Ethnography of Deaf Individuals: A Struggle with Health Literacy

by

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ABSTRACT OF THE DISSERTATION

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Health literacy has been defined by the Institute of Medicine (IOM) 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." Inadequate health literacy has effects on a person's health beyond age, income, employment status, education level, and race. Cultural and linguistic minorities are at greater risk for having low health literacy. Members of the Deaf ASL community define themselves as a cultural and linguistic minority group. Persons who are Deaf are at risk for low health literacy for a number of reasons including socioeconomics, poor education and linguistic discordance with their health care provider.

The research question that this study considered is: How does someone who is Deaf obtain, process, and understand basic health information and use that information to make appropriate health decisions? An ethnographic study was conducted in order to understand health literacy from the perspective of someone who is culturally Deaf. The informed consent was translated into
American Sign Language (ASL) and video recorded. Twelve interviews and 75
hours of participant observation were conducted. All interviews took place in a
place of privacy with 2 interpreters.

The themes that were identified were: communication, going to the doctor,
audism, Deaf culture, family, and privacy. Themes were identified based on
observations across interviews and participant observation. Many themes were
interrelated. Several implications for future research and practice were noted
including how privacy with the Deaf community impacts health literacy, how
family dynamics may influence health literacy with the Deaf community and the
effect of having an in-person interpreter versus a virtual interpreter during a visit
with a health care provider.
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Chapter One – Introduction and Perspective

Introduction

Health literacy has been linked to better health outcomes in different populations (Berkman et al., 2011; Nielsen-Bohlman et al., 2004; Weiss, 2007). Health literacy, as opposed to disease knowledge, health behavior, preventive care, and medication compliance, has been the only factor that has been consistently demonstrated to have a direct effect on health outcomes (Berkman et al., 2004). Inadequate health literacy exerts a stronger prediction of a person’s health than age, income, employment status, education level, and race (Ad Hoc, 1999). However, there is limited or no available information about health literacy for several at risk groups, including limited English proficiency populations and Deaf American Sign Language (ASL) users. Health disparities have been seen in those that are culturally Deaf, particularly in the areas of preventive health, cancer screening, cardiovascular health, sexual health and mental health.

Persons of Interest

The population of interest for this study is those who consider themselves culturally Deaf. Members of the Deaf ASL community define themselves as a cultural and linguistic minority group (Benedict & Sass-Lehrer, 2007; Lane et al., 1996; Murray et al., 2007; Vernon & Leigh, 2007; Woodcock & Pole, 2007). Culturally Deaf individuals communicate primarily through sign language which is a visual language with no written form (McKee et al., 2015).

Many authors differentiate members of the cultural group from those with the auditory problem by referring to the Deaf (with a capital D) as anyone in the
cultural group and deaf (with a lower-case d) as anyone with a profound hearing problem (Obasi, 2008; Rokke & Scogin, 1995; Steinberg et al., 2006; Vernon & Leigh, 2007; Woodcock & Pole, 2007). While other researchers have used the term “culturally Deaf” or “member of the Deaf-World,” their description of the population is similar to those who use “Deaf.” (Jones et al., 2007; Lane et al., 1996; Margellos-Anast et al., 2005). Therefore, to be consistent with the majority of published articles the term “Deaf” will be used in this paper when referring to the cultural group, while the term “deaf” will be used when referring to the audiological problem. Padden and Humphries (2006) note that a person can be both deaf and Deaf. However, not all persons who are deaf are Deaf.

Membership in Deaf culture is based on shared values and a shared way of doing things, not just a common characteristic. Obasi (2008), in a review of Deaf culture, attempts to differentiate Deaf persons from others who might be considered disabled. He notes that members of Deaf culture do not consider themselves disabled, they, in general, do not want to change their hearing status, and they focus on having a common language (Obasi, 2008).

Relatively recently, there has been discussion about how those that are culturally Deaf view themselves and the world, a Deaf epistemology (De Clerck, 2010). While there is no universal agreement to what constitutes a Deaf epistemology, typically the description includes a focus on members having a shared experience (Hauser et al., 2010). McKee and Hauser (2012) comment that there are aspects of Deafness that can be positive, specifically, an increased resilience and ability to resist oppression.
While no cultural norm applies to all members of a cultural group, Deaf persons have unique cultural values and norms, and a unique history (Stebnicki & Coeling, 1999). Many Deaf persons see their hearing status as a good thing, associating it with their cultural identity. Many Deaf persons choose to associate primarily with other Deaf individuals. Many Deaf individuals also wish for Deaf children to pass on their language and cultural roots (De Clerck, 2010; Hauser et al., 2010; McKee & Hauser, 2012; Miller, 2010). This differs from other disabled groups (Lane, 2005). Another example of a cultural norm in Deaf society is that it is impolite to not maintain eye contact during a conversation with a Deaf person, while in some other cultures prolonged eye contact may be considered disrespectful (Scheier, 2009). Deaf persons also have their own way of conducting introductions and departures (Lane, 2005). In the Deaf community, it is common to see people introduce themselves with their full names, where they grew up and/or went to school. The Deaf school is visualized as a cultural exchange center for the Deaf community, where both language and culture are transmitted to the next generation. Deaf persons will often say they are from that school (My name is Mary Smith. I’m from Marie Katzenback School for the Deaf.) (Andrews et al., 2004). Also, if the person introducing themselves is hearing, that introduction must include how they fit into the Deaf community (ie, are they an interpreter or a sign language student? Who else do they know who is Deaf?). These are just a few examples of the many cultural norms in the Deaf community.
Age, educational level and other demographics have not been shown to influence group identity in members of the Deaf community (Margellos-Anast et al., 2005). The Deaf community is more broadly defined than Deaf culture, Eckert (2010) differentiates those who are culturally Deaf from the Deaf community of interest. He states that the Deaf community can include anyone who has an interest in and supports the goals of the Deaf and often includes sign language interpreters, family of Deaf persons and Deaf educators (Eckert, 2010). Those who are culturally Deaf are necessarily members of the Deaf community, but not vise-versa (Eckert, 2010). Padden (1980) defines a Deaf community as “a group of people who live in a particular location, share the common goals of its members and in various ways, work toward achieving these goals (p. 92). A deaf community may include persons who are not themselves Deaf, but who “actively support the goals of the community and work with Deaf people to achieve them” (Padden, 1980, p. 92). According to Obasi (2008), many in the hearing public believe that the defining characteristic of the Deaf community is their lack of hearing, while those in the Deaf community state that the defining characteristic is their ability to sign. Those with greater fluency in sign language enjoy a higher status within the community, especially those Deaf who are born of Deaf parents (Harmer, 1999; Lane et al., 1996).

**Health Literacy**

Health literacy has been defined by the Institute of Medicine (IOM) 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” (Nielsen-Bohlman et al., 2004, p.4). Zarcadoolas et al. (2005) define health literacy as “the wide range of skills and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks, and increase quality of life” (p. 196-197). Previous research has shown that persons who are Deaf have difficulty obtaining health related information and difficulties understanding basic health information, suggesting that a person who is Deaf is more likely to have low health literacy (Pollard & Barnett, 2009). While there are articles that discuss health literacy in the Deaf community, only a few studies of health literacy in the Deaf community have been reported in the literature (Kushalnagar, Ryan et al., 2018; McKee et al., 2015; Smith & Samar, 2016).

Deaf persons have higher rates of both physical and mental illness than their hearing counterparts, necessitating accurate and complete understanding of health information. Recently the first comprehensive survey of the health needs of the Deaf community was conducted in Rochester, New York (Barnett, Klein et al., 2011). It showed that Deaf persons have higher rates of obesity compared to members of the hearing community (34% verses 26%), have attempted suicide rates five times higher than that of the hearing community (no actual percentages were given) and have higher rates of interpersonal violence (21% verses 6%) (McKee, Barnett et al., 2011). Additionally, Deaf persons have been noted to have higher rates of HIV than that of the hearing community (5% verses 3%) (Bat-Chava et al., 2005).

Prior to that survey almost all available research combined Deaf persons
with anyone with hearing loss. For example, Woodcock and Pole (2007) found that Canadians who had “hearing problems” were significantly more likely to have cardiac and other chronic diseases and were significantly more likely to report experiencing depression than those not reporting hearing problems. These findings were based on a secondary analysis of a national survey (actual rates were not reported) (Woodcock & Pole, 2007). While this can provide a useful starting place, when Deaf are combined with those who are culturally hearing, such as persons who develop hearing problems later in life, we may not obtain an accurate picture of what is happening in the Deaf community. Persons who are Deaf and consider themselves a distinct cultural group have unique needs and difficulties in obtaining, processing, and understanding basic health information and services.

The purpose of this study is to examine health literacy from the perspective of individuals who are culturally Deaf.

**Concern to be Addressed**

The concern to be addressed in this study is the need for greater understanding of health literacy from the perspective of someone who is culturally Deaf. Someone who is Deaf is at risk for having lower levels of health literacy due to multiple factors. Some of the factors that may influence a person’s health literacy include low general literacy levels, limited English proficiency, membership in a minority population, and socioeconomic factors (Nielsen-Bohlman et al., 2004; McKee et al., 2014; Singleton et al., 2004; Zazove et al., 2013).
Low General Literacy Levels

The National Assessment of Adult Literacy (NAAL) has been used as a proxy measure for health literacy of adults living in the United States (NNLM, 2013). Using this measure, health literacy is divided into four levels: below basic, basic, intermediate, and proficient (NAAL, 2006). A proficient health literacy level equates to a reading level above tenth grade (NAAL, 2006). According to the NAAL only 12% of the US population has a proficient health literacy level (NAAL, 2006).

The average reading level for someone who is Deaf upon leaving high school is between third and fourth grade (Allen, 1994; Holt, 1994; Jones et al., 2005). Freel et al. (2011) found that a sample of Deaf college students at Gallaudet University had an average grade reading level of 5.8.

According to the 2012 survey of health and vital statistics (USHHS, n.d.) 19.8% of Deaf and Hard of Hearing have less than a high school education. According to Blanchfield et al. (2001), there is an average high school dropout rate of 44.4% among the deaf, compared to 18.7% in the hearing. Nationally, among those that are hearing there is a 12.8% graduation rate from places of higher education, while those that are deaf have a graduation rate of 5.1% (Blanchfield et al, 2001). Of note, these figures are not specific to the ASL community, there is no information available specific to the Deaf community. The lower educational level puts someone who is Deaf at a great disadvantage considering that most medical literature is written at approximately a tenth-grade reading level (Nielsen-Bohlman et al., 2004; McKee et al., 2014).
Several studies have demonstrated that a frequent source of information in the Deaf community is other members of the community. For example, Bat-Chava et al. (2005) found that deaf individuals were seven times more likely to receive information about HIV/AIDS from their friends than their hearing counterparts. Joseph et al. (1995) found that 81% of Deaf college students stated that their friends were their main source of information about sexual health, while “most young people consider their parents to be their most important source of information about sexuality” (p. 338). McKee, Schlehofer et al. (2011) found that a majority of cardiovascular knowledge obtained by Deaf individuals in their study was from personal experience or members of their community.

This kind of peer exchange has benefits and drawbacks in such a close-knit community. When trying to disseminate information, it may be easier for that information to reach the maximum number of people, however, there can be concerns about confidentiality and one’s willingness to seek needed resources, especially about sensitive topics such as HIV prevention (McKee, 2017). Also, there may be limited opportunities to correct misunderstandings or to build upon previous knowledge (McKee, Barnett et al., 2011)

**Limited English Proficiency**

An individual whose primary language is not English, and thus has Limited English Proficiency (LEP), is at greater risk for health problems than someone who speaks English as their native language (Yip, 2012). Additionally, having a primary language other than English has been associated with poor patient
outcomes such as increased use of diagnostic testing, increased use of emergency services and poor patient satisfaction in the United States (Hoffman-Goetz et al. 2009).

American Sign Language (ASL) is the primary language used by the Deaf community in the United States (US) and Canada (Valli, 2005). ASL is a visual-manual language with a structure and grammar different from that of spoken English and no written form (Valli, 2005). English is frequently considered a second language among those that are Deaf (Lane et al., 1996).

There is almost no research done on health literacy in those who use ASL as their primary language, however, parallels can be drawn to other LEP groups. In a diverse group, Sentell and Braun (2012) found low health literacy in 44.9% of respondents with LEP, compared with 13.8% in those without LEP. Todd and Hoffman-Goetz (2011) found lower health literacy scores in a group of older Chinese immigrants who learned English as a second language. Additionally, Koskan et al. (2010) found that Spanish speaking Hispanics consistently scored lower on health literacy measures than English speaking counterparts. Sudore et al. (2009) looked at language agreement and health literacy in assessing communication barriers between physicians and their clients. In a sample of 771 participants, 76% went to a physician who spoke the same language as the participant (53% were English Speaking with an English-speaking physician, 23% Spanish Speaking) the remaining 24% were Spanish Speaking with an English-Speaking physician (Sudore et al., 2009). The authors found that those
with a language mismatch between physician and participant had the most communication barriers (Sudore et al., 2009).

**Minority Populations**

Diverse minority groups have lower health literacy than their Caucasian counterparts. For example, in 2003, 14% of Caucasians surveyed had proficient health literacy, whereas only 2% of African Americans had proficient health literacy (Kutner et al., 2006). Koskan et al. (2010) found inadequate health literacy more likely in both English and Spanish speaking Hispanics. Doty (2003) found Hispanic Americans were more likely to have difficulty “understanding medical instructions” than non-Hispanics even after controlling for language comprehension. Sentell et al. (2011) found more Asian Americans/Pacific Islanders in Hawaii had lower health literacy scores than their white counterparts (23.9%-15.9% compared with 13.2%). Members of the Deaf community consider themselves a minority group. While at this point health literacy rates for the Deaf community are unknown, it is reasonable to think that Deaf persons would also have lower health literacy due to their status as a minority group.

**Low Income**

According to the Institute of Medicine report, adults living below the poverty level have lower than average health literacy than adults living above the poverty threshold (Nielsen-Bohlman et al., 2004). However, this is not unexpected, since poverty is intertwined with many other socio-demographic variables that also affect health literacy (Balsa and McGuire, 2001). There is little evidence related to the current economic status of the Deaf community. Much of
what is currently available is anecdotal, and what evidence exists is very much related to the person’s educational attainment. The Bureau of Labor Statistics collects data on persons with disabilities, including persons who are Deaf, but does not separate out unemployment rates for the Deaf (Bureau of Labor Statistics, 2013). Persons with disabilities have an unemployment rate almost twice that of those without disabilities (12.8% vs. 6.7%) (Bureau of Labor Statistics, 2013). In a study of persons who are Deaf, Schley et al. (2011) found a relationship between completion of a college degree program and increased income over the duration of one’s lifetime and decreased use of Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). However, this study only tracked those who applied for admission to Rochester Technical Institute for the Deaf (RTID) (Schley et al., 2011). Given the elevated high school dropout rates previously noted and the low performance while in school it is reasonable to assume that many D/deaf high school students do not apply for admission to college.

The Phenomenon of Interest

There is no consistent definition of health literacy used in the literature. The Institute of Medicine defines health literacy 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,” this is the definition that will be used in this study (Nielsen-Bohlman et al., 2004, p. 2). Based on this definition, it is clear that health literacy is more than just the ability to read. Health literacy is needed for virtually every aspect of navigating the
health care system, from reading health information, to calculating medication dosage, to voting on health issues (Nielsen-Bohlman et al., 2004). The Institute of Medicine report clarifies that a person’s capacity “refers to both the innate potential of the individual, as well as his or her skills” and is affected by that person’s education, culture, language and the setting (Nielsen-Bohlman et al., 2004, p. 32). Other definitions have specified aspects of health literacy such as the ability to use technology, motivation, networking and social skills in addition to literacy and numeracy (Bernhardt et al., 2005; Nutbeam, 2008).

Health numeracy is probably the most commonly included concept to be added to the definition of health literacy. While there is no standard definition of health numeracy, the Center for Disease Control and Prevention (CDC) defines numeracy as the “ability to access, use interpret, and communicate mathematical ideas, to engage in and manage mathematical demands of a range of situations in adult life” (CDC:Health Literacy, 2016). Rothman et al. (2008) found that although health literacy and health numeracy were related, some clients who had adequate health literacy still were lacking in health numeracy skills. Health numeracy encompasses skills such as calculating the dosage of a medication, following directions on an appointment slip and calculating calories (Rothman et al., 2008). Rothman et al. (2005) found that even participants with adequate literacy skills had difficulty with numeracy tasks when trying to interpret a food label.

Since health numeracy is infrequently measured as a separate concept, it is still unclear the exact impact it has on a person’s health outcomes. One study
that did separate the two concepts investigated the impact of health literacy and health numeracy on the use of patient portal technology (Taha et al., 2014). The sample of 51 adults from the Miami area had disproportionately high health literacy scores (86% scored adequate on the TOFHLA), yet 52.9% could not answer the majority of numeracy of questions (Taha et al., 2014). Internet experience and health numeracy scores were significantly related to successfully completing tasks on a simulated patient portal (Taha et al., 2014).

Technology has had a significant impact on how one obtains health information and more recently how one accesses health services. Baur (2005) looks at how the internet could affect someone with low health literacy. Frequently, material on the internet poses the same reading demands as print material (reading level above recommendation for the target population) and imposes additional barriers of the technology (Baur, 2005). However, technology has the potential for bringing health information to all in new and novel ways (including those with limited health literacy) if those with literacy challenges are taken into account when the technology is being designed (Mackert et al., 2016). Bickmore and Paasch-Orlow (2012) discuss an interactive computer program that people who have lower health literacy scores tend to prefer over live interactions because it allows them to seek information at their own pace and not feel intimidated.

**The Purpose of the Research**

The purpose of the proposed qualitative study is to examine health literacy from the perspective of individuals who are culturally Deaf. As a distinct cultural
group, Deaf persons are entitled to culturally competent care. Cultural, social, and family influences are of critical importance in shaping attitudes and beliefs (Nielsen-Bohlman et al., 2004). Culture gives significance to health information and influences how a person communicates with health care providers (Nielsen-Bohlman et al., 2004). Understanding how Deaf persons obtain process and understand basic health information and “make appropriate health decisions” will allow health care providers to eventually develop culturally appropriate interventions for this population.

**Foundational Assumptions**

As a cultural group, Deaf persons have a unique way of viewing the world. This worldview informs their definition of health and health literacy, which has an impact on how they communicate with their health care providers, as well as how they look for and interpret health related information.

Communication difficulties experienced by Deaf persons affect their health. The use of Sign Language interpreters has been found to increase Deaf persons’ satisfaction with the health care provider experience and also increase the likelihood that a discussion of preventative services will occur. However, having an interpreter does not guarantee good communication (Barnett, McKee et al., 2011; Steinberg et al., 1998). No research has yet been done to examine the effect of the presence of sign language interpreters on the health literacy of their Deaf clients, however, having an interpreter available has been shown to increase health literacy in other language groups (Qualified, 2007).
Contributing to communication difficulties is the fact that Deaf persons often use health services without the aid of an interpreter. Steinberg et al. (2006) found that despite the legal requirement to provide ASL interpreters, certified medical interpreters were infrequently available and alternatives to certified interpreters (such as speech-reading or writing) were inadequate. Ubido et al., (2002) found that fewer than 10% of Deaf women they surveyed fully understood what happened during a medical appointment. An inability to communicate with persons in the health care system may have an impact on a Deaf person’s health literacy.

**Research Question**

The research question that this study aims to consider is: How does someone who is Deaf obtain, process and understand basic health information and use that information to make appropriate health decisions?

**The Significance of the Study**

There are several reasons why a qualitative study that explores the views of health literacy by Deaf persons is important. While Deaf persons may not constitute the largest minority group in the United States, understanding how the Deaf view health literacy could impact a large number of people. The exact size of the Deaf community in the US is not known because the US Census and other national surveys do not differentiate Deaf persons from others with hearing problems. However, estimates of the size of the US Deaf population range from 100,000 to over one million people (Barnett & Franks, 1999).
While low health literacy has a huge economic impact in the United States (decreased health literacy is estimated to cost $106-$236 billion annually) little research has been done on the economic impact of deafness, and none has been done on the potential economic impact of improving health literacy in the Deaf (Emmett & Francis, 2015). The most recent was a study done by Mohr et al. (2000) with the aim of both estimating the economic burden of “hearing impairment” and providing baseline costs against which to compare future interventions. According to Mohr et al. (2000) Deafness costs society approximately $297,000 over the lifetime of the person, with the lifetime per person cost for those who are pre-lingually deaf (and thus more likely to be culturally Deaf) exceeding one million dollars, mostly in loss of productive work days. It is likely, however, that this estimate is on the low side for the culturally Deaf, because this figure does not include costs such as sign language interpreters needed at health visits and disparities in health status between Deaf and hearing.

As stated previously, sign language interpreters are necessary for adequate communication with health care providers and good communication is necessary for increased health literacy (Nielsen-Bohlman et al., 2004). While there is no literature directly linking health literacy to the use of sign language interpreters, sign language interpreters increase understanding during medical visits. Sign language interpreters are recommended if language concordant providers are not available, since interpreters are associated with better adherence to preventative services (McKee, Barnett et al., 2011). Thus, the
increase in cost that could be incurred by having sign language interpreters could be expected to be offset by a greater decrease in overall health care costs. Therefore, increasing health literacy in this population could have a significant economic impact.

A goal of Healthy People 2020 is to eliminate health disparities, including “differences that occur by gender, race or ethnicity, education or income, disability, geographic location, or sexual orientation” (OMHD, 2009). People who are Deaf are considered a vulnerable group. As noted above, they are likely to be less educated, have a lower income, and have a poorer health status than their hearing counterparts. Along with a lack of health knowledge and mistrust of healthcare providers, these factors put them at risk for health disparities (Barnett & Franks, 1999; Steinberg et al., 2002). Lower health literacy scores have been linked to lower health knowledge. Kandula et al. (2009) studied the impact of a multimedia diabetes educational program and found that those diabetes with lower health literacy scores had less knowledge of diabetes at baseline than those without diabetes. Osborn et al., (2011) tested a model of health literacy and found that health literacy was directly related to knowledge and indirectly related to self-efficacy through knowledge in a sample of hypertensive clients. Several authors acknowledge that Deaf persons have less health knowledge than their hearing peers (Margellos-Anast et al., 2006; Orsi et al., 2007). Anecdotal evidence suggests that this is at least partly due to communication barriers and inability to access appropriate information (Margellos-Anast et al., 2006).
According to Robbins et al. (2001) culturally based interventions are the best way to address health disparities. People who are Deaf are part of a cultural group that is at an increased risk for low health literacy, which is associated with poor health. Increased health literacy has been shown to have beneficial health outcomes (Berkman et al., 2011, Nielsen-Bohlman et al., 2004 & Weiss, 2007). Culturally relevant interventions to increase health literacy can help to reduce the health disparities experienced by Deaf persons. Understanding how Deaf persons obtain process and understand basic health information and make health decisions is the first step towards the development of interventions to improve health literacy in this population.
Chapter 2 - Literature Review

Purpose of a Literature Review in Qualitative Research

Qualitative and quantitative studies are fundamentally different because they are each associated with a different philosophical perspective. Quantitative research is done from the perspective that truth is constant and knowable, and stresses precise measurement and analysis of the relationships between variables (Denzin & Lincoln, 2003). Qualitative researchers generally have the mindset that the truth is not set in stone, and is socially constructed (Denzin & Lincoln, 2003). Table 1 shows some of the differences between qualitative and quantitative research.

Several approaches fall under the general heading of qualitative research, including ethnography, phenomenology, and grounded theory (Roper & Shapita, 2000). Different approaches to qualitative research may appear similar at first glance. For example, they may use similar data collection techniques; however, they differ in the types of information they are attempting to elicit. In ethnography, which will be used in this study, the purpose is to “describe experiences within a cultural context” (Comings et al., 2000, p. 12).

In qualitative research, a literature review is used to demonstrate knowledge of previous work in the area, provide the basis for research, and the context for interpreting findings (Meadows, 2003; Ryan et al., 2007). Different qualitative approaches have different views on the purpose and appropriate use of a literature review (Ryan et al., 2007). Meadows (2003) states literature reviews need to be appropriate for the approach being employed. Ethnography attempts to examine the person in the context of his or her culture and
understand their perceptions of the subject at hand (Ryan et al., 2007). In ethnographic studies, the literature review is used to “demonstrate knowledge of previous work in the area, as well as frameworks used in the analysis of the data” (Ryan et al., p. 740).

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<td>Advantages</td>
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<td>Example</td>
<td>Woodcock &amp; Pole (2007) compares the health status of</td>
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<td>Canadians with and without hearing loss.</td>
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<td>Purpose of Lit Review</td>
<td>● Develop/define research question</td>
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The research literature on health literacy in Deaf persons is limited, thus, in this chapter, other cultural and linguistic minorities are examined. The intent of this literature review is to situate the study within the current literature and to
establish gaps in the current state of scientific knowledge of health literacy in Deaf persons. Also, this literature review will establish the appropriateness of the ethnographic approach. The literature review will be expanded as appropriate in the data analysis section.

**Background of the Phenomenon**

**History of Health Literacy**

According to the Institute of Medicine (IOM) health literacy is defined 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" (Nielsen-Bohlman et al., 2004, p.4). The World Health Organization (WHO) states that health literacy has three categories: functional health literacy, conceptual health literacy and health literacy as empowerment (Kanj & Mitic, 2009). Functional health literacy is defined as “skills that allow an individual to read consent forms, medicine labels, and health care information and to understand written and oral information given by physicians, nurses, pharmacists, or other healthcare professionals and to act on directions by taking medication correctly, adhering to self-care at home, and keeping appointment schedules” (Kanj & Mitic, 2009).

The term health literacy was first mentioned in the 1970s, but there was very little research done on health literacy until 1992 when the National Adult Literacy Survey (NALS) was conducted. The NALS was the first rigorous study of adult literacy in the United States (Comings et al., 2000). The NALS was undertaken by the Department of Education and focused on functional literacy.
Literacy skills were ranked from level one to level five, level one being the lowest level of proficiency (Comings et al., 2000). It does not seek to measure health literacy, however, the NALS did provide a starting place for comparison.

According to the NALS, approximately 22% of the sample fell into the lowest category (level one) and an additional 25-28% fell into level two (Kirsch et al., 1993). Individuals at levels one and two had more difficulty with more problematic literary tasks (Kirsch et al., 1993). For example, someone who falls into level two could be expected to have difficulty using the label to identify substances that may interact with an over-the-counter medication or calculating the employee share of health insurance cost based on income and family size (White et al., 2008).

The follow up survey, the National Assessment of Adult Literacy (NAAL), was conducted in 2003 and was designed in such a way so that it could be compared to the NALS. The NAAL was the first comprehensive study to specifically include health literacy (Institute of Education Sciences, n.d.). Participants (n= 17,178) completed the background data and at least one question on the literacy scales in either English or Spanish (Greenberg et al., 2007). Participants were drawn from households across the United States, and state as well as federal prisons, and were weighted to represent the population of the United States (Greenberg et al., 2007). There are four categories of health literacy in the NAAL based on scores ranging from 0 to 500: Below Basic (0-184), Basic (185-225), Intermediate (226-309), and Proficient (310-500) (Kutner et al., 2006). Frequently, researchers have combined NAAL participant scores in two
or more categories for comparison sake. For example, White et al. (2008) reported results separately for proficient (12%), and intermediate (53%), but grouped basic and below basic together (36%). Similarly, Cutilli and Bennett (2009) reported each health literacy level but discussed basic and below basic as if they were a single group (i.e. “more adults aged 65 and older had below basic or basic health literacy than younger groups” (p. 31).

