IMPROVING EXPERIENCES OF CULTURALLY DEAF
INDIVIDUALS WHEN ACCESSING HEALTHCARE AND MENTAL HEALTH SERVICES

By

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ABSTRACT

The purpose of this thesis is to present best practice recommendations to optimize care for culturally Deaf people. In the United States, 6.25% of the population has hearing loss and 1% of Americans cannot hear spoken language well enough to be able to derive meaning from it (Brown, Hughes-Bell, & McDuffie, 2015). Culturally Deaf people who use American Sign Language (ASL) to communicate are at risk for negative health outcomes due to being part of a vulnerable population. Barriers to equal access for Deaf clients exist at the provider level, the client level, and system-wide. A literature review was performed utilizing keywords “deafness and mental health”, “deafness and healthcare”, and “deafness” in the CINAHL and PubMed databases. Twenty-seven articles met inclusion criteria. Providers can improve by obtaining cultural sensitivity training regarding Deaf culture and assessing communication needs and level of language fluency of Deaf clients prior to care. Providers who can communicate in ASL directly are preferred in primary prevention and mental health services. Providers should use assessment tools normed on the Deaf population. The Plan-Do-Study-Act (PDSA) model will be used to guide implementation and evaluation of the best practice recommendations (Deming.org, 2016).
CHAPTER ONE

The purpose of the thesis is to highlight research findings in regards to barriers that Deaf people face when attempting to access medical or mental healthcare. The goal of the thesis is to make best practice recommendations that will optimize physical and mental healthcare for Deaf people so that they are receiving access that is equivalent to what the hearing population receives. When healthcare providers utilize evidence based recommendations during all aspects of care, the hope is that Deaf patients will experience a higher level of satisfaction with care, get screened adequately for medical and mental health conditions, utilize medical and mental health services more often, increase health literacy, and use methods of primary health prevention more often than secondary or tertiary levels of prevention. Additionally, interventions at the level of the Deaf consumer and at the organizational level are needed to create a pathway to equal access.

Prevalence, Etiology, and Communication in Deafness

Approximately 6.25% of the United States population has some degree of hearing loss, and 1% of the population has a hearing loss that makes spoken language incomprehensible (Brown et al., 2015). Of those with hearing loss, a sub-category of culturally Deaf individuals rely on a visual/manual form of communication such as American Sign Language (ASL) to access information (Lin, Niparko, & Ferrucci, 2011). A culturally Deaf person has many identifiable characteristics including: 1) loss of hearing pre-lingually (i.e., prior to the acquisition of speech), 2) communicates expressively and receptively through the visual language of ASL, 3) self-identifies as a member of Deaf culture, and 4) may feel a sense of pride about being a member of Deaf culture and does not associate a hearing loss as a medical illness (Sheppard, 2014).
Many factors can cause hearing loss and 50% of cases are the result of a genetic cause (Landsberger, Sajid, Schmelkin, Diaz, & Weiler, 2013). Additional factors include illness in utero (e.g., measles), illness shortly after birth (e.g., otitis media, high fever), and use of antibiotics that are harmful to hearing (Landsberger et al., 2013). Environmental factors such as noise exposure are also a cause of deafness, but more often affect older adults who are not members of the culturally Deaf community (Landsberger et al., 2013). In one-third of all cases of hearing loss, a syndromic condition is identified which includes additional manifestations of a wide variety of symptoms which may make accessing healthcare extremely challenging (Landsberger et al., 2013). The 2005 Survey of Income and Program Participation reported approximately 1.2 million people in America are unable to understand spoken language even with the use of assistive listening technology and are considered functionally deaf (Landsberger et al., 2013).

Methods of communication used by those with a hearing loss varies depending on how the person learned to communicate, if the person utilizes technology (e.g., hearing aids, cochlear implants) to access sound within their environment, and the degree to which they identify with the Deaf or hearing culture (Landsberger et al., 2013). Additionally, the level of knowledge that a person with hearing loss has regarding topics of health or ways to utilize or access healthcare varies depending on the person’s level of communication and overall knowledge of how to best utilize the healthcare system. Due to differences in communication, a person with a hearing loss may have difficulty accessing healthcare, problems interacting with healthcare professionals, inability to advocate for themselves, and limited comprehension of health information.

**Defining Cultural Deafness**
People with hearing loss communicate in a variety of ways including oral spoken language, signed manual language (e.g., ASL), or by utilizing written communication (Landsberger et al., 2013). Additionally, a person with a hearing loss may use the term “hard-of-hearing”, “deaf”, or “Deaf” (with a capital D) when referring to themselves (Landsberger et al., 2013). A person who self-identifies as “Deaf” (with a capital D) rejects the view that hearing loss is an impairment or pathological in nature and instead views deafness as a source of identity and pride (Landsberger et al., 2013). The members of the Deaf community have distinct values, traditions, and a common visual language (ASL) with grammar, syntax, and vocabulary that is distinct from English as their primary mode of communication (Landsberger et al., 2013). The individuals that identify as “deaf” (with a lower-case d) are acknowledging a physical condition of hearing loss and may not identify with Deaf culture as much as they do with the hearing world (Landsberger et al., 2013). The term “hard-of-hearing” refers to a physical condition of having a hearing loss and identifying with the hearing world rather than the Deaf culture (Landsberger et al., 2013). Individuals who are “deaf” or “hard-of-hearing” may utilize spoken English for expressive communication while speech-reading and written English are used for receptive communication (Landsberger et al., 2013).

