

ONLINE HEALTH INFORMATION SEEKING AND THE DEAF: AN EXAMINATION
OF HOW THE DEAF UTILIZE THE INTERNET FOR HEALTHCARE PURPOSES

A Thesis

Presented to

The Faculty of the Jack J. Valenti

School of Communication

University of Houston

In Partial Fulfillment

Of the Requirements for the Degree of

Master of Arts

By

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ABSTRACT

Our modern world and digital technology are evolving at an unimaginable pace, which has greatly impacted healthcare. However, some populations such as the Deaf may not fully incorporate this evolution due to differences in culture, health disparities, varying communication methods, and uncertainty management choices. Therefore, the overall objective of this research is to assess the potential impact of the digital technology on Deaf healthcare access and their resulting health. The objectives of the study are: (a) to assess the utilization patterns of online health information seeking by the Deaf; and (b) to examine the relationship between healthcare satisfaction and online health information seeking. To examine the objectives I propose a single research question: What is the relationship among patient satisfaction, language concordance, and online health information seeking by the Deaf? The study proposes to administer initial pretest via an in-person, cross-sectional survey to help inform the participants of the purpose of the focus group and to gather some background information and their feelings towards certain topics. It also proposes conducting an in-person focus group with pretest participants and an in-person interview with a key informant of the Deaf community to better understand the pretest answers. In the results I discovered the participants usually seek to reduce or manage uncertainty through family, friends, doctors, or printed materials instead of the internet.

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CHAPTER ONE: INTRODUCTION

“Little is known about disease trends, underlying attitudes, or health behaviors among Deaf or hard-of-hearing people. This population is woefully understudied and underserved.”

– Thomas A. Pearson, MD, MPH, PhD
Founding Director
Rochester Prevention Research Center
University of Rochester Medical Center

The advancement of digital technology has impacted healthcare by increasing the number of ways individuals can access health information. The internet, email, smart phones, and social media sites are just a few examples of the evolution in this new digital age. These changes are influencing every aspect of our lives including how we search for and receive healthcare. For example, some patients can now view their medical records online through a patient portal or email their doctors with questions about their recent diagnosis, medication, or lab results. Furthermore, a multitude of health information can be found on self-diagnosis sites such as WebMD. This allows patients to be proactive in determining what they have (Tustin, 2010). While certain populations seem to be embracing these rapid changes with ease, many minority groups are not. One of these groups is the Deaf.

According to the World Federation of the Deaf, approximately 70 million people in the world are classified as deaf. More specifically, in the United States about one million people are identified as deaf (Mitchell, 2006). In Austin, TX, where the Texas School for the Deaf is located, it is estimated that 8.8% of the 1.6 million residents are deaf or hard-of-hearing (Deaf411). However, since there are only a few surveys that collect information to identify people with deafness, an accurate number is almost impossible. An additional complication is the multiple definitions of deaf. Even at Gallaudet University, the world's only university designed to accommodate deaf students, the definition is distinguished three different ways: (1) in both ears, (2) cannot hear and understand any speech, and (3) at best

can hear and understand words shouted into the better ear (Harrington, 2004). Generally speaking and in this paper, the term *Deaf* refers to a group of people who see their hearing loss as a cultural identifier and not a disability, whereas the term *deaf* simply refers to a simple loss of hearing (Smith, Massey-Stokes, & Lieberth, 2012). People who are Deaf in the United States also see American Sign Language (ASL) as their dominant means of communication. Many people believe that ASL is just signed English but this is incorrect. In fact, ASL has its own “unique syntax, structure, and cultural context” (Lieu, Sadler, Fullerton, & Stohlmann, 2007, p. 542).

The Deaf are extremely protective of their culture due to their extensive discriminatory history. For most of their history the Deaf were treated as subordinate society to the hearing majority. At the epicenter of the centuries-long discrimination is language (PBS: Introduction). There was and continues to be a divide between whether or not the Deaf should be taught sign language as it is considered the natural method of communication, or if they should be taught spoken and written language in order to be mainstreamed into society (PBS: Introduction). In ancient times the deaf were considered unable to learn and deafness was considered a sin (PBS: Timeline). In the 1500s, the first attempt at educating the deaf was made by a doctor named Geronimo Gardano in Italy (PBS: Timeline). In 1760, the first free public school for the deaf was establish in France by Charles Michel De L’Eppe, a French priest (PBS: Timeline). In 1817, Thomas Hopkins Gallaudet travelled to Europe to meet De L’Eppe’s successor, Archbishop Roche Sicard (PBS: Timeline). Laurent Clerc, one of Sicard’s instructors, returned to the United States with Gallaudet to form the American School for the Deaf (PBS: Timeline).

In 1864, Gallaudet University was established as a college specifically for the deaf (PBS: Timeline). The establishment of the American School for the Deaf and Gallaudet University was significant for the United States because as much as twenty-five percent of the residents in Martha's Vineyard, MA, were deaf due to a hereditary hearing problem. (PBS: Timeline). During the 1870s, the uprising of oral communication began and was led by Alexander Graham Bell (PBS: Timeline). In 1892, the first electrical hearing aid was invented in direct relation to the rising belief in oral communication (PBS: Timeline). In 1964, the teletypewriter, or TTY, was invented, which allowed deaf people to use phone lines to communicate (PBS: Timeline). Also during that year, oral communication was deemed a failure (PBS: Timeline). In the 1970s, total communication, a combination of sign- and speech-based communication, took hold (PBS: Timeline). In 1985, cochlear implants were approved for clinical trials (PBS: Timeline). In 1988, students and faculty at Gallaudet University protested the election of another hearing president forming the 'Deaf President Now' protest (PBS: Timeline). After eight days, Elisabeth Zinser, the hearing president stepped down and I. King Jordan, a Deaf man, was selected as the new president of the University (PBS: Timeline). Meanwhile, Congress recommended ASL "be used as the primary language for the deaf, with English as a second language" (PBS: Timeline).

According to the National Institute of Deafness and Other Communication Disorders (NIDOC), "about 2 to 3 out of every 1,000 children in the United States are born deaf or hard-of-hearing [and] nine out of every 10 children who are born deaf are born to parents who can hear." This means these children may experience language and communication barriers from birth. If their parents do not know ASL, which is most often the case, children

are left with no way to communicate. Sadly, this is only the beginning of a long journey in the world of language and communication barriers.

With this vast amount of history and experienced discrimination, it is important Deaf culture, including the use and preference of ASL, is understood and respected especially in medicine. The Deaf often adopt ASL as a primary language and English as a secondary language. As a result, researchers have found that Deaf adults often read English at a sixth grade level (Zazove, Meador, Reed, & Gorenflo, 2013). However, health information is often written at a high school reading level (Karras & Rintamaki, 2012; Estey, Musseau, & Keehn, 1991). This reading level gap in part causes the Deaf to experience poor communication between themselves and their doctors, and rely on possibly incorrect and inconsistent information from peers and the internet (McKee & Paasche-Orlow, 2012). Health information in print and online is written at the same reading level. Deaf patients are at high risk for inadequate health literacy due to lower English proficiency, communication and language barriers in healthcare, and a lack of ASL accessible health information. Although the internet is rapidly growing with online health information, there is a severe lack of information in ASL (Smith et al., 2012).

In short, while certain societal groups are embracing rapid changes in technology with ease, many other minority groups are not. Instead, they are at risk for experiencing the digital divide due to a lack of access to technology. One such group is the Deaf. In addition, on average a Deaf adult who has graduated high school and uses American Sign Language as his or her primary language will read English at a sixth grade level. This is a significant problem because medical information is written at a high school reading level. If Deaf patients cannot understand medical information from the physician or written materials given

to them, where do they turn? Research with other minority populations shows patients turning to the internet for help. However, little if any research has examined what the Deaf do when they do not understand. Do they follow the same pattern? This is what I hoped to understand. Specifically I aim to examine one research question:

RQ: What is the relationship among patient satisfaction, language concordance, and online health information seeking by the Deaf?

CHAPTER TWO: REVIEW OF LITERATURE

Most current literature examines the broad use of the internet when seeking for health information. Deaf patients who use ASL are unique in that they “struggle with poor communication, language discordance, and possibly inadequate health literacy partly because of decreased opportunities to correct misinformation, and limited health surveillance” (McKee & Paasche-Orlow, 2012, p. 9). This literature review examines the use of online health information seeking, culture, health disparities, varying communication methods, theories of Uncertainty Management and Motivated Information Management, and the Model of Online Health Information Seeking.

Online Health Information Seeking

Technology is becoming a dominant method of communicating and finding information. However, if you experience a language barrier between you and the information you seek, technology may not be helpful. This is especially important since almost everything can be found either in duplication or in its entirety online, including health information.

Health information seeking is defined as “the search for and receipt of messages that help ‘to reduce uncertainty regarding health status’ and ‘construct a social and personal (cognitive) sense of health’” (Cotton & Gupta, 2004, p. 1796). Traditionally health information was sought through doctors; however, how patients have turned to seeking health information online (Cotton & Gupta). This newfound reliance on the internet causes concern about a possible negative effect on the relationship between patients and doctors (Tustin, 2010). If the information patients find online is inaccurate or is not confirmed with

the doctor, patients could end up becoming sicker. Also, patients may start self-diagnosing and -medicating, and forgo seeing the doctor altogether.

Online health information seeking by the patient can be done either before or after a doctor's appointment (Tustin, 2010). Patients may also seek health information online because they believe they received inaccurate diagnosis information or the doctor lacked empathy in the appointment (Tustin). Patients may turn to the internet for supplemental information on a medical topic or because traditional media, such as newspapers and magazines, do not offer adequate information (Tustin). Patients who are satisfied with their doctors rely less on finding health information online (Tustin). The opposite is also true; patients who are dissatisfied with their doctors or appointments search for more online health information (Tustin).

A good percentage of people seek health information online due to its easy accessibility. Specifically, sixty-six percent of internet users who look online seek information regarding a specific disease or medical problem and fifty-six percent of internet users are seeking information on a certain medical treatment or procedure (Levco, 2012). Furthermore, of the total number of internet users looking for medical information online, twenty-four percent search for drug safety and recalls, fourteen percent search memory loss, dementia, or Alzheimer's, and seventeen percent search ways to manage chronic pain (Levco). Also, the most trusted online resources are those posted by doctors, then nurses, then hospitals at sixty percent, fifty-six percent, and fifty-five percent respectively (Kotenko, 2013).

Factors such as age, gender, children, and income also play a role in seeking health information. Older generations perform more poorly than younger generations when using

the internet (Mesch, Mano, & Tsamir, 2012). Also, women are “more likely to search for health related information online” due to traditional gender roles (Mesch, Mano, & Tsamir, p. 855). Having a child at home also serves as motivation for searching the internet for medical information (Mesch, Mano, & Tsamir). In addition, seeking online health information is “inversely associated with income” (Mesch, Mano, & Tsamir). In other words, as income goes up, health information seeking goes down. This may be because those who have higher incomes have more financial resources to find a doctor who they are satisfied with. However, while those factors may influence online seeking habits, the purpose for seeking health information online may stem from patients lack of confidence in doctors (Mesch, Mano, & Tsamir, p. 855).

Culture

Cultural values and beliefs play a significant role in patient health. Part of a patient’s culture includes language. Therefore, using the language connected to the patient’s culture in healthcare is crucial. The distinction between groups of the hearing loss community such as the deaf/Hard-of-Hearing and the Deaf needs to be better understood in healthcare. The terms *deaf* or *hard-of-hearing* refers to people who have any degree of hearing loss, whereas the term *Deaf* refers to a group of people who share “common language (such as ASL), experiences, and set of beliefs that are different from the white, hearing, middle-class norm in U.S. society” (Harmer, 1999, p. 74). The combination of ASL, unique values, social behaviors, and other features creates Deaf culture (Pollard, Dean, O’Hearn, & Haynes, 2009, p. 232). However, many doctors forget signed languages require an extensive amount of facial and body expressions (Pereira & Fortes, 2010). Just as hearing people change the tone,

pitch, or volume of their voice to indicate emphasis, the Deaf express emphasis through increased expressions.

Relationships between doctors and patients are very important when it comes to diagnosis, medication, and adherence to treatment. However, differences between hearing and Deaf cultures can affect these relationships and lead to culture clash and language discordance.

Culture Clash

Very few doctors, if any, receive training related to Deaf cultural issues nor do they know or understand ASL well enough to communicate with patients (Karras et al., 2011). This lack of cultural awareness can “embarrass Deaf patients and could be perceived as disregard, disrespect, or even derogation of those who are Deaf” and is known as culture clash (Karras et al., p. 4).