In one study using the NAAL, 12% of those surveyed had proficient health literacy, 53% had intermediate health literacy, 22% had basic health literacy and 14% had below basic health literacy (Kutner et al., 2006). However, these scores vary widely when you look at demographics. For example, people who consider themselves White scored 58% Intermediate and 14% Proficient, while people who consider themselves Hispanic scored 31% Intermediate and 4% Proficient (Kutner et al., 2006). See Figure 1 for a breakdown of health literacy by race from the 2003 NAAL.

![Health Literacy by Racial/Ethnic Groups: 2003](image)

**Figure 1: Adults' Health Literacy by Racial/Ethnic Groups: 2003**

Currently, Healthy People 2020 includes a health literacy objective (“Improve health literacy of the population” HC/HIT-1) (healthypeople.gov, 2014). Mentions of health literacy in the Patient Protection and Affordable Care Act H.R. 3590 (USDHHS, 2010) and the release of the National Health Literacy Action Plan (USDHHS, 2010) also reflect current national attention to health literacy. According to Vernon, Trujillo et al., (2007) low health literacy is estimated to cost the United States economy between $106-238 billion annually.

**Measures of Health Literacy**

Several health literacy measures are currently available in English and other written and spoken languages. Some of the most popular instruments used to test health literacy are the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1991), Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995), and the Newest Vital Sign (NVS) (Weiss et al., 2005). Both the REALM and the TOFHLA have valid shortened forms, the REALM-SF and S-TOFHLA, making them the most popular instruments seen in the reviewed literature (Arozullah et al., 2007; Baker et al., 1999).

The REALM is a word recognition test; participants are given a list of medical terms and asked to read each word aloud (Davis et al., 1991, Davis et al., 1993). Any word that the participant mispronounces or cannot pronounce is given zero points; any word pronounced correctly is given one point (Davis et al., 1991, Davis et al., 1993). There are cut-offs for low, marginal and adequate health literacy, which correspond to reading grade levels (i.e., a score of 19-44 of
a possible 66 is considered marginal and corresponds to a reading level between fourth and sixth grade) (Davis et al., 1991, Davis et al., 1993).

The original REALM has 66-items and takes under five minutes to administer, while the shortened form has seven items and takes less than a minute to administer (Arozullah et al., 2007, Davis et al., 1991). First developed in 1991, Davis et al. (1991) first tested the REALM with a sample of 207 adults from Arkansas and Louisiana primary care clinics, aged 17-87 (M=47). Approximately half of the participants were white (46%), and half were black (54%) (Davis et al., 1991). The REALM was correlated with the Slosson Oral Reading Test (SORT) (0.95, p<0.0001) a standardized reading recognition test that evaluates the ability to correctly pronounce words at different difficulty levels and the Peabody Individual Achievement Test-Revised, a test for reading comprehension, (PIAT-R) (0.94, p<0.0001) (Davis et al., 1991). Inter-rater reliability was tested by having a second person sit in the room and simultaneously score 20 instruments (0.99, p<0.001) (Davis et al., 1991).

Since Spanish is a phonetic language it is possible to pronounce a word accurately having never heard it before. Thus, the Spanish version of the REALM was not a valid measure of literacy, however a word recognition instrument is available in Spanish that is based on the REALM, the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA) (Lee et al., 2006). In the SAHLSA, participants read aloud a list of words, but unlike the REALM, participants then connect these words with another term with a similar meaning to demonstrate understanding (Lee et al., 2006).
The TOFHLA uses the Cloze procedure (Parker et al., 1995). In the Cloze procedure, words are removed from a passage, in this case every 5th to 7th word, and replaced with a blank (West Virginia Department of Education, n.d.). Possible words are provided that could fit into that blank space, and participants are asked to choose the most appropriate word to fit into the blank space based on the rest of the passage (West Virginia Department of Education, n.d.).

The full length TOFHLA has 50 reading comprehension items and 17 numeracy items and requires approximately 22 minutes to complete (Parker et al., 1995). This version was developed in California in 1993 using a convenience sample of 200 (Parker et al., 1995). Internal consistency was tested, Cronbach’s alpha (0.98) and test-retest reliability was tested via Spearman-Brown (0.92) (Parker et al., 1995). The TOFHL was compared to the REALM (r=0.84, p<0.001) and the Wide Range Achievement Test - Revised (WRAT-R) (r=0.74, p<0.001) (Parker et al., 1995).

The shortened version (S-TOFHLA) requires approximately seven minutes to complete and has 36 reading comprehension questions (Baker et al., 2004; Baker et al., 1999). The S-TOFHLA uses the two of the three reading passages that are used in the original TOFHLA and does not add additional passages. The passages included in the TOFHLA (and thus the S-TOFHLA) are taken from reading material that an average person is likely to see during a medical encounter, including Medicare’s Rights and Responsibilities and instructions for an Upper GI series (Baker et al., 2004). Internal consistency via Cronbach’s alpha for the four numeracy items is 0.68, for the reading comprehension items is
0.97, correlation between the two section is 0.60 (Parker et al., 1995). The entire S-TOFHLA (0.80, p<0.001) and both the reading (0.81, p<0.001) and numeracy subscales (0.61, p<0.001) were compared to the REALM (Parker et al., 1995).

The S-TOFHLA is available in Spanish and can be administered on paper or via electronic means (Aguirre et al., 2005; Chesser et al., 2014, McLeod-Sordjan, 2011). The reading portion of the longer TOFHLA is valid in adolescents as well as adults (Chisolm & Buchanan, 2007). There are also Korean language and Hebrew language instruments based on the TOFHLA, however, major changes were made to the instruments to make them more culturally relevant, so results are not comparable across cultures (Baron-Epel et al., 2007; Lee et al., 2009). Smith and Samar (2016) translated the instructions of the S-TOFHLA into ASL, however, they administered the actual instrument in English stating that since the instrument was so heavily dependent upon reading comprehension, if translated into ASL it would no longer measure functional health literacy.

The Newest Vital Sign (NVS) measures both reading comprehension and numeric comprehension, using a nutrition label from a container of ice cream (Weiss et al., 2005). The NVS can be administered in less than three minutes and is appropriate for routine screening in a clinical setting (Weiss et al., 2005). Recently, McKee et al., (2015) described the translation of the NVS into ASL. This is the first and only valid and reliable instrument to measure health literacy available in ASL (McKee et al., 2015).
McKee et al. (2015) recruited 239 hearing English speakers and 166 Deaf ASL users (n=405) from the Rochester area between January 2012 and September 2013. The authors correlate the ASL-NVS with the PIAT-R, instead of other current measures of health literacy, because other measures are unsuitable in a Deaf population; the REALM is pronunciation based and the TOFHL is too heavily based on reading comprehension (McKee et al., 2015). The PIAT-R has participants point to the picture which best describe the sentence and is thus non-threatening and can be useful for those with limited literacy (McKee et al., 2015). The Spearman correlation was between the PIAT-R the ASL-NVS in the Deaf group (r=0.64; p<0.01) and the NVS (r=0.67; p<0.01) (McKee et al., 2015). Test-re-test analysis was also conducted to assess reliability with seven Deaf participants after one month (0.84; p=0.02) (McKee et al., 2015).

As stated previously, the World Health Organization defines health literacy 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" (Nielsen-Bohlman et al., 2004, p. 2). A primary weakness of the available instruments is that they do not measure the full breadth of the dimensions of health literacy. Most of the current measures use a person’s ability to read and/or calculate as a proxy for health literacy. While that can provide insight into a person’s capacity to obtain (and perhaps understand health information) it may not measure all dimensions of the concept.
There is no consistent definition of health literacy used in the literature. The Institute of Medicine defines health literacy 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,” this is the definition that will be used in this study (Nielsen-Bohlman et al., 2004, p. 2). Based on this definition, it is clear that health literacy is more than just the ability to read. Health literacy is needed for virtually every aspect of navigating the health care system from reading health information to calculating medication dosage to voting on health issues (Nielsen-Bohlman et al., 2004). Nielsen-Bohlman et al. (2004) reporting for the Institute of Medicine clarify that a person’s capacity “refers to both the innate potential of the individual, as well as his or her skills” and is affected by that person’s education, culture, language and the setting (p. 32). Other definitions have specified aspects of health literacy such as the ability to use technology, motivation, networking and social skills in addition to literacy and numeracy (Nutbeam 2008; Bernhardt et al., 2005). The Institute of Medicine states that culture, society, the educational system, the healthcare system and the individual can all have an impact on health literacy (Nielsen-Bohlman et al., 2004).

Health numeracy is probably the most commonly included concept to be added to the definition of health literacy. While there is no standard definition of health numeracy, the Center for Disease Control and Prevention (CDC) defines numeracy as the “ability to access, use interpret, and communicate mathematical ideas, to engage in and manage mathematical demands of a range of situations
in adult life” (CDC:Health Literacy, 2016). Rothman, et al. (2008) did a critical review of the current state of health numeracy based on the current literature and their own experience. The authors found that although health literacy and health numeracy were related, some clients who had adequate health literacy still were lacking in health numeracy skills (Rothman et al., 2008). Health numeracy encompasses skills such as calculating the dosage of a medication, following directions on an appointment slip and calculating calories (Rothman et al., 2008). Rothman et al. (2005) found that even participants with adequate literacy skills had difficulty with numeracy tasks when trying to interpret a food label.

Since health numeracy is infrequently measured as a separate concept, it is still unclear the exact impact it has on a person’s health outcomes. One study that did separate the two concepts investigated the impact of health literacy and health numeracy on the use of patient portal technology. Taha et al. (2014) examined the ability of a sample of 51 adults from the Miami area to perform health management tasks. The sample had a disproportionately high health literacy scores (86% scored adequate on the TOFHLA), yet 52.9% could not answer the majority of numeracy of questions question (Taha et al., 2014). Internet experience and health numeracy scores were significantly related to successfully completing tasks on a simulated patient portal (Taha et al., 2014).

The proposed ethnographic study will provide a rich description of health literacy in the context of Deaf culture. Thus, it will expand our understanding of the multiple dimensions of the phenomenon from the perspective of someone in the Deaf community, not simply their ability to read English.
**Health Literacy in the deaf**

Little research has previously been done on health literacy in persons who are culturally Deaf, however, there are a few notable exceptions. Pollard and Barnett (2009) used a modified version of the REALM to look at knowledge of health-related vocabulary in 57 adults recruited as part of a larger “health screening activity” during a Deaf event. All participants self-identified as Deaf (rather than Hard-of-Hearing or Hearing) (Pollard & Barnett, 2009). Rather than asking participants to pronounce words, the authors asked participants to indicate whether or not they understood a word by crossing out any words they did not know the meaning of, and circling words they could define (Pollard & Barnett, 2009). The investigators found that even though the sample was highly educated, over one-third missed sufficient words to suggest a reading level below ninth grade (Pollard & Barnett, 2009). Also, the pattern of missed words was different than what would be expected in a hearing, English speaking sample (compared to the standardized norms for the instrument) (Pollard & Barnett, 2009). The authors did not offer an explanation for why the Deaf sample had difficulty with different words than those expected in a hearing population, but the authors did point out that this may put someone who is Deaf at even more risk for health consequences related to low health literacy (Pollard & Barnett, 2009).

A similar pattern was found in members of the Amish community in eastern Ohio (Holmes and Tuscarawas counties) (Katz et al., 2013). The authors compared REALM scores for Amish (n=143) and non-Amish (n=154)
males and females (Katz et al., 2013). In both males and females, the Amish group had lower scores (p<0.001), moreover, members of the Amish community had the most difficulty pronouncing words at the beginning of the REALM, despite the fact that the REALM was designed to have the words that are easiest to pronounce at the beginning (Davis et al., 1991; Katz et al., 2013). The Amish community can also be considered a cultural and linguistic minority since English is often their second language (Katz et al., 2013).

Singleton et al. (2004) found that elementary school children with different signing ability showed patterns of word use in their writing that was different from hearing single language students and hearing English as a Second Language (ESL) students. The authors examined the word usage of 72 deaf students with various levels of ASL proficiency (20 low skill, 20 moderate skill and 32 high skill) and compared them to 60 hearing ESL speakers, and 61 hearing monolingual English speakers (Singleton et al., 2004). The ESL students were all from different languages (Singleton et al., 2004). All deaf students wrote significantly fewer words than any of the hearing students (Singleton et al., 2004). Also, those students who were highly skilled or moderately skilled in ASL showed unique word use that was similar to monolingual English speakers, while those students with low ASL skills had significantly worse unique word use than ESL students (Singleton et al., 2004). Both ESL and English monolingual speakers had similar use of function words, but ASL users of all levels used function words less frequently (Singleton et al., 2004).
No studies were found that specifically address word use in Deaf adults. McKee et al. (2015) and Zazove et al. (2013) both reported a 6th grade reading level in adult Deaf participants. Traxler et al. (2014) compared comprehension of complex sentences across three groups: Deaf (n=68), hearing English speaking (n=31), and hearing bilingual (ESL) (n=34). The Deaf group was subdivided into native signers (those who had been signing from birth) (n=22), early signer (those who learned ASL prior to puberty) (n=24) and late signers (those who learned ASL after puberty) (n=22). The authors found that the group of Deaf persons had the least accuracy on the whole, however, those in the sample who were native ASL users had the greatest accuracy in the group of signers (lower than the hearing monolingual group, but comparable to the hearing bilingual group) (Traxler et al., 2014). Also, Deaf adults had an easier time reading sentences with a passive voice than hearing readers (Traxler et al., 2014).

Kelly et al. (2001) looked at reading comprehension in 46 deaf college students in Rochester, New York. All students that were recruited had already had their reading ability tested via a standardized test as part of an English development course in which they were enrolled (Kelly et al., 2001). The authors found that regardless of scores on the reading ability tests, these students had difficulty writing the answers to reading comprehension questions (Kelly et al., 2001). However, students who tested as having a higher reading ability were able, using ASL, to explain the passage they read (Kelly et al., 2001). The small sample size makes it difficult to draw definitive conclusions, but it adds to the
evidence that suggests Deaf persons have a lower literacy level than the general hearing population.

Kushalnagar, Ryan et al. (2018) also examined health literacy in college students, but that study looked at critical health literacy. The authors investigate the relationship between critical health literacy and with whom the person discusses health information in ASL using college students (n=38) compared with a control group of hearing students (n=38) (Kushalnagar, Ryan et al., 2018). A computer-based survey in English and ASL and responses to video, which were scored according to a rubric were used (Kushalnagar, Ryan et al., 2018). The authors found that functional health literacy and critical health literacy were not correlated, however, 95% of the sample had adequate health literacy, this is atypical in the Deaf community (Kushalnagar, Ryan et al., 2018). Additionally, health related discussion with friends was related to critical health literacy, but discussions with family were not (Kushalnagar, Ryan et al., 2018). The authors speculate that social groups may be more important sources of information than family (Kushalnagar, Ryan et al., 2018).

In summary, the limited literacy research on Deaf community members suggests that there are differences between those that are culturally Deaf and the hearing majority, in how they obtain health information and how they process this information. Low health literacy may be one explanation for the high risk for health disparities experienced by Deaf persons. The qualitative study proposed here will provide insight into how the Deaf Community obtains process and uses
health information and can serve as the basis for targeted interventions to increase health literacy in the Deaf community.

**Health Literacy in Cultural Minorities**

Shaw et al. (2009) state that an understanding of health literacy that neglects cultural beliefs is necessarily limited. The National Network of Libraries of Medicine (NNLM) acknowledges that while culture is only a piece of health literacy, health literacy is affected by “belief systems, communication styles, and understanding and response to health information” which are basic components of culture (NNLM, 2014, para.3). Lower health literacy scores have been found in ethnic minorities when compared to Caucasians. In addition to the NAAL scores already discussed above, Myaskovsky et al. (2011) found lower health literacy scores, as measured by the REALM-SF, in African Americans compared to the Caucasians in a sample of participants with spinal cord injury.

The Institute of Medicine report *Health Literacy: A Prescription to End Confusion* states that health literacy requires understanding between all parties involved in a person’s health care, including the person’s health care providers (Nielsen-Bohlman, et al., 2004). The level of health literacy will be affected if there are language barriers (e.g., ASL vs. English) or misunderstanding between the patient and the provider. Several studies have focused on communication problems between clients and health care providers.

Diaz and Allchin (2013) reviewed the importance of having appropriate communication and concluded that language barriers, cultural barriers and low health literacy could all affect good client-provider communication. The authors
did not do original research but summarized the positions of the Joint Commission’s National Patient Safety Goals (Diaz & Allchin, 2013).

Doty and Ives (2002) and Doty (2003) reported findings from the Commonwealth Fund 2001 Health Care Quality Survey in Hispanics. The authors found a number of differences between Hispanics’ and Caucasians’ approaches to health care, including reporting difficulty communicating with health care providers (Doty, 2003; Doty & Ives, 2002). The Commonwealth Fund 2001 Health Care Quality Survey was conducted from April to November 2001 via telephone survey (Doty, 2003; Doty & Ives, 2002). The final sample (n=6722) was weighted to accurately represent the adult US population using Census data (Doty, 2003; Doty & Ives, 2002). Doty and Ives (2002) and Doty (2003) look just at those classified as Hispanic (instead of non-Hispanic white, African American, or Asian). Hispanic was further broken down based on language: primarily spoke English (n=691) and primarily spoke Spanish (n=387) (Doty, 2003). Doty (2003) focuses primarily on the implications of lack of insurance coverage in the sample. While the authors do not explicitly discuss health literacy, many of the issues they do discuss, such as lack of education and lack of access, have been shown to be related to health literacy (Doty, 2003; Doty & Ives, 2002).

Similarly, Sudore et al., (2009) compared physician-patient dyads who had the same language with those whose primary language differed. The authors used data collected from baseline interviews from three previous studies at two different San Francisco area hospitals (Sudore et al., 2009). The same three questions were asked from the Interpersonal Processes of Care (IPC) instrument
to assess communication with healthcare providers and health literacy was assessed via the TOFHL and the TOFHL-S (Sudore et al., 2009). The IPC is a valid and reliable instrument, however, limited data is provided regarding the specific question used from the instrument to assess communication with health care providers (Sudore et al., 2009).

The authors found that language barriers likely magnified the effects of low health literacy (Sudore et al., 2009). Poor communication was present even when interpreters were regularly used or when providers and patients spoke the same language (Sudore et al., 2009). In their sample (n=771), 53% were English-speaking with an English-speaking provider, 23% were Spanish-Speaking with a Spanish-speaking provider and 24% were Spanish speaking with an English-speaking provider (Sudore et al., 2009). In bivariate analysis, the authors found those with limited health literacy and language discordance were most likely to have poor communication (p<0.001).

Zanchetta and Poureslami (2006) summarized the findings of the Second Canadian Conference on Literacy and Health, looking specifically at newcomers to Canada. This article presents a review of other presented research, specifically focusing on newcomers to Canada, not original work. One of the findings that the authors report is that “some immigrants express discomfort discussing traditional practices with health care providers” thus creating a possible breakdown in communication (Zanchetta & Poureslami, 2006, p.527).

Another possible cause of communication issues between healthcare providers and members of the minority communities may stem from a lack of
trust. Both, Boulware et al. (2003) and Hausmann et al. (2013) found that non-Hispanic African American respondents (n=49 and n=127, respectively) were less likely to trust their physicians than non-Hispanic Caucasians (n=69 and n=303, respectively). Armstrong et al. (2007) similarly found higher levels of distrust among African Americans and Hispanic members of their sample, but found that socioeconomics and environment also played a role in physician trust. For example, in one of the cities included in their sample, African Americans of a higher socioeconomic status (as measured by educational attainment, insurance coverage and household income) had higher levels of trust than their Caucasian counterparts, but the opposite was true in those of lower socio-economic status (Armstrong et al., 2007).

While lack of trust is not a part of the definition of health literacy, having a trusting relationship can impact whether or not persons are likely to utilize the information presented by their health care providers. While evidence on this subject is scant, there is some evidence to suggest that Deaf persons also have a lack of trust towards their health care providers (Alexander et al., 2012; Steinberg et al., 1998; Steinberg et al., 2002).

Steinberg et al. (1998) conducted 54 individual and group semi-structured interviews with adults (ages 18-78) who used ASL as their main form of communication regarding their beliefs about mental illness. Interviews consisted of questions about knowledge, beliefs, and attitudes about mental health issues and services, as well as demographics and family background (Steinberg et al., 1998). The authors found that many of those interviewed had a negative
impression of those providing mental health services and felt that they would be
discriminated against (Steinberg et al., 1998). There was also the view that Deaf
persons were powerless within the mental health system (Steinberg et al., 1998).
Unfortunately, no information is given about the trustworthiness of this study.
The authors have few direct quotes from participants, and no information about
how they determined if the themes they obtained were accurate (Steinberg et al.,
1998).

Steinberg et al. (2002) used focus groups to interview 45 women who self-
identified as Deaf. Each focus group had 4-8 women and lasted approximately 2
hours (Steinberg et al., 2002). Participants were recruited from a meeting of
Deaf Women United (DWU) in Rochester, New York and an annual meeting of a
state association for the Deaf (Steinberg et al., 2002). The authors are aware
that the participants are not representative of Deaf persons in the area.

Participants report being confused and fearful of healthcare encounters
and thus avoiding these encounters (Steinberg et al., 2002). Health care
providers that accommodated the individual’s communication needs engendered
more trust and made the person feel more comfortable (Steinberg et al., 2002).
The difficulties faced by women in this sample are even more daunting, when
you consider that the women in the sample are more educated and more likely to
have insurance than average in the Deaf Community (Steinberg et al., 2002).
Steinberg et al. (2002) discuss how members of the community are involved in
every stage of the study and detailed their methodology for the reader.
Alexander et al. (2012) wrote a commentary focusing on the communication issues Deaf persons often face in the United Kingdom (UK). While lack of trust was not the main thrust of the article, the authors do point out that 30% of British Sign Language (BSL) users avoided going to their primary doctor rather than deal with the health care system (Alexander et al., 2012).

Higher health literacy has been associated with better health outcomes in other minority groups. For example, Brega et al. (2012) examined health literacy in 2,594 diabetic Native Americans and Alaskan Natives from 138 tribes in 13 different states. They found that higher health literacy was related to better health outcomes (better glycemic control), and health knowledge mediated the relationship between health literacy and behavior (Brega et al., 2012). It should be noted that in this study, health literacy was measured using seven items taken from three different questionnaires. Reliability and validity were not addressed directly, however the authors stated that items used were “…shown to accurately identify patients with inadequate Health Literacy” (Brega et al., 2020, p. 62).

The effect of culture on health literacy is not limited to those with a language barrier. Doty (2003), and Doty and Ives (2002) found that while those of Hispanic origin who spoke primarily Spanish had the worst outcomes, even those who spoke primarily English had poorer health outcomes than those of Caucasian origin. The authors did not ask about each participant’s first language, but divided participants based on comfort level with the language and which language was primarily spoken at home (Doty, 2003).
Sentell et al. (2011) conducted a secondary analysis of the Hawaii Health Survey (HHS) in which they examined health literacy in 5,399 Asian American and Native Hawaiian adults (>18 years old). The HHS is a population-based telephone survey conducted in English, random households were called from all islands in Hawaii to gain a sample (Sentell et al., 2011). Four percent of those contacted were excluded for not being able to speak English well enough to complete the survey (Sentell et al., 2011). Asian Americans were divided into Japanese (n=1201), Native Hawaiian (n=810), Filipino (n=731), and other Asian American/Pacific Islanders (n=380) (Sentell et al., 2011). Information was also collected on White non-Asians (n=2277) for comparison purposes (Sentell et al., 2011). Sentell et al. (2011) treated each sub-group of Asian American/Pacific Islanders as a distinct cultural group and concluded that these different cultural groups had different health literacy levels and different health needs.

The authors used a single item screener, “How confident are you in filling out medical forms by yourself?” to screen for health literacy (Sentell et al., 2011). While the authors claimed that the one question had been validated against both the REALM and the TOFHLA, an overwhelming percentage of their sample had adequate health literacy. A more diverse sample would lend confidence to the claim that this question correlates well with validated instruments (Chew et al., 2004; Sentell et al., 2011). The measure the authors use was validated between 2001 and 2002 in a sample of patients from a VA clinic in Seattle (Chew et al., 2004). In that sample, the majority of respondents had adequate health literacy (88%) (Chew et al., 2004). Similarly, in this sample only 16.7% of those sampled
had low health literacy (Sentell et al., 2011). Validation of the question used in a sample with a wider variation in health literacy levels would yield greater confidence in the results.

Weekes (2012) conducted a systematic review of the literature of health literacy in African Americans, all using TOFHLA, TOFHLA-SF, REALM or the NVS. In the 23 studies she examined, the author found that lower health literacy scores influenced understanding of a number of areas including informed consents, perceived susceptibility to disease, and adherence to medical protocols (Weekes, 2012).

In summary, studies have shown lower health literacy associated with cultural minority groups is complex and has a number of associated factors, but culture must be taken into account when studying health literacy.

**Health Literacy in Language Minorities**

Although linguistic minority and cultural minority groups are not mutually exclusive, both groups have been shown to have low health literacy scores. Consequently, both linguistic minority and cultural minority factors are believed to play a role in health literacy.

Koskan et al. (2010) conducted a systematic review of health literacy in Hispanic adults. Across studies, they found lower levels of health literacy in Hispanic persons that spoke either English or Spanish, with the lowest levels in those that spoke Spanish (Koskan et al., 2010).

As stated above, Doty (2003) looked at English proficiency and insurance coverage in a large diverse sample of Hispanic adults that included both those
whose primary language is English or Spanish. She found that those without health insurance who had limited English proficiency had the highest risk for having poor communication with their health care providers. English-speaking Hispanics with health insurance reported communication problems similar to those of African Americans and Caucasians (Doty, 2003). These findings suggest that other limited English groups (such as Deaf persons) may have similar difficulties communicating with health care providers.

Deaf persons tend to define themselves as a linguistic and cultural minority rather than a disability group (Padden & Humphries, 2006). One would expect them to have similar difficulties obtaining, processing, and understanding basic health information as other ethnic or linguistic minorities. The NIH’s report “A Prescription to End Confusion” recognizes the importance of culture in several different aspects of health literacy, including communication, health beliefs, and lifestyle changes (Nielsen-Bohlman et al., 2004). While we can infer that Deaf persons would have both communication issues and issues stemming from their history interacting with the hearing world, an ethnographic study on health literacy that focuses on members of the Deaf culture would give us greater insight into this community. At this point, we do not know how similar or dissimilar Deaf persons are to other cultural and linguistic minority groups.

**Research Question**

The research question that this study aims to consider is: How does someone who is Deaf obtain, process and understand basic health information and use that information to make appropriate health decisions?
Chapter 3 - Methods

In Support of Methods

Ethnography is defined as “the study and systematic recording of human cultures or the product of such research” (Merriam-Webster, 2016). Levi-Strauss (1963) expands on this definition by stating “Ethnography consists of the observation and analysis of human groups considered as individual entities. Ethnography thus aims at recording as accurately as possible the respective modes of life of various groups” (p. 2). In short, ethnographies describe a person’s experiences within that person’s cultural context.