ASL is the primary method of communication among the Deaf which is not the same as spoken or written English. There are a variety of reasons why it is difficult for a Deaf person to obtain equal accessibility for communication during interactions with the healthcare system and these reasons will be explained later. Deaf people experience more challenges when accessing medical or mental healthcare than those who identify as “deaf” or “hard-of-hearing”, therefore, the focus of this thesis will remain on those who identify with Deaf culture. There are other manual languages that can be used by people with a hearing loss including Manually Coded
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English (i.e., a visual version of English), a combination of English and ASL (i.e., pidgin sign), or Cued Speech (i.e., mouth movements in combination with handshapes that denote different English phenomes) although the Deaf community generally utilizes ASL (Landsberger et al., 2013). Another consideration regarding Deaf culture is that the level of language fluency of the individual person varies greatly depending on the extent of exposure to the language, age at which the exposure to language began, level of mental capacity, the family of origin (Deaf vs. hearing), educational experiences, and participation in the Deaf community (Landsberger et al., 2013).

Culture Clash

Historically, there has been differing viewpoints regarding deafness. On one side, the medical model sees deafness as a pathological medical diagnosis which needs to be treated, cured, and then eliminated (Pray & Jordan, 2010). The advent of the cochlear implant in the late 1980s created an opportunity to treat profound nerve deafness by stimulating the nerves inside the inner ear through an external processor and microphone (Pray & Jordan, 2010). The receiver and electrode array is surgically implanted and once healed, the device can be turned on so that the user can detect sound. The use of cochlear implants is in direct opposition with the Deaf culture view of deafness as a personal characteristic which is not something that needs to be fixed or eliminated (Thew et al., 2012; Landsberger et al., 2013). Generally, there is no controversy when a late deafened adult obtains a cochlear implant because he/she lived as a hearing person prior to the onset of deafness and is a consenting adult (Pray & Jordan, 2010). However, the Deaf community has been opposed to implanting pre-lingually Deaf children because the surgery is seen as very risky and the child is not old enough to consent to the procedure (Pray & Jordan, 2010). Additionally, implanting a young Deaf child could take away the opportunity for the child to participate in Deaf culture and learn ASL because most Deaf
children are born to hearing parents who may not have an interest in learning ASL or teaching it to their child (Pray & Jordan, 2010). The decision to use a cochlear implant is a personal choice that many in the culturally Deaf community may not want because they feel they are already whole people who are not searching for a cure and prefer to live their lives within the Deaf community.

**Legal Considerations**

Legal mandates exist within the United States of America that require equal access and effective communication at all health care settings for the Deaf population. They include the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA), and the Civil Rights Act of 1964. In addition, there are often state laws that mirror the Federal law and provide additional requirements (NAD.org, 2016).

Section 504 of the Rehabilitation Act of 1973 mandates equal access for Deaf patients to all federal health care services, facilities, and health care providers who are recipients of federal financial assistance (NAD.org, 2016). Titles II and III of the ADA law requires equal access for Deaf people to all public, state, local, and private health care providers (NAD.org, 2016). Finally, Title VI of the Civil Rights Act of 1964 mandates that individuals with limited English proficiency are required to have appropriate language access (e.g., ASL interpreters) in all health care settings (NAD.org, 2016).

The U.S. Federal Court deemed provision of mental health care using a hearing provider and ASL interpreter as inadequate and not functionally equivalent to the mental health services that hearing people utilize (Wilson & Schild, 2014). Deaf people are not getting equal access to mental health care, however, the ADA states there must be a federally funded program to provide equal access for disabled individuals to all services that nondisabled persons can access
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(Wilson & Schild, 2014). The courts ruled that a culturally/linguistically competent provider was not mandatory in health care settings other than mental health (Wilson & Schild, 2014).

Technological Advances

Improvements in the case of visual communication have also improved communication access for the Deaf. The use of videoconferencing or “videophone” services allow a person to visualize another person via live television imaging that is usually connected over an internet connection and which two people who sign can directly communicate with one another (Austen & McGrath, 2006). Another method is video relay which involves three parties, 1) the signing Deaf person, 2) the hearing person, and 3) the ASL interpreter who signs the message of the hearing person to the Deaf person and then verbalizes the signed communication of the Deaf person to the hearing person. There are two types of video relay which differ by equipment required for the service and wait time (Ferguson & Liu, 2015). With video relay service (VRS), dedicated interpreters are always available and only the Deaf person needs a videophone which is free to them per FCC regulations (Ferguson & Liu, 2015). With video relay interpreting (VRI), a laptop with a video camera and reliable internet connection are required and the wait time to find an interpreter can be much longer because the interpreters are not connected with an immediate service (Ferguson & Liu, 2015).

