pollard and Barnett (2019), the understanding of English written health terms were gauged in Deaf and Hard of Hearing persons using a modified version of the REALM (Rapid Estimate of Adult Literacy in Medicine) that asked participants to self-report their understanding of 66 medical vocabulary words. The REALM, originally designed as a word-pronunciation questionnaire for hearing people, was modified to understand how well people that are Deaf or Hard of Hearing understand the terms that might be given to them on a pamphlet, medication insert, or office paperwork (p. 183). The findings show that 90% of the 57 participants understood at least 68.4% of the medical terms in the REALM (p. 184). However, almost a third of the participants reported that they only understood vocabulary that correlates to below a ninth grade reading level, “which is considered indicative of low health literacy” (p. 184). The authors recognize that their sample was educated, and found it concerning that out of the 31.6% of participants that took the REALM that were found to have low health literacy, 21.7% had college degrees (p. 184).

Pollard and Barnett (2019) note that although this test does not gauge the correlation of the knowledge of the terms on the REALM with actual health outcomes, it can be reasonably inferred that the lack of knowledge in these terms may lead to poor health outcomes overall (Pollard & Barnett, 2019, p. 185). This shows that Deaf and Hard of Hearing patients need to understand terms commonly used in health practice, and there must be a more efficient way than English writing. Although this presents a barrier in practice, it is simply a need that is not being met in this demographic.

Noteworthy Examples of Communication Failures

There are multiple deficits that can be found in all aspects of health literacy when it comes to Deaf and Hard of Hearing patients. Take, for example, Mprah’s (2013) work on the access of sexual health information by people who are Deaf and Hard of Hearing in Ghana. This study identifies the issues that these people have when trying to access service and information for sexual and reproductive health purposes. The study highlights many of these barriers, including, but not limited to, communication barriers, ignorance of Deafness, attitudes towards Deaf people, the issue of Deaf patient literature and conversation literacy, limited time during consultations, and more (p. 27). Although limited time and privacy can affect both the hearing and the Deaf alike, it is specifically challenging for a Deaf or Hard of Hearing patient to overcome barriers that are not easily remedied by the patient. The lack of the appropriate tools for the patient to understand the information given and the biases that health care providers, and patients themselves, might have contributes to the inefficiency of health literacy, in this particular case sexual health. Deaf and Hard of Hearing patients are unique, in the same way that any hearing person is unique. The care, as implied it Mprah's (2013) study, must be tailored to the patient and their needs in order to provide the best care for the patient.

Another interesting study, done by Woodroffe et al. (1998), views the situation from the other side of the story. Whereas most of these other studies have focused on the retention of knowledge of the patient based on questionnaires and highlighted the specific struggles when accessing healthcare, this study highlights the attitudes of Deaf and Hard of Hearing patients towards AIDS and their knowledge of the illness. It was found that on average, Deaf and Hard of Hearing patients were usually in the same ballpark when it comes to understanding AIDS and how it is transmitted (para. 23). However, the trend still showed a slighter higher understanding of AIDS and transmission by hearing patients, thus highlighting the slightly lesser quantified values for health literacy in Deaf and Hard of Hearing patients (para. 24). The results, as stated in the study, could be greatly confounded for several reasons, however. Firstly, the group who participated in the survey was not random (para. 31). The entire group was from a region in Michigan, were not believed to be severely disadvantaged, and were administered the questionnaire entirely in English. So, there is reason to believe that the gap between Deaf and Hard of Hearing health literacy and hearing health literacy when it comes to AIDS is much wider than it may be portrayed to be in this study. Despite these shortcomings in the study, there is still reason to believe that the deficit that was perceived at all is because of the healthcare and information that the Deaf and Hard of Hearing participants received was not in their preferred method of communication.

Some of this information may seem dated, and therefore irrelevant, by a critical reader. An astute critic might even point out how technology has solved communication barriers by AI language processing and translation along with the advent of videotelephony. Nevertheless, miscommunication in more modern times, despite the advancements society has provided within the realm of technology, still prevails. This is evident in an encounter between a patient who is Deaf and Parkwest Hospital in 2017 in Knoxville, Tennessee, as reported by Gregory Raucoules (2019). This patient had his leg partially amputated after three visits to Parkwest where the proper translation services were either denied or unsuccessfully implemented. To begin with, the outright denial of the request for an ASL interpreter by the patient is a clear violation of Title III in the American Disabilities Act (ADA), but also a violation of ethical standards for most hospitals, including Parkwest itself. According to their very own Civil Rights Notices webpage, the facility "provides free aids and services to people with disabilities to communicate effectively with us, such as qualified sign language interpreters" (Covenant Health 2022). It is important to note that this webpage was accessed in 2022 while this incident happened in 2017. Nonetheless, it is common for most medical professionals and systems to abide by an ethical code, which most likely includes a hefty provision for informed consent, obviously implying that those with Limited English Proficiency (LEP) must be provided with translation services to achieve such a goal. These violations and legalese details, however, are only pertinent when discussing a denial of translation services; what if services were provided, but so poorly that denial of such services is just as good?

During the patient's second visit with Parkwest, after being redirected from a nearby emergency room after the pain in the patient's leg and foot increased, a "Video Remote Interpreting Device" was provided by the hospital for a consultation with a vascular surgeon in leu of live interpretation services, shares Raucoules (2022). In theory, this is just as good as live interpretation services, and far more gracious than an outright denial. However, the videophone provided was “ineffective due to consistent disconnections and blurry picture as a result of the hospital’s firewall” (Raucoules, 2019). Therefore, the patient was not provided a channel of communication to ensure true informed consent. Technology is only useful by proper execution and accommodation to the situation. Consider a tin can telephone as an illustrative, albeit whimsical, analogous example to a videophone with connection issues. A hearing individual would most likely be confused and unsure if they were being informed about their surgery the next day through such a device, so why would Parkwest consider their mediocre videotelephony services sufficient?

Lastly, during the third encounter between the patient and Parkwest, the patient underwent surgery to remove the blood clots that were found to cause the patient’s pain and insert a medical device. This time, the patient’s daughter served as the interpreter (Raucoules, 2019). It is clear that the patient no longer trusted the hospital to provide the avenue for communication needed for total understanding and instead took matters into his own hands. However, it has been shown that having a person’s relatives or friends act as interpreters for patients is never a good idea, except in cases of emergency. As told by Abi Rimmer (2020) at BMJ, relatives can cause a misinterpretation of information through lack of neutrality, selective disclosure of information, and most important of all, confidentiality. In most cases, it is important to have a professional interpreter to be neutral, passive, and “provide a degree of assurance around quality, accuracy, and confidentiality” (Rimmer, 2020). Unfortunately, the patient later had a partial amputation of his limb at a different hospital system after the surgery he had at Parkwest left him “heavily sedated and with a blue foot” (Raucoules, 2019). In the end, this experience demonstrates not only the existence of communication errors in the age of technology, but also the persistent severity of the consequences associated with such errors, as evident in the loss of a man’s leg. The communication failures that have happened, and will continue to happen, can only be resolved through successful implementation of any strategy, live interpretation or otherwise.

