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Senescence Disorder Literacy Among Prelingual/ Culturally Deaf Individuals Age 50 and Older

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Walden University
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Abstract

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MA, New York University, 2002

BS, Lincoln University, 1977

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology

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Abstract

The preferred method of communication for most prelingual/culturally Deaf individuals is American Sign Language (ASL), and members of this linguistic/cultural minority community are often not recognized as being bilingual. Many prelingually/culturally Deaf individuals have limitations and deficits in English proficiency; which can lead to deficits in general knowledge of health-related terminology. Current projections are that older adults are expected to live longer, and will also experience the development of, increases in and more extended periods of living with senescence/age-related health disorders, also includes prelingual/culturally Deaf individuals. This quantitative research project, utilizing the theoretical framework of health literacy and a modified version of the REALM (Rapid Estimate of Health Literacy in Medicine), utilizing American Sign Language (ASL) graphics; analyzed the convergence of prelingual/cultural Deafness and health literacy related to senescence/age-related disorders. An evaluation of a sample population of 27 Deaf participants, on health-related items of medical words, medical conditions medical procedures, and medical/numeracy instructions revealed significant deficits in all areas of health literacy. These deficits are critical and impact one's ability to manage effectively, age-related disorders. The results of this study will inform the health care community of the unrecognized magnitude, implication, and the need for positive social change in health care policies and procedures related to the appropriate provision of medical, health care, and health-related information for prelingual/culturally Deaf individuals.

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Dedication

Dedicated to the three most influential educators in my life, my mother Jessie Mae Felder Hart, whom I lost 35 years ago and still miss dearly. I will never forget the mantra she believed in and taught me "Get a good education because an education can and will take you far, as far as you wish to go; and an education is one thing that no one can ever take away from you."

I also dedicate this to my beloved godmother Adeline Sheffield, who was a teaching colleague of my mother during their early years of teaching in South Carolina, and someone who stood by me as if she were truly my mother all those 34 years since the death of my mother. I miss our telephone chats during which it appears that I could make you laugh so easily. Godmother was a major figure in and throughout my who life, ever since my early childhood, and never missed a birthday, Christmas or holiday without some form or token of love being expressed by her to me. Although we lived on opposite ends of the country, I never met her until the summer between my senior year of high school and freshmen year of college. Albeit life only afforded me just one opportunity to visit her at her home on the west coast, we bonded as if we visited each other, face-to-face, on a regular basis. The loss of her in the spring of 2013 just after she reached the age of 96 greatly saddened me because I had so wished that she would be able to enjoy the fruits of her encouragement as I completed this doctoral degree.

Additionally, I also dedicate this to a new dear and close friend Patricia Ann Miller, Ph.D. whom I suddenly and unexpectedly lost over the 2013 Thanksgiving holiday. Although we had only met just about five years earlier, we bonded over the fact

that she was born and raised in the same small town in Georgia where my father was born and raised. We felt a kinship as if we knew that somewhere along our bloodlines we would discover that we were actually and truly related. She had self-appointed herself as my personal doctoral dissertation mentor and was determined to get me through this doctoral degree process as quickly as possible. I miss our almost daily telephone conversations and all of your encouragement and advice and wish you were here to see me complete this process (with all of your help, of course).

Finally, I dedicate my dissertation to Dr. Derrick Griffith, Ph.D., who tragically lost his life in Metro Liner train accident a mere two weeks before his graduation. He was a best friend and mentor to my niece and took the time to mentor and encouraged me to complete my dissertation just 6 months prior to his untimely death.

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Chapter 1: Introduction to the Study

Introduction

People with disabilities, such as deafness, have the same health needs as non-disabled people. Often, because of their disability, they may also experience a constricted or a "thinner" margin of health (Ho & Kehn, 2007), due to either or both poverty and social exclusion. Higher levels of vulnerability to secondary conditions (comorbidities) are what the medical community delineates as "thinner margins of health." Moreover, individuals with the disability of prelingual Deafness are often more vulnerable to secondary conditions (comorbidities) due to deficiencies in health literacy (Pollard & Barnett, 2009). Margins of health are affected by access, or lack thereof to health-related information that informs, is ascribed by or produces better health behaviors. Better health habits are based on knowledge of health-related information which in turn influences better self-efficacy in the management of personal health care. Better health practices include awareness of the importance of exercise, diet, cessation of the use of illegal, as well as overuse or abuse of legal drugs, medications, and substances such as alcohol, and tobacco (Dejong et al., 2002; Kailes, 2014).

Researchers have suggested that people with disabilities face barriers in accessing the health and rehabilitation services they need (World Health Organization [WHO], 2014), and prelingual/culturally Deaf individuals are no exception. Prelingual/culturally Deaf individuals, because of their means of communication, very often experience communication barriers. The presuppositional standpoint of this research study is that these communication barriers result in health literacy deficits that can and often do result

in poorer health behaviors leading to thinner margins of health (Barnett, McKee, Smith, & Pearson, 2011). Similar to the general population, prelingual/culturally Deaf individuals can be expected to experience senescence/age-related health disorders, especially as they advance in age. With the onset of age-related disorders, prelingual/culturally Deaf individuals, from a medical perspective, are also considered as experiencing health related comorbidities (Venes, 2009).

Although exact numbers are estimated at best, many individuals with auditory losses that range between severe to profound levels of deficits are self-identified members of a minority, cultural, linguistic group that is often described as a community (Brodwin, Tellez, & Brodwin, 1995; Lane, Hoffmeister, & Bahan, 1996; Parasnis, 1998; Wilcox, 1989). Members of this community self-identify themselves with and by utilizing the capital letter D in the word Deaf (Padden & Humphries, 1997; Parasnis, 1998). Thus, in this self-defining and self-ascribing manner, members of this group wish to be identified as Deaf (Lane et al., 1996; Padden & Humphries, 1997; Parasnis, 1998; Wilcox, 1989). Additionally, many individuals who self-identify as being members of the prelingual/culturally Deaf community are also individuals who can be characterized as members of any one of the senior citizen cohorts. These cohorts are colloquially referred to as the "Baby Boomers" age 50-68 (Abeles et al., 1998; Alliance for Aging Research [AAR], 2006); "Young-Old" age 65-74; Old-Old age 75-84; and "Oldest-Old age 85+" (Cohen-Mansfield et al., 2013; Transgenerational Design Matters, 2009). Therefore, these Deaf individuals also can and, should be considered members and part of a secondary cohort of individuals who are or will soon be a part of the 65 and older portion of the aging population of the United States.

The trajectory of the aging population of the United States projects a substantial increase in the overall percentage of individuals within the United States population turning 65 and over, between 2010 and 2030 (AAR, 2006). National health care providers and policymakers project that there will be a marked and sustained increase in the need to provide health care services for chronic health and age-related disorders for adults over the age of 65 (AAR, 2006). The anticipated increase in demand for health-related services is especially true in light of the projected increases in life expectancy and longevity (Dalton et al., 2003). In response to this looming problem, the medical community has begun to recognize and address the issue of the increased burden and demands that the growing elderly population and their presupposed increasing number of age-related health care disorders, will place on the medical community (AAR, 2006). Caring and providing health related services for a growing number of aging individuals experiencing age-related disorders will place an enormous burgeon on the resources of the medical and health care community (AAR, 2006; National Academy on an Aging Society [NAAS], 1999).

The health care industry has begun to recognize and address the general issue of access to health care information as part of their efforts to prepare for the previsedonslaught of aging individuals colloquially termed as the "Silver Tsunami" (AAR, 2006; Mann, 2004). The question is, are these efforts, regarding health education and literacy, enough to help stem the tide? More precisely, are these efforts inclusive of, extendable to, or appropriate for the underserved and often an under-recognized population designated as prelingually/culturally Deaf? If not, why not? The premise of this research project was that current methods and approaches of disseminating health-related

information have not been pertinent to or effective for members of the Deaf community. Therefore, what are the determinant factors for these efforts not being appropriate to and for the Deaf community? The assumption and the theoretical framework of this research study were that levels of literacy and more specifically health literacy, among prelingual/culturally Deaf individuals might be a major determinant factor in the appropriateness of current methods of dissemination of health-related information.

The assumption of the theoretical framework of this study was that there might be unrecognized health literacy deficits among members of the Deaf community who are 50 and older. More precisely, do members of this linguistic community possess or exhibit deficits in the health literacy knowledge that is explicitly related to age-related disorders? The overall social change perspective of "handicapping," is the basis upon which this research study rests. The fundamental social change questions this study sought to answer was: Do current policies, procedures, and methods of disseminating health information "handicap" prelingual/culturally Deaf individuals, especially those over the age of 50 with or without age-related disorders? Do prelingual/culturally Deaf individuals exhibit deficits in their health literacy of age-related disorders? If so, are these deficits substantial enough that the health services community need to recognize and address this issue? According to Davoli (n.d., p.1 & 2) "The [prelingual/culturally] Deaf represent a large medically underserved population …. and currently the Deaf community has unmet health needs …. [even more specifically] there is a lack of data on the health concerns of Deaf individuals".

Background of the Problem

Although the United States Census Bureau maintains a relatively accurate account of the number of citizens in all age ranges within the United States, the Census Bureau, unfortunately, does not collect or maintain any information on the number of citizens who are prelingually Deaf. The latest research conducted by researchers at Gallaudet University projects the number of culturally Deaf individuals to be approximately 18% of the population or 421,000 individuals in the United States and Canada (Gallaudet University, 2014).

Prior to the 1960s and the development and widespread use of vaccines for many common viral and bacterial infections, in utero and early childhood (prelingual) exposure to these infections often caused prelingual deafness. Therefore, it is reasonable to suspect that some individuals who consider themselves members of the culturally Deaf community are also members of one of the senior citizen cohorts. A portion of this group's deafness may, in fact, be due to maternal infections contracted during the rubella epidemic of the mid to late 1940s through mid-1960s (Hunt, 2011). Additional causes for prelingual deafness include other in utero infections that fetuses were exposed to during the gestation period (Billings & Kenna, 1999; Glickman, 2010; Kral & O'Donoghue, 2010).

One of the significant sequelae experienced by women exposed to rubella, as well as other viral and/or bacterial infections, during their pregnancies, are birth defects in the form of various levels of hearing loss and/or prelingual deafness in their infant child (Billings & Kenna, 1999; Kral & O'Donoghue, 2010). Pollard and Barnett (2009) along with various other researchers (Barnett et al., 2011; Barnett, McKee, Smith, & Pearson,

2011; Pollard, Dean, O'Hearn, & Haynes, 2009) have conducted prior research on the issues of health inequities and deficiencies in health-related knowledge in the prelingual/culturally Deaf community. These researchers have established and validated theories around the issues of deficits in general health-related knowledge among prelingual/culturally Deaf community members of all ages. This study specifically focused on knowledge (health literacy) of senescence disorders among prelingual culturally Deaf individuals age 50 and older.

Just as with any aging individual in the general population, many of the aging Deaf individuals can expect to and will experience age-related health concerns and disorders (AAR, 2006). The current study evaluated whether or not the volunteer participants, age 50 and over who self-identified as being members of the culturally Deaf community, were assessed to have deficits in health literacy. Evaluations conducted sought to assess whether the volunteer participants possessed a practical level and understanding of information that is related to age-related health issues and disorders; or, at the very least, a functional degree of understanding of the health-related terminology associated with age-related disorders.

A lack of health-related knowledge can have a significant impact on and be an antecedent for morbidities, or even co-morbidities, as well as, mortality (Agrawal, Plaz, & Niparko, 2008; Pandhi, Schumacher, Barnett, & Smith, 2011). In 2004, Mann, W.C projected that the aging of America is and will continue to be a significant social concern for health care providers and policy makers for at least the next 13 years as the United States continues to experience a growing number of individuals attaining the age of 65

and over. It should be noted that the health-related concerns as they relate to aging individuals would also include members of the culturally Deaf community.

Statement of the Problem

> There is considerable evidence that the health information needs of the 'early-deafened' population [have] not been well served…The dearth of literature related to the Deaf community's size, health status, access to health care, adherence to screening guidelines, and adequacy of health information [has been found to be remarkably limited]. Further, what has been published in the health science literature has been more focused on the pathology of deafness than on deaf individuals as members of a cultural group whose health care and health information needs must be addressed (Sadler et al., 2001, p. 105).

This quantitative research study sought to investigate this unrecognized and rarely addressed problem/issue of adequate and appropriate access to health-related information for individuals who are prelingual and culturally Deaf (Davoli, n.d.; Pollard, Dean, O'Hearn, & Haynes, 2009). Barriers exist in their attempts to access healthcare and healthcare information, as well as, barriers in effective communication between them and their health care provider (Davoli, n.d.). Davoli (n.d.) posits that limited English proficiency (LEP) patients often receive inadequate patient education and information.

Deficits in the knowledge of health-related information, which in essence, basically, constitutes health literacy and health numeracy, can affect an individual's self-efficacy in their management of health disorders (Squiers, Peinado, Berkman, Boudewyns, & McCormack, 2012). Communication barriers can be an impediment on

multiple levels, and important health related information is often missed by Deaf individuals (Parasnis, 1998, p. 129). Due to their audiological status and English literacy levels (Mitchell, 2014), many prelingual/culturally Deaf individuals experience communication barriers in accessing health-related information which is most often presented in direct (face-to-face) conversations or via other auditory forms such as radio, television, or ambient conversations. Alternatively, such information may also be presented in written form. Parasnis (1998, p. 129) posits that "the subtle information that even children can and do pickup by overhearing casual conversations between parents and other adults as well as the wealth of incidental information transmitted through casual conversations among peers" (e.g., classmates, co-workers and neighbors), is missed and not accessible to a Deaf individual. In situations where the Americans with Disabilities Act is not adhered to, and equal communication access is eschewed, often for financial reasons, the Deaf person often must rely on speech-reading (lip-reading) or verbal summaries or even shorten written summaries (Parasnis, 1998, p. 129).

"Most patient education material is written at a grade level too high to be understood" (Mayer & Villaire, 2009, p. 1) by many hearing individuals, and even more specifically by most Deaf individuals. Written health information (handouts and brochures) are usually presented at a 7th grade or higher reading level (Mayer & Villaire, 2009). With their inability to attend to spoken language and with many Deaf individuals possessing an average 3rd to 4th grade English reading comprehension level (Jones, Renger, & Firestone, 2005, p. 27) these inabilities gravely affect the prelingual Deaf person's competence in accessing written health related information. The general zeitgeist perception is that an individual can or should be able to understand written

health information if that individual can read (Mayer & Villaire, 2009). Unfortunately, in actuality, the advanced reading skills of even a hearing high school or higher-grade level educated person does not necessarily guarantee that an individual will truly understand health information in the general manner and form in which such information is usually presented (Mayer & Villaire, 2009). Hence, even for many college educated individuals, health-related terminology may not truly be understood (Mayer & Villaire, 2009). Therefore, it stands to reason that the form and manner in which the general presentation of health information is proffered far exceeds the literacy level of many in the general populace and most specifically the health literacy of a vast number of prelingual/culturally Deaf individuals.

With the current practice of most patient education information and materials being written at an eighth-twelfth grade reading level, Mayer and Villaire (2009) proffers a suggestion by stating that it is essential that future creations of patient education information be presented at a reading level no higher than a third to fifth reading level. Unfortunately, Pollard, Dean, O'Hearn, and Haynes (2009, p. 232) asserts that even with such efforts, current "methods of adapting health education material for hearing LEP (Limited English Proficiency) populations do not reach deaf audiences with equal effectiveness." Very often, even words that appear to be simple and easily understood to and by the provider are not necessarily clear to the patient (Mayer & Villaire, 2009), and would most likely be unclear to a Deaf patient. Additionally, some words used in a medical context, are not clear and possibly even have an opposite meaning from how it is typically and colloquially used (Mayer & Villaire, 2009). For individuals, unfamiliar with medical terminology phrases such as "negative results" or "benign" may be

perceived as bad or as indications that something is wrong. Whereas, in the medical context, the phrases “negative results” and “benign” actually have positive connotations and implications (Mayer & Villaire, 2009).

The quantitative aspect of this study employed prelingual/cultural deafness as the independent variable. The independent variable of prelingual/cultural deafness was theorized to influence the dependent variable of health literacy. Similar, but differently from a previous study conducted by Pollard and Barnett (2009), health literacy was evaluated via the use of a modified/pictorial version of a well-known health literacy evaluative tool known as the REALM (Rapid Estimate of Adult Literacy in Medicine) (Davis et al., 1991).

Purpose of the Study

The anticipated outcome of this quantitative research study was to acquire an inferential understanding of the health literacy among many prelingual/culturally Deaf individuals age 50 and over as it related to their knowledge of health-related information for senescence/age-related disorders. A health literacy evaluation was to reveal whether (generalized) significant deficiencies in health literacy, was or was not exhibited or possibly did or did not exist among the selected demographic population.

The sparse health data that does exist about prelingually Deaf adults indicated that members of this cohort persist that they experience poorer health than do hearing adults in the general United States population (Barnett, McKee, Smith, & Pearson, 2011, p. 1). As evidenced by the minimal research conducted to date, members of this cultural, linguistic group, the prelingual/culturally Deaf, are at a substantially high risk for experiencing poorer outcomes in chronic age-related health disorders due to deficits in

knowledge of health-related terminology (Pollard & Barnett, 2009), which was also referred to as health literacy in this research study. By quantitatively evaluating the health-related terminology knowledge (i.e., health literacy) of 27 participants, the proposed goal for conducting this study was to add to the literature that addresses the issues of health literacy of prelingual/culturally Deaf individuals. The results of this study may help to inform members of the health care community, as well as, health care policy makers, of the need to conduct further research in establishing policies and procedures that address the needs of members of the prelingual/culturally Deaf community. Additionally, the results of this study may inspire other researchers to continue research in methods and procedures that will help to abate the issue of knowledge and understanding of health-related information, as experienced by many prelingual/culturally Deaf individuals.

Research Questions

Overarching Research Question: Do prelingual/culturally Deaf individuals over the age of 50 experience deficiencies in knowledge of senescence/age-related health terminology (deficits in senescence-related health literacy) and/or health numeracy?

RQ1 - Quantitative: Do prelingually/culturally Deaf adults, age 50 and over, experience significant deficits in senescence health-related knowledge also referred to as senescence health literacy? (As measured by use of a modified [pictorial] version of the shorter version of the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1991; Davis, Long, & Jackson, 1993; & Murphy, Davis, Long, Jackson, & Decker, 1993).

(1) Do members of the prelingual/culturally Deaf community, over the age of 50, experience deficits in knowledge of health-related terminology and health-related numeracy?

(2) Do these same prelingual/culturally Deaf individuals, over the age of 50, experience deficits in knowledge of senescence/age-related health disorders?

(3) For which senescence/age-related health disorders are deficiencies in knowledge found to be the greatest?

(4) For which senescence/age-related health disorders are deficiencies in knowledge found to be the least?

Hypotheses

Prelingual/cultural deafness will serve as the independent variable while scores on the modified pictorial health literacy instrument will serve as the dependent variable. As stated earlier, the independent variable of prelingual/cultural deafness was theorized to influence the dependent variable of health literacy and health numeracy. Therefore, the null and alternative hypothesis was stated as follows:

Null (H_0) Hypothesis: No significant levels of deficit in health literacy and/or health numeracy will be evidenced by the scores achieved by prelingual/culturally Deaf individuals on the modified version of the health literacy instrument.

Alternative (H_1): A significant level of deficit in health literacy and/or health numeracy scores will be evidenced by the scores achieved by prelingual/culturally Deaf individuals on the modified version of the health literacy instrument.

Theoretical Framework

The present study exploring the knowledge of health-related terminology (health literacy) of prelingually/culturally Deaf individuals was examined through the lens of the overarching theoretical framework delineated as Health Literacy Skills (Lie, Carter-Pokras, Braun, & Coleman, 2012). Utilizing health literacy as the theoretical framework, the intent was to quantify and generalize from inferential statistical data the general levels of health-related knowledge (i.e., health literacy) of prelingual/culturally Deaf individuals, age 50 and older. Health Literacy is defined by Squiers, Peinado, Berkman, Boudewyns, and McCormack (2012, p. 30) as a theoretical concept that encompasses "the relationship between health literacy and health-related outcomes and depicts how health literacy functions at the [internal/micro] level of the individual."

Definitions for the construct "health literacy," incorporates the influences of many factors. These factors can be both internal or external, mediating and/or moderating factors (Squiers et al., 2012) and exist on various levels, to include personal and family settings [micro], community [meso], culture, and media [macro] (Squiers et al., 2012). Moderators, according to Squiers et al. (2012) are variables that exert directional influence on the relationship of both the independent and dependent variables; whereas, mediators are variables that explain why. These mediating and moderating micro, meso and macro factors are the same concepts that are often the underpinnings of many of the theoretical and conceptual frameworks used in health psychology (Marks et al., 2008), community psychology (Nelson & Prilleltensky, 2010). These factors are also concepts that are used in educational psychology, among many other social/political disciplines. Despite the differences between the differing principle frameworks of health literacy, the

major health literacy frameworks (health literacy; functional health literacy; critical health literacy; and medical health literacy) all epitomize the effects that health literacy has on the health-related outcomes (Squiers et al., 2012) of good health and/or an individual's abilities to effectively manage their health-related disorders.

Quantitative evaluation of health literacy can be measured through various established and validated instruments. Some of the most-popular health literacy evaluation instruments consist of The Rapid Estimate of Adult Literacy in Medicine (REALM; Davis et al., 1991; Davis, Long, & Jackson, 1993; and Murphy, Davis, Long, Jackson, & Decker, 1993). Other health literacy evaluation instruments include: The Test of Functional Health Literacy in Adults [TOFHLA] (Parker, Baker, Williams, & Nurss, 1995); The Health Activities Literacy Scale [HALS] (Rudd, Kirsch, & Yamamoto, 2004); The Medical Achievement Reading Test [MART] (Hanson-Divers, 1997); and The Demographic Assessment of Health Literacy [DAHL] (Hanchate, Ash, Gazmararian, Wolf, & Paasche-Orlow, 2008), among many others. The construct of health literacy is more conceptual and abstract than concrete and pragmatic. Therefore, health literacy evaluation instruments appear to have face validity, based on the viewpoint and the assumed construct stance of each researcher or research project (Squiers et al., 2012). Hence, an accurate and unequivocal construct validity for any one of these instruments can be contested based on the congruity or difference in the conceptual/theoretical framework of various research projects.

Nature of Study

The goal of this study was to ascertain whether there were significant deficits in the senescence-related health-related knowledge (i.e., health literacy) among prelingual/culturally Deaf individuals, age 50 and older. The age demographics of participants included in this study starts with Deaf individuals age 50-68 who are otherwise known as "Baby Boomers," as well as, those who are also part of the cohort delineated as the "young old" (65-74). Fortunately, the study was able to recruit and include prelingual/culturally Deaf individuals well over the age of 68. Older participants would be considered members of an additional combination of cohorts of the senior citizen population otherwise designated as the "old-old" (75-84) and the "oldest old" (85+).

Since the health industry projects increasing life longevity for individuals who are or will be part of the young-old, old-old and oldest old segments of the population, the health industry also projects that these same individuals will experience longer periods of living with chronic senescence/age-related disorders (Christ & Diwan, n.d). The National Institutes of Health commissioned report and article *Is 90 the New 85? Perhaps* (November 26, 2011) indicates that the fastest growing segment of the population is the older population. The authors proffer a suggestion that perhaps the "yardstick" designation for the entry age for the cohort that is deemed as oldest old might need to be revised from 85 to 90 years of age. Such a change in the concept of oldest-old would be similar to how, in the past few decades, the entry age for the designation of elderly, old or senior citizen has been moved up from 50 to 65

Aspiring and seeking to gain inferential knowledge about the health literacy of members of the prelingually Deaf cohort, age 50 and older, the results of this study will be used to inform the social orientation of the prelingual/culturally Deaf community within the healthcare industry. Since members of this linguistic community do not necessarily reside in any one specific location or geographical area, a "Snowballing" (Vogt, 1999) recruitment method was employed to recruit participants. The recruitment goal for the sample population for this study consisted of recruiting at least 27-34 participants, and if additional participants were located and agreed to volunteer to participate, they would be included in the study. The final number of recruited participants was 27. Participants who volunteered needed to meet the linguistic, audiological and age demographics of this study; which was age 50 and older, severe to profoundly deaf, and utilizes American Sign Language as their preferred and primary method of communication. Data from this quantitative inquiry, utilizing a modified pictorial form of a health literacy evaluation instrument, was evaluated to determine if any significant deficits in knowledge of senescence-related disorders (health literacy) can be generalized to exist among community members who are prelingual/culturally Deaf, age 50 and older. Statistical analyses of *t* tests and correlations were to be applied to participant scores achieved on the modified health literacy instrument. Ultimately, the results of this study will be used to advocate for social justice within the healthcare industry by identifying and exposing the communication/power imbalances that currently occur within the healthcare industry.

Operational Definitions

American Sign Language: The fifth most commonly utilized language in the United States, also used by many Deaf individuals in Canada (Lane, Hoffmeister, & Bahan, 1996). A language that does not follow or resemble English in form or syntax; and is a language that developed from and is based on French Sign Language [FSL] (Padden & Humphries, 1997).

Aural*:* Of or relating to the ear or to the sense of hearing ("Merriam-Webster," n.d; Marschark, 2009, p. vii); to hear with the ear (Venes, 2009, p. 215).

Baby Boomer**:** An individual born between the years of 1946 to 1964, who [has or] will be turning 65 between the years 2011 and 2029 (AAR, 2006).

CODA[s] (Child/Children of Deaf Adult[s])**:** Hearing individuals who are children of Deaf Adults (Lane, Hoffmeister, & Bahan, 1996, p. 16 & 170). Individuals whose parent(s) is/are culturally Deaf and utilize sign language as the language of communication used in the home; a child whose first language usually, is, sign language.

Cued Speech (CS): A method of communicating that uses both lip reading and manual gestures made near the mouth. It is used to help hearing-impaired people clarify the difference between words that are otherwise easily misinterpreted during speech reading (Venes, 2009, p. 554). A system of manual signals (a specific set of hand shapes produced at specific locations around the face/upper body) that visually represent the phonemes or sounds of spoken language. Initially conceived as an aid to speech reading, it has been used in educational settings and, with modifications, to accompany various spoken languages (Marschark et al., 2005; Trezek, Gampp, Wang, Paul, & Woods, 2007)**.**

Culture: "The integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values and institutions of racial, ethnic, religious or social group" (Andrulis & Brach, 2007, p. S123).

Cultural Deafness: An individual who self-identifies as a member of the linguistic community of the Deaf. "It is not merely a camaraderie with others who have similar physical conditions, but is, like many other cultures in the traditional sense of the term, historically created and actively transmitted across generations" (Padden & Humphries, 1997, p. 2). Most members of this linguistic community experienced a severe to profound hearing loss before the acquisition of language and use or prefer to communicate nonverbally using manual communication known as sign language (Parasnis, 1998; Wilcox, 1989). Any person who self-identifies with the Deaf community and who also self-identifies as belonging to this distinct linguistic and cultural group (Padden & Humphries, 1997). An individual or group of individuals who utilize American Sign Language (ASL) as their primary means of communication or primary communication among themselves and also who, "hold a set of beliefs about themselves and their connection to the larger society (Padden & Humphries, 1997, p. 2). Hearing individuals, more notably, children born to Deaf parents (CODAs), are also accepted and deemed by the Deaf community as "Culturally Deaf" (Lane et al., 1996, p. 16 & 170; Padden & Humphries, 1997, p. 49).

Deaf/deaf: **"**Deaf people are both Deaf and deaf" (Padden & Humphries, 1997, p. 3). Individuals who have hearing losses greater than 75 to 80 dB, utilize vision as their primary input or source of (communication), and cannot understand speech through the ear (Hardman, Drew, & Egan, 2011, p. 11).

deaf: Partial or complete lack of the sense of hearing or the ability to hear (Venes, 2009, p. 579-580). "The lowercase "d" is used when referring to the audiological condition of not hearing/ [or any level of] hearing loss" (Padden & Humphries, 1997, p. 2; Parasnis, 1998).