Early studies regarding the use of telemental health utilizing videophones in England highlighted complications with use (Austen & McGrath, 2006). First, there did not appear to be adequate access to telemental health for the medical or mental health practitioners (Austen & McGrath, 2006). Next, the staff in medical services were just as familiar and confident with using the videoconferencing as those who were providing services for the Deaf (Austen & McGrath, 2006). These findings suggest that in 2006, the use of teleconferencing for mental
health treatment for the Deaf was still novel and not widely used or accessible for this purpose (Austen & McGrath, 2006).

As technology advanced, the benefits of telehealth became recognized. Wilson & Schild (2014) reviewed the literature in the area of mental health and the use of telehealth and found that telehealth is a good alternative for Deaf people because Deaf people utilize this technology frequently to communicate, Deaf people are eligible to get the necessary equipment for free through the FCC which is mandated by the ADA, and VP technology is different than commercial technology in a few important ways. First, VP transmits smoother, faster, and clearer picture quality. Second, VP has good low-light image quality and a high-definition picture transmission. Third, VP technology has higher security than regular videoconferencing equipment and there is a less chance for hackers to interfere which means it is compliant with the Health Insurance Portability and Accountability Act (HIPAA) of 1996. Next, it was specifically created with Deaf users in mind. Finally, it is highly regulated by the FCC and has strict standards (Wilson & Schild, 2014).

Prevalence of Mental Health Disorders in the Deaf

Deaf people also have difficulty obtaining equal access to mental health services. Research has shown that having an acquired deafness (e.g., deafness caused by an illness such as rubella) is associated with increased incidence of mental health problems (Fellinger, Holzinger & Pollard, 2012). Acquired deafness occurs in 30-39% of the population of individuals with a hearing loss (Fellinger et al., 2012). Additionally, a study in Denmark found that being Deaf and having additional disabilities triples the risk of having psychosocial difficulties (Fellinger et al., 2012). Similarly, a study conducted at a school for the Deaf in the United States found that children with hearing loss had a four times greater prevalence of psychosocial difficulties than
their hearing peers (Fellinger et al., 2012). In the United States, 27% of children with a hearing loss have additional diagnoses that place them at risk of having mental health illness (Fellinger et al., 2012). Prior research suggests that rates of emotional and behavioral problems are twice as high in children with hearing loss when compared to hearing children (Fellinger et al., 2012). The mental health issues of the Deaf are similar to the hearing population, however prevalence rates for specific types of mental illness differ between Deaf and hearing groups.

Several studies explored the differences of mental health issues between the adult Deaf and hearing population. Diaz, Landsberger, Povlinski, Sheward, & Sculley (2013) found similar rates of mood disorders, psychotic disorders, adjustment disorders, eating disorders, cognitive disorders, and personality disorders in both groups. The Deaf group had higher rates of impulse control disorders, attention deficit/hyperactivity disorder, pervasive developmental disorder, and intellectual disabilities than the group of hearing subjects. The group of Deaf participants had lower rates of anxiety disorders, bipolar disorders, and substance use disorders when compared to the hearing group (Diaz et al., 2013).

Fellinger et al. (2012) reported that Deaf people do not have a specific pathophysiology of mental health disorders, rather hearing and Deaf individuals have mental health disorders that are commonly seen in all humans. In a study that collected interview information from the parents of Deaf children, the results showed a 26% rate of lifetime depression in a representative sample of schoolchildren between the ages of 5-16 (Fellinger, Holzinger, Sattel, Laucht, & Goldberg, 2009). Landsberger & Diaz (2010) found that rates of psychotic disorders (e.g., schizophrenia), mood disorders (e.g., bipolar, major depression), anxiety disorders, learning or language disorders, eating disorders, and cognitive disorders (e.g., dementia) were similar amongst a Deaf and hearing group of psychiatric inpatients. However, impulse control disorders
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(23% vs 2%) and pervasive developmental disorders (10% vs 0%) were found more often in the Deaf group of inpatients. Lower rates of substance abuse disorders (20% vs 45%) were found in the Deaf group of inpatients. In regards to Axis II diagnoses according to the DSM-IV-TR (2000), borderline intellectual functioning was similar in the group of hearing and Deaf inpatients. Mild mental retardation was more likely to be a diagnosis in the group of Deaf inpatients (33% vs 3%), while personality disorder was more likely to be a diagnosis in the hearing group (17% vs 43%) of psychiatric inpatients (Landsberger & Diaz, 2010). Fellinger et al. (2012) reported Autism rates among Deaf and hard of hearing people between 2-4% which is higher than the hearing population. Autism is difficult to diagnose among Deaf individuals because there are overlapping characteristics in Autism such as ritualistic behaviors, language delay, and difficulties in social relationships (Fellinger et al., 2012).