THERAPIES AND PREVENTION CARE

Deaf and Hard of Hearing patients need healthcare that works for them. As shown, it simply is not enough to continue providing healthcare in a way that places this group at a disadvantage. There needs to be health equity across all groups in order to provide the best care, increase health literacy, and thus the quality of life in all patients. One action towards this goal was implemented by O’Hearn and Pollard Jr. (2008) as presented in their study on the effectiveness of modifying a certain type of therapy for Deaf and Hard of Hearing patients. DBT, or Dialectical Behavior Therapy, is a type of therapy that was originally used to help treat suicidal women with borderline personality disorder that has since been modified for use as a cognitive behavioral therapy that decreases suicidal ideation, self-injury, emergency room visits, inpatient stay duration, and overall costs for mental health treatment. It was found that DBT had been adapted for all types of uses: inpatients, patients with eating disorders, the elderly, couples, and even patients that speak a different language, such as German or Spanish. However, there was no adaptation for Deaf and Hard of Hearing patients in America. O’Hearn and Pollard Jr. (2008) identify and acknowledge the barriers that Deaf and Hard of Hearing users may have when participating in DBT, primarily around the fact that DBT was originally used in written material, which is a large problem for some ASL native speakers. The authors suggest modifying

DBT to accommodate three levels of English written literacy, in summarization: low, medium, and high. The material can range from low, meaning primarily imagery use if there is printed material and communication through ASL, to high, which accommodates for ASL speakers that are comfortable with written English written material to an extent. When DBT for the Deaf was used on a group of participants in the study, it was found that the response of the patients to the modified form of therapy reacted quite positively. In fact, some participants "request[ed] to repeat skills training modules, either at the completion of the modules, or at a later time when they feel they need a refresher" (O'Hearn & Pollard Jr, 2008, p. 412). Some commented on the changes that made DBT work better for them as compared to when they participated in the hearing form of the therapy with an interpreter. This material is a step forward for the conversation that needs to be held as far as serving the Deaf and Hard of Hearing community the way they need to be served. The materials that are provided by O'Hearn and Pollard Jr. (2008) are helpful, and the positive response from the participants are milestone. However, there must be more research and more effort in adapting this information to allow for higher health literacy levels in this population.

COMMUNITY OUTREACH AND STRATEGY THEORIES

A way to increase inclusion can be through community-based outreach and focus. For instance, a study done by Barnett et al. (2011) focused on inclusion of Deaf and Hard of Hearing patients in public health surveillance programs through an adapted, culturally appropriate survey based on the Behavioral Risk Factor Surveillance System (BRFSS). In this study, the researchers worked in tandem with members of the community to make a survey that prioritized the concerns of the population in question and was culturally and linguistically sensitive. Then, over a period of 6 months, Deaf and Hard of Hearing individuals were recruited through multiple forms of communication to complete the survey in order to collect the data from a portion of the population that otherwise would not have answered the survey designed for hearing people. The survey successfully collected information on the health status and health risks of the Deaf and Hard of Hearing individuals in the community and collected valuable information about average weight, suicide attempts, smoking status, and more. This allows for the collection of data of everyone, not just hearing patients. Although the survey was conducted by Barnett et al. (2011) in an area where the members of the community were primarily educated and predominantly white, the response to the survey was outstanding and provided a glimpse of what is needed in not just Rochester, NY, but in every community across the world.

In order to successfully reach out to any population, it is best to ask members of the community in order to understand and appropriately communicate with said population, as can be seen in Barnett et al.'s (2011) study. To properly identify where the issue might be, it makes sense to ask the population that suffers from it. This is exactly what the authors continued with after their first study. In 2017, they used a revamped version of the Rochester Deaf Health Survey (RDHS-2008) that was not originally used in the study from 2011 called the RDHS-2013. This survey was edited based on the responses to the 2008 version, which included revisions on existing questions and adding more to the survey in order to increase the quality of data collect and place emphasis on the issues that matter most to the population it serves. This survey was also able to do something that the RDHS-2008 could not accomplish, which was gather data based on changes in the population over time. As expected, it highlights the findings that otherwise would not have been found in the same population in Rochester, NY. It emphasizes, once again, the importance of reaching out to every single part of the community in order “enhance access to health care, public health programs, and community preventive services” (Barnett et al, 2017, p. S251). It empowers the population that has been ignored for so long and increases the response to fight for their health and make more informed decisions based on their current health status. This needs to be taken to the next level and adapted for specific communities as needed, including populations in the South.

A study put forth by Mathos and Pollard Jr. (2015) chronicles their effort in their attempt to combine a force of members in order to utilize community resources in order to create more specialized health services for those that are Deaf, Hard of Hearing, or even Deafblind. These members consisted of a mix of hearing and Deaf and had members fighting for causes along the spectrum of Deaf, Hard of Hearing, and Deafblind. These members established their first set of goals: “resource awareness, information gathering about consumer needs, public outreach and community education, direct service development, workforce development, and mentoring opportunities for young professionals” (Mathos & Pollard Jr., 2015, p. 188). Starting with tasks that did not require much trust within the community up to large tasks, such as mentoring Deaf students pursuing social work, the group was able to reach out to the community, gather information needed in order to serve them, and implement resources, such as peer support services, to better their community. This was an effort made in an area in West Pennsylvania, which may not suffer from the same issues as many communities might in the South, including, but not limited to, social stigma and lower general literacy.

Some general steps are listed in a piece done by Barnett et al. (2011) that can be done to increase health literacy, and thus quality of life. There are some major recommendations for public health, such as working with the community to address health inequities that cause unequal access to health information, and there are some issues that are presented on the reasons for the health inequities that Deaf and Hard of Hearing people endure. However, each community is different, and each need a personalized approach based on cultural needs, social stigmas, population, preferred methods of communication, and so on. In the South, particularly in more rural parts, it is important to ask if health literacy is equal to that of hearing patients when it comes to Deaf and Hard of Hearing patients, and how to bridge the gap to increase quality of life and healthcare through increased health literacy and introduction of community-based efforts and specialized healthcare.

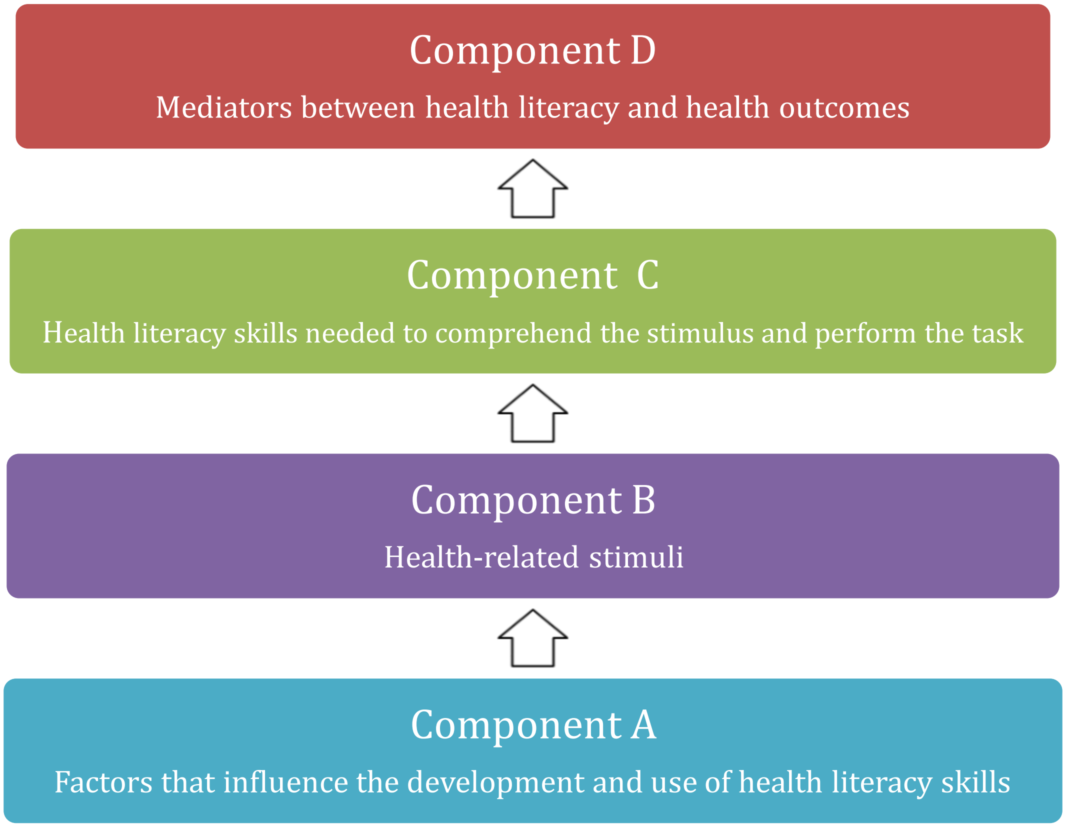
THEORETICAL FRAMEWORK

Health literacy, as previously discussed, is an ever-changing concept. For example, the personal and organizational health literacy definitions mentioned previously from the CDC were last updated in 2020, making the definitions more pertinent in today's world. Therefore, the specifics of these words as defined are important, but not the focus of discussion. Instead, it is more beneficial to understand the general concept of each type of literacy when deriving conclusions on how to best guide the public to practice good health literacy. There are multiple barriers when it comes to having good health literacy, and for the DHH, the most obvious barrier is language. However, the issue at hand is not the simple recognition of a language barrier. The question is not only where, from the first moment of care to the last, but also when this barrier presents itself.