Culture clash is a conflict between differences in values and beliefs. Conflict between different cultures makes exchanging information and sustaining longer treatments much more difficult. Culture clash damages the independence of Deaf patients, the access they have to medical services, and the effectiveness of their treatment (Pereira & Fortes, 2010). It can also lead to confusion on the behalf of the doctor between the purposes of the Deaf patient’s companions, interpreters, and family members who accompany the patient to the appointments for support or assistance. This confusion can act as a substantial barrier to healthcare (Pereira & Fortes).

Culture clash leads to additional problems including doctors rushing through the appointment, failing to provide an interpreter, talking down to or treating the patient as unimportant because he or she was Deaf, disclosing health information to third parties such

as interpreters, not understanding Deaf culture, refusing to communicate with the Deaf patient, speaking to the interpreter instead of the patient, and pressuring the Deaf patient to make an immediate health decision without consulting other trusted family and friends for their opinions (Karras, Rintamaki, & Peek, 2011). The most commonly reported problem was doctors not providing an ASL interpreter for Deaf patients during visits (Karras et al.; Stein & Teplin, 2011). Additionally, many Deaf patients regarded their doctors as culturally insensitive because they did not maintain eye contact or speak clearly when providing medical treatment (Lieu et al., 2007). Doctors fluent in ASL may be a crucial factor in addressing the health communication barriers Deaf patients' experience (McKee, Barnett, et al. 2011).

Language Discordance

As stated previously, part of a culture is language. If an appointment is conducted in the patient's primary language, fewer problems are likely to arise. However, if an appointment is conducted using a language unfamiliar to the patient, more problems are likely to surface. Deaf patients who report having a similar language understanding of his or her doctor are more likely to report a greater number of services (McKee, Barnett, Block, & Pearson, 2011; Lieu et al., 2007). In other words, services are more likely to be followed when language concordance was established. The opposite is also true; Deaf patients who report having a doctor whose views are conflicting with their own were more likely to report a smaller number (Lieu et al.). Language discordance also causes doctors to assume medical terminology such as "glaucoma, bowel, smear, and penicillin" mean something to the patient (Lieu et al., p. 542). In reality, many Deaf patients do not find any value in the terms (Lieu et al.). This discord is fostered by doctor's beliefs of the Deaf patients' ability to understand the

information provided to them (Lieu et al.). When a Deaf patient has an appointment, many times he or she leaves with remaining questions. Because of the language barrier, Deaf patients are uncertain about how to ask the questions, or when they did ask the doctor did not understand it.

Health Disparities

A large percentage of the Deaf population experiences a disparity based on factors such as age, gender, motivation, income, and education (Cotton & Gupta, 2004; Mesch, Mano, & Tsamir, 2012). The Deaf experience distinct health disparities including low health literacy and limited English proficiency, deciphering online health information, and access to adequate healthcare.

Low Health Literacy and Limited English Proficiency

Health literacy, which is defined as “the ability to understand medical information including drug prescriptions, the etiology of diseases and the outcome of various health related behaviors,” is crucial when deciphering medical terminology (Mesch, Mano, & Tsamir, 2012, p. 855). Health literacy is directly related to reading levels; if the patient has a low English reading level, his or her health literacy will most likely also be low. This is a problem when doctors use terms that are above the patient’s health literacy level. The US Department of Health and Human Services defines Limited English Proficiency (LEP) as the inability to communicate effectively in English because it is not the primary language and fluency has not yet been developed.

One significant reason for the lack of information regarding the Deaf’s low health literacy and its influence on LEP is due to the relatively low numbers of Deaf in the United States population as compared to other minorities (McKee & Paasche-Orlow, 2012; Smith et

al., 2012). “Spanish-speaking populations, by virtue of their size, have garnered the majority of LEP and non-English health literacy research funding in the United States” consequently resulting in other non-Spanish voices not being heard compounded by not having the collective power that other groups have (McKee & Paasche-Orlow, 2012, p. 9).

Approximately ninety million people in America experience inadequate health literacy and more than twenty-four and a half million Americans experience LEP, and those numbers do not include illegal aliens or Deaf ASL users (McKee & Paasche-Orlow).

Both limited health literacy and LEP pose substantial health communication barriers but when combined together the negative effects are magnified (McKee & Paasche-Orlow). Additionally, “low health literacy is related to these inequities and negatively affects overall health and quality of life” (Smith et al., 2012, p. 44; McKee & Paasche-Orlow). Sadly, current research areas are unable to create and deliver innovative methods “to increase the ability of a health consumer with LEP and inadequate health literacy to make appropriate healthcare decisions” because it is too poorly equipped (McKee & Paasche-Orlow, p. 8). In order to become better equipped to create the methods needed, researchers need to “understand how culture, language, literacy, education, and disabilities” work together to propagate health disparities and outcomes (McKee & Paasche-Orlow, p. 8).

Deciphering Online Health Information

Inaccurate online health information is another health disparity the Deaf experience. While many hearing people are aware of inaccurate health information online, many of the Deaf may lack the ability to determine the accuracy of health information due to a lack of confidence using the internet or finding it to be too challenging (Karras & Rintamaki, 2012). Furthermore, while “the internet has transformed how people seek and access health

information...Deaf people are hesitant about using the internet over concerns about it being too complex or beyond their basic English literacy skills” (Karras & Rintamaki, p. 194-195). Consequently, since the Deaf usually experience LEP, they could feel discouraged from using the internet as a source of health information.

A Deaf patient’s illness is almost certainly able to improve if he or she is able to access quality health information. If the health information found is accurate, it may help the patient. On the other hand, if the health information found is inaccurate, it may cause the patient to get sicker. Overall, access to accurate information on the internet is paramount in the health communication process for the Deaf.

Access to Adequate Healthcare

Access to adequate healthcare is an additional health disparity the Deaf experience. Deaf patients are not always able to develop self-care techniques, which can lead to them becoming passive patients and believing that treatment is performed on them instead of with them (Karras & Rintamaki, 2012). In addition, nurses can “impact both the delivery of healthcare and the patient’s perceptions about that care” (Lieu et al., 2007, p. 541). Patients spend significantly more time with the nurses than doctors; nurses take the patient’s vital signs and symptoms while doctors diagnose the problem and prescribe treatment. Therefore, nurses are a crucial part in providing Deaf patients with adequate healthcare.

Despite requirements put forth by the ADA, many hospitals continue failing to provide ASL interpreters for Deaf patients due to “costs, inconveniences, or ignorance of their legal obligation” (Lieu et al., 2007, p. 542). More specifically, Title III “requires places of public accommodations...to pay for qualified interpreters when necessary to ensure effective communication with a deaf person” (Stein & Teplin, 2011, p. 1097). Both doctors

and patients require a licensed professional interpreter to ensure successful and secure medical communication (Lieu et al.). Although family members or friends are not adequate interpreters for healthcare settings and, subsequently, are “unlikely to possess the breadth of signing skills needed to convey complex medical concepts that might need to be explained,” they are still frequently used in place of certified interpreters usually due to the hospitals failure to provide one (Lieu et al., p. 543).

Varying Communication Methods

The Deaf’s reliance on ASL as a preferred method of communicating contributes to communication barriers between doctors and patients (US Department of Justice, 2003). The communication mode a Deaf individual chooses to communicate through is based on several variables including “the age of onset and type of hearing loss” along with education (North, 2013, p. 1). As a Deaf patient advances through the education system, he or she may “choose other methods of communicating, depending on who he/she is communicating with” (North, p. 1). Some common methods of communicating in addition to ASL are Contact Language/Pidgin Sign English (PSE), which is a “combination of ASL and Manual English,” Signing Exact English (SEE), Auditory Verbal Unisensory, Cued Speech, and Oral Auditory (North, p. 1-2). In a medical setting, many of the same communication methods are used. According to the ADA, “hospitals must provide effective means of communication for patients, family members, and hospital visitors who are deaf or hard-of-hearing” (USDJ, p. 1).

In addition to speech, writing, and sign language, “gesture, pantomime, drawings, pictures, models, charts, and other communication visual aids” can be used by patients to communicate with doctors (DiPietro, Knight, & Sams, 1981, p. 2). Additionally, using a

combination of two or more communication methods may be more effective than just one used alone (DiPietro et al.). This multitude of methods demonstrates that there is no one method that is adequate for all areas of medical communication. When Deaf patients experience a serious lack or breakdown of communication, they most often leave the encounter “with doubts, having been unable to express their feelings, symptoms, and the history of their medical needs” (Pereira & Fortes, 2010, p. 33). Not only are Deaf patients unable to communicate in their preferred language, but also they have trouble conveying their ailments to their doctor. The outcome can only intensify the negative health of the Deaf patient. Doctors must work with the patient to decide which communication method works best, which can include verbal, ASL, or written.

Verbal Communication

While verbal communication is not very popular among patients, it is commonly used by doctors. This particular mode is significantly problematic as Deaf patients cannot hear the doctor and very rarely accurately lipread. Deaf patients who use a combination of oral, signed, and spoken communication have a higher rate of reporting if their doctor did not provide an interpreter during the medical visit compared to those who used signed English or written notes to communicate (Karras et al., 2011). Deaf patients who communicated primarily orally “were almost three and half times more likely to feel as though their physician did not understand their Deafness than participants who used sign language and speech simultaneously, signed English or writing” (Karras et al., p. 10).

American Sign Language

Interpreters: The ADA specifies which method of communication is deemed effective based on the communication interaction involved. In communication exchanges that

are more complicated and require more interaction, using a qualified interpreter may be necessary (USDJ, 2003). Types of interpreters include sign language interpreters, oral interpreters, cued speech interpreters, Computer Assisted Real-Time Transcription (CART), and video phones (USDJ, 2003). The type of interpreter required for the appointment depends on the Deaf patient's primary mode of communication. Qualified interpreters are trained to relay the message from the hearing doctor, to the Deaf patient, and back again. Though doctors report they understand the significance of interpreters, their failure to utilize them when treating Deaf patients is all too common and can be harmful (Karras et al., 2011). Ultimately, this can have a negative effect on the Deaf patient's diagnosis and treatment and can lead him or her to feel mistreated (Karras et al.).

Friends and Family: When certified interpreters are not used, family members or close friends are usually called upon next by doctors to serve as informal interpreters. While this may work at specific times, such as providing family medical history during an emergency, it also causes a breach in confidentiality (Karras et al., 2011). It can also inhibit free conversation, constrain the doctor-patient interaction, contribute to mistrust towards the doctor, and even prompt the Deaf patient to avoid healthcare altogether (Karras et al.). Using family and friends can also affect the Deaf patient's ability to resolve his or her own health problem, especially young Deaf adults as they try to prove themselves as self-sufficient (Karras et al.).

Doctors with ASL/Deaf Knowledge: If doctors do not provide a qualified interpreter and a family member or friend is not available, Deaf patients may rely on hearing doctors with knowledge of ASL and Deaf culture. Disappointingly, there are few doctors who understand and have the ability to sign ASL (Lieu et al., 2007). Because of this deficiency of

knowledge and skills, many doctors are unfamiliar “with Deaf culture, including preferred styles of communication” (Lieu et al., p. 541). This can lead to inadequate communication by either one or both of the parties. Therefore, many Deaf patients abandon attempts to explain their symptoms and seek additional information elsewhere (Lieu et al.).

Written Materials

Notes: Another available accommodation is written communication. This includes using paper to pass written questions and answers between the patient and doctor with or without the assistance of an interpreter. This is more effective than doctors’ attempts to verbally speak to Deaf patients. Using this method allows patients to point out words they do not understand for further clarification. Unfortunately this option takes significantly more time, something doctors do not have an abundance of. The ADA also states that exchanging written notes or pointing is only effective for short and simple face-to-face communication (USDJ, 2003). Therefore, it is not an adequate means of communicating in a doctor’s appointment.

Text Messaging: A second type is text messaging. Text messaging can be done in two forms: TTYs and cell phone texts. TTYs allow doctors and Deaf patients to type their messages back and forth to each other similar to using paper and pen but quicker than actually writing it all out. This allows the patients to type back if they do not understand what the doctor is saying instead of leaving the appointment confused. Unfortunately this method is hardly every used anymore. Therefore, the Deaf are turning to text messaging. However, this is not practical in a medical encounter because typing lengthy questions or answers using only thumbs takes quite a bit of time that doctors do not have.