Kvam, Loeb, & Tambs (2007) found that the risk of experiencing mental distress was more than doubled for the Deaf group when compared to the hearing population. A higher percentage of hearing respondents replied “not at all” to mental distress variables than the Deaf population and Deaf respondents were significantly more likely to report “extremely” to each anxiety and depression indicator when compared to the hearing group. Those who became Deaf before age 9 expressed feelings of hopelessness and had more mental distress more often than those who became deaf later in life. Finally, Deaf subjects had more symptoms of depression and anxiety than the hearing group (Kvam et al., 2007).

Sheppard (2014) conducted a qualitative study with Deaf participants who attempted to access healthcare. Among the themes described by the participants were “feeling depressed” and “emotional chaos leading to depression”. Additionally, lack of a therapeutic bond with a healthcare provider created feelings of chaos inside the Deaf person which led to depression
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(Sheppard, 2014). A study of the Deaf community by Barnett et al. (2011) found higher rates of intimate partner violence and suicide when compared to the hearing community. Pollard, Sutter, & Cerulli (2014) found similar results through Deaf respondents reporting high rates of emotional abuse and much higher rates of forced sex than respondents from the general population. Experiencing intimate partner violence was correlated with increased utilization of emergency room services (Pollard, Sutter, & Cerulli, 2014).

Significance to Healthcare

Members of the Deaf community will attempt to access both medical and mental healthcare because they have health needs similar to the population at large. Medical professionals will likely care for a Deaf patient at some point in their career. In order to provide functionally equivalent care to a Deaf person, the healthcare team is responsible for understanding the specific needs of a culturally Deaf person. Physicians, pharmacists, nurses, psychologists, psychiatrists, and social workers are the members of the healthcare team that play a particularly important role in providing culturally sensitive care for Deaf people. Knowledge regarding Deaf culture must be gained during the time these providers are attending college, and professors within these training programs are key players to ensure that the next generation of medical professionals are prepared to provide culturally sensitive care.

At the institutional level, the healthcare system as a whole must understand the legal requirements in regards to equal access to healthcare and mental healthcare for the Deaf population. Hospital administrators, congressmen, and staff at the insurance companies have a responsibility to understand what is involved in providing functionally equivalent healthcare and mental health services for the Deaf. Policies within these institutions must allow for equal access
and funds should be appropriated for this cause. Awareness of Deaf culture is needed at all levels of care and among all health providers to decrease the risk of health disparities in the Deaf.

Summary

A significant amount of the United States population has a hearing loss that makes it unable for them to access and understand spoken language. Among the population with hearing loss, the people that consider themselves Deaf utilize ASL for communication. ASL is not the same as the English language, therefore this population has difficulty in accessing functionally equivalent medical and mental healthcare. Members of Deaf culture are proud and do not want to "fix" the Deafness or become hearing. This perspective is different than the medical model which sees deafness as a pathology needing to be eradicated. Medical and mental health professionals will come into contact with Deaf people in the scope of their provision of care and need to be culturally sensitive while serving the Deaf client.
CHAPTER TWO

Review of Literature

This review of the literature will highlight challenges that Deaf people face when accessing medical or mental healthcare. In addition, literature on the effectiveness of interventions to overcome barriers for the Deaf population will be reviewed. The search was conducted using PubMed and CINAHL and focused on articles published between 2006-2016. The keywords “Deaf”, “healthcare”, “mental health”, and “health literacy” were used to find relevant peer-reviewed research studies. The results of these studies will be used to propose best practices to create an equal access experience for Deaf patients in medical and mental healthcare.

Barriers to Medical Care for Deaf Patients

A study by Reichard, Stolzle, & Fox (2011) compared Americans without a disability and Americans with a physical or cognitive disability to see if health disparities between these groups were present. The results of the study found that adults with disabilities in the United States who also have chronic health conditions received fewer preventative services and reported a lower level of health status when compared to individuals who did not have a disability but had the same chronic health conditions (Reichard et al., 2011). This suggests that the healthcare system is not effective in assisting people with a disability in regards to tertiary health prevention or that barriers exist in the current healthcare system which make it more difficult for those with a disability to access services.

Culturally Deaf people are also underserved and particularly vulnerable when it comes to emergency disaster response. Engelman et al. (2013) highlighted gaps in emergency preparedness training for the Deaf community provided by state agencies. When training is provided, it is not standardized, evaluated, or a significant part in the emergency management
infrastructure (Engelman et al., 2013). Additionally, the community-based organizations that
serve Deaf clientele also have gaps in emergency preparedness training (Engelman et al., 2013).
These gaps increase the vulnerability of the Deaf population and render them unable to prepare,
respond, or recover when emergencies arise (Engelman et al., 2013).