The general agreement amongst most research is that the result, increased personal health literacy, is only achievable through more community outreach and stronger organizational health literacy. This is evident in "The Health Literacy Skills Framework" by Squiers et al. (2012). This article provides a framework, cleverly called the Health Literacy Skills framework (HLS), that describes the factors leading to positive "health-related behaviors and outcomes" in detail

(Squires et al., 2012, p. 48). This framework is notably one of the few that describes the “full pathway” from start to finish, influenced by previous works that only provided insight on a few facets of the big picture idea of health literacy. This all-encompassing framework is the key to understanding this research and pinpointing the issues that prevent people who are DHH from achieving a satisfactory level of health literacy. In fact, an individual who has familiarized themselves with this theory would be able to identify and isolate such an issue in practice when it comes to reaching the desired health outcome for a patient who is DHH.

FIGURE 1: HEALTH LITERACY SKILLS FRAMEWORK



The HLS is best understood as a "bottom-up" approach, similar to theories such as Maslow's Hierarchy of Needs, where each need supports the one above it. This is visually interpreted in Figure 1. The HLS comprises of four different components, or "needs," listed in ascending order: (a) factors that influence the development and use of health literacy skills, (b) health-related stimuli, (c) health literacy skills needed to comprehend the stimulus and perform the task, and (d) mediators between health literacy and health outcomes (Squiers et al., 2012, p. 47). For the purposes of our research, we will focus on components (a) and (b), influential factors in the development and use of health literacy skills and health-related stimuli, heretofore referred to as Component A and Component B, respectively. These two components are where the problem starts for those that are DHH.

Component A, or the influential factors in the development and use of health literacy skills, points to the factors of our lives, including but not limited to demographics, individual resources, capabilities, and prior knowledge. The population in question for this research is particularly influenced by three of these factors: individual resources, capabilities, and prior knowledge (Squiers et al., 2012, p. 47). To elaborate, individual resources describe an individual's employment, social support, culture, language, literacy, and education. Capabilities describe an individual's vision, hearing, verbal ability, memory, and cognitive function. Lastly, an individual's prior knowledge refers to disease and illness experiences, conceptual knowledge of health and health care, and familiarity with health care vocabulary. As one may conjecture, a person who is DHH is immediately disadvantaged in a hearing world upon these factors. An individual in our population focus who lacks a higher level of education, primarily uses ASL, has negative past experiences with health care, and/or does not have a good understanding of conceptual knowledge in health to begin with would indicate a deficit in their Component A.

Component B, or health-related stimuli, refers to an individual's ability to understand and interpret information given to them in an appropriate way. Note that this communication can occur either "interpersonally or mediated channels" (Squiers et al., 2012, p. 49). Additionally, consider the difference between the words "understand" and "interpret." Any given English speaker can understand an English sentence, but not every individual can interpret the true meaning of such a sentence. The difference is quite subtle and hard to distinguish, but there is a difference between understanding a surgical procedure and interpreting the potential benefits and drawbacks to such. An individual who knows English as a second language in written or verbal forms, has difficulty understanding English in written or verbal forms along a varying range of complexity, and/or have difficulty negotiating or conversing in English in written or verbal forms would indicate a deficit in their Component B.

Using the SAHL-E and open-ended questions about a participant's experiences in health care, collected data can then be analyzed to indicate where the deficit lies in the sample if present. Furthermore, the recognition of the specific component can then be used to help suggest remedies for the issues being encountered in this population. Along with this established framework used to help identify the problems, the SAHL-E can provide insight on the participant's anticipated deficit. If the participant does poorly on the SAHL-E, it will indicate a deficit in Component A. However, if the participant performs well on the SAHL-E but also shares negative experiences based on their current audiological status, there may be a deficit in Component B despite performing well on the tool designed to catch a rapid estimate of health literacy.

This tool will work best for comparison to the HSL framework for two reasons: the tool lends itself towards compatibility with online sharing, and the participant's attempt to understand and interpret the English words and text can clearly distinguish the participant's deficit. Thus, using this tool and framework, the questions present themselves: why do people who are DHH have lower health literacy than those that are hearing? Is it due to little to no information that is readily accessible? Is it due to uncaring healthcare settings? Is it due to ignorance of hearing? Is it due to insufficient interpretation services? Using these questions along with these tools, the validity of this research question can be thoroughly evaluated.

CHAPTER II

RESEARCH QUESTIONS, OBJECTIVES, AND METHODS

RESEARCH QUESTIONS

Do patients who are DHH have a lower average health literacy than that of their hearing counterparts in the South? If so, what are options that can help close the gap between these two demographics? If not, to what factors do we owe for such a result? Lastly, what are the thoughts, experiences, and advice that participants offer to help better understand the shortcomings of health care for those that are DHH, and how can this information be used to inform future practices to increase cultural understanding, moments of care, and overall quality of life?

OBJECTIVES

In this study, there are three objectives. First, the average SAHL-E score from the participants will be calculated then compared to the average health literacy of several states in the South, both individually and holistically. Second, the information participants volunteered about their personal traumas, experiences, and wishes in health care will be analyzed and categorized based on popular trends within the study to estimate frequency and severity of notable shared occurrences across participants. Lastly, this research will provide possible strategies and suggestions for those in and around health care settings to improve patient outcomes and increase positive experiences of patients who are DHH through moments of care.

METHODS

The only strict exclusion criterion was whether the participant identified themselves as “hearing.” All participants who identified as such were immediately sent to the end of the survey and thanked for their time. The only strict inclusion criterion was whether the participant identified themselves as one of the following: “d/Deaf,” “hard of hearing/Hard of Hearing,” “DeafBlind/low vision,” “Late-deafened,” or “Other.” If the participant selected “Other,” they were then asked to explain and describe their identity. If the participant selected one of the options above, they were then prompted to continue the survey. The survey did not ask participants to identify as deaf or Deaf, hard of hearing or Hard of Hearing, etc., as both groups were considered when comparing to hearing participants. Age of onset, amplification status, and primary language were not assessed in this survey. All other aspects of the participant, including gender, race, religion, social status, economic status, age, and location were not criteria collected to exclude, but rather perform statistical analysis and comparison.

This survey was held online through Qualtrics, a dedicated website to surveys and data collection. The participant could complete the survey anywhere, anytime, on any device they pleased. The survey was notably designed for compatibility with screen readers and for participants who desired to complete the survey on their smartphone. This survey, while limited to online interaction, allowed for data collection in multiple states with ease.