Printed: A third type is providing Deaf patients with printed materials, such as pamphlets and brochures, in ASL. Health information for Deaf patients must take into account their “English literacy, ASL usage, Deaf sociocultural characteristics, and fund-of-information deficits...[which] are serious limitations in one’s factual knowledge compared to that of the general population, regardless of normal IQ and educational achievement” (Smith et al., 2012, p. 44). In addition, “the reduction and prevention of health disparities in the Deaf population may depend heavily on the creation and distribution of...health education materials in formats that are linguistically accessible, culturally affirming and relevant, and that contain accurate, up-to-date information” (Pollard et al., 2009, p. 237). Unfortunately, this method has not been introduced in mass production and, therefore, is a weak method of communication.

Uncertainty Management Theory

Uncertainty Management Theory (UMT) demonstrates how communication is crucial in managing uncertainty (Karras & Rintamaki, 2012). UMT states that “uncertainty can be appraised as either good or bad [and] how people appraise uncertainty drives their information-seeking behaviors, as information can be utilized to manipulate uncertainty” (Karras & Rintamaki, p. 196). Uncertainty that is seen as comfortable will be considered positive and maintained (Karras & Rintamaki). Uncertainty that is seen as uncomfortable will be considered negative and reduced (Karras & Rintamaki). In addition, UMT shows the “need to understand the motivations that drive online health information seeking among Deaf people, focusing on how they may seek out or avoid such information, depending on their appraisal of uncertainty” (Karras & Rintamaki, p. 196).

Motivated Information Management Theory

Similar to UMT, the Motivated Information Management Theory (MIMT) “proposes that the information management process begins when individuals become aware of an important issue for which they desire more or less uncertainty than they have and follow the process of information management by three hierarchical phases: (a) interpretation, (b) evaluation, and (c) decision” (Karras & Rintamaki, 2012, p. 196). MIMT poses that people seek information because they become “aware of an important issue for which they desire more or less uncertainty than they have, not that it necessarily begins when uncertainty is high” (Afifi & Weiner, 2004, p. 174).

The first phase, interpretation, “is characterized by awareness of an uncertainty discrepancy about an important issue and the anxiety that ensues” (Afifi & Weiner, 2004, p. 171). Uncertainty is present “when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general” (Brashers, 2001, p. 478). During this phase “anxiety motivates individuals to make assessments about their information-management options” (Afifi & Weiner, p. 175).

The second phase, evaluation, “reflects expectations about the outcomes of an information search and perceived abilities associated with that decision” (Afifi & Weiner, 2004, p. 171). This phase is divided into two general of ideas (a) outcome assessments, and (b) efficacy assessments (Afifi & Weiner). Outcome assessments are “the expected outcomes that a search for information may produce” (Afifi & Weiner, p. 175). Outcome assessments consist of (a) outcome expectancies, (b) outcome importance, and (c) outcome probability (Afifi & Weiner). Outcome expectancies are “individuals’ assessments of the benefits and

costs of a particular information-seeking strategy” (Afifi & Weiner, p. 176). Outcome importance is “the importance of a specific outcome for the self and/or the relationship” (Afifi & Weiner, p. 176). Outcome probability is “the perceived likelihood that an action will result in the expected outcomes” (Afifi & Weiner, p. 176).

Efficacy assessments are “the extent to which individuals perceive themselves as able to successfully reduce the anxiety through such a search” (Afifi & Weiner, 2004, p. 175). Efficacy assessments can be divided into (a) coping efficacy, (b) communication efficacy, and (c) target efficacy (Afifi & Weiner). Coping efficacy refers to the “extent to which individuals believe that they have the emotional, instrumental, and other resources...to manage the process- and results-based outcomes they expect from the information-management strategy under consideration” (Afifi & Weiner, p. 178). Communication efficacy refers to “individuals’ perceptions that they possess the skills to complete successfully the communication tasks involved in the information-management process” (Afifi & Weiner, p. 178). Target efficacy is “the belief that the information target is able and willing to provide complete information” (Afifi & Weiner, p. 179). Target efficacy consists of (a) target ability and (b) target honesty (Afifi & Weiner). Target ability refers to access of information (Afifi & Weiner). Target honesty refers to a willingness to provide the information sought after (Afifi & Weiner).

The third phase, decision, “involves the selection of information-management strategies” (Afifi & Weiner, 2004, p. 171). In this phase individuals can manage uncertainty-related anxiety by (a) seeking relevant information, (b) avoiding relevant information, or (c) cognitively reappraising the situation (Afifi & Weiner). Seeking relevant information can be done through (a) passive strategies, (b) active strategies, and (c) interactive strategies (Afifi

& Weiner). Passive strategies “involve unobtrusive observation of the targeted information provider” (Afifi & Weiner, p. 181). Active strategies “include manipulating the environment in order to examine the target’s response or asking third parties for information about the target” (Afifi & Weiner, p. 181). Interactive strategies “involve interacting with the target” (Afifi & Weiner, p. 181).

Avoiding relevant information means staying away from “situation or persons who may offer relevant information and/or would turn down opportunities to receive information” (Afifi & Weiner, 2004, p. 182). Those who choose this method believe the “reduction of the uncertainty-related anxiety is likely more damaging than beneficial” (Afifi & Weiner, p. 182). People may also choose to avoid relevant information because they “deem information seeking to be moderately risky [or]...choose not to devote the resources necessary to actively seek information” (Afifi & Weiner, p. 183).

Cognitively reappraising the situation means reducing uncertainty-related anxiety by “cognitively altering the need for uncertainty management, not reducing it through actual information gathering [which] may take the form of shifts in the perceived level of issue importance, the desired level of uncertainty, or the meaning of uncertainty” (Afifi & Weiner, p. 183). Specifically, MIMT demonstrates “the need to determine how Deaf people approach and appraise health-related issues, both as an antecedent and as an outcome of online health information seeking” (Karras & Rintamaki, 2012, p. 196).

Model of Online Health Information Seeking

Through UMT and MIMT, the Model of Online Health Information Seeking (MOHIS) was proposed, “which provides a framework for understanding health information seeking on the internet and includes the following components: (a) awareness, (b)

management, (c) appraisal, (d) action, and (e) strategy” (Karras & Rintamaki, 2012, p. 196). In the first phase, awareness, “individuals develop awareness to a relevant health issue about which they lack adequate understanding” similar to the interpretation phase of MIMT (Karras & Rintamaki, p. 196). In the second phase, management, individuals determine whether or not they will decrease, increase, or maintain their uncertainty “regarding the health issue [which] leads to either information avoidance or information seeking” similar to the decision phase of MIMT (Karras & Rintamaki, p. 196). In the third phase, appraisal, individuals use several antecedent variables, including “demographics, experience, salience, efficacy, social networks, information intent, and culture,” to appraise the internet “as a potential information source” (Karras & Rintamaki, p. 196). In the fourth phase, action, individuals choose either “(a) avoidance, where the internet is negatively appraised and avoided, or (b) utilization, where the internet is positively appraised and utilized” (Karras & Rintamaki, p. 196). In the fifth stage, strategy, if individuals chose the avoidance action in the fourth stage, they will seek information to reduce uncertainty and anxiety elsewhere than the internet. If individuals chose the utilization action in the fourth stage, they will develop “an information-seeking strategy...to gather information from the internet” (Karras & Rintamaki, p. 196).

Although MOHIS is not specific to the Deaf, it does provide a useful framework for guiding research on online health information seeking by the Deaf (Karras & Rintamaki, 2012). How the Deaf experience MOHIS may be specific to their population; Deaf and hearing people “diverge in their previous experiences, number and strength of ties in their social networks, and cultural beliefs toward medicine, which could then affect the manner in which they assess the internet as an information source” (Karras & Rintamaki, p. 197). LEP also plays a “vital role in medium assessment and utilization” (Karras & Rintamaki, p. 197).

Summary

In summation, seeking health information is common practice the hearing majority and some other minorities. However, it is unknown if it is common practice by the Deaf. The Deaf are distinctly different than those labeled deaf/hard-of-hearing due to their connection to Deaf culture. This contrast causes significant conflict between hearing doctors and Deaf patients such as culture clash and language discordance. These conflicts lead to additional health disparities including low health literacy and LEP, believing inaccurate online health information, inadequate access to healthcare, and varying communication methods. While there is a significant amount of literature on online health information seeking as a whole, very little focuses specifically on the Deaf. Using UMT, MIMT, and the MOHIS provide excellent frameworks to examine the relationship between language concordance, patient satisfaction, and the Deaf's online health information seeking habits.

CHAPTER THREE: METHODS

Initially I planned to do a single cross-sectional survey with two organizations who work with Deaf adults in the Southwestern United States. I chose a quantitative design with 100 participants in the beginning because of the lack of numerical data on the Deaf. One organization was unable to be contacted to set up the research study so I decided to focus all my attention and effort on the second location. I recruited participants at the single research location by standing in front of the congregation, stating what I wanted to do, and asking for volunteers. Those who were interested picked up flyers, signed the consent form, and took the survey on a single Sunday. After conducting the survey I realized two things. First, I did not gather enough data that day to complete the quantitative study I wanted as I only had eight participants complete the survey, and second, I noticed some very interesting written responses to the participant's open-ended questions that I wanted more information about. Because I had weak data I opted to triangulate my methods by conducting an interview [Appendix H] and a focus group [Appendix F], and decided to turn the survey into an initial pretest [Appendix D]. I chose the interview because the participant could provide me with an outsider's view of the problems the Deaf experience in healthcare. I chose a focus group because it allowed the participants to feed off each other's responses and would be faster than conducting individual interviews with each of the survey participants.

The pretest was conducted to gather background information on the participants as well as their feelings towards certain health topics. The focus group questions aimed (a) to assess the utilization patterns of online health information seeking by the Deaf and (b) to examine the relationship between healthcare and doctor satisfaction and online health information seeking. Specifically, the questions focus on satisfaction with healthcare

experiences, healthcare communication, and internet usage. The interview was also conducted with a hearing person who has been involved in the Deaf community for a majority of his life. The interview questions aimed to understand an advocate's view on how the Deaf could be better served in healthcare both during appointments and online. His questions for the interview followed the same major themes as the pretest and focus group questions.

Participants

All focus group and interview participants were drawn from a church in the Southwestern United States. For the initial pretest survey, eight individuals volunteered. To qualify for the pretest, participants had to have been at least 18 years old, identify with the Deaf culture, are medically labeled as deaf, have experience reading English, are members of at least one Deaf organization in Houston, and prefer to communicate in ASL. For the follow-up focus group, six of the eight pretest participants volunteered. Four participants participated in the focus group and two participants answered the same set of questions via email, as they were unable to make it to the focus group but still wanted to participate and contribute. From this point forward the two additional participants who completed the questions via email will be counted as focus group participants although it will be noted in the results who participated via email. For the interview, I selected the hearing person because he is a key informant and cultural broker of the Deaf community. For the purpose of participant privacy, all names and locations have been changed.

Procedures

To collect participants for the research study, flyers were handed out at the research location [Appendix A]. From the flyers potential participants were able to contact me via cell

phone and email. Potential participants were screened using recruitment pre-survey [Appendix B]. If they meet the criteria they were scheduled to take the pretest. A face-to-face physical paper copy of the pretest was used to collect demographics and background information because of the Deaf's lack of confidence using the internet and their finding it to be too challenging, as demonstrated in the literature review. The pretest was administered in an auditorium at the research location during their weekly Deaf social and took approximately sixty minutes to complete.

Prior to administering the pretest, I provided the participants with my name, university and Deaf community affiliations, purpose of the study, topic of interest, and the consent forms [Appendix C]. My reason for including personal background information was to build trust with my participants. I wanted them to know that I have an invested interest in their responses and healthcare experiences. Participants wrote their answers on printed copies of the pretest and were encouraged to provide other possible participants to the research study. At the conclusion of the pretest all participants were thanked for their time and contribution. All participants were entered into a drawing to win a \$150 gift card to Walmart or HEB.

For the focus group, potential participants were emailed [Appendix E] to inform them of the opportunity to participate. The contact information was taken from the information they provided to be notified if they won the \$150 gift card. The focus group was conducted with the same participants who completed the cross-sectional pretest and was moderated by the location's usual interpreter. I acted only as an observer taking notes throughout and asked some follow-up questions if necessary. The focus group was held in the location's Board Room and also took approximately sixty minutes to complete. Participants and the moderator

were videotaped for the focus group. Prior to starting the focus group, participants, the moderator, and I thoroughly reviewed consent forms, ground rules, and each person's role in the interaction. Again, participants were thanked for their contribution. Because the moderator voiced the participant's responses, Synergy Transcription Services was able to transcribe the video following the conclusion of the focus group.