Deaf people are less healthy than the population as a whole. A recent clinical trial in the
United Kingdom (UK) assessed the health of the Deaf population compared to the hearing
population (Emond et al., 2015). In this cross sectional trial, 298 Deaf people aged 20-82 years
completed an interview and health assessment at clinics in the UK which utilized interpreters in
British Sign Language (BSL), the UK equivalent to ASL. The sample was stratified according to
age, race, and gender and modeled the current population of the UK. The rate of diabetes in the
Deaf population was similar to that of the hearing population in the UK. However, Deaf adults
had higher levels of risk factors for cardiovascular disease, hypertension, and diabetes (e.g., high
blood pressure, high cholesterol) and the prevalence of obesity was higher in the Deaf
population. In Deaf patients with diabetes, understanding of glucose tolerance was lower and
ability to maintain euglycemic control was less than that of the hearing patients with diabetes.
Finally, lower levels of smoking and alcohol consumption were reported in the Deaf population
when compared to the hearing population (Emond et al., 2015). A similar study by Barnett et al.
(2011) in the United States also found that the Deaf community had fewer current smokers and
higher levels of obesity. Due to these differences in health status between the culturally Deaf
population and the hearing population, it is necessary to determine what creates these disparities.

Challenges for Culturally Deaf people in Accessing Healthcare: Qualitative Literature

Sheppard (2014) sought to explain the experiences that Deaf adults have when they are
attempting to access and receive healthcare. Specifically, the author wanted to describe barriers
to accessing healthcare, communication barriers, and childhood experiences that Deaf adults had when they accessed healthcare in their past. In order to richly describe the experiences in a meaningful way, nine Deaf adults were interviewed and videotaped on three separate occasions for 30-60 minutes. An ASL interpreter translated the author’s voiced English questions into ASL so that the interviews could be conducted in the Deaf adult’s native language. The study was qualitative and hermeneutic in nature; this means that the interviews richly described the experience of the Deaf adults and also used the narrative to interpret the meaning of that shared experience. The participants were recruited in a purposive manner and any individual that was over the age of 18 and who self-identified as culturally Deaf was invited to participate.

The results suggested four themes including: 1) feeling depressed, 2) emotional chaos leading to depression 3) Deaf – not broken, and 4) reaching out. Emotional chaos consisted of the times they went to the doctor as children and the doctor did not believe that they were Deaf or continued to focus on the etiology of the deafness rather than accepting the child and handling the current healthcare concern. For Deaf adults, the feelings of pain and loneliness from these encounters led to feelings of depression. According to one Deaf adult, “The medical perspective is very different about deafness – a lot of deaf kids grow up with that medical, that pathological perspective you know, mom and dad don’t understand, so the kids, they hear, they’re broken” (Sheppard, 2014, pg. 507). The participants perceived the barriers in communication too overwhelming, so instead of participating in preventative healthcare, they most frequently visited the emergency room to access services. A quantitative study by McKee, Winters, Sen, Zazove, and Fiscella (2015) found similar results in that Deaf patients were significantly more likely to use the emergency department than hearing patients over the prior 36 months.
Other issues communication barriers highlighted by Sheppard (2014) related to an inability to lip-read the provider who was using spoken English. Sometimes, the Deaf patient asked the provider to communicate through writing and the provider was not willing or gave up communication efforts. Due to language barriers, the Deaf patients were confused and frightened about procedures that were done to them without ample explanation. Many Deaf patients leave encounters with providers without ever having their health needs addressed (Sheppard, 2014).

**Challenges Providers Face during Assessment of Deaf Patients**

There is a wide variety of language fluency in the Deaf population (Landsberger et al., 2013). A Deaf person may have a level of receptive language skills that exceed their ability in expressive communication, or the opposite may be true. Rates of language dysfluency among inpatients who are Deaf has been reported to be between 66%-75% (Landsberger et al., 2013). In a study that investigated the experience of a Deaf patient during a pharmacy visit, the Deaf patients reported that the pharmacy staff continued to use spoken language even though the staff member knew the patient was Deaf (Ferguson & Liu, 2015). The use of written communication was attempted, but the handouts that were provided tended to be complex and not understood by the Deaf patient (Ferguson & Liu, 2015). American Sign Language is a visual language that does not correlate to written English; Deaf individuals vary widely in their acquisition and understanding of written English and may be at risk for social isolation due to lack of communication (McKee et al., 2015).

Accurate assessment of pain is necessary knowledge when determining how to best manage patient pain. Unfortunately, current pain scale measurement tools used by nurses to assess pain level in patients have not been studied with members of the Deaf community and these scales rely on the patient being able to communicate in spoken language. Palese et al.
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(2011) conducted a qualitative study using descriptive phenomenology in order to gain a rich description of the ways that nurses administered different pain scales, the ways Deaf patients communicate their pain, and which pain scales were preferred by culturally Deaf individuals. During the first phase, 10 Italian nurses who had experience working with Deaf patients were selected to participate in a focus group regarding which types of pain scales were used for Deaf patients and how they administered the scales. Data was collected until data saturation was achieved. The nurses reported the use of four different pain scales with Deaf patients. Nurses utilized family members or caregivers as communication mediators, wrote on pen and paper, spoke slowly to facilitate lip reading, maintained eye contact, read the patient’s lips, had the patient communicate pain via the call bell, or called for a sign language interpreter in order to communicate with the Deaf patients. Based on the results of the first phase, a presentation was created for 16 Deaf Italian participants highlighting the Numerical Rating Scale (NRS), the Visual Analog Scale (VAS), the Faces Pain Scale (FPS), and the Iowa Pain Thermometer (IPT). The participants were asked to discuss the effectiveness of each pain scale and each way the nurses communicated with Deaf patients during a focus group (Palese et al., 2011).