Ethnography has its origins in Anthropology but is currently used in many social sciences and is thought of as useful for “getting under the skin” of the target population (Anderson, 2009). It is considered a qualitative philosophy and is seen as learning from people rather than merely learning about them. In doing an ethnography, one wants to understand something from the perspective of “the people under study” (Lopez-Dicastillo & Belintxon, 2014). Ethnographies can be used to answer a variety of questions, from very broad questions about an entire culture or subculture to very specific questions about a smaller group within a culture (Fetterman, 2010).

Culture affects a person’s health in many ways. According to the NIH report “A Prescription to End Confusion” a conceptual understanding of the interconnections between culture and literacy through the idea of cultural literacy can provide insights into the deeper meanings of how diverse populations in the United States come to know, comprehend, and make informed decisions based
on valid data regarding their health (Nielsen-Bohlman et al., 2004). In short, culture affects someone’s ability to obtain, process and understand basic health information and services, which is the definition of health literacy (Nielsen-Bohlman et al., 2004).

As discussed previously, most Deaf persons who use American Sign Language as their primary means of communication, consider Deafness a culture, not a medical condition. Thus, looking at health literacy of the Deaf through ethnography is appropriate because it keeps their culture central.

**Ethnographic Methods**

**Sampling.** In qualitative research, unlike quantitative research, participants are chosen based on who can provide the best information to answer the research question and enhance our understanding of the topic under study (Sargeant, 2012). Morse (1991) describes purposeful sampling as when the researcher first chooses to “interview informants with a broad general knowledge of the topic. . . then as the study progresses, the description is expanded with more specific information and participants with particular knowledge are sought (p. 129).” This is done to include a broad range of variation of the phenomenon under study (Coyne, 1997). This is what was be done in this study.

Purposeful sampling was combined with snowball sampling. Snowball sampling is often used in populations that are difficult to access or that are in some way marginalized (Crossman, 2018). The idea of snowball sampling is that like a snowball rolling downhill picks up more snow, a study can start with a small number of participants and slowly pick up more participants (Given, 2008).
This researcher began learning sign language in high school but did not start learning ASL until after graduating from college. This researcher’s first ASL teacher was Deaf and first introduced her to other Deaf persons. This researcher started regularly attending Deaf events, and it is known that this researcher is a PhD student interested in health in the Deaf community. Prior to beginning the research, Deaf persons were excited about this work and many had expressed an interest in assisting this researcher in any way possible.

Because this researcher had connections in the Deaf community, it was possible to purposefully select two or three persons who are representative and communicated well about their experiences for the initial interviews. After this, those participants who have completed the interviews and have first-hand experience about the process, were asked if they can recommend one to three other members of the community who might be willing to participate. Those who agreed were given a recruitment flyer with this investigator’s contact information and a brief explanation of the study (See amendment B).

Towards the end of the study, particular attention was paid to those who might have differing opinions. Therefore, later in the study it was also be asked, “Can you think of someone who might have a different experience with health and health care than you, and who might be interested in participating in the interviews?” In this way, a broad range of perspectives was captured.

Also, this researcher already belonged to several Facebook groups that focused on the Deaf community in New Jersey: NJ Deaf, ASL Social Club of NJ, ASL Signers of NWNJ, New Jersey Association of the Deaf, and Deaf Night Out-
New Jersey. Initially, this researcher approached established contacts in the Deaf community about participating in interviews, and posted on these Facebook groups in order to recruit participants. These initial interviews provided a broad understanding of health literacy in the Deaf community based on first-hand knowledge. This was done because the Deaf community is diverse, and there may be some parts of the community that have a different experience, so every effort was taken to see what is common to the Deaf community and what variations exist.

To identify potential variations in experiences and perspectives, this researcher sought out local meetings of the Rainbow Alliance of the Deaf and New Jersey Black Deaf Advocates, in order to give members of these diverse organizations an opportunity to participate. Again, this was done to ensure that all members of the community have the opportunity to participate. Inclusion criteria were adults (over the age of 18) who self-identify as Deaf. Given the variation within the Deaf community, self-identification was the best way to gain the fullest understanding of how Deaf persons actually understand health literacy.

Since sufficient participants could not be recruited using purposeful sampling, snowball sampling and recruiting on multiple websites, recommendations were sought from local interpreters. ASL interpreters are cultural brokers in the Deaf community and may have access in areas this researcher does not.
Informed consent. Informed consent was obtained from each participant, with all consent information in both ASL and written English. Written English informed consents were written in plain language at approximately 7th grade level, according to the Flesch-Kincaid readability scale integrated into Word 2013. Once the written English informed consent was approved by the institutional review board at Rutgers University, it was translated into American Sign Language and Video Recorded. The video was closed captioned. This was done so that each participant received the same information during the consent process in whichever communication method they prefer.

In order to translate the consent form, a translation-back translation process was employed. First, an ASL GLOSS was written based on the written informed consent in coordination with a member of the Deaf community to ensure the consent is culturally correct. Since ASL has no written form, a GLOSS is the written version of which signs will be used in the correct grammatical structure for ASL. For example, a GLOSS representation of “Do you want to go to the movies?” would be YOU MOVIE GO?

Then, someone who is bilingual in English and ASL signed a first draft of the consent based on the GLOSS. This draft was back translated into English by someone different who is bilingual in English and ASL. Differences in translation were discussed as a group with the primary investigator, original translator and back translator until agreement was reached on an acceptable translation. This process continued through as many drafts as necessary until there were no discrepancies. The final video recording was also closed captioned.
Consenting was done by the primary investigator immediately prior to the interviews. Participants had the opportunity to ask any questions prior to beginning the interviews and were assured that the interviews could stop at any point and that all information is confidential. They were also given the opportunity to take the consent and the DVD of the consent home to review and ask advice of friends and family if they wish to do so prior to consenting to the interview.

IRB approval was obtained prior to beginning the study.

**Interviews.** It can be argued that the interview is the ethnographers most important data gathering technique (Fetterman, 2010). Heyl (2001) defines ethnographic interviewing as a method where there is an ongoing respectful relationship between interviewer and interviewee characterized by genuine exchange of ideas that elicit the meaning the person makes about the world around them. Interviews should be comprehensive and long enough to adequately elicit the interviewee’s perspective about the topic under investigation (Ortiz, 2003). Ethnographic interviews can be formal or informal and can take place at any point in the study, however, the ideal time is after the investigator has a good working knowledge of the fundamentals of the community (Fetterman, 2010). In an ethnographic interview, the interviewer takes the role of learner and the informant or participant takes the role of teacher (Spradley, 1979/2016).

In the study reported here, semi-structured interviews were conducted with select persons who consider themselves culturally Deaf in order to
investigate health literacy from their perspective. Interviews took place in northern New Jersey at a place of the participant’s convenience. Privacy was ensured at each location. Chairs were arranged in a triangle with a video camera behind this investigator, so that the signing from both the participants and the interpreters could be captured.

All interviews were conducted in ASL and were voice interpreted. In ASL non-manual features affect the meaning of a sign (Valli, 2005). For example, the same sequence of signs can change the meaning by emphasizing different signs: HOME YOU, can either be a question (are you going home?), a statement (you are home) or an imperative (go home!) (Valli, 2005). Therefore, all interviews will be videotaped in order to catch nuances of the language.

Even though this researcher is conversational in ASL, it is important that qualified interpreters were also involved in the interviews. Sign language interpreters are often cultural brokers in the Deaf community of interest. Also, while this researcher is conversational, there were nuances of the language that may have been missed by this researcher. Primarily certified interpreters were approached to participate in the study. The initial interpreters approached were those with whom this investigator had formed a relationship over previous years. Recommendations were taken for other experienced and qualified interpreters. All interpreters were Human Subjects Certified. Two interpreters were used for each interview so they can switch off during the interview.

Sheppard (2011) recommends conducting sample interviews when working with interpreters. She states that it helped not only facilitate everyone
becoming familiar with the research process and identify potential problems, but assisted in assuring the interview questions were culturally relevant (Sheppard, 2011).

In New Jersey, interpreters typically charge a minimum of $50-$70 per person per hour, with more experienced interpreters capable of charging more. Since the interpreters used in this study will all have multiple years of experience and were certified, they can demand a higher rate. Interpreters were paid $50 per hour for the human subjects training once the training had been completed and $75 per hour for each interview.

Interviews were video recorded. Since ASL is a visual language, video recording provided more useful information than simply audio recording interviews. The video camera was set up in such a way that the participant and the interpreter are captured on the recording. The participant, researcher, and interpreter were seated in a triangle for each interview. This researcher’s feelings and impressions were recorded in a field journal following each interview. If any participant had refused video recording, the option of audio recording would have been offered, if that was also refused, one of the interpreters will be asked to transcribe the interviews. The video camera was tested prior to the first interview to ensure it is sufficiently high quality to see both signing and the facial expressions by recording the teacher of a sign language class.

A trial interview was conducted prior to the start of the study, both to ensure that the interviews were culturally competent and to make sure that the
interpreters understand the interview process and are able to ask any questions they might have prior to the start of the study. At the end of each interview participants were asked if they could be contacted again one more time for a follow-up interview at a later date to validate themes that were emerging from the interviews.

An interview guide was created based on the research question. Interviews were scheduled based upon participants’ and interpreters’ schedules.

**Participant observation.** Participant observation is a key to any good ethnography. The ethnographer must become involved and immersed in the culture (Fetterman, 2010). Participant observation is defined as “a technique of field research by which an investigator studies the life of a group by sharing in its activities” (Fetterman, 2010, p. 37).

As part of the process of learning ASL, and becoming acquainted with the Deaf community, this researcher has been going to Deaf Coffee Chats for many years. Deaf Coffee Chats are any of multiple social events that take place at a café, coffee shop, bookshop or anywhere else you can buy food and drinks (deafcoffee.com, 2019). It is open to anyone who is Deaf or Hard of Hearing (HOH) as well as sign language students and anyone involved in the larger Deaf Community of Interest. The number of sign language students who attend these events often vary widely based on the time of year and the requirements of the individual teachers in the area. This researcher has used the opportunities these events provided to build relationships within the community, as well as improve
her own skills in ASL. Typically, these events take place once a month, and this researcher has attended regularly.

ASL Slams can be thought of as Deaf open mic nights. According to their website, “ASL Slam is a monthly event that offers the stage to audience members to come up and rap, rhapsodize and rehash or just relate in sign language (www.aslslam.com, 2019).” Monthly ASL Slams take place in New York City, Boston, Chicago, and Orlando, as well as tours currently taking place in Australia and Norway (www.aslslam.com, 2019). In ASL Slams, this researcher mostly observed the performances, but also used every opportunity to make contact with Deaf persons and establish herself as a part of the wider community of interest. Also, something like an ASL slam is a great opportunity to see ASL used differently than in a more conversational setting.

For this study, the investigator continued to take part in local Deaf events, such as Deaf Coffee Chat and ASL Slam NYC as a participant observer. These events provided opportunities for Deaf persons of interest (both Deaf and Hearing) to interact. These events were advertised and typically held in a public venue, so anyone with an interest in sign language could attend. In addition to attending as many Deaf events as possible, the investigator made every effort to attend events that she was invited to by Deaf persons. Specific note was made of any health-related conversations that took place during the night, anything that might impact what the primary investigator was seeing during the interviews. These conversations will be noted in the primary investigator’s reflexive journal.
In the past this researcher’s participation in Deaf events has been centered around learning the language and building relationships. This researcher’s area of interest was well known among people who attended the local Deaf Coffee Chat and supported by most Deaf persons who attended these events, because the time was taken over a period of time to assure people that I was interested in them and was not using the community for my own gain. During Deaf chat a wide variety of topics were covered in conversation, including conversations about a person’s health. For example, at a recent chat a long conversation surrounding atrial fibrillation took place. These conversations will be taken note of in the primary investigator’s reflexive journal.

According to Fetterman (2010), participant observation requires “close, long-term contact with the people under study” (p. 39). Having already spent years attending Deaf events and becoming a part of the Deaf community of interest, less time will be required for participants who are culturally Deaf to become accustomed to this investigator.

**Description of the Setting**

Participant observation took place in a public setting where members of the Deaf community of interest gather, and at events to which the investigator had been invited. For example, a Deaf Coffee Chat takes place once a month at a local coffee shop. People can come and go freely, everyone “talks” (in sign language) with everyone, and it is generally ASL students’ first experience with Deaf culture. Deaf events attended were located in New Jersey or New York City.
In addition to participant observation, during the same time period interviews were conducted with persons who consider themselves culturally Deaf, in a private room away from other Deaf persons. Privacy is a concern for the Deaf community since it is such a small community, therefore privacy was maintained, and assurances of confidentiality were provided (as described below under protection of human subjects) (Piper & Holland, 2008). Interpreters were employed for the interviews, even though this investigator is familiar with ASL, in order to provide assurances of a correct understanding of each participant’s responses. Therefore, each interview was individually evaluated in order to maintain a balance between confidentiality and getting the most out of each interview. This was done as an ongoing process during each interview. Each participant was assured of confidentiality and informed that only the research team will know who is participating in the research study and have access to any data. Any concerns about confidentiality were addressed, and participants were assured that they can stop the interview at any time or have their data removed from the analysis process at any point prior to publication.

**Characteristics of the Participants**

Persons who define themselves as culturally Deaf were invited to participate in one-on-one interviews. There is great diversity in the Deaf community, regarding signing ability as well as race, gender, education and sexual orientation (PBS, 2007). In order to include as much diversity as possible from the Deaf community, self-identification is the only inclusion criteria.
Members of the community who are Deaf-Blind were excluded from this study because as a specific subgroup of the Deaf community they have a specific set of needs.

**Protection of Human Subjects**

As stated above, privacy and confidentiality are concerns in the Deaf community. The Deaf community tends to be very small and interconnected (Sheppard, 2011). Plus, there is an inherent distrust of the medical/research community based on deafness historically being treated as a medical condition that needed to be cured, and sign language being denied as an acceptable means of communication (Boness, 2016). The fact that this investigator uses sign language and has been active in the Deaf community for many years was used to build credibility with the Deaf community and with the Deaf community of interest as possible gatekeepers (including family, friends and interpreters).

Only members of the research team had access to the original video tapes. When transcribed, all participants were assigned a random number and no identifiable information was used in the transcripts. All information, including the videotapes, transcripts, and field notes were kept in a secure and locked location separate from any identifiable information.

**Data Analysis**

In ethnography, data analysis is an ongoing process that begins as soon as the investigator selects a problem (Fetterman, 2010). Data analysis is iterative, with ideas building on one another as they emerge during the study (Fetterman, 2010). Data analysis began immediately after the first interview was
completed and continued through the end of data collection. There are multiple techniques that can be used throughout the study.

Data analysis can be deductive or inductive (Burnard et al., 2008; Nigatu, 2009; Stuckey, 2015). In deductive data analysis (also known as preset theme analysis) the researcher already has some idea of the themes he or she expects to find in the data based upon previous work or the literature (Burnard et al., 2008; Nigatu, 2009, Stuckey, 2015, Taylor-Powell & Renner, 2003). Deductive data analysis is best when the qualitative research is a smaller part of a larger research study (Burnard et al, 2008; Nigatu, 2009). In inductive data analysis (also known as emergent theme analysis), themes are defined as a result of working with the data (Burnard et al., 2008; Nigatu, 2009, Taylor-Powell & Renner, 2003). Inductive data analysis is best when qualitative research is the major component of the study (Nigatu, 2009). In inductive data analysis themes emerge from the raw data, the researcher does not start with any preconceived notion of what the themes will be (Taylor-Powell & Renner, 2003).

While the literature review suggested some themes that might occur during the study, this study was primarily focused on inductive reasoning, since little is known about how Deaf persons view aspects of health literacy. An inductive approach to data analysis allowed for more flexibility as the study progressed. The video tape of each interview was watched twice to better understand the data.

After gaining an understanding of the data from viewing the video tapes, interviews were transcribed verbatim. This took place as soon as possible after
the interview, with every effort being made to begin to transcribe the interview the same day. Transcripts were based on the verbal translation of the interpreters during the interviews, however, transcripts were checked against the original signs by an interpreter who is already involved in the study, but was not involved in that particular interview. A short segment of the video was sent to the interpreter (approximately 5 minutes) with the transcription. If there were discrepancies, the entire video was reviewed by the primary investigator.

Verbatim transcripts were transferred into Nvivo © data analysis software package, which is available at Rutgers Office of Information Technology for download.

Transcripts were read through to identify themes. On the first read through, a short descriptive statement was written next to each pertinent group of phrases. Short descriptive phrases could start to be written on the first reading of the transcript, because the primary investigator had watched the videos multiple times to become familiar with the raw data.

On the next reading, the data was searched through to verify or disqualify the themes that were found (Burnard et al., 2008). On subsequent readings of the transcript, themes were organized. Depending on what themes emerge during the first reading, some themes were combined into larger categories, while other themes were compared based on the importance of the themes or how themes were related (Taylor-Powell & Renner, 2003). Data were read and re-read in order to identify themes in a “constant search for meaning and understanding.” (Burnard et al., 2008)
Data analysis began immediately after the first interview was completed and continued until the primary investigator saw no new themes when analyzing the interviews. Burnard et al. (2008) state that analysis may inform subsequent data collection. In this study, the possibility was left open to modify future data collection based on themes that are emerging. For example, questions were added to the interview to explore themes that were emerging in previous interviews.

To ensure data saturation, a diversity of participants were sought out. When no new themes emerged from a diversity of participants, data saturation was achieved. O’Conner and Gibson (2003) recommend keeping your original question in mind during the analysis phase. The authors state that given the amount of data that could be generated by a series of interviews, keeping the question you are trying to answer in mind during the analysis phase is essential (O’Conner & Gibson, 2003).

A reflexive journal was kept after each interview and during or after each participant observation. Notes from the reflexive journal were used to validate information obtained from the interviews.

**Trustworthiness**

Guba (1981) proposes four criteria to be considered in evaluating trustworthiness in a qualitative study: credibility, transferability, dependability, and confirmability.

Credibility is equivalent to internal validity and “seeks to ensure that the qualitative researcher is actually studying the concept they purport to study”
Korstjens and Moser (2018) suggest several ways to ensure credibility: prolonged engagement, persistent observation, triangulation and member checking. Prolonged engagement involves spending sufficient time in the field so that one can build trust and become familiar with the setting and the context. Persistent observation dovetails with prolonged engagement, as the researcher focuses on the people and topics that are most likely to reveal information pertinent to the research question (Korsteins & Moser, 2018). This researcher began the process of learning the language and building relationships within the community prior to beginning the research.

Triangulation involves using different data sources, in this case participant observation and interviews (Korsteins & Moser, 2018; O’Conner & Gibson, 2003). Another form of triangulation is having a diversity of sources (O’Conner & Gibson, 2003). In this study, multiple different perspectives from within the Deaf community were sought out.

Sharing findings with participants can not only help to crystalize ideas formed in the field, but it will help to establish credibility (Shenton, 2004). O’Conner and Gibson (2003) state that the best way to examine the validity of a researcher’s interpretation is to return to the participants. As stated above, participants were invited for a follow up interview at the end of their initial interview for this member check. Participants are checking to make sure their words are represented accurately, to confirm that the researcher has correctly understood them, and perhaps to confirm some preliminary themes. Only those
participants who agreed were contacted for a follow up interview. It was made clear that participants can decline to participate in the follow up at any point.

Transferability is equivalent to external validity and is “concerned with the extent to which the findings of one study can be applied to other situations” (Shenton, 2004, p. 69). The main technique used to establish transferability is thick description (Korsteins & Moser, 2018). Thick, detailed descriptions are essential to not only provide the raw data for participants to check, but also to ensure future readers accurately understand the culture under study (Shenton, 2004). There is debate among qualitative researchers about the extent to which transferability should be considered in each study, since each small community under study is unique, and while elements may speak to another similar community, all results will not be directly applicable (Denzin & Lincoln, 2003). It is the investigator’s responsibility to provide sufficient details so the reader can determine where other communities are similar and where they are different.

Dependability is equivalent to reliability and shows that if the same study was done under the same circumstances with the same participants, the same results would be obtained (Shenton, 2004). Dependability relies on detailed planning and following that plan as well as reflection at every step during the study (Shenton, 2004). In this study, there was a detailed plan in place, and it was followed as closely as possible. Frequent contact was kept with this researcher's advisory committee, and they were kept abreast of any variations from the plan.
Confirmability is associated with objectivity. Keeping detailed field notes and using multiple methods to confirm the findings will maintain a study that is focused on the participant’s point of view (Shenton, 2004). In this study, field notes were kept after each contact with the Deaf community, including notes about the participant’s demeanor (anything that cannot be picked up on a video recording) and the investigator’s own thoughts and feelings, in order to identify any bias.

Finally, peer-debriefing was planned to be used to confirm the themes. Peer-debriefing compares how someone external to study has coded the results into themes with how the primary investigator has coded them (O’Conner & Gibson, 2003). O’Conner and Gibson (2003) recommend sending a few de-identified passages that have already been coded along with a list of codes to a colleague and have them code the data, so that the codes can be compared. In this study, two other doctoral students were contacted to confirm themes. However, neither student was able to participate in peer-debriefing. This researcher made multiple outreach attempts to find someone to assist with peer-debriefing, but was unsuccessful. Burnard et al. (2008) point out that care must be taken when sharing the results with participants. The investigator must present themes in a manner the participants can recognize and must ensure that too much time has not passed between the first and second interview (Burnard et al., 2008).

In summary, when attempting to understand health literacy from the perspective of Deaf persons an ethnographic study is an appropriate means of
gaining this understanding. Both in depth interviews and participant observation were used to determine how someone who is Deaf obtains, processes and understands basic health information, and uses that information to make appropriate health decisions.
Chapter 4 – Context and Informants

Historical and Sociocultural Context of the Research

The history of Deaf culture is long and complicated and is intrinsically bound with the history of signed languages. There are many wonderful books on Deaf culture and Deaf history; what is presented below is brief and superficial at best.

Some of the first references to someone who is Deaf are in ancient Greece. Aristotle believed that the ability to reason was directly connected with the ability to hear and thus people who were deaf could not be educated (handspeak, 2020). This philosophy was largely believed until the 16th century (exceptions do exist, but these exceptions will not be explored here) (handspeak, 2020). During the Middle Ages, persons who were born deaf and could not communicate verbally were barred from legally inheriting property or managing an estate (Peet, 1857). It is interesting to note that the law at the time drew a distinction between persons that are born deaf and those who acquire deafness through accident or malady (Peet, 1857). While it was noted as early as 1510 that persons who are Deaf are capable of learning, the first formal school for the Deaf was not established until 1750 in Paris (Jay, 2020).

The story of sign language in the United States broadly starts with Thomas Gallaudet and Laurent Clerc. In 1815, Thomas Gallaudet traveled to Europe to study methods of educating persons who are Deaf (handspeak, 2020). Gallaudet originally attempted to gain access to the Braidwood family of schools in England, which taught oralism via a proprietary method (Thomas, 2020).
Oralism is a method of teaching persons who are deaf that focuses primarily on spoken communication through speech-reading and producing speech (yourdictionary, n.d.). Braidwood was not willing to share their methods, so Gallaudet ended up at the school for the Deaf in Paris under Abbe Sicard (Thomas, 2020). After a relatively short time, Gallaudet was able to convince Laurent Clerc (at the time a recent graduate from the school) to return with him to the United States and help open what would become the American School for the Deaf in Hartford, Connecticut. Graduates of this program stayed on to become teachers or went on to found other schools for the Deaf across the country (ASD, n.d.). Deaf schools became centers of Deaf culture, as communities built up around these schools and Deaf teachers passed culture down to the next generation (Padden & Humphries, 2006).

The Second International Congress on Education of the Deaf held in 1880 (commonly referred to as the Milan Conference) in Milan Italy, declared oral education superior to manual education and passed a resolution banning sign language in schools (Wfdeaf, 2016). The conference was planned by the Pereire Society, a group known to oppose the teaching of sign language. The majority of those invited were known oralists, including Alexander Graham Bell who was described as a “positive eugenicist” because he favored social remedies “to the Deaf problem,” rather than forced sterilization (Padden & Humphries, 2006). An apology was eventually issued in 2010 for the harm caused by the resolutions issued at the Milan conference, yet those resolutions continue to have a lasting effect on education (Wfdeaf, 2016). American Sign Language (ASL) was not

Audism was first defined by Tom Humphries in his doctoral work as “the notion that one is superior, based on one’s ability to hear or behave in the manner of one who hears” (Humphries, 1977, p. 12). Eckert and Rowley (2013) argue that audism can take many forms; among them covert, overt, individual, institutional, and metaphysical. All forms of audism result in a hearing perspective being given priority over a Deaf perspective (Eckert & Rowley, 2013). The 1990 Americans with Disabilities Act (ADA) was designed to provide certain protections from discrimination by legislating linguistic access. According to the ADA, public institutions including hospitals and doctors’ offices are required to provide such access. Yet 30 years after the ADA became law, this is still not always a reality (USDOJ, 2014).

Given the cultural and historical context, it is reasonable to explore how participants who consider themselves culturally Deaf manage health information. The research question was: How does someone who is Deaf obtain, process, and understand basic health information and use that information to make appropriate health decisions?

**Introduction to the Participants**

Due to confidentiality concerns, each participant will not be described in detail in this chapter in order to maintain each individual’s privacy. Confidentiality concerns are a well-known problem within the Deaf community (Gertz & Boudreault, 2016). Because the Deaf community is small and close knit and it is
common for members of the Deaf community to know details of each other’s lives, every effort was made to not reveal personal information (Whyte et al., 2013).

A total of 12 interviews were conducted. There were five male and seven female participants. Ages varied widely with some participants of college age while others were past retirement age (20 years old - 64 years old). Eight of the participants identify as White, two as Hispanic, one as African American, and one as more than one race. Each participant was assigned a random number between 10 and 300 using a random number generator when they signed the consent form. Participants will be referred to by this number and not by their names. Participants were given the option of using a pseudonym, but none of the participants took this option.

Four out of the twelve participants who were interviewed were previously known to this researcher. All participants were greeted in ASL, and there was a period of light conversation prior to the start of the interview. Those who had previous interactions with the researcher greeted her and appeared more comfortable in the beginning. However, no differences were noted in the content of the interview based on whether or not the participants were known to the researcher.

It is essential to ethnography to immerse oneself in the culture being studied. Various factors can affect one’s acceptance in the Deaf community, including signing ability and time spent in the community. (The following section describing a participant observation will be in present tense because it is the
convention for the results of ethnographies to be written in present tense (Fetterman, 2010.) For example, this researcher is observing the effect of signing ability on one’s acceptance by the group during a participant observation. It is common for students to attend Deaf chat events. Attendance at chats is frequently a requirement as part of ASL classes, so it is not unusual to see new faces at a Deaf event. At one such event there is a new person who signed very well. She is accepted much more easily into the local Deaf community than someone who came for the first time and did not have that same signing ability. The person who signed well later revealed that she is nearly finished with an interpreting degree from an out of state University and had spent time in other Deaf communities.

On another occasion, this researcher observes the effect of time spent on acceptance. A large group of students attended the event, but only stays long enough to obtain the evidence of their visit required by their professor. After they leave, there is a group of fewer than ten people, who were a mix of Deaf and hearing, but all who had been actively involved in the community for an extended period of time. The Deaf members of the group are visibly frustrated. There are comments made about how students like that don't care about the culture; they just want to get what they need. While the group acknowledged that some students do stay and grow, they agreed that the smaller group of those who are invested in the community is better.