This research employs mixed methods, since the SAHL-E is a form of quantitative analysis while the participants volunteer information that was qualitatively analyzed. Qualitative research is defined as “the investigation of phenomena, typically in an in-depth and holistic fashion, through the collection of rich narrative materials using a flexible research design” (Polit Beck, 2014, p. 389). Additionally, quantitative research is defined as “the investigation of phenomena that lend themselves to precise measurement and quantification, often involving a rigorous and controlled design" (Polit Beck, 2014, p. 389). This study uses both forms of research, although one may argue that there is more emphasis on the qualitative portion in comparison to the quantitative SAHL-E. This study is also considered a form of descriptive research. According to Polit and Beck (2014), descriptive research is "research that typically has as its main objective the accurate portrayal of people's characteristic or circumstances and/or the frequency with which certain phenomena occur" (p. 379). This prospective, non-experimental, descriptive study will allow the gathering of anonymous general health literacy levels of those that self-identify as DHH while also providing valuable information about experience. These data were then used quantitatively for comparison, but also qualitatively for discussion and recommendation.

As previously mentioned, the primary tool used in this survey for data collection is the Short Assessment of Health Literacy – English (SAHL-E) from the Agency for Healthcare Research and Quality (AHRQ) (2019). The SAHL-E is one of four research tools designed by researchers who are funded by the AHRQ to gauge health literacy in individuals. These tools are free for anyone to use as part of the AHRQ's initiative for "inclusion of populations with limited literacy in research and study health literacy disparities." To assess the potential of using this tool in our target population, the validity and reliability of this work must first be evaluated.

The integrity of the tool we are using in this research is evident in "Short Assessment of Health Literacy – Spanish and English: A Comparable Test of Health Literacy for Spanish and English Speakers" by Lee et al. The authors tested the validity and reliability of the SAHL-E using several different methods, including but not limited to: testing correlation between the REALM and the English TOFHLA and comparing a participants scores to their respective levels of education, psychometric assessment, and field testing and verification of association questions. The instrument development of this tool provided satisfactory results, with the validity and reliability tests producing a reliability of 0.89 and a value higher than 0.9 when testing Cronbach's alpha. Therefore, this research tool is valid for use when testing for health literacy levels. Additionally, this tool seems to fit the research questions and purpose quite well.

It must be noted, however, that this tool has not been explicitly tested for use with populations such as the DHH population. In fact, in all research the author is aware of, there has not been a case where this particular instrument had been used in this population. As previously mentioned, tests such as the REALM have been adapted for use in the DHH population, so the adaptation of the SAHL-E is not impractical. In the same breath, it must also be noted that the SAHL-E was not particularly designed for online use. Though a reasonable person should not express much concern over this adaptation, since the test is quite simple and easy to format for online distribution without loss of meaning or purpose, it must be noted that this tool is designed to be administered between a participant and administrator in person.

The SAHL-E consists of 18 questions. Each question asks the participant to look at a given keyword, then select a word out of the three presented options that most closely relates to the keyword. To view the SAHL-E in its entirety, please see Appendix A. To view the entire survey presented to the participant, which includes the SAHL-E, please see Appendix B.

The project was then sent for approval by the University of South Alabama's Internal Review Board (IRB) on November 19th, 2021. The package was sent to the IRB as an exempt review, indicating less than minimal risk for the participant, under Category 2, defined as "research that only includes interaction involving the use of educational tests…, [and] survey procedures." To view the letter of approval from the University of South Alabama IRB, please see Appendix C. To view the information sheet presented to all participants before beginning the survey, please see Appendix D. The data collected from the participants was stripped of any identifying information through the Qualtrics platform that could potentially be used to reidentify an individual. The data will be deleted from all devices owned by the primary investigator, including Qualtrics data, no later than the end of May 2022 after the final defense.

The primary recruitment strategy was "snowball sampling." The survey was initially primarily distributed to the following entities that expressed interest in sharing the survey through word of mouth to their colleagues and respective members, totaling four organizations from Alabama, Louisiana, and Tennessee. The survey was then also primarily distributed to another professional organization after a period of time with offices in Georgia, Florida, Texas, and Tennessee. These organizations were then encouraged to spread the survey, either to other potential candidates directly or to organizations that would be willing to spread the word. Out of the four institutions that were originally contacted, two responded positively, but it was deduced that only one organization was actively distributing the survey. After following up with the remaining three institutions, only one responded positively, but is still suspected to not have distributed the survey. Three representatives from the most recent professional organization contacted responded positively and distributed the survey.

CHAPTER III

RESULTS

The data collected through the SAHL-E section was quite surprising. To start, the final number of participants totaled 14, and out of the 10 participants who completed the SAHL-E portion of the survey, each scored good health literacy. Four participants scored 18 points out of a total of 18 points, one scored 17, and five scored 16, all above the 15-point minimum for good health literacy. Four of these scores were not accounted for due to the following: one participant only completed Question 0-1 and abandoned the survey, another only completed Question 0-1 and Question 1-1 before abandoning the survey, yet another was immediately prompted to the end of the survey after identifying as “hearing,” and one final participant who did not meet the inclusion criteria in a peculiar way. This last participant, who is assumed to have fatigued after Question 2-8, skipped to the qualitative portion of the survey. To clarify, they scored perfectly on 5 out of the first 8 questions, leaving 2 questions blank and marking the last as “I don’t know.” However, the data cannot be counted since this individual, when confronted with Question 1-1, selected “Other,” and proceeded to explain that they were the parent of a “deaf part sighted man.” This participant, who shall heretofore be referred to as Participant 06, did respond to the rest of the survey, though quite halfheartedly. See Figure 2 below for results of the SAHL-E.

The data collected in the second portion of the survey was far more insightful and useful. In this portion, there were 9 participants who responded, and 8 of those participants provided meaningful responses. See Table 1 below for a complete list of responses. The one respondent that did not interact meaningfully with the questions in the survey only answered with the same response and is notably identified as Participant 06.

FIGURE 2: SAHL-E RESULTS

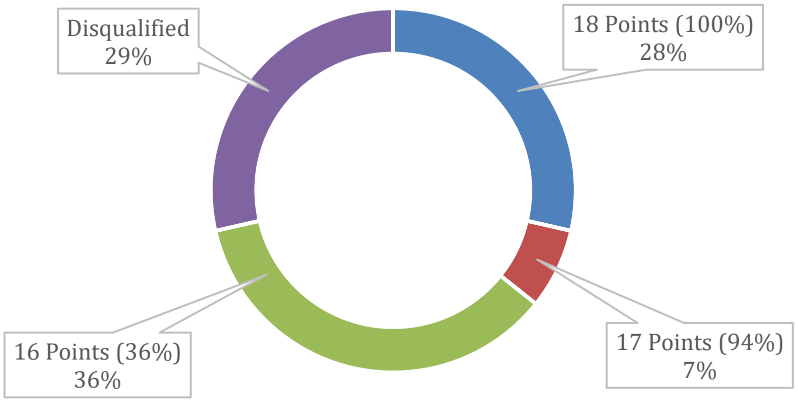


Table 1: Participant Responses to Trauma in Healthcare Questions

Participant Number	Question	Response
Participant 01	4-1	Yes.
	4-2	No.
	4-3	No.
	4-4	No.
	4-5	Yes. After CI surgery, a nurse left the IV needle in my arm and it was not discovered until the next day at home.
	4-6	Treatment.
	4-7	Treatment.
Participant 04	4-1	Yes.
	4-2	
	4-3	Yes. Scheduled a mental health appointment for medication maintenance. When I said I needed an ASL interpreter the receptionist said, "I don't think we can do that because of privacy reasons." I explained that if I'm the one asking, I know that the doctor isn't responsible for privacy during my appointment. I made the appointment 3 weeks out, provided the name of a local interpreter agency. 2 days before the appointment I called to confirm, and confirm that an interpreter would be provided. I was told that I could not be accepted as a patient there.
	4-4	Yes. See above.
	4-5	