The NRS is an 11, 21, or 101 point scale that rates pain between 0 (no pain) to 10, 20, or 100 (worst pain you have ever experienced). Deaf participants reported this scale as confusing because with many other scales a higher rating is used to describe a desirable situation, so the Deaf patients were rating themselves as having pain when in reality they had little or no pain (Palese et al., 2011). The nurses were unable to communicate effectively with the Deaf patients about instructions on how to rate pain with this scale (Palese et al., 2011). The VAS is a 100mm horizontal line and patients are asked to make a mark on the line to demonstrate pain level. A mark near the left represents less pain and a mark near the right represents more pain. Deaf
patients reported, “Written horizontally it has no meaning, it is only a line, whereas vertically it may give the idea of growth or an increase. Pain increases, from a low base to a high level. Exactly as it does in sign language” (Palese et al., 2011, pg. 96). Therefore, the Deaf participants did not think the VAS could adequately assess pain level for Deaf patients. The FPS is a pediatric scale that shows six different facial expressions and asks the participant to point to which describes their pain level. The Deaf participants stated, “Someone has to explain that the faces relate to the amount of pain and for what reason” (Palese et al., 2011, pg. 96). Since sign language is heavily reliant on facial expressions to communicate many different ideas, the Deaf participants could not understand that the faces of the scale related to their pain level and it is was not reported to be a useful scale to rate their pain. The Iowa Pain Thermometer (IPT) shows a vertically aligned thermometer that is colored white at the base and increases in intensity of red color to the top. Descriptors are on the right side of the thermometer and range from “no pain” to “The most intense pain imaginable”. The patient marks one of the 12 circles next to the thermometer to indicate the intensity of the current pain. In the Palese et al. (2011) study, the ITP was reported as be the most understandable for the Deaf. Unfortunately, the pain scales used most often by the nursing staff were not effective in assessing the pain level of a Deaf patient.

An additional issue with healthcare providers when they are caring for Deaf patients is that appropriate screening tests are not being ordered by providers. For example, a study by Berman et al. (2013) found that Deaf women reported doctors did not order a mammogram and this was a reason that the Deaf women did not receive adequate screening for breast cancer. The same study reported that 58.4% of Deaf women listed their primary care physician as a source of health information. If a Deaf patient does not receive education regarding screening tests and
they are not ordered for the patient it is difficult for the patient to receive appropriate preventative screening or attain optimal health.

**Challenges Deaf Patients Face when Accessing Healthcare**

It appears that communication is a major barrier that Deaf people face when attempting to access healthcare. For example, Ferguson & Liu (2015) sought to identify communication barriers and needs for Deaf and hard-of-hearing (D/HH) patients when they seek pharmaceutical care and to understand the impact of poor communication on medication compliance and medication errors among the D/HH population.

This qualitative study held focus group discussions with 20 participants that were videotaped for data collection. The sample was composed of D/HH individuals from the Midwestern United States who were over the age of 18 and who utilized ASL as their primary mode of communication. All participants were taking 2 or more long-term prescription medications and the mean number of medications taken among the group was 3. The barriers described among the focus groups were communication issues, medication use and safety, information resources, and satisfaction with pharmacy visits (Ferguson & Liu, 2015).

In the area of communication issues, the results suggested that D/HH did not understand the roles and responsibilities of the staff members in the pharmacy, were unsure who could help them and in what capacity each person could operate. Secondly, D/HH could not hear their name being called when the prescription was ready and they did not know how to advocate for their own communication needs. Finally, Deaf patients reported that ASL interpreters were not available at the clinic so patients went home and used video relay services to call the pharmacy and ask further questions (Ferguson & Liu, 2015).
Half of the Deaf patients in this study expressed confusion on how to take the prescription. The participants did not understand the side effects of the medication and lacked clarity on the generic vs. the brand name. Most importantly, one-third of the sample experienced an adverse event due to incorrect use of the medication which was not reported to the pharmacist (Ferguson & Liu, 2015). Deaf patients received their information from a variety of resources. All of the participants stated that they went to their children for help with understanding how to take their medications, some stated they asked their friends or spouse, and only 10% of the sample asked the pharmacist questions directly through the video relay ASL interpreter (Ferguson & Liu, 2015). Seven of the 20 participants considered their primary care physician as the main source of information regarding medications with an ASL interpreter present while three participants consulted the internet for information about medications (Ferguson & Liu, 2015).

Half of the patients reported adequate satisfaction with pharmacy visits and services. The only factor that patients considered when rating satisfaction was whether or not they received the medication. Satisfaction was not correlated with the amount of education received about the medication (Ferguson & Liu, 2015). Deaf people were unsure which pharmacy staff to ask questions regarding health information and were unaware that pharmacists could educate patients regarding medications and take the blood pressures (Ferguson & Liu, 2015). Of the 20 participants, four reported they had never received education on the proper way to take their medications (Ferguson & Liu, 2015).