For the interview, the participant was emailed [Appendix G] asking him if he would like to contribute to the research study. His contact information was found online. The interview took place in his office and took approximately forty-five minutes to complete. The researcher and the participant were audiotaped for the interaction. Before starting the interview, the participant read and signed the consent form. At the end he was thanked for his participation. The audio recording was transcribed by Synergy Transcription Services following the conclusion of the interview.

Variables Overview

Previous literature has examined patient satisfaction and online health information seeking in medical settings with other minority groups, yet little focuses on the Deaf. Therefore, this study aimed to examine the relationship among patient satisfaction, language concordance, and online health information seeking by the Deaf. This question was answered by examining how a Deaf patient's frequency of seeking health information online is dependent upon his or her satisfaction with the doctor.

Patient Satisfaction

Patient satisfaction can be divided into two subsections: language concordance and patient satisfaction with the doctor. Language concordance between the doctor and the patient can be conducted via someone or something being used as an interpreter, or by the

doctor if he or she is fluent in ASL. Patient satisfaction with the doctor stems from language concordance and patient needs being met. The questions being asked in the focus group and interview establish common communication habits between Deaf patients and their doctors.

Language Concordance: The use of an interpreter during medical settings can improve healthcare experiences and outcomes of patients with LEP (Greene, Ngo-Metzger, Legedza, Massagli, Phillips, & Iezzoni, 2005). Patients who use interpreters rate their overall provided healthcare highly (Greene, et al.) Therefore, the use of an interpreter in a medical setting is crucial to how patients perceive their healthcare (Greene, et al.) In addition, doctors who are fluent in ASL are an important aspect of addressing communication barriers Deaf ASL users experience (McKee, Barnett, et al., 2011). Overall, ratings and quality of care between language concordant doctors and using an interpreter does not differ (Greene, et al., 2005). If doctors are not fluent in ASL and fail to employ an interpreter, Deaf patients may leave the appointment with unanswered questions. This can encourage patients to go online to seek the health information they desire via group support forums, health or medical association websites, and online health articles (Li, Orrange, Kravitz, & Bell, 2014).

Patient Satisfaction with the Doctor: In addition to better communication contributing to better quality healthcare, it is also associated with higher satisfaction (Pollak, Alexander, Tulskey, Lyna, Coffman, Dolor, Gulbrandsen, & Ostbye, 2011). One method used for better communication, and therefore higher satisfaction in healthcare, is motivational interviewing (MI) (Pollak, et al.). MI has been successful in changing health related behaviors through utilizing the techniques of reflective statements and praise (Pollak, et al.). When used by doctors, MI encourages support for patient autonomy which can lead to higher satisfaction and self-efficacy (Pollak, et al.). This is crucial for minority patients such as the Deaf. In

addition, patients are more satisfied when doctors are empathic, use reflective statements, and show high support for patient autonomy (Pollak, et al.). Also, patients feel better and less anxious when doctors show compassion for as few as 40 seconds (Pollak, et al.). Doctors who use reflective statements allow the patients to drive the conversation more than when just questions are asked (Pollak, et al.). This, in turn, encourages patient empowerment and autonomy as well as equaling the power between patient and doctor (Pollak, et al.).

Online Health Information Seeking

Approximately eight out of ten Americans use the internet to seek health information (Chung, 2013). Seeking health information online can provide patients with a sense of empowerment (Chung). However, patients can also feel overwhelmed and confused by the amount and content of health information online especially when they lack health literacy like the Deaf (Chung). Most commonly, patients who seek health information online are younger women who have graduated college, have been using the internet for many years, and live in higher income households with constant internet access (Chung). In addition, typically patients who are older, less educated, and are minorities use the internet less frequently for seeking health information (Chung). Regardless, people who have a current health problem or are experiencing a stigma from it use the internet for seeking health information (Chung). Also, patients could seek online health information to better understand the information received in their previous appointment or prepare for an upcoming visit (Chung). Even though patients can now easily access, track, and manage their personal health records, patients who are associated with a minority culture are less likely to reap the benefits due to a lack of access to technology (Chung). However, because the Deaf are a unique minority in that they cross racial, ethnic, and socioeconomic status boundaries, it

is necessary to understand their specific use and familiarity with the internet in regards to online health information seeking. These questions asked in the focus group and interview establishes common internet usage habits between Deaf patients and their doctors. It is believed that Deaf patients may seek additional health information online if their needs are perceived as not being met just as UMT and MIMT suggest.

Data Analysis

Themes were initially established in the pretest. Therefore, the focus group and interview questions were focused to those themes. However, even though a codebook and categories were not created following traditional qualitative steps, after the transcripts were received, they were still printed and read for thorough analysis to check for any additional themes.

CHAPTER FOUR: RESULTS

Because the data was collected through an initial pretest and a qualitative scope, the results are divided between pretest responses and themes developed from the focus group and interview. Only those who completed the interview, and pretest and the focus group, including emailed responses, are discussed in this study. The two participants who completed the pretest but did not participate in the focus group are not included. Both the focus group and interview transcriptions have been sanitized to fill in implied terms in interpreting from ASL to English. However, the implied meanings behind the participant's responses are still true.

Pretest Results

The first participant, Marlie, is a 42 year old, white, Deaf woman, who graduated with an Associate's Degree. She stated that her proficiency in understanding English is only good when she is lipreading or reading text. Overall, she is fairly satisfied when she visits her doctor three to four times per year; however, she wishes her doctor provided better communication. She stated:

Overall I wish for better communication because my anxiety is high and I have no patience. I've had a family member come with me since I was little but now they are too busy or too old. I would like to have better communication without having to depend on my family. My doctors don't take emails on the weekends or text either.

Although she prefers the doctor to use an ASL interpreter, she and the doctor usually resort to oral communication. Therefore, she asks the doctor to repeat the information multiple times until she fully understands. Because of this she feels she and her doctor frequently misunderstand each other, and feel hurried and awkward during the appointment.

In order to offset the confusion experienced during the appointment, she spends at least one hour after the doctor's appointment seeking health information online to better understand what the doctor said in the appointment. She then takes the information she learned online back to her doctor to make sure she fully understands. She also asks family and friends for their experiences as well, depending on the illness. Finally, she stated, "Online information helps me understand better than the doctors do. Doctors tend to hurry and use few words. Sometimes I like to hurry because their lack of communication makes my anxiety high." Marlie participated in the focus group via email.

The second participant, Kenny, is a 71 year old, white, Deaf man, who completed some college courses. He believes he is proficient in understanding English and signing ASL. Overall, he is pretty satisfied with his healthcare experiences when he visits the doctor three to four times per year; however, successful communication depends on doctors and nurses speaking slowly, keeping their mouths uncovered, and talking face-to-face while maintaining eye contact. Problems usually arise when healthcare professionals have no patience or look down while talking to him. Although he is usually satisfied with his doctor, he almost never supplements the information provided during the appointment with online health information. Occasionally he seeks healthcare information online before going to a doctor's appointment but almost never seeks it afterwards. He also almost never speaks to his doctor about what he finds online. Usually if he does seek health information online it regards health insurance.

The third participant, Maggie, is a 72 year old, white, Deaf woman who did not finish high school. However, she does feel very proficient in understanding English and signing ASL. She too feels satisfied with her healthcare experiences when she visits the doctor three

to four times per year. She states that she has a good doctor who uses an interpreter, and always listens to her and answers her questions. In addition to feeling satisfied with her healthcare experiences as a whole, she also feels exceptionally satisfied when communicating with her doctor. She always uses some type of ASL through an interpreter; if a person cannot physically be there she and the doctor use a video phone to communicate. She states that, “When I make phone call to set up a doctor’s appointment I ask for it to be put in the computer for them to ask for an interpreter for me.” She only occasionally seeks health information online before seeing her doctor and almost always seeks health information online after seeing her doctor. However, she never mentions the information she finds online to her doctor during her appointments.

The fourth participant, Annie, is a 56 year old, white, Deaf woman who completed some college courses. She rates her proficiency in understanding English and signing ASL as excellent. She is very satisfied with her healthcare experiences overall when she visits her doctor about twice per year. However, she is not sure she is always able to say or ask everything she thinks is important during the doctor’s appointment. She also sees her communication with her doctor as satisfactory. Usually during the appointment she will lipread the doctor but if she does not understand the information, she will begin writing notes back and forth in order to clarify. She states, she sometimes does “not understand through lipreading so then my doctor writes notes so I understand clearly.” Although she may have unanswered questions during the appointment, she does not usually seek health information online for further clarification. Only occasionally does she seek health information online before or after the doctor’s appointment, and only sometimes mentions the information she

does find to the doctor during her appointment. Annie participated in the focus group via email.

The fifth participant, Nettie, is a 66 year old, white, Deaf woman who graduated from high school. She feels her proficiency in understanding English and signing ASL is very good. She is extremely satisfied with her overall healthcare experiences when she visits her doctor once a year for an annual check-up. She is also very satisfied with her communication with her doctor. She states she was brought up communicating orally through lipreading and therefore prefers that method to communicate with her doctor. She stated, “my doctor is wonderful in making sure I understand what he says to me.” On average she spends about four hours per day online; however, none of that time is devoted to seeking health information. She states she does not and would not seek health information online “because my doctor has brochures for me.”

The sixth participant, Larry, is an 83 year old, white, Deaf man who completed graduate school. He also rates his proficiency in understanding English and signing ASL as very good. Overall he is very satisfied with his healthcare experiences when he visits his doctor three to four times per year. He rates his communication satisfaction with his doctor as satisfactory and indicates during the appointment his doctor uses written notes to communicate with him, which is preferred. He does not spend any time online usually and does not seek health information online either. Therefore, health information that could be found online is not discussed with his doctor.

The interview participant, Lenny, is a 62 year old, white, hearing man who graduated with a double Master’s Degree in Religious Education and Divinity. In the interview he stated, he has been involved with the Deaf community for forty years. He’s a pastor of a

completely Deaf parish and has been a missionary to the Deaf community throughout the United States. His church has a history of working with the Deaf and wrote the first ASL book and early missionaries. In college, he learned ASL and worked at a Deaf school nearby where he and other students would go once a week to give the teachers a break and play with the kids. Later he became a dorm parent to those children. The language is what initially caught his attention because it was interesting. “Once you’ve learned the language you realize how different it is.”

Although the moderator did not actually contribute to the focus group information, it is important to include her credentials and background. Terrie has a Master of Science in Education in Counseling from the State University of New York at Brockport, and a Bachelor of Arts in Drama from the State University of New York at Fredonia. She also has additional education in ASL, counseling for the hearing impaired, rehabilitation counseling, family counseling, and drug and alcohol counseling. In the past she has been an interpreter, counselor, and adjunct faculty instructor. She interprets in a variety of settings for individuals who are Deaf and has a working knowledge of Spanish. Terrie was chosen to interpret and moderate the focus group because she and the participants know each other and she is a trusted member of the Deaf community. During the focus group she too asked follow-up questions if necessary.

Qualitative Themes

From the pretest, three major themes were established. Then the focus group and interview questions elaborated on them. The first theme, “*Things don’t translate well*,” refers to healthcare communication satisfaction, which examines language concordance. The second theme, “*My old doctor was no good*,” refers to healthcare experience satisfaction,

which examines patient satisfaction. Together these two themes examine the participant's overall satisfaction with their doctors. The third theme, "*The internet is a starting point*," refers to online health information satisfaction, which works directly with online health information seeking.

These themes are not mutually exclusive; there is some overlap among them. For example, communication before, during, and after the doctor's appointment influences the patient's satisfaction with the appointment experience. That experience can influence the patient's online health information seeking behaviors. Then, what is or is not found online can influence the patient's future communication with his or her doctor. In essence, the process is cyclical.

"Things don't translate well:" Healthcare Communication Satisfaction

Participants revealed three distinct situations where communication with their doctor occurs: (1) before the appointment, (2) during the appointment, and (3) after the appointment. Before the appointment, participants discussed communication while setting up their appointment and in the waiting room. During the appointment, participants discussed the importance of informing medical staff of being Deaf, using multiple modes of communication, and their preference for communicating with their doctor. After the appointment, participants discussed gathering information from other sources including their doctor, friends and family, and written materials.

Before The Appointment: Participants begin communicating with their doctors when they set up an appointment. Lenny, the interviewee, stated:

The biggest challenge the Deaf encounter when going to the doctor is communication. Things have gotten a lot better with technology now and with video

phones. It used to be they had to find a TTY to be able to call somebody and try to set an appointment, or they'll go in person to make the appointment for next week so they've got to make two trips and there's no way to interface with that person.