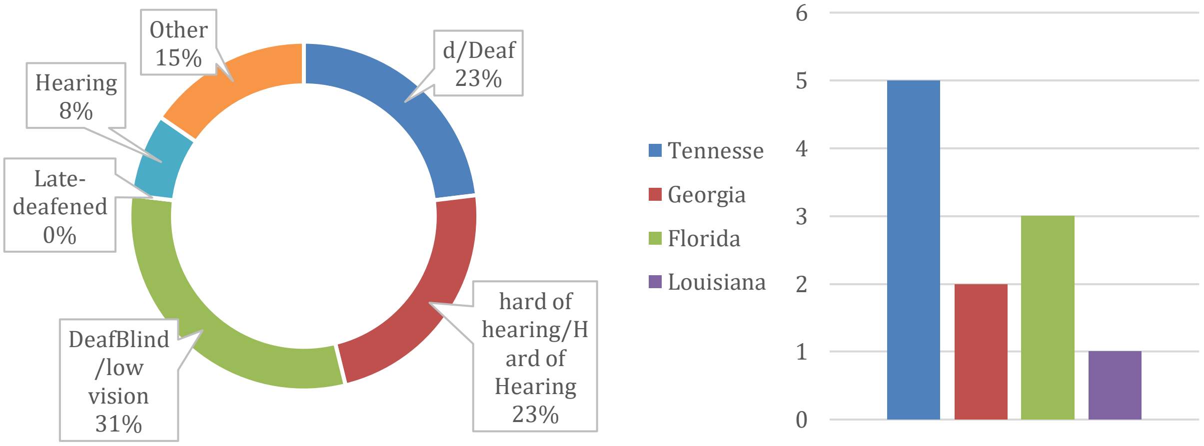
	4-6	A professional who treats me as a whole person, and listens to my concerns. I do not expect to have to worry about communication.
	4-7	
Participant 06	4-1	No.
	4-2	Yes. they do not try to communicate nor do they read body language
	4-3	Yes. they do not try to communicate nor do they read body language
	4-4	No.
	4-5	Yes. they do not try to communicate nor do they read body language
	4-6	
	4-7	
Participant 08	4-1	
	4-2	No.
	4-3	Yes. When I was told that I would be Deaf-Blind as a young adult and realized that the eye doctor should have identified the condition when I was a teenager..
	4-4	Yes. When informed that I have Usher Syndrome USH2a, i consulted second opinions and sought assistant from state agencies. Now a struggle to get further services.
	4-5	Yes. There is a lack of follow-up by state agencies with the case management to ensure that the recipetient does or does not need additional services for their needs.
	4-6	End result for the services needed for outcome of satisfaction.
	4-7	Quality diagnosis and care for health needs.
Participant 09	4-1	Yes.
	4-2	Yes. I was having a colonoscopy and the doctor promised I would be kept comfortable. He lied. I was in agony. I begged him to stop, over and over. I will never have that procedure again.
	4-3	Yes. I had surgery, and the anesthesia didn't work correctly. I was paralyzed but not unconscious. I was aware of everything happening and could smell my flesh as the surgeon cauterized bleeding vessels. At first, they claimed I made this story up. When it was clear I didn't, the surgeon blamed the anesthesiologist and vice-versa. In the end, nobody took responsibility or even apologized.
	4-4	No.
	4-5	No.

	4-6	I expect it will be harder for me to get the proper care. But I have found doctors I trust and work with them to get the best care I can.
	4-7	I seek referrals from my Primary Care doctor or trusted friends.
Participant 10	4-1	Yes.
	4-2	No.
	4-3	Yes. While not related to my HOH status, learning of a heart valve problem can be traumatic.
	4-4	No.
	4-5	No.
	4-6	Clear communications and explanations of the situation, whether emergency or routine. Appropriate treatment and follow-up.
	4-7	I have learned that few in the healthcare system are trained or accepting of my HOH status. Masking only complicates this problem. I don't mind wearing a mask, I do mind when a healthcare provider doesn't accommodate my hearing condition by not speaking slowly, clearly, and in my direction. Emergency care personnel are actually better at this than my normal providers.
Participant 11	4-1	Yes.
	4-2	No.
	4-3	Yes. TIA; emergency room...could not tell them no MRI because of my CI.
	4-4	No.
	4-5	No.
	4-6	understanding, knowledge, caring attitude, affordable
	4-7	na
Participant 13	4-1	Yes.
	4-2	Yes. While deafened, I tried to communicate with a nurse who refused to let me use speech to text to do so. I have also encountered rude and impatient medical personnel.
	4-3	No.
	4-4	No.
	4-5	No.
	4-6	Professional, courteous, informative, timely treatment
	4-7	Professional, courteous, informative, timely treatment
Participant 14	4-1	Yes.
	4-2	Yes. My mother's surgeon told her she wouldn't do well if she had a procedure at another hospital,

		which her PCP said she could. He didn't want to lose her as a patient.
	4-3	No.
	4-4	No.
	4-5	Yes. For my elderly mother, despite all my efforts, when hospitalized, the physicians would ask my mother questions or give her medical information, which was dangerous due to her short term memory loss. Also very poor coordination between the Hospitalist and her PCP and specialists.
	4-6	I expect a respectful health care professional and staff; I expect them, once I explain by hearing loss, to work with me to ensure complete and accurate communications. I've found when I explain my needs, they usually do try to communicate better.
	4-7	Not sure what you are asking. I need good, expert care by professionals who keep up with the science, and effective communications.

In this survey, all participants identified themselves as White or Caucasian. Similarly, all identified themselves as having higher level of education, with the lowest level of education selected was “some college.” The average age of the participants is 64 years old (minimum 40, maximum 77). Six participants had professional degrees, 3 had undergraduate degrees, and one had completed some college. See Figure 3 below for a complete description of the demographics.

Figure 3: Participant DHH Status and State Composition



CHAPTER IV

DISCUSSION AND CONCLUSION

DISCUSSION

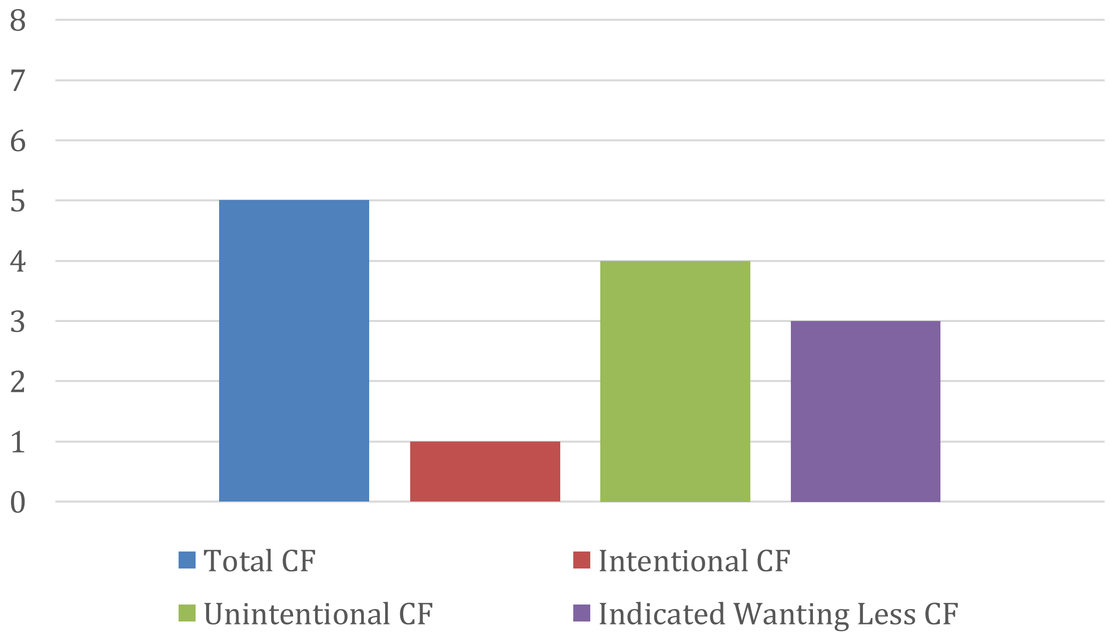
RESULTS

The results from the SAHL-E are, to the slight disappointment of the primary researcher, practically meaningless. Since all the participants seemed to do just fine with the SAHL-E, there is not much to consider in the way of analysis. This is most likely due to the education levels and age of the population. However, there is some information to be gleaned from the data.