Deaf: "The upper case "D" is used when referring to a particular group of hearing impaired (deaf) or "culturally Deaf" individuals who share a language – American Sign Language (ASL) – and is the language of a cultural group" (Padden & Humphries, 1997, p. 2). "Refers to deaf individuals who share a language (ASL in this case) and cultural values that are distinct from the hearing society" (Parasnis, 1998, p. xiii).

Deficits of Health-Related Terminology/Knowledge: Are evaluated by using a validated and sometimes a modified version of a validated instrument such as the TOFHLA/s-TOFHLA (Test of Functional Health Literacy in Adults) or the REALM – Rapid Estimate of Adult Literacy in Medicine (Davis et al., 1991). These instruments measure, evaluate and estimate health-related reading comprehension levels. The REALM instrument has previously been utilized in research with the Deaf population (Pollard & Barnett, 2009).

Disability: Is defined as "any physical, mental, or functional impairment that limits a major activity…a condition resulting from a loss of physical functioning; or, difficulties in learning and social adjustment that significantly interfere with normal growth and development" (Hardman et al., 2011, p. 11). Furthermore, it is defined by (Pollard & Barnett, 2009) as a limitation on one's ability to perform tasks, activities, and roles at the expected levels in physical and social contexts.

Disorder: A disturbance in normal functioning (mental, physical, or psychological)" (Hardman et al., 2011, p. 11). "A pathological condition of the mind of body" (Venes, 2009, p. 671).

Elder/Elderly*:* A person over 65 years old (Venes, 2009, p. 732). According to the definition used in the master thesis of this term, for statistical and public health purposes, is regarded to apply to any individual age 65 or older.

Functional Limitation*:* Is an evaluative measure of an organ's activity level, ability or inability to perform its intended action in a manner or within a range consistent with the expected purpose of that organ or organ system. Brodwin, Tellez, and Brodwin, (1995, p. 6) define it as "the inability to perform an action or set of actions, either physical or mental, because of physical or emotional restriction (often referred to as a disability)." Additionally, it is defined as "any restriction in the performance of activities resulting from disease, injury, or environmental restrictions" (Venes, 2009, p. 1343).

Gloss/Glosses/Glossing: English words used to translate the meaning of AASL sentences are an approximation known as 'Glosses' (Moore & Levitan, 2003, p. 75).

Handicap: "A limitation imposed on a person by the environment and the person's capacity to cope with that limitation" (Hardman et al., 2011, p. 11).

Health Literacy*:* "The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (Andrulis & Brach, 2007, p. S122**;** Mayer & Villaire, 2009). A theoretical concept that encompasses "the relationship between health literacy and health-related outcomes and depicts how health literacy functions at the [internal/micro] level of the individual" (Squiers et al., 2012, p. 30).

Functional Health Literacy: According to Peerson and Saunders (2009, p. 288), the general term health literacy is a misnomer and is a much broader, umbrella term that includes functional health literacy. Functional health literacy consists of the basic reading and writing skills required to enable an individual to understand and follow health messages (information).

Medical Health Literacy: In its various forms, according to Peerson and Saunders (2009), means the type of health-related knowledge and skills (basic reading and numerical skills) that allow an individual to, primarily, function well in a health care setting/environment.

Critical Health Literacy: "Refers to an individual's ability to critically analyze health related information that is presented to them" as defined by Peerson and Saunders (2009).

Health Related Numeracy (Quantitative Literacy): The skill or the ability to read, understand, and manipulate numbers for negotiating simple measurements conversion or dosing medication safely Oldfield and Dreher (2010, p. 206). It is also simply defined as the ability to use quantitative information (numeracy or quantitative literacy) effectively (Berkman, Davis, & McCormack, 2010). Lipkus and Peters (2009) equate this term and skill to quantitative literacy. Additionally, Lipkus and Peters (2009) posit that there are six critical functions or factors that encompass health numeracy. The functions and factors include computation skills; the ability to seek more information based on the numerical data. It also encompasses the capacity to interpret the meaning of the numbers and assess the value of the numbers and whether or not one can accept the

validity of the numerical data. Lastly, health numeracy should promote healthy behavioral change.

Health Related Terminology: Is evaluated utilizing various validated, instruments, some modified to meet and evaluate various non-English linguistic dialects. The REALM – Rapid Estimate of Adult Literacy in Medicine (Davis et al., 1991; Davis, Long, & Jackson, 1993; Murphy, Davis, Long, Jackson, & Decker, 1993), is one such instrument used to evaluate/estimate health-related reading and comprehension levels. These reading comprehension levels are generally recognized to equate to and represent health literacy.

Impairment: Focus is on the organ or organ system and encompasses **"**any loss or abnormality of psychological, physiological, or anatomical structure or function" (Venes, 2009, p. 1165).

Limited English Proficiency: An individual who is unable to communicate effectively in English because their primary language is not English and they have not developed fluency in the English language. A person with Limited English Proficiency may have difficulty speaking, reading or comprehending English. A LEP person will benefit from an interpreter who will translate to and from the person's primary language (U.S. Department of Health & Human Services, n.d., p. 1). As defined by Divi, Koss, Schmaltz, and Loeb (2007, p. 60) limited English proficiency consists of an aggregate of any of the following factors. "A limited ability or inability to speak, read, write or understand the English language at a level that permits the person to interact effectively with healthcare providers or social service agencies."

Lip-Reading/Speechreading: Interpreting what is being said by watching the speaker's lips, facial movements and expressions (Venes, 2009, p. 1351 & 2166).

Morbidity: "The state of being diseased" (Venes, 2009, p. 1492). Any incidence of disease and disability; an inability or capacity to function; or any condition that causes functional limitations. Whereas, co-morbidity is defined as any health-related conditions existing simultaneously with and usually independently of another medical condition ("Merriam-Webster," n.d.). Any disease that worsens or affects a primary illness (Venes, 2009, p. 498).

Old: Refers to those aged 65 and older (U.S. Department of Commerce - Economics and Statistics Administration - U.S. Census Bureau, 2010, p. 1).

Young Old: 65-74 years of age (Cohen-Mansfield et al., 2013; Transgenerational Design Matters, 2009).

Old-Old: 75-84 years of age [fast growing] (Cohen-Mansfield et al., 2013; Transgenerational Design Matters, 2009).

Oldest-Old: 85 years of age and above; individuals age 85 and older (Cohen-Mansfield et al., 2013; Transgenerational Design Matters, 2009).

Oral: Concerning the mouth (Venes, 2009, p. 1639); uttered by the mouth or in words; spoken, using speech or the lips especially in teaching the deaf ("Merriam-Webster," n.d.).

Oralism: "The method of conducting all instruction in speech and requiring students to learn only through speechreading [lip reading]" (Van Cleve & Crouch, 1989, p. 107).

Postlingual Deafness: A hearing impairment that develops after a [person] has learned a language (Venes, 2009, p. 1857).

Prelingual Deafness: Is defined as occurring before the development and use of speech and language. A hearing impairment that is present in infancy and childhood before language skills are acquired (Venes, 2009, p. 1878). A hearing loss or deafness evaluated to be severe to profound and present either at birth or occurs prior to the development of spoken language, which is usually before the age of 3 (Moores, 2001, p.12). Padden and Humphries (1997) two major researchers and pioneers of Deaf culture and Deaf history delineate prelingual deafness as occurring at birth or prior to the age of one. Generally, prelingual hearing loss includes any congenital hearing losses that are present at birth, or emerges in a newborn or infant from the age of one up to three years of age, and most specifically before acquired speech and language capabilities have emerged (Moores, 2001).

Profound Hearing Loss: A loss of hearing measured at a loss level of greater (>) than 90-95 dB (Kral & O'Donoghue, 2010).

Senescence: The process of growing old; the period of old age (Venes, 2009, p. 2098). A deteriorative process; an increased probability of death with increasing chronological age (Blackburn & Dulmus, 2007, p. 19-20).

Senior Citizen*:* An elderly person; *especially* one who has retired ("Merriam-Webster," n.d.)**.**

Snowball Sampling: A technique for finding research subjects. One subject (or member of the community) gives the researcher the name of another subject, who in turn provides the name of a third potential subject, and so on. This technique is especially

useful when the researcher wants to contact people with unusual characteristics who are likely to know one another – members of a small group, for example (Vogt, 1999, p. 268).

Scope and Delimitations, Limitations, and Assumptions

The following sections will describe the scope, delimitations, limitations, and assumptions of the current study. The scope and delimitations section will entail and describe the demographics and the circumscription of the targeted population. The limitations section contains a discussion of a different circumscription of the targeted population, this time based on the limitation of geographical area from which the targeted population was solicited. The assumption section simply postulates that the participants who took part in this study were honest, truthful and earnestly completed the evaluation to the best of each one's abilities.

Scope and Delimitations

The extent of this research project specifically involved participants from the prelingually/culturally Deaf population. Hearing, hard-of-hearing and even late deafened individuals age 50 and older were outside of the bounds of this study, and what can be answered by this study. Only participants who utilize American Sign Language as their preferred and primary method of communication were eligible to participate in this research study. Participants had to affirm that they had a severe to profound hearing loss measured at a loss level of 71-95 dB for a severe hearing loss or 95 dB or greater (>) loss for a profound hearing loss (Brodwin, Tellez, & Brodwin, 1995; Kral & O'Donoghue, 2010). Willing participants had to be prelingually deaf. Participants had to affirm that they lost their hearing (preferably) prior to the age of 3 but no later than the age of 5.

Participants had to self-identify as a member of the culture and community designated as Deaf (Padden & Humphries, 1997). All Deaf participants had to be at least age 50 or older; therefore, Deaf participants had to meet the demographic age parameter of at least, being born by the year 1964.

The theoretical concept and framework of resilience were not chosen as appropriate for this research project because the focus of this investigation was on levels of health literacy. The concept of resiliency and coping mechanisms within the Deaf community was assumed. Resiliency among members of the community is evidenced by their abilities to navigate the daily barriers of everyday life situations. Seeking to understand the conceptual and theoretical framework of health literacy as it applies to prelingual/culturally Deaf individual informed the choice of research questions. Since the overarching issue is health literacy, this research study sought to understand: *Do prelingual/culturally Deaf individuals over the age of 50 experience deficiencies in knowledge of senescence/age-related, health terminology (health literacy)?* Therefore, the theoretical framework of health literacy was the best fit to answer those questions.

Limitations

Depending upon the regional area where research is conducted, the Deaf community may be small (Padden & Humphries, 1997). Therefore, research may need to be carried out in several regions. The Deaf community can tend to be somewhat of a closed community to outsiders, aka hearing individuals (Padden & Humphries, 1997); therefore, access to the targeted population is often difficult to establish. Participant recruitment methods included snowballing, as well as, establishing a working relationship with social service agencies that specifically provide culturally appropriate and efficient

(signed) services to members of the Deaf community. External validity concerns about the inferences drawn from this population were controlled for as best as possible. It was difficult to determine if there are external validity issues due to the limited size of and limited geographical area in which this research was conducted. Concerns of internal and/or external validity can only be abated through a larger, possibly nationwide survey/research project.

Assumptions

It is assumed that participants were open and honest, to the best of their abilities, in answering the quantitative health literacy evaluation instrument. As with many research studies, results may not be necessarily generalized (Lester, 1999) to all members of the Deaf community age 50 and older, and may or may not simply be limited to the individuals and/or regional areas where the research was conducted. After a pilot study and focus participant review of the modified instrument was completed with one Deaf individual, the external validity of the modified health literacy instrument was assumed to equate to the original standardized evaluation instrument, the REALM.

Significance

"Deaf…individuals face significant barriers to accessing health care, resulting in documented inequities" (Withers & Speight, 2017, p. 107). The previously stated assertion that only sparse amount of health data exists on Deaf individuals (Barnett et al., 2011, p. 1) serves as the premise that supports the belief held by many prelingually deaf adults, about their linguistic minority community. Many Deaf individuals believe that comparatively, Deaf individuals experience poorer health [or thinner margins of health] than do hearing adults in the general United States population (Barnett et al., 2011). The

report submitted by the Agency for Healthcare Research and Quality (AHRQ) (2011), a sub-division of the Department of Health and Human Services, suggests that low health literacy in older Americans has been linked to poorer health status, higher risk of death, as well as, more frequent emergency room visits and hospitalizations. Mayer and Villaire (2009) concur with these assertions in stating that patients with poor (health) literacy skills do not receive the best quality healthcare and habitually overuse high-cost healthcare venues, such as emergency rooms and hospitals. Additionally, such individuals are more often re-hospitalized for failure to adhere, correctly, to discharge and aftercare instructions (Mayer & Villaire, 2009).

Furthermore, the same HHS/AHRQ report also postulates that over 75 million English-speaking American adults have limited health literacy which in essence limits their abilities to understand and use basic health information (AHRQ, 2011). Again, Mayer and Villaire (2009) concurs by stating that as many as 36% of Americans exhibit health literacy skills that equate to basic or below basic reading comprehension levels. These levels of health literacy are most probably attributable to the fact that many Americans, possibly as many as 90 million Americans, possess a fifth grade or less reading level (Mayer & Villaire, 2009). The HHS report's authors also associated a direct link between low health literacy, understanding medical instructions/labels and a greater likelihood of taking medicines incorrectly, which also involves health numeracy. Not only does Mayer and Villaire (2009) agree with the HHS report in stating that individuals with poor health literacy skills have trouble with reading, understanding and acting correctly on medical instructions, as well as, taking their medications as

prescribed; such individuals also experience problems with navigating the healthcare system and actively participating in their healthcare decision-making process.

According to the IOM (Institute of Medicine; Andrulis and Brach, 2007, p. S122) the relationships between diversity and health literacy must be viewed from within a cultural and linguistic milieu, and this perspective has yet to be fully investigated or delineated. Such statements and perspectives can also be directly applied to the community of prelingual/culturally Deaf individuals. Two anecdotes in the Andrulis and Brach (2007, p. 127) article most poignantly attest to the interrelatedness of the issues of health literacy and cultural diversity. In one anecdote, they describe how easily the Spanish word for 11 can be confused with the English word once, which landed a Hispanic man in the emergency room. In a second anecdote, they describe a situation in which a mother was instructed to give her sick child a teaspoon of medicine, but because she only had chopsticks and soup spoons in her kitchen, she ended up giving the child large soup spoonfuls instead.

Summary

Baby Boomers are individuals born between the years 1946 and 1964 represent a substantial portion or percentage of the nation's population (United States Census Bureau, 2010), the leading portion of this cohort attained the age of 65 as of 2011. Owing to the circumstance that vaccines for viral diseases that cause birth defects were not widely available until the mid-late 1960s, there is a significant probability that a considerable number of prelingual/culturally Deaf individuals are part of one of the senior citizen cohorts delineated as "Baby Boomers" – ages 50-68 (Abeles et al., 1998; AAR, 2006); "Young-Old" – ages 65-74; "Old-Old" – ages 75-84; and "Oldest-Old" –

ages 85 and older (Cohen-Mansfield et al., 2013; Transgenerational Design Matters, 2009). Prior to the development of vaccines for rubella and other transmittable viral diseases, as many as 20,000 infants were infected with rubella in any given year (Hunt, 2011).

With the projected increase in longevity, it is projected that members of this cohort will experience chronic senescence/age-related disorders for a longer period of their life span (Christ & Diwan, n.d). Unlike individuals who were members of the young-old, old-old and oldest-old cohorts in the past, current members of these cohorts are projected to experience chronic age-related disorders for longer periods than similar cohort members did in the past (Christ & Diwan, n.d). The negative aspect of chronic disorders is that they usually continue to consist throughout an individual's life (Brundtland, 2002); albeit, from a positive perspective, the World Health Organization states that chronic diseases of long duration generally progress slowly.

Most chronic, age-related disorders are inevitable owing to the medical industry's current lack of complete knowledge about the full mechanisms of these disorders (Han 2011, p. 2). Although some health and age-related disorders, such as some forms of lung cancer, are preventable, by avoiding tobacco (Han 2011, p. 2). Additionally, the afflictions of most chronic diseases do not resolve themselves either spontaneously nor are they completely cured by medication (Han 2011, p. 1-2). Hence, once a person has a chronic disease, the chronic disorder will most probably exist for the rest of his/her life (Brundtland, 2002). Therefore, in an effort to ensure, better quality of life during these projected expanded life spans and to reduce instances of severe morbidities or

comorbidities, as well as, to advance decreases in higher rates of mortality, health literacy can be viewed as a critical factor in the health management equation.

Research has shown that a significant number of prelingual/culturally Deaf individuals experience deficits in knowledge of general health-related terminology [health literacy] (Barnett et al., 2011; Barnett, McKee, Smith, & Pearson, 2011; Pollard et al., 2009; and Pollard & Barnett, 2009). Prior research with prelingual/culturally Deaf individuals has been limited in the scope and nature of how and what deficits in health-related knowledge (health literacy) are studied. Prior research in this area has been conducted by examining only general health literacy or only one health-related disorder per each of the few research projects that have been conducted. Additionally, previous research has included participants, from a population that spanned the age gamut, starting with ages as low as 18 (Pollard & Barnett, 2009). No previous study has specifically investigated the levels of senescence-related health literacy of prelingual/culturally Deaf individuals, specifically starting at the age of 50 and over. Nor has any previous study evaluated Deaf individuals age 50 and older for an aggregation of chronic age-related health disorders. By assessing whether any significant deficiencies in knowledge of an aggregation of age-related, chronic health disorders exists among prelingual/culturally Deaf individuals age 50 and older, the anticipated assumption was that this study would inspire and galvanize continuing Deaf community analysis and research in combating communication barriers to health-related information. Most notably, future, health literacy research should revolve around the aging Deaf population and their need to access health information and services; their need to make informed health decisions, as

well as, their ability to manage age-related health conditions by being able to follow health and numeracy instructions.

It was anticipated that knowledge gained from this study will help to inform health service providers and policy makers, as well as, inform procedures and approaches to providing health-related information to prelingually/culturally Deaf individuals. A review of the literature in the next chapter reexamines the factors of prelingual/cultural deafness and health literacy, and specifically discussed age-related disorders. The implication(s) associated with the quantifiable factor of health literacy of prelingual/cultural deaf individuals age 50 and over and their knowledge of age-related health disorders was the focus of the literature review. The literature review and this research study also elucidated problems and issues that need to be addressed to counteract the influences of these factors.

A review of the literature for this study included an analysis of the factors that are crucial to understanding the needs of the under-recognized community of the prelingual/culturally Deaf. Chapter 2 examines the differences between audiologically deaf and prelingual/culturally Deaf. Additional and major factors in Deaf history and Deaf education that has had a resounding and lasting effect on the education and literacy of Deaf individuals who would fit into the age range of the participant population of this study was also discussed. Deaf culture was discussed and defined, as well as, the major theoretical framework of this study, health literacy; to include health numeracy, functional health literacy, medical health literacy, and critical health literacy. Statistics for the United States aging population, morbidity and mortality rates and most common age-related disorders were included in the literature review section of this study.

Chapter 2: Literature Review

Introduction

Chen, Youdelman, and Brooks (2007) in their article entitled *The Legal Framework for Language Access in Healthcare Settings: Title VI and Beyond* addressed the legal framework for language access in health care settings from a legal and governmental perspective. Their framework was based on the basic intent of Title VI of the 1964 Civil Rights Act granting equal access, to include communication access, for all individuals, for any facility receiving federal financial assistance. Although the legal aspects of Title VI along with the Americans with Disability Act, as they relate to accessibility, were examined and included in the basic conceptual and social theory of this research project, they were not the central premise of this research project. Generally, in the United States, equal access to health care is not perceived to be a major problem, due to the aforementioned regulations. The major problems center on the issues of communication of information and health literacy. As discussed by Safeer and Keenan (2005), these issues need to be addressed via analyzing the methods and ways health care professionals disseminate and communicate health and health care information. Deaf individuals often experience barriers to health-related information, information that is usually presented in the form of spoken and/or written language. Challenges confronting Deaf individuals include their inability to comprehend spoken language and on an average third-fourth to sixth-grade reading level (Jones, Renger, & Firestone, 2005, p. 27).

Most health care materials are written at eighth, ninth, tenth-grade or higher level. While many hearing adults read on at least an eighth to ninth-grade reading level, many more hearing adults, 21%-23%, also read at an even lower level of fifth grade or lower (Safeer & Keenan, 2005). Additionally, for adults whose primary language is not English (ESL) this problem is compounded even further. These issues of deficits in English literacy and comprehension are the basis for what Pollard and Barnett (2009, p. 232; 2009, p. 182) term as a "fund-of-information deficit." Deficits in health literacy are also otherwise denoted as "fund of information deficits" (Pollard & Barnett, 2009). This health literacy fund-of-information deficit is specifically the basis of several research projects conducted by Pollard and Barnett and others. Their research directly relates to a segment of the American population that is often not recognized as having or utilizing another form of language as their primary language and way of communicating, the prelingual/culturally Deaf. Deficiencies in health literacy negatively impact the health-related self-efficacy of Deaf individuals in the form of poor comprehension of health-related information and poor adherence to prescribed health directives. Ultimately, this results in poorer self-health care management and poorer health care outcomes. The issue of health literacy and fund-of-information deficit was investigated in this study.

Literature Search Strategy

The goal of this literature review was to obtain a comprehensive aggregation of research literature, and studies specifically focused on prelingual/culturally Deaf individuals who self-identify as members of the Deaf community**.** The literature review included literature and research on general senescence/age-related disorders, general

population health literacy, as well as, the health literacy of prelingual/culturally Deaf individuals. I conducted a literature review utilizing the online library and resources of Walden University along with additional online resources. The following databases and websites were utilized in accessing scholarly peer-reviewed information, articles, and research studies/reports. The American Psychological Association (apa.org); Agency for Healthcare Research and Quality; United States Department of Health and Human Services (HHS); United States Department of Commerce – Economics and Statistics Administration – United States Census Bureau (Census.gov), EBSCO; CINAHL, CINAHL Plus with full text, East Stroudsburg University, ERIC; Educational Testing System (ETS); Government Printing Office (GPO); MEDLINE, National Center for Biotechnology Information (NCBI); National Institutes of Health (NIH), PubMed, Google Scholar, SAGE, Science Direct; Ovid Nursing Journals Full Text, SAGE full text, The National Academies Press; ProQuest; United Nations Department of Public Information. Also, due to the limited number of studies and the uniqueness of the population of focus, it is necessary to include seminal background information from renowned authors and texts (books) in the field of cultural deafness. These authors and their seminal works include Lane (1989) *When the Mind Hears – A History of the Deaf*; Lane (1996) *A Journey Into the Deaf World*; Moores (2001) *Educating the Deaf*; Padden and Humphries (1997) *Deaf in America – Voices from a Culture*; Parasnis (1998) *Cultural and Language Diversity and the Deaf Experience*; and Wilcox (1989) *American Deaf Culture*.

An explicit set of inclusion and exclusion criteria was utilized during the literature review search. Explicit criteria were necessary to define and establish the specific

demographic population criteria (inclusion and exclusion) due to the broad colloquial and general zeitgeist use of the terminology deaf. The establishment of this very explicit criteria was fundamental, paramount, vital and critically necessary in the literature review process to ensure that literature reviewed and included in this research process met the very specific characteristics of the intended participant population. The demographic criteria for inclusion in the analysis of populations in the literature research and review consisted of the very specific constructs of *prelingual Deaf(ness) and cultural(ly) Deaf(ness)*. The key search terms and strategy for this literature review, although broad, necessitated attention to the characteristic details and meaning of the most-important construct, Deaf versus deaf. Studies that involved individuals who were deemed as *postlingually, audiologically deaf* were excluded; to include *late-deafened and hard of hearing individuals*. Also excluded are individuals who although deemed prelingually Deaf, are also considered as "*Oral/Aural"* individuals, whose preferred method of communication is not American Sign Language. Other search terms/criteria included: *American Sign Language (ASL); Baby Boomer; Communication in Health Settings; Chronic Disorders/Diseases; CODA (Child[ren] of Deaf Adult[s]); Cued Speech; Culture; Cultural Competency; Culturally Deaf; Cultural Deafness; deaf; Deaf; Deaf Culture; Disability; Diverse populations; Effective Communication in Health Settings; Elder/Elderly; Functional Limitation[s]; Language; Health; Health Communications; Health Communications - Written Material Design; Health Literacy; Health Material Design; Health-Related Literacy; Health Terminology; Health-Related Terminology; Hearing Loss; Impairment; Literacy; Limited English Proficiency; Minority Health; Health Quality Improvement; Linguistic Competence; Language Barriers in Health*

Settings; Morbidity; Mortality; Numeracy; Health-Related Numeracy; Old; Old-old; Oldest-old; Young-old; Profound Hearing Loss/Profound Deafness; Readability; Severe Hearing Loss/Severe Deafness; Senescence; Speech-reading/Lip-reading; and Senior Citizen.

Theoretical Foundation

Health Literacy is the theoretical foundation upon which the current study was based. Although there are several and various conceptual frameworks upon which various researchers define the construct of health literacy, the integrated conceptual model was chosen for this study. The integrated conceptual model of health literacy was deemed to be most applicable, for this study, due to the broad, basic and inclusiveness of the various constructs found to be the basis of many and various established theories of health literacy. Although, the construct of health literacy is differently defined by various researchers, in its most comprehensive/integrated form this construct involves and entails the necessity of an individual's ability to gain, comprehend and utilize health related information. Furthermore, the construct of health literacy is often influenced by systemic as well as individualized socio-linguistic factors, such as language and communication; factors that were taken into and under consideration in the current study.

Health Literacy

The integrated conceptual model for health literacy, according to Kushalnagar et al. (2015, p. 830) "requires not only accessing health information but also understanding and utilizing health information to appraise and use the health-related information to maintain and improve health." Therefore, health literacy, in one of its most fundamental

forms, is defined as “the degree to which individuals can obtain, process and understand basic health information and services needed to make appropriate health decisions” (Mayer & Villaire, 2009, p. 1). The leading and noted researchers in the area of health literacy tend to posit that their positions as to what defines health literacy differ, but the following definitions and descriptions of their positions on health literacy, essentially conform to one another. Synthesizing the positions of Pleasant et al., (2011, p. 11) and Squiers et al. (2012, p. 31), there is a lack of true and accepted theoretical frameworks to precisely circumscribe what is meant by health literacy. This stance is supported by an additional corroborative statement from Peerson and Saunders (2009) in which they state that the lack of theory is due to and has caused researchers to define health literacy in various ways depending on the need or goal of the study being conducted. Additionally, variations in the definition(s) of the construct of health literacy are often because such research is or has been conducted by various researchers utilizing various and different applications of the construct(s)/variable(s) that can be used to ascribe the term health literacy.

Based on their research, Pleasant et al. (2011) concluded that too many of the current measures of health literacy simply focus on the individual’s reading and comprehension abilities. They posit that current instruments exclude other critical factors that should be measured, such as how the individual utilizes health information and the effectiveness of communication between health providers and the patient. Most current versions of health literacy tests “over” utilize standard reading tests while others only assess word recognition and not necessarily the patient’s comprehension, understanding or knowledge (Pleasant et al., 2011, p. 13), all of which are essential factors and

components of literacy. Additional problematic areas in health literacy testing consist of the fact that these evaluative examinations lack cultural sensitivity; do not evaluate spoken communication skills or lack thereof, and employ ambiguous item wording, among many other questionable factors (Pleasant et al., 2011, p. 14).