Deaf people have a lower level of health literacy when compared to hearing peers. McKee et al. (2015) adapted and validated a previously used instrument called the Newest Vital Sign (NVS) that measured health literacy and could be translated into ASL. The main goal of the study was to document the prevalence of the lack of health literacy among the Deaf in
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comparison to hearing peers utilizing this new measurement tool in a cross-sectional study design. The NVS measures individual health literacy by determining how many questions (out of six) a person can accurately answer when looking at a nutrition label and is an optimal tool to assess health literacy in healthcare settings (McKee et al., 2015). Respondents were labeled with “inadequate health literacy” if they answered zero or one item correctly, “at risk for limited health literacy” if they answered two to four items correctly, and “adequate health literacy” if they answered five or six items correctly (McKee et al., 2015).

The study participants consisted of 405 individuals that were between the ages of 40-70 (McKee et al., 2015). Of the 405 participants, 239 were hearing and 166 were Deaf ASL users from Rochester, NY that were recruited through convenience sampling. McKee et al. (2015) controlled for gender, ethnicity, age, education, and income when they ran the statistical analysis and found that Deaf adults were significantly more likely to have inadequate health literacy when compared to their hearing counterparts. Specifically, the Deaf participants were 6.9 more times likely than hearing participants to fall into the “inadequate health literacy” category (McKee et al., 2015). Deaf participants also had fewer correct answers regarding cardiovascular health knowledge when compared to hearing individuals (McKee et al., 2015). The Deaf participants who had inadequate health literacy were more likely to have a lower education level, lower English reading literacy, lower income, and were older than the Deaf participants who had “adequate” or “at risk” health literacy (McKee et al., 2015).

A study by Yao et al. (2012) investigated baseline knowledge about cervical cancer and cancer in general in Deaf women who were ASL users and hearing women. Yao et al. (2012) hypothesized that Deaf women would have less cancer knowledge than hearing women at baseline. After viewing a cervical cancer education video in ASL with English subtitles and
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voice over, the authors hypothesized that both groups would have a significant increase in knowledge and this gain would be equal for both groups. The quantitative prospective cohort study included 127 Deaf women aged 19-93 and 106 hearing women aged 18-85 all who lived in Southern California or Central Wisconsin (Yao et al., 2012). At baseline, Yao et al. (2012) found that the Deaf women had less general cancer knowledge, cervical cancer knowledge, and total cancer knowledge than the group of hearing women.

A similar study was conducted regarding breast cancer knowledge of Deaf adults. Breast cancer is the most common type of cancer in women (American Cancer Society, 2016). Hickey et al. (2013) assessed the breast cancer knowledge and screening behaviors of 122 Deaf women in southern California who were ASL users and over the age of 18. The study was quasi-experimental and tested breast cancer knowledge prior to viewing an educational video in ASL, after viewing the video, and two months after watching the video to determine how much of the information the participants retained. At baseline, participant rating of perceived breast cancer knowledge and actual breast cancer knowledge was significantly positively correlated, which suggests that those who felt they had deficient knowledge performed poorly on the breast cancer knowledge questionnaire when compared to those participants who perceived they had a lot of prior breast cancer knowledge (Hickey et al., 2013). A little less than half of the participants (49%) reported they had little or no information about breast cancer. The women over age 40 who were adherent with the national breast cancer screening recommendations had greater breast cancer knowledge than those who did not follow the screening recommendations (Hickey et al., 2013).

Another study regarding breast cancer knowledge amongst Deaf women was conducted by Berman et al. (2013) and included 209 participants in southern California over the age 40 who
were not breast cancer survivors, did not have college degrees, and were native ASL users. The results showed incomplete knowledge among Deaf women regarding breast cancer and women with lower levels of education, income, and membership in a racial/ethnic minority had the lowest levels of breast cancer knowledge. Women who were over age 60, Caucasian, and women with higher income levels were more likely to have correct knowledge regarding breast cancer.

Deaf women reported inconsistent knowledge in regards to screening for breast cancer, risk factors for acquiring breast cancer, and information about breast cancer treatment and factors that can aid in a successful recovery. Approximately 46% of the sample reported age 40 as the appropriate age to start screening for breast cancer through mammography and 85% of participants stated that mammography should occur every year or every two years, however only 65% of the subjects knew that the goal of mammography was to provide a picture, diagnose cancer, and show problems with the breast (Berman et al., 2013). The women listed incorrect risk factors for acquiring breast cancer such as bumping the breasts and did not recognize accurate risk factors such as age and obesity (Berman et al., 2013). Only 51% of the sample knew the purpose of a biopsy and even less women (35%) were able to correctly state the goal of chemotherapy in breast cancer (Berman et al., 2013). The majority of the sample (75%) knew that early cancer diagnosis increases the chance for a successful recovery.