Firstly, the questions that were missed by some participants were notably the same question. Participant 01 and Participant 04 both missed Question 2-13, marking the same incorrect answer. This question used the keywords "directed," "instruction," and "decision." There is not a similarity between these signs according to HandSpeak, and online ASL dictionary, but it is interesting to note that the participants provided the same misinterpretation, "decision." Additionally, Participant 05 and Participant 12 both missed Question 2-18, also marking the same incorrect answer. This question used the keywords "syphilis," "contraception," and "condom." The participants both selected "contraception." Once again, according to HandSpeak, the signs for "contraception" and "condom" are not similar, and there is no sign for "syphilis." Thus, although the reason why the participants both selected the wrong answer is not clear, it is a detail of interest. All other questions that were answered incorrectly were not found to have any consistent pattern with other incorrect answers.

On the other hand, the qualitative portion of the survey provides a small, yet promising, glimpse into the realities of those who are DHH. Most notable were the interactions that resulted in communication failures. See Graph 1 for communication failure types. Alarmingly, out of the 8 respondents, 5 noted experiences that had a communication failure of some kind. Most of the responses expressed these communication failures as unintentional, but frighteningly, one experience noted an incident of intentional communication failure. It makes sense that the largest issue recognized in the data is communication failures given the nature of the interaction being studied, but it is unacceptable to see such a large percentage of respondents experiencing such.

Graph 1: Patient Identified Communication Failures (CF)



Aside from communication failures, multiple participants also identified other issues they experienced. Three participants communicated broken trust, 5 noted traumatizing experiences, and 3 referenced to instance of betrayal. Additionally, 8 participants described what they expect from healthcare and 6 described what they need when they seek healthcare. It is important to note that although all participants did well on the SAHL-E, those that had a perfect score did not report experiences as intense as those that scored lower. Although coincidence is possible, it seems that those with more traumatic experiences did not perform as well on the SAHL-E.

Aside from the answers to the survey, the sample size demographics may provide insight about the answers collected. The average age of the sample size is 64 years old. The older ages of these participants are most likely attributed to the fact that this survey was distributed through organizations that typically do not comprise of younger individuals. These individuals may have more free time on their hands, leading to their participation. Additionally, these participants had very high education levels, most likely due to the same organizational factor. If more staff and faculty filled out the survey compared to members, it will most assuredly yield education levels as we have collected. There is indication of sample bias since the sample was quite the opposite of diverse. However, this sample bias may not be the key to explaining inadequate health literacy, but most assuredly the lack of specialized healthcare.

The reader is urged to learn one thing from this data: the inequality in this demographic. Although all participants were white, older, and more educated, communication failures far exceed those expected of individuals who share these exact same characteristics but are not DHH. This discovery should be considered in the context of other conditions, characteristics, and demographics. For instance, those who are DHH may also be a part of other disadvantaged groups, such as minorities, the LGBTQ+ community, those in poverty, and so on. If a group such as the one captured in this research have such a high rate of communication failures that can impact their care negatively, what data would we find when considering others?

This research begs for further conversation. Clearly, more research must be completed in this field of study to work towards the goal of better health literacy. Although live interpretation and compassionate healthcare personnel have been proven to positively influence health outcomes, there are other effective options as well. For instance, diversity and compassion training for healthcare personnel can go a long way. It is safe to conjecture that most institutions and clinics have some sort of sensitivity training, but it would do patients who are DHH better to have training dedicated just for handling communication errors and avoiding them. Experiences such as Participant 13's nurse refusing to use text-to-speech could so easily have been avoided by reaching out to a dedicated translation service or consulting with a supervisor to resolve the issue. Further, training should be more specific for different fields. Nurses have far too much on their plate these days, but training office staff specifically to handle facilitation of communication with a person who is DHH would be quite useful for both sides of the experience.

These are all actions that can be taken today, but there are also exciting, and quite futuristic, solutions that could be implemented. For instance, the SignAloud gloves, created by Thomas Pryor and Navid Azodi at the University of Washington, are designed to recognize ASL signs using sensors and translate into audible English (Massachusetts Institute of Technology, n.d.). This can allow a patient to speak their native language and rely on AI to translate for them instead of trying to type English in text-to-speech software or have a family member translate. Although this only solves one channel of communication instead of both, it is a solution that is quite possible to widely implement in the day and age of technology.

LIMITATIONS

Throughout the course of this research, many limitations presented themselves and inhibited better data collection and quality. To start, the survey itself is presented in English. Although the researcher attempted to design a survey that offered both English and ASL instruction, the implementation did not proceed. The online survey software, Qualtrics, would not have lent itself to video formats, and the research project itself had no funds to ensure accurate and timely translations. Special care, however, was made to enable the survey to work on phones and tablets as well as computers in addition to being totally accessible to those who use a screen reader.

There were no incentives provided for those that participated in the survey. This, of course, could have led to having less responses to the survey. To add, outreach to those in the DHH community are frequently denied by organizations that have rules against sharing research surveys with their members. Since there was no immediate gain or incentive other than benefiting from future research that can help their community, the survey did not travel very far.

Additionally, with the advent of the COVID-19 pandemic and the following transition to online-only communication, potential participants may have been uninterested due to sheer fatigue of technology. Endless emails, phone calls, and video chats can be overwhelming for most. Therefore, an email asking for voluntary participation in a survey may have been overlooked or intentionally ignored. In the same respect, some people in these organizations may not be enrolled in list servs or newsletters that the survey was shared through.

In recent times, the cochlear implant (CI) has become a more popular choice for those who are DHH. There are hearing tests that allow for detection of hearing difficulty in newborn babies, effectively diagnosing a child and allowing for medical intervention if the parents wish. Therefore, the reason why this sample is older could be traced to advanced medical techniques that allow devices such as the CI to be more commonplace in younger generations.

Due to sample size, certain data analyses and interpretations were not feasible. Correlation comparison and more advanced statistical methods would have been employed for a larger turnout, but these methods cannot be meaningfully used on data from only 10 participants. To credit the researcher, reminders were dutifully sent to each organization that expressed interest, but seemingly to no avail for the most part.

Recruitment of the DHH population in the South has been a particularly challenging aspect of this research. Although human research in general typically has difficulty with recruitment, this specific demographic within this region is quite hard to reach with only one primary researcher and no funding. Some recruitment was easily done by reaching out to organizations committed to serving the DHH, as one can see. However, it seems that other strategies are more fruitful, such as using social media marketing.

Social media marketing is a great way to reach an audience given the proper resources. One study by Kobayashi et al. in 2013 describes a framework that allowed them to achieve their target sample size of 250 and yield satisfactory results. This framework used four channels of recruitment: mass media, community events, organizations, and personal media. Mass media describes websites, flyers, brochures, and the like. Community events refer to events that cater to DHH individuals, such as festivals and social events. Organizations, such as the ones contacted in this study, were also contacted. Lastly, personal media is the communication from one friend, family member, or coworker to another about the survey in the study. Using this combination of outreach, the data collection was excellent and allowed the researchers to effectively target, communicate, and recruit participants for their study.