**Description of the Audit Trail**

*Informed consent*
The English version of the standard informed consent was re-written in plain language at approximately 7th grade level, according to the Flesch-Kincaid readability scale integrated into Word 2013. This English version was approved by the Institutional Review Board (IRB) at Rutgers University. Once the English version was approved by the IRB, a written English GLOSS was written with the assistance of someone who is English/ASL bilingual. Since ASL has no written form, a GLOSS is the written version of which signs will be used in the correct grammatical structure for ASL (Valli & Lucas, 2000). The GLOSS was reviewed by a person who is culturally Deaf, who made suggestions which were incorporated. A rough draft of the consent form was signed on camera by a person who is culturally Deaf. The rough draft was then back translated into English by someone who is English/ASL bilingual and had not previously seen any version of the consent form. Three changes to the translation were suggested after discussion, one of the changes was made. Two were rejected after giving translators more context. All persons involved in the translation agreed that these choices made the meaning more clear.

Once a final version of the GLOSS was developed, time was booked at the television studio on the Rutgers New Brunswick Campus to make a final version. The same person who signed the rough draft of the consent signed the final version of the consent form. This researcher was able to review the final version of the consent form prior to completion. It required several attempts for the closed captioning to line up with the signing, but the employees at the television studio were willing to work with this researcher until we had a product
that met with my approval. This researcher received a digital copy and a CD that could be copied as needed. Therefore, every person who was interviewed received the same information during the consenting process.

**Interpreters**

Three interpreters were recruited for this study. All of the interpreters who were recruited were highly experienced in interpretation in a variety of settings. All three completed Human Subjects Protection Training and obtained certification.

**Test interview**

A test interview was conducted after IRB approval was obtained. This interview was conducted in Saddle Brook, NJ, in a private conference room. All three of the interpreters were available for this test interview. The three interpreters and the participant debriefed with this researcher after the interview. Wording was changed on one question that the participant found confusing to make the meaning more clear. The physical environment was also discussed, including seating arrangement, and placement of the camera. This test interview was helpful in making the subsequent interviews go more smoothly. The total time of the test interview including debriefing was approximately 3 hours.

**Recruitment**

After approval was granted by Rutgers IRB, two culturally Deaf persons were approached to be interviewed. The researcher was acquainted with both of these individuals and believed they could provide broad general knowledge about health literacy in the Deaf community. One person agreed to be
interviewed right away and a time was set up at the mutual convenience of the participant and the interpreters. The other individual expressed interest, but when asked for availability kept putting it off, and eventually stopped answering emails from this researcher.

The plan to employ snowball sampling did not work in this sample. Every participant who was interviewed stated that they would be willing to ask their friends to be interviewed. However, only one additional person was recruited via referral from another participant. Local Deaf schools were approached to inquire if members of their alumni organization might be interested in participating. Also, local Deaf organizations were approached to see if their members might be interested in participating in this study. Multiple messages were posted on Facebook to recruit participants. The most successful approach for recruitment was the assistance of interpreters. They contacted potential participants and were able to act as cultural brokers. This approach had to be used with caution, however, since this researcher did not want to ask the interpreters in her acquaintance to risk breaking their code of ethics. Of the 12 participants who were interviewed, six participants were recruited by one of the interpreters on the team, three were approached directly by this researcher, two were recruited via Facebook and one was referred by another participant.

Emails were sent to Lake Drive School for the Deaf in Mountain Lakes, NJ and Bruce Street School in Newark, NJ, however, this researcher received no response from either school. An advertisement was placed in NJ Deaf, without response. This researcher contacted the Rainbow Alliance of the Deaf and New
Jersey Black Deaf Advocates, requesting they contact their members to see if anyone was interested. Flyers were provided to these organizations to provide to their members. No one was recruited from these outreach attempts. Recruitment was an ongoing process until saturation was achieved.

**Participant Observation**

Between September 2019 and February 2020 this researcher attended 24 Deaf events to engage in participant observation for a total of 75 hours. Events scheduled after February 2020 were cancelled due to the COVID 19 outbreak. Twenty-two of the 24 Deaf events took place in New Jersey. Two took place in New York City. All but one participant observation took place in the evening. The one that took place during the day was at a Deaf church in Newark, NJ.

With the exception of two events in September, events in New Jersey were found through the website [www.deafcoffeechat.com](http://www.deafcoffeechat.com). These events were recurring events that were open to the public and took place in West Orange (5), Rockaway (4), East Hanover (5), Ramsey (1), Hamilton (1), and Linden (1) New Jersey. Two of the events that took place in Bloomfield and Montclair NJ were advertised on [www.deafcoffeechat.com](http://www.deafcoffeechat.com), but when this researcher went to the location, no one else was in attendance. Of the remaining two events, one was advertised on Facebook as an ASL poetry event in Newark NJ. The other was an annual event held by a local community college in Union NJ.

The events that took place in East Hanover and West Orange, NJ were the events that this researcher regularly attended prior to beginning interviews for this research project. This researcher also occasionally attended the event that
took place in Rockaway, NJ. There was a slightly different group that attended each group regularly, however, there was some overlap. For example, when this researcher went to the group in Linden, there were people who recognized this researcher and she was readily accepted as part of the group. The only exception to this was Hamilton, NJ, which is located in Central NJ, approximately 90 minutes south of the other locations. This location had a different mix of people. This researcher was accepted at this location once it was shown that she signed. At Deaf events, this researcher spent the majority of time sitting and conversing about everyday topics. If topics about health came up in conversation, they were noted in the researcher’s reflexive journal after the event. However, the researcher did not specifically introduce the topic of health in order to not influence the results.

**Interviews**

A total of twelve interviews were conducted between October 2019 and July 2020. Ten interviews were conducted in person and two interviews were conducted over Zoom. Two were conducted in October 2019 (both on the same day) in Saddle Brook NJ. Four interviews were conducted in December 2019. Three took place on December 18th and one on December 19th. All four of those interviews were conducted at Bergen Community College (BCC). Three took place in a private office, and one took place in a classroom that was not being used. Four interviews were conducted in February 2020, each on their own day. One took place in the library at Union County College, in a private room. The other three took place in an office at BCC.
Participants interviewed in December 2019 requested the interviews take place at BCC because it was convenient for them. Privacy was ensured for all interview locations. For the interviews in February, this researcher attempted to obtain the original location, however that location was no longer available. Alternate locations were obtained that were convenient for all participants. The participant who was interviewed at Union County College requested this location.

The final two interviews took place after Rutgers IRB approved a change to virtual interviews due to COVID 19. These interviews took place via Zoom at the participants’ request. The participants who were interviewed virtually were offered an alternate platform of their choice (Webex, Skype, Google Meet, etc) and all chose Zoom as the most convenient.

For both the in-person and the virtual interviews, this researcher and two interpreters were present. This researcher facilitated all of the interviews. The consenting process was similar with the virtual and the in-person interviews. In both cases, participants were given the written English version and shown the ASL version of the consent form. They were given an opportunity to ask questions prior to signing the consent form. Participants were given a copy of both the English and ASL consent form to take home. With the virtual interviews, a copy of the English and ASL consent forms were mailed to the participants prior to the interview. Instead of signing a consent form, virtual participants indicated consent to participate, which was recorded. Other than that, the process for consenting was identical.
It was noted that it was easier for participants to cancel with virtual interviews. The only participants who did not show up were those scheduled for virtual interviews. This happened once when attempting to check the data with a participant that had previously been interviewed and with a new participant.

The shortest interview was 23 minutes and 19 seconds, the longest was 1 hour and 42 minutes. The mean length of the interviews was 46 minutes. The questions for the interviews were primarily based on the interview guide (Appendix B). Follow up and clarifying questions were added as necessary, and additional questions were added to the interview guide as preliminary themes began to emerge from the data analysis (Appendix C). When more information was needed, probes, such as “tell me more” or “can you expand on that” were used.

All interviews took place in ASL and were voice interpreted with two ASL interpreters. All interviews were videotaped. Each participant was offered the option of conducting the interview without the video recording for privacy, but all agreed to video recording the interviews. Light conversation took place both before and after each interview to put the participant at ease and to assure the participant that the researcher also signed.

**Data Analysis**

Fetzerman (2010) noted that analysis in an ethnography has no single form, takes place throughout any ethnographic endeavor, and is often iterative. Data analysis began as soon as the first interviews were completed. This researcher viewed video recordings of the interviews twice. It was found while
viewing the first interviews that time for reflection was required between watching segments of the interviews. Therefore, it was most efficient to watch the interviews in 10-15 minute segments, allow a few minutes to digest what was watched and then return to the recording. Notes of any observations noted while processing the recordings were made in the reflexive journal. While this process took longer, it was more fruitful than watching the recordings straight through.

After the entire recording was viewed twice, this researcher transcribed the interview verbatim based on the voice interpretation. Braun and Clarke (2006) state that transcription can be seen as a key phase of interpretation, because it allows the researcher to become familiar with the data. Thus, this researcher transcribed all interviews verbatim.

In cases where this researcher had trouble understanding the voicing or wanted to verify the accuracy of what was heard, this researcher could refer to what was signed. Accuracy of the transcription was verified by another member of the research team. The interpreter who was not involved in that interview was sent one page at random, and the section of video that corresponded to that page of transcription (approximately 5 minutes of video).

Transcripts were transferred into Nvivo © data analysis software package. Coding was done in several stages.

1. Initial Coding: During the initial coding, the researcher read through the data several times to familiarize herself with the content. Broad sections were coded for future use, and notes were made. Data was reviewed iteratively in order to look for patterns.
2. Line by line coding: Line by line coding was accomplished by coding with more detail. Each line or phrase was coded. During line-by-line coding, the participants’ own words were used whenever possible. Different coding methods were used (see table 2 for details).

3. Categorization: Similar codes were moved into the same category. For example, when describing privacy, some people used the word “privacy”, while others used “confidential”, and still some others stated it was “no one else’s business.” These codes were all placed in the same category.

4. Determine theme: By continually analyzing and sorting categories, themes emerged. The larger categories became overarching themes, while the smaller categories became subthemes.

Coding was an iterative process. There were times when this researcher had originally thought a piece of data belonged in one theme, but eventually it ended up fitting better somewhere else. For example, there is a segment where a participant talks about being frustrated with an experience with an interpreter. First, this was put under interpreter. Then it became clear that not having an interpreter needed to be a separate sub-theme. Finally, that segment of the interview was moved to the sub-theme of frustrations.

Once themes began to emerge, this researcher contacted three participants who had previously agreed during the first interview to be contacted again. The participants verified that the emerging themes were correct, and that this researcher had not missed anything important. Discrepancies were
discussed until an agreement was reached. For example, participant 270 (61-year-old Caucasian Female) discussed the idea of misunderstanding, until it was clear that miscommunication was a better way to label that subtheme. All three participants agreed that “interpreters” was an important subtheme under communication.

<table>
<thead>
<tr>
<th>Coding methods</th>
<th>Description</th>
<th>Examples</th>
<th>Text Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attribute coding</td>
<td>Features of participants</td>
<td>Participants age, gender, etc.</td>
<td>5 male and 7 female participants</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Features of sites</td>
<td>Room too small, poor camera placement</td>
</tr>
<tr>
<td>Emotion coding</td>
<td>Participants’ sentiments and feelings</td>
<td>Frustrated</td>
<td>That's my request, you know. So, I feel like it's so frustrating that the VR through the laptop is a different service.</td>
</tr>
<tr>
<td>In vivo coding</td>
<td>Codes using participants' words</td>
<td>Don’t discuss</td>
<td>My issues? Oh, no, no, no. Nuh-uh. I don’t discuss it</td>
</tr>
<tr>
<td>Value coding</td>
<td>Codes of participants' values or belief</td>
<td>Feeling invisible, no access, accommodations are refused</td>
<td>And sometimes I feel like they ignore me</td>
</tr>
<tr>
<td>Narrative coding</td>
<td>Codes of participants' stories</td>
<td>Falsehoods, didn’t know, help other people,</td>
<td>I know one person in particular who</td>
</tr>
</tbody>
</table>
misunderstanding, didn’t understand, communication.

is as a nutritionist, and like they said I can’t do this, this, this this, this.

Whoa, whoa, whoa, whoa. I was like, this can’t be right. So, I was like, hold on a sec. So, I read it and I was like, no, you can, like you can read these, you can have these in specific amounts. And they were like, Oh, I had no idea, I thought I had to completely cut it out. So, I don’t understand why. I don’t know what happened in that communication process that broke down. That was one in particular thing I noticed.
Chapter 5- Description and Discussion of Themes

The research question that this study aims to consider is: How does someone who is Deaf obtain, process, and understand basic health information and use that information to make appropriate health decisions? An ethnographic study was conducted in order to understand health literacy from the perspective of someone who is culturally Deaf. The themes that were identified were: communication, going to the doctor, audism, Deaf culture, family, and privacy. Themes were identified based on observations across interviews and participant observation.

| Table 3  Themes and Subthemes: Obtain Process and Understand |
|------------------------|-----------------|-----------------|
| **Theme**               | **Sub-Theme Facilitate** | **Sub-Theme Barrier** |
| Communication          | Interpreters     | Interpreters |
|                        | Good Fit         | No interpreter |
|                        | Preferred Method | VRI            |
|                        | Technology       |                 |
|                        | Ask Questions    |                 |
| Go to the Doctor       | Relationship     | Relationship   |
|                        | Health is Important | Money        |
|                        |                  | Rushed         |
| Audism                 |                  | Lack of Access |
|                        |                  | Refused        |
|                        |                  | Feeling invisible |
|                        |                  | Need to educate |
|                        |                  | Negative Feeling |
| Deaf Culture           | Having Access    |                 |
|                        | Helping Others   |                 |
|                        | Aware of Rights  |                 |
|                        | Feeling Accepted |                 |
|                        | Natural Language |                 |

**Obtain, Process and Understand**

Several themes are noted related to how participants obtain, process and understand information about their health (see table 3). Some of the themes had
elements that could both facilitate and act as barriers to obtaining information.

Other themes described only facilitators or barriers.

**Communication**

Communication is discussed by every participant that is interviewed.

Participants relate both positive and negative experiences with communication. The need for successful communication is noted in both the interviews and during participant observation activities.

Participant 270 (61-year-old Caucasian female) discusses the need for an interpreter. She talks about the need to constantly think about whether or not the message is being conveyed correctly.

So, without an interpreter it's very difficult we have to write back and forth we try to gesture of course, do what we can. So, with an interpreter, like I want to make sure that the interpreter is right. I kinda make sure that, make sure everything's going. Sometimes I'll have to manage that situation to make sure that the communication is 100% successful.

Participant 270 (61-year-old Caucasian female) also relates how much stress would be relieved if she could communicate without having to think about it.

I would be so excited they could just sign and chat and not have to go back and forth with question and that. That would be cool. That would be cool. The stress would be just on my shoulders and be so much more relaxed in my interactions. That would be nice.

This sentiment of communication being important is also observed during participant observation. During a participant observation one conversation is observed. During a Deaf chat, a participant states he is having some symptoms. Other participants comment that it seems like he might want to go to the doctor to get that checked out. The person who is having symptoms is hesitant to go to
the doctor because he had trouble communicating in the past. The doctor in that case did not want to provide an interpreter, and the participant left the doctor feeling like he did not have all of the information that he needed. Participants did not feel they had access to adequate communication. Accessibility is a prerequisite to having adequate health literacy (Perlow, 2010).

**Interpreter.** Having an interpreter present made it easier to obtain, process and understand information. Every participant interviewed spoke about how important it is to have an interpreter available. Even those who did not regularly use interpreters with their primary care provider wanted the option of having an interpreter available if they needed one, for example for a specialist.

Participant 270 (61-year-old Caucasian Female) comments that the entire point of having an interpreter is to facilitate communication. She also notes how important it is for not only for her and her family who are also Deaf, but the entire Deaf community.

So, um that the reason we have interpreters is to make sure that these, that our communication is successful and that we're able to understand each other fully. . . Like, it's not only me, like for my family as well, for my family members as well, this is an ongoing issue. Like, I'm sure there are other Deaf people who are dealing with this, like, the whole Deaf community of course.

Participants recognize that interpreters facilitate communication in both directions. This is not just for the benefit of the person who is Deaf, but also for the benefit of the health care provider. Participant 153 (55-year-old Caucasian Female) states this is a desire of hers.

With an interpreter. You know, with a clear interpreter there. With clear interpreting, uh, and you know being able to translate and to speak for me.
You know to have it go both ways, from English to ASL and ASL to English.

**Good Fit.** Interpreters not only facilitate obtaining health information but can also facilitate understanding and processing health information. During participant observation, this researcher is able to observe discussions that included interpreters. Many of these conversations center on the idea of not just conveying the right words, but conveying the appropriate meaning to the other party, picking up on nuances. In one memorable example of this at a Deaf chat, a video from a famous interpreter is brought up and viewed. He is performing a comedic routine where he begins by signing a song word for word. Although the words are correct, it’s not understandable. About halfway through, he switches to ASL, suddenly the meaning becomes clear. This video really captures the importance of making sure the message comes across and is understandable. Thus, interpreting is more than simply translating the words from one language to another.

During the interviews, participants expressed a desire for an interpreter who is both qualified and a “good fit” for them. Qualified may or may not mean that the interpreter is certified. To the participants, being qualified really meant the interpreter is able to transfer information from one party to another, and therefore is capable of doing the job. There is a sense that just because an interpreter may be capable in one setting, they may not be in another.

For example, participant 222 (60-year-old Caucasian Male) describes a situation in which he had to go to court. The first time he went with an interpreter and could not understand what was happening, even with the interpreter, so he
came back a second time with a certified Deaf interpreter (CDI). He was ultimately able to understand better when he came back the second time.

I know one time I went to court and I brought an interpreter and I didn’t really understand what was going on. So, we agreed to ah, adjourn and come back in two weeks and then we brought a CDI and that was much, much better. It was a big change. Now there was still some issues. CDI really had to explain things very in-depth and was exhausted by the end of the day. But communication was much clearer for everyone.

This is echoed by participant 132 (20-year-old Hispanic Male) when discussing problems, he had during a medical appointment. He felt the interpreter over video relay was using too much English, and that did not match his language preference.

Another thing I would like is to have a high-quality interpreter. I’m not good with English. You know, I really, I grew up with ASL. I understand ASL more clearly. I feel I would want the interpreter to match my language.

It’s not that one interpreter is necessarily less skilled than the other, but just is not skilled in that particular area. Participants want an interpreter present at their health care encounters who is qualified in handling such discussions.

Participant 299 (51-year-old Latino Male) describes how he researches his interpreters prior to his appointment to make sure they are qualified. He is worried about one interpreter because he could not find much information about her. However, he is pleasantly surprised when they meet, and she is able to meet his needs.

For example, one woman, she is from Washington DC, and she moved here, she was following her husband or something. So, I spent a little time researching that. Washington DC, what is she doing here in NJ? So, I went back, and I found that, trying to figure out what her sign experience was. Found out that she went to Gallaudet University and she freelanced for 4 years, but that’s all it said. But then I meet her and her signing was
real clear, she explained that, I explained that I did a little research on her before I came here and found the information that you were from DC so I asked what are you doing here? She explained that she came to follow her husband’s job and that’s why she moved here. She had one or two little errors, because of her accent and that was it, and she’s been great.

Even if the participant feels that the interpreter is qualified, participants still want the interpreter to fit well with them, to be able to match their tone and style. Part of this is correctly conveying the participant’s emotions. Participant 270 (61-year-old Caucasian Female) describes how important it is to have an interpreter who is not only qualified, but someone who will correctly convey every aspect of what she is trying to communicate. There are times when she ends up advocating for herself and her husband if the interpreter is not a good fit.

So, with an interpreter, they like have to copy my voice and they have to make sure that if I’m pissed, they aren’t going to, to cover it up by being like, Oh, it's fine or whatever. I want them to match my prosody. . . As well, also, it's important to have an interpreter who matches the Deaf client, the Deaf patient, you need someone who’s on par like you can just grab any interpreter. Oh yeah, I understand sign. I can tell them, you know, I can tell that my husband like, oh, you understand. I'm like uh huh. You’re not going have you have problems and it's not a good match. Sometimes I end up expanding and then, the, everyone in a room is just shocked.

**No Interpreter.** A major barrier noted around the use of interpreters is not having an interpreter. Seven out of twelve participants discuss times when they requested an interpreter, but then there was no interpreter at the appointment. Participant 82 (39-year-old African American Female) noted how this is not a unique event.

Yeah, No interpreter. That seems to be a normal experience. There's no interpreter there.
This is a sentiment echoed by others both during the interviews and during participant observation. Three participants who were interviewed stated that if there is no interpreter they will not continue with the appointment, they will reschedule. Participant 153 (55-year-old Caucasian Female) is particularly upset when discussing this, as she had to reschedule multiple times recently.

There is no one available. No interpreter there. So, then I have to reschedule my appointments and that is very disappointing. . . Well, I have to reschedule the appointment and then I remind them in person, I need the interpreter, but again and again it’s happened. So, four times so far since December, I don’t understand why. . .I notice many of the secretaries, they forget to set up the interpreter. And you have to nudge them, remind them, you have to follow up and ask and inform, please set up the interpreter.

In addition to frustration, worry and anger, there is a feeling that staff at their doctor’s office did not take the requests for interpreters seriously. Participants had to keep checking to make sure that their requests were being honored.

Participant 299 (51-year-old Latino Male) states that he gets the name of the interpreter in advance, this way he can make sure that an interpreter has been booked, and can research the interpreter to make sure they are qualified.

So, what I do, is I end up going two weeks before the appointment to make sure that everything works out, and whether or not the interpreter is there. And I ask for the name of the specific interpreter. And the reason why I ask for the name of the interpreter because I need to do my research. Is it a good interpreter? Are they qualified? Are they certified? Are they health care certified? Do they have any past experience with this specific medical situation? So, to make sure when I arrive at the appointment that the interpreter is there.

**Video Relay Interpreting.** Another major barrier noted around the use of interpreters is using video relay interpreting (VRI). Eight out of twelve
participants interviewed spoke about experiences they had using VRI. The overwhelming preference is for a live, in-person interpreter instead of someone on a screen. Feelings ranged from “it’s better than nothing” to “I won’t use it.” There are frequent complaints about technical difficulties.

Participant 173 (25-year-old African American and Hispanic Female) describes a few of the difficulties she faces.

Well, one thing did come up, but they only had the video relay for deaf and hard of hearing. And it was blurry and confusing and not clear. The doctor, it was hard for them to hear what was happening, they [VRI] couldn’t hear the doctor, that kind of really mediocre access. I feel like that could be improved.

Another problem the participants mention is the quality of the signing. Participant 270 (61-year-old Caucasian Female) speculated that perhaps the signing is regional. The interpreter could be calling in from anywhere in the United States and is not necessarily from the same geographic region as the person they are interpreting for.

The signing is different, the interpreter is from all over the United States. So sometimes the signs are regional, you know, and that's very difficult to comprehend. So, I really prefer like if you’re in New Jersey to use a New Jersey interpreter like New York, whatever someone from the tristate area, you know, makes it easier linguistically.

The same situation happened to participant 132 (20-year-old Hispanic Male). He describes a situation when his primary care provider used VRI during his annual physical. He describes a mismatch that occurred between himself and the interpreter on VRI.

Like. Something like drug. So, the sign for drug. (sign for illicit) But instead they use this sign for drug (almost looked like the sign for small, but with thumb and forefinger). I was like what? So, I had to ask what you mean, what is that? And then they spelled it. D-R-U-G.
Participant 270 brought up a point that is also heard during participant observation. An in-person interpreter is able to fully comprehend the situation. Someone that is on screen is not able to make adjustments for what is happening in the environment.

And even in a hospital, like, you know, I, I insist on having a real-life interpreter. I don’t want VRI. So, like if someone is sick or they’re, they can’t communicate properly, obviously, you know, someone on an ipad screen is gonna have some issues. So, a real-life interpreter can get on the ground, can bend over, can see what’s going on. Can understand the whole situation, and with VRI they are kind of stuck on this whatever tripod that they are on.

More than one person refuses to use VRI. Participant 177 (62-year-old Caucasian Female) recounts a time when she goes to the hospital for a procedure and had requested an interpreter in advance. Instead of getting an in-person interpreter, the hospital brings in the screen for VRI. She refuses to use the VRI.

I made the request and they were like, oh, we can use the VP. And I said, oh, no, oh, no, that’s not happening. I was like, fine, we’ll have to write things back and forth. And we just had to go real slow and wrote every single thing down. But I refused to use VP, it shuts down, it doesn’t work, it disconnects, it’s blurry, it does not work well. I can’t stand it.

**Preferred method.** There are several participants who discuss their preferred communication method. While some participants say they prefer to use an interpreter, some say they prefer a different method of communication, such as writing back and forth.

When participants felt like their choice is respected, the participant had a better interaction with health care providers. For example, participant 177 (62-year-old Caucasian female) discusses how she prefers to write back and forth
with her doctor, because she can then be sure she understands everything clearly.

I always sit down with the doctor. We have a one on one and they write in English. That’s it, plain and clear, not medical jargon. They put it in plain. I remember this, I had with my husband a long time ago, he was taking this medication and the time was it an hour? It was like this weird jumble of like when you take the medication and the doctor, like the doctor couldn’t even understand it. So, the doctor had to write everything down of take this medication here, take it then, take it now. Like day one take 2, day three take this and then it was clear that it was in plain English. And my husband and I understood absolutely clearly when he was able to write everything out.

Participants who express that they had a positive experience discuss how this is something they figured out over time. The method of communication that works best is the right fit for them and their health care provider. Additionally, there were instances where participants chose to use one method of communication with one provider and another with a different provider.

Participant 222 (60-year-old Caucasian Male) talks about how he is comfortable writing notes back and forth with his primary care provider. This participant prefers writing back and forth both because he has already developed a rapport with his primary care provider, and he wants to ensure his understanding. However, if he goes to a specialist then he wants an interpreter.

But since I, like with my primary I can go in and write things back down. . . but if it’s something that is potentially serious especially with a specialist, I’m going to bring an interpreter and make sure I get all of the information I need.

Technology. Participants used technology in different ways to facilitate communication. At times, this approach is very effective, and at other times it is
not. Use of technology is described during interviews and observed during participant observation. For example, it is a common during a Deaf chat for someone who is Deaf to try to communicate something to one of the ASL students. After several attempts to sign in different ways or fingerspell have failed, the person who is Deaf might pull out a cell phone and type what they are trying to say.

During the interviews, the use of technology is especially obvious when participants discussed making appointments. Two participants stated that they would physically walk into the office whenever they need to make an appointment. However, most participants used some form of technology: email, video phone (VP), or texting. Technology can create a level playing field where participants do not have to struggle to be understood.

Participant 222 (60-year-old Caucasian Male) talks about how easy it is to make an appointment via his video phone.

Yeah, I use my videophone. Um, it’s one or two minutes, and it’s live and they’re there it’s usually pretty quick. It’s painless, it’s just very fast, um, it’s like, oh you want the appointment setup.

Participant 153 (53-year-old Caucasian Female) states how she wishes technology would be more effectively used by health care providers. In this way they could proactively reach out to members of the Deaf community to ensure the community members understand their health.

Like the nurse, can like send an email, or the nurse could call the patient as a follow up, like hey, how was your appointment with the doctor, whatever. If, did you understand everything, then the nurse could double check. Did you understand everything the doctor had to share with you, no? OK, would you like a picture of what he’s talking about? Would you
like a picture? Oh, sure. Fine. And then being about to send that information and those pictures along through email.