While variations in ascribing a construct are or may be very acceptable in and for many areas of research, the comparative analysis research on the meaning a health literacy conducted by Squiers et al., (2012) differs slightly with the study carried out by Pleasant et al., (2011). The research of Peerson and Saunders (2009), as well as, the research of Squiers et al. (2012) indicates that there are many and different viewpoints on the exact definition of health literacy. The majority of the theoretical and conceptual frameworks that were examined illustrate that health literacy affects health-related outcomes (Squiers et al., 2012, p. 31). Squiers et al. (2012) comparative analysis highlights the fact that many, if not most, of the same construct variables, are included in the theoretical and conceptual frameworks of most of the various theories and definitions of health literacy. Three of the health literacy constructs that were reviewed in this study include functional health literacy, medical health literacy, and critical health literacy.

Functional Health Literacy

Health literacy is actually a misnomer and is a much broader, umbrella term that includes other literacy components to include functional health literacy (Peerson & Saunders, 2009, p. 288). Functional health literacy consists of the basic reading and writing skills needed and required to enable an individual to understand and follow health messages information (Peerson & Saunders, 2009). Functional health literacy is also delineated as consisting of the skills and abilities a person needs to not only successfully

function in a health-related situation, but also the skill and ability to complete health-related tasks successfully (Berkman, Davis, & McCormack, 2010, p. 14). Pearson and Saunder (2009, p. 288) lists the following skills and abilities as essential components of functional health literacy. Reading consent forms, medication labels, and inserts; being able to comprehend other written and oral health care information provided by any healthcare professional, and being able to act upon the required and given information, correctly. The basic concept of this skill delineated as functional health literacy also includes correctly following and adhering to procedures and directions for taking medications, self-care, and appointment schedules.

Medical Health Literacy

Another component of health literacy, according to many of the aforementioned researchers, is medical health literacy. In its various forms, it means the type of health-related knowledge and skills (basic reading and numerical skills) that allow an individual, primarily, to function well in health care settings and environments (Peerson & Saunders, 2009). Basic reading and numerical skills are necessary components for safe and effective self-health care management. Self-healthcare management includes reading and comprehending health care instructions; numerical skills are also needed to adhere effectively and correctly to medical and prescription instructions.

Critical Health Literacy

The third component of health literacy is referred to as critical health literacy. Critical health literacy refers to “an individual’s ability to critically analyze health-related information that is presented to them” (Peerson & Saunders, 2009). This nomenclature delineates more advanced cognitive skills and abilities that the individual uses in

combination with social skills (Sorensen et al., 2012, p. 4). Furthermore, critical health literacy skills are used together to not only critically analyze health-related information, but also to "exert greater control over life events and situations" (Sorensen et al., 2012, p. 4).

In a report conducted by the Agency for Healthcare Research and Quality (AHRQ, 2011), a subdivision of the Department Health and Human Services, the AHRQ states that due to limited health literacy, more than 75 million English-speaking adults in the United States experience difficulties in understanding and correctly utilizing basic health information. Mayer and Villaire (2009) corroborate this statement by stating that one in two adults in the United States is affected by poor health literacy. Considering what has been discussed earlier, regarding the English literacy levels of many prelingual/culturally Deaf individuals, this factor becomes most relevant when applied to prelingual/culturally Deaf individuals.

Health literacy as the theoretical framework of this study was most applicable because it 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" (Andrulis & Brach, 2007, p. S122). Without the ability to hear, with the communication barriers most prelingual Deaf individuals face, and with the lower reading comprehension levels Deaf individuals experience, their capabilities to access health-related information is severely impacted. Health literacy is posited as a dynamic state and not a constant that may transform based on the demands and requirements of the medical situation (Andrulis & Brach, 2007, S123). Therefore, the individuals' literacy abilities and capacities do not entirely predicate health literacy. It is also influenced by

the demands and requirements the presented health information necessitates in order for the individual to decode, interpret, and assimilate the information into a health message (Andrulis & Brach, 2007, p. S123). Taken together, these statements emphasize the fact that health literacy is a product of multiple levels of abilities within each individual and not [necessarily] determined, solely by an individual's ability to read, understand, process, and act on health information. Hence, many other multifaceted factors such as culture, language, social exclusion should be and must be taken into consideration.

The Institute of Medicine defines the concept "health literacy" as a "constellation of skills necessary to function effectively in the health care environment and act on health care information" (Squiers et al., 2012, p. 31). These skills comprehensively include "the ability to interpret documents, read and write prose [print literacy], use quantitative information [numeracy or quantitative literacy], and speak and listen effectively [oral literacy]" (Berkman, Davis, & McCormack, 2010). Health literacy as described and defined by Sorensen et al. (2012, p.3) is:

> Linked to [general] literacy and entails people's knowledge, motivation, and competence to access, understand, appraise and apply health information in order to make judgments and make decisions in everyday life concerning health care, disease prevention, and health promotion, [in order] to maintain or improve quality of life during their life course.

Health literacy is also defined as the ability to obtain, process, and understand basic information and services needed to make appropriate health decisions (Wallace, 2006, p. 85). Pleasant et al. (2011, p. 14) added the factors of being able to find, understand, evaluate and communicate and then utilize said information to make

informed decisions; and that such decisions are the critical determining factors of health literacy.

Literature Review

A literature review for this study required reviewing literature in several different areas to effectively link together all of the major components that had influencing effects on and in the study. Defining and discussing Prelingual Deafness was necessary to distinguish the major differences between prelingual – before the acquisition of language deafness and post-lingual deafness – deafness that occurs after the acquisition of language. A review of Deaf history brings attention to the historical effects that previous educational systems had on older Deaf individuals's education and English literacy skills to include mathematical (numeracy skills) and dovetails with the section on health literacy and health numeracy. A review of Deaf culture, highlighting the fact that there are cultural differences between this linguistic, cultural minority population and the hearing population, dovetails with later discussions on cultural competency within the health care field. Finally, reviews of aging population statistics, senescence/age-related disorders and morbidity, and mortality along with prelingual deafness are the main justifications for the current study.

Prelingual Deafness

While the exact amplitude of the Deaf community is unknown, a 1996 estimation of the occurrences of hearing impairment in the general population was approximated to be around 9% (Padden & Humphries, 1997, p. 4). More current estimations for the number of individuals in the United States and Canada who can be classified or self-

identify as deaf/Deaf is guesstimated to be between 550,000 to one million adults (Current Estimates, 2004; Mitchell et al., 2005; Pleis & Lethbridge-Cejku, 2006; Samady et al., 2009, p. 480). The only extensive efforts at enumerating a more precise number of deaf/Deaf individuals in the United States was conducted by researchers at Gallaudet University in 2004, and then repeated in 2010, and again in 2014. Although their initial results were published in July 2004, their latest updated calculation estimates this figure to be around 18% of the population or 421,000 individuals in the United States and Canada (Gallaudet University, 2014). Since non-clinical delineations of what levels of hearing loss equate to the various descriptive levels of hearing impairment (hard of hearing or deaf), and since neither the United States Department of Health nor the United States Census has tracked this information since the 1930 census (Gallaudet University, 2014); the best estimate of the size of this population is a "guesstimate" (Gallaudet University, 2014).

The prevalence of permanent prelingual hearing loss is 1.2 to 1.7 cases per 1000 live births with between 20-30% of these prelingual losses evaluated as profound hearing losses (Kral & ODonoghue, 2010, p. 1438). Prevalence of prelingual hearing loss has been found to occur up to 6 years of age as an outcome of medical illnesses such as meningitis and thereby increases the number of children diagnosed as experiencing prelingual hearing losses (Kral & ODonoghue, 2010). Additionally, a delayed diagnosis of a prelingual hearing loss may be the result of a delayed onset of a genetic hearing loss or infrequently, there is simply a missed or late diagnosis of prelingual hearing loss (Kral & ODonoghue, 2010, p. 1438). Instances of a delayed diagnosis in identifying a prelingual hearing loss are additional factors that contribute to the confusion in

determining the exact size of the prelingually Deaf population here in the United States. Higher prevalence of prelingual hearing loss is more often found in developing countries as a result of the lack of access to immunizations for childhood viral and bacterial diseases, or as a result of the greater risks for exposure to ototoxins, along with consanguinity [a close bloodline inheritance] (Kral & ODonoghue, 2010, p. 1438). Consanguinity, genetic, or inherited hearing losses account for at least 50% of cases of permanent hearing losses in children (Kral & ODonoghue, 2010, p. 1441).

The inability of individuals with severe to profound prelingual hearing losses to understand or comprehend spoken language means that they cannot hear or overhear spoken information or radio and television broadcasts or other channels of public information that may include health-related information. Additionally, their reading comprehension levels limit their ability to understand written health care information which is usually presented at a seventh to eighth grade or higher reading level (Mayer & Villaire, 2009). Pollard, Dean, O'Hearn, and Haynes (2009) are champions and advocates for the need for additional studies that call attention to a community that is often disregarded; the Deaf community, as well as the collective limited English Proficiency (LEP) of many of the members of this community. According to Pollard et al., (2009) this group is threatened by health discrepancies connected to low health literacy. Pollard et al., (2009) reiterate that this group experiences a lack of access to health information conveyed by radio, television, or ambient auditory sources such as public dialogue, which only serves to intensify this population's low health literacy. Prior studies have shown that methods used for adapting health education materials for hearing LEP populations do not reach Deaf audiences with equal efficacy (Pollard et al.,

2009). The effects of deficiencies in health-related knowledge on the prelingually/culturally Deaf community can be ascribed to a lack of access to health-related information. The levels of deficits in health-related information that is often and normally acquired or gained through direct communication [oral], ambient auditory sources and/or through written materials was investigated in this study.

"Various reasons for inequities [in health care] have been identified, including poor health literacy and biologic health differences related to deafness etiologies" (Withers & Speight, 2017, p. 107). Therefore, antecedents of prelingual deafness can vary from naturally occurring congenital birth defects to in utero exposure to toxic chemicals (drugs or environment), or microorganisms (bacteria or viruses). Prior to the development of vaccines for many of the various common communicable viral and bacterial diseases, the antecedent for many prelingually and congenital hearing losses is/was in utero and or postnatal exposure to various microorganisms. Additionally, exposure to toxic environmental situations, and postnatal health complications that resulted from some of these very same viruses, bacteria or microorganisms also causes prelingual deafness. Prelingual hearing loss can sequelae from perinatal anoxia (hypoxia), Rh factor incompatibility (Moores, 2001; Strong & Prinz, 1997), or prenatal exposure to viruses, often referred to and by the acronym TORCH (Billings & Kenna, 1999, Moores, 2001). **TORCH** infections include **T**oxoplasmosis, **O**ther viruses, **R**ubella, **C**ytomegaloviruses, and **H**erpes simplex viruses, as well as, syphilis and meningitis (Glickman, 2009; Kral & O'Donoghue, 2010; Moores, 2001). Postnatal prelingual hearing losses may also sequela from measles and mumps (Kral & O'Donoghue, 2010). Prior to the development of vaccines that protected young children

and pregnant women against contracting various viral infections, most specifically rubella, the rubella epidemic of the 1950s to the mid-1960s caused many babies to be born with congenital birth defects to include prelingual hearing loss (Marschark, 2009; Moores, 2001). Additionally, some infants lose/lost their hearing as prelingual infants due to the side effects, complications or reactions to medications or high fevers resulting from contracting these various post-natal viral, bacterial, micro-bacteria, fungi and amoebae infections, and health conditions such as meningitis (Brauer et al., 1998). Prelingual hearing loss may also be the sequela of physical accidents; among a host of other causes. Viral infections along with various other types of infectious and contagious diseases can be and have been implicated as one of many causes of congenital or prelingual hearing loss for many members of the age 50 and older "Baby Boomer" cohort of Deaf individuals.

Congenital rubella syndrome along with other biologic infections and diseases contracted in utero or early childhood are known causes of prelingual deafness (Hunt, 2011). The rubella pandemic was not eradicated until the mid to late 1960s (Hunt, 2011). Therefore, there is a considerable probability that a substantial portion of the approximately 4.8 million people with prelingual, profound to severe hearing losses, who cannot hear or understand normal speech (Barnett & Franks, 1999, p. 1754) are also part of one of the senior citizens/elderly cohorts and can be projected to experience chronic senescence health disorders. Senescence disorders were also described as age-related health disorders in this study. Alliance for Aging Research [AAR] (2006) anticipates an onslaught in the aging of the American population, which will also include Deaf individuals. Aging individuals are projected to live longer with longer periods of

experiencing age-related disorders (Christ & Diwan, n.d). Therefore, policies and procedures established and utilized by health policy makers, as well as, health service providers will need to be amended to be more inclusive of and specifically addressed to and for American Sign Language users.

Currently, individuals, including Deaf individuals, who are 50 to 68 years of age are members of a cohort known as the "Baby Boomer" Generation. The "Baby Boomer" cohort of the national population represents a proportionally significant segment of the US population (Federal Interagency Forum on Aging-Related Statistics [FIFARS], 2012) and for the next 15 years is projected to continue to add to the increasing numbers of senior citizens over the age of 65. As this segment of the population continues to grow in numbers, and with the current increase in life span expectancy, the phenomenon and occurrence of age-related chronic health disorders can be expected to increase (Christ & Diwan, n.d), in general, for all of the aging population, inclusive of the prelingual/culturally Deaf population. Therefore, this study evaluated health literacy among culturally Deaf individuals age 50-65 and older. The significance of this study was to evaluate the need for members of the prelingual/culturally Deaf community to possess good health literacy to effect good or better self-management of age-related disorders. The importance of health literacy, (knowledge and comprehension) has been equated by the healthcare industry as extremely conducive and positive factor(s) in abating incidents of additional morbidities and possibly as a factor in decreasing higher rates of disorder mortalities (Pleasant et al., 2011). As individuals age, their propensity for age-related chronic illnesses increases, therefore, self-efficacy in health management thereby becomes an important and vital factor in the management of chronic age-related

disorders and other health disorders. One of several factors that can foster health self-efficacy is health literacy. Based on this premise, evaluation of any deficiencies in knowledge of health-related terminology of age-related disorders that Deaf adults over the age of 50 may possess was the purpose and goal of this research study**.**

Prelingual deafness is defined as a hearing loss or deafness evaluated to be severe to profound and present either at birth or occurs prior to the development of spoken language, which is usually prior to the age of three (Moores, 2001, p.12). Congenital rubella syndrome along with other biologic diseases contracted in utero or early childhood are known causes for prelingual deafness that arise at birth or transpires prior to the development of spoken language. Hearing loss is the most common after effect of congenital rubella infection (Hunt, 2011; Vernon, 2006). As stated earlier, the rubella pandemic was not eradicated until the late 1960s. Therefore, there is a high probability that a substantial portion of the approximately 4.8 million people [who] cannot hear or understand normal speech (Barnett and Franks, 1999, p. 1754; Billings and Kenna, 1999) are prelingually deaf. Additionally, a substantial portion of these prelingually Deaf individuals may be part of the "Baby Boomer" cohort. The fact that the probability of a considerable number of Baby Boomers may be prelingually Deaf is particularly important when you combine these factors with the factors delineated by Glickman (2009). Glickman (2009, p. 357) posits that more so than in the general population, the occurrence of lower IQs, poorer educational performance and language aphasias are more often found in the population of children whose etiology for prelingual deafness is the sequela of prenatal rubella. Furthermore, meningitis is another primary cause of prenatal hearing loss and that in utero exposure to meningitis is a leading cause of brain damage

(Glickman, 2009, p. 357). Infants such exposed are found to exhibit lower intelligence, poorer educational performance, and greater language problems, along with other co-morbidities disabilities (Gickman, 2009).

The most striking effect of a prelingual profound hearing loss is the lack of development of spoken language [that] affects daily communication that ultimately restricts learning and literacy (Kral & O'Donoghue, 2010, p. 1438). The enormity of the probable impact of the combination of prelingual deafness with the two other looming issues of: (1) the increasing number of individuals living to the age of 65 and beyond with chronic health disorders, and (2) coupled with the effects of deficits in health-related terminology knowledge (health literacy), should be of concern to all, and especially to members of the health care industry. This combination of factors has the propensity to have an impact that will affect and encompass all aspects these individuals' lives and their interaction with society. Justified concern about the combined effect of these three factors and their effects on Deaf individuals and their interaction with society is evidenced in the following quote from an article from the *"Pervasive Computing"* magazine. "An effort is underway to alert policymakers and others that the leading edge of the baby boom is about to overwhelm our national health care system" (AAR, 2006; Mann, 2004). Albeit, this is a technology periodical; a periodical not directly related to the health care discipline, the statements made in this report are profound, timely, and eye-opening. The alarm being sounded by the Alliance for Aging Research [AAR] (2006) and Mann (2004) is further enhanced by the statement that "the need to address this [issue] is urgent, before the "silver tsunami" hits."

Prior research in general English language comprehension levels of Deaf individuals conducted by various researchers to include Andrulis and Brach, (2007); Brach, Fraser, and Paez, (2005); Jacobs, Shepard, Suaya, and Stone, (2004), indicates that the same English language comprehension issues that many hearing individuals face, most specifically those for whom English is a second language; is very similar to the experiences in health literacy comprehension that many prelingually Deaf individuals face (Barnett & Franks, 1999; Barnett, McKee, Smith, & Pearson, 2011; Samady et al., 2009; Youdelman & Perkins, 2005). Prior research conducted by Jones, Renger and Firestone (2005, p. 27) on the health literacy of Deaf individuals concluded that many Deaf individuals comprehend spoken language on average at a third to fourth-grade reading level. Many young deaf students from both residential and public schools fail to complete high school; only 52% graduate, 19% receive certificates and 29% age out or drop out (Danek & Seidman, 1995, p. 207). The median reading level of a deaf high school graduate in the United States is 4th to 5th grade (Barnett & Franks, 1999, p. 1756; McKee, Barnett, Block, & Pearson, 2011, p. 3-4). Additionally, the medical vocabulary knowledge of Deaf adults in the United States is similar to that of non-English-speaking immigrants in the United States (Barnett & Franks, 1999). Unfortunately, for members of the Deaf linguistic/cultural community, their deficits in English, is an unrecognized issue. Similarly, their deficits in knowledge of health-related terminology continue to be an unacknowledged issue that remains particularly unaddressed by members of the medical community, as well as by society-at-large (Davoli, n.d.).

Deaf History

> American Sign Language is not poor English; it is unique. It not only differs from English in its syntax and vocabulary, but its visual form is also so strange to hearing people that for decades it was not recognized as a language (Van Cleve & Crouch, 1989, p. 106).

The most historically damaging event, for Deaf individuals, occurred in 1880 at the World Conference for the Deaf in Milan, Italy (Lane, 1989; Lane et al., 1996; Padden & Humphries, 1997). Through manipulative demonstrations put forth by the Italian Deaf school system (Lane, 1989), and supported by the influential and championing support of the "infamous" Alexander Graham Bell (Lane, 1989; Lane et al., 1996); worldwide "sweeping reforms" were evoked in Deaf education. Alexander Graham Bell was revered by hearing people for his invention of the telephone, but for Deaf individuals, he holds a most despicable and contemptible position of being "their strongest adversary in the controversy over sign language…and the most feared enemy of the American Deaf," according to George Veditz (Van Cleve & Crouch, 1989, p. 114). Alexander Graham Bell's family history shaped his advocacy of oralism and opposition to sign language. His mother was hard-of-hearing, and he grew up utilizing the two-handed English (British) manual alphabet to communicate with her; and his father was a college professor who developed and taught deaf students via a method called 'Visual Speech' (Van Cleve & Crouch, 1989, p. 114). From these factors, it is surmised that his inventive work was influenced by his need to seek to foster amplification and not simply to develop what became known as the telephone.

Unfortunately, in initiating the reforms expounded by A.G. Bell and others at the 1880 Milan Congress (conference), Deaf schools, worldwide, began to ban the use of sign language in the classroom, and replaced signed communications, in the classroom, with "the oral method" (oralism). "The Milan Congress thus seemed to give international approval to the idea that deaf children should be forced to communicate without sign language" (Van Cleve & Crouch, 1989, p. 110). The great Deaf American statesman, George Veditz, was among the few individuals who remain unconvinced and tried to raise the collective voices of the few dissentients against the sweeping reform of oralism. In their book *"Deaf in America: Voices from a Culture,"* Padden and Humphries (1997, p. 35-36) paraphrases parts of George Veditz's Milan rebuttal and closing remarks. Re-paraphrased as follows: "These men have tried to…make people believe that the oral method is really the one best means of educating the Deaf…in truth, the oral method is the poorest".

Unfortunately, for the Deaf, the few voices raised against the sweeping reform to oralism, fell on "deaf ears." For nearly the next 100 + years, sign language took a back seat to oralism - the oral method of teaching deaf children. Oralism then became the standard and practice in almost all schools worldwide. The residential schools for the Deaf here in the United States also adopted these reforms. Most residential schools for the Deaf in the United States were historically state run and funded schools. There were very few, if any, private schools for the Deaf. The banning and restrictions against the use of sign language in the American residential schools were enforced so strictly that horror stories of the harsh treatments students would receive if caught using sign language, persist to this day. The banning of sign language in schools most specifically

applies to older members of the Deaf community who attend k-12 schools for the Deaf before the reversal of the 1880s educational reforms. The reforms were not instituted until the late 1970s, early 1980s and reforms continued well into the 1990s with the enactment of the ADA (American with Disabilities Act). Therefore, this factor helps to account for the deficits in English literacy found among many older Deaf Americans and would include and be most applicable to the targeted age group of this research project.

"My Third Eye" (Padden & Humphries, 1997; Lane et al., 1996) is a most conspicuous and notable Deaf play that continues to pass down and depict this horrific era in Deaf culture and history. This play depicts a typical Deaf residential school and reminds generations of Deaf individuals who attended these schools of the caning and dunking punishments they would receive if they were caught signing or were unsuccessful in the oralism training (Padden and Humphries, 1997, p. 36-37). Deaf students who were unsuccessful in oralism programs were eventually labeled "Oral Fail" (Padden & Humphries, 1997, p. 52). Through the oral method of educational training, Deaf students would spend almost all of their school day trying to learn to articulate. Therefore very little time was actually devoted to academic subjects and training (Padden & Humphries, 1997; Lane et al., 1996, p. 241).

> Student's success was measured by what they knew in English, but most [students] had great difficulty learning English (or much else) through oral instruction [methods]. The level of accomplishment was low, both as measured, and in fact. Residential schools typically [were] divided into lower, middle, and upper schools. The low expectations they [had] for many students [matched] the inferior quality and limited variety of academic offerings . . . [which could be

> evaluated by] the upper school [curriculum, which] may well not offer high-school level instruction (Lane et al., 1996, p. 241).

Even today, in the United States, Deaf school children learn English "laboriously" similar to how one learns a foreign language; and their English syntax structure is not standard English nor grammatically correct (Wilcox, 1989, p. 104).

Deaf students were eventually allowed to change to manual instruction (signed instruction) once they were deemed "Oral Failures," but this would usually occur sometime during their adolescence years (Padden & Humphries, 1997, p. 52). Hence, most of the formative academic years were spent on articulation training and very little didactical instruction time was devoted to the core academics of (English) reading comprehension, writing in English sentence syntax, or numeracy (mathematics). These factors support the need to evaluate (health) literacy proficiency for many Deaf individuals age 50 and older.

In the United Stated, educational programs and the designation of bilingual education for limited-English-proficient (LEP) students, in actuality, exclusively refers to students who are hearing and oral and whose primary language is a spoken non-English language (Parasnis, 1998, p. 38). Hence, this essentially does not describe a prelingually Deaf student or individual. Additionally, despite the similarities and parallels, the core tenets of Title VII of the Elementary and Secondary Education Act, the act does not encompass programs that address deaf student issues (Paranis, 1998, p. 38). Furthermore, it was not until the dawn of the social, cultural awareness, and civil rights era of the 1960s was any political and legislative attention given to the educational needs of students who were non-English speaking (Parasnis, 1998, p. 41). Essentially and

unfortunately, these social and political, legislative acts still did not dovetail to meet the educational needs of prelingually Deaf students.

Deaf Culture

Many of the individuals who have experienced some form of early and profound to severe hearing loss were referred to as prelingually deaf throughout this paper. Many of these individuals consider themselves to be, part of a linguistic and cultural (sociocultural) minority subsisting in a world that barely recognizes or acknowledges the existence of this minority group (Lane et al., 1996; Padden & Humphries, 1997; Parasnis, 1998; Wilcox, 1989). Most individuals who self-identify as members of this minority linguistic group utilize (American) Sign Language as their preferred method of communication (Padden & Humphries, 1997, p. 3). They also view themselves as proud members of a "linguistic/cultural" minority group that has its own rich history, distinct traditions and ways of "doing things" (Lane et al., 1996; Padden & Humphries, 1997; Parasnis, 1998; Wilcox, 1989). Additionally, they utilize idiomatic expressions and phrases that do not equivalently translate into English (or any spoken language) but are imbued with meaning to members of this population (Padden & Humphries, 1997; Parasnis, 1998).

A culturally Deaf person is an individual who identifies his or herself as part of a linguistic minority group whose primary and preferred method of communication is through manual communication, otherwise known as Sign Language (SL), specifically American Sign Language (ASL) here in the United States. Individuals who self-identify as culturally Deaf not only utilize ASL as their preferred and primary method of communication, they are also proud to identify themselves as part of this cultural and

linguistic minority group, delineated by the use of the capital letter D in Deaf. The small d is used to denote the medical model or auditory status of an individual evaluated to have a severe to profound hearing loss which is referred to as deaf or deafness. Such a person may be hard-of-hearing or late-deafened and may or may not self-identify as being part of the linguistic community that utilizes manual communication [ASL] and most often will not learn to communicate via manual communication [ASL].

The capital letter "D" is used when referring to this minority linguistic group or members of this group, as a means of identifying this group as a "cultural" group, and is not intended as a denotation of their audiological status (Padden & Humphries, 1997; Parasnis, 1998). Additionally, as proud members of this cultural and linguistic minority group, most members do not necessarily or wholly embrace the socio-political model known as the "medical model" of disability (Parasnis, 1998). Proponents of the medical model advocate from a clinical perspective. Proponents of the medical model approach the disorder of prelingual deafness by attempting cure or at least manage and mitigate the disorder/disability through invasive techniques such as surgery, or assistive technology such as cochlear implants or hearing aids, or at the very least, intensive interventions such as speech training and therapy (Parasnis, 1998, p. 8).

Therefore, efforts to engage with members of the Deaf community should not emanate from the medical model perspective. Engagement with members of the Deaf community should be respectful of their cultural self-identity, the same as it should be with any other minority, linguistic or cultural group; and as accorded by the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973 (National Association of the Deaf [NAD], 2000); Parasnis, 1998). Conversely, Parasnis (1988, p.

8), a proponent, of the culture of Deafness states that shifting the focus from a disability perspective to view these individuals as cultural/linguistic group has sparked discussions as to whether "deafness should be regarded as a disability or a hearing variation." Support on either side of this debate most probably hinges on which perspective one subscribes to; the "medical model of deaf" or the 'sociocultural model of Deaf."

Health Literacy and Health Numeracy (Quantitative Literacy)

Utilizing a combination of terms in searching the Merriam-Webster's Online Dictionary, the dictionary defines health as "the condition of being sound in body, mind or spirit," and defines literacy as "the ability to read and write." Combining the definition of health literacy as put forth by both The United States Department of Health and Human Services (USDHHS) and the Institute of Medicine's (IOM); they both define health literacy as the degree to which individuals can obtain, process and understand basic health information and services needed to make appropriate health decisions. Based on the earlier discussions about prelingual deafness and Deaf history the issue of literacy in general and more specifically health literacy directly relates to this study. The focus of this study was on prelingual/culturally Deaf individuals over the age of 50, especially when health self-efficacy is viewed in the light of general literacy that in turn directly correlates with health literacy.