This study only uses one recruitment channel as described in Kobayashi et al.'s work and was not the most effective at reaching out and targeting the desired population. If this research were able to use the four recruitment strategies as explained, the results and sample size would be much more satisfactory and allow for better data analysis and interpretation.

The last limitation to discuss pertains to Louisiana law. When the primary researcher initially reached out an organization in Louisiana at the beginning of this study, the response was positive. Over time, however, responses were few and far between. The organization had written a letter of support for IRB approval but was not used as the IRB application had already been sent. After initially sharing the survey with the organization on the 30th of November 2021, and following up on the 21st of January 2022, after no response, the primary researcher received an email from President of the organization on the 3rd of February 2022. This email stated that the term “hearing impaired” was no longer acceptable in their state due to legislation, and requested the use of the terms “Deaf,” “DeafBlind,” and “Hard of Hearing.” The term was coined unacceptable due to the cultural standpoint of the word “impaired,” and the primary researcher was informed that other states discourage the use of the term as well.

This survey was created in ignorance of the Louisiana law that forbade the use of the term “hearing impaired.” The primary contact at the organization did not share any information about the discontinued use of the term before the survey was published, so changes could not be made without reapproval from the IRB. Not only did this impede the sharing of the survey with the members of the LCD, but also discouraged sharing the survey to other organizations that would have further distributed it. Despite this, there was still one response from a participant who stated that they were from Louisiana.

IMPLICATIONS

The largest implication for this research is quite clear: regardless of education, race, or age, the individuals who are DHH need accommodations, such as live interpretation and sensitivity training for healthcare personnel, to provide consistent, higher quality healthcare outcomes. The issues presented and described in this research will not simply fade away and will consequently persist unless action is taken. Technological advancements, such as the SignAloud gloves, are seemingly worthwhile investments. Better online translation services are needed, with crystal clear video and audio feeds, are needed for safe and proper use. Allowing the use of text-to-speech in emergent situations is critical when there is no interpretation service available. Last, but certainly not least, continuing education and training for those in the health field that interact with patients need to be implemented in practice along with compassion, not in written, forgotten company procedure.

These results only corroborate with the information found in the literature explored above. There are communication errors abound that exist today, as seen in this study, and will continue to exist until better solutions are in place. As compared to the 1998 study done by Woodroffe et al., this study has a sample that is not otherwise disadvantaged. In fact, both studies provide information that shows the sample had satisfactory health literacy. However, this only fulfills the needs of Component A as discussed previously if the reader recalls. The real deficit is in Component B, it seems, for the group in this research. However, this can be reasonably extrapolated to members in the DHH community outside of this study.

The next researcher that decides to perform research in this population must learn one thing: use social media to reach out to potential participants outside of organizational membership. If funds are available, use them to promote advertisements for research participation and develop a solid strategy as the one employed by Kobayashi et al.'s research.

CONCLUSION

As this research concludes, the reader, healthcare workers, organization leaders, social workers, interpreters, and any other individuals who may be involved, must know one thing: there needs to be a fundamental change in the understanding and implementation of healthcare for those that are DHH. There has never been, and never will be, a one-size-fits-all approach to any patient one may encounter, and that includes those who are DHH. Cultural sensitivity, social determinants of health, and pure compassion are the qualities every institution must keep in mind when dealing with any patient.

If one knew the future catastrophic, life-altering health outcome of one communication failure today, would they change their ways and do what is best for the patient? Hopefully, the researcher conjectures. Why not implement strategies that are designed to keep such horrors away, then? These strategies, laced with compassion, care, and true hope for the wellbeing of another, are the key to making a difference in the lives of others, such as those that participated in this study. Even if this study is forgotten and tucked away, and even if there is only one single difference in this community as a result of this work, this research will have then served its sole purpose.

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APPENDICES

APPENDIX A

The 18 items of *SAHL-E*, ordered according to item difficulty (keys and distracters are listed in the same random order as in the field interview)

Stem	**Key or Distracter**		
1. kidney	__urine	__fever	__don't know
2. occupation	__work	__education	__don't know
3. medication	__instrument	__treatment	__don't know
4. nutrition	__healthy	__soda	__don't know
5. miscarriage	__loss	__marriage	__don't know
6. infection	__plant	__virus	__don't know
7. alcoholism	__addiction	__recreation	__don't know
8. pregnancy	__birth	__childhood	__don't know
9. seizure	__dizzy	__calm	__don't know
10. dose	__sleep	__amount	__don't know
11. hormones	__growth	__harmony	__don't know
12. abnormal	__different	__similar	__don't know
13. directed	__instruction	__decision	__don't know
14. nerves	__bored	__anxiety	__don't know
15. constipation	__blocked	__loose	__don't know
16. diagnosis	__evaluation	__recovery	__don't know
17. hemorrhoids	__veins	__heart	__don't know
18. syphilis	__contraception	__condom	__don't know

Instruction for Administering *SAHL-E*

***SHORT ASSESSMENT OF HEALTH LITERACY-ENGLISH* (*SAHL-E*)**

Interviewer's Instruction

The *Short Assessment of Health Literacy-English*, or *SAHL-E*, contains 18 test items designed to assess an English-speaking adult's ability to read and understand common medical terms. The test could help health professionals estimate the adult's health literacy level. Administration of the test could facilitated by using laminated 4"×5" flash cards, with each card containing a medical term printed in boldface on the top and the two association words—i.e., the key and the distracter—at the bottom.

Directions to the Interviewer:

1 Before the test, the interviewer should say to the examinee:
"I'm going to show you cards with 3 words on them. First, I'd like you to read the top word out loud. Next, I'll read the two words underneath and I'd like you to tell me which of the two words is more similar to or has a closer association with the top word. If you don't know, please say 'I don't know'. Don't guess."

2. Show the examinee the first card.

3. The interviewer should say to the examinee:
"Now, please, read the top word out loud."

4. The interviewer should have a clipboard with a score sheet to record the examinee's answers. The clipboard should be held such that the examinee cannot see or be distracted by the scoring procedure.

5. The interviewer will then read the key and distracter (the two words at the bottom of the card) and then say:
"Which of the two words is most similar to the top word? If you don't know the answer, please say 'I don't know'."

6. The interviewer may repeat the instructions so that the examinee feels comfortable with the procedure.

7. Continue the test with the rest of the cards.

8. A correct answer for each test item is determined by both correct pronunciation and accurate association. Each correct answer gets one point. Once the test is completed, the interviewer should tally the total points to generate the *SAHL-E* score.