Annie stated, "I call with the interpreter relay. Before the video phone we had TTY. It was lousy and very hard to call." Marlie explained, "With the video phone and texting I think it's easier to get through the offices." Maggie said, "Most of the time I call for a doctor's appointment or I send a text to Kelsey Seybold. After my kids grew up they couldn't help me anymore so I'd ask another adult to make the phone call for me." Kenny stated that he calls "through a video phone and it's wonderful. Before video phone we depended on friends to call." Nettie said she too uses "a video phone to set up my appointment." Larry also stated, "I call on a video phone." Marlie said, "I ask my mom for help to call them for me."

Once they arrive to the appointment, they must check in at the front desk and wait in the waiting room before being called back. Nettie stated she "informs the person there that she's Deaf and only lipreads." Annie said when she's in the waiting room "I watch the door open and I see them say my name." Maggie does something similar, "They call my name, I look up, we make eye contact, and then I go." Kenny said "I watch the door and watch for them to say my name. If I can't see what they're saying I have to sit in a special chair to watch the door."

During The Appointment: After they make it to the back of the office for their appointment they begin informing the doctors and nurses they are Deaf. Nettie stated, "The nurse enters the room and I tell her that I'm Deaf. Then I go to the lab and tell them that I'm Deaf. I communicate by lipreading." Maggie also tells the staff, "I'm Deaf and I lipread."

Similarly Kenny will “warn the doctor and let him know I’m Deaf. I tell him I lipread so please speak slowly.”

Usually, multiple modes of communication are required during the appointments because of the differences in languages being used. Most of the time the communication modes are a combination of verbal and written information. Written information usually takes the form of notes written between the patient and the doctor. The notes are most often used by doctors to break down and explain difficult terms or concepts. Lenny stated:

Things don’t translate well. We as hearing people pick up a lot of context from all around us from the time we were born that they never had. All their input has been visual and just what people signed to them.

Marlie stated:

I always remind them I am Deaf so they speak clearly and patiently with me.

Sometimes I repeat after my doctor to make sure I understand correctly. If I am wrong or confused I sometimes make him or a nurse write me a note. If I am not patient or afraid we misunderstood each other, the notes are helpful. Sometimes we ask each other to repeat what was just said and then make a note with that information. If I don’t understand I ask them to repeat themselves or face me since I’m a lipreader, and make a note for me. I understand my doctor better if he is willing to be patient with me, faces me, and speaks clearly. It’s hard to understand and lipread other people who have a mustache, beard, false teeth, or a small mouth.

Similarly, Annie said:

At first you can’t tell that I’m Deaf so I ask ‘Can you slow down to talk? If I don’t understand can you write it down?’ If I don’t understand the words, then he writes on

a piece of paper so it's clear. I stop when I don't understand a word. If the word is simple then I understand it.

Kenny does the same thing:

With medical vocabulary when I don't understand I ask him to please write it down and explain what it means. Hearing people listen and the Deaf don't listen. We don't know the words so it makes it harder to read. Some of the words you cannot make simpler so I type it on my phone as a note. If I say the words the wrong way and he can't understand me then I'll go to the note section and show him.

Larry also uses more modern technology along with notes. He stated:

We talk back and forth on the computer. It saves time and is faster that way. If I don't understand a word I ask him what it means and he changes it until I can understand it.

The writing is okay. We write back and forth and then we change when I ask him what something means. I just ask him what it means with expression and then he changes the words. I really have a hard time with those big words. You need to change that into smaller words so I can understand them. I need simplified words.

Given the choice of having either a video phone or an interpreter, participants were split. Marlie said:

I know an interpreter would be helpful and make the appointment easier and faster. Having an interpreter would be great. However, I wish my doctors accepted emails and texts instead of just phone calls. I'm not always home and I don't answer voice calls. I hate for the nurse to call back since I always miss the call. We always miss each other for a day or more. Text and email are my favorite means of communication.

Larry agreed with Marlie saying, “I want the person. I want the interpreter, not the phone.” Annie disagreed and said, “I don’t want a person because sometimes they’re late or don’t show up. I prefer to go by myself.” Maggie agreed with Annie saying, “I prefer a video phone.” Kenny also agreed with Maggie and Annie saying, “When you get an interpreter sometimes they don’t show up so that’s why I use the video phone.”

Given the choice of either having an interpreter or not having one at all, participants were also split. Annie stated, “I would choose not having one.” Maggie disagreed saying, “I prefer an interpreter.” Kenny stated:

I would bring an interpreter. If you don’t get an interpreter the doctor refuses to pay for one. With this interpreter card you can call the number on your phone and the interpreter hears the doctor’s voice. The interpreter is right there. I sign back to the and the interpreter’s voice goes back to the doctor.

Lenny, who has acted as an interpreter for Deaf patients before, said:

They are very mistrustful of outsiders and they’ll only talk to people who they’ve known all their lives and they trust. That’s one of the obstacles of getting healthcare. When they need interpreters, being a trustworthy person in the Deaf community, they’d ask me to go interpret for them so I’d go to the doctors’ offices and hospitals and interpret for them there. Sometimes the doctor didn’t even see the need for me because the Deaf patient was doing okay just sort of talking to him. I think the Deaf patient wanted me there for clarification on medications. That’s what he’s worried about.

Participants also indicated that having the doctor sign to them in ASL would be the best scenario. Larry said, “It’s always a struggle. The doctor doesn’t try to sign. Teach them

sign language. Having a doctor sign in ASL would be ideal.” Annie agreed, “Having a doctor sign in ASL would be best.” Maggie also agreed, “Having a doctor sign in ASL would be great.” Kenny followed suite saying, “Having a doctor sign in ASL would be perfect. Teaching doctors sign language would help improve communication.”

After The Appointment: After participants leave the appointment, they usually leave with unanswered questions but how they answer those questions varied. Most of the time the information comes from three other sources including family or friends, doctors, and printed materials. Marlie said, “I ask family and friends for their history and opinions for more information. If they have no information on the topic, I will ask the doctor.” Annie stated, “I talk to my friends who had similar experiences.” Kenny also said, “I talk to friends. I ask for more information through friends.” Larry said:

Sometimes friends will tell me about a better doctor or medication. I call my doctor to ask if I can use it. The doctor says because of my health it would not be good for me. I say in closer touch with my doctor because it’s safer than friends. Friends could give me the wrong information.

Similarly, Nettie said, “I get all the information I need from my doctor. He has brochures in the office that he gives to me.” Maggie, on the other hand, stated, “I read health magazines. I’m just curious and want to find out.” Interestingly, four of the six focus group participants watch Dr. Oz on a regular basis. Annie stated, “I watch Dr. Oz.” Maggie said, “I watch Dr. Oz every day.” Larry explained, “I watch Dr. Oz and learn something new from it so I understand more.” Kenny also said, “Sometimes I watch Dr. Oz. It’s very good but I miss it sometimes.” Lenny elaborated on the subject by stating “Communication has arrived

to whatever it is. I'll interpret their paperwork for them and say 'this is good, this is bad, this is okay, this is what you need to worry about, ask about this next time.'”

“My old doctor was no good:” Healthcare Experience Satisfaction

Participants also exposed three areas that influence their satisfaction with their doctors: (1) longevity, (2) likes, and (3) dislikes. Participants made a clear distinction about the importance of the duration with a doctor between family doctors and specialists. They also discussed clear likes and dislikes about present and past doctors.

Longevity: How long a patient sees a doctor can greatly depend on that person's satisfaction with him or her. Typically, patients choose doctors who they are happy with and leave doctors they are unhappy with. Once the patient finds a doctor who works well with them and understands how to communicate with a Deaf patient, they stick with them. Marlie stated, “Some of these people have had their doctor's forever.” However, dealing with specialists can be difficult because the amount of time required to establish a relationship and adequately communicate with each other is not possible. Lenny stated:

Another challenge is when you're referred to a specialist or they bring in another person or you have to change doctor. Then you're there, you can't understand them, and you don't have an interpreter with you because you got along fine without one in the past.

Nettie stated:

I've been seeing this doctor for the past 15 years. I believe that most of the problems in the Deaf community are with the hospitals and the staff. It's hard to communicate with others in the hospitals due to the fact that they are not used to Deaf patients. I have to keep reminding them that I'm Deaf.

Larry said, “I’ve been going to the old doctor for many, many years but the other doctor about five years. He explains everything.” Kenny stated:

I’ve been seeing my doctor for 15 years. Most of the time I think the doctor communicated with me well but it depends. My family doctor is fine but the specialists are different. It depends if they have patients who are Deaf or not. You never know. They write it on paper but they don’t tell me what they wrote. I couldn’t read his writing.

Maggie “has been with this doctor for nine years.” Annie had just recently switched doctors, “I’ve been seeing my doctor for almost one year so I’ve only been there two times.” Marlie said she’s been going to this doctor so long “he is a family friend. If you’re already a patient of theirs then they know how you are and understand the situation.”

Deaf patients are willing, however, to forgo a doctor they’ve been with for a while if the care they are receiving becomes inadequate. Annie stated, “The old doctor sounded like he didn’t care about me at all so I go to the new doctor who’s perfect for me.” Maggie agreed saying, “My old doctor was no good. The new doctor gave me everything that I needed. It’s perfect. The new is much better than the old.”

Likes About Doctor: Deaf patients must also weigh their likes and dislikes about doctors to see if they are going to continue seeing them. Nettie said:

My doctor understands me and all the nurses have respect for me because I inform them that I’m deaf. He has been good to me, he understands that I’m Deaf and, he makes sure he faces me. He’s willing to repeat himself if I didn’t understand him. He always asks questions about my health and how I’m feeling. He is very patient and

wonderful. He treats me like a friend and he knows both of my daughters by their names. I'm very comfortable with him and wouldn't trade doctors.

Larry explained he likes his doctor because "We understand each other. He explains everything to me. He says, 'This is better, we need to work on this, this is a little bit low,' or whatever. He's fine. I get all the information I need." Kenny explained he liked his family doctor because:

He's concerned about me. He knows all my history, what happened to me, checks on me, and looks at me. When he's working on the computer he turns around and talks to me. Most of the time the other doctors just look at the computer and I can't see them. He turns around so I like him. I like that he tries to avoid medicine so I like that about him too.

Maggie explained she liked this doctor because:

We talk to each other like we're good friends. I was taking Lipitor for five years for my cholesterol. My back became stiff. I was walking like an old lady. I ran out of medication and went to see the doctor. He said to stop the Lipitor because it causes people to become stiff. He gave me another medication and I felt so much better.

Annie explained her new doctor is nice and gave her the perfect medicine. She also said:

I feel much better. I went into the office to see the new doctor and he asked me to show him how the video phone worked. He started talking to me so I felt he was excited that I was Deaf. He asked for my help.

Marlie explained, “I like to be with someone who knows me. I like doctors who are very patient with me, are willing to give me a note, and repeat as much as he can with a lot of patience.”

Dislikes About Doctor: There are also several frustrations the participants expressed about visiting the doctor. Lenny said:

At hospitals I don't know what's wrong with ADA that they just won't do it. The Deaf tell me 'I lay in bed three days and every day I ask for an interpreter and they would not get me one. I'm a prisoner there.' It's not just the doctors they're interacting with. It's all the nurses and therapists; three or four people every day they do not understand. They look at their faces and think they don't care. My concern is they are not being served well. I've known two people who've gone to the hospital twice, the hospital said there was nothing wrong, sent them home, and they both died. They treat a lot of the physical stuff but not the mental stuff. You can't go in as an interpreter because as that role you can't say anything; you're just the conduit. If anyone knew what Deaf meant, they'd know the right questions to ask.

Larry stated, “My doctor's always referring me to other doctors. That's the one thing I don't like.” Kenny elaborated saying:

Sometimes when I go to different doctors I don't like that doctor. I inform him that I'm Deaf, he says 'okay,' and then goes back to his normal thing just talking. Then I say 'please say it again.' I can't see his mouth. I'm so frustrated with that. So the next time I would never an appointment with that same doctor. I'd find a better one instead. That doctor had no patience with me.

He gave a second example explaining:

If I had a problem and the doctor said I don't have a problem, that's not a good doctor. I don't think the doctor knows how to communicate with a Deaf person. I was a little bit frustrated with him. I said, 'what's wrong with me?' He said 'you're okay.' I left there not knowing exactly what was wrong with me.