The American Medical Association's (AMA) definition of health literacy is "the ability to obtain, process and understand basic health information and services needed to make appropriate health decisions and follow instructions for treatment" (AMA, 1995-2014, para. 1). Deficits in the knowledge of health-related information can be directly related to deficits in health literacy as well as health numeracy and can have a severe

effect on an individual's self-efficacy in the management of their health disorders. Oldfield and Dreher (2010, p. 206) describe health numeracy skill as the ability to read, understand, and manipulate numbers for negotiating simple measurement conversions or for safely dosing medication. Therefore, the way the AMA (1995-2014) delineates health literacy as "a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment" encompasses both health literacy and health numeracy.

In their review of the literature, Oldfield and Dreher (2010, p. 209) identified self-efficacy, along with health-related experience and general literacy as antecedents to health literacy; with self-efficacy influencing health-seeking behaviors, but more importantly, general literacy as a measure that directly influences health literacy. Prior discussion revealed that there are several accepted and varied definitions of the term health literacy and Wallace (2006, p. 85) offers the most basic definition which is similar to the AMA's. The most basic definition of health literacy is the ability to obtain, process, and understand basic information and services needed to make appropriate health decisions (AMA, 1995-2014; Wallace, 2006). The Oldfield and Dreher (2010, p. 205-206) research identifies and reveals that there are variations in meanings, as well as, various other definitions for the term, health literacy. Additionally, as many as an estimated two-thirds of American adults age 60 and older have inadequate or marginal literacy skills and thusly are identified as a vulnerable population (Oldfield & Dreher, 2010, p. 204).

According to the 2003 National Assessment of Adult Literacy (NAAL), 60 million people or nearly 40% of the American adult population, has limited health

literacy (Andrulis & Brach, 2007, p. S123). Furthermore, "nearly two decades of research have linked limited literacy with challenges in health care, including lower health knowledge, misinterpretation of prescriptions, and lower receipt of preventive services" (Andrulis & Brach, 2007, p. S122). Individuals with limited English proficiency or [limited] communication abilities are at [a] high[er] risk for health disparities and adverse health effects…to include lower patient satisfaction, [poorer patient] adherence to prescribed protocols, [higher] use of health services, and [more deficient] education regarding healthy behaviors (McKee, Barnett, Block, & Pearson, 2011, p. 2). Forty-five percent of American residents with limited health literacy are members of ethnic and racial minority groups (Andrulis & Brach, 2007, p. S123). The self-identified linguistic and cultural group of prelingually Deaf individuals can also be added to this percentage.

Prelingually/culturally Deaf individuals are members of a linguistic minority group that often faces communication barriers in conducting their ADLs **(**activities of daily living**)** and in accessing many daily life activities and services. These activities and services include access to services and activities that hearing individuals most often access very easily, without much thought or effort and in most cases, take such access as a given or for granted. These services and activities of daily living are activities that able bodied hearing individuals and even some hearing individuals with various other physical disorders and or disabilities, can access and do and most often access very easily, without much thought or effort and in most cases, take such access as a given or for granted.

For many culturally Deaf individuals whose most proficient method of communication is through American Sign Language, one of the major barriers/issues they

encounter is an effective transliteration of health-related information. According to McKee, Barnett, Block, and Pearson, 2011 the difficulties and linguistic differences between Deaf individuals who utilize ASL and the hearing/speaking clinicians Deaf individuals encounter, pose a major challenge in preventive care for Deaf individuals. Currently the concerns of the health industry, as these concerns relate to language and how it is used in health care [settings], generally involve [patients] who speak, read, or write in a dialect other than English (Andrulis & Brach, 2007, p. S123). The crux of this research study was encompassed in the following two paraphrases. Use of the same language by clinicians and patients [linguistic concordance] is an important determinant of whether patients seek, understand, and adhere to providers preventive services recommendations. Language concordant, otherwise known as, the communication between the patient and the provider, is associated with higher appropriate use of preventive services by Deaf ASL users" (McKee, Barnett, Block, & Pearson, 2011, p.2).

The above statements elucidate that there are unrecognized and rarely addressed problems of effective access to health-related information for individuals who are prelingually/culturally Deaf. For many Deaf ASL users, there are deficits in written English proficiency. These deficits in written English proficiency also lead to deficits in knowledge of health-related information. Written English deficiencies can also be directly associated with deficits in health literacy and health numeracy. Additionally, these deficits can and often do have an adverse effect on the individual's self-efficacy in the management of health-related disorders.

As stated earlier, deaf individuals often experience barriers to health-related information that is usually presented in the form of spoken and/or written language. The

challenges and communication barriers that confront many Deaf individuals not only include an inability to comprehend spoken language but in many cases, also include deficits in English literacy skills. According to According to Young et al. (2016, p. 2) "the majority of Deaf people who have been deaf since birth or early childhood, have lower than average levels of literacy in the written word in comparison with hearing people." In many cases, this deficit equates to an average, reading comprehension level of third to fourth grade (Jones, Renger, & Firestone, 2005, p. 27). The inability to hear or comprehend spoken language means that a deaf/Deaf person cannot auditorily process spoken information addressed directly to them. Nor can they comprehend ambient oral/aural information such as radio and television broadcasts or other channels of public information that may include health-related information. Additionally, deficits in reading comprehension levels impact on one's ability to comprehend written health care information which is usually presented at a seventh to eighth grade or higher reading level (Mayer & Villaire, 2009). Pollard, Dean, O'Hearn, and Haynes (2009) have advocated for the need for additional studies that call attention to the Deaf community, a community that is often underserved or disregarded because of communication barriers and/or limited English Proficiency (LEP). Additionally, this group is threatened by health discrepancies connected to low health literacy (Pollard et al., 2009). The lack of access to health information conveyed by radio, television, or ambient auditory sources such as public dialogue, which this group experiences, only serves to intensify this population's low health literacy (Pollard et al., 2009). Unfortunately, studies show that current methods for adapting health education materials for hearing LEP populations do not reach deaf audiences with equal efficacy (Pollard et al., 2009).

Furthermore, additional and other studies with senior citizens indicate that senior citizens are at greater risk for lower health literacy (Oldfield & Dreher, 2010, p. 206). According to and as illustrated in a study that included an examination of older adults' perceptions of their numeracy ability, conducted by Taha, Sharit, and Czaja (2012, p. 418 & 416) "older adults tend to overestimate their numeracy." The results of the study conducted by Taha, Sharit, and Czaja (2012, p. 431-432) infer that senior citizens "may believe that they can comprehend and use the numeric information…when in fact, they cannot." Taha, Sharit, and Czaja (2012, p. 432) also state that the false assumptions about their health numeracy literacy that senior citizens believe "could easily lead to serious problems such as taking medications incorrectly or believing that abnormal test results are in the proper range." Research conducted by Wallace (2006, p. 85) suggests that the factor of health literacy has a strong implication for adherence to treatment regimens and poses threats of poor clinical outcomes. Additionally, Oldfield and Dreher (2010) posit that the defining characteristics of literacy that are most often associated with health literacy include numeracy skills along with comprehension and decision-making abilities. These skills, in actuality, are no different from the skill sets needed and used by other subsets of the general population.

Oldfield and Dreher (2010, p. 206) describe health numeracy skills as the ability to read, understand, and manipulate numbers for negotiating simple measurement conversions or dosing medication safely. Similarly, Taha, Sharit, & Czaja (2012, p. 418) cites Golbeck, Ahler-Schmidt, Paschal, and Dismuke (2005, p. 375) definition of health numeracy as the "degree of capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, bio-statistical and probabilistic health information

needed to make effective health decisions." Additionally, Oldfield and Dreher (2010, p. 207) delineate comprehension as the ability to use context and prior knowledge to make sense of information provided and make appropriate decisions as they relate to health risk behaviors. Ultimately, Taha et al. (2012, p. 420) posit that an evaluation of health numeracy skills "tests one's ability to understand directions for taking medications." Importantly, Taha et al. (2012, p. 431) cite Donelle, Hoffman-Goetz, and Arocha (2007, p. 652) in states that "the reporting of health literacy without disaggregating prose from numeracy obscures health numeracy skill." Finally, Taha et al. (2012, p. 431) state that their study results "clearly underscore the importance of separately evaluating the health literacy and health numeracy of an individual." The threats that are posed by not separately addressing these issues are noteworthy, compelling and will continue to be ongoing issues, if not addressed. Essentially, research in this area discussed in this study, seemingly suggests that a quick health and numeracy literacy assessment should be adopted as part of the intake procedure for all patients.

Low health literacy for Deaf individuals is an outcome of a lifetime of limited access to health information (Davoli (n.d.). Another important element Davoli (n.d., p 1) postulates is the fact that "hearing children in hearing families are privy to the sharing of family medical information." Whereas, Deaf children, even during their own routine doctor visits, are often unable to access, gain knowledge of, or often misunderstands their own personal or family medical histories (Davoli, n.d.). Knowledge of personal and even family medical history can be a critical factor in health care self-awareness, health self-efficacy, and self-health care management.

> Hearing individuals have access to incidental learning through auditory mediums, such as public conversations, television, and radio broadcasts. Something as simple as overhearing a conversation on the subway about a stranger's blood pressure medication, or a radio announcement about the warnings of cigarette smoking during pregnancy, are missed by Deaf individuals (Davoli, n.d., p. 1).

Thus, the ongoing and commonly unrecognized and rarely addressed problem of effective access to health-related information for individuals who are prelingually/culturally Deaf was at the core of the efforts of this research study.

In direct relation to this study, Andrulis and Brach (2007) adduce an imperative point when they reference the Institute of Medicine's (IOM) position on health literacy. "Health literacy must be viewed in the context of language and culture" (Andrulis & Brach, 2007, p. S122). From the perspective of this research project there exists a diverse, distinct, and separate culture of deafness delineated and denoted by the use of the capital letter D in the word Deaf. Additionally, members of the culturally Deaf cohort can be included when Andrulis and Brach (2007, p. S123) states that when it comes to health care, among the most-vulnerable patients are the culturally diverse patients with limited literacy and limited English proficiency (LEP).

Based on the background information cited at the beginning of this chapter, there is a high probability that a substantial number of culturally Deaf individuals are members of the larger portion of the US population known as the Baby Boomer generation. Members of the Baby Boomer generation, including the culturally Deaf and all aging members of this cohort and older cohorts, will have a tremendous impact on the

healthcare system over the next 13 years. In recent years, the United States, as part of a national effort to facilitate the expanding number of individuals with language diversity evidenced by the growing number of individuals with Limited English Proficiency (LEP) and limited English comprehension skills; access to health-related information has been translated into and is often printed and distributed in many different formats and languages. Unfortunately, these formats have not been found to be effective for the culturally/prelingually Deaf population (Pollard et al., 2009); essentially, because American Sign Language does not have an indicted (written) format. Contrived and English influenced methods and formats, such as "cued speech" have been constructed and tried in an effort to indite ASL into a written format (Marschark, 2009; Trezek, Gampp, Wang, Paul, & Woods, 2007). However, these formats have not been necessarily effective nor accepted by the Deaf community as a whole (Marschark, 2009; Trezek et al., 2007). Since American Sign Language is a visual language, any efforts made to indite ASL into a written/printed format would entail a massive and cumbersome pictorial format. Therefore, similar and prior efforts used to address the problematic issue of differences between English and other languages still do not adequately address the problematic issues that exist between English and American Sign Language syntaxes. The sentence structure (syntax) of American Sign Language does not align with the syntax of the English language. American Sign Language is directly derived from (European) French Sign Language and to this day retains most of the structure of the syntax of the language of French and other Latin/Romance based languages.

Health-related research and educational programs have historically excluded [the] Deaf ASL (population) as participants (McKee et al., 2011, p. 2). Additionally, research

with other language minority groups demonstrates that bilingual clinicians [cultural concordance/competency] have better [patient] health outcomes, achieve better patient satisfaction and understanding, which ultimately helps to decrease patient misunderstandings of diagnoses and treatment protocols (McKee at al., 2011, p. 4). All of which ultimately affects not only the patient's self-efficacy in health care but also affects the health care industry's bottom line, by helping to foster lowered health care expenditures (McKee et al., 2011, p. 4). Culturally Deaf individuals, on the average, understand each other 100% of the time (Wilcox, 1989, p. 22). It is not until a Deaf individual is faced with needing to communicate with or through a "not-so-skilled interpreter or a hearing person" does the amount of information they receive become fragmentary and comprehension drops down to between 50-70% (Wilcox, 1989). Unfortunately, for Deaf patients, health care disparities are exacerbated by the fact that most physicians and healthcare providers are not adequately prepared to provide linguistically and culturally competent care to and for Deaf patients (Davoli, n.d., p. 2). Additionally, most physicians and healthcare providers have a limited understanding of Deaf culture, report discomfort in dealing with Deaf patients and believe that Deaf patients do not trust them (Davoli, n.d.).

Most Deaf patients are not able to directly access or speak to their healthcare provider, and this is especially true if they the Deaf patient wishes to speak with their health care provider in their native language of American Sign Language (Davoli, n.d., p.1). Therefore, Deaf patients experience greater difficulties in communication with their health care provider and Deaf patients are also often misunderstood and worst yet misdiagnosed (Davoli, n.d., p.1). Additionally, "alarmingly, more than 50% of the

healthcare providers who have Deaf patients do not provide access to a certified sign language interpreter" (Davoli, n.d., p.2). Access to a qualified and certified interpreter is a Deaf patient's legal right under the law - the ADA [Americans with Disabilities Act] (Chen, Youdelman, & Brooks, 2007; National Association of the Deaf [NAD], 2000; U.S. Department of Health & Human Services, n.d.).

Historically, the tradition for bridging the communication gap between the Deaf patient and the health care provider has consisted of the use of "an adaptive fit" utilizing either one or a combination of the three following methods. The Deaf patient is either faced with a situation of lack of or poor communication between themselves and the health care provider, by utilizing such methods as lip reading (speech-reading) or writing back and forth (McKee et al., 2011). Writing back and forth often affects the level of effectiveness of the communication, and the spontaneity and "richness" of the conversation is often lost. Writing back and forth also requires a general degree of literacy that often far exceeds the fourth to sixth-grade reading and writing levels mentioned earlier. Writing back and forth is especially problematic in situations where the healthcare provider possesses a limited knowledge and understanding of Deaf culture, as noted earlier, and is unaware of deficits in the levels general and/or health literacy the Deaf patient may possess. Historically, the second method for bridging the communication gap was that the Deaf patient was often expected to make the arraignments for and often pay the cost of finding, securing, and providing their own interpreter. The cost of paying for a certified interpreter, especially one that is well versed in medical terminology translation, can be and most often is prohibitive for many

low SES (socioeconomic status) Deaf patients, especially those who are receiving SSDI (Social Security Disability Insurance).

Alternatively, and historically, the third and one of the most common methods for bridging the communication gap between health care providers and Deaf patients has been for the Deaf patient to utilize a friend or family member as an interpreter (Skot, Jeppesen, Mellentin, & Elklit, 2016). Not only does this method of bridging the communication gap violate the present federal guidelines and regulations of Health Insurance Portability and Accountability Act of 1996 (HIPPA; Public Law 104-191; U.S. Department of Health & Human Services [HHS], n.d.), it possibly places friends and family members of the Deaf patient in a very emotional and/or precarious position. Ninety percent of Deaf children are born into hearing families (Padden & Humphries, 1997). Additionally, very and most often, hearing family members do not learn to communicate effectively with their deaf family members (Davoli, n.d., p. 1). Therefore, accurate and efficient translation of vital health information and communications may not occur utilizing this method of bridging the communication gap.

Since only about 10% of the time, are Deaf children born to Deaf parents (Davoli, n.d.; Padden & Humphries, 1997), this factor results in hearing children being born to Deaf parents 90% of the time. These hearing children born to Deaf parents, in Deaf culture, are referred to as CODAs – Child/Children of Deaf Adults. Historically hearing children of Deaf adults (CODAs) are often enlisted and utilized as interpreters for their Deaf parents, very often even at a very young age, as young as 6. Although CODAs, at a very young age, sometimes as young as five, six, or seven, become very accustomed to serving as interpreters for their Deaf parents, a health situation, places a CODA in what

can be a highly emotional situation. Situations such as translating "bad" health news, or needing to be in the examination room while their parent is being examined by a doctor not only violates the Deaf patient/parent's rights to privacy and confidentiality under HIPAA, it also places the CODA in a very uncomfortable position. Due to the nature of what needs to be translated, confidentiality can be violated. Additionally, the CODA may not be able to translate correctly or interpret the genuine or exact nature of what the healthcare provider is saying. Ultimately, both the parent and child may be placed in a very awkward and emotional situation. Therefore, this course of action would violate the Deaf person's right to health status confidentiality, granted under the federal Health Insurance Portability and Accountability Act (HIPAA). HIPAA ensures and protects their right to reveal or not reveal to their family and/or friends just as much or as little as they feel or deem necessary or wish to reveal. Additionally, since the family member or friend may not be versed or skilled in medical terminology and how to best to translate such terminology into ASL, critical and grave misunderstandings can occur. Effective interpretation is of particular importance as it relates to the seriousness or lack thereof of the disorder and or requirements needed for self-health care management. Due to the possible emotional nature of a diagnosis, the family member or friend, out of love and caring for the Deaf individual, may take it upon themselves to spare the "poor" Deaf child, parent or friend the full interpretation of a very negative diagnosis. Such actions foster poor health self-efficacy in the personal health care management by Deaf individuals.

Today, most health-related information is now available in various languages and in various written formats to include handouts and pamphlets, as well as written

information accessible over the internet. Additionally, other forms of access to health-related formation are available through oral/verbal formats of radio or television announcements (PSAs – Public Service Announcements), or simply via conversations with health care providers, family members and/or co-workers and friends. Sadler et al. (2001, p. 105) state that "the Deaf community is one of the minority populations least commonly addressed in health promotion efforts." Unfortunately, for this, linguistic group, oral/aural communication and language (literacy) barriers are precisely the factors that isolate them from the oral/verbal, mass media healthcare messages or other forms of oral/verbal communications that hearing individuals access on a daily basis. Sadler et al. (2001, p. 105) also state that the uniqueness of the Deaf community's culture and method of communication serves as a unique barrier to health information and care not experienced by or common to other minority groups. Many people, including clinicians, are unaware that: (1) the grammar and syntax of ASL is not identical to Standard English, (2) that sign language is not universal, and (3) believe that Deaf ASL users can understand non-sign-based communication [written or lip/speech reading] (McKee et al., 2011). Research has shown that note-writing and speech-reading (lip-reading), commonly used by clinicians to communicate with Deaf patients, are very likely ineffective (McKee et al., 2011, p. 3). Speech reading (aka as "lip-reading") is inadequate because the majority of English sounds are not clearly visible on the lips (McKee et al., 2011, p. 4). Additionally, many times, and it is not uncommon, that during face to face conversations, most individuals tend to turn their heads, often cover their mouths/faces, or tend to look down or away (in a different direction) while talking. These typical human actions often occur and is especially true in today's "techno" society

where health care professionals are often looking down (which makes their mouths/lips non-visible) while they are simultaneously talking to the patient and entering notes into a laptop or at the very least into a case file. Add to this, the fact that many United States health care providers are foreign born and have accents and/or pronounce words and move their lips and mouths in a fashion that is difficult for many hearing patients to understand, no less to expect a Deaf patient to lip-read/speech-read accurately.

Morbidity and Mortality

The first wave of members of the Baby Boomer cohort reached the age of 65 in the year 2011. Projective research indicates that the anticipated growth in the number of individuals who are or will be part of the elderly cohort, reaching and living past the age of 65 and older, will continue to increase for the next 20 years. Although, the medical community has begun to contemplate and address the issues that caring for and serving this burgeoning number of individuals will place on the health care industry; little if any research or planning has been focused on serving and accommodating prelingually/culturally Deaf members of the Baby Boomer cohort. Considering, the premise of the projected growth in the number of individuals living to and beyond the age of 65 and over; extrapolated to the Deaf community would indicate a similar expectation for Deaf members of the Baby Boomer cohort. Thereby, the Deaf community can be expected to experience senescence/age-related disorders at the same rate as, if not at an even higher rate, than hearing Baby Boomers. As stated earlier, deficits in health-related knowledge are associated with poor self-health management and increasing incidents of morbidity, and mortality. Therefore, there is an assumed propensity for higher rates and percentages of morbidity and mortality among the targeted population of this study.

Morbidity can be defined as any incidence of disease (Venes, 2009), while disability can be defined as an inability or lack of capacity to function or any condition that causes functional limitations (Venes, 2009). Functional limitations often occur early in the disablement process and are not as closely associated with an individual's environment as a total disability (Martin et al., 2010). A total disability affects major limitations on ADLs – Activities of Daily Living (personal care tasks such as bathing) or IADLs – Instrumental activities of daily living (routine household tasks), whereas minor disabilities may or may not have any major impact of ADLs or IADLs.

From a medical perspective prelingual deafness is viewed as a disability; a disability that needs to be addressed, fixed, or cured; albeit, members of this linguistic community would strongly beg to disagree. Comorbidity is defined as any health-related condition or conditions existing simultaneously with and usually independently of another medical condition (Venes, 2009). Therefore, from a medical perspective, and in the broadest sense of the definition of co-morbidity, a physical limitation such as a prelingual hearing loss would be viewed as a disability. Additionally, from a medical perspective an individual with prelingual deafness who is also experiencing an age-related health disorder, would be regarded as experiencing co-occurring disorders, or co-morbidity. Therefore, prelingual/culturally Deaf individuals with any age-related disorder would be considered from a medical perspective as experiencing comorbidities.

As defined earlier, disability is "any physical, mental, or functional impairment that limits a major activity; a condition resulting from loss of physical functioning; or, difficulties in learning and social adjustment that significantly interfere with normal growth and development" (Hardman et al., 2011, p. 11). Additionally, disability is also

viewed as a limitation on one's ability to perform tasks, activities, and roles at the expected levels in physical and social contexts (Pollard & Barnet, 2009). Considering these definitions, the cultural/linguistic population of this study can be and often is delimitated, by society, by one if not all of the above definitions and these delimitations are essentially the overarching zeitgeist or societal perspective. The zeitgeist perspective is most often more aligned with the American medical perspective; a perspective aligned more often than not with the World Health Organization's (WHO) definition of health, wellness, and illness (World Health Organization [WHO], 2014). The World Health Organization's perspective and definition of these terms are delineated as:

> "Disabilities" is an umbrella term, encompassing impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation; is a difficulty encountered by an individual in executing a task or action. A disability is not just a health problem; it is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by individuals with disabilities requires interventions to remove environmental and social barriers (WHO, 2014, p.1).

The goal of this research study was to address one of the social barriers that members of this cultural-linguistic community encounters – the barrier of limited access to age-related, health-related information; which results in deficits in age-related health literacy.

Senescence/Age-Related Disorders

Depression, cataracts, glaucoma, blindness, [late] deafness, osteoporosis, diabetes, emphysema, asthma, hypertension (high blood pressure) cardiovascular/coronary diseases (heart disease, angina), stroke, cancer, and arthritis are the most common chronic diseases in the U.S elderly population (Center for Disease Control and Prevention, 2011; Han, 2011). The most common age-related disorder groups consist of cancer of all types, cardiovascular disease, asthma and emphysema and adult onset diabetes, as well as hypertension (High Blood Pressure); Martin et al., 2009). Additional prevalent age-related health disorders consist of, stroke, high cholesterol, arthritis, osteoporosis, cataracts, glaucoma and macular degeneration, along with kidney and bladder problems. Advances in medicine and health care knowledge often help to abate or at least lessen many of the negative aspects of many of the aforementioned age-related health disorders. These advances can and often do produce better long-term health outcomes to include decreases in rates of age-related morbidity and mortality. As discussed throughout this study, lower rates of morbidities and mortalities can be directly associated with good health care management, and better health care management is directly related to informed knowledge. Knowledge about disorders and age-related disorders, in particular, is crucial to overall effective health care management. Better health care management is associated with lower morbidity rates, as well as lower mortality rates and higher rates of longevity and good health longevity at that. Therefore, an interdependence of these factors is clearly, evident.

Aging Population Statistics

"Older people are a rapidly growing proportion of the world's population…people are living longer, but that does not necessarily mean they are living healthier" (National Institutes of Health [NIH], 2016, p. 1). "The increase in our aging population presents many opportunities and also several public health challenges that we need to prepare for" (NIH, 2016, p. 1). The NIH (2016, p. 1) states that "the world's older population continues to grow at an unprecedented rate from today's rate of 8.5 (617 million) people worldwide, and individuals age 65 and over is projected to increase by nearly 17% (1.6 billion) worldwide by 2050." "America's 65 and older population is projected to nearly double over the next three decades, from 48 million to 88 million by 2050" (NIH, 2016, p. 1). The global population of the "oldest old," people aged 80 and older, is expected to more than triple between 2015 and 2050, growing from 126.6 million to 446.6 million (NIH, 2016, p. 1).

The Alliance for Aging Research (2006), reports that nearly nine out of ten or somewhere between 81%-90% of Americans by the time they reach the age of 65, will need to acquiesce or admit to experiencing or living with at least one chronic health disorder. A recent research study and report of Americans aged 65 and up, released by the NIH, found that in 2011, older U.S. women experienced an increase and reversal in improvement of the likelihood of living with moderate disabilities to 14% (National Institutes of Health/U.S. National Library of Medicine [NIH/USNLM], 2016, p. 1). These percentages had previously decreased from 13% in 1982 to 10% in 2004 (NIH/USNLM, 2016, p. 1). Conversely, the prevalence for men for those same moderate disability issues dropped between 1982 and 2004 and has stayed virtually unchanged

(NIH/USNLM, 2016, p. 1). The NIH/USNLM defines moderate disabilities as "problems with daily activities such as shopping, doing household chores or managing money. In other words, the health industry projects that at least 80% of American senior citizens will have at least one chronic health condition while multiple chronic conditions will be the experience of the majority of senior citizens (Han, 2011). As of 2011, individuals who are part of the Baby Boomer cohort started turning 65, with an average of 10,000 people turning 65 every day (AAR, 2006). Whereas in 1982 a 65-year-old man could expect to live, on average, another 14 years, has now seen an increase to 19 years, of almost disability-free time by 2011(NIH/USNLM, 2016, p. 2). Conversely, the average 65-year old woman has only experienced a projected 2-year increase, from 18.5 to 20.5 additional years of disability-free life expectancy (NIH/USNLM, 2016, p. 2). With increasing life longevity, the Alliance for Aging Research (2006) projects that in 2030, 72 million people or one out of five Americans will be 65 or older; and by 2050, AAR (2006) projects that the 65 and older population will be estimated to be between 80 and 90 million Americans. The combination of these projected morbidity statistics with the projected increase in the number of individuals attaining and living well beyond the age of 65 produces what the Alliance for Aging Research (AAR, 2006) deems as a "Silver Tsunami" effect that can overburden the health care system. No doubt, this "Silver Tsunami" will be inclusive of members of the prelingual/culturally Deaf community.

In his article, Mann (2004) gives credit to the industries of science and technology for expanding human longevity; and research provides evidential facts that advances in science and technology has in indeed expanded longevity. Research into the use of

medical rehabilitation and therapies coupled with mechanical mechanisms, therapeutic modalities and devices for improving, restoring, and replacing lost, underdeveloped or deteriorating human functions, indicates that these advances in science and technology have simultaneously produced a dramatic increase in the longevity phenomenon. Consequently, the longevity phenomena will be seen, worldwide, not just in the United States aging population. The consequence of the longevity phenomena will be a projected, marked and a sharp increase in the number of individuals living well past the age of 65.

This increase is projected to be at a rate of at least a 50% increase by the year 2030 (Mann, 2004, p. 12). In 2010, there were 40 million people age 65 and over in the United States, accounting for 13 % of the total population (Federal Interagency Forum on Aging-Related Statistics [FIFARS], 2012). The United States senior citizen population, in the year 2030, is projected to be twice as large as 2000 (FIFARS, 2012), growing from 35 million to 72 million and representing nearly 20 % of the total United States population (Federal Interagency Forum on Aging-Related Statistics [FIFARS], 2012, p. xv). Prospective census data estimates that one of the largest cohorts of The United States population, "the Baby Boomers" started turning 65 as of 2011, and this marked, and substantial growth in the United States population of individuals over the age of 65 will continue for the next 13 years (FIFARS, 2012). "Americans who make it to age 65 typically have many years left ahead…So how can we make that time high-quality?" (NIH/USNLM, 2016, p. 2).