There are times however, when technology produces less than ideal results. This happens when the technology is used as a compromise, instead of being the participants’ choice. Participant 173 (25-year-old African American and Hispanic Female) describes an experience where she prefers to have an interpreter present but uses the voice to text app out of necessity, because an interpreter is not provided.

And I can't understand what's happening. So, we just do some typing on the phone, using the app Evo, it’s a voice-to-text app. So, they can listen, and I can, and I can read what they're saying. But it's hard to understand because some of the words are huge and some of the words I don't understand. They should have an ASL interpreter not the video relay and not this, trying to do using alternate technology to try to communicate. It's so important for me to have that access, that communication access. So, I left.

This participant is obviously frustrated with the lack of communication access available to her, and more so because she later states that this is a typical experience for her.

**Ask Questions.** Asking and having questions answered, and receiving in depth explanation, are aspects of communication that facilitate understanding and processing in this study.

Participants describe situations where they are unsure of information they receive and sought out additional information. Participants stress how important it is to ask questions and to keep asking until they are fully satisfied. Participant 204 (34-year-old Caucasian Female) discusses how she doesn’t feel afraid to
ask questions. She will ask her doctor or her family, or whomever she thinks she can get information from most readily.

If I don’t understand anything I will either ask dad or [the doctor] to explain or repeat something. It depends. . . . I kept, I would, I wouldn’t be afraid to ask them can you say it again, slowly? Or if mom or dad were near me or somebody else, I would ask them, can you tell me what they said? I couldn’t understand them.

For the majority of participants their health care provider was the primary source of information. Participant 153 (55-year-old Caucasian Female) describes how she calls (using video relay) her doctor’s office if she has a question and needs further explanation. This participant also includes the nurse at her doctor’s office, stating the nurse will answer her questions and give her any additional information she needs.

So, if there is something I don’t understand, sometimes I'll call the doctor's office and I'll request to talk with the nurse, directly. So, they can explain more specifically. I have a specific question, something I didn’t understand, could they answer that? And they’ll go ahead and expand on it, so I understand more clearly.

This same participant also recognizes that there are other resources available. She discusses one occasion when she calls her pharmacist and receives further explanation about how to use an inhaler she recently received.

Sometimes I’ll call the pharmacy, and then the person in the pharmacy. The pharmacist themselves, they know, how something works with the inhaler. And the pharmacist themself can explain it to me. Give me the instructions.

This participant was the only participant who spoke about getting information from providers other than her physician.

Other participants expressed their willingness to go out of their way to ensure that they received an in-depth explanation. For example, participant 222 (60-
year-old Caucasian Male) discusses the fact that he could go to a doctor with an office in the same town in which he lives. He chooses to travel farther in order to have a health care provider who will take more time with him and offer more in-depth explanation.

New Jersey’s doctors, you know they are always, not quite enough time. They are always running short. But if you go over the bridge to New York, they are a little more willing to listen and explain things more in depth.

**Miscommunication.** Actual or potential miscommunication is seen as a barrier to obtaining, processing and understanding health information. A fear of miscommunication is present in many interactions. Five participants relate instances when they or someone they knew in the Deaf community, experience a breakdown in communication. Participants who were interviewed are aware of the potential consequences of miscommunication in a health care situation.

Participant 299 (51-year-old Latino Male) tells a story of miscommunication. Someone he knows missed a crucial piece of information and ended up living with cancer for a year before she found out about her diagnosis.

What ended up happening was I think 4 or 5 years ago there was one interpreter that was interpreting for a Deaf woman, and she had cancer and the interpreter never told her what the doctor had said. And had completely obscured the point. So every time she went to see the doctor, she tried to figure out why the medication keeps changing and she spoke to one of her friends and her friend’s daughter who is a CODA [Child of a Deaf Adult], but not like, not a certified interpreter but she is a CODA but she trusts her and she and her daughter went with her to the appointment and the doctor said I told you, you have cancer. I, me, I have cancer. How long have I had cancer? You’ve had it for a year. But the interpreter, but there was like such a confusion happening because of that. So, because of that situation really impacted, impact Deaf people and Deaf communities, so that’s why people tend to be scared.
This is an important story. It shows that even under the best circumstances, a person needs to be vigilant about ensuring effective communication and not trusting that task to anyone else. Participants were asked to think about a time they had a question or needed more information about their health. Seven out of twelve participants state that they never had any questions.

Five participants discuss instances when they experience misunderstandings or miscommunications. All five participants recognize this is a problem. They speak about tactics they employ to avoid miscommunications, such as verifying the information or getting their health care provider to write the information down for them.

Participant 222 (60-year-old Caucasian Male) states that the reason he likes to have a written record of his visit with his primary care provider is so that he can bring that home and refer back to it. He feels like there is less of a chance for miscommunication that way.

The reason why, we write back and forth is because with the paper, like I bring it home and I do the research from there.

Other participants recognize that there are consequences to misunderstandings. Participant 177 (62-year-old Caucasian Female) notes that you cannot let embarrassment prevent you from asking questions. She relates a story about someone she knows who ended up having serious complications due to misunderstanding. This person did not understand what was said at her doctor’s appointment but didn’t let anyone know she didn’t understand. The
participant speculates that it might have been embarrassment that prevented that person from clarifying the information.

I know of one person who went to the doctor and she just yes’d him to death. Oh yeah, I understand, oh yeah. But she didn't follow up, she didn’t follow the medication and like her poor husband found just like all these medication bottles just like lined up, she wasn't following up with it. She didn't like, and like, and her body just went into complete and utter chaos like she was in really bad shape because she didn't follow up with it. Because she didn’t understand it. So, she was like, oh okay. And then her husband was like, if you don’t understand it, please ask me. I'll call the doctor. We'll clarify this... Ah, it’s probably the case, like, I know like some people are embarrassed because these things, like it's really, it's really nothing to be embarrassed about. Like you ask, like you ask anyone, like, there's no simple questions. You can't ask the question because there are no stupid questions. You have to ask.

**Go to the Doctor**

Participants who are interviewed speak frequently about both positive and negative aspects of interactions with their physicians. Ten out of twelve participants reported that their physician is a major source of health information. Participants report that they ask questions of their physician and will check information they receive elsewhere (such as the internet) with their health care provider. Participant 173 (25-year-old African American and Hispanic Female) describes the process she goes through to make sure she has the correct information. She will both check on the internet and verify with her doctor.

In the doctor's office, I'll tell them what’s going on and what issues I'm having, and sometimes I'll do extra research [on the internet] either before or after I see them. But if I'm not sure about what I find on the Internet, then I'll go again to the doctor. Sometimes the words on the internet are just really difficult to understand and they confuse me, and I don't know what they mean. So sometimes I'm like, OK, I give up on that, and I just, I trust the doctor, the doctor went to school for this. So, I might research on the Internet. And if I'm not sure, then I will check with the doctor.
Participant 132 (20-year-old Hispanic Male), states that he wishes he had the opportunity to ask more questions of his health care providers. However, he feels that impediments such as insufficient staffing do not allow for him to have the kind of access he wants.

I wish I could go straight to the experts and ask more questions. But sometimes that’s not possible because the schedule it is just too busy. But sometimes I wish I could just go directly to a person, consistently see a person and have them answer my questions. But I know that the staffing, with the staffing that’s not possible, and they can't hire enough people to do that, to have that kind of access, but I guess something like that.

Relationship. The relationship with one’s health care provider could both facilitate health literacy or be a barrier. Having a good relationship with one’s health care provider is seen as important in nine out of 12 interviews. Multiple factors are reported to impact one’s relationship with their health care provider, including consistency and trust.

Participants note that once they find a doctor that they like and feel understood, they preferred to stay with that same doctor. There is a feeling that many doctors do not understand the needs of the Deaf community, so having consistency with one doctor is preferred. Both participant 132 (20-year-old Hispanic Male) and participant 82 (39-year-old African American Female) discuss their preference to stay with the same doctor.

132: And again, you know, I prefer to go to the same doctor over and over, because then they get used to having a Deaf persons around, rather than having new people all the time, and then it's confusing and they don’t understand how to deal with me. So, it’s easier to go to the same person and have them get used to me over time.

82: They try to refer me to a different doctor. I don't want to do that. I want to continue to see the doctor I've seen. I don't know this other person. I don't trust them. Maybe they're not a doctor I know
Eight participants who are interviewed mention trust as being important in their relationship with their health care provider. Participant 153 (55-year-old Caucasian Female) states “Yeah for the most part I can trust them, yeah. Yes, the relationship is important.” Participant 299 (51-year-old Latino Male) discusses that it takes time to build trust and how it sometimes required multiple tries to find a physician that he could trust.

I went to many different doctors at that point. They gave me a slew of answers, oh my goodness. 17 to 4, 3 (one left and went to another place), anyway, I had three that were really good doctors. And I really trusted them. . . But like, that trust, you have to build trust, it takes time.

For the most part, participants report having a positive relationship with their health care provider. They view the provider as trustworthy, however, there are instances when the participants describe a loss of trust.

Participant 295 (64-year-old Caucasian Female) describes a situation where she feels like she is misled and taken advantage of by her physician. The participant trusts that the physician would not do a hysterectomy unless there is evidence it is necessary, but the physician performed a total hysterectomy despite no evidence of cancer.

I had had a hysterectomy. I thought it was my whole thing, inside that was bad. And the doctor said, if I see something bad do you want me to take it out? And I said yes. So, I thought, I trusted him. Apparently after the surgery, when the doctor transcribed the OR report, the lab tech said I do not have cancer. My sister said then why did they take the whole thing if there was no cancer? I don’t understand why he did that. If it was better for me to have the ovary removed but keep the uterus. But that was a long time ago.

The participant feels like she was misled in this situation, which prompted her to avoid seeking any additional information from that health care provider.
The participant also does not ask the provider any additional questions once this trust has been lost.

Five out of twelve participants who are interviewed state that the personality of a health care provider is important. Participants want a health care provider who is friendly, understands Deaf culture and takes time with them. Participant 153 (55-year-old Caucasian Female) discusses a time she changes providers because she feels the physician is not a good match for her.

I have, it really depends on the personality of the doctor. . . He was not very comfortable with Deaf people. And he was like, ah, trying to keep the appointment short, and sweet. Um, we would just, he would just, rush upon subjects. Like a medication list, like he gave me the list and that was it. He was like, here you go, here’s your medication, bye, see you later, I'll see you next appointment. I was like, whoa, whoa, whoa, whoa! Hold your horses! Like, I feel like you are rushing here. Like, I just felt like, you’re rushing to try and get out of here, because the doctor just was not comfortable having the interpreter in the room and dealing with the Deaf individual. And I realized like, it was not me as a patient, like it was the doctor. He was not comfortable with an interpreter. I finally, I just changed doctors and because he just didn’t seem comfortable with the whole situation, so I changed and everything, then I found a better doctor.

Interactions with the physician as well as other members of the office staff can have an impact on how a participant is able to obtain health information. In addition to being unfriendly, participants mention difficulty with the front desk staff giving them push back about being able to hire interpreters. Participant 270 talks about one of these occurrences.

So sometimes they don’t know how to do it, so I ask them to contact the manager and then they get, if they need like an agency name, I'll give them a list of names, I'm prepared to do that. Sometimes it's a good experience, sometimes it's bad. They’ll call me like Oh, no, we couldn’t, the manager said no. I was like, whoa, whoa wait, you can’t say no.
In this case the participant also has to give the office staff the names of interpreting agencies to call. She later comments about needing to educate the doctor and staff about the American with Disabilities Act (ADA). This is particularly frustrating because she feels that since the ADA is almost 30 years old, there should be more awareness of what services are covered by the act.

*Health is Important.* Participants who already believed that health is important were more likely to be open to new information about their health and how to keep themselves healthy. Participant 132 (20-year-old Hispanic Male) discusses trying to find new information to keep himself healthy.

Whether it’s health or helping me stay strong and keeping my body healthy. I might find something new in a new diet or a new way of eating that helps you become healthier or stronger.

He goes on to say he will verify this information with his doctor, because he finds that the most trustworthy source of information.

*Rushed.* Persons who are interviewed preferred in-depth explanations. They complained about how there are times when they felt rushed and only received a superficial explanation.

Participant 222 (60-year-old Caucasian Male) and participant 295 (64-year-old Caucasian Female) complained about their providers not spending sufficient time with them. Both of these participants describe how unhappy they are when they are not given a detailed explanation of what is going on.

222: Then that’s one thing, but, you know, if the doctors are like, quick and superficial and don’t have time to answer my questions fully, I’m not so happy about that.
295: [I was unhappy] because the doctor didn’t explain anything in depth about my health. So, all I heard was like, that’s good, it’s good, it’s good. There was no explanation behind it.

**Money.** Participants note logistical issues around obtaining health information. Money (including not having insurance) and lack of transportation are issues that negatively affect obtaining health information. Participant 177 (62-year-old Caucasian Female) discusses how some members of the Deaf community do not have access to screenings because of limited resources. This comment is made after stating that some members of the Deaf community would not use community resources, such as town wide blood pressure and cholesterol screenings, because of a lack of linguistic access. So, members of the Deaf community can face multiple barriers at once.

You know, some people, some Deaf people don't really have, some of them don’t have insurance, they can’t afford it. There’s no money, so there is a need there. That’s some of the other reasons why Deaf people don't attend these kinds of things. Sometimes they don’t have transportation, they don’t have cars. They can't get there. You know transportation is very limited, so that's also another difficulty.

**Audism**

Participants express multiple ways in which they feel discriminated against both during interviews and during participant observation. There are multiple ways participants express their experiences of discrimination. Some talk about times when they are refused services or expressed feelings of not being given access to necessary services. Others discuss feeling invisible, being judged, or other negative feelings. Other participants talk about needing to constantly educate health care providers. Audism negatively affects one’s ability to obtain, process and understand health information.
Lack of Access. Participants express both during interviews and participant observation the feeling there were services they could not access because they were Deaf. Participants express frustration because they felt they did not have the same options that were available to other people. Participants feel that an individual who is hearing would have better access to services, even if that person is a part of a different linguistic minority.

This is highlighted by participant 177 (62-year-old Caucasian Female), who feels that members of the Deaf community did not have access to community screenings. She expresses the idea that persons who are culturally Deaf do not feel it is worth their time, because they will not have access to the content.

Some towns, um ah, what do you call it, like ah, like free blood pressure screenings and free, you know, diabetic glucose checks. But they don’t, there’s other things, but Deaf people are like, ah I don’t worry about it, like they don’t want to be bother with it. They don’t do it. But like they provide these, like some of them, they provide it, in Spanish. But there’s no interpreting for deaf, there’s no ASL interpreting. They have Spanish interpreting; they don’t have it in ASL. So, the Deaf community doesn’t even bother with it because there’s no access, there’s no linguistic access.

Participant 270 (61-year-old Caucasian Female) describes an event when she is dealing with a sick family member. She feels that the provisions the hospital made are inadequate to meet her needs. It makes a lasting impression on her.

Like, if, a, hearing is sick, they’re able to get that help as quickly and need to get whatever therapy they need. And so like, I’ll never forget that, just like, Oh my God. Oh, wow.
You can see from that statement that she feels there is an imbalance between access to treatment for her and her family and the access she might receive if she is hearing.

**Refused.** Several participants discuss times when they requested services to enable them to have access (usually interpreters) and were refused these services. The individual’s immediate reaction varied based on the situation, but there is an overall sense of exasperation. The participants feel more than just frustration because this is something that happens all the time.

Participant 132 (20-year-old Hispanic Male) relates an experience going to the doctor. He had requested an interpreter when he made the appointment and had agreed to video relay interpreting (VRI) when the office said that is all it could provide. When he arrived for the actual appointment the office did not want to provide that either.

Where's the video interpreter? You have a machine. You know, I sign that way at least I could see through the interpreter. But it seemed like they kind of refused. They didn't want to do it. My mom noticed something odd. So, she explained that they need to have the video, the video interpreter for me. So, it was a little bit of an argument. So, you know, I explained the process. I told them when I made the appointment that I needed to have this.

During one particular Deaf chat, this very idea came up in conversation. One woman states that in the past she often felt pressured to not use services that she knew she needed. She states that the office staff would say that they could give her an appointment in 2 weeks if she didn’t need an interpreter, but if she needs an interpreter, she would have to wait 6 weeks. She feels that put pressure on her to not use an interpreter so the office would not have to pay for
it. She states that she felt stuck. She needed to see this doctor, but she also needs to understand what is being said in the appointment.

**Feeling invisible.** Participants describe feelings of being overlooked, feeling ignored or made to feel invisible. While not explicitly stated, there is a sense that participants feel as if they were less valuable when describing these interactions. An example is when participant 132 (20-year-old Hispanic Male) described an experience going to his doctor for a routine checkup. He is there alone and could not tell when the person is calling his name. He watches as the waiting room emptied around him, waiting for over an hour and a half. He assumed someone called his name and when he didn’t respond immediately, he is skipped and they went to the next patient, even though he informs them ahead of time that he is Deaf.

But it’s tough because I can’t even hear when they call me. You know, I don’t know when it’s my turn. And sometimes I feel like they ignore me, they skip me, you know they go to the next person because I didn’t answer.

Participants express feelings of being judged, especially if they are viewed as not conforming to the healthcare practitioner’s expectations. There is pressure to make life easier on the health care provider.

Participant 132 (20-year-old Hispanic Male) describes a situation during a visit with a health care provider. The participant feels offended because the health care provider asks if he can read lips. He feels as if he is being asked to change how he communicates in order to make the health care provider’s life easier.
Another thing that is really important, don’t judge me, this actually happened to me. I went to this doctor, I think it was a woman, a while ago, this first time meeting me, so we didn’t really know each other. I was trying to ask some questions. I have some sort of general physical. And there are some questions, I’m giving all the answers. And she said, can you read lips? And I said no, no, I don’t read lips. And I was like, why would you ask me that question?

**Need to Educate.** Participants report that their health care providers are often unaware of their rights, and it falls to the person who is Deaf to educate the health care provider. Participant 270 (61-year-old Caucasian Female) discusses how she wishes that her health care providers already had this knowledge. She expresses frustration because it seems like every time she has to go to a new doctor, she has to start all over again, informing them of her rights.

So sometimes I wish like they already knew like with the ADA law because it passed back, all the way back in 1990, 1991. Like this is not a recent thing. I wish they already knew it, they already had this so that. Like sometimes you have a young doctor, young like group that doesn’t understand that. Like you should learn this in medical school that, explain it to you, the ADA and how the office is required to look for an interpreter and have all of these services already set up because many of them don’t. Like, take 20 minutes in medical school, oh you have a Deaf patient, OK, this is what it is, and just expand upon that and tell them that it’s his responsibility to call an agency or to get it to get an interpreter. Fill out what specific things like, like it’s a tax write off. You can like, they don’t realize you can do this. Many of them have no idea. And they fight with me over it and they will yell at the interpreter. And the interpreter is like ghuh, you know, they’re not to blame for this.

When this researcher confirmed with the participant that she needed to educate her health care providers she responded “Yes, always. Always. I, it’s countless. It will be until the day I die.”

**Negative Feelings.** The most common feeling expressed by participants is frustration. Many participants express feeling like their experiences shouldn’t
be happening or those in positions of responsibility (such as health care providers) are not fulfilling their obligations.

Participant 173 (25-year-old African American and Hispanic Female) describes a situation where she is going to a doctor’s appointment alone for the first time. She informed the office ahead of time that she wanted an interpreter, but it is not until she arrived that she finds that an interpreter is not hired for her. Instead, the office expresses the feeling that video relay is just as good. The participant’s perspective is not taken into account.

And then I want to go by myself. So, I make an appointment, I let them know that I need an interpreter. And then I go to the doctor. There’s no interpreter. I’m so frustrated. I remind them again; I need an interpreter. They said, oh, no, you don’t need it. You don’t need it.

Other participants express feelings of anxiety, particularly centered around uncertainty regarding what would happen at their doctor’s appointment.

Participant 153 (55-year-old Caucasian Female) speaks to what she would like to see the front desk staff do in order to relieve some of that uncertainty and how it would relieve the anxiousness of members of the Deaf community.

Many Deaf individuals are really just wondering like will I have an interpreter there? Is this going to happen? Will I have what I need? You know, then the Deaf person is there worrying. It’s best that the front desk already arrange it. And make sure that they have the interpreters, then call and double check with the Deaf individual before the appointment to let them know [for example]. Hey, just so you know, hi, I’m calling to confirm your appointment, for September 21st, on Tuesday and you have an interpreter that is ready and set, your interpreter’s name is Tim.

**Deaf Culture**

Different aspects of Deaf culture are seen to be important when discussing health literacy. Within the theme of Deaf Culture, having access,
helping other members of the Deaf community, having a health care provider who is aware of their rights, feeling accepted and ASL being a natural language were seen as facilitators to obtaining, processing and understanding health information.

**Having Access.** Many participants relate positive experiences during which they feel like they do have access. Having access could mean different things, depending on the situation. It could mean the health care provider taking the time to use pictures and show the participant what is going on or demonstrating how to do something. Or it could simply mean making the process for getting an interpreter easy. Participants feel that being given better access was a sign that their culture was respected.

Participant 153 (55-year-old Caucasian Female) describes her current health care provider, and states that she feels they provide her with the access she needs. She feels this comes from an understanding of Deaf culture.

But the medical center I go to, now. . . They know how to work with the Deaf, they know Deaf culture. They know Deaf access, they know they need to have an interpreter, it’s perfect.

Other participants describe access as their physicians taking the time to show them results or demonstrate how to use items related to their health. Participant 295 (64-year-old Caucasian Female) describes a recent doctor’s appointment she had that she describes as a positive experience. She has questions about how to use both her new inhaler and her blood pressure cuff and the physician takes the time to demonstrate how to use both. Also, this physician made her feel like it is not a burden to take the extra time to spend with her.
And I told her I don’t understand how to do the inhaler. She said don’t worry about it. She showed me how to do it... She said alright. She said maybe you’re doing it wrong. I said OK, show me how to do it. She showed me how to do it. Fine.

**Helping Other People.** Five out of twelve participants who were interviewed discuss sharing knowledge with other members of the Deaf community. Two participants stated that other members of the community would seek them out to ask them questions. Another participant said that he would offer the information if the situation presented itself. This is seen as an appropriate thing to do to help the community, and a positive side of the lack of privacy in the Deaf community (discussed below). Participant 132 (20-year-old Hispanic Male) discusses how sharing information is seen as a positive within the Deaf community.

That's really important to the Deaf community. They make sure people are aware; they know what's going on. If somebody has an answer to something, they'll share it with other people. They don't keep quiet about it. It's impossible in the Deaf community to keep a secret anyway, but, you know, Deaf people if they know something, they'll tell other people and help support each other. So there really is that community aspect to it.

Participant 270 (61-year-old Caucasian Female) feels it is her responsibility to help other members of the Deaf community. She also states that she willingly contributes the information she has to her community, because others look to her as a resource.

No, I'm happy to share my information with other people. Like, general information, yeah, with the Deaf community, as a whole. If they ask me... Like if I'm socializing in the Deaf community, you know, obviously, I get those requests. Sometimes people will call me. That happens, it's not often, but it's pretty rare, but it happens.
This behavior is also observed during participant observation. If someone states, “oh yes, my doctor says I have this diagnosis” group attendees who have more information are expected to share that information. For example, at one Deaf chat, someone stated that her husband has diabetes. She is then expected to explain what diabetes is, and that there is a difference between type 1 and type 2 diabetes. Because her husband has type 2 diabetes, he doesn’t need to take insulin. All of this is new information to many others who were involved in the conversation.

**Aware of Rights.** Participants express frustration with feeling like they are constantly educating health care providers about their rights. They express a marked preference for providers who are already aware of their rights. Participant 153 (55-year-old Caucasian Female) states that she has an excellent relationship with her doctor and part of the reason is the doctor knows and is respectful of her rights.

The doctor knows my rights, they are aware. And the doctor is very respectful of my rights.

Another participant gave an example of one medical group she frequented that she described as better, because they displayed a patient bill of rights that included the right to have a sign language interpreter. So, if anyone gave her problems about having an interpreter present, she could point to the patient bill of rights they have displayed.

Like this has been since more than 20 years now, I've been dealing with this. But, you know, especially with [them] . . . they tend to be more aware. They provide interpreters, but they don't always like all departments, like sometimes they're just like, what I have to provide an interpreter? Like I have to talk to a manager. And they'll have something
posted, like patient rights, and like on the bottom it would say sign language ASL interpreter. And they’re like Oh. And I’m like yes! finally, you know, there have been something like a document that says it. So... they have that posted, so people can see the patient rights, so they don’t really give me a hard time. I just noticed that I just learned that last summer. I was like, I had no idea, I’ve been doing this for such a long time.

It is interesting to note that having this document displayed did not automatically mean that the staff in that office was aware she was entitled to an ASL interpreter. It only meant that she did not have to fight as hard when they gave her a problem.

**Feel accepted.** Participants discuss feeling accepted within the Deaf community. They feel they could be themselves with other members of the Deaf community. Participants express pride in their Deafness. Participant 173 (25-year-old African American and Hispanic Female) expresses this, contrasting it with her previous experience with her cochlear implant. She states her preference for using sign and the Deaf community.

And the cochlear implant I pretty much took off and stopped using, because I was in the Deaf world. And that’s a different place and they accepted me for who I was, and it’s very, very different from the hearing world. I’m Deaf. I have a group of people who are like me and many of us don’t want to use a cochlear implant. We sign. That’s how we communicate. And we’re comfortable with that and proud to be Deaf.

She continues in this vein when she discusses what she feels the ideal reaction would be when a baby is born Deaf.

I really wish when babies were born Deaf, now I know, I understand it’s natural for the hearing parents to be upset, that their baby is different. But the doctors need to say, hey, you know, don’t worry, they are going to be OK. This is America. We have all kinds of resources for deaf people. We have Deaf programs. We have sign language. Through all these things your kid can be successful. They can drive. They can do all kinds of things; you just have to believe in them. Let them believe in themselves. I
think if the approach was different when they're born, they would grow up being very, very different.

**Natural Language.** Participants report a deep appreciation for American Sign Language (ASL) as a natural language. Participants express a desire to be understood, and feelings that ASL and Deaf culture are inseparable. Participant 173 (25-year-old African American and Hispanic Female) states that desire to be understood. She expresses frustration at the feeling that health care providers are trying to “fix” people who are Deaf, when she feels her Deafness is not something that needs to be fixed.

Deaf culture is precious, you know. In our culture ASL is a natural language and doctors are only influencing people to get cochlear implants, um, and they are really risky operations and they are really trying get Deaf people to be fixed. And the problem is Deaf people are so delayed in their education. It's not a natural process, they don't have a natural language. And so, they have a lot of health problems as a result.

Participants stated a preference for a physician that signed. Three participants that were interviewed stating an ideal experience would include a physician who signed. Participant 177 (62-year-old Caucasian Female) expresses a desire for the people she interacts with to know sign language. When the participant is asked what an ideal health care experience would look like for her, she responded she wants a physician who signs.

One who signed! Definitely. I wish medical school would provide, would require a class in medical school for signing. I wish that would be a requirement, not an option, not optional at all. A required course, learn some sign language, especially for the nurses, the nurses too

**Making Decisions**
Participants discussed Family and Privacy as important to making decisions about their health. These themes and subthemes are shown on table 4.