Marlie explained:

My doctor's refusal to provide me with an interpreter leads to more problems and hurts my self-esteem. I hate to ask the doctor for an interpreter unless it's a major issue or in the emergency room. I prefer the doctor to be aware and prepared for an interpreter instead of refusing. Sometimes I avoid going to a doctor who is not patient or refuses to work with me through notes. If doctors don't understand me or are not willing to be patient, face me, and speak clearly with me, they should get Deaf patients an interpreter.

Maggie gave similar examples of bad experiences she had that caused her to leave her doctor.

One male doctor I didn't like at all. I don't know what kind of doctor he was but I didn't like him. I went to see the doctor and asked what my results were. He looked at the computer and said 'Oh you're fine. You have nothing to worry about.' I said 'I still take cholesterol medicine. I want to know what my number is.' He didn't tell me. My cholesterol was fine but I was curious about what my score was. I need to know that. During an appointment with my old doctor he looked down at the chart, put his arm over the counter, slumped over, and fell asleep while he was standing up. When he woke up he gave me a prescription for Actonel, then I went home. I looked it up

when I got home and discovered it's used for seizures. I don't have seizures. I decided to drop the doctor. I went to a different doctor instead.

“The internet is a starting point:” Online Health Information Satisfaction

Participants lastly discussed three reasons for using the internet for online health information seeking: (1) details, (2) clarification, and (3) comparison. They also revealed several frustrations they experience when using the internet, which is a fourth subtheme. Participants distinctly separated searching for health information online for details or additional information, clarification or understanding information, or comparison or testing information. They also gave clear examples of problems they experience when seeking health information online. Lenny stated during the interview, “The internet is a starting point. It's a place to start gathering information to formulate your questions and go to your doctor and talk about them.” He also stated, “What the Deaf do use the internet for are vlogs, video blogs that are in sign. There's tons of vlogs out there that are in sign language that a lot of Deaf people look at because it's more accessible than reading English.”

Details: One way the participants use online health information is to gather additional information. Nettie stated, “Aetna has a wonderful website that I can go into to look up more information about health.” Marlie said, “I like to know more details, see pictures, and read other people's feedback. I always want to check the information before and after the doctor's appointment for any more questions or concerns.”

Clarification: Another way participants indicated they use online health information is to better understand information. Nettie stated, “If I'm not sure about words I can look them up.” Marlie explained, “I think it helps educate me more than the doctor. I search for health information online to make sure I understand more than just what the doctor told me.”

Maggie said, “I send emails to my doctor asking him about my problem.” Annie does something similar, “I ask about medicine and make sure it’s the right thing.” Kenny stated:

When I have the name of the medication and I don’t know what it’s for I pull up the information on the computer and it explains it. For example, if I have shingles and I don’t know what that means, I go to the internet and pull up an explanation, pictures, and what causes it. I had chicken pox before so the doctor gives me a shot to prevent shingles. I didn’t know that so I found out more information. That helps me better understand how it works.

Comparison: The last way participants said they use online health information is to test or challenge information. Marlie explained:

I get frustrated if I see different details between the internet and my doctor. I like to hear the doctor’s opinions and compare if they are different. I like to see how much the doctor knows about the information I find online. If the information online is the same as the doctor’s, I will feel more comfortable with the doctor. If the information is different, it makes me think the doctor doesn’t know anything and I will get a second opinion.

Maggie stated, “Sometimes when I’m concerned about my thyroid medication I keep looking for medication on the internet that would be better.” Kenny also said, “I’m not really that smart with medical vocabulary. The words are just so big. I go back, check, and find out what it means. I don’t know or understand what it means so I keep on checking.”

Frustrations: Marlie stated, “I get frustrated if I don’t get enough information.”

Kenny said, “My frustration with the internet is when it crashes or is hung up for a time.”

Lenny stated:

If they are looking up information on the computer, language, especially on the internet, even though they've tried it, they are technical terms and kind of a high level, college age level at least high school level and the Deaf don't read at that level in English. They read a little lower like sixth, seventh, or eighth grade, but you get to the high school level. Stuff we take for granted because we've heard all our lives growing up, the Deaf have no sense of.

CHAPTER FIVE: DISCUSSION

There are many challenges the Deaf encounter when seeking accurate health information on the internet and in the doctor's office. Yet there are many simple solutions that have been proposed in hospitals around the country, and potentially around the world, in hopes to decrease or eliminate the health literacy disparity between the hearing and Deaf communities. Through accommodating Deaf patients and educating both doctors and patients, and by understanding the Deaf community's health literacy and access to healthcare situation, we can address the challenges of health disparities and communication barriers.

Analysis: This research broadly explained there is not a definitive relationship among patient satisfaction, language concordance, and online health information seeking when it comes to the Deaf. The lack of a relationship among the three variables is demonstrated in how Deaf participants indicated they move throughout the Model of Online Health Information framework. The participants showed they rely more on their doctors or trusted family and friends to answer any unaddressed questions. A lack of language concordance leads to less patient satisfaction, ultimately resulting in seeking health information elsewhere. Because Deaf patients experience the same language discordance online as they do in the appointment, they usually either forgo the internet completely or use it only as a last resort. Therefore, Deaf patients do not follow the same pattern of seeking health information as other minority groups.

One aspect that needs to be better understood to more adequately assist Deaf patients is culture. Culture greatly influences how Deaf patients communicate with their doctors, how much they seek health information online, and how satisfied they are with their doctors. For those Deaf patients who are postlingually Deaf and rely on lipreading, Lenny stated:

You learn to speak and you're talking just fine. People say you don't need an interpreter because they can understand you just fine. You can, but they can't. They are talking nice, you can understand them, they've got good voice, but what you're throwing back at them, they are missing. They are still guessing at 70% of what they see on your lips. They assume a lot because you can understand them but they can't understand you. You wonder if they are not a little bit doctor-averse because they've been seeing doctors and therapists since the age of two, and having tests on them, and hearing aids, and cochlear implants, and all this stuff. I think they are kind of fed up with doctors and hospitals, and so they only see doctors when they need them.

In addition, research has shown medical staff often forgets signed languages such as ASL require facial and body expression to be considered complete communication. The signs are what hearing people consider verbal communication and the expressions are what hearing people would consider nonverbal communication. Without one or the other the communication is incomplete. Because computerized interpreters do not allow for complete facial and body expressions to be shown, they are not adequate substitutes for in-person interpreters during medical appointments.

Also, culture clash can lead to confusion about the purpose of the interpreter if a Deaf patient has not commonly used one in the past. Lenny provided a great example of this when he accompanied a Deaf friend to a doctor's appointment and the doctor did not understand why Lenny was there. Rushing through the appointment can also cause problems. Hearing patients are used to being rushed through the doctor's office but Deaf patients are not. As Marlie stated, when she feels rushed, her anxiety increases and she wants to get finished as soon as possible. This means she frequently leaves the appointment with many unanswered

questions. She also stated the doctor's failure to provide an interpreter, which is another indicator of culture clash, leads to her to experience lower self-esteem.

Not understanding Deaf culture or being culturally insensitive is also a sign of culture clash. Kenny provided a good example when he described the doctor not looking at him when he spoke to Kenny. Instead the doctor either looked down or at the computer.

Language concordance is also an important concept in culture. Most participants stated they communicate with their doctor by lipreading and writing notes. Although neither party is using his or her dominant language, they are both agreeing on a means of communication providing language concordance.

Another aspect that needs to be better understood is how the Deaf communicate. As demonstrated by the participants, many use a combination of communication methods to effectively communicate with their doctors. For these participants, most often a combination of verbal and written communication was used. Marlie, Annie, Nettie, and Maggie lipread and use notes. Kenny and Larry use video phones and supplement with notes as well. Participants also noted that having a doctor personally communicate with them in ASL would be the most ideal situation. None of the participants stated they regularly use interpreters, family, or friends to interpret on their behalf during an appointment. In addition, Maggie indicated she can text her doctor's office to set up an appointment, and Marlie stated she would like her doctor's office to do so as well. All of the focus group participants also agreed that having one place to find health information online that's similar to the video blogs they already use would be helpful.

Successful communication requires adequate comprehension of the information, which is difficult when a person experiences low health literacy like the Deaf. Health literacy

is crucial when understanding difficult medical terms. Larry provided a great example of how he and his doctor write back and forth to break down those words until he understands them. This stems from lower health literacy that all the focus group participants experience as evidenced by their request of notes to explain. Additionally, participants rate their English proficiency high but they emphasize in the focus group the importance of doctors breaking down and explaining difficult medical terminology, which indicates the opposite of their pretest results.

In addition to health literacy as a health disparity, deciphering online health information can also be a challenge. Usually medical information found online is written at the same reading level as printed information. Therefore, if Deaf patients do not understand information that is printed and given to them by their doctor, the online health information will also not be helpful, again stemming from lower health literacy.

This study did not confirm the assumption that Deaf patients who find inaccurate health information would begin self-diagnosing and -medicating, and not see a doctor at all. This may stem from the fact that the participants do not rely heavily on the internet as a means of finding health information. When participants did seek health information online, most of the time it was to gather details, or confirm or clarify information that was discussed during the appointment. Also, most participants stated they were satisfied with their doctors most of the time, which could have contributed to their lack of online health information seeking.

Another reason Deaf patients are not receiving adequate healthcare is because of a lack of interpreters being provided. As Marlie pointed out, she has been refused an interpreter and therefore does not request one unless it is for an emergency. Other focus group

participants rely solely on video phones or lipreading to conduct the appointment. Neither are adequate means of communicating. Also, friends and family who do not have medical backgrounds may suggest more harmful information than helpful information, as demonstrated in Larry's example.

UMT connects communication and reducing, managing, or increasing uncertainty. Specific to this study, the participants indicated they reduce uncertainty regarding medical information through a combination of friends, family, doctors, some printed materials, and the internet. Some participants take information provided to them by their doctors as enough and do not seek additional information. In this situation they are managing any uncertainty they may have instead of increasing or decreasing it. None of the participants increased their uncertainty.

MIMT states that as people become aware of an issue they begin the information management process to either decrease, manage, or increase uncertainty, similar to UMT. The process consists of three steps: (a) interpretation, (b) evaluation, and (c) decision. Many of the participants stated they continue asking questions to their doctor during appointments to minimize uncertainty. Usually they ask about breaking down difficult or confusing medical terms and medication. When participants enter the interpretation phase, some chose to reduce anxiety and uncertainty and other chose to manage it. In the evaluation phase, similar to UMT, participants sought information from friends, family, doctors, the internet, and printed information such as brochures. In the decision phase, most participants worked to reduce or manage uncertainty by seeking relevant information. The most common method of seeking this information is through an active strategy.

As previously discussed, MOHIS is a framework for understanding online health information through a five step process. These steps include (a) awareness, (b) management, (c) appraisal, (d) action, and (e) strategy. Take for example a Deaf patient being diagnosed with diabetes. In the awareness phase, the patient develops mindfulness about his or her diagnosis and wants to know more about it. The patient then moves to the management phase, where he or she decides to decrease uncertainty. After making that decision, the patient moves into the appraisal phase where he or she uses previous knowledge to make a decision about whether or not to use the internet. Similar to the participants, the patient decides to not use the internet. He or she then moves to the action phase and seeks to decrease uncertainty by asking other trusted friends, family, and doctors instead of online. Because of that choice, the patient never reaches the fifth phase of strategy. This is the common course taken by Deaf patients as demonstrated by the focus group and interview participants.

Limitations: There are several limitations to this study. The first set of limitations comes from the difficulties from my small sample size. There were not enough participants for meaningful statistical results and because the pretest had already been conducted, the qualitative themes were based more on the already established concepts than from the emergent data.

Additionally, health literacy was not measured in either the pretest or the focus group due to time constraints. This is important in understanding how well the participants understood the questions. Also, the pretests were administered via paper without an interpreter due to financial restraints. Using an interpreter may have yielded more accurate results. Also, the pretests were conducted in a group setting instead of an individual setting.

Therefore, participants may have felt some competition to rush through the pretests. Because the participants were in groups, when they had questions, they would first ask amongst themselves. Then, if they still did not understand a question, they would come ask me.

The participants also deemed words and phrases such as “seeking,” “credible,” “satisfactory,” and “European American” confusing. For example, one participant chose the “other” option for cultural identity and wrote in White. ASL and English proficiency questions could have been rephrased with more simple terms to match their perceived English reading level. In addition, more questions could have allowed for “other” to be an option. This would have allowed participants to expand more on their thoughts and allow for more accurate feedback. Financial resources of the participants were not measured. Learning this information would have helped provide a better understanding of how much participants are able to spend on finding adequate healthcare. Lastly, the sample population was extremely small. Having more participants would have provided a more accurate understanding of their healthcare experiences.