Thanks to advancements in medical technology, members of the young-old, old-old and even oldest-old cohorts (85 years old and older) are living longer. Although

advancements in medical technology have been incredible and awe-inspiring, these advancements have not developed to the point where age-related disorders can be wholly or mostly eradicated. Unfortunately, as individuals age their propensity for age-related, chronic health illnesses and disorders increases and frequently brings about morbidities and often even co-morbidities. Self-efficacy in self-health management then becomes an important and vital factor in the management of chronic age-related disorders as well as other health related disorders, referred to as morbidity or co-morbidities. Self-efficacy in self-health care management requires health literacy. Therefore, the importance of health literacy can be viewed as a major contributing factor in self-efficacy in personal health care management with the ultimate goal of abating the early worsening of age-related morbidities and early mortalities.

Although the health inequalities that Deaf people experience are finally being increasingly recognized, according to Young et al. (2016, p. 2), the noteworthy needs of Deaf people, in terms of access to health services and care need to be a focus of interest, because Deaf people are largely invisible in the clinical trials literature because of the confounding variables introduced by sign language users. The premise that there is a lack of data on the health of Deaf individuals (Barnett et al., 2011, p. 1) is supported in an article by Steinberg, Barnett, Meador, Wiggins, and Zazove. The assertion that prelingual/culturally Deaf individuals "use health care services differently than the general population and that little research has been carried out to understand the reasons [why]" (Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006, p. 260) is in direct concordance with the premise of Barnett et al., 2011. The same article referenced a study conducted by Steinberg et al. (2006) that collected information about health care

communication and perceptions of clinician's attitudes. The stated conclusions were that communication difficulties were "ubiquitous"; and that "fear, mistrust, and frustration were prominent" factors that culturally Deaf individuals often report as difficulties in accessing and using health care services (Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006). In another study conducted by Pollard and Barnett (2009), they conclude deaf individuals are at an increased risk for fund-of-information deficits, including deficiencies in health-related information. Pollard and Barnett's (2009) research on health information knowledge, as an aspect of health literacy, demonstrates an association between low health literacy and health disparities among members of the prelingual/culturally Deaf population. This premise of deficits in health literacy is further supported by the position taken by Young et al. (2016, p. 2) that "familiarity with a word (lexical item) does not always confer familiarity with its meaning…and is compounded by a wide range of lay meanings attached to concepts and words." Furthermore, Young et al. (2016, p. 2) posit that we choose our words on the basis of our linguistic knowledge, while often lacking the experience of when or how to use these terms, with and/or without fully understanding them.

Combining the positions put forth by the researchers cited in the previous paragraph, it becomes most evident that Deaf individuals are at particular risk for low health literacy, but very little research has been conducted on this topic. The most probable reason for the lack of research in this area is because the deaf community is a "unique" and more often-overlooked limited English proficiency (LEP) group (Pollard, Dean, O'Hearn, and Haynes, 2009). With this group being gravely "at risk for health

disparities associated with low health literacy" (Pollard et al., 2009), it is almost imperative that research in the area of the Deaf community be continued and fostered.

Limited English proficiency combined with the lack of access to health information conveyed via radio, television, or ambient auditory sources, such as public and private conversations, further aggravates this population's low health literacy. Barnett et al. (2011, p. 1) supports and expounds on Pollard et al. (2009) statements by adding many prelingually deaf adults have experience low health literacy due to a lifetime of limited access to information. Interestingly, much of the information that is inaccessible to Deaf individuals is often considered common knowledge among hearing persons (Pollard et al., 2009). In support of statements and positions stated earlier in the health literacy and health numeracy section, Young et al. (2016, p. 2) states that "in terms of background knowledge, whether deliberately or incidentally, Deaf people commonly experience highly limited access to information on a wide range of everyday subjects because it is not available in a signed language." Therefore, the acquisition of incidental and everyday information is hampered by limited access to the spoken word. Furthermore, "many adults, deaf since birth or early childhood, do not know their own family medical history, having never overheard their hearing parents discussing this information with their doctor" (Pollard et al., 2009), other family member(s), or any other close associate. For some age-related, chronic disorders such as diabetes and heart disease, lack of knowledge of family history is or can be a risk factor. Diabetes and heart disease are just two among many of the age-related, chronic health issues that Deaf "Baby Boomers" can anticipate experiencing at a higher than normal probability as they age; especially and in light of any deficits in health-related knowledge.

Summary and Conclusions

The dawn of the second decade of the new millennium also ushered in the precursory, prefatory phase for the cohort of the US population attaining the age of 65 during the time span of 2011 through 2029. As of 2011, national statistics projects that, for the next 20 years, a continuing number or approximately 10,000 individuals a day are and will be turning 65, resulting in the fact that 72 million or one out of every five Americans will be age 65 or older by the year 2030 (AAR, 2006). By 2040, 80 to 90 million Americans will be age 65 or older, and by 2050, 21 million Americans will be over the age of 85 or older (AAR, 2006). The cohort colloquially referred to as "Baby Boomers" encompasses individuals born between the years 1946 and 1964 (AAR, 2006; Abeles et al., 1998; Martin, Freedman, Schoeni, & Andreski, 2009) and the prelingual/culturally Deaf members of this cohort were the target subjects of this study.

Thanks to advances in medicine and medical technology, more individuals are and will continue to reach the age of 65 and older and will live well into their more advanced years, to become part of a cohort designated by clinicians as the "oldest old". For many, the successful achievement of reaching and attaining the age of 65 will be accompanied by senescence/age-related, chronic health disorders, and disabilities. The Center for Disease Control and Prevention (2011) posits that a significant number of individuals 65 and older will experience health problems and chronic diseases. The chronic diseases that the CDC projects to be most prevalent are cardiovascular disease, cancer, and hypertension. Additionally, the CDC projects that 80 % of these individuals

will suffer from at least one chronic health condition with most suffering from multiple chronic conditions.

Research has shown that in the United States, and in recent decades, there has been a general and overall positive trend for declines in late-life morbidity and disability, for older Americans. This trend emerged in the 1980s, continued throughout 1990s and has continued into the first decade of the twenty-first century. Unfortunately, there is no guaranteed for this trend to continue into the future (Martin, Schoeni, & Andreski, 2010). Controversy exists among health researchers as to whether Baby Boomers will enter their later life stages with better or worse age-specific rates of morbidity and disability than earlier cohorts (Martin, Freedman, Schoeni, & Andreski, 2009). A projection proposed by the Institute of Medicine (IOM) suggests that despite the advances in medical care and technology, research foretells a swelling in numbers for the highest rates of morbidity and disability for the Baby Boomer cohort (Martin et al., 2009). Previous research (Crimmins, 2004; Crimmins & Saito, 2000; Freedman & Martin, 2000; Freedman, Martin, Schoeni, & Cornman, 2007, Martin et al., 2009) indicates that notwithstanding the declines in most measures of late-life morbidity and disability, unfortunately, the reports of many of the age-related chronic conditions among senior citizens has increased in recent decades. This ominous projection becomes a most important fact in that it will not only have consequential and significant implications on the quality of life for future older adults but will also pose as a major impact on the medical, health care and the social services systems. Increases of chronic conditions among older adults will impact

and affect the health industry's ability to provide quality care to the projected swelling numbers of individuals over the age of 50 with age-related disorders.

The Agency for Healthcare Research and Quality (AHRQ, 2011) states that in an effort to improve national health literacy the United States Department of Health and Human Services (HHS) initiated a "National Action Plan" as of May 2010. The question is and still remains; are and will these efforts be inclusive of or applicable to the prelingual/culturally Deaf members of the US population? Albeit, the AHRQ states that this multi-sector action plan will engage the collaborative participation of health care organizations, professionals, policymakers, communities, individuals and families; the question, once again, is or will prelingual/culturally Deaf individuals and communities continue to be overlooked and excluded, from the decision-making processes? The AHRQ (2011) posits that part of the goals and objectives of the action plan are to improve upon the "jargon-filled language, dense writing with complex and elaborate explanations" found in most patient handouts. It should also be noted that such efforts in revising how health-related information is presented should also be inclusive of how best to present health-related information to prelingual/culturally Deaf individuals.

As stated previously, for many, if not most, prelingual/culturally Deaf individuals, their preferred language of choice does not conform to the English language syntax. American Sign Language also does not have a written format and cannot be accessed aurally/orally. Add to that, very few individuals outside of the Deaf community know and/or can effectively communicate in their language of preference. With those statements in mind, it is easy to understand how ineffective and unsuccessful current

methods of access to health care information would be for a Deaf individual. Especially since a significant portion of this cohort usually only completes high school, and on average only obtains a fourth to sixth grade, English reading comprehension level (Mayer & Villaire, 2009). Prior research has validated these unfortunate realities. Unfortunately, most health-related information is presented at a seventh grade or higher reading comprehension level (Mayer & Villaire, 2009). These issues become major issues when viewed in the context that "communication is vital to appropriate, efficient, and successful healthcare" (McKee et al., 2011, p. 3).

The trajectory of this lack of access to health-related information for members of this group, in particular for those over the age of 50, has not been specifically targeted and investigated. The general health literacy of this portion of the population stands to become an even more salient issue as a significant portion of the United States population reaches the age of 50 and older and begins to experience many of the age-related health care complications that usually accompany the aging process. If the health care community continues to be slow in addressing the problem of deficits in health literacy found within some segments of the population; their actions will only continue to affect a grievous disservice to certain segments of the aging population. Even more, precisely the lack of action will most grievously affect the underserved population of the culturally Deaf, especially the segment of this cohort that is projected to experience age 50 and over age-related health morbidities. From the medical model perspective, individuals who are part of the culturally Deaf cohort, as well as being a member of the Baby Boomer cohort, with age-related disorders, would be viewed as experiencing co-morbidities. From a medical model perspective, this would mean that this segment of the population, "Deaf

Baby Boomers", likely would need to access health care services sooner and possibly more often than the average "hearing Baby Boomer".

"Literacy, culture, and language can and do affect patients' abilities to participate in treatment decisions and manage their own acute, and chronic conditions.… [additionally] these factors play distinct and prevalent roles in medication errors" (Andrulis & Brach, 2007, p. S127), to include health numeracy errors. As a means to abate these deleterious effects, and effect lower rates of mortality, morbidity, and co-morbidities, effective patient-provider interactions are needed and fundamental to achieving successful clinical outcomes (Andrulis & Brach, 2007, p. S125). Essentially the aforementioned and cited articles support the need for medical practitioners to assess and take into consideration the English literacy levels and health-related knowledge (health literacy) of their patients from the time of the patient's initial visit. Additionally, many of the literature review articles suggest that the use of quick assessment tools such as of the TOFHLA/s-TOFHLA (Test of Functional Health Literacy in Adults) or the REALM/REALMs (Rapid Estimate of Adult Literacy in Medicine) be incorporated into the initial intake evaluation. Primary health care investigators should carefully consider including and adding patients" health literacy skills as a key demographic variable on the patient intake form (Wallace, 2006, p. 85).

The literature view indicates that only a meager amount of research that has been conducted to date on this population. The issue of knowledge of and/or access to health care information for prelingual/culturally Deaf individuals was prevalently highlighted throughout the literature review. This modest meta-analysis indicates that there is and continues to be a great need to conduct even more research in this area. Therefore, it is

particularly imperative that attention will be paid to the issue of equal access to health-related information. This issue will become even more salient and urgent as the small and often unrecognized segment of the national general "Baby Boomer" population, the Deaf "Baby Boomer" cohort, reaches the ages of 50, 60, 65 and older. The lack of some of the most rudimentary health statistics about the deaf population thwarts many researchers and most of their "efforts to engage deaf communities in setting priorities for health improvement and chronic disease prevention programs" (Barnett et al., 2011, p. 1). Therefore, due diligence must also be given to the Deaf "Baby Boomer" (50 and older) portion of United States population that is and will soon become part of the American geriatric population; meaning that they will also soon experience, if not already experiencing, age-related, chronic disorders. Pollard and Barnett (1999, 2009, 2011), among others, are two major researchers in the field of health literacy as it relates to individuals who are culturally Deaf, and both indicate that research is lacking in this area.

Chapter 3: Research Method

Introduction

The approach of this research study was from a quantitative perspective. The intent of this research study was to evaluate, prelingual/culturally Deaf individuals over the age of 50 and their levels of health literacy as it relates to senescence/age-related disorders. This chapter contains specifications of the following elements: The study design; variables; sample population description; purposeful sample size; the role of the researcher; ethical considerations; limitations; research questions and methods of inquiry; instruments and materials; data collection procedures; data quality; data analysis; and a conclusion.

The most basic and non-auditory method of imparting health care information is through written materials. Most written health care information is presented at approximately a 7th to 8th grade or higher reading level (Mayer & Villaire, 2009), making English literacy and numeracy proficiency, major factors for self-efficacy in health care management. With the average, reading comprehension level of many Deaf adults approximating around a third to fourth-grade reading level (Jones et al., 2005), this factor may negatively influence the health related self-efficacy of Deaf individuals in the form of poor comprehension and lack of awareness or knowledge of health-related information. Such negative influences may result in more mediocre self-health care management and poorer health care outcomes. Ultimately, this results in more mediocre self-health care management and poorer health care outcomes. Utilizing a modified form of a standardized health literacy evaluation instrument, the intent of this research project was to study and identify deficits in knowledge of age-related health literacy issues that

may be uncovered. Additionally, the intent of the study was to collect evaluative data that may be used to generalize and infer the health literacy levels of a substantial number, if not many of the population of prelingual/culturally Deaf participants age 50 or older.

Methodology

With the overarching Research Question being*:* Do prelingual/culturally Deaf individuals over the age of 50 experience deficiencies in knowledge of senescence/age-related health terminology, or more simply stated deficits in senescence-related health literacy. This dissertation research study was designed to align with a standard Post-Positivistic design utilizing a quantitative approach. Thus, the evaluation procedure and process can be noted simply as (QUAN) (Creswell & Plano Clark, 2011). Inferential statistics resulting from the utilization of quantitative analysis of *t* tests and ANOVAs. These descriptive statistics tests were used to test for statistical significance of differences, if any, among the mean scores and percentages for males versus females and age groups of 50-64; young old of 65-74; old-old of 75-84 and oldest-old of 85 and older. Descriptive statistics consisting of the mean, median and mode was used to determine quantitative scores on the health literacy test. The overall mean and median scores on the health literacy evaluation instrument were evaluated for between age groups to ascertain whether there are any quantifiable differences in scores. Additionally, mode scores were presented for the health literacy terms most often correctly identified and for the health literacy terms most often incorrectly identified.

A G*Power analysis was ran utilizing G*Power 3.0.10.lnk software that is free and available on the internet. The parameters that were inputted into software program was: *T*- tests – Means, and Difference from Constant (one sample case). Analysis: A

priori: Compute required sample size. Input: Tails 1; Effect size d = 0.5; α err prob. = 0.05; Power (1-β err prob.) = .0.8. Output: Noncentrality parameter δ = 2.598; Critical t = 1.705618; Df = 26; Total sample size = 27; Actual Power = 0.811832. An additional analysis was ran with Input: Tails 2; Effect size d = 0.5; α err prob. = 0.05; Power (1-β err prob.) = .0.8. Output: Noncentrality parameter δ = 2.915476; Critical t = 2.034515; df = 33; Total sample size = 34; Actual Power = 0.807778. Thus, the sample population size was projected to consist of between 27 to 34 prelingual/culturally Deaf individuals, age 50 and older. All aspects of the study were approved by the Walden University IRB, approval number 08-26-15-0231063. Request for extension was approved via email dated August 16, 2016.

Research Study Design and Rationale

Many, if not most, scientific/experimental research studies tend to employ quantitative methods, and this study also employed post-positivism quantitative research. The quantitative dependent variables were the resulting scores on an evaluative health literacy evaluation instrument, with prelingual/cultural deafness serving as the independent variable. The methodology of this study employed a quantitative assessment of health literacy utilizing an instrument modeled after an established health literacy evaluation instrument known as the REALM. Permission to model the instrument that was used in this study was sought from the lead and primary developer of the REALM, who stated "you may use REALM (also it is in the public domain)" (T. Davis, Ph.D., personal communication, January 18, 2015) (Appendix A). Permission to utilize the health related ASL pictures from the American Sign Language Medical Dictionary (Costello, 2000) was sought and acquired from the publishing company (Appendix B).

Quantitatively, the health literacy instrument was designed to reveal if any deficits exist in each participant's knowledge of (senescence) age-related health-related terminology (health literacy). A standard post-positivistic research design that adduces quantitative data was deemed best and chosen for the research project. The need for quantitative data that exposes any deficiencies in health literacy was a necessary inference in supporting the theoretical concept of this research project. Additionally, quantitative data deduced by this study will be viewed by members of the health care industry as valid and unimpeachable evidence of the need to address the issue of health literacy, most specifically, within the Deaf community.

Sample Population Selection Procedures and Size

I conducted an initial pilot study and focus group to evaluate the validity and reliability of the modified health literacy instrument. An initial pilot study and focus group consisting of 1 Deaf individual over the age of 50 was convened prior to the conduction of the actual study. The anticipated purposeful sample population size was anticipated to be between 27-34 Deaf individuals. The actual purposeful sample population of participants for this research study consisted of 27 individuals who were prelingually/culturally Deaf and age 50 or older. Hearing individuals were not recruited nor participated in the main nor the focus group, as the intent of this study was to study and evaluate health literacy within the Deaf population utilizing modifications that apply directly to supporting the communication methods and literacy of that specific population. Therefore, the opinions of the focus and pilot participant were taken into consideration and used to evaluate the validity of the modified health literacy evaluation instrument that was used in this research study; a study that consisted of

prelingually/culturally Deaf individuals only. Health literacy of hearing, hard-of-hearing and/or late deafened individuals age 50 and older was outside of the bounds of the intent of this study and what this study was designed and intended to investigate.

For this study, qualified participants had to utilize American Sign Language as their preferred and primary method of communication. Participants were required to affirm that they have a severe to profound hearing loss measured at a loss level of 71-95 dB for a severe hearing loss or 95 dB or greater (>) loss for a profound hearing loss (Brodwin, Tellez, & Brodwin, 1995; Kral & O'Donoghue, 2010). Due to Health Insurance Portability Accountability Act [HIPPA] regulations, I did not require any participant to present proof of their level of hearing loss. Each participant was required to sign an affirmation that attested to their level of hearing loss, and I required proof of age identification or authentication by the site administrators. In order to qualify as a participant, the individual's hearing loss must be a minimum of 71-95dB to qualify as having a severe hearing loss, again authenticated by the site administrators. By signing this document each participant attested to be experiencing a lifelong hearing loss that has been professionally evaluated to be severe to profound; and evaluated to be experiencing a loss of, at the very least, 71dB > or greater.

In essence, willing participants had to be prelingually deaf. Participants had to affirm that they lost their hearing (preferably) prior to the age of 3 but no later than the age of 5. Participants had to self-identify as a member of the culture and community designated as Deaf (Padden & Humphries, 1997, p. 3). All Deaf participants had to be at least age 50 or older; therefore, Deaf participants had to meet the demographic age parameter of at least, being born before or by the year 1964.

A snowballing recruitment method was utilized since this population tends to be small, somewhat closed to outsiders, and widely spread-out throughout any one geographic area. Contact, requesting recruitment help, was made with the few culturally Deaf individuals I knew, and as a last resort, through social service agencies that specifically provide services to the culturally Deaf. Deaf community members were asked to refer other community members who match and fit the research population parameters. Due to this population's uniqueness and the limited number of individuals that most likely can be found in any one geographical area, the study participant selection size was limited to a minimum of 27-34 prelingual/culturally Deaf individuals. If, any, and as many, additional qualifying participants were located, they would have been invited to participate and be included in the study.

Ethical Procedures

This research project did not specifically ask for nor required any participant to divulge any protected health information that is defined as protected by HIPAA (Health Insurance Portability and Accountability Act) of 1996 (Cushman, 2014). Therefore, information and data collected were limited to the requirements of the study – health literacy scores. Participants' specific health-related information or status was not directly solicited. The possibility did exist that [a] participant[s] may self-disclose such health-related information during the course of the testing. If health related information was, freely divulged, per federal regulations, such information was kept strictly confidential and does not appear in the final research data nor will such information be connected to the participant in any way (Cushman, 2014). In order to protect participants' identities, per NIH, [NIH-NIDCD] (2010) and the Collaborative Institutional Training Initiative

[CITI] (2014), each participant's response sheet was assigned a sequential number. The sequential number was noted on the consent form, which will be filed and kept secure as advised in CITI training. Names and any other definitively identifying information will only appear on the consent forms, which will, again, be held and kept secure, as advised in CITI training.

During this study, interactions with the members of the targeted population, the prelingual/culturally Deaf, was based on and follow the research guidelines set forth by the National Institutes of Health-National Institute on Deafness and Other Communication Disorders [NIH-NIDCD] (2010) and the Collaborative Institutional Training Initiative [CITI] (2014). Per the suggestions contained in the *"Guidelines on Communicating Informed consent for Individuals Who Are Deaf or Hard-of-Hearing and Scientists"* (NIH-NIDCD, 2010); a CODA, who is a member of the Deaf community and works as a qualified and certified interpreter was contacted and solicited to help with this research project. Such a person would be considered as a "cultural broker" per the NIH-NIDCD guidelines. As a certified interpreter, the interpreter must ascribe to the confidentiality code of ethics as set forth by the licensing body of the National Association of the Deaf (NAD) and the Registry of Interpreters for the Deaf (RID). The limits of this interpreter's involvement consisted only of pre-recorded interpretation (signing) of the recruitment materials, consent form, evaluation instrument instructions and debriefing statement (Appendix E); and acting as a recruiting agent for participant referral. The CODA/interpreter did help to facilitate the research project by helping to affect community recruitment and participation through the recruitment method designated as snowballing. Informed consent was offered to the participants in both

written and signed formats (via video and live). The written consent and information form was "glossed" to meet ASL syntax and utilized words that approximate about a fifth-grade English comprehension and reading level. The signed format was presented via video and sometimes supplemented live by me or with the help of the qualified/certified staff interpreter or Deaf staff member, but most often was presented via video of the interpreter signing the informed consent.

Role of the Researcher

My role was to evaluate and determine which evaluative instruments would be used in the study. Additionally, I administered and collected all of the data from the health literacy instrument and then analyze all the responses (results) from the modified quantitative instrument. I was always present during and administration of the health literacy evaluation instrument (quantitative). I was the only individual handling, reading, and reviewing, as well as, storing all the assessment study materials and responses. Except when in use or being transported to a testing site, all evaluation instruments were and will be kept secured for up to 5 years in a locked file cabinet in my home.

Instrumentation and Operationalization of Constructs

As described earlier in the definition of deficits of health-related terminology/knowledge, the concept of "health literacy" is evaluated by using a validated, and/or sometimes a modified version of a validated instrument such as the TOFHLA/s-TOFHLA (Test of Functional Health Literacy in Adults) or the REALM – Rapid Estimate of Adult Literacy in Medicine (Davis et al., 1991). These instruments measure, evaluate, and estimate health-related reading comprehension (health literacy) levels. The REALM instrument has previously been utilized in research with the Deaf

population (Pollard & Barnett, 2009). The theoretical framework, of this concept, also includes sub-components designated as functional health literacy, medical health literacy, and critical health literacy.

Optimal conditions to the conduction of this research study would have been to conduct the study in a private secluded room/area, working with one participant at a time. During the initial evaluation session, there were times that the certified interpreter/CODA was needed or used to help with signed interpretations of questions the participants may have had or expressed, prior to the administration of the quantitative health literacy evaluation instrument. Unfortunately, during the assessment sessions at the first agency, it became unavoidable and necessary to administer the health literacy instrument to more than one individual at a time. There were no additional perceived risks to the validity of the study or risks to the participants when the administration of the health literacy instrument occurred in a group situation. I am conversationally fluent in American Sign Language and did observe the group of participants to determine if any passing/signing of information occurred.

I conducted this study utilizing an instrument modeled after and what can be considered as a modified (pictorial) form of the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1991; Davis, Long, & Jackson, 1993; and Murphy, Davis, Long, Jackson, & Decker, 1993). Although, the REALM is designed as "a word recognition test and not a reading comprehension instrument," its intended use is to assist medical practitioners to identify patients with poor (health) literacy skills (Davis et al., 1991 and Davis et al., 1993). In its original form, the REALM consists of common and standard medical terminology and assists medical practitioners in evaluating the patient's

ability to read common medical words, but does not assess the patient's comprehension of the meaning of those words (AHRQ). The instrument that was used in this study can be described as a modified graphic (pictorial) form of a health literacy scale (the REALM). It was intended to assess and evaluate basic knowledge, comprehension, understanding, and interpretation of senescence/age-related, chronic health disorders, and medical terminology through matching and associating the correct picture of the physiological portion of the body that is most closely associated with each medical terminology picture; or matching the proper ASL graphic picture of the sign for the written English word.

The quantitative component of this research study was used to evaluate health literacy by utilizing a modified version of the Rapid Estimate in Adult Literacy in Medicine (REALM) (Davis et al., 1991; Davis, Long, & Jackson, 1993). The original REALM instrument has been tested and validated for validity and reliability. Utilization of this modified quantitative research instrument resulted in quantifiable information about any levels of deficits in health-related information for prelingual/culturally Deaf senior citizens. These results can serve as the basis for further research into the relationship between deficits in health-related knowledge (health literacy) and access to health-related information.

Limitations and Threats to Validity

Keeping in mind and recognizing the vast amount of diversity (culture, ethnicity, Social Economic Status [SES], religion, and education) that can and does exist within the targeted population of this research study; limitless diversity is a factor that will need to be considered as one of the limitations of this study. Specific and stringent guidelines

were employed to identify qualified participants, but an enormous amount of diversity still exists among the qualified and selected participants (the population). Additionally, the purposeful sample population did only come from a limited regional area, which may or may not also be seen as a limitation and/or threat to validity. Therefore, in an effort to diminish, as much as possible, these effects and threats to validity, a variation of the nonprobabilistic sampling method known as 'snowballing' was applied and used in this research study. Snowballing is used in research because it can be more practical than probabilistic sampling, especially when working with limited populations and sometimes it is the only way to reach a particular population (Batavia, 2001). "It is a useful approach if it is difficult to locate the targeted population of a study…[and] has the advantage of word of mouth advertising for a difficult to locate population" (Batavia, 2001, p. 47). Unfortunately, it is a sampling method in which not all subjects that make up the population of interest have an equal chance of being included in the research study; which was the case in this study. Therefore, the possibility of limitations does exist due to the variability in numbers of the targeted population that may reside in any one geographical area and due to the limitation or my inability to be able to sample subjects from across the nation.

Data Analysis Plan

Overarching Research Question: Do prelingually/culturally Deaf adults, age 50 and over, experience significant deficits in senescence/age-related, health-related knowledge and literacy? As measured by use of a modeled after, [pictorial] version of the shorter version of the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis

et al., 1991; Davis, Long, & Jackson, 1993; & Murphy, Davis, Long, Jackson, & Decker, 1993).

RQ1: Quantitative: Do prelingual/culturally Deaf individuals over the age of 50 experience deficiencies in knowledge of senescence/age-related health terminology?

(1) In general, do members of the prelingual/culturally Deaf community, over the age of 50, experience deficits in knowledge of health-related terminology as measured by scores on a health literacy evaluation instrument?

(2) In general, does this same sample of prelingual/culturally Deaf individuals, over the age of 50, experience deficits, specifically, in the knowledge of senescence/age-related health disorders?

(3) For which age-related health disorders are deficiencies in knowledge found to be the greatest and the least?

(4) For which age group are deficits in health-related knowledge found to be the greatest or the least.