<table>
<thead>
<tr>
<th>Themes</th>
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<td><strong>Family</strong></td>
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<td>Autonomy</td>
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<td><strong>Privacy</strong></td>
<td>Health Promoting Behaviors</td>
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**Family**

Different participants want different levels of family involvement in their decision-making process. Some participants want complete independence (or only superficial involvement from their family). Other participants are heavily dependent upon their family and want their families’ input.

**Independent.** Eight participants describe their family as having no or only minimal influence on their health decisions. Participants describe wanting independence, wanting to do it themselves or on their own, and their families’ influence being superficial. There were participants that acknowledged that experiences with health care providers could be easier when family is present. Yet they still expressed a desire for independence. Participant 173 (25-year-old African American and Hispanic Female) discusses a time she went to a health care provider and problems she faced. That experience is different from previous experiences when her mother is present for the visit.
Usually my mom goes, but this most recent time I wanted to be independent and I went by myself without her. I told her, you know, I didn't need to be there. I didn't want her to be the interpreter, I wanted to do this myself. And she said okay, fine. And then I went, and I was frustrated because there was no interpreter. And I left. You know, I'm already so dependent on her I really wanted to be independent and show I could do it myself.

**Dependent.** Four out of twelve participants stated a preference to have family involved in their care. Participants stated that they know their family cares and wants to be involved in what's going on with them. Participants stated that their family members have a better understanding of how things work at their doctor and can enable the visit to go more smoothly. None of the participants interviewed discussed using their family as interpreters instead of getting a professional, however, this was heard during participant observation. The person most likely to be solicited for advice is either a parent or sibling.

Participant 204 (34-year-old Caucasian Female) discusses the fact that her father comes with her to every appointment because he wants to make sure her health care providers are aware of everything that has been happening in her life. She wants his input and encourages him to be there. The participant is happy with this arrangement.

So, he [my father] wants to make sure that the doctor is aware of everything that has been happening. Whether it was the neurologist or if I had to see a dermatologist, for some side effects from the medicine, or um, ah, I forget the other kinds of doctors I've seen as well.

During participant observation, participants talk about the “dinner table syndrome.” Participants speak about how frustrating it could be to try and talk to their family and not receive accurate information or to be told “I'll tell you later.” There is a feeling that they were being left out of important information. Only one
participant who is interviewed spoke about family members not providing health care information.

Participant 299 (51-year-old Latino Male) discusses how his mother used to provide his health history at health care provider appointments, but now he needs to provide that information himself. He feels he doesn't know all of the information and keeps going to his mother to ask for the information. The participant is trying to make decisions without all of the pertinent information.

I have to fill all the information, family history, my mom used to take care of that. And whatever, now I do it myself, pages and pages and I don’t know this information. I said, “I'll be right back” and I went home. And I was like “Mom, help me” here it is. Yes, No, Yes, No, on all this and then I took a picture of it. And I told my mom I needed that family history information. And I keep that in a folder. And she said she’s working on it. And I said to my mom what would happen if my little cousin asked, you know? If my brother asked? I need everything right here written down. But she never did.

**Autonomy.** Participants discuss having to figure out what works best for them. Participants discuss trying different things to determine what best works for them, using experience to decide what course of action matches their needs, and knowing themselves. Participant 132 (20-year-old Hispanic Male) talks about looking in different places for information about his health. He states that he needs to determine what works best for him after evaluating all of the information and where it comes from.

I might find something new in a new diet or a new way of eating that helps you become healthier or stronger. I might change my diet depending on that. But for me, not really so much, you know I kinda figure out what works, or I prefer to follow what’s best for me. Sometimes it’s hard to decide, though. I might try something new. Where’s it from? Where’d I get the information? Um, you know, the doctor might have to say, yeah, yeah, that’s true. That really does work, or that doesn’t. But given the choice over the internet or the doctor, I’ll follow the doctor every time. You
know the internet is fast, but it doesn't always give the best information. So, I trust the doctor more.

Some participants were working towards autonomy, while others expressed a lack of autonomy. Participants express feeling like they had to accept whatever their health care provider said, like they didn’t have a voice. Other participants describe this as having to “put up with it,” “cooperate” or “just suffer.” These participants did not feel like they were an active part of making decisions about their own health.

Participant 82 (39-year-old African American Female) discusses how she does not have an active voice in her doctor’s appointment. She feels more like she is going to be examined, rather than to be an active participant in her own health.

So, I've just been making through, making, you know, kind of suffer through it. There’s a lot of times I feel it's a brief thing it's OK. I just go in and I leave.

Participant 132 (20-year-old Hispanic Male) expands on this when he talks about not wanting to feel judged. This participant describes an instance when the health care provider asks for permission before examining him but does not actually wait for an answer. The participant speculates that the health care provider does not understand the time delay required for an interpreter to convey the information to him and for him to respond.

You know, if the doctor's evaluating me doing an exam, I would appreciate it if the medical staff would clarify permissions, for example, you know, I realized I'm not looking at them, I'm looking at the hands of the interpreter. So sometimes they would, for instance, ask for permission to do whatever they have to do. But by the time I give permission, they've got it, or they've got their hands on me because of that delay I’m watching the interpreter. I wait for their permission. I say yes, but then they've gone
ahead without waiting for me to respond. They don’t understand the delay in communication.

**Privacy**

Participants were asked who they discussed their health with or who they asked for advice about their health. Five participants expressed a desire for privacy, stating that their information is confidential, personal, they do not discuss it with anyone, they keep their information to themselves. They do not share with other people and it is no one else’s business. There is a sense that the Deaf community is a small place, and everyone knows everyone else’s business. Participants do not talk about their personal information for fear of gossip.

Participant 177 (62-year-old Caucasian Female) states that she does not talk about her personal life because she is afraid being the target of gossip and misinformation.

My issues? Oh, no, no, no. Nuh-uh. I don’t discuss it that’s my business. You know, because like people don’t keep a secret, you know. They gab, and then there’s gossip and then it all just end up being a big game of telephone. By the time it reaches the last person, it’s completely changed.

**Health Promoting Behavior**

Participants express the belief that health is important to the individual. When discussing having good health, participants identified different behaviors such as having a good diet or exercising. Participant 270 (61-year-old Caucasian Female) talks about how important having good health is to her. She gave an example of healthier living as adding more exercise to her lifestyle.

All of them, you know, urology, all of the specialists. Yeah, it’s important. It’s my health, it’s my health, I want access to my, to the information. It’s my body. And we should all have good health. Not Perfect, you know, of
course, as you’re getting older, you realize how precious the good health is. . . I did do, like exercise, like walking, if I walk more or I was able, instead of using the elevator. I’m sorry, no, I’m not using the elevator. What I mean, is like the stairs instead of the elevator. Those kinds of things to tweak my behavior like that kind of stuff is. Like, but if I’m, like, out, in the sun in my mind I’ve got all this stuff going on, I’ve got to find a day like where to go and how to do these different things, if I have the time.
Chapter 6 – Discussion of Findings

The Research Question

The research question that was considered: How does someone who is Deaf obtain, process, and understand basic health information and use that information to make appropriate health decisions?

Relationship among Themes and Extant Literature

Many of the themes discussed in the previous chapter were related to one another. Below is a discussion of how those themes were related.

Communication

Communication is important to Deaf persons who participated in this study. Communication was related to almost every other theme: “Go to the Doctor, Audism, Deaf Culture and Family.

Communication and Go to the Doctor. Participants spoke about issues related to communication that they experienced during encounters with their health care providers. Some of these encounters were positive and some were negative. Participants stated that they were constantly considering if and how successful communication was going to be achieved. This is reflected in the literature (Kuenburg et al., 2016; Mprah, 2013; Naseribooriabadi, et al., 2017). Mprah (2013) conducted focus groups exploring Deaf persons’ perception of barriers to information about sexual and reproductive health. The author found communication between participants and health care providers to be a major barrier (Mprah, 2013). Kuenburg et al. (2016) and Naseribooriabadi et al. (2017) both conducted reviews of the literature. Naseribooriabadi et al. (2017)
specifically examines health literacy among persons who are Deaf, while Kunburg et al. (2016) examines access to health care for persons who are Deaf. Both articles found communication barriers with health care providers to be widespread.

Many articles aimed at health care providers focused on how to communicate with members of the Deaf community (Alexander et al., 2012; Meador & Zazove, 2005). Alexander et al. (2012) recommend using qualified interpreters, stating “without an interpreter, the clinician cannot make an adequate clinical assessment or explain the diagnosis and treatment, and the patient is denied the opportunity to discuss his or her concerns (p.979).” Meador and Zazove (2005) make a number of recommendations that could be useful for clinicians. These include not keeping secrets, being aware of ADA requirements to provide interpreters and being aware that persons who are Deaf tend to start with the most important topic and then “wind down” (Meador & Zazove, 2005, p. 218).

However, it does not appear that the lived reality of persons who are Deaf has been changed despite these attempts to educate health care providers. Harmer (1999) notes that individuals who are D/deaf encounter “extraordinary communication barriers” when having encounters with their health care provider (p. 73).

Participants that were interviewed could not take successful communication for granted. They often felt that they bore the responsibility of ensuring that communication was successful. This is despite the fact that the
Americans with Disabilities Act (ADA) requires that businesses and not-for-profits that serve the public ensure that communication with the deaf is “equally effective as communication with people without disabilities (Department of Justice, 2014).” Participants were aware of the ADA but felt that their health care providers were not adequately aware of ADA requirements. This is supported by Pendergrass et al. (2017) who found that Nurse Practitioners were unaware of their responsibilities under the ADA and thought of interpreters as a last resort. Meanwhile, interpreters were the preferred means of communicating for many participants in the study reported here.

Several participants in the study reported here, describe feeling like they need to put in extra work when seeing their health care provider in order to have a comparable experience to someone who is hearing. Participants describe taking it upon themselves to educate health care providers about the providers’ responsibilities under the ADA.

Ebert and Heckerling (1995) found that physicians in their survey thought that signing should be the primary method of communication for someone who is Deaf. However, less than one quarter of those physicians used interpreters as a preferred means of communicating with patients who are Deaf. This suggested that while physicians might believe that members of the Deaf community need interpreters, it has not yet become common practice.

Interpreters have been shown to facilitate communication when utilized at health care provider encounters (Karliner et al., 2007). Karliner et al. (2007) conducted a review of the literature and found that medical interpreters had a
positive impact on patients with limited English proficiency. In a study of 91 Deaf adults using focus groups to examine health care accessibility, participants stated that they had the best experience when there was an interpreter present with medical experience (Steinberg et al., 2006).

Yet, participants in the study reported here who wanted to use interpreters continued to have problems with access. Participants stated that office staff were poorly trained in how to obtain an interpreter and that staff was resistant to providing an interpreter when one was requested. Participants reported putting in additional effort, such as checking to make sure that an interpreter was scheduled and reminding the office staff not to wait until the last minute to schedule one.

Participants were aware of the cost of hiring an interpreter and worried that health care providers were unwilling to provide an interpreter due to the cost. Hiring an interpreter can be perceived as too expensive. Health care providers may be hesitant to provide an interpreter due to the perceived cost in relation to be the perceived benefit. Yabe (2020) discusses providers preferences for in-person interpreters or video relay interpreting (VRI) in critical care and non-critical care settings. The author found that cost was a factor in deciding which service to use (Yabe, 2020). In the study reported here, study participants overwhelmingly preferred a live interpreter over having someone on screen. This is supported by Yabe (2020) who found that Deaf and Hard of Hearing participants preferred an in-person interpreter, while providers sometimes preferred an in-person interpreter and sometimes had no preference. Lower cost
was noted as a benefit of using VRI. While VRI may be cheaper, participants stated that it does not produce the same quality of interpreting as a live interpreter.

Much of the current literature that exists regarding off-site interpreting speaks to its benefits compared to not having an interpreter (Masland et al., 2010). However, Kushalnager et al. (2019) surveyed persons who are Deaf and Hard of Hearing and found that more than half of those that had used VRI in the past year were dissatisfied with the service. The authors note that persons who are Deaf are often not given a choice about in person vs virtual interpreting and suggested this may contribute to the dissatisfaction (Kushalnager et al., 2019). In the study reported here at least one participant opted for an alternate means of communication if they requested an in-person interpreter and only VRI was offered.

**Communication and Deaf Culture and Audism/Deaf Culture.** Tom Humphries defines audism as an “audiocentric set of assumptions and attitudes” (Eckert & Rowley, 2013, p. 105). The definition incorporates the idea of having a hearing centric perspective and a preference for a hearing culture (Humphries, 2001). Many of the examples given by Humphries revolved around the preference for spoken language over signed language (Humphries, 2001).

Deaf culture has a different set of values, which is Deaf-centric. Audism prioritizes speaking and speech reading, while Deaf culture prioritizes signing. Communication, especially signed language, is an essential part of Deaf culture. American Sign Language (ASL) is the natural language of the Deaf community
and is vital to transmitting the values, traditions, and mores of the culture to the next generation. In 1988, Padden and Humphries first described Deaf Culture. They noted that it is not linked to a geographic region, but sign language plays a central role.

Participants in this study describe encounters in which they felt discriminated against. These included times when those with whom they were interacting acted as if hearing culture was superior. One of the most frustrating parts of audism for participants was when they felt like they were not being provided with the same level of access as others. Participants felt that services were out of reach because there was no way for them to communicate. They felt that interpreters were available in spoken languages, such as Spanish, but were not available in ASL. The experiences that participants discussed, such as not being provided with an interpreter, or being expected to know how to speech-read are commonplace. Similar experiences were noted by Swannack (2018) who looked at the health care experiences of members of the Deaf community in Cape Town South Africa. She reported that while members of the Deaf community viewed sign language interpreters as the ideal means of bridging communication barriers with health care providers, interpreters were rarely provided for visits (Swannack, 2018).

Participants continue to be plagued by a history that devalues signed languages and the Deaf experience, and prioritizes the medical model of deafness. One participant even drew a connection between education, social issues, and health care. This participant stated that she believed persons who
are Deaf had health problems because they lacked education. She also believed that health care providers should accept persons who are Deaf regardless of which they used, but she felt pressured to use her cochlear implant by both her family and her health care provider. The Institute of Medicine states that culture, society, the educational system, the healthcare system and the individual can all have an impact on health literacy (Nielsen-Bohlman et al., 2004).

For years sign language was not even considered a language, until William Stokoe observed that ASL had the same features as a spoken language (Stokoe, 2005). Prior to that it was it thought to be a form of pantomime (Stokoe, 2005). His work provided the groundwork for ASL being valued on par with other languages.

Oralism dominated Deaf education in the United States beginning with the Milan Conference in 1880. To this day many audiologists tell parents not to sign to their children because it will prevent them from acquiring spoken language, despite there being no evidence to support this assertion (Moores, 2010). In many oral schools, sign language was only taught to those that were considered “oral failures”. Sign language was seen as a less prestigious form of communication. It was seen as something you did when you could not speak, instead of something you chose (Moores, 2010). Deaf culture places a high value on signed communication.

**Communication and Family and Audism.** Participants discussed various interactions with their family, including how their family both facilitated and posed a barrier to communication during health care encounters. Some
participants wanted to have their family involved in their health care visits. They discussed how having family members present could make their visit easier. Other participants discussed how their family did not sign and how that made communication more difficult in general and at health care visits in particular.

The majority of children who are born deaf are born into families where they are the only person who is deaf. Approximately 95% of parents of deaf children do not learn sign language (McKee et al., 2019; Vaccari & Marschark, 1997). This leads to complicated communication within a family. Several participants, when discussing interactions with their family, noted that their immediate family does not sign, making communication with their family difficult.

Having easy communication with one’s family has been shown to have several benefits in the Deaf community. For example, Deaf children of Deaf parents (compared with Deaf children of hearing parents) have better academic performance, a more positive self-image, and are less prone to impulsivity (Vaccari & Marschark, 1997). The authors suggest that ease of parent-child communication is at least partly responsible for these results (Vaccari & Marschark, 1997). Joseph et al. (1995) found that Deaf teenagers were most likely to receive information about basic concepts of sex education such as birth control and sexually transmitted disease from their peers. Their hearing counterparts were most likely to receive this information from their parents (Vaccari & Marschark, 1997). The authors did not address the rationale behind this. However, the lack of a common language between the teenager and their parent is a reasonable explanation for this difference.
The same participant mentioned earlier discussed how she feels pressured by her family to wear her cochlear implant. This could be an example of audism since her family expected her to conform her communication to make her hearing family more comfortable.

In the study reported here, participants reported that if someone in their family did sign, their family was called upon to interpret for them. Barnett (2002) notes that adult family members of persons who are Deaf are frequently called upon to interpret in health care settings, even though this is problematic. Other participants noted that when a hearing parent or sibling went with them to an appointment it was common for the health care provider to address the hearing family member instead of talking with the participant. At least one participant recalled a time when her doctor’s office requested to speak to her mother instead of her, when trying to discuss issues about the participant’s health. The participant felt this was inappropriate.

**Go to the Doctor**

Participants discuss different aspects of their experiences with their health care providers. The relationship between the participant and their health care provider is related to Deaf Culture. Also, this theme is related to participants’ making appropriate health decisions through the theme of Health Promoting Behaviors and audism’s subtheme of need to educate.

**Go to the Doctor and Deaf Culture.** Participants in this study held a cultural view of deafness which can contrast with a medical view of deafness. As noted previously, Deaf culture views deafness positively and many of those who
consider themselves a part of the cultural group do not want their deafness fixed. This is in line with how Deaf culture is described in the literature (Andrews et al., 2004; Lane et al., 1996).

The medical model views deafness as a deficit, a sensory/physiological condition, that needs to be fixed with hearing aids or cochlear implants (Hauser et al., 2010; Young, 1999). It is possible that having a medical model view of deafness could negatively impact how a health care provider interacts with a person who is Deaf.

During the interviews, participants noted the importance of a good relationship with their health care provider. Participants stated that having access to services, having a provider who is aware of their rights, and feeling accepted were aspects of Deaf culture that are related to a good and trusting relationship with their provider. Participants in the study reported here discussed instances when they felt pressured to forego having an interpreter due to pressure from their health care provider. As noted earlier, cost was seen as a barrier to providing an in-person interpreter (Yabe, 2020). Ku and Flores (2005) argue in that interpreting services should be reimbursed by health insurance companies in order to increase the regular use of such services. Brennan et al. (2013) conducted a literature search to evaluate trust in the patient-provider relationship. They found that while there are still gaps in the literature, a reciprocal trusting relationship is important for positive health outcomes (Brennan et al., 2013). If members of the Deaf community feel pressured this could effect the trusting relationship. No research was located that addressed how a trusting
relationship could be affected by how health care provider’s perceives the interpreter.

**Go to the Doctor and Health Promoting Behavior.** Yom Din et al. (2014) note that a person’s visits to their general practitioner can influence that person’s lifestyle. Health care providers can identify unhealthy behaviors and educate persons to make better decisions (Yom Din et al., 2014). The World Health Organization (WHO) defines health promotion as “interventions that are designed to benefit and protect individual people’s health and quality of life by addressing and preventing the root causes of ill health, not just focusing on treatment and cure” (WHO, 2020).

Several participants in the study reported here discussed times when they tried to find information about how to keep themselves healthy. Health care providers were described as a main source of information for participants who were looking for health promotion information. Even when participants first went to other sources of information, such as the internet or books, they sought out health care providers to verify the accuracy of that information.

Low computer literacy has been linked to low health literacy. Persons with low health literacy have been shown to have difficulty accessing digital communication, such as websites (Bickmore & Paasche-Orlow, 2012). Participants in the study reported here used the internet to research topics about their health. However, they stated that they often found the information on the internet confusing and were unsure whether they could trust this information.
Participants stated that they were more likely to trust information from their health care providers than from the internet.

Pinilla et al. (2019) studied how diabetes was conceptualized by members of the Deaf community in Munich, Germany. They found that participants frequently turned to the internet for information about their health. Pinella et al. (2019) did not report how trustworthy the participants considered this information. Bodie and Dutta (2008) reported that most hearing adults who access health information on the internet found the information a trustworthy supplement to information received from their health care provider. The study reported here found that participants found information on the internet confusing and preferred information from their health care provider.

**Deaf Culture**

In addition to the relationships previously noted, Deaf culture is also related to privacy.

**Privacy.** The Deaf community tends to be small and interconnected. This can be beneficial to members of the community, fostering a sense of connection. However, it can also lead participants to be cautious about discussing personal information. Participants stated that they were not likely to discuss their health with anyone for fear of it becoming fodder for gossip. The participants that were interviewed preferred to keep their information to themselves in order to ensure their privacy. This is consistent with Steinberg et al. (1998) who stated 46% of Deaf participants would not discuss mental health issues even with a close friend. However, McKee et al. (2011) found that a majority of cardiovascular
knowledge obtained by Deaf individuals in their study was from personal experience or members of their community. It is possible that a person who is Deaf may be more likely to discuss a medical topic in general but not discuss personal experiences.

Interpreters are considered part of the larger Deaf community of interest (Eckert, 2010). Meador and Zazove (2005) discussed the need for confidentiality in a research setting and note that it parallels privacy concerns in clinical settings, especially when working with interpreters. Mwaeri (2018) acknowledged that the concern for privacy in the Deaf community is not limited to the United States. Mwaeri (2018) discusses a situation in Kenya, where qualified interpreters are difficult to obtain. The author states that privacy in a health care setting can be compromised simply by having a third party in the room. The Registry for Interpreters for the Deaf, Inc. (RID) has a code of conduct that includes maintaining confidentiality (RID, 2020).

**Contribution of Findings to Current Knowledge**

There is evidence in the literature that members of the Deaf community visit their health care provider at a different rate than hearing counterparts. However, there is limited evidence to explain the differences. Zazove et al. (1993) found that participants who are deaf and hard of hearing visited their physicians more frequently than a hearing control group. The study by Zazove et al. (1993) included both participants who were deaf and hard of hearing. Barnett and Franks (2002) found that compared to the general population, postlingually deafened persons (persons who became deaf after acquiring the ability to speak)
visited the physician more often, but prelingually deafened persons visited the physician less often. The authors do not specifically ask about membership in the Deaf community but assume that those that are prelingually deafened are more likely to be culturally Deaf (Barnett & Franks, 2002). It is possible to consider oneself culturally hearing even though deafened from birth. Conversely, one can become deafened later in life and consider oneself a part of Deaf culture. Neither article offered an explanation for this behavior.

In the study reported here, most participants reported frequent visits with their health care providers. The study reported here only inquired if participants self-identified as part of the Deaf community; all identified as members of the Deaf community.

Based on participant responses in the current study there are several possible factors that may affect how often a person sees their health care provider. Participants stated that they received the majority of information about their health from their health care providers. They viewed their health care providers as a trusted source of information. However, participants also noted that communication was often a struggle. It is possible that more visits are necessary to obtain all the needed information from the health care provider due to this communication barrier. Participants discuss how they have to call their health care providers on a regular basis to clarify information. If the calls are unsuccessful, additional visits may be necessary.

Participants in the current study reported feeling rushed at visits with health care providers, and receiving superficial explanations of their health
problems. This was documented by Nemon (1980) who surveyed deaf and hard of hearing individuals about their satisfaction with their health care providers. They found survey respondents felt rushed through their appointments (Nemon, 1980). O’Hearn (2006) studied satisfaction in Deaf women’s experience with prenatal care. The author notes that one woman had increased satisfaction because her doctor took the time to explain what was happening to her and made sure she understood (O’Hearn, 2006).

Another factor that may explain why the Deaf see their health care provider more frequently is privacy. Participants in this study discussed how privacy is a concern for them. Privacy concerns prevented them from discussing their health with others in the Deaf community because such information is often freely shared within the community. The Deaf community is small and tight knit, and people are frequently interconnected. This could make participants even more reliant on their health care providers for information.

Participants did state that they used the Internet to research information about their health. However, several participants stated that they found this information confusing and would check with their health care providers to verify if the information was accurate. This may be due to the lower reading level documented in the Deaf community and the fact that health information is frequently written at a 9th or 10th grade level or higher (Stossel et al., 2012). For example, Vargas et al. (2015) found the readability grade level of ten different websites about breast reconstruction after breast cancer surgery between 10.7 and 15.8. Zazove et al. (2013) found the average reading level of a sample of
106 deaf adults in Michigan was approximately 6th grade, with lower reading levels associated with membership in the Deaf community. Thus, much written health information is inaccessible to the average person who is Deaf. This need for further clarification may also contribute to why Deaf persons see their health care provider more frequently.

For the majority of the Deaf community, ASL is their primary language and written English is a second language. Interestingly, when discussing searching for information on the internet none of the participants mentioned resources that were in ASL or specifically targeted to the Deaf community. Though limited, there are resources available in ASL, for example, the National Center for Deaf Health Research (NCDHR) produce videos in ASL on a variety of topics and maintains a list of other resources. In a study with 32 college aged students from National Technical Institute for the Deaf (NTID), it was found that ASL health videos were difficult to find (Kushalanger et al., 2015). This may be due in part to the fact that two large websites were recently shut down, deafhealth.org and Medline + in ASL, thus making information in ASL more scattered. Participants may not have mentioned these resources because they had similar issues with access.

Finally, participants note that they did not take advantage of community screening because there was no linguistic access. No studies could be found directly comparing how frequently persons who are Deaf use preventative services compared to persons who are hearing. Tamaskar et al. (2000) found
that Deaf and Hard of Hearing persons were less likely to be offered information on preventative services from media or their health care providers.

McKee et al. (2011) found that in a group of (n=89) 50 to 75-year-old Deaf persons, subjects were more likely to get a flu vaccine if they had language concordance with their healthcare provider. None of the participants in the study reported here had a provider who signed. MacKinney et al. (1995) found an improvement in a number of preventative services when participants were provided with an ASL interpreter for all primary care office visits. Tamaskar et al. (2000) also found that persons who are Deaf are more likely to consider a preventative service important if it was performed at the last visit. Otherwise, persons in their study who were Deaf rated preventative services as less important than their hearing counterparts (Tamaskar et al., 2000). Deaf persons using preventative services less frequently may contribute to the fact that Deaf persons see their health care provider more frequently.

Participants in the study discussed here talked about how important it was to have an interpreter to facilitate communication. It is typically the front desk staff at their health care provider that participants depend on to arrange the interpreter. Participants reported that office staff lack knowledge in this area. Several participants reported having to educate their providers about how to arrange for an interpreter. Participants also reported that providers were unaware that they are legally obligated to provide an interpreter when one is requested. Participants also reported having to go back and check to make sure that an interpreter had been arranged. They reported being treated with
insensitivity in their initial interaction. More education is needed for medical office staff regarding the ADA, how to find an interpreter and Deaf Culture in general.

Participants overwhelmingly expressed a preference for in-person interpreters over video relay interpreting (VRI). Participants discuss technical problems they’ve experienced such as slow or spotty connection or not being able to hear or see the interpreter. There were also issues of the interpreter not being able to match the participant’s language. It was also noted that with VRI the interpreter is stuck on the tripod, but a live interpreter is able to fully assess a situation and kneel down, bend over, or whatever the situation calls for. This is consistent with Yabe (2020) who found that limited placement, poor connectivity, and limited language assessment were all negatives of using VRI.

Healthcare providers may be unaware that persons who are Deaf prefer an in-person interpreter. Several participants in this study refused to use VRI if an in-person interpreter was not provided. The costs of having an in-person interpreter may be outweighed by the fact that there might be fewer visits necessary if an in-person interpreter was available to facilitate communication.
Chapter 7 – CONCLUSION

Summary

Health literacy is defined as the ability to obtain, process, and understand basic health information and put that information into practice (Nielsen-Bohlman, et al., 2004). Inadequate health literacy is a stronger predictor of a person’s health than age, income, employment status, education level, and race (Ad Hoc, 1999). Health literacy is worse in persons who are cultural minorities and linguistic minorities compared to the general population (Nielsen-Bohlman et al., 2004).