Limitations also exist with the participants. First, all participants are white, deaf, and middle to older age. Some have residual hearing, hearing aids, or cochlear implants. Some also have the ability to vocalize. Researchers have stated that older people do not perform as well as younger people when seeking health information online. Previous research also stated women tend to seek health information online more frequently than men. Marlie and Maggie seek health information regularly. Kenny and Annie seek health information online only occasionally. Neither Larry nor Nettie seeks health information online at all. Therefore, this information is not generalizable; it is only specific to this small group of individuals. Also, because I am not fluent in ASL, I am not able to accurately judge neither the participants nor

the interpreter's competency in ASL. Lastly, both the pretest and focus group consent forms were in English. The results of the study will also be in English. If participants read the results, they may not fully understand them.

Future Research: There are multiple areas for future research. Lenny stated during his interview:

You're just starting where people access information. You have to get to the doctor's office and hospitals, you have to find out why they are not treating the Deaf. You might want to get to schools and see what's going on in the school system.

Both hospitals and schools are excellent areas to better understand how the Deaf are seeking health information. Specifically, Deaf students who just graduated high school and moved to college would be interesting. Before moving, their parents would choose their doctors. After they move, they have to start all over again, finding a doctor that understands them as a Deaf person and figuring out how to communicate. The same situation occurs in education. While living at home, Deaf students are taken care of by their parents. After graduation and moving out, they must navigate a new place alone. Another area for future research would be examining the differences between the Deaf and other cultures.

Conclusion: I believe the best way to provide Deaf patients with adequate healthcare are two-fold. First, we need more ASL proficient medical staff. This burden does not fall solely on the shoulders of doctors and nurses. It also includes therapists, administrative staff, and other hospital and clinic staff. It also does not mean everyone should be fluent in ASL. I am only suggesting more people have a working knowledge of ASL similar to how people currently have working knowledge of Spanish, and a handful of doctors and nurses specialize

in working with Deaf patients. In my opinion, specializing in working with the Deaf is no different than specializing in working with other minority patients.

Many researchers have observed and tested methods for lessening the communication process breakdown between hearing doctors and Deaf patients. For example, after conducting an exercise that reversed the roles of pharmaceutical students and Deaf patients from the community, researchers concluded that the role-reversal was an effective way of teaching students that healthcare delivery is dependent on sufficient communication between doctors and patients (Mathews, Parkhill, Schlehofer, Starr, and Barnett, 2011). Ultimately, the students were able to better understand what it was like to have a communication barrier. Implementing this teaching strategy in more medical schools would help encourage more cultural sensitivity by medical staff.

Thankfully some progress is already being made. According to a friend of mine who is on the State Board, the state of Texas is currently working on creating its own Medical Interpreter Certification for sign language interpreters. It will be a specialty certificate designed to test and assess the skills of those wishing to engage in medical interpreting. It will be the only one of its kind in the nation for the field of ASL interpreting.

Second, we need to provide Deaf patients a place to go online to find health information in a way that makes sense to them. For example, if written health information was also adequately interpreted, video recorded, and uploaded to corresponding websites, Deaf patients could receive the health information in a language that was more familiar. Researchers believe that the best way to proceed in addressing this lack of health information is through a web-based response that addresses the “unique health information and communication needs of Deaf patients” (Smith et al., p. 41-42). Although websites such as

www.deafhealth.org have health education in ASL that defines certain medical terms, it is not extensive.

These suggested improvements should be implemented in every type of school that trains students to work in healthcare fields, and it should go one step further. Just as some doctors can translate other language like Spanish, even just minimally, the same should be imposed for ASL. By having a better understanding of the Deaf culture and their preferred mode of communication, doctors could influence the patient's hospital experience dramatically. Implementing use of ASL in hospitals would also help to remove the ethnocentric view many hearing people experience. Doctors could develop a new understanding of the frustration Deaf patients and their families experience when seeking treatment for illnesses, resulting in potential doctors becoming more culturally sensitive. In due course, these improvements could help doctors move toward a more culturally sensitive approach to medicine.

I am optimistic that in the future hearing and Deaf communities can work together to establish a solution to improve patient-doctor interactions and online health information for the Deaf. With a few alterations, technology could become a wonderful source of health information for the Deaf.

Appendix A: Recruitment Flyer

This project has been reviewed by the University of Houston Committee for the Protection of Human Subjects (713) 743-9204.

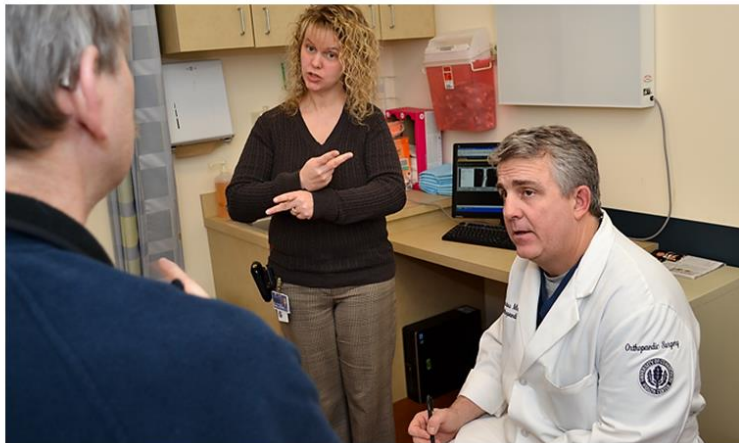


ONLINE HEALTH INFORMATION SEEKING AND THE DEAF

Are you **Deaf** and interested in assisting in **Healthcare Research**?

Paige Bukowski is a Master's student at the University of Houston in the School of Communication. She is currently working on her thesis which focuses on (a) assessing the utilization patterns of online health information seeking by the Deaf; and (b) examining the relationship between healthcare satisfaction and online health information seeking.

She is recruiting Deaf participants to complete her thesis survey. Please contact Paige via text message or email using the information provided below to set up a time to take the survey. Paige will be available during that time for questions. Participants must be over 18 years old and Deaf. All participants will be entered in a raffle to win a \$150 gift card to Walmart or HEB (winner's choice).



Paige Bukowski
Text: 254-855-3518
Email: pmbukowski@uh.edu

The survey will take approximately one hour to complete. You will be given a paper copy of the survey in a face-to-face setting. The survey will be completed in the Auditorium across from Warren Chapel immediately after church on Sunday. On the next side is a list of dates and times you may take the survey.

Dates & Times:

- February 8 starting at 12:30
- February 22 starting at 12:30

UNIVERSITY of
HOUSTON
JACK J. VALENTI SCHOOL of COMMUNICATION

University of Houston
101 Communications Building
Houston, TX 77204-3302

Appendix B: Recruitment Pre-Survey

Are you over 18 years old?

☐ Yes

☐ No

Have you graduated from high school?

☐ Yes

☐ No

Do you identify with Deaf culture?

☐ Yes

☐ No

Are you medically labeled as deaf?

☐ Yes

☐ No

Do you have experience reading English?

☐ Yes

☐ No

Are you a member of at least one Deaf organization in Houston?

☐ Yes

☐ No

Do you prefer to communicate in American Sign Language?

☐ Yes

☐ No

Appendix C: Administering the Pretest

Thank you for participating in my research study. My name is Paige Bukowski and I am currently working on my Master's thesis at the University of Houston. Specifically I am interested in online health information seeking habits of the Deaf. I earned my Bachelor's degree in Communication at Texas A&M University. While there I was an active member of Deaf Aggies & Friends (DeAF) and completed four semesters of American Sign Language. While in Houston I attend the Deaf church service.

Specifically, the pretest questions focus on healthcare experience satisfaction, healthcare communication satisfaction, and internet usage and satisfaction.

The purpose of my research is to answer the following research question:

What is the relationship among patient satisfaction, language concordance, and online health information seeking by the Deaf?

Please do not write your name on any of the research materials including the survey. Remember, this is a voluntary survey; you may withdraw at any time without penalty and refuse to answer any question. If you have any questions, please feel free to ask. I will be available through the duration of the survey.

Appendix D: Participant Pretest

SECTION I: BACKGROUND INFORMATION

The first set of questions is just about whom you are and your background.

These will only be used to help explain some of your other responses.

What is your gender?

1. Male
2. Female

What is your age?

What is your cultural identity?

1. European American
2. African American
3. Hispanic American
4. Asian American
5. Middle Eastern American
6. Pacific Islander
7. Native American
8. Other: _____

Are you Deaf?

1. Yes
2. No

What is your highest education level?

1. High School
2. Some College
3. Associate's Degree
4. Bachelor's Degree
5. Graduate School

How would you rate your proficiency in understanding English?

1. Poor
2. Fair
3. Good
4. Very Good
5. Excellent

How would you rate your proficiency in signing American Sign Language?

1. Poor
2. Fair
3. Good
4. Very Good
5. Excellent

SECTION II: HEALTHCARE EXPERIENCE SATISFACTION

The second set of questions is about your experiences and satisfaction with healthcare.

How would you rate your healthcare experiences overall?

1. Very Unsatisfactory
2. Unsatisfactory
3. Neutral
4. Satisfactory
5. Very Satisfactory

How often do you have an appointment with your doctor?

1. Once a year
2. Twice a year
3. 3-4 times a year
4. Once a month
5. Twice a month
6. 3-4 times a month
7. Once a week

During your appointments with your doctor, do you feel:

	Strongly Disagree	Disagree	Slightly Disagree	Not Sure	Slightly Agree	Agree	Strongly Agree
Satisfied with the medical care you receive							
Satisfied with his / her reasoning and explanations							
Your doctor's office has everything to provide good care							
Allowed to say everything you think is important							
Treated equally and with respect							
Confident in your diagnosis and treatment							
Your doctor listens to you and answers your questions							

SECTION III: HEALTHCARE COMMUNICATION SATISFACTION

The third set of questions is about your communication satisfaction with your doctor.

How would you rate your communication satisfaction with your doctor?

1. Very Unsatisfactory
2. Unsatisfactory
3. Neutral
4. Satisfactory
5. Very Satisfactory

What is your preferred method of communication when meeting with your doctor?

- | | | |
|-----------------------|--------------------|--------------------|
| 1. ASL: interpreter | 5. Cued Speech | 9. TTY |
| 2. ASL: family/friend | 6. Oral / Auditory | 10. Video Phone |
| 3. ASL: doctor | 7. Lipreading | 11. Text Messaging |
| 4. Signed English | 8. Written | 12. Other: _____ |

Why is the previous method your preferred method of communication?

What is your most common method of communication when meeting with your doctor?

- | | | |
|-----------------------|--------------------|--------------------|
| 1. ASL: interpreter | 5. Cued Speech | 9. TTY |
| 2. ASL: family/friend | 6. Oral / Auditory | 10. Video Phone |
| 3. ASL: doctor | 7. Lipreading | 11. Text Messaging |
| 4. Signed English | 8. Written | 12. Other: _____ |

What are some of the common problems you experience when going to a doctor's appointment?

During your appointments with doctor, does he / she do a good job of:

	Strongly Disagree	Disagree	Slightly Disagree	Not Sure	Slightly Agree	Agree	Strongly Agree
Making sure you understood his / her explanations							
Using language you could understand							
Check his / her understanding of what you said							
Ask you questions in a clear, understandable manner							
Contribute to a trusting relationship							
Show compassion							
Be open and honest							

SECTION IV: INTERNET USAGE & SATISFACTION

The fourth set of questions is about your usage and satisfaction with using the internet.

On an average day, about how much time do you think you spend online?

On an average day, about how much time do you spend online seeking health information?

How often do you seek health information before you visit the doctor?

1. Never
2. Almost Never
3. Occasionally / Sometimes
4. Almost Every Time
5. Every Time

How often do you seek health information after you visit the doctor?

1. Never
2. Almost Never
3. Occasionally / Sometimes
4. Almost Every Time
5. Every Time

How often do you mention the information you learn online to your doctor?

1. Never
2. Almost Never
3. Occasionally / Sometimes
4. Almost Every Time
5. Every Time

Please tell me any websites that you use to seek health information.

When thinking about seeking health information online, do you generally find the websites:

	Strongly Disagree	Disagree	Slightly Disagree	Not Sure	Slightly Agree	Agree	Strongly Agree
Easy to find							
Use language you could understand							
Credible							
Easy to understand							

Please explain why you would or would not seek health information online.