Analysis: T- tests and ANOVAs conducted on the scores resulting from the health literacy evaluation instrument.

Social Change Implications and Dissemination of Findings

At the conclusion of this research study, and once all data has been analyzed, it will be important to disseminate the results and findings to other researchers in the field of deafness, as well as, other health care and/or deafness stakeholders, to include practitioners and policy makers in the health care field. This research study and its results and findings were summarized and crafted into formats acceptable for publication and will be submitted for publication in health care, and deafness related peer-reviewed

journals (journals yet to be determined). As the overarching goal of this research study was to increase awareness of Deaf-related issues, I will also seek additional opportunities to present the results and findings of this study at professional, discipline related, health-related, and deafness-related conferences, as well as possibly at a Walden University Poster Session. Additional opportunities will be sought to present these research findings and results, whether in written form or orally at local, state (tri-state) and national governmental and health care policy forums, with the intent, to influence these agencies and organizations to act upon the results and outcomes.

Summary

The purpose of this research study was to investigate any significant impact and interrelatedness between prelingual/cultural Deafness and health literacy related to senescence/aging disorders. The next chapter focuses on presenting the methodological results of a quantitative study of whether there is an interrelatedness of prelingual Deafness and health literacy as it relates to knowledge of senescence/age-related health disorders (terminology). Utilizing an independent variable of prelingual deafness and the dependent variable of health literacy, scores indicating the interrelatedness, if any, of the dependent variable of age-related, health literacy, was examined. Quantitatively, results were based on scores from a modeled after modified, pictorial health literacy test. Statistically, results of inferential *t* tests, as well as, the mean, median and modes of the health literacy test was used to represent the results of the health literacy test. Implementation of the study consisted of a pilot study with an initial focus participant utilizing one prelingual/culturally Deaf individual. Deaf individuals who qualified as actual study participants were prelingually Deaf experiencing a hearing loss of 71> dB;

age-50 and older, and utilize American Sign Language as their primary mode of communication. Participant recruitment was conducted through referrals from within the Deaf community, otherwise known as a “snowballing” method of recruitment.

Chapter 4: Results

Introduction

This quantitative research study was developed and designed to investigate and evaluate the health literacy and health numeracy of older, prelingual-culturally Deaf individuals. More specifically, the purpose and focus of this study were designed to assess whether deficits in health literacy and health numeracy, if any exists and to what extent, could such deficits be detected among early-onset, prelingual, culturally Deaf individuals age 50 and older. The overarching research question was: Do prelingual/culturally Deaf individuals over the age of 50 experience deficiencies in knowledge of senescence/age-related health terminology (deficits in senescence-related health literacy) and health numeracy?

Research Question

RQ1 - Quantitative: Do prelingually/culturally Deaf adults, age 50 and over, experience significant deficits in senescence health-related knowledge also referred to as senescence health literacy? This overarching and embracive research question was further deconstructed into and explored the following sub-questions:

(1) Do members of the prelingual/culturally Deaf community, over the age of 50, experience deficits in knowledge of health-related terminology and health-related numeracy?

(2) Do these same prelingual/culturally Deaf individuals, over the age of 50, experience deficits in knowledge of senescence/age-related health disorders?

(3) Which area(s) of senescence/age-related health disorders are deficiencies in knowledge found to be the greatest?

(4) For which senescence/age-related health disorders are deficiencies in knowledge found to be the least?

This research question and its aliquots served as the underpinnings for the null hypothesis and the alternative hypothesis of the research study. With the independent variable of prelingual/cultural deafness theorized to influence the dependent variable of health literacy and health numeracy; the null and alternative hypothesis was stated as follows:

Null (H_0) Hypothesis: No statistically significant levels of deficit in health literacy and health numeracy will be evidenced by the scores achieved by prelingual/culturally Deaf individuals on the modified version of the health literacy instrument.

Alternative (H_1): A statistically significant level of deficit in health literacy and health numeracy scores will be evidenced by the scores achieved by prelingual/culturally Deaf individuals on the modified version of the health literacy instrument.

Data Collection Methods

The data collection section will discuss in detail the pilot and community participatory studies which helped to refine the evaluation instrument. The assessment instrument scale and format details how the instrument was developed, based on a health literacy evaluation instrument currently in use for hearing individuals. The recruitment, consent, instructions and evaluation process of the main study details exactly how the study was adapted to match the specific linguistic needs of the targeted population.

Finally, the results of the main study are discussed and then further elucidated by analyses of each subsection and question contained in the evaluation instrument.

Pilot and Community Participatory Studies

I conducted an exploratory pilot study with two hearing individuals over the age of 50. The purpose of this initial exploratory phase of the study was to elicit the opinions of hearing individuals over the age of 50; as to whether the health terminology that was initially included in the revised REALM evaluation instrument, a modified [pictorial] version of the shorter version of the Rapid Estimate of Adult Literacy in Medicine (REALM; Davis et al., 1991; Davis, Long, & Jackson, 1993; Murphy, Davis, Long, Jackson, & Decker, 1993), would be, in their opinion, pertinent and relevant to the health literacy of older adults. The same exacrevised REALM pictorial American Sign Language instrument could not be given to these individuals due to their lack of knowledge of American Sign Language. Therefore, these hearing individuals were given the terminology contained in the evaluation instrument that was in the form of written English.

Subsections that could be equally and comparatively conducted in written English were the Medical Conditions, Medical Procedures, and Medical/Numeracy Instructions. This written English format simply included written age-related health words, which the hearing individuals were asked to match with a picture of the correct health procedure, related body part, and health instruction. These two individuals performed extremely well on all the subsections of the evaluation instrument that could be equally present in a written English form. They expressed an opinion that the instrument was straightforward and very easy for them to complete. One participant, age 67, achieved an aggregate

overall score of 29 out of 30 or 96.7% as follows: Medical Conditions – 17 out of 18 items correct or 94.44%; Medical Procedures – four out of four items correct or 100%; and Medical/Numeracy Instructions – eight out of eight items correct or 100%. The second participant, age 65, achieved an aggregate overall score of 26 out of 30 items correct or 86.67% as follows: Medical Conditions – 18 out of 18 items correct or 100.00%; Medical Procedures – three out of four items correct or 75%; and Medical/Numeracy Instructions – five out of eight items correct or 62.5%. The hearing pilot study participants attempted to answer all evaluation questions and did not skip over any questions; a phenomenon that was not found to be true when testing the pilot and main study Deaf participants.

The initial modified pilot study American Sign Language evaluation instrument, utilized in this study, consisted of 103 health literacy items divided into five categories: Sample Question (eight items); Medical Conditions (eighteen items); Medical Procedures (four items); Medical/Numeracy Instructions (nine items); and Health Related Words (64 items). The survey instrument was initially designed to include black and white pictures of health-related signs gleaned from the *Random House Webster's American Sign Language Medical Dictionary* (2009), with permission from Random House Publishing (Appendix B).

The second exploratory pilot study sought input concerning the evaluation instrument items and content from two Deaf community members (cultural brokers), but only one invited participant participated. The 2nd invited participant canceled and was a "no-show," three times. These Deaf community members (cultural brokers) were personally known to me and known to be higher functioning in command of English

lexicon than most or the average Deaf individual(s). The second pilot study utilized the initial modified American Sign Language 103 item evaluation instrument. The Deaf (pilot) participant, age 62 achieved an aggregate score of 58 correct answers out of the 103 items, resulting in an aggregate overall score of 56.31%. Her aggregate score was composed of eight out of eight (100%) correct answers on the sample questions; 16 correct answers out of 18 for a score of 88.9% (2 or 11.11% incorrect responses) on the Medical Conditions section. For the Medical Procedures A section, she scored three out of four answers correct for a 75% score (one or 25% incorrect responses) for that section. In the Medical/Numeracy Instructions section, she scored 100% for all eight items. In the Health-Related Words section, which was the longest section, containing 64 items, this cultural broker was only able to correctly answer 22 out of the 64 items for an aggregate score of 34.38% for the section. The rest of items in this section were either incorrectly answered/identified or not answered/skipped over as follows: Six or 9.38% incorrectly answered or identified; and 36 or 56.25% not answered or skipped over.

The participant mentioned above , serving as a cultural broker for this research study, was specifically recruited to provide her specialized cultural insight, perspective, introspective and opinion about the items contained in the survey instrument. As stated the initial survey instrument consisted of 104 items; and with the insightful input of this cultural broker, the survey instrument was revised and gleaned down to 41 items plus eight and then nine sample questions. One additional question was later added to the sample questions, increasing the number of questions in this section to nine. A change in procedure form was submitted to, and approval was received from Walden's IRB committee for the revised survey instrument.

Scale and Format

As stated above, the original adapted and modified REALM evaluation instrument utilized in this study consisted of 96 health literacy items divided into four categories: Medical Conditions (18 items); Medical Procedures (four items); Medical/Numeracy Instructions to include (nine items); and Health Related Words (65 items). The evaluation instrument utilized in this study was modeled after and modified from the original Rapid Estimate of Adult Literacy in Medicine created and developed by Davis et al. (1991) (Appendix A). The original REALM is "a *word recognition* test - not a reading comprehension instrument. Adults are asked to decode and pronounce words (Davis et al., 1991). Since pronunciations and vocalizations are essentially not possible for the targeted population of this study, modification of the instrument and how it was used was necessary. Although there are many other health literacy instruments (mentioned earlier) that are often used in health care settings, most current health literacy instruments have been developed and devised in various languages for oral/speaking individuals. The REALM was found to best suited for modification to meet the needs of culturally Deaf individuals who are not oral; and whose language, American Sign Language, is a visual language and does not have a written form. Attempts have been made to "gloss" and transform this language into some sort of written form, but these attempts and forms have not been received well and have been rejected and are not used by or within the culturally Deaf community (Mulrooney, 2010, pg. 7).

Permission to model after and modify the REALM (Rapid Estimate of Adult Literacy in Medicine) (Davis et al., 1991) was sought from AHRQ (Agency for Healthcare Research and Quality) a government agency that originally stated that they

could grant permission for use and modification. Permission was finally sought from and granted by Davis, the developer and owner of the copyrights to the original REALM evaluation instrument (Appendix A). Permission to utilize pictures from the *Random House Webster's American Sign Language Medical Dictionary* (2009) was obtained from the publishing company of Penguin Random House, who had the authority to grant copyright permission (Appendix B).

The initial modified evaluation instrument utilized in the pilot study consisted of 104 health literacy items divided into four categories: Medical Conditions (18 items); Medical Procedures (four items); Medical/Numeracy Instructions (nine items); and Health Related Words (65 items), along with eight example/sample questions. The construction of the evaluation instrument also involved the use of the Gallaudet True Type Fingerspelling Font (Gallaudet True Type Font, 1991).

Consent and Instructions – Evaluation Process

Participant instructions, which explained how to complete the evaluation instrument, were present in three formats. Before starting the evaluation, participants first viewed a signed video, signed by a certified interpreter, and CODA, who signed the instructions and to how to complete each section. The first part of the video presented the standard Informed Consent signed in American Sign Language, along with basic instructions as to how to complete all the sections of the evaluation instrument. During the actual evaluation sessions, the video was stopped once the first portion, Informed Consent, of the video was viewed. If and once the participant agreed to participate in the evaluation survey, the participant was given a consent form to sign and then the Sample/Example Questions. Prior to starting the actual evaluation, each participant was

initially given originally eight, then later nine sample questions to try to complete. This additional measure I conducted to ensure that the participants understood what they were supposed to do and how to complete each section of the actual evaluation.

The video was then re-started and stopped once the instructions for each section was given, at which time the participant was then asked to complete that section of the evaluation instrument. Once the participant indicated that they had completed a section, or had done as much as they could; the signed video was started again, giving the participant instructions as to what would be involved in the next section, as well as, how to complete the next section.

After participants completed the initial "example/sample" section, and if they agreed to continue their participation in the evaluation survey, the first section, Medical Conditions was then given to them. The Medical conditions section was a one-page evaluation constructed to include 18 health-related words, listed in two columns. These 18 health-related words consisted of conditions associated with and often experienced by aging individuals. Each condition/word was typed in standard American English and spelling and captioned underneath each word was the word typed out utilizing American Sign Language handshapes to spell the same word; utilizing the Gallaudet True Type font software consisting of standard ASL handshapes. Above the two columns of words, at the top of the page were the instructions, typed in standard American English, instructing the participant to match the part of the body that is most often or most closely associated with the words listed below; which were words that are related to various age-related health conditions. These instructions and video instructions were made general enough to basically instruct the participant how to complete all sections of the evaluation

instrument. Underneath the written English instructions contained in each subsection were the same instructions in signed pictures that represented each English word. Each signed picture word was subscripted in ASL handshapes, spelling out the word in ASL handshapes utilizing Gallaudet True Type Font software.

The second section, Medical Procedures, originally consisted of four common medical procedure words, with each word typed and spelled in standard American English and subscripted in Gallaudet True Type Font. Underneath these four common medical procedure words were ten pictures of various parts of the body, and the participant was instructed to match the medical procedure word with the correct body part that the procedure involved, numbered one-ten. The instructions for this section were simply typed in standard American English, since the signed video instructions and the initial instructions in the first section, Medical Conditions, essentially instructed the participant as to how to complete each section of the evaluation instrument. Medical Procedures was later revised into two sections with the addition of seven additional medical procedures that were also health procedures often associated with health procedures an aging individual may receive in accessing health care services.

The third section was Medical Instructions which also evaluated health numeracy, later became section four due to the addition of a second Medical Procedures section (B). Originally Medical Procedures B consisted of nine health-related instructions or instructional words, then later increased to 12 items after modifications to the initial instrument, based on suggestions from the cultural broker. The original fourth section consisting of 65 items, entitled Health-Related Words, was eliminated based on input from the cultural broker who stated that the section was too long and too difficult for the

average Deaf individual to complete. The original 65 items consisted of typed standard English medical/health-related words, subscripted in Gallaudet True Type Font; and instructed the participant match these 65 items/words with 65 pictures of a sign or signs that would be needed to express the typed English word.

As the evaluation process continued, the assessment instrument had to be revised and gleaned down once again, due to many, if not most of the participants' frustrations with and inability to complete various subsections of the evaluation instrument. Therefore, to not lose the consent and interest to participate of most participants, it was deemed that it would be best to glean the evaluation survey down to 28 items, with nine example/sample questions, administered prior to the actual assessment (Appendix D).

Main Study Recruitment Process

The first step in the main recruitment process was to develop a recruitment flyer that was appropriately constructed to recruit culturally Deaf participants. A recruitment flyer was prepared and, as much as possible, "semi glossed" into an easier to comprehend format in English - about a fifth-grade level. The intent was to have these flyers placed and distributed at agencies that provide services to the culturally Deaf community and or at sites where Deaf community members gather for socializing or social events. The overall intent was to affect a snowballing recruitment process.

The information contained on the final written recruitment flyer briefly described the purpose of the research study and provided contact information to enable interested potential participants to contact me. The contact information included an email address, as well as, a contact number to use if the potential participant desired to contact me via text, TTY or via telephone relay; and that number could also be used to communicate

with me via Skype or FaceTime. The flyer also informed interested participants that they could access a "secured" signed recruitment video online at https://vimeo.com/151871246 (Hart, 2016), which would further explain, in sign language, the purpose of the research study.

The signed recruitment video was developed and placed as a secured video on a website called *Vimeo.com*. The signed recruitment video was signed in culturally accepted American Sign Language by a cultural broker/CODA for whom American Sign Language is her first language. The signed video explained the nature and reason for the research study, who I was and my credentials. Additionally, the video explained that participation in the study was voluntary; that the participant could choose not to participate without the fear of discrimination and if the participant agreed to participate, the participant could choose to cease to take part in the study at any point in time during the study. The video concluded by, once again, providing the interested potential participant with information as to how to contact me.

Results

Due to major differences in languages, comparison of between hearing and Deaf individuals on two of the subsections cannot be and is not necessarily equal. Therefore, limited comparisons, as a measure of health literacy, was only analyzed on three of the subsections of the evaluation instrument. These subsections that were presented in the exact same manner with the two hearing pilot study participants (considered to possess general health literacy and education) and the one pilot study Deaf individual (considered

to possess higher functioning in command of English lexicon). Comparison results are presented in Table 1 as follows:

Table 1

Comparison of Health Literacy on Three Subsections by Age and Hearing Status - Pilot Participants

Participant	Age	Medical Conditions	Medical Procedures A	Medical Instructions
1. Hearing	67	17/18 = 94.44%	4/4 = 100%	8/8 – 100%
2. Hearing	65	18/18 = 100%	3/4 = 75%	5/8 = 62.5%
3. Deaf	62	16/18 = 88.89%	3/4 = 75%	8/8 = 100%

Note. *[1]Mean age 64.67 of the three female pilot participants (both hearing and Deaf) very closely approximates the mean age 64.92 of the female participants in the main study.*
[2]The original evaluation instrument (Appendix C) contained a 64-item Health-Related Words subsection, which the Deaf pilot participant advised would be too long and difficult for the average Deaf participant, so this section was deleted from the evaluation survey used in the main study. On this section, the Deaf pilot participant correctly answered 22 out of 64 (34.38%), incorrectly answered/identified 6 (9.38%), and did not answer/skipped over 36 = 56.25%.

Comparing the mean averages for these three subsections with those of the main study and the three pilot participants further supports the deficits in health literacy theoretical framework of this study:

Table 2

Comparison of Health Literacy by Grouped Means – Pilot and Main Studies

Participants	Mean Age	Medical Conditions	Medical Procedures A	Medical Instructions
Hearing (pilot)	66	97.22	87.5%	81.25%
Deaf (pilot)	62	88.89%	75%	100%
Deaf (main study)	69.39	3.6%	30%	35.5% (9/9 modified)

The target population for both the second pilot and main studies were prelingual/culturally Deaf individuals age 50 and older. Recruiting for the main study occurred within the five boroughs of New York City. Main study participants were evaluated at two Deaf service agencies in New York City. Through snowballing (Vogt, 1999) and more specifically with the help of cultural brokers and staff and administrators at two Deaf service agencies, a total of 27 culturally Deaf individuals over the age of 50 were recruited and agreed to serve as evaluation participants. Specific domicile information for each participant was not deemed necessary; therefore, exact residential information for and about each participant was not collected. The only demographic information that was collected was gender, age, and CODA status. Correlational analyses revealed no significant correlational relations between any of the variables of gender, age or CODA status, nor for any of the dependent variables (evaluation scores).

Table 3 summarizes the participants by age and gender. Twenty participants (87%) indicated that neither parent was Deaf, 1 had one Deaf parent, and 2 had two Deaf parents.

Table 3

Age by Gender

	Percent	Mean Age	Range
Males (n = 14)	51.9%	73.85 (SE = 1.9)	61-86
Females (n = 13)	48.1%	64.92 (SE = 2.8)	51-86

For the nine sample questions, four (14.81%) participants were unable to respond to or skipped over all items in this subsection. Thirteen 48.15% of the participants produced a combination of skipped over or incorrect responses, and only 10 (37.04%) out of the 27 participants were able to correctly respond to all questions in this subsection resulting in (M = 5.22, 58%, SE = .63). The mean did vary from zero ($t(26) = 8.3$, $p < .01$), which indicates they responded better than chance to the items.

For the 18 Medical Conditions questions, twenty participants from Agency 1 were evaluated, and 19 (95%) participants either skipped over or were unable to complete any items in this subsection (M = .65, 3.6%, SE = .65). Only one (5%) participant was able to answer any items correctly, and properly responded to 13 of the items (72.2%). The mean did not vary significantly from zero ($t(19) = 1.0$, $p > .01$). Due to the difficulties participants from Agency 1 experienced in completing this subsection, a decision was made to not evaluate the final seven participants from Agency 2 on the Medical Conditions subsection.

Similar to the Medical Conditions Questions section, due to difficulties participants from Agency 1 experienced in completing the four Medical Procedures A questions in the subsection; again, a decision was made not to evaluate the seven participants from Agency 2, in this section. Therefore, only the 20 original participants from Agency 1 were evaluated on this subsection. The mean total score for the Medical Procedures A questions was (M = 1.2, 30%; SE = 0.32) out of a possible score of four. This mean did significantly vary from zero ($t(19) = 3.7$, $p < .01$), indicating that nine (45%) participants performed better than chance by responding with a combination of correct and incorrect responses. Eleven (55%) individuals were unable to answer any of

the questions; with these scores removed the mean became 2.67 correct (66.7%; SD = .71). The adjusted mean indicates that only the nine participants who did attempt to complete this subsection, correctly identified items a little more than 50% of the time.

All 27 combined participants from both Agency 1 and Agency 2 were evaluated on the seven Medical Procedures B questions section. No participants were able to correctly respond to all items in this subsection, resulting in a mean total score of 1.59 (22.7%; *SE* = .39) out of a possible total score of 7. This mean did significantly vary from zero ($t(26) = 4.13$, $p < .01$) for the 13 participants who responded with a combination of correct, incorrect and skipped over responses. Fourteen (51.85%) individuals were unable to answer any of the questions; with these scores removed the mean became 3.58 correct (51.1%; SD = 1.3). The adjusted mean indicates that the 13 or 48.15% of the evaluated participants who attempted to respond to the items in this subsection correctly identified items in this subsection a little more than 50% of the time.

Finally, the mean score for Medical/Numeracy Instructions, for all 27 participants from both Agency 1 and Agency 2, was 4.26 (35.5%; *SE* = .90) out of a possible total score of 12, this mean did significantly vary from zero ($t(26) = 4.76$, $p < .01$). Four (14.81%) participants correctly responded to all 12 items in this subsection, 12 participants (44.44%) responded with a combination of correct, incorrect and skipped over responses. Eleven (40.74%) individuals were unable to answer any of the questions; with these scores removed the mean became 6.4 correct (53.3%; SD = 4.3). Again, indicating that only 16 (56.26%) of the participants attempted to and were only able to correctly identify the items in this subsection a little of 50% of the time.

Table 4

Overall Health Literacy by Evaluation Subsections

Health Literacy	Sample Questions	Medical Conditions	Medical Procedure A	Medical Procedure B	Medical Instructions
	M = 5.22 (58%; SE = 0.63)	*M* = .65 (3.6%; *SE* = *0.65)*	*M* = 1.2 (30%; *SE* = 0.32)	*M* = 1.59 (22.7%; *SE* = 0.39)	*M* = 4.26 (35.5%; *SE* = 0.90)

Through analyses, it became apparent that there were three distinct groups of older Deaf adults in the current sample (only the 20 participants from Agency 1 who attempted all of the tests are included). The groups were determined by summing the scores on all tests (M = 11.8; SD = 8.6; range 0-27). One group, considered as most deficient in health literacy, exhibited severe deficits in health-related literacy and were unable to complete any of the questions on the surveys. In the present study, 2 (7.4%) individuals fell into this category. The second category consisted of those who exhibited semi literacy in health-related disorders (under one standard deviation above the mean total score of 11.8; i.e., scores of 1-20.4), encompassed 13 (48.1%) individuals who fell within this group. Finally, the group of participants who exhibited sufficiency in health literacy consisted of those higher than one standard deviation from the mean; this group consisted of 5 individuals (18.5%). I will examine each of the groups separately.

Examining each of these three groups by age revealed that the participants exhibiting the lowest proficiency in health literacy group (n = 2; *M* = 80 yrs.; range 76-84) were older than the semi conversant in health literacy group (n = 13; *M* = 71.6 yrs.;

range 61-86). The age range for the group exhibiting the highest level of health literacy fell within the same age range as the group of participants who exhibited semi health literacy (n = 5; *M* = 74.4 yrs.; range 68-86). For gender, both participants in the deficient in health literacy group were males. The semi conversant in health literacy group consisted of 6 (46%) females and 7 (53.8%) males, while the group sufficient in health literacy consisted of: Males = two (40%), Females = three (60%). All participants with Deaf parents were in the deficient in health literacy and semi conversant in health literacy groups. The breakdown for each question for the semi conversant in health literacy and health literate groups are shown in Table 5.

Table 5

Conversant versus Semi Conversant in Health Literacy Grouped by Evaluation Subsections

Health Literacy	Sample Questions	Medical Conditions	Medical Procedure A	Medical Procedure B	Medical Instructions
Semi Conversant (n = 13)	*M = 5.1 (72.9%; SE = 0.83)*	*M* = 0	*M* = 1.08 (27%; SE = 0.4)	*M* = 1.15 (16.4%; SE = 0.44)	*M* = 1.15 (9.6%; SE = 0.76)
Conversant (n = 5)	*M* = 6.2 (88.6%; SE = 1.5)	*M* = 2.6 (21.7%; SE = 2.6)	*M* = 2 (50%; SE = 0.6)	*M* = 4 (57.1%; SE = 1)	*M* = 10.4 (86.7%; SE = 0.4)

Further analysis of each subsection by gender produced mixed results. Comparing the 13 females to the 14 males on each subsection revealed the following results displayed in Table 6. These results indicate the possibility that

prelingual/culturally Deaf males over the age of 50, may experience greater difficulty in being able to correctly comprehend follow and adhere to health-related medical information and instructions. Difficulties in comprehending, thus then being able to follow medical instructions properly should be viewed as problematic in fostering good and proper personal health care management.

Table 6
Responses by Gender

	Correct	Incorrect	Not answered	Not given
Sample Questions. Using the words below, please match the words with the ASL sign associated with these words.				
Females (13)	60.68%	23.93%	1.71%	13.68%
Males (14)	60.32%	14.29%	4.76%	20.63%
Medical Conditions. Using the pictures below, please match the part of the body most often associated with the health-related word				
Females (8)	10.41%	2.77%	87.50%	
Males (12)	0.46%	0%	99.54%	
Medical Procedures A. Using the pictures below, please match the pictures with the ASL sign(s) that are associated with the medical procedure.				
Females (8)	43.78%	15.63%	40.62%	
Males (12)	20.83%	18.75%	60.75%	
Medical Procedures B. Using the words below, please match the ASL sign(s) associated with these words.				
Females (13)	24.18%	24.18%	51.64%	
Males (14)	24.49%	18.37%	57.14%	

(*table continues*)

	Correct	Incorrect	Not answered	Not given
Medical/Numeracy **Instructions.** These questions assess your knowledge of medical instructions. Instructions that tell you: How Much - What to Do - What Time. Please match the written instructions - numbers 1-7, with the correct medical instructions - letters A-L.				
Females (13)	46.79%	10.90%	42.31%	
Males (14)	27.98%	7.74%	64.28%	

Analyses by Research Questions

RQ1 - Quantitative: Do prelingually/culturally Deaf adults, age 50 and over, experience significant deficits in senescence health-related knowledge also referred to as senescence health literacy? (As measured by use of a modified [pictorial] version of the shorter version of the Rapid Estimate of Adult Literacy in Medicine (REALM; Davis et al., 1991; Davis, Long, & Jackson, 1993; Murphy, Davis, Long, Jackson, & Decker, 1993). This overarching and embracive research question was further deconstructed into and explored the following sub-questions:

(1) Do members of the prelingual/culturally Deaf community, over the age of 50, experience deficits in knowledge of health-related terminology and health-related numeracy?

It is apparent that there are three distinct groups of older Deaf adults in the current study. One group exhibited severe deficiencies in health literacy and were unable to complete any of the questions on the surveys. In the present study, two individuals fell

into this category. The second group, who exhibited semi health literacy (n =13) were able to answer some of the questions correctly. The third group exhibited some proficiency in health literacy (n = 5) were able to answer higher than one standard deviation of the overall mean of the questions correctly. All of the sub-scores for the semi and literate groups were significantly greater than zero, indicating a greater than chance performance on the measures. Cronbach's alpha for Medical Procedure A was .837; for Medical Procedure B was .817 and for Medical/Numeracy Instructions was .919, indicating high internal consistency for the responses. Table 7 shows a breakdown of each question.