Persons who are Deaf consider themselves part of a cultural and linguistic minority group. Membership in Deaf culture is based on shared values and a shared way of thinking and doing things, not just a common characteristic (hearing loss). For most persons who are Deaf, their primary language is American Sign Language (ASL), and English is a second language. In addition to having limited English proficiency, other risk factors for low health literacy in the Deaf community include low general literacy levels, membership in a minority population, and socioeconomic factors (Nielsen-Bohlman et al., 2004; McKee et al., 2014; Singleton et al., 2004; Zazove et al., 2013).

The study reported here asked how does someone who is Deaf obtain, process, and understand basic health information and use that information to make appropriate health decisions?

An ethnographic study was conducted in order to understand health literacy from the perspective of someone who is culturally Deaf. This researcher
conducted 12 interviews and participant observation. Participant observation took place at 24 different events for a total of 75 hours. Participant observation occurred during the same time period (between September 2019 and February 2020) the interviews were being conducted. Prior to starting data collection, the informed consent was translated into ASL and videotaped. Three ASL interpreters were recruited and they obtained Human Subjects Certification. Limited demographics were collected on participants in order to maintain confidentiality. Participants that were interviewed ranged between 20 and 64 years old. Ten interviews were conducted in person. The final two interviews were conducted over Zoom due to COVID-19 restrictions. The average length of the interviews was 46 minutes, with the longest being 1 hour and 42 minutes (Zoom) and the shortest being 23 minutes (in person). No difference in average length was noted overall between the in-person and Zoom interviews. Interviews were conducted in ASL with two interpreters at each interview. Each interview was video recorded and transcribed verbatim, and then analyzed for themes.

Seven themes were identified in this ethnographic study. These were: communication, going to the doctor, audism, Deaf culture, family, privacy, and health promoting behaviors. Themes were identified based on participant responses across interviews and participant observation. Several subthemes emerged for 5 of the 7 themes. For the theme Communication, subthemes included interpreters, preferred method, technology, ask questions, and miscommunication. For the theme Going to the Doctor, subthemes included relationship, health is important, feeling rushed, and money. For the theme
Audism, subthemes included lack of access, refused, feeling invisible, need to educate, and negative feeling. For the theme Deaf Culture, subthemes included having access, helping others, aware of rights, feeling accepted, and natural language. For the theme Family, subthemes included independent, dependent, and autonomy. The themes of Privacy and Health Promoting Behaviors did not include subthemes. Both facilitators and barriers to health literacy were identified, many themes were interrelated.

**Conclusions**

All of the participants who were interviewed discussed communication. Participants felt responsible for ensuring effective communication with their health care provider. Participants discussed employing different methods of communication with their health care provider depending on the participants comfort level and their level of knowledge. For example, participants were more likely to request an interpreter if they were seeing a specialist and had little previous knowledge of the topic under discussion.

While not every participant wanted an interpreter in every situation, every participant stressed how important it was to have qualified interpreters available. Interpreters was a subtheme of communication. Participants spoke at length about the need to have a qualified interpreter who matched them linguistically. Participants preferred to have an interpreter available for health care visits, however, participants continue to experience difficulties communicating. One of the main reasons participants experienced communicating were difficulty obtaining interpreters. Participants noted that both their physician and the
physician’s office staff were uneducated about their responsibility under the American with Disabilities Act (ADA). More training is needed for all health care providers on their responsibilities under the ADA and the benefits of providing adequate communication.

Several participants in the study reported here described feeling like they need to put in extra work when seeing their health care provider in order to have a comparable experience to someone who is hearing. Participants described taking it upon themselves to educate health care providers about the providers’ responsibilities under the ADA.

Technology provided a means of communication access for participants; however, technology was not a substitute for having an interpreter present. Participants discussed experiences with video relay interpreters (VRI), such as poor internet connection, linguistic mismatch (the interpreter couldn’t match the participant’s style of signing) and inability to adjust to the situation at hand. Participants overwhelmingly preferred having an in-person interpreter. Participants viewed costs as a barrier to hiring an interpreter, and some opted to forego an interpreter due to pressure from their health care provider. This could negatively affect a trusting relationship.

Health care providers were described as a main source of information for participants who were looking for health promotion information. Participants noted that they preferred health care providers who took time with them and did not make them feel rushed. Having a better awareness of the needs of the Deaf
community and Deaf culture may make health care visits go more smoothly for everyone involved.

Even when participants first went to other sources of information, such as the internet or books, they sought out health care providers to verify the accuracy of that information. Participants in the study reported here used the internet to research topics about their health. However, they stated that they often found the information on the internet confusing and were unsure whether they could trust this information. Although limited, ASL resources are available online, this information was not mentioned by participants. The information may be difficult to access by members of the Deaf community and may be unknown to health care providers.

Deaf culture was not well understood by health care providers. Participants experienced audism from their health care providers. For example, participants described encounters where the health care provider expected the participant to speech-read instead of relying on an ASL interpreter. Participants felt that interpreters were more likely to be provided by health care providers for other languages, such as Spanish. Also, participants felt they could not take advantage of health screenings, such as health fairs, because of being denied linguistic access. Provider awareness and acceptance of Deaf Culture appear key to establishing the participants’ trust and improving their level of accessibility to health care.

Participants discussed family and privacy as important when making health decisions. Some participants wanted their family involved in their health
care visit. While they acknowledged that it might make a visit to their health care provider go more smoothly, other participants wanted to be independent. Some participants reported healthcare providers were resistant to this desire for independence, which was made apparent by asking to speak to a family member instead of attempting to discuss concerns directly with the participant. Participants felt this was because it was easier for the health care provider to communicate with a family member instead of directly with them. Family members often do not sign.

Participants were asked if they discuss their health with anyone prior to making a decision, and if they asked anyone for advice. The majority of participants stated they did not discuss their health with anyone due to concerns about privacy within the close-knit Deaf community. Therefore, there is a real concern about information being spread unintentionally among their community peers. Participants chose not to discuss personal information out of a concern that it would end up going beyond what that person had intended. The literature addressed the need for interpreters to be aware of privacy issues, but almost no literature was found addressing privacy concerns within the Deaf community (Meador & Zazove, 2005; Mwaeri, 2018; Steinberg et al., 1998).

**Strengths and Limitations**

**Strengths**

This researcher used ethnography to develop a deeper understanding of participants' experiences regarding obtaining, understanding, and processing health information and using that information to make health decisions. This
research uncovered perspectives of the participants and gave voice to a seldom studied group. Also, this study was conducted in a geographic area that does not have a dense concentration of members of the Deaf community, and therefore it is possible to be more representative of the resources available to most members of the Deaf community.

The entire study, including the consent form, was conducted in American Sign Language (ASL). In order to ensure that every participant received the same information during the consent process, the consent form was translated into ASL and videotaped using professional equipment (television studio). Members of the community were involved in the translation work group.

The findings of this qualitative study were based on sound ethnographic methodology. This researcher collected socio-cultural data on the experiences of members of a Deaf community regarding health literacy. Data included participant observations as well as individual interviews to explore the experiences, beliefs, attitudes, and behaviors of participants. The researcher was able to modify research questions in order to illuminate data that needed additional clarification. For example, after participants started bringing up problems with video relay interpreters (VRI) a question was added to the interview guide stating that other participants had discussed experiences with VRI and asking what experiences they had with VRI.

The use of multiple technologies to collect and record the data generated a large amount of data which were analyzed. In-person interviews were videotaped and Zoom interviews were recorded using the program’s internal
feature (with participant consent). Observations during participant observations were recorded in a reflexive journal.

The researcher’s involvement in the community for almost ten years prior to beginning this study helped establish trust with the participants.

Limitations

There was a wide range of ages and some variation in race, however the majority (67%) of those interviewed were Caucasian. Being cognizant of ethical issues that could arise if too much personal information were requested from each participant, few demographics were collected. Some additional demographic data that may have been helpful include income, educational level, language preference and when the person became Deaf (pre- or post-lingually). This researcher’s familiarity with the population may also be a limitation, due to this researcher’s bias.

While probing was done, there are specific instances where it would have been useful to have more information. For example, in a particular case when a participant was describing a breakdown in communication, it would have been useful to know more details about the entire situation, or if other factors such as culture may have played a part. For example, in that specific situation it would have been helpful to know more about the individual perception of the situation.

Recruitment was more difficult than anticipated. Prior to beginning the study, members of the Deaf community expressed enthusiasm for this study. However, several persons that were approached declined to participate or did not
return the messages when approached by this researcher. It is possible that those who agreed to participate were different from those who did not.

**Implications for Knowledge Generation and Practice and Recommendations**

There are multiple recommendations for knowledge generation and implications for practice.

**Implications for Knowledge Generation**

Participants in this study discussed a preference for in person interpreters over video relay interpreters (VRI). The literature highlighted the benefits of video relay over not having an interpreter, but there is limited literature comparing in-person interpreters and VRI. Future research could investigate the benefits of having an in-person interpreter on a person’s understanding and the relationship to health outcomes. Future research might also investigate if having an in-person interpreter affects the number of repeat visits. Would having an in-person interpreter save the health care provider money in the long run?

Participants in the current study desired different levels of participation from their family. Having a family member involved in a visit with the health care provider made the visit go more smoothly for some but others desired independence from their family. More research could be done about how family dynamics affect the health of a person who is Deaf. For example, what effect does family acceptance of Deaf culture, or having a person who signs in the family, have on how well a person obtains health information.
Participants in the study reported here discussed a need for privacy. Participants did not want to talk about their health problems due to worries that their private information could spread within the community. Additional research could be done about how privacy concern within the Deaf community affects a person’s health. Does the Deaf community differ from other cultural and linguistic minority groups, and if so how?

Additional qualitative research with the Deaf community could be carried out to confirm the findings of this study. More research is needed from the perspective of members of the Deaf community. For example, the Deaf community is not homogeneous and different participants may have different perspectives. Therefore, a larger study asking similar questions may reveal a broader perspective.

Participants in the study reported here discussed how they use the internet but did not report regularly using ASL resources. A study that looks at how persons who are Deaf find, use and perceive ASL resources would be useful, especially given that two important resources in ASL no longer exist. Is more education needed for persons who are Deaf to be able to locate resources or do the resources need to be revised in some way to make them more accessible?

Implications for Practice

Participants discussed difficulties obtaining an interpreter when one was requested. Participants shared stories on resistance from both health care providers and office staff. Office staff and health care providers appeared
unaware of their responsibilities under the Americans with Disabilities Act (ADA). As a result, participants felt that they needed to educate providers, including nurse practitioners. Providers need additional training regarding their responsibilities under the ADA. Specifically, nurse practitioners were noted in the literature to not fully understand that they needed to provide an interpreter to facilitate communication. Nurse practitioner programs should include information about the ADA and how to fulfill their commitments.

Participants also discussed times when they were made aware of the financial burden of obtaining an interpreter. There were times when participants felt pressured to not use an interpreter. Participants stated they felt caught in the middle of this situation. A possible solution may be for insurance companies to reimburse providers for interpreters, and thus remove the financial burden.

Providers should also be prepared to train office staff. Office staff is typically a person’s first point of contact, and the front office staff is usually the one who is scheduling an interpreter for the appointment. When interpreters were not provided, participants had to make the decision about whether they would reschedule or continue with the visit without an interpreter. If participants decide to reschedule, this could result in a delay in care and have a negative impact on their overall health. Making sure the office staff is aware of how to schedule an interpreter can make the experience better for members of the Deaf community.

Participants in the study reported here noted that it was important for providers to be aware of Deaf culture to establish a trusting relationship. Trusting
relationships with health care providers have previously been reported as being important to health outcomes. Providers should make every effort to educate themselves on Deaf culture in order to foster this trusting relationship.

Participants in the study reported here noted that health care providers did not always communicate directly with them but often tried to communicate through a non-signing hearing family member. Health care providers and office staff could be trained not only on interpreters but on technology such as video relay services that can facilitate communication with members of the Deaf community.

Participants stated that they used the internet to look for information about their health. However, none of the participants stated that they used resources specifically designed for members of the Deaf community. Resources in ASL are available on the internet, yet participants did not state that they used these resources. The Deaf community needs to be better educated regarding the resources that are available on the internet. Also, health care providers should be made aware of what resources are available, since they are a primary source of information for participants.

Participants complained that community resources, such as health fairs, were not linguistically accessible. Interpreters should be provided for all community screening events. Participants noted that interpreters were provided for other languages, so similar accessibility should be provided for the Deaf community.
Health care providers are the primary source of information for members of the Deaf community. Participants noted that they preferred health care providers who took time with them and did not make them feel rushed. Health care providers may need to consider adding additional time for visits with Deaf patients. Some participants with complex needs stated that they would like to follow up with a nurse to ensure that they understood. Perhaps a nurse care manager would be beneficial for members of the Deaf community. Also, the teach-back method should be used when instructing members of the Deaf community to help avoid misunderstandings and improve their comprehension.

Persons who are Deaf are part of a cultural minority. Culture factored in when assessing when looking at health literacy. This study investigates health literacy from the perspective of members of the Deaf community, and reveals themes that were not previously well identified in the literature.
References


Boness, C. L. (2016). Treatment of Deaf Clients: Ethical Considerations for


Hoffman-Goetz, L., Meissner, H. I., & Thomson, M. D. (2009). Literacy and
Cancer Anxiety as Predictors of Health Status: An Exploratory Study. 
*Journal of Cancer Education*, 24, 218-224. 
https://doi.org/10.1080/08858190902910871


Improvements in Preventive Care and Communication for Deaf Patients: Results of a Novel Primary Health Care Program. *Journal of General Internal Medicine*, 10, 133-137. https://doi.org/10.1007/bf02599667


https://nnlm.gov/outreach/consumer/hlthlit.html


Starks, H. & Trinidad, S. B. (2007). Choose your Method: A Comparison of


Weiss, B. D., Mays, M. Z., Martz, W., Castro, K. M., DeWalt, D. A., Pignone, M.


Young, A. M. (1999). Hearing parents’ adjustment to a deaf child-the impact of a


## Appendix A

### Summary of Articles cited in Chapter 2

<table>
<thead>
<tr>
<th>Citation</th>
<th>Research Question/ Purpose</th>
<th>Theoretical Framework</th>
<th>Methods</th>
<th>Sample</th>
<th>Results</th>
<th>Conclusion</th>
<th>Problems with Study</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aguirre, A. C., Ebrahim, N., &amp; Shea, J. A. (2005). Performance of English and Spanish S-TOFHFLA among publicly insured Medicaid and Medicare patients. Patient Education and Counseling, 56, 332-339.</td>
<td>Analyze the psychometric properties of the English and Spanish S-TOFHLA for three patient populations</td>
<td>None Stated</td>
<td>English and Spanish S-TOFHLA</td>
<td>936 non-Hispanic and (primarily African American) 368 Hispanic patients completed the English S-TOFHLA 1066 Hispanics completed the Spanish S-TOFHLA</td>
<td>Validity of both versions of the S-TOFHLA was supported by strong positive relationships with education and inverse relationship with age.</td>
<td>Most results are consistent with 1992 NALS, however women performed better S-TOFHLA than men in both English and Spanish. No explanation is given for this difference. Overall, the S-TOFHLA is a useful research tool for estimating health literacy.</td>
<td>Author's state that while sample size is large, it is not diverse.</td>
<td>Differe ntiates subgroups of Hispanics</td>
</tr>
<tr>
<td>Armstrong, K., Ravenell, K., L., McMurphy, S. &amp; Putt, M. (2007). Racial/Ethnic Differences in Physician Distrust in the United States. American Journal of Public Health, 97 (7), 1283-1289.</td>
<td>Examine the racial, ethnic and geographic variation in physician distrust in the United States</td>
<td>States a theoretical framework having trust as an essential component of the patient/physician relationship, but doesn't state</td>
<td>Secondary analysis of Community Tracking Study Telephone survey</td>
<td>11422 household in 20 communitie s with at least 5% Black and 5% Hispanic</td>
<td>In a multivariate analysis gender, education, race/ethnicity, age, insurance coverage, and household income all influenced physician trust. Patterns also varied by site.</td>
<td>On average, higher distrust for physicians among members of Hispanic and Black communities.</td>
<td>Large comparison group (white). Out of the 11422 people in the study 7905 were white. Some cities</td>
<td>Best statement in the article is that problem is probably more complex that previously suggested.</td>
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<tr>
<td>Advantages and disadvantages of TOFH LA, S-TOFH LA, and REAL M.</td>
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<td>None Stated</td>
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<tr>
<td>Describe the development of an abbreviated version of the Test of Functional Health Literacy in Adults (TOFHLA) to measure patients’ ability to read and understand health-related materials.</td>
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<tr>
<td>Evaluate health care utilization in deaf taking into account socio-economic group (age of onset)</td>
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<td>The Andersen Behavioral Model of Health Services Use</td>
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<tr>
<td>“used a community participatory approach to develop and administer an ASL-accessible health survey to estimate deaf individuals”</td>
<td>Community involvement in survey development, focus of the methods section is on how they involved the Deaf community, which I guess is appropriate, Low incidence of Smoking Higher obesity in Deaf, increased suicide attempts, Higher Lifetime and Past Year Partner Violence.</td>
<td>Mostly White, Well Educated. Rochester has a lot of deaf-centric resources, so</td>
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<td>Would Community Participatory Research be considered Theoretical Framework? Not well explained</td>
<td>Need to investigate reason behind low smoking. Community Based a success</td>
<td></td>
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<tr>
<td>Name</td>
<td>Summary</td>
<td>Methods</td>
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<td>-------------------------------------------------------------------------</td>
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<tr>
<td>Sign Language Users to Identify Health Inequities. American Journal of Public Health, 101, 2233-2244.</td>
<td>Identify health inequities.</td>
<td>d in article.</td>
</tr>
<tr>
<td>Baron-Epel, O., Balin, L., Daniely, Z. &amp; Eidelman, S. (2007). Validation of a Hebrew Health Literacy Test. Patient Education and Counseling, 67 (1-2), 235-239.</td>
<td>Validate an instrument (S-TOFHLA) to measure health literacy in Hebrew</td>
<td>None Stated</td>
</tr>
<tr>
<td>Boulware, L. E., Cooper, L. A., Ratner, L. E., LaVeist, T. A. &amp; Powe, N. R. (2003). Race and Trust in the Health Care System. Public Health Reports, 118, 358-365.</td>
<td>Assess the independent relationship between race and trust in physicians, hospitals and health insurance plans</td>
<td>None stated</td>
</tr>
<tr>
<td>Brega, A. G., Ang, A., Vega, W., Jiang, L., Beals, J., Mitchell, C. M., . . .</td>
<td>Understand why health literacy is related to outcomes. tested a theoretical</td>
<td>Secondary Analysis Health literacy measured</td>
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**Note:** The table above provides a structured overview of various studies focusing on health literacy, its measurement, and implications for health outcomes, including validation of Hebrew Health Literacy Tests, assessment of health trust in medical professionals, and the relationship between health literacy and health status and risk.
<table>
<thead>
<tr>
<th>Robideaux, Y. (2012). Mechanisms Underlying the Relationship between Health Literacy and Glycemic Control in American Indians and Alaska Natives. Patient Education and Counseling, 88, 61-68.</th>
<th>framework proposing that diabetes-related knowledge and behavior mediate the relationship between health literacy and glycemic control</th>
<th>via 7 items from 3 different questionnaires</th>
<th>138 tribes in 13 states</th>
<th>Knowledge mediates relationship between health literacy and behavior</th>
<th>enhancing outcomes among AI/ANs with diabetes.</th>
<th>measured via valid and reliable instruments. Thus results are suspect.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesser, A. K., Woods, N. K., Wipperman, J., Wilson, R. &amp; Doug, F. (2014). Health Literacy Assessment of the STOFHLA: Paper Versus Electronic Administration Continuation Study. Health Education and Behavior, 41 (1), 19-24.</td>
<td>assess if administration of the Short Test of Functional Health Literacy in Adults (STOFHLA) through a computer-based medium was comparable to the paper-based test in terms of accuracy and time to completion</td>
<td>None Stated</td>
<td>A randomized, crossover design</td>
<td>Randomized STOFHLA</td>
<td>57 participants completed baseline and follow up, additional 23 completed only baseline. English Speaking, 18 &amp; older recruited from a Midwestern family medicine residency program Overwhelmingly white and well educated</td>
<td>no significant difference between paper- and computer-based surveys</td>
</tr>
<tr>
<td>Chew, L. D., Bradley, K. A. &amp; Boyko, E. J. (2004). Brief Questions to identify Patients with Inadequate Health Literacy. Family Medicine, 36 (8), 588-594.</td>
<td>Validates one question to screen for low health literacy</td>
<td>None stated</td>
<td>Participants were given 16 health literacy questions along with the STOFHLA Answers on a likert like scale</td>
<td>N=332 Pudget Sound VA clinic in Seattle Predominately white male</td>
<td>3 questions could potentially find marginal health literacy</td>
<td>Each of the 3 questions could be used as an effective screening test for inadequate health literacy. Only small percentage with low (4.5%) or marginally (7.5%) health literacy</td>
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<tr>
<td>Chisolm, D. J., &amp; Buchanan, L. (2007). Measuring Adolescent Functional Health Literacy: A Pilot Validation of the Test of Functional Health Literacy in Adults. <em>Journal of Adolescent Health</em>, 41, 312-314.</td>
<td>This paper presents a preliminary construct validation of the TOFHLA in teens using the same method used previously in adults.</td>
<td>TOFHLA</td>
<td>50 young people, aged 13–17 years</td>
<td>Correlations between the TOFHLA-R and both the WRAT-3 and REALM were statistically significant suggesting that the tools are measuring the same underlying construct. TOFHLA-N was not correlated to the REALM and WRAT-3</td>
<td>This study supports the use of the TOFHLA-R in adolescent populations.</td>
<td></td>
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<tr>
<td>Cutilli, C. C. &amp; Bennett, I. M. (2009). Understanding the Health Literacy of America: Results of the National Assessment of Adult Literacy. <em>Orthopedic Nursing</em>, 28 (1), 27-32.</td>
<td>Review results of NAAL and implications for practice</td>
<td>N/A</td>
<td>19,000 adults (including 1,200 prisoners)</td>
<td>12% scored proficient, 53% had an intermediate level of health literacy, 22% had basic health literacy and 14% had below basic health literacy, Those with the lowest levels are health literacy are most likely to be: &gt;65 years old, male, Black or Hispanic; speak other than English school, have &lt; a high school diploma; at or below poverty; have Medicare, Medicaid, or no insurance; and do not</td>
<td>It is estimated that one in four adults have inadequate health literacy and another 25% have only marginal health literacy</td>
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<td>Acknowledges that there may have been some self-select bias. Does not discuss how this sample scored on the various health literacy measures, only if they were consistent.</td>
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<tr>
<td>Authors</td>
<td>Title/Description</td>
<td>Language</td>
<td>Criterion</td>
<td>Test Details</td>
<td>Validation Details</td>
<td>Study Details</td>
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<tr>
<td>Diaz, D. A. &amp; Alchin, L. (2013).</td>
<td>Importance and Promotion of Linguistic Safety in the Healthcare Setting. Clinical Journal of Oncology Nursing, 17 (4), 374-375.</td>
<td>None Stated</td>
<td>n/a</td>
<td>n/a</td>
<td>Language barriers, cultural barriers and low health literacy all affect patient care and a breakdown in any of these areas affect good communication.</td>
<td>There are few incentives for health care facilitators to improve communication with clients.</td>
</tr>
<tr>
<td>Davis, T. C., Crouch, M. A., Long, S. A., Jackson, R. H., Bates, P., George, R. B. &amp; Bairnsfather, L. E. (1991).</td>
<td>Rapid Assessment of Literacy Level of Adult Primary Care Patients. Family Medicine, 23 (6), 433-435.</td>
<td>Test validity of the REALM</td>
<td>None Stated</td>
<td>Correlated with two other instruments</td>
<td>Highly correlated with other two word recognition instruments (concurrent validity). Good Test-Retest and Inter-rater Reliability Takes 3-5 minutes to administer.</td>
<td>Could be a useful instrument for practice to determine what kind of teaching material a person needs (low literacy, all pictorial, etc.).</td>
</tr>
<tr>
<td>Davis, T. C., Long, S. W., Jackson, R. H., Mayeaux, E. J., George, R. B., Murphy, P. W. &amp; Crouch, M. A. (1993).</td>
<td>Rapid Estimate of Adult Literacy in Medicine: A Shortened Screening Instrument. Family Medicine, 25 (6), 391-395.</td>
<td>Evaluate the validity of the shortened version of the REALM</td>
<td>None Stated</td>
<td>Face validity, criterion validity.</td>
<td>Highly correlated with other standardized tests.</td>
<td>Quicker to administer than the original while still a valid test of reading ability.</td>
</tr>
<tr>
<td>Dotty, M. M. (2003).</td>
<td>Hispanic Patients Double Burden: Lack of Health Insurance and Limited English. The Commonwealth Fund, Retrieved from <a href="http://www.commonwealthfund.org">http://www.commonwealthfund.org</a></td>
<td>None Stated</td>
<td>Based on a national survey conducted by telephone in April through November of 2001. nationally representative sample of 6,722 adults ages 18 to 64 includes 2,773 non-Hispanic whites, 885 African Americans.</td>
<td>Hispanics lacking English language proficiency face the greatest barriers to care, especially if they are uninsured.</td>
<td>The health needs of the burgeoning Hispanic population will continue to grow and long-term negative health effects are likely if barriers to care, both financial and linguistic, persist.</td>
<td>Significance is the only statistic that is given anywhere in the article (and %) would be a See table A-3 for significance (not mentioned anywhere in actual article).</td>
</tr>
<tr>
<td>Doty, M. M. &amp; Ives, B. L. (2002). Quality Health Care for Hispanic Populations: Findings from The Commonwealth Fund Health Care Quality Survey. Retrieved from <a href="http://www.commonwealthfund.org/~media/files/publications/fundreport2003/feb/hispanicpatients%20double%20burden%20lack%20of%20health%20insurance%20and%20limited%20English/doty_hispanicdoubleburden_59220pdf.pdf">http://www.commonwealthfund.org/~media/files/publications/fundreport2003/feb/hispanicpatients%20double%20burden%20lack%20of%20health%20insurance%20and%20limited%20English/doty_hispanicdoubleburden_59220pdf.pdf</a> on February 5, 2014.</td>
<td>Report findings from Health Care Quality Survey in Hispanics.</td>
<td>None Stated</td>
<td>Telephone interviews in multiple languages</td>
<td>6722 adults living in continental US</td>
<td>Hispanic adults are at high risk for lacking basic access to medical care both because of socio-demographic factors such as insurance and communication barriers with their health care provider. The authors do not draw conclusions, simply present facts. However, one can see there are differences in how Hispanic adults approach health care and white Americans approach health care. Prese nt a numbe r of statisti cs, but do not use them to draw a picture based on the current literatu re. Not really a problem, but could have been better.</td>
<td>better article if was discussed</td>
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<tr>
<td>Freel, B. L., Clark, M. D., Anderson, M. L., Gilbert, G. L., Musyoka, M. M. &amp; Hauser, P. C.</td>
<td>investigate ASL proficiency and reading skills within a sample of deaf</td>
<td>None stated</td>
<td>Cross sectional, descriptive</td>
<td>55 Deaf from DC area – college students, graduate</td>
<td>1) Sig relationship between signing skill Need to emphasize ASL and English equally. ASL has been</td>
<td>The mean Passa ge Comprehensi on</td>
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<td>none</td>
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</table>

Hispanics are further categorized by language ability into two groups: English (N=691) Spanish (N=387).
### Deaf Individuals' Bilingual Abilities: American Sign Language Proficiency Skills and Family Characteristics

*Psychology, 2 (1), 18-23.*

- (2011). Deaf individuals, & ascertain the impact of familial characteristics on language and literacy development.