If there are any Deaf friends or family who may be willing to participate in this research, please provide their names, phone numbers, and email addresses below. This is optional.

Name

Phone Number

Email Address

Appendix E: Focus Group Email

First I want to thank you for participating in my master's thesis survey on Sunday, March 8. As you may recall, the survey asked you about how satisfied you are with your healthcare experiences, how satisfied you are with your doctor, and how you use online health information.

After analyzing the survey results, I decided a focus group with those of you who completed the survey is necessary for the research study to gain more in-depth information. The focus group will take place on Sunday, March 22 in the Board Room at St. Dominic Village immediately following Mass. It will be facilitated by Toni Flagg; however, I will also be present as an observer in case there are any questions.

The questions that will be asked are focused on the same topics as the survey. This follow-up focus group is strictly optional to gain further insight to better understand if, how, when, and why you seek health information online. Also, your participation in the focus group does not impact your chances to win the \$150 gift card discussed prior to completing the survey.

You will also be video recorded so I can transcribe the conversation that occurs, but your contribution will be confidential. This means your name will be changed and I will be the only person who views the video. After I have the information I need, it will be deleted to protect your privacy.

Your email address was obtained from the contact information you provided for the raffle. If you have any questions regarding the focus group, please email me at pmbukowski@uh.edu or text me at 254-855-3518. This project has been reviewed by the University of Houston Committee for the Protection of Human Subjects 731-743-9204.

Thank you again for your participation.
Paige Bukowski

Appendix F: Focus Group Questions

OPENING

1. Welcome
 - Thank participants
 - Purpose: To assess the utilization patterns of online health information seeking by the Deaf and to examine the relationship between healthcare satisfaction and online health information seeking
2. Introductions
 - Facilitator: Toni Flagg
 - Observer: Paige Bukowski
 - Participants
3. Assurance of confidentiality
 - Names will be changed
 - Participants can't be connected back to prior pretest
4. Ground rules
 - No right or wrong answers
 - Please respect different views
 - Please offer as much detail as possible
 - You do not have to answer any question that makes you uncomfortable
 - It's okay to respond to each other – Toni is here to moderate, not interview; Paige is here to observe and clarify and questions

QUESTIONS

Satisfaction with Healthcare Experiences

1. Describe a recent or typical doctor's appointment from start to finish.
 - How did you make the appointment?
 - What happened when you arrived?
 - What happened during the appointment?
 - Were you satisfied with the appointment? Why or why not?
2. Tell me about your doctor.
 - How long have you been seeing this doctor?
 - What do you like about this doctor? Why?
 - What don't you like about this doctor? Why?
 - How do you think this doctor treats you as a patient?

Satisfaction with Healthcare Communication

3. How do you communicate with your doctor?
 - Are you comfortable communicating that way? Why or why not?
 - Do you feel like your doctor understands you? Why or why not?
 - Do you feel like you understand your doctor? Why or why not?
 - What would help improve communication between you and your doctor? Why?

Satisfaction with Online Health Information

4. Do you use the Internet? Why or why not?
 - What do enjoy about the Internet?
 - What frustrates you about the Internet?
 - Do you search for specific health-related information? Explain.
 - Has your doctor asked you to look for health information online? Explain.
 - Do you talk to your doctor about health information you find online? Explain.
 - Besides the Internet, where else do you get your health information?

CLOSING

1. Ask participants if they'd like to add anything else
2. Thank participants

Appendix G: Interview Email

Dear Research Participant,

As you may recall, on Sunday, March 8 several Deaf members of St. Dominic completed a survey to assist me with completing my master's thesis. The survey asked participants how satisfied they are with their healthcare experiences, how satisfied they are with their doctor, and how they use online health information. After analyzing the survey results, I decided a one-on-one interview with you is necessary for the research study to gain more in-depth information.

Would you be interested in participating?

Please note that you will be audio recorded so I can transcribe the conversation that occurs but your contribution will be confidential. This follow-up interview is strictly optional to gain further insight to better understand if, how, and why or why not the Deaf seek health information online.

Your email address was obtained online. If you have any questions regarding the interview, please email me at pmbukowski@uh.edu or call me at 254-855-3518. This project has been reviewed by the University of Houston Committee for the Protection of Human Subjects 731-743-9204.

Thank you again for your participation.
Paige Bukowski

Appendix H: Interview Questions

OPENING

Thank you for agreeing to this interview. As a reminder, I would like to ask you a few questions about if, when, why, and how the Deaf seek health information online. Do you have any questions before we begin?

DEMOGRAPHICS

Age:

Gender:

Education:

Race:

QUESTIONS

- 1) Describe your involvement in the Deaf community.
 - What initially interested you in this community?
 - How long have you been part of the Deaf community?
 - What are some strengths of the Deaf community? Explain.
 - What are some challenges faced by this community? Explain.
- 2) Do you seek health information online for yourself? Why or why not?
 - How do you use the health information you find online?
 - Do you think the Internet is an important tool for health information? Why or why not?
- 3) Has a Deaf person ever asked you for health-related information? Explain what happened.
 - What information did you provide? How?
 - Did you help them with online information? Why or why not?
- 4) How often do you think the Deaf seek health information online? Why?
 - What challenges do the Deaf encounter when seeking health information online? Explain.
 - What advantages does the Internet offer the Deaf community? Why?
 - How could the Internet better help the Deaf community? What works and what needs to change?
- 5) What do you think doctors could do to better assist Deaf patients? Explain.

CLOSING

Is there anything else you would like to add before we finish up today? Thank you for your time today. If you have any questions, please feel free to contact me. My cell phone number and email address is at the bottom of your consent form.

References

- Afifi, W.A. & Weiner, J.L. (2004). Toward a theory of motivated information management. *Communication Theory*, 14 (2), 167-190.
- Brashers, D.E. (2001). Communication and uncertainty management. *Journal of Communication*, 51 (3), 477-497.
- Chung, J.E. (2013). Patient-provider discussion of online health information: Results from the 2007 Health Information National Trends Survey (HINTS). *Journal of Health Communication: International Perspectives*, 18 (6), 627-648.
- Cotton, S.R. & Gupta, S.S. (2004). Characteristics of online and offline health information seekers and factors that discriminate between them. *Social Science & Medicine*, 59, 1795-1806.
- Deaf411, Inc. (2009). In depth: Austin, TX: A little bit of everything. Retrieved from <http://www.deaf411online.com/reports/page15.php>
- DiPietro, L. J., Knight, C. H., & Sams, J. S. (1981). Health care delivery for Deaf patients: The provider's role. *American Annals of the Deaf*, 126 (2), 106-112.
- Estey, A., Musseau, A., & Keehn, L. (1991). Comprehension levels of patients reading health information. *Patient Education and Counseling*, 18, 165-169.
- Green, A.R., Ngo-Metzger, Q., Legedza, A.T.R., Massagli, M.P., Phillips, R.S., & Iezzoni, L.I. (2005). Interpreter services, language concordance, and health care quality: Experiences of Asian Americans with limited English proficiency. *Journal of General Internal Medicine*, 20 (11), 1050-1056.
- Harmer, L. M. (1999). Health care delivery and deaf people: practice, problems, and recommendations for change. *Journal of Deaf Studies and Deaf Education*, 4 (2), 73-110.

- Harrington, T. (2004) *Local and regional deaf populations*. Gallaudet University Library.
Retrieved from <http://libguides.gallaudet.edu/content.php?pid=119476&sid=1029190>
- Karras, E. & Rintamaki L.S. (2012). An examination of online health information seeking by deaf people. *Health Communication*, 27 (2), 194-204.
- Karras, E., Rintamaki, L. S., and Peek, D. M., (2011). Problematic physician-patient interactions reported by deaf patients. Paper presented at the annual meeting of the International Communication Association, TBA, Boston, MA Online.
- Kotenko, J. (2013). The doctor will see you now: How the internet and social media are changing healthcare. Digital Trends. Retrieved from <http://www.digitaltrends.com/social-media/the-internet-and-healthcare/>
- Levco, J. (2012). Infographic: How social media is changing health care. Ragan's Health Care Communication News. Retrieved from http://www.healthcarecommunication.com/Main/Articles/Infographic_How_social_media_is_changing_health_ca_8131.aspx#
- Li, N., Orrange, S., Kravitz, R.L., & Bell, R.A. (2014). Reasons for and predictors of patients' online health information seeking following a medical appointment. *Family Practice*, 31 (5), 550-556.
- Lieu, C.C., Sadler, G. R., Fullerton, J.T., & Stohlmann, P.D. (2007). Communication strategies for nurses interacting with patients who are deaf. *Dermatology Nursing*, 19 (6), 541-551.
- Mathews, J.L., Parkhill, A.L., Schlehofer, D.A., Starr, M.J., & Barnett, S. (2011). Role-reversal exercise with deaf strong hospital to teach communication competency and cultural awareness. *American Journal of Pharmaceutical Education*, 75 (3), 1-10.

- McKee, M.M. & Paasche-Orlow, M.K. (2012). Health literacy and the disenfranchised: the importance of collaboration between limited English proficiency and health literacy researchers. *Journal of Health Communication: International Perspectives*, 17 (3), 7-12.
- McKee, M.M., Barnett, S.L., Block, R.C., & Pearson, T.A. (2011). Impact of communication on preventative services among deaf American sign language users. *American Journal of Preventative Medicine*, 41 (1), 75-79.
- Mesch, G., Mano, R., & Tsamir, J. (2012). Minority status and health information search: A test of the social diversification hypothesis. *Social Science & Medicine*, 75, 854-858.
- Mitchell, R. E. (2006) How many Deaf people are there in the United States? Estimates from the survey of income and program participation. *Journal of Deaf Studies and Deaf Education*, 11 (1), 112-119.
- National Institute on Deafness and Other Communication Disorders (n.d.). Quick Statistics. Retrieved from <http://www.nidcd.nih.gov/health/statistics/Pages/quick.aspx>
- North Carolina Division of Services for the Deaf and Hard of Hearing (2013). *Communication methods used by individuals who are deaf or hard of hearing*.
- PBS (n.d.) Introduction. Retrieved from <http://www.pbs.org/wnet/soundandfury/culture/deafhistory.html>
- PBS (n.d.) Timeline of Deaf History. Retrieved from <http://www.pbs.org/wnet/soundandfury/culture/dhpop/popup4.html>
- Pearson, T. A. (n.d.) *National Center for Deaf Health Research: Research*. University of Rochester Medical Center. Retrieved from <http://www.urmc.rochester.edu/ncdhr/research/>

- Pereira, P. C. A. & de Carvalho Fortes, P. A. (2010). Communication and information barriers to health assistance for deaf patients. *American Annals of the Deaf*, 155 (1), 31-37.
- Pollak, K.I., Alexander S.C., Tulskey, J.A., Lyna, P., Coffman, C.J., Dolor, R.J., Gulbrandsen, P., & Ostbye, T. (2011). Physician empathy and listening: Associations with patient satisfaction and autonomy. *Journal of the American Board of Family Medicine*, 24 (6), 665-672.
- Pollard, R.Q. Jr., Dean, R.K., O'Hearn, A., & Haynes, S.L. (2009). Adapting health education materials for Deaf audiences
- Smith, C.E., Massey-Stokes, M., & Lieberth, A. (2012). Health information needs of d/Deaf adolescent females: A call to action. *American Annals of the Deaf*, 157 (1), 41-47.
- Stein, M.S. & Teplin E. (2011). Rational discrimination and shared compliance: Lessons from Title IV of the Americans with Disabilities Act. *Valparaiso University Law Review*, 45 (3), 1095-1141.
- Tustin, N. (2010). The role of patient satisfaction in online health information seeking. *Journal of Health Communication: International Perspectives*, 15 (1), 3-17.
- US Department of Health & Human Services (n.d.) *Limited English Proficiency (LEP)*. Retrieved from <http://www.hhs.gov/ocr/civilrights/resources/specialtopics/lep/>
- US Department of Justice, Civil Rights Division, Disability Rights Section (2003). *ADA business brief: Communicating with people who are deaf or hard of hearing in hospital settings*.
- World Federation of the Deaf (n.d.) *FAQ*. Retrieved from <http://wfdeaf.org/faq>
- Zazove, P., Meador, H.E., Reed, B.D., & Gorenflo, D.W. (2013). Deaf persons' English reading levels and associations with epidemiological, educational, and cultural factors. *Journal of Health Communication: International Perspectives*, 18 (7), 760-772.