In addition to gaps in knowledge regarding breast cancer, Berman et al. (2013) highlighted communication difficulties and lower screening rates for breast cancer among Deaf women when compared to the rate of breast cancer screening in the population of hearing Californian women. Specifically, Berman et al. (2013) reported that the Deaf population is at a greater risk for miscommunication during a healthcare encounter when compared to people who speak languages other than English. This study found that 10% of Deaf women had never been
screened for breast cancer and only 57% of Deaf women were compliant with the national screening recommendations for breast cancer. This rate was substantially lower than the 79% screening rate of Californian hearing women (Berman et al., 2013).

System-Wide Failures in the Delivery of Healthcare to Deaf Patients

A potential issue within the system of healthcare is the lack of funding directed towards equal access provisions. The Federal government has provided funding for equal access for Deaf people in some areas. For example, qualified Deaf individuals are eligible to receive a free videophone (VP) through the Federal Communications Commission (FCC) which is mandated by the ADA so that equal access to telecommunication services can exist for Deaf people (Wilson & Schild, 2014). To date, the Federal government has not provided funding to ensure that ASL interpreters are providing quality interpretation (e.g., have a license), or that interpreters can be accessed easily in all situations. Ferguson & Liu (2015) reported that Deaf people were unable to find ASL interpreters in places such as the pharmacy. In addition, health insurance providers do not reimburse for services such as telehealth which would allow a Deaf person to easily access care in the native language of ASL (Wilson & Schild, 2014). Additionally, research suggests that Deaf patients miss information when they attempt to lip-read or use pen and paper for communicating with healthcare staff and this type of communication is frequently attempted during visits with healthcare providers (Palese et al., 2011).

An additional issue with the medical system is the lack of cultural sensitivity on the part of the medical staff and this is not limited to professionals in the United States. A study in Brazil surveyed nurses who had worked with Deaf patients who use Brazilian Sign Language (Machado et al., 2009). The nurses reported that they did not understand the purpose of Brazilian Sign Language (BSL) and assumed that it was equivalent to spoken Brazilian language. In addition,
nurses reported they had not been instructed about Deaf culture during nursing school (Machado et al., 2009). All of these inconsistencies in the healthcare system make equal access to healthcare for the Deaf improbable unless changes are made to enable access.

**Barriers to Mental Health Care for the Deaf**

Challenges in establishing effective communication between a Deaf client and the healthcare provider can be caused by language disparities on the part of the provider or the client (Levine, 2014). Research has found that only 2% of Deaf people that would benefit from mental health services actually receive these therapies (Wilson & Schild, 2014). In the medical care arena, Deaf patients are likely to request a licensed ASL interpreter for clear communication between a non-ASL healthcare provider and the Deaf patient. However, in the mental health arena, a qualitative study with Deaf adults found that Deaf adults did not want an ASL interpreter for mental healthcare and would prefer a clinician that was fluent in ASL (Sheppard & Badger, 2010). Another qualitative study by Cabral, Muhr & Savageau (2013) investigated the mental health experiences of the Deaf and hard of hearing adults in the mental health system of a large metropolitan city in Massachusetts. The Deaf participants reported a theme of “stigma” within the Deaf community regarding mental health illness and described the stigma using four facets. Two of these facets apply to the potential reason why a Deaf client would prefer a signing mental healthcare provider. First, the Deaf and hard of hearing community lacks proficiency in knowledge regarding mental illness and do not have an understanding of people who have a mental illness. The Deaf participants felt that a hearing person who had a mental illness would be able to understand mental illness better than a Deaf person, but would not able to communicate effectively with a Deaf person with mental illness for support purposes. Second, the Deaf participants reported a high level of gossiping within the Deaf and hard of hearing community.
Deaf people with a mental illness felt that their information would not be kept private or confidential by anyone, which included the ASL interpreter (Cabral et al., 2013). The Deaf respondents also reported that there are not enough mental health clinicians that are fluent in ASL and if they wanted to request an ASL interpreter that there was either no interpreter available, the wait time for an interpreter was long, or the interpreter was not skilled in providing clear and accurate interpreting services (Cabral et al., 2013).

Accurate diagnosis of a mental health disorder is challenging when working with the Deaf population and the degree of language fluency of the Deaf patient directly impacts the ability of the provider to determine an accurate diagnosis. The terms used in mental health assessment by clinicians such as “psychosis” and “depression” are abstract and results of a research trial reported that only 22% of Deaf and hard of hearing respondents understood the meaning of psychosis (Cabral et al., 2013). Sheppard & Badger (2010) found variation among how Deaf people described “depression” and some could not understand the term in ASL or English. If the patient does not understand these concepts that are being asked about during a mental health exam and language skills are limited, this may lead to a poor assessment and an incorrect diagnosis followed by ineffective interventions (Cabral et al., 2013).

Mental health clinicians generally assess a patient for language dysfluency (e.g., odd and unusual expressions of language coupled with behavior observation) which can be an indicator of a mental illness diagnosis (Glickman, 2007). However, if a Deaf person was deprived of language from an early age they may show a high level of language dysfluency even in their best efforts to communicate. For example, researchers have reported that Deaf patients with schizophrenia are more likely than hearing patients with schizophrenia to report having visual hallucinations with at least one out of two Deaf patients reporting hallucinations (Landsberger &