Table 7

Responses by Question

	Correct	Incorrect	Not answered	Not given
Sample Questions				
1. Medication	22 (81.5%)	1 (3.7%)	4 (14.8%)	
2. Kidney	13 (48.1%)	10 (37.0%)	4 (14.8%)	
3. Vitamins	23 (85.2%)	0	4 (14.8%)	
4. Hip	15 (55.6%)	8 (29.6%)	4 (14.8%)	
5. Muscle	15 (55.6%)	8 (29.6%)	4 (14.8%)	
6. Nausea	20 (74.1%)	3 (11.1%)	4 (14.8%)	
7. Injection/Shot	11 (40.7%)	11 (40.7%)	5 (18.5%)	
8. Fever	15 (55.6%)	8 (29.6%)	4 (14.8%)	
9. Obese	7 (25.9%)	4 (14.8%)	1 (3.7%)	15 (55.6%)
Medical Conditions. Using the pictures below, please match the part of the body most often associated with the health-related word				
1. Reflux/Gerd	0	1 (3.7%)	19 (70.4%)	7 (25.9%)
2. Asthma	0	1 (3.7%)	19 (70.4%)	7 (25.9%)
3. Alzheimer	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
4. Bronchitis	1 (3.7%)	0	19 (70.4%)	7 (25.9%)

(*table continues*)

	Correct	Incorrect	Not answered	Not given
5. Cardiovascular	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
6. Cataract	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
7. Nausea	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
8. Pulmonary	0	1 (3.7%)	19 (70.4%)	7 (25.9%)
9. Stroke	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
10. Colitis	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
11. Emphysema/C.O.P.D.	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
12. Hypertension	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
13. Disk	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
14. Glaucoma	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
15. Gastritis	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
16. Lumbar	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
17. Ulcer	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
18. Macular Degeneration	1 (3.7%)	0	19 (70.4%)	7 (25.9%)
Medical Procedures A. Using the pictures below, please match the pictures with the ASL sign(s) that are associated with the medical procedure.				
1. Colonoscopy	9 (33.3%)	1 (3.7%)	10 (37%)	7 (25.9%)
2. Dialysis	1 (3.7%)	9 (33.3%)	10 (37%)	7 (25.9%)
3. EKG (electrocardiogram)	9 (33.3%)	1 (3.7%)	10 (37%)	7 (25.9%)
4. EEG (electroencephalogram)	5 (18.5%)	4 (14.8%)	11(40.7%)	7 (25.9%)
Medical Procedures B. Using the words below, please match the ASL sign(s) associated with these words.				
1. Dialysis	6 (22.2%)	4 (14.8%)	17 (63%)	
2. EKG (electrocardiogram)	8 (29.6%)	3 (11.1%)	16 (59.3%)	
3. EEG (electroencephalogram)	1 (3.7%)	10 (37%)	16 (59.3%)	
4. X-Ray	8 (29.6%)	5 (18.5%)	14 (51.9%)	
5. Colonoscopy	10 (37%)	3 (11.1%)	14 (51.9%)	
6. CT Scan (or CAT Scan)	5 (18.5%)	7 (25.9%)	15 (55.6%)	
7. MRI (Magnetic Resonance Imaging)	5 (18.5%)	7 (25.9%)	15 (55.6%)	

(*table continues*)

	Correct	Incorrect	Not answered	Not given
Medical/Numeracy **Instructions.** These questions assess your knowledge of medical instructions. Instructions that tell you: How Much - What to Do - What Time. Please match the written instructions - numbers 1-7, with the correct medical instructions - letters A-L.				
1. Keep Elevated	13 (48.1%)	2 (7.4%)	12 (44.4%)	
2. P.T.	6 (22.2%)	3 (11.1%)	18 (66.7%)	
3. Once Daily	10 (37%)	2 (7.4%)	15 (55.6%)	
4. Take orally	10 (37%)	3 (11.1%)	14 (51.9%)	
5. Twice a Day	10 (37%)	2 (7.4%)	15 (55.6%)	
6. Three Times a Day	10 (37%)	2 (7.4%)	15 (55.6%)	
7. Tbsp.	10 (37%)	2 (7.4%)	15 (55.6%)	
8. Tsp	11 (40.7%)	1 (3.7%)	15 (55.6%)	
9. Dose	12 (44.4%)	0	15 (55.6%)	
10. OTC	18 (29.6%)	3 (11.1%)	16 (59.3%)	
11. Rx	10 (37%)	1 (3.7%)	16 (59.3%)	
12. Bed Rest	9 (33.3%)	2 (7.4%)	16 (59.3%)	

(2) Do these same prelingual/culturally Deaf individuals, over the age of 50, experience deficits in knowledge of senescence/age-related health disorders?

In Table 7, Medical Conditions subsection (for which only 20 participants from Agency 1 were evaluated) elucidates that most participants in this study exhibited the greatest deficits in knowledge of age-related medical/health conditions. Out of 18 senescence/age-related health disorders, only one participant attempted to answer the questions in this section, but incorrectly answered 3 of the questions. All other participants appeared to be unable to complete this section and did not attempt to address any of the questions in this section. Participants were able to perform slightly better on

the subsections of Medical Procedures A & B and Medical/Numeracy Instructions, although percentages for questions not answered or skipped over in these subsections were still considerably higher than the percentages for questions answered correctly.

(3) Which area(s) of senescence/age-related health disorders are deficiencies in knowledge found to be the greatest?

Based on the overall results of all five subsections, almost all of the participants in this study exhibited deficits in health literacy in all subsections. The study participants exhibited the most difficulty in identifying senescence/age-related health disorder words related to identifying Medical Conditions, as indicated by 19 out of 20 participants skipping over or not being able to identify any of the items in this subsection correctly.

(4) For which senescence/age-related health disorders are deficiencies in knowledge found to be the least?

Based on the overall results from all five subsections, participants exhibited the least deficiency in completing the Sample Questions subsection which consisted of a variety of simple medical and health-related words. Six participants (22.22%) from Agency 1 correctly identified and matched all the words in this subsection; 20 participants (74.07%) correctly identified and matched most of the words in this subsection, and only one individual was unable to correctly identify or match any of the words in the subsection. Therefore, overall, participant responses in this subsection were found to be the best and most correct compared to the other four subsections.

Summary and Conclusions

After observing the great distress, the 27 prelingual/culturally Deaf older adults exhibited in completing the evaluation instrument necessitating the need to simplify the assessment instrument repeatedly, the results of descriptive analyses validated the premise that significant deficits in health literacy existed within the targeted sample population. The data indicated that the sample was composed of three distinct groups of older Deaf adults. One group was functionally deficient in health literacy and unable to respond to or understand any of the questions. The second, semi conversant in health literacy group was able to respond to a few questions, and the third group appeared to be the most conversant in the health literacy questions, both groups scored above chance. The data also indicated that significant differences in health literacy do not necessarily always exist between genders. Females and males scored equally as well on the subsections of Sample Questions and Medical Procedures B; but females scored significantly higher than males on all other subsections of Medical Conditions, Medical Procedures A, and Medical Instructions. Comparing these results and distress experienced by the Deaf participants to the ease and effortlessness with which the hearing pilot participants were able to complete the subsections they were evaluated on, is a strong indicator of deficits in health literacy among Deaf individuals over the age of 50. In Chapter 5, I will interpret these data as it relates to previously cited literature and theory.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Based on a literature review of the prior research in this area, the purpose and nature of this study were to evaluate and attempt to answer the following overarching research questions and sub-components.

RQ1 - Quantitative: Do prelingually/culturally Deaf adults, age 50 and over, experience significant deficits in senescence health-related knowledge also referred to as senescence health literacy? (As measured by use of a modified [pictorial] version of the shorter version of the Rapid Estimate of Adult Literacy in Medicine (REALM; Davis et al., 1991; Davis, Long, & Jackson, 1993; Murphy, Davis, Long, Jackson, & Decker, 1993). This overarching and embracive research question was further deconstructed into and explored the following sub-questions

(1) Do members of the prelingual/culturally Deaf community, over the age of 50, experience deficits in knowledge of health-related terminology and health-related numeracy?

(2) Do these same prelingual/culturally Deaf individuals, over the age of 50, experience deficits in knowledge of senescence/age-related health disorders?

(3) Which area(s) of senescence/age-related health disorders are deficiencies in knowledge found to be the greatest?

(4) For which senescence/age-related health disorders are deficiencies in knowledge found to be the least?

Based on the experiences gained while conducting these evaluations, there was clear evidence that low and limited health literacy was far more extensive than anticipated (Table 4). The sample mean 5.22 (58%) was found to be the highest for simple medical and health-related words presented in the first subsection. Subsection 2 – Medical Conditions consisted of 18 words related to senescence health conditions. Although only the first 20 participants were evaluated on this section, the mean 0.65 (3.6%) for correct responses was found to be the lowest, with only one participant attempting to match the 10 pictures of various parts of the body with the 18 written words of disorders that specifically affect that part of the body.

For the Medical Procedures A subsection which consisted of attempting to match the pictures, correctly with four health-related medical procedures; again, only the first 20 participants were evaluated and achieved a mean of a mere 1.2 (30%). Medical Procedures B was conducted with all 27 participants and consisted of the same four medical procedures, plus three more medical procedures. This time participants were asked to match the written words with the correct ASL sign for the written medical procedure word and achieved an overall mean of 1.59 (22.7%). The last subsection, Medical Instructions, consisted of 12 typical medical/numeracy instructions that a patient might be asked to follow in managing their health care or taking medication. All 27 participants were evaluated on this subsection and achieved a group mean score of 4.26 (35.5%), the second highest overall mean score. As denoted in Table 7, the underlying reason for such low means on most of the subsections was due to the participants not attempting to answer or skipping over the questions.

The modified instrument utilized in this study was based on the original REALM. Although the two instruments are not equally comparative, due to language and how responses were solicited; the REALM utilizes the following four categories of correct responses as a measure of grade-equivalent reading levels. Zero-18 (0%-27%) ≤ third-grade; 19-44 (29%-67%) fourth-sixth-grade; 45-60 (68%-91%) seventh-eighth-grade; and 61-66 (92%-100%) ≥ ninth-grade (Wallace, 2006). Temperately utilizing these categories as a comparison, the results obtained in the pilot and main studies are as follows. In the pilot study, the hearing participants achieved aggregate scores of 97.22% on the Medical Conditions, 87.5% on Medical Procedures A and 81.25%, all of which would comparatively equate to 8^{th}-9^{th} ≥ grade on the original REALM. The higher functioning Deaf pilot study participant achieve scores of 88.89% Medical Conditions, 75% Medical Procedures A, and 100% Medical/Numeracy Instructions, which would again comparatively equate to 8^{th}-9^{th} ≥ grade on the original REALM. Using these same REALM grade level percentages to evaluate the aggregate percentages achieved in the main study, participants scored what could be viewed as less than third grade literacy as follows. Fifty-eight percent on medical and health-related words (Sample Questions), 3.6% Medical Conditions, 30% Medical Procedures A, 22.7% Medical Procedures B, and 35.5% Medical/Numeracy Instructions. Comparatively the results of this study indicate a severe deficit in health literacy.

Interpretation of Findings

Comparing the results of the current study to one previously conducted (Pollard & Barnett, 2009) relative to this population and utilizing the REALM as the evaluation instrument, the outcomes of the present study were significantly lower. In an earlier

study Pollard and Barnett (2009) evaluated 57 Deaf participants (27 women, 29 men, 1 unspecified), 80.8% of whom possessed a college degree, they ranged in age from 21-67 (M = 44.3, SD = 12.0), compared to the age range of 51-86 (M = 69.38, SD = 9.68) for the participants in the current study.

The original REALM has a maximum score of 66 and scores in the Pollard and Barnett (2009) study ranged from 8-66 (*M* = 58.3, *SD* = 12.4). In the Pollard and Barnett study (2009) the 80.8% of participants with college degrees demonstrated a risk for low health literacy; therefore, Pollard and Barnett (2009) inferred that the general deaf population is likely at an even higher risk for low health literacy. Additionally, Pollard and Barnett (2009) stated that most participants (68.4%) indicated that they understood more than 90% of the REALM items. In the Pollard and Barnett study (2009) one-third or 31.6% of the participants earned scores comparable to the REALM's below ninth-grade level, indicating low health literacy; 29.6% with high school degrees, as well as 21.7% with college degrees also scored well below ninth-grade range. Although the results of the current study and the Pollard and Barnett (2009) study are indicative of deficits in health literacy, factors that may have influenced the extreme difference in results between the two studies may be the older mean age of the participants in the current study, as well as levels of education (education demographics were not collected for the current study).

In a comparison of the current study to the prior research conducted by Pollard and Barnett (2009), the results of the present study confirm and extend the limited prior knowledge of this population, as well as, supports the alternative hypothesis that critical deficits in health literacy exist among prelingual/culturally Deaf individuals. Deficits in

health literacy is further underpinned by the research of Young et al. (2016, p. 2) in which they conclude that “familiarity with a word (lexical item) does not always confer familiarity with its meaning…and is compounded by a wide range of lay meanings attached to concepts and words." Additionally, the results of this study possibly also support Mayer and Villaire's (2009, p.5) theory that "some words used in a medical context, are not clear and possibly even have an opposite meaning from how it is typically and colloquially used." Therefore, low scores achieved by participants in all subsections in the current study again helps to confirm and extend the prior knowledge in this area of research.

The results of the present study examined in the context of the theoretical framework of health literacy, indicate that deficits in health literacy do exist among the general population of prelingual/ culturally Deaf adults over the age of 50. Due to major differences in languages (American Sign Language vs. English), comparisons of health literacy, between hearing and Deaf individuals are difficult to make. Considering the language differences, only a limited comparison, on three of the subsections, as a measure of levels of health literacy can be drawn between the two hearing pilot study participants and the Deaf main study participants. Comparisons could only be conducted on three subsections of the evaluation instrument that were presented in the exact same manner to the two hearing pilot study participants (considered to possess general health literacy and education) and the main study Deaf participants. Comparing the correct response percentages of 3.6% for Medical Conditions for Deaf participants in the main study, with the correct response percentage of 97.22% on this subsection for the two hearing pilot study participants, the comparative results are indicative of a severe deficit

in health literacy, in this area, for Deaf individuals. The average correct response rate for Medical Procedures A was 30% for the Deaf participants and 87.5% for the hearing participants, and the average for correct Medical/Numeracy Instructions responses for the Deaf participants was 35.5% compared to the average of 81.25% for the hearing pilot study participants. Even this limited comparison of the health literacy theoretical framework, premise, and alternate hypothesis of this study was further supported by the limited comparison of the hearing and Deaf participants' averages on these three subsections.

Limitations of the Study

The principal limitation of this study was the limited geographical area from which the main study sample population was recruited. External validity concerns about the inferences drawn from this sample population were controlled for as best as possible, but difficulty existed in controlling for external validity issues due to the limited geographical area of the research project. These limitations could be abated through a larger study that is conducted as a major and funded research study. Albeit, the geographical area of this study was limited, the results of this study still offer basic generalizability to the health literacy of the prelingual/culturally Deaf population over the age of 50.

Several unforeseen impediments were experienced while conducting the present study. The first was a reoccurring request encountered in proctoring these evaluations. Many of the Deaf participants consistently stated that they had never seen the pictorial signs used in the evaluation instrument and asked for the pictures of the sign(s) to be personally signed to them instead. They stated that they would understand the signs if

signed, but not the static picture of a sign. A similar comparison of this phenomenon can be made to the literacy level of a hearing person who may understand an oral utterance, but not be able to identify or comprehend the same word when presented in a written form. Since sign language has no written form and is a fluid-movement language, this factor may most likely explain their preference to see the actual movement of a signed word. This factor may also explain why many participants asked for the pictures of the signs to be signed to them as opposed to them being able to decipher a static picture of a signed word. It is apparent, from the results of this study that static pictures are not necessarily effective in communicating with a Deaf individual and should only be employed as a communication method of last resort. This phenomenon may also be ascribed to the influence of conceptual socio-linguistic/cultural factors (Withers & Speight, 2017) based on the community of signers with which the participant interacts. Wherein there may be different signs used to express the same concept, based on the area of the country where the person lives. This socio-linguistic conceptual factor is comparable to spoken English colloquialism used by individuals in different parts of the United States or the differences in language usage between American and British English.

Another unanticipated impediment to the research design, treatment (survey instrument, including the Sample Questions) and the proctoring of the survey instrument may be ascribed to the medical condition of presbyopia that appears to have impacted some if not many of the participants over the age of 50. Although typed English words were presented in 12 pitch Arial fonts, known to be one of the easiest fonts to read and comprehend (Bernard, Liao, & Mills, 2000); and pictures of ASL signs were presented at

a size averaging 1.5" x 1.5", some participants still appeared to have encountered problems in deciphering and comprehending the signs. Even with an added modification to how the treatment (survey instrument, including the Sample Questions) was presented, utilizing 31" x 24" poster size pages of all the pages of the evaluation instrument, posted on the front wall of the evaluation room participants were still unable to decipher the signs. Pictures on the posters were doubled in size to 3"x 3.5"; words doubled 2.5 times to Arial 30 point. Participants were also allowed to either walk up to the posters or have the posters placed on the table where they were sitting, but still appeared not to be able to comprehend the written English word or the pictures of the ASL signs that represented the words. Therefore, even the oversized posters of the evaluation instrument did not appear to have helped or facilitated their ability to complete the subsections of the assessment instrument. Again, this phenomenon may also be ascribed to the influences of socio-linguistic/cultural factors (Withers & Speight, 2017) discussed earlier or general literacy/education level, as well as age and vision related issues of presbyopia.

It should also be noted that in the main study the Sample Questions subsection included written words to be matched with (a) picture(s) of the correct ASL sign(s) that represented the written word(s), Deaf participants produced their best results in this section. Visually, this subsection may have appeared to have been presented or displayed in a more concise and much clearer format, (clearer in terms of the lesser number of pictures needed to represent each sign); therefore, easier to decipher and comprehend than subsequent subsections. Also, this was the first subsection to be presented, and there is a possibility that participants were not experiencing test anxiety or fatigue as they attempted to complete this first subsection of the evaluation. It should be noted that the

Medical Conditions B subsection was presented in the same manner as the Sample Questions subsection, but at this point, participants were possibly experiencing test anxiety or fatigue, being that this was the fourth of five subsections of the evaluation instrument; and they had already struggled through three previous subsections.

Implications and Recommendations

Withers and Speight (2017) identified various reasons for the inequities in health care for Deaf individuals but posited that the communication barrier is one of the major factors. The present study revealed that health literacy and comprehension of health-related terminology are part of communication problem. Inferring from the data collected during this study, the high probability of deficits in English literacy and comprehension most probably serves as the underpinning of even greater deficits in comprehension of health-related and medical instructions literacy and numeracy for, specifically, older members of the prelingual/culturally Deaf community. Implications of this phenomenon may be based on sociolinguistic and interpersonal factors (Withers & Speight, 2017). Additionally, this phenomenon may also be based on different educational systems (oral vs. signing), where and when an older person was educated, as well as, the community of signers with which the participant interacts with, and the area of the country where the participant lives. All of these influencing factors may have a strong influence on which signs the participant is accustomed to using to represent a particular word or concept. Additionally, a conclusion may be made that pictorial signs that are found in sign language dictionaries and medical sign language dictionaries are more for hearing individuals. These dictionaries can and should be viewed as a basic effort to facilitate the learning of sign language by hearing individuals and as a very basic

effort to facilitate health-related communication between the health care practitioner and the Deaf individual.

Therefore, when it comes to presenting medical information and instructions to a Deaf individual, medical professionals need to understand that not only will a document or pamphlet or instructions written in English not be viable nor work well, a document/pamphlet or instructions presented in pictorial (handshapes spelling the words or pictorial presentations of the sign for the word) is not necessarily a viable option either. Therefore, utilization of a sign language interpreter or some other method of dynamic visual communication is vital and necessary. Fortunately, utilization of interpreters has finally become increasingly standard practice during face-to-face interactions with health care providers. Unfortunately, the present healthcare protocols do not address nor assist members of the Deaf community with at home self-care or health management, in the form of providing interpreters. Thus, at the very least, medical documentation and instructions will need to be made available and given to a Deaf patient in some non-static format, such as in a signed video format, which can be achieved through the use of technology and online venues. Currently, many of the larger healthcare systems maintain online websites where they post health-related and health management information. Therefore, consideration should also be given to providing this same healthcare and self-care management information and instructions in an accessible, non-static ASL video format.

Although, the United States currently has four federal laws (Title VI of the Civil Rights Act of 1964; Section 504 of the Rehabilitation Act of 1973; Title II of the 1990 Americans with Disabilities Act; and Title III of the 2010 amended Americans with

Disability Act) that mandate equal communication access for Deaf individuals in all health care settings (Olson & Swabey, 2016), unfortunately these mandates are not always strictly adhered to. Even in violation of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and Public Law 104-191 which was enacted on August 21, 1996, many health care practitioners continue to believe that it is the Deaf individual's responsibility to bridge the communication gap by providing and paying for their own interpreters. Often the expectation of healthcare professionals is that the Deaf individual will bring a family member, child, or close family friend (Skot et al., 2016) to serve as an interpreter to bridge the communication gap, which is in direct violation of the HIPAA protocol. Not only is the use of a family member or close friend a violation of HIPAA, in many households when only one family member is deaf, family members often never fully learn American Sign Language and therefore would be inadequate in effectively translating very technical medical information. While it is true that securing the services of an interpreter is not always easy, especially in rural areas where access to a certified interpreter can be limited to nonexistent; acquiring the services of a certified interpreter can also be time-consuming, require attention to coordination of appointment schedules, and not to mention costly. However, under governmental laws, it is still the responsibility of the healthcare professional/setting to facilitate and pay for the bridging of the communication gap.

A positive social change may be effected through the governmental support of a program similar to what is in place in France (Mauffrey, Berger, Harteman, & Bouillevaux, 2016). Although in France, the acquisition and cost of securing interpreting services are borne by the patient, governmental public policy provides a "disability

compensation benefit." This benefit consists of a monthly allowance that will cover and pay for approximately six hours of interpreting services. Covered interpreting services that the Deaf individual can utilize in and for any area of their daily living (Mauffrey et al., 2016). In the United States, due to the disability designation status of many, if not most, prelingual/culturally Deaf individuals over the age of 18, they are eligible for or do receive Medicaid benefits. Prelingual/culturally Deaf individuals may also qualify for Medicare benefits at a younger age, based on their disability status; but they are definitely eligible if they are over the age of 65. According to Betancourt, Green, and Carrillo (2002), a similar type of benefit service that covers the cost of interpreter services for all Medicaid recipients exists in the state of Washington. The major difference between the programs in force in France and the program in effect in the state of Washington is that the request for interpreter service must be generated by the provider or social service agency in the state of Washington. Whereas, in France, the Deaf individual can personally request the services of an interpreter for any ADL and have the cost of the interpreter covered and paid for by the governmental program. Positive social change can be effected by changes in United States governmental policies related to Medicaid and Medicare; changes that would provide monthly stipends to cover a specific amount of the cost or a specific amount of time to be used to secure interpreting services, similar to the program currently in force in France.

In medical situations, the vital need for a one-on-one, real-time interaction between the medical practitioner, an interpreter, and the Deaf individual is now increasingly acknowledged, but a phenomenon that is not always strictly adhered to. Again, this need may be especially true for older Deaf individuals who were educated during the era of

educational practices where “oralism” (speaking) was emphasized over teaching and educating Deaf individuals in the basics of English comprehension of reading and writing English. As stated earlier, “the median reading level of a deaf high school graduate in the United States is 4th to 5th grade” (Barnett & Franks, 1999; McKee, Barnett, Block, & Pearson, 2011). Additionally, previous researchers have indicated that “the medical vocabulary knowledge of Deaf adults in the United States is similar to that of non-English-speaking immigrants in the United States” (Barnett, 2002, p. 380).

With today’s technology and internet access, eliciting the services of an interpreter can be easily achieved by contracting with agencies that employ certified, online interpreters. Thus, reducing the cost of and the probability of not being able to secure the services of an in-person interpreter at the time health care services and important health care management instructions are being presented by the practitioner and received by the Deaf patient. Through the advances in technology and the widespread availability and use of the internet, positive social change in meeting the communication challenges requiring an interpreter can be effected through real-time online certified interpreter services, which does currently exist. One emerging type of technology is known as Video Remote Interpreting (VRI) in which a remotely, or off-site sign language interpreter provides interpreting services using a web camera or video phone (Withers & Speight, 2017). Whiters and Speight (2017) also posit that use of VRI technology is becoming increasingly popular due to convenience and comparatively low cost versus the cost of hiring an interpreter. Albeit, while there is still a cost (borne by the healthcare practitioner or healthcare setting) associated with utilizing this method of bridging the

communication gap, it is readily accessible, nationwide, and in most cases, does not violate HIPAA regulations.

Video Remote Interpreting services employ certified interpreters and all certified interpreters are bound by confidentiality mandates and subject to strong disciplinary actions for breaches of confidentiality. Unfortunately, Whiters and Speight (2017) also state that there are many situations where this method of accommodation may be ineffective due to sociolinguistic/cultural and interpersonal factors mentioned earlier. Additionally, in some instances, certain software may fail to comply with specific federal or state legal mandates concerning effective, confidential communication (Whiters & Speight (2017). Additional problematic factors may also include the following technical issues: Line-sight issues of small or poorly anchored/located monitors that make the interpreter difficult to see and understand; unclear or broken internet connections; and some non-HIPAA-compliant software (Whiters & Speight, 2017). Nevertheless, these factors and issues can be easily addressed to help ensure and effect better health-related communication and comprehension issues between Deaf individuals and health-service providers.

Social change can and should also support continued research and advancement in the use of another form of technology, known as Sign Language Recognition [SLR] (Wu, Sun, & Jafari, 2016). This is an emerging technology which entails glove and vision-based recognition technology. A special SLR glove (wearable inertial measurement unit [IMU]) worn by a Deaf person on one or both hands, translates the signed movements into text or speech on a hearing person's cell phone. "Speech recognition on the Deaf person's cell phone translates speech into sign language images/videos" (Wu, Sun, &

Jafari, 2016, p. 1281-1282). Wu, Sun, and Jafari (2016) state that IMU gesture recognition systems have attracted much research attention due to their low cost and low power consumption and has already been studied and tested with Chinese Sign Language, resulting in a 92.5% accuracy rate for 439 Chinese Sign Language words. Results of testing with 80 commonly used ASL signs have yielded 85.24% and 96.16% accuracy (Wu et al., 2016). While the initial investment in such technology for professional use may be costly and may even be prohibitive for a private healthcare practitioner, larger healthcare settings may find such technology to be more cost effective in the long run.

Regarding addressing conversancy and comprehension of medical instructions and numeracy in self-health care, again technology, more specifically web-based technology, can be used to abate these issues. Kushalnagar et al. (2015, p. 831) state that "there is a clear need to develop effective health information materials and programs that are accessible to and benefit Deaf individuals who use ASL." Kushalnagar et al. (2015) also state that their research aligns with the work of other researchers in recommending that the next steps forward in promoting accessible health information for the Deaf population should be the evaluation and planning for a “free web-based repository of reliable health resources." Kushalnager et al. (2015) suggest that these web-based resources be produced and delivered in both ASL and English print formats. Unfortunately, the factor of differing sentence syntax that may present the information differently can be viewed as a continuing problem and issue regarding content conformity.

A review of the literature suggests cultural and linguistic competency training as an additional social change to address the issue of communication, comprehension, and health literacy with Deaf individuals. Anderson, Scrimshaw, Fullilove, Fielding, and

Normand (2003) define cultural and linguistic competency as a set of congruent behaviors, attitudes, and policies that enable effective work in cross-cultural situations. "Failure to understand and manage…culture difference may have significant health consequences for minority groups in particular…Culture competency in health care describes the ability…to provide care to patients with diverse…linguistic needs" (Betancourt, Green, & Carrillo, 2002, p. V).