9. A score between 0 and 14 suggests the examinee has low health literacy.

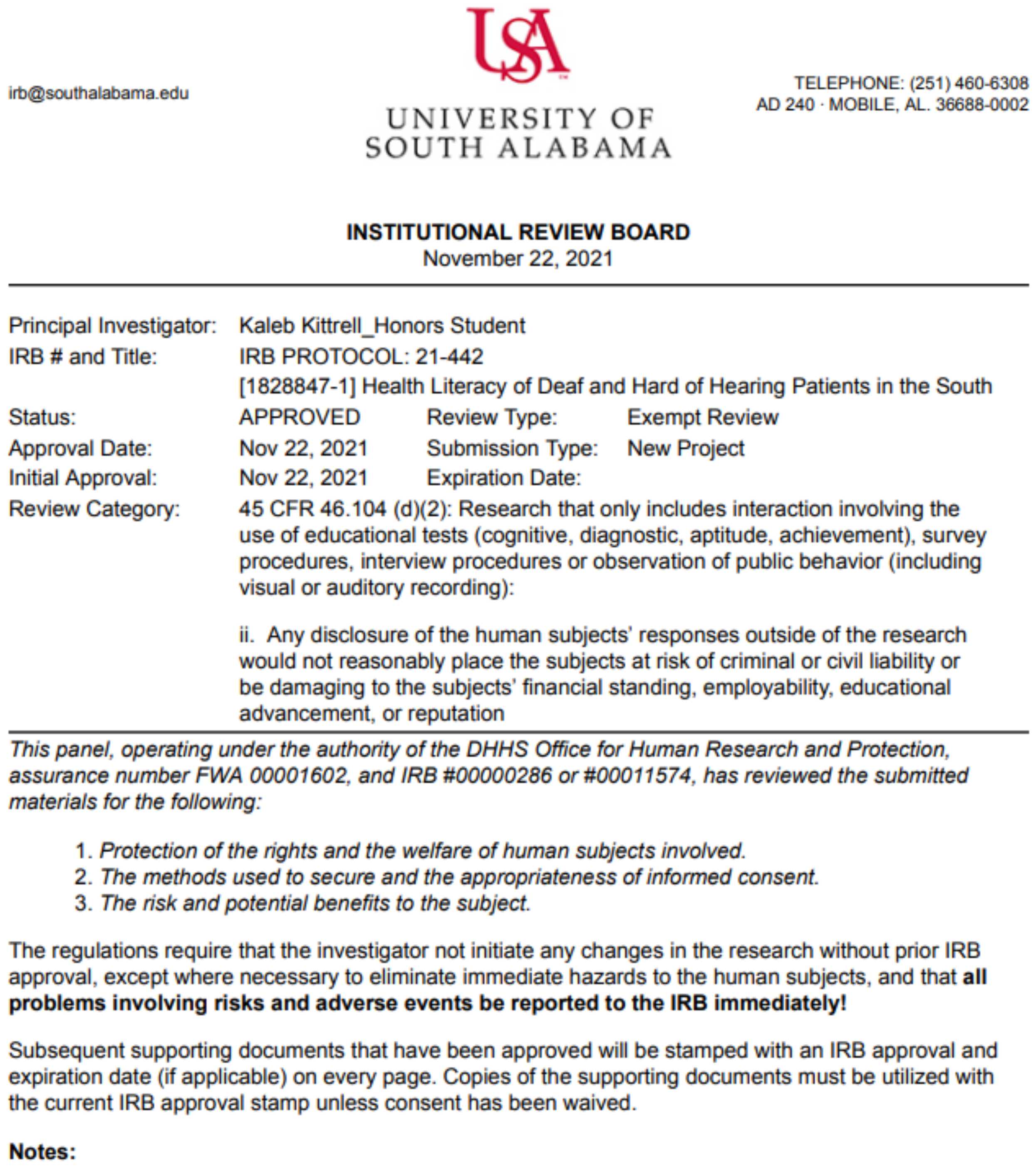
APPENDIX B

Consent (Part 0)	0-1	**Information Sheet (Appendix D)**	I agree.
			I disagree.*
Quick Demographics (Part 1)	1-1	How would you identify yourself?	d/Deaf
			hard of hearing/Hard of Hearing
			DeafBlind/low vision
			Late-deafened
			Hearing*
			Other (if so, please explain)
SAHL-E (Part 2)	2-1 2-18	**SAHL-E (Appendix A)**	
Follow-Up Demographics (Part 3)	3-1	What state are you from? (AL, MS, etc.)	(small free response box)
	3-2	How old are you?	(small free response box)
	3-3	What is your race? (Select all that apply to you.)	American Indian or Alaska Native
			Asian
			Black or African American
			Hispanic or Latino
			Native Hawaiian or Other Pacific Islander
			White or Caucasian
			If other, please specify.
	3-4	What is your highest level of completed education?	Some High School
			High School Diploma/GED
			Some College
			Undergraduate Degree
			Professional Degree
	3-5	Are you currently working towards a diploma, certificate, or degree? If so, please indicate.	No.
			Yes. (small free response box)
	3-6	Do you currently have health or pharmacy insurance? State or federally funded insurance, private insurance, or other policies apply.	Yes.
			No.
Trauma in Healthcare (Part 4)	4-1	Do you trust your healthcare provider?	No.
			Yes.

	4-2	Has your trust ever been broken by a healthcare provider? If yes, please describe.	No.
			Yes. (large free response box)
	4-3	Have you been traumatized by healthcare encounters? If yes, please describe.	No.
			Yes. (large free response box)
	4-4	Have you ever delayed seeking healthcare because of your d/Deaf or HoH status? Or based on trauma? If so, please describe.	No.
			Yes. (large free response box)
	4-5	Have you ever experienced betrayal in healthcare? “Betrayal” can be defined as a patient experiencing harm that is made worse by health care systems. In other words, “slipping through the cracks of health care.” If so, please describe.	No.
			Yes. (large free response box)
	4-6	What do you expect when you seek healthcare?	(large free response box)
	4-7	What do you need when you seek healthcare?	(large free response box)

*Selecting this answer immediately closed the survey and thanked the participant for their time.

APPENDIX C



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INSTITUTIONAL REVIEW BOARD
November 22, 2021

Principal Investigator:	Kaleb Kittrell_Honors Student		
IRB # and Title:	IRB PROTOCOL: 21-442 [1828847-1] Health Literacy of Deaf and Hard of Hearing Patients in the South		
Status:	APPROVED	Review Type:	Exempt Review
Approval Date:	Nov 22, 2021	Submission Type:	New Project
Initial Approval:	Nov 22, 2021	Expiration Date:	
Review Category:	45 CFR 46.104 (d)(2): Research that only includes interaction involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior (including visual or auditory recording): ii. Any disclosure of the human subjects' responses outside of the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation		

This panel, operating under the authority of the DHHS Office for Human Research and Protection, assurance number FWA 00001602, and IRB #00000286 or #00011574, has reviewed the submitted materials for the following:

1. *Protection of the rights and the welfare of human subjects involved.*
2. *The methods used to secure and the appropriateness of informed consent.*
3. *The risk and potential benefits to the subject.*

The regulations require that the investigator not initiate any changes in the research without prior IRB approval, except where necessary to eliminate immediate hazards to the human subjects, and that **all problems involving risks and adverse events be reported to the IRB immediately!**

Subsequent supporting documents that have been approved will be stamped with an IRB approval and expiration date (if applicable) on every page. Copies of the supporting documents must be utilized with the current IRB approval stamp unless consent has been waived.

Notes:

APPENDIX D

Health Literacy of Deaf and Hard of Hearing Patients in the South
Kaleb Kittrell
klk1722@jagmail.southalabama.edu | (205) 657-2313

You are invited to voluntarily participate in a research project designed to gather valuable insight on the health literacy of hearing-impaired individuals in the traditional "Southern" region of the United States.

The purpose of the study is to gain a generalized understanding on average health literacy levels of hearing-impaired individuals in the South to provide emphasis on the lack of specialization in health care and procedures designed for the specified demographic. This will take no longer than 15 minutes to complete. Participation will remain anonymous, and no identifying data will be collected.

Procedure: You will be asked to provide basic demographics, answer a series of 18 questions to rapidly determine health literacy, and answer follow up questions about trauma in healthcare. You have the right to refuse to answer any questions that you do not wish to complete and/or answer.

Benefits and Risks: There is no direct benefit to the individual participant. However, the potential benefit of participating in this study will expand the knowledge of health literacy in hearing impaired individuals in all areas of the Unites States. The results of which will be beneficial to suggesting modifications to health education for the demographic.

Incentives: No incentives will be provided for completing the survey. All answers will be kept no later than May 2022 after all data has been collected and presentation of thesis is completed. All information will be used for research purposes only.

You can withdraw at any time without consequence. Please contact me at klk1722@jagmail.southalabama.edu or the Institutional Review Board at the University of South Alabama at (251) 460-6308 if you have questions about your rights as a research subject.

USA Institutional Review Board	
Approved:	11/22/2021
IRB Number:	21-442/1828847-1