- (2011). Deaf individuals, & ascertain the impact of familial characteristics on language and literacy development.


<table>
<thead>
<tr>
<th>Study</th>
<th>Methodology</th>
<th>Findings</th>
<th>Implications</th>
<th>References</th>
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<tbody>
<tr>
<td>(2011).</td>
<td>Deaf individuals, &amp; ascertain the impact of familial characteristics on language and literacy development.</td>
<td>1) Sig relationship between maternal education and native signing ability and English reading skill.</td>
<td>Model accounted for 38.4% of variance.</td>
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<tr>
<td>Katz, M. L., Ferketich, A. K., Paskett, E. D. &amp; Bloomfield, C. D. (2013).</td>
<td>Health Literacy Among the Amish: Measuring a Complex Concept Among a Unique Population. Compare health literacy of Amish with non-Amish in the same geographic area.</td>
<td>Amish scored lower than non-Amish on REALM in same geographic area when compared by gender.</td>
<td>Many Amish participants had limited or marginal health literacy.</td>
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<tr>
<td>Article</td>
<td>First study is descriptive and second study is quasi-experimental</td>
<td>States an n of 46, but that’s for both studies. Really they have an n=20 for study one (divided into 2 groups) and an n=26 for study 2 (divided into 3 groups)</td>
<td>No real difference between high and low readers in study 1. In study 2, only high readers improved from intervention. No difference based on reading habits</td>
<td>Don’t offer an explanation for these results. State that teachers of the deaf need to be aware of difference in reading level and possibly employ strategies to encourage concentrating on entire text.</td>
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<td>Kelly, R. R., Albertini, J. A., &amp; Shannon, N. B. (2001). Deaf College Students' Reading Comprehension and Strategy Use. American Annals of the Deaf, 146 (5), 385-400.</td>
<td>Article recounts two studies both looking at reading comprehension and the difference between high and low level readers</td>
<td>None stated</td>
<td>States an n of 46, but that’s for both studies. Really they have an n=20 for study one (divided into 2 groups) and an n=26 for study 2 (divided into 3 groups)</td>
<td>No real difference between high and low readers in study 1. In study 2, only high readers improved from intervention. No difference based on reading habits</td>
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<td>Kirsch, I. S., Jungeblut, A., Jenkins, L., &amp; Kolstad, A. (1993). Adult Literacy in America: A First Look at the Results of the National Adult Literacy Survey. Retrieved from <a href="http://files.eric.ed.gov/fulltext/ED358375.pdf">http://files.eric.ed.gov/fulltext/ED358375.pdf</a></td>
<td>Profile the literacy level of US adults</td>
<td>None Stated</td>
<td>Random sample of 13600 people over the age of 16 and 1100 prisoners in 11 states Black and Hispanic households were oversampled adults whose proficiencies were within the two lowest levels were far less likely than their more literate peers to be employed full-time, to earn high wages, and to vote.</td>
<td>Low literacy effects every aspect of one's life and it is both a person's personal responsibility and the responsibility of government agencies, businesses and families</td>
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<td>Investigate the relationship between critical health literacy and with whom the person discusses health information among ASL using college student</td>
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<td>None stated</td>
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<td>Computer based survey in English and ASL and responses to a scenario shown in a video (scored according to a rubric)</td>
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<td>38 Deaf who use ASL and 38 hearing</td>
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<td>Functional health literacy was not associated with critical health literacy</td>
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<td>Health related discussions with friends was related to critical health literacy, but discussion with family was not</td>
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<td>Perhaps those who could communicate with their parents are resources for their friends who could not communicate with their family</td>
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<td>95% have adequate health literacy (atypical)</td>
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<tr>
<td>Some results presented separately</td>
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<td>Provides overview of NALS</td>
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<tr>
<td>None stated</td>
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<td>One on one interviews using computer assisted personal interviewing. In English or Spanish</td>
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<td>19,000 adults: 18000 in the community and 1200 in prisons. Weighted to represent total population</td>
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<td>See original for results</td>
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<td>Health literacy scores were correlated with education, age, language, race, gender, and socioeconomic factors.</td>
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<td>Health literacy is complex and multiple factors are correlated with health literacy.</td>
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<td>Introduction provides good definition of health literacy</td>
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<td>Develop a valid health literacy test for Spanish Speaking population</td>
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<tr>
<td>None Stated</td>
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<td>Compared with the TOFHLA-S, test-re-test reliability after 2 weeks, English version of SALS and REALM were correlated</td>
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<td>202 English Speaking and 201 Spanish Speaking participants</td>
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<td>Test re-test used subset of n=40 Factor analysis</td>
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<td>Correlates well with TOFHLA-S, has good reliability.</td>
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<td>Valid and easy to administer test of health literacy but may take more time than is reasonable in a clinical setting.</td>
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<td>Most of sample was from Mexico (n=141), with no more than 22 from Based on the REALM</td>
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<td>REALM was designed to test reading level, SALS</td>
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<tr>
<td>Lee, T. W., Kang, S. J., Lee, H. J., &amp; Hyun, S. I. (2009). Testing Health Literacy Skills in Older Korean Adults. <em>Patient Education and Counseling</em>, 75, 302-307.</td>
<td>Develop a valid and reliable screening test for limited health literacy for older Korean adults.</td>
<td>None Stated</td>
<td>A pool of 102 items was generated based on empirical referents, which, after expert review, field study, and content validity, was reduced to 29 items with three subscales. Rasch analysis was also performed to assess the unidimensionality of the construct and item adequacy.</td>
<td>Nearly half of participants did not complete elementary school, 77% had monthly income of less than $1000 USD and needed at least 300 for factor analysis.</td>
</tr>
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</table>

What are the experiences of Deaf people living in Newfoundland regarding end-of-life and palliative care services?

**Methodology**

Interviews

- Naturalistic approach
- No formal analysis of video, only transcripts.
- Audio analyzed using thematic and discourse analysis

7 participants (4 men and 3 women) ages ranging from 40-65 ASL Deaf

Participants had limited knowledge of death and palliative care services and support services

Communication difficulties biggest challenge faced by Deaf

Better training is needed for health care providers on how to communicate with Deaf esp end of life issues. Thus, Deaf can be educated on all options.

Only analyzing translation makes some analysis suspect

Deaf encounters with the Health care system are often characterized by communication difficulties, fear, mistrust, and frustration.


Overview of different methods of obtaining qualitative data and problems with each

n/a

n/a

n/a

Claims to discuss a variety of qualitative methods, but really concentrate on interviews

Not a bad overview, but could get most of the information provided here elsewhere


Determine whether provider language concordance is associated with improved receipt of

None Stated

Cross-sectional study

Over 95% white

89 deaf respondents aged 50-75 years from the Deaf Health Survey

Deaf respondents who reported having a concordant provider were more likely to report a greater

Language-concordant patient–provider communication is associated with higher appropriate

Question only asked about most recent visit, so it is

Article suggests using tele-health to expand
<table>
<thead>
<tr>
<th>Services Among Deaf Sign Language Users. American Journal of Preventative Medicine, 41 (1), 75-79.</th>
<th>preventive services among deaf respondents</th>
<th>number of preventive services when compared to deaf respondents who reported having a discordant provider even after adjusting for race, gender, income, health status, health insurance, and education. use of preventive services by deaf ASL users.</th>
<th>possibl e partici pants were put into wrong group reach of existin g ASL fluent physici ans.</th>
</tr>
</thead>
<tbody>
<tr>
<td>McKee, M. M., McKee, K., Winters, P., Sutter, E. &amp; Pearson, T. (2014). Higher Educational Attainment but not income is protective for Cardiovascular Risk in Deaf American Sign Language (ASL) users. Disability and Health Journal, 7, 49-55.</td>
<td>Examine whether educational attainment and/or annual household income were inversely associated with cardiovascular risk in a sample of Deaf ASL users. None Stated cross-sectional study self-report</td>
<td>302 Deaf respondents aged 18-88 years from the Deaf Health Survey Deaf respondents who reported &lt;high school education were more likely to report the presence of a CVDE compared to Deaf respondents who reported having &gt;4 year college degree after adjustment. However, low-income Deaf individuals were not more likely to report the presence of a CVDE compared to high-income</td>
<td>Low educational attainment was associated with higher likelihood of reported cardiovascular equivalents among Deaf individuals. Higher income did not appear to provide a cardiovascular protective effect for Deaf respondents. Since this was done in Rochester, anywh ere else in the countr y is likely to be worse.</td>
</tr>
<tr>
<td>Reference</td>
<td>Investigate risk perceptions of cardiovascular disease among Deaf ASL users, linking perceptions to features of Deaf culture and communication.</td>
<td>None Stated</td>
<td>Four focus groups were conducted in Rochester, New York in ASL</td>
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<tr>
<td>McLeod-Sordjan, R. (2011). Assessing Functional Health Literacy Among Hispanic Elders With Chronic Disease. <em>The Journal for Nurse Practitioners</em>, 7 (10), 839-846.</td>
<td>Outline the linguistic and culturally sensitive tools available to assess FHL in the elderly Hispanic population.</td>
<td>None Stated</td>
<td>Critique of 4 different instruments that have been translated into Spanish.</td>
</tr>
<tr>
<td>Miller, M. S. (2010). Epistemology and People who are Deaf: Deaf Worldviews, Views of the Deaf World, or My Parents are Hearing. American Annals of the Deaf, 154 (5), 479-485.</td>
<td>Epistemology generally defined and specifically applied to Deaf community. 2 kinds of epistemology intensively looked at</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Mohr, P. E., Feldman, J. J., Dunbar, J. L., McConkey-Robbins, A., Niparko, J. K., et al. (2000). The societal costs of profound hearing loss in the United States. International Journal of Technology Assessment in Health Care, 16 (4), 1120-1135.</td>
<td>Provide a comprehensive, national, and recent estimate of the economic burden of hearing impairment. A secondary objective is to establish a baseline cost for interventions aimed at reducing the level of hearing impairment. The underlyin g conceptual framework we use is a cohort-survival model with a Markov process. (not explained)</td>
<td>cohort-survival model</td>
<td>Secondary analysis</td>
</tr>
<tr>
<td>Myaskovsky, L., Burkitt, K. H., Lichy, A. M., Ljungberg, I. H., Fyffe, D. C., Ozawa, H., Switzer, G. E., Fine, M. J. &amp; Boninger, M. L. (2011). The Association of Race, Examine the association of race and culture with QOL factors such as perceived health status in people with spinal cord injury</td>
<td>None Stated</td>
<td>Cross-sectional multi-site 6 different sites REALM-SF</td>
<td>275 people with spinal cord injury age 16 and older</td>
</tr>
<tr>
<td>Cultural Factors, and Health Related Quality of Life in Persons with Spinal Cord Injury. Archives of Physical Medicine and Rehabilitation, 92, 441-448.</td>
<td>Consistent at all of the sites. Instructions not consistent?</td>
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<td>NNLM. (2014). National Network of Libraries of Medicine. Health Literacy. Downloaded from <a href="https://nnlm.gov/outreach/consumer/hlthlit.html">https://nnlm.gov/outreach/consumer/hlthlit.html</a> on February 26, 2016.</td>
<td>Health literacy is a huge problem, and one that should be a priority because it impacts so many other areas</td>
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<th>Identify key role of organizations such as the Dept of Health and Human Services to foster research, guide policy and develop knowledge</th>
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<tr>
<td>Pollard, R. Q. &amp; Barnett, S. (2009). Health Related Vocabulary Knowledge Among Deaf Adults. Rehabilitation Psychology, 54 (2), 182-185.</td>
<td>investigate health-related vocabulary knowledge in a sample of deaf adults.</td>
</tr>
<tr>
<td>Pollard, R. Q., Dean, R. K., O’Heam, A. &amp; Haynes, S. L. (2009). Adapting Health Education Material for Deaf Audiences. Rehabilitation Psychology, 54 (2), 232-238.</td>
<td>Describes the process of adapting material for a Deaf population so that they are culturally appropriate, not just translation.</td>
</tr>
<tr>
<td>Ryan, F., Coughlan, M. &amp; Cronin, P. (2007). Step-by-step guide to Critiquing Research. Part 2: Qualitative Research. British Journal of Nursing Research, 16 (12), 738-744.</td>
<td>Addresses fund of information differences between Deaf and hearing</td>
</tr>
<tr>
<td>Schley, S., Walter, G. G., Weathers, R. R., Hennessey, J. C., Burkhauser, R. V. (2011). Effect of Postsecondary Education on the Economic Status of Persons who are Deaf or Hard of Hearing. Journal of Deaf Studies and Deaf Education, 16 (4), 524-536.</td>
<td>examines the effect that postsecondary education has on earnings and the duration of time spent in the Social Security disability programs for young persons who are deaf or hard of hearing.</td>
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<td>Analyzed using chi-square</td>
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<td>with negative health outcomes, specifically poor self-reported health in Japanese, Filipinos, Other AA/PI, and Whites, Diabetes in Hawaiians and Japanese and Depression in Hawaiians</td>
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<td>n/a</td>
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<td>Examines cultural influences on health literacy, cancer screening and chronic disease outcomes. Connects cultural beliefs with ability to follow instructions</td>
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<td>Summery / Editorial piece</td>
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<td>n/a</td>
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<td>Only minimally touched on health literacy. More focused on health promotion in a more general sense.</td>
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<td>assess English vocabulary use by deaf children on an</td>
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<td>None Stated</td>
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<td>Students were asked to retell “The Tortoise and the</td>
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<td>72 deaf elementary school students of various</td>
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<td>All deaf writers showed significantly lower use of function words</td>
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<td>ASL-proficient, deaf second-language</td>
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<td>Deaf students were sampled</td>
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<td>Writing samples are included from 4</td>
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<p>| n/a |
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| It is imperative that health care providers have the capacity to understand and address diverse health cultures as we seek to tackle low health literacy among multiple groups. |</p>
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<tr>
<th>Study</th>
<th>Methodology</th>
<th>Participants</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Smith, S. R. &amp; Samar, V. J. (2016). Dimensions of Deaf/Hard-of-Hearing and Hearing Adolescents’ Health Literacy and Health Knowledge. Journal of Health Communication, 21 (sup 2), 141-154.</td>
<td>Measure health literacy and health knowledge in Deaf/Hard of Hearing Adolescents and Compare it to Hearing Adolescents</td>
<td>Nutbeam</td>
<td>Descriptive Comparison between groups</td>
</tr>
<tr>
<td>Steinberg, A. G., Sullivan, V. J. &amp; Lowe, R. C. (1998). Cultural and Linguistic Barriers to Mental Health Service Access: The Deaf Consumer’s Perspective. American Journal of Psychiatry, 155 (7), 982-984.</td>
<td>Understand the knowledge attitudes and beliefs about mental health in the Deaf community</td>
<td>None stated</td>
<td>Interviews in ASL</td>
</tr>
<tr>
<td>Steinberg, A. G., Wiggins, E. A., Barmada, C. H. &amp; Sullivan, V. J. (2002). Deaf Women: Experiences and Perceptions of Health Care System Access. Journal of Women’s Health, 11 (8), 729-741.</td>
<td>None Stated</td>
<td>Focus groups with a subsample also completing a written survey (n=20)</td>
<td>45 Deaf women who chose ASL as their primary form of communication</td>
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<tr>
<td>Study</td>
<td>Research Question</td>
<td>Methodology</td>
<td>Sample Size</td>
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<td>Sudore, R. L., Landefeld, C. S., Perez-Stable, E. J., Williams, B. A., Schillinger, D. (2009). Unraveling the relationship between literacy, language proficiency and patient-physician communication. Patient Education and Counseling, 75, 398-402.</td>
<td>Examine whether the effect of health literacy (HL) on patient-physician communicatio varies with patient-physician language concordance and communicatio type.</td>
<td>Cross-sectional Questionnaires</td>
<td>771 outpatients, 53% English speaking, remaining Spanish speaking.</td>
</tr>
<tr>
<td>Sudore, R. L., Landefeld, S., Williams, B. A., Barnes, D. E., Lindquist, K. &amp; Schillinger, D. (2006). Use of a modified Informed Consent Process Among Vulnerable Patients: A Descriptive Study. Journal of General Internal Medicine, 21, 867-873.</td>
<td>Describe a modified consenting process used in a RCT about advanced directives. Determine if any other factors (race, language, etc) play a role in comprehensio n of consent form</td>
<td>TOFHLA-SF</td>
<td>204 participants who could speak either English or Spanish “well or very well”</td>
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</table>
| Traxler, M. J., Corina, D. P., Morford, J. P., Hafer, S. & Hoversten, L. J. (2014). Deaf Readers Response to Syntactic Complexity: Evidence for Self-Paced Reading. Memory and Language | Does syntactic complexity affect deaf readers in the same way that it affects hearing readers? Do deaf readers respond to helpful semantic cues? | None Stated | 3 groups Single time | 68 Deaf participants, subdivided into native signers, early and late | Deaf had the least accuracy, however, those who were native ASL users had the greatest accuracy in the group (lower than the monolingual) | Native ASL users were similar in comprehensi on to bilingual. Differences between the three groups of Deaf could lead to a theory of Deaf reading. | ?? Bilingual groups came from a variety of differ ent first langua ges?? States that they compa re to bilingual to deem if proble m is linguist ic or due to
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<th>Cognition, 42, 97-111.</th>
<th>that supplement syntactic structure cues?</th>
<th>(n=31) and bilingual (n=34) group, but comparable to the bilingual group.</th>
<th>hearin g status. But there are also educational issues that should be taken into account.</th>
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<td>Estimate that the annual cost of low health literacy ranges from $106 billion to $238 billion When one accounts for the future costs of low health literacy the real present day cost of low health literacy is closer in range to $1.6 trillion to $3.6 trillion.</td>
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<td>Both human and financial costs to low health literacy.</td>
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<td>Estima te of costs</td>
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<td>See first page of article for good overview.</td>
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<td>Methodology</td>
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<td>Weekes, C. V.</td>
<td>2012</td>
<td>African Americans and Health Literacy: A Systematic Review. The Association of Black Nursing Faculty Journal, 23 (4), 76-80.</td>
<td>Provides a systematic review of the current literature related to the health literacy of African American adults.</td>
</tr>
<tr>
<td>Weiss, B. D., Mays, M. Z., Martz, W., Castro, K. M., DeWalt, D. A., Pignone, M. P., Mockbee, J., &amp; Hale, F. A.</td>
<td>2005</td>
<td>Quick Assessment of Literacy in</td>
<td>Develop a quick and easy screening tool in both English and Spanish</td>
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<td>Reference</td>
<td>Study Title</td>
<td>Study Design</td>
<td>Data Source</td>
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<td>White, S., Chen, J. &amp; Atchison, R. (2008).</td>
<td>Relationship of Preventive Health Practices and Health Literacy: A National Survey.</td>
<td>Descriptive</td>
<td>N=18,100</td>
</tr>
<tr>
<td>Woodcock, K. &amp; Pole, J. D. (2007).</td>
<td>Health Profile of Deaf Canadians: Analysis of Canada Community Health Survey.</td>
<td>Cross-Sectional Secondary Analysis</td>
<td>Used data from Canada Community Health Survey (CCHS), 131,535 Canadians aged 12 and older</td>
</tr>
<tr>
<td>Zanchetta, M. S. &amp; Pourehslami, I. M. (2006).</td>
<td>Health Literacy within the Reality of Immigrants’ Culture and Language.</td>
<td>Report from conference</td>
<td>Not original research</td>
</tr>
<tr>
<td>Zazove, P., Meador, H. E., Reed, B. D. &amp;</td>
<td>Investigate the association of reading level with family.</td>
<td>Cross-sectional</td>
<td>106 participants recruited</td>
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cultural, linguistic and hearing loss variables.

from two other studies the authors were involved in 84% were Caucasian and 60% had completed at least high school (meaning 40% of sample did not complete high school) at an average of 6th grade. In multivariate analysis, higher scores were associated with higher income, college degree, and teacher using English. Other variables significant in single analysis.

low in a Deaf population. being a memb er of the Deaf comm unity shown that highly educat ed Deaf person s often have significant misco mmuni cation proble ms with their physici ans; writing with these person s has been shown to be problema tic
Invitation to Participate in a Research Study!

Help Teach us about Your Experiences with Health Information

Would you be willing to help us?
Are you an Adult (18-89) Member of the Deaf Community?

What to expect: One interview about your experience with health care providers (doctors, nurses)  How you get information about your health  How you understand that information, and how you use that information

Interviews will be used to better understand health from YOUR perspective!

Interviews will be done in ASL

Time: No more than 2 hours
Where: Place of your choosing
Will be scheduled at your convenience

Please text or email if interested
Janine Pezzino, RN (Principal Investigator)
180 University Ave, Room 202 C
Newark, NJ 07102.
(862) 368-8996 v/t
jpezzino@rutgers.edu
Appendix C – Original Interview Questions

Interview Questions

“Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”

I want to know about what it is like for you to get information about your health. I’m really interested in your experiences and your point of view, so there is no right or wrong answers to any of these questions.

- What is a typical experience with a doctor (or other health care provider) like for you?
  - When you have a typical doctor’s appointment, what do you do to prepare? Please describe for me the process starting with deciding you need to make an appointment.
  - What is a typical experience talking to your doctor like for you?
- What are some problems you face when you see the doctor? (If it doesn’t come up ask about communication barriers/talking to their doctor)
- Please give me an example of a time when you had a question about your health? What did you do to get information? Did you change your behavior based on this information?
- Do you ever use the internet to look for information about your health? Where do you go? How do you decide if it’s a webpage that can be trusted?
- Think about a time you had to make a decision about your health. What did you find confusing? How did you make a decision?
- When you have a question about something related to your health where do you go for an answer? (Is there a person you go to for an answer?)
  - How do you determine if the information you receive is trustworthy?
- Who do you discuss your health with? Would you talk to the same person about any health-related issue?
- What do you see as common health concerns for your community?

(Other questions to be inserted as follow up based on participants answers)
Appendix D – Final Interview Questions

Interview Questions

“Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”

I would like to know about what it is like for you to get information about your health, how you understand that information and how you use that information. I’m really interested in your experiences and your point of view, so there is no right or wrong answers to any of these questions.

- Think about the last visit you had to your doctor, please describe that appointment for me starting me when you decided to go to the doctor.
  - Was this a typical experience for you?
    - If not already discussed make sure you touch on how you make the appointment
- What are some problems you face when you see the doctor? (If it doesn’t come up ask about communication barriers/talking to their doctor)
- Some other people have mentioned problems they have had with VRI. Tell me about an experience you’ve had with VRI.
- What would you consider an ideal experience with your doctor?
- Please give me an example of a time when you had a question about your health? What did you do to get information? Did you change your behavior based on this information?
- Do you ever use the internet to look for information about your health? Where do you go? How do you decide if it’s a webpage that can be trusted?
- When you have a question about something related to your health (maybe something about keeping yourself healthy) where do you go for an answer? (Is there a person you go to for an answer?)
- Think about a time you had to make a decision about your health. What did you find confusing? How did you make a decision?
  - How do you determine if the information you receive is trustworthy?
- Who do you discuss your health with? Would you talk to the same person about any health-related issue?
- What kind of role does your family play in your health? Do you take care of other people in your family? What are some challenges?
- What do you see as common health concerns for your community?

(Other questions to be inserted as follow up based on participants answers)
Appendix E – Abbreviation List

Abbreviation List

ADA – American with Disabilities Act
ASL – American Sign Language
BCC - Bergen Community College
BSL - British Sign Language
CDC - Center for Disease Control and Prevention
CDI - certified Deaf interpreter
DWU - Deaf Women United
ESL - English as a Second Language
HHS - Hawaii Health Survey
HOH – Hard of Hearing
IOM - Institute of Medicine
IRB - Institutional Review Board
IPC - Interpersonal Processes of Care
LEP - Limited English Proficiency
NAAL - National Assessment of Adult Literacy
NALS - National Adult Literacy Survey
NCDHR - National Center for Deaf Health Research
NNLM - National Network of Libraries of Medicine
NTID - National Technical Institute for the Deaf
NVS - Newest Vital Sign
PIAT-R- Peabody Individual Achievement Test-Revised
REALM - Rapid Estimate of Adult Literacy in Medicine
REALM-SF - Rapid Estimate of Adult Literacy in Medicine, Short Form
RID - Registry for Interpreters for the Deaf, Inc.
RTID - Rochester Technical Institute for the Deaf
SAHLSA - Short Assessment of Health Literacy for Spanish-speaking Adults
SORT - Slosson Oral Reading Test
SSDI - Social Security Disability Insurance
SSI - Supplemental Security Income
S-TOFHLA – Shortened Test of Functional Health Literacy in Adults
TOFHLA - Test of Functional Health Literacy in Adults
UK - United Kingdom
US - United States
VP – Video phone
VRI – Video Relay Interpreting
WHO - World Health Organization
WRAT-R - Wide Range Achievement Test - Revised
Definitions

Audism - discrimination against a person who is deaf or hard of hearing.

Culturally Deaf - refers to individuals who identify with and participate in the language, culture, and community of Deaf people, based on a signed language.

Cultural Minority – a group that is subordinate or lacks power in society due to their beliefs, way of thinking or working, etc.

Disability Group - a person who has a physical or mental impairment that substantially limits one or more major life activity.

Linguistic Minority - a group that is subordinate or lacks power in society due to their non-dominate language

Deaf ("big D deaf") – person with a hearing loss that identifies themselves as culturally deaf (see above).

deaf ("little d deaf") – person with a hearing loss that identifies with hearing society (holding values of the hearing world and associates with hearing people). Often deafened later in life.

Deaf Culture - the culture of Deaf people based on a signed language and values, traditions and behavior norms specific to the Deaf community. Deaf culture offers a strong sense of belonging and takes a socio-cultural point of view of deafness, rather than a pathological perspective.

*Deaf Community* - **deaf and hard of hearing individuals who share a common language, common experiences and values, and a common way of interacting with each other, and with hearing people.**


Appendix G - Letter of Commitment

To Whom It May Concern,

Janine M. Pezzino, RN, PhD© has been granted permission to carry out research on *Ethnographic Study of Health Literacy in the Culturally Deaf* at this facility. I have been informed of the purposes of the study and the nature of the research procedures. I have also been given an opportunity to ask questions of the researcher. It's to my knowledge this study will include members of the deaf community undergoing interviews in order to gain a more sound understanding of their perspective of AS. Janine will have access to this location's conference room in order to conduct before mentioned interviews in a private setting. No BAYADA employees or clients will partake in this research.

Please feel free to reach out with any questions or concerns.

Narolyn Paredes

Director (HAN)\ BAYADA Home Health Care

299 Market Street, Suite 320, Saddle Brook, NJ 07663

0: 201-343-7101 \ Cisco Ext: 067716 \ Fax 201-580-4988 \ bayada.com

March 8, 2019