Anderson, et al. (2003) further posit that services provided in an appropriate cultural and linguistic manner have the potential to reduce health disparities because when a patient does not understand the health care provider and the provider does not understand the patient, the quality of health care can be compromised. "[The language] chasm can have a sizable impact on health outcomes…access, quality, patient satisfaction and sometimes cost" (Brach, Fraser, & Paez, 2005, p. 242). Additionally, Anderson et al. (2003, p. 69) states that the "inability to communicate, between the healthcare provider and the patient, creates a barrier to accessing health care, undermines trust in the quality of the medical care received, decreases the likelihood of appropriate follow-up, and can result in diagnostic errors and inappropriate treatment". Ultimately, cultural competency training is designed to improve skills such as language and communication (Anderson et al., 2003). McKee, Smith, Barnett, and Pearson (2013, p. 159) state that "research with Deaf ASL users indicates that language concordance and cultural competence of physicians are associated with positive health care experiences, adherence with preventive services recommendation, and appropriate health care use."

"Health care experts in government, managed care, academia, and community health…make a clear connection between cultural competence, quality improvement, and

the elimination of [health] disparities" (Betancourt et al., 2002, p. VI). Munoz-Baell, Ruiz-Cantero, Alvarez-Dardet, Ferreiro-Lake, & Aroca-Fernandez (2011) support the idea of training health care professionals in the language of the Deaf: Sign Language. Besides advocating for interpreters Brach et al. (2005) also supports the training of bilingual physicians. Unfortunately, like McKee, Smith, Barnett, and Pearson (2013, p. 158) state that "Deaf and hard-of-hearing individuals are underrepresented among physicians and frequently overlooked in diversity recruitment efforts for physicians-in-training." McKee, Smith, Barnett, and Pearson (2013, p. 160) also state that Deaf and Hard of Hearing physicians "can provide linguistically accessible and culturally appropriate health care to patients who have historically been marginalized in the health care system." Unfortunately, "some…technical standards specifically require physical attributes (not an outcome or skill) including the ability to hear…[and] these medical school technical standards violate the principles of the ADA" (McKee, Smith, Barnett, & Pearson, 2013, p. 160-161).

Finally, initial efforts in addressing the issue of deficits in health literacy among and access to health-related information for Deaf individuals, especially those over the age of 50 should start with and be based on participatory research. Munoz-Baell et al. (2011) posit that it is important that government, policy-makers, and health professionals adopt more of a social approach in their action plans to address this issue. Munoz-Baell et al. (2011) support a shift in focus to a more participatory approach. An approach in which members of the Deaf community are allowed self-representation that affords them the opportunity to participate in the decision-making processes in the planning, implementation, and evaluation of policies, procedures, and services related to the

provision of access to health services and proposed methods aimed at increasing health literacy among Deaf individuals. McKee et al. (2013), as well as other social researchers, agree that we need to build collaborative, multidisciplinary health care teams that include Deaf and Hard-of-Hearing physicians, allied healthcare professionals, as well as members of the Deaf community-at-large.

Conclusions

"Populations of Deaf sign language users experience health disparities unmeasured by current public health surveillance" (Barnett et al., 2017, p. S250). Based on this statement and the outcomes and conclusions revealed in the present study it is apparent that further and continued research in this area and with this underserved population is vitally necessary. The current study also revealed two unanticipated factors that may heavily influence health literacy among Deaf individuals over the age of 50. The first factor being the vision condition of presbyopia which most often specifically effects the near-vision abilities of older adults; which in this study may have been a major factor and cause in participant comprehension of items in the evaluation instrument. Combining this first unanticipated factor with a second unanticipated factor, there was a possibility that socio-linguistic/cultural influences affected the abilities of Deaf participants to recognize and comprehend the static pictures of ASL signs that represented the health-related words.

Nevertheless, the potential impact for a positive social change based on the results of present study calls for heightened awareness, by health care practitioners and health care policy makers, of the deficits in health-related literacy exhibited by prelingual/culturally Deaf individuals, especially for those Deaf individuals over the age of 50. Positive social

change needs to be effected through concerted efforts to establish and enforce regulations and guidelines for the use of effective methods of communicating and disseminating medical information and instructions to members of the Deaf community. To abate health literacy and comprehension deficits, these policies, and guideline, methods and procedures need to specifically address and match the needs of the prelingual/culturally Deaf, especially those over the age of 50. Therefore, social change, from the highest level of government down to the individual health care practitioner needs to occur. Social change should start in the form of recognition of the need to address the socio-linguistic barriers (Withers & Speight, 2017) the underserved prelingual/culturally Deaf community faces in accessing and comprehending vital health-related information.

It is apparent from the results and outcomes of the present study that the theoretical deficits in comprehension and English literacy as proposed by Barnett and Franks (1999); Jones, Renger, and Firestone (2005); and McKee, Barnett, Block, and Pearson (2011), which is supported by their prior research, presents as the underpinnings for deficits in medical, health-related literacy and comprehension. Conceptual knowledge or comprehension as defined by Luckner and Handley (2008, p. 6) is the "active process of constructing meaning from text; and involves accessing previous knowledge, understanding vocabulary, and concepts, making inferences, and linking key ideas." Therefore, social change needs to support further and continued research in the area of increasing health literacy comprehension for members of the Deaf community who use American Sign Language as their main and preferred method of communication. The efforts can and should occur through a compilation of the aforementioned recommendations. Starting with governmental and support in: (1) Assuring the

acquisition of interpreters in health-related situations. (2) Support for further research in advancing technology that can aid in breaking down the communication barrier, bridging the gap and increasing health literacy. This technology should include VRT (video remote technology), SLR (sign language recognition) technology, and access to free online, web-based repositories of reliable health resources presented in a format concordant with ASL. (3) Lastly, increased support for enhanced cultural competency training of hearing physicians and health care professionals, as well as, opening medical (physician and allied health) training to Deaf and Hard-of-Hearing individuals. These initiatives need to and should be guided by inclusion and through participatory research and efforts.

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Appendix A:

Published Instrument Permission Request Letter and Instrument

Dr. Terry C. Davis

I am doctoral candidate in the Department of Health Psychology at Walden University, located in Minneapolis, Minnesota. I am writing to you today to request permission to reprint a portion of the following work, as well as, utilize your instrument as a template for the health literacy survey I wish to conduct. My doctoral dissertation research focuses on health literacy among prelingual/culturally Deaf individuals age 50 and older. For that reason, I would like to model my evaluation instrument largely based on your Rapid Estimate of Adult Literacy in Medicine.

☒ The following credit line is acceptable:

Davis, T. C., Crouch, M. A., Long, S. W., Jackson, R. H., Bates, P., George, R. B., & Bairnsfather, L. E. (1991). REALM (Rapid Estimate of Adult Literacy in Medicine) [Screening instrument]. Published instrument. Retrieved from tdavis1@lsuhsc.edu

OR

☐ I prefer the following credit line:

I believe that you, Dr. Terry C. Davis, are currently the holder of the copyright and my research indicates that you are the individual that should be contacted in order to receive original copies and permission to use this health literacy survey. If you do not currently hold the rights, please provide me with any information that can help me contact the proper rights-holder. Otherwise, your permission confirms that you hold the right to grant this permission. This request is for permission to include and modify the above content as part of the following doctoral research dissertation project that I am preparing.

Prelingual/Cultural Deafness, Health Literacy and Senescence Disorders: A Mixed-Methods Study

This request is for a non-exclusive, irrevocable, and royalty-free permission, and it is not intended to interfere with other uses of the same work by you or anyone else. I would be please to include a full citation to your work and other acknowledgement as you might request.

I would greatly appreciate your permission and thank you in advance for your consideration. If you require any additional information, do not hesitate to contact me at the address and number above.

Please feel free to maintain a duplicate copy of this request for your records. If you agree with the terms as described above, please sign the form where indicated below and return the signed copy, via email. If, you prefer, I can also send you this request letter and form by postal mail with an enclosed self-addressed return envelope.

Sincerely

Please complete this page and return one copy to me, together with the attached letter. A second copy is enclosed for your convenience.

Please check one:

☒ I claim full rights in this work.
OR
☐ I claim no rights in this work.
OR
☐ I claim only the following rights in this work:

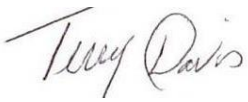
_____

For other rights, please contact (name): _____

(address): _____

I warrant that I have the legal authority to grant the rights specified.
I hereby grant permission for the use of the item as outlined in the accompanying letter.

Permission is hereby granted:

Signature: 

Name & Title: Terry C. Davis, Ph.D, Professor
Company/Affiliation: Departments of Medicine and Pediatrics, LSU Health Sciences Center Shreveport

Date: 19 January 2015

1/18/15

Davis, Terry

To: Me

You may use REALM (also it is in the public domaine)however modifying will change validity

I think their are already
HL tests for individuals w hearing loss. I cant remember name of author- a physician in Rochester (?) who also has little hearing,
He may have published inJ health Communication

Hope this helps
Terry

Gmail
by Google

REALM
2 messages

To: ., Jill K. Fri, Jan 30, 2015 at 2:48 PM

Hi

We're excited that you are interested in health literacy and pursuing it as part of your doctoral education. I've attached the signed form and the items that comprise the REALM kit. This includes the REALM manual, score sheet, and word list. I have assumed based on your email and the document that it is the regular 66-item REALM that you are interested in? (I mention that because there are modified, shortened versions of the test.)

Dr. Davis is out of the country right now, so if you need any further assistance please contact me, and I will do my best to help you. If there is anything about which I am unsure, I'll get in touch with her and get back to you as soon as possible.

Best regards,

Jill

--

Jill

Research Associate

Department of Medicine and Pediatrics
Tel

Rapid Estimate of Adult Literacy in Medicine (REALM) ©

Patient Name/ Subject # _____ Date of Birth _____ Reading Level _____

Date _____ Clinic _____ Examiner _____ Grade Completed _____

List 1	List 2	List 3
Fat	Fatigue	Allergic
Flu	Pelvic	Menstrual
Pill	Jaundice	Testicle
Dose	Infection	Colitis
Eye	Exercise	Emergency
Stress	Behavior	Medication
Smear	Prescription	Occupation
Nerves	Notify	Sexually
Germs	Gallbladder	Alcoholism
Meals	Calories	Irritation
Disease	Depression	Constipation
Cancer	Miscarriage	Gonorrhea
Caffeine	Pregnancy	Inflammatory
Attack	Arthritis	Diabetes
Kidney	Nutrition	Hepatitis
Hormones	Menopause	Antibiotics
Herpes	Appendix	Diagnosis
Seizure	Abnormal	Potassium
Bowel	Syphilis	Anemia
Asthma	Hemorrhoids	Obesity
Rectal	Nausea	Osteoporosis
Incest	Directed	Impetigo

SCORE

List 1 _____

List 2 _____

List 3 _____

Raw Score _____

Appendix B:

Random House Permission Request

Permission Request dated 09/08/2015

shinchey@penguinrandomhouse.com <shinchey@penguinrandomhouse.com> Thu, Sep 24, 2015 at 11:41 AM

To:

Dear Requester,

A response for your request dated 09/08/2015 is attached.

If any requested selections or rights are not covered by the attached letter and are not addressed below, you can expect to receive additional correspondence from our department.

Sincerely,
Penguin Random House LLC Permissions Department

LETTER_0000005976.PDF
205K

Penguin Random House

Permissions Department, 1745 Broadway, New York, NY 10019 Telephone: 855-278-8634 Fax: 212-572-6066
Email: permissions@penguinrandomhouse.com

September 24, 2015

RE: 77 sign illustrations from RANDOM HOUSE WEBSTER'S AMERICAN SIGN LANGUAGE DICTIONARY
[Request

#14685]

Dear

We have no objection to your use of the above material in your dissertation, as requested in your letter of 09/08/2015, subject to the following conditions:

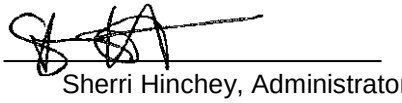
1. Such material must be reproduced exactly as it appears in our publication;

2. Full acknowledgement of the title, author, copyright and publisher must be given;

3. If your dissertation is ever considered for publication or broadcast, or commercially or privately reproduced in any manner not specified in your request, you must reapply for permission. Please be aware that a fee may be assessed for any such use.

Best wishes for the success of your paper.

Sincerely,



Sherri Hinchey, Administrator, Copyright & Permissions Penguin Random House LLC
shinchey@penguinrandomhouse.com

212-572-2606

Appendix C:

Senescence-Related Health Disorder Literacy Scale

Senescence-Related Health Disorder Literacy Scale

Participant Name: _____

Date of Birth: _____

Ethnicity/Race: _____ **Gender:** **Male** _____ **Female**

Date: _____ **Results:** _____

On the following pages, you will be asked to identify health conditions (words) that are generally associated with and/or generally experienced by individuals as they age. In an effort to evaluate your knowledge of age-related health disorders, you will be asked to please match and write the number of the picture associated with the following health-related words. The words and pictures in this evaluation instrument are associated with parts of either the body, medical procedures, or age-related health conditions.

I thank you for agreeing to take the time to participate in this study.

Thank You

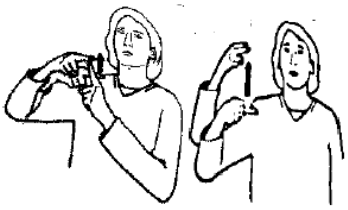
Thank you! I am grateful for your time and interest in participating in this research and for any additional information and recruitment assistance that you may wish to provide.

1. Medication: _____
2. Kidney: _____
3. Vitamin(s): _____
4. Hip: _____
5. Muscle: _____
6. Nausea: _____
7. Injection/shot: _____
8. Fever: _____

A. 

B. 

C. 

D. 

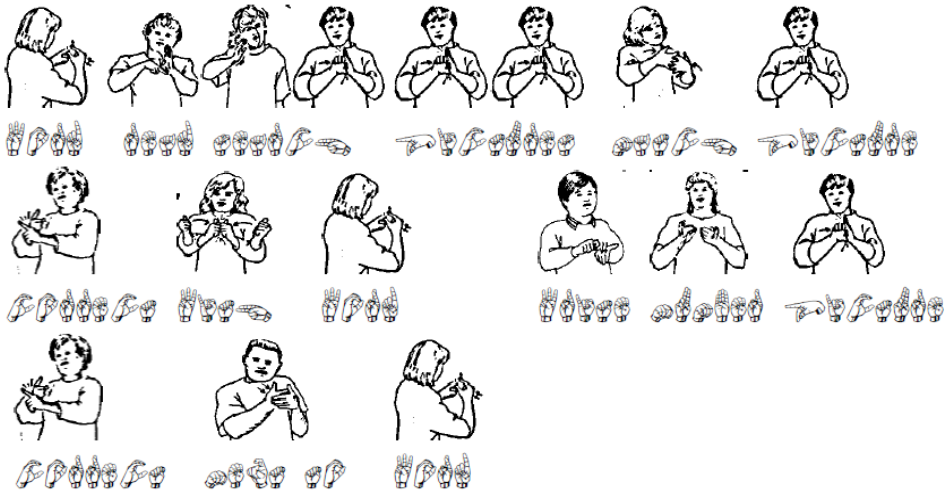
E. 

F. 

G. 

H. 

1. **Medical Conditions:** Using the pictures on the next page (page 3), please match the part of the body that is most often or most closely associated with these words that describe various health conditions. On the line next to the word, write the number of the picture of the part of the body that is affected by these health conditions. Some words can and may be matched with more than one health condition (picture); some pictures may not match with a (any) word.



Reflux / Gerd: _____ Esophagus/Throat

Asthma: _____ Lungs

Alzheimer: _____ Brain

Bronchitis: _____ Lungs

Cardiovascular: _____ Heart

Cataract: _____ Eye

Colitis: _____ Colon

Emphysema/C.O.P.D. _____ Lungs

Hypertension: _____ Blood Pressure

Disk: _____ Spine

Glaucoma: _____ Eye

Gastritis: _____ Stomach

Lumbar: _____ Spine

Nausea: _____ Stomach

Pulmonary: _____ Lungs

Stroke: _____ Brain

Ulcer: _____ Stomach

Macular Degeneration: _____ Eye

2. **Medical Procedures:** Using the pictures below, please match the pictures with the medical procedure (words below) associated with these pictures. On the line next to the medical procedure (word) write the number of the picture (below) that is associated with the medical procedure that is used to examine the part of the body associated with the procedure; some pictures may not match with a (any) word in this section.

Colonoscopy: _____ Colon

Dialysis: _____ Kidney

EKG (electrocardiogram): _____ Heart

EEG (electroencephalogram): _____ Brain

1. 

Eye

2. 

Heart

3. 

Kidney

4. 

Colon

5. 

Lungs

6. 

Brain

7. 

Spine

8. 

Esophagus (Throat)

9. 

Stomach

10. 

Blood Pressure

3. **Medical Procedures:** Using the words below, please match the words with the ASL sign(s) associated with these words.

1. MRI (Magnetic Resonance Imaging): _____ E
2. Dialysis: _____ A
3. EKG (electrocardiogram) : _____ B
4. EEG (electroencephalogram): _____ D
5. X-Ray: _____ C
6. Colonoscopy: _____ G
7. CT Scan or CAT Scan: _____ F

A

B

C

D

E

F

G

4. **Medical Instructions** These questions assess you knowledge of medical instructions that tells you: *How Much - What to Do - What Time*.

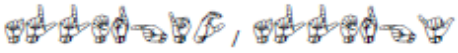
Please match the medical instructions (letters A-G) with the correct written instructions (1-7) below.

1. Keep Elevated: _____
2. Dose: _____
3. Once Daily: _____
4. Take orally
5. Twice a Day: _____
6. Three Times a Day: _____
7. Tbsp: _____
8. Tsp: _____

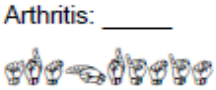
A. I am to take my medication in the mornings and at night.
B. How much medication I should take.
C. Tablespoon
D. Raise/Lift/Up
E. I am to take my medicine only 1 time each day.
F. I am to take my medicine mornings, afternoon and night.
G. Teaspoon
H. Take by mouth

5. **Health-Related Words:** Using the pictures on the next page, please match these health related words with a picture. On the line next to the word, write the number of the picture of the part of the body that is associated with, illustrates/shows or is described by the following health-related words. Some pictures can and may be associated/matched with more than one word

Allergic/Allergy: _____



Arthritis: _____



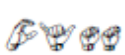
Bed Rest: _____

Biopsy: _____

Blood Pressure: _____

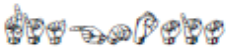
Blood Test: _____

Cyst: _____

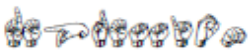


Diabetes: _____ Insulin Shot

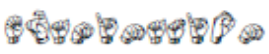
Diagnosis: _____



Depression: _____ Sad

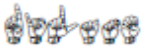


Examination:



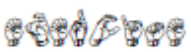
Diarrhea: _____

Dilate: _____

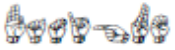


Dose: _____

Exercise: _____



Fatigue: _____ Tired



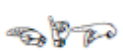
Fever: _____

Fracture: _____ Broken

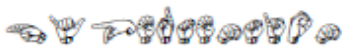
Healthy Diet: _____

Hemorrhoids: _____ Rectum

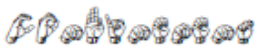
Hip: _____



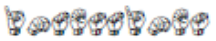
Hypertension: _____ Blood Pressure



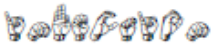
Confinement: _____



Intestines: _____:

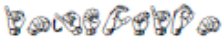


Infection



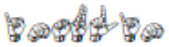
Inflamed: _____

Injection: _____



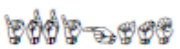
Immobilize: _____

Insulin: _____

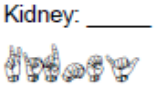


Insomnia: _____

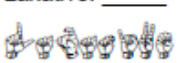
Irrigate _____



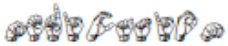
Kidney: _____



Laxative: _____



Medication: _____

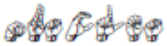


Tablespoon: _____

Teaspoon: _____

Jaundice: _____ Yellow

Muscles: _____

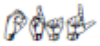


Nausea: _____

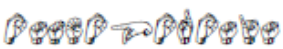
Obesity: _____

Oncology: _____

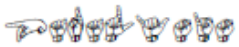
Oral: _____



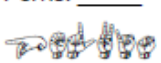
Osteoporosis: _____ Spine



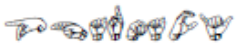
Paralysis: _____



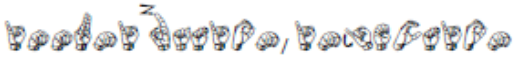
Pelvis: _____



Pharmacy: _____



Immunization/Injection: _____ Shot



10

Pharmacy: _____

Rectal: _____ Rectum

Kidney Stone: _____

Rheumatism: _____

Ointment/Salve: _____

Rx: _____

Physical Fitness: _____

Sleep Apnea: _____

Pre-Operative: _____

Sprain: _____

Prescription(s): _____

Spine: _____

Prolapse: _____

Sterile: _____

Protocol: _____

Thermometer: _____

Recover: _____

Urine: _____

Reoccur: _____

Vertigo / Dizzy: _____

Vitamin(s): _____

OTC (Over-the-Counter Medication): ___

Prescription Medication(s): _____

13

1. 

Allergy/Allergic

2. 

Arthritis

3. 

Bed Rest/Confinement

4. 

Biopsy

5. 

Blood Pressure

6. 

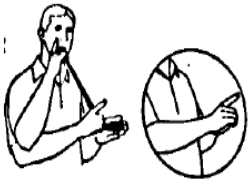
Blood Test

7. 

Diabetes

8. 

Depression

9. 

Diagnosis

10. 

Dose

11. 

Fatigue

12. 

Fever

13. 

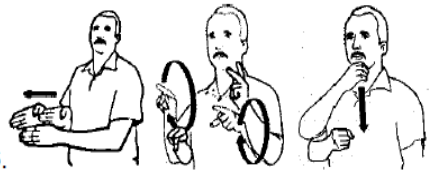
Cyst

14. 

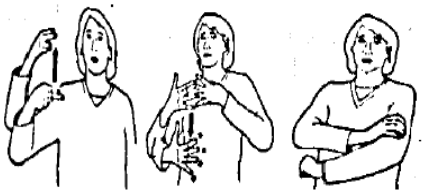
Fracture

15. 

Hip

16. 

Geriatics

17. 

Hypertension / High Blood Pressure

18. 

Hypotension / Low Blood Pressure

19. 

Infection

20. 

Immobilize

21. 

Insulin

22. 

Insomnia

23. 

Medication

24. 

Irrigate

15

25. 

Muscle

26. 

Nausea

27. 

Fast / Abstain

28. 

Obesity

29. 

Oncology

30. 

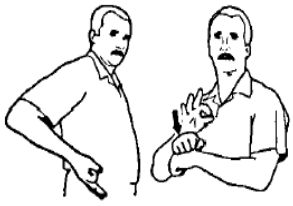
Osteoporosis

31. 

Paralysis

32. 

Pharmacy

33. 

Kidney Stone

34. 

Ointment/Salve

35. 

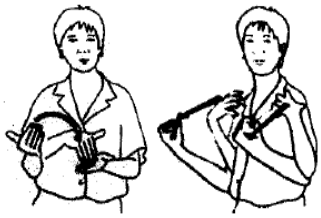
Over-the-Counter Medicine

36. 

Oral

37. 

Protocol

38. 

Recover

39. 

Reoccur

40. 

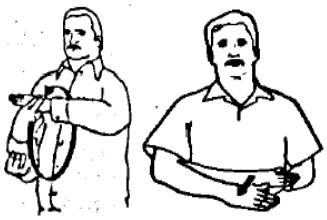
Rheumatism

41. 

Sprain/Dislocation

42. 

Spine

43. 

Sterile Dressing

44. 

Vitamins

45 

Urine

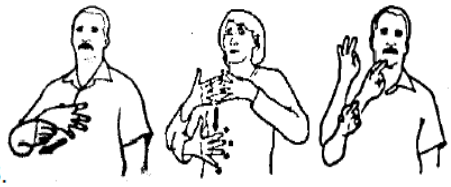
17

46. 

Thermometer

47. 

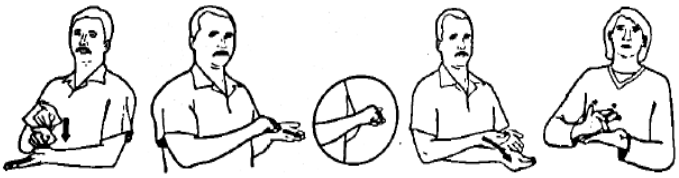
Vertigo

48. 

White Blood Cell/Leukocyte

49. 

Stable

50. 

Perscription/ Perscription Medication

51. 

Hyperglycemia

52. 

Hypoglycemia

Appendix D:

Senescence-Related Health Disorder Literacy Scale (Revised)

Senescence-Related Health Disorder Literacy Scale

Participant Name: _____

Date: _____

Date of Birth: _____

Gender: Male Female

Are you a CODA?	**Yes**	**No**
Are Both Your parents Deaf?	**Yes**	**No**
Is Your Mother Deaf?	**Yes**	**No**
Is Your Father Deaf?	**Yes**	**No**

Participant's Coding Number: _____

Results: _____

On the following pages, you will be asked to identify health conditions (words) that are generally associated with and/or generally experienced by individuals as they age. To evaluate your knowledge of age-related health disorders, you will be asked to please match and write the number of the picture associated with the following health-related words. The words and pictures in this evaluation instrument are associated with either parts of the body, medical procedures, or age-related health conditions.

Again, I thank you for taking the time and agreeing participate in this research.

Thank You

Thank You

1. **Medical Words:** Using the words below, please match the words with the ASL sign(s) associated with these words.

Please match the correct picture below with the corresponding correct words below.

1. Medication: _____
2. Injection/shot: _____
3. Vitamin(s): _____
4. Obese: _____
5. Muscle: _____
6. Nausea: _____
7. Kidney: _____
8. Fever: _____
9. Hip: _____

A.

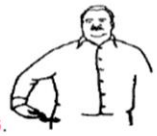
E.

B.

F.

C.

G.



D.

H.

I.

2. **Medical Procedures:** Using the words below, please match the words with the ASL sign(s) associated with these words.

1. Dialysis: _____
2. EKG (electrocardiogram): _____
3. EEG (electroencephalogram): _____
4. X-Ray: _____
5. Colonoscopy: _____
6. CT Scan or CAT Scan): _____
7. MRI (Magnetic Resonance Imaging): _____

A

B

C

D

E

F

G

H

3. **Medical Instructions:** These questions assess you knowledge of medical instructions. Instructions that tell you: *How Much - What to Do - What Time*.

Please match the written instructions - numbers 1-7, with the correct medical instructions - letters A-L.

1. Keep Elevated: _____
2. P.T.: _____
3. Once Daily: _____
4. Take orally: _____
5. Twice a Day: _____
6. Three Times a Day: _____
7. Tbsp: _____
8. Tsp: _____
9. Dose: _____
10. OTC: _____
11. Rx: _____
12. Bed Rest: _____

A. I am to take my medication in the mornings and at night.

B. How much medication I should take.

C. Tablespoon

D. Raise/Lift/Up

E. I am to take my medicine only 1 time each day.

F. I am to take my medicine mornings, afternoon and night.

Appendix E:

Debriefing Statement

Thank you so much for participating in this study! I will be using the information from all of the evaluations for my doctoral dissertation research study. Again, I want to make it clear that I will never divulge your name nor any of your personal information. Your information will be compiled with that of all of my other participants to derive data for my dissertation research study, only. If, for any, reason I may need to quote you in writing my dissertation, I will always assign a random letter or number and never use your real name.

Would you like a copy of the results of the study?

YES NO

If yes, please print name and address below:

Name: _____

Street Address: _____

City:_____ State:_____ Zip Code:_____

E-mail Address: _____

Please realize it may be a year before all of the analyses are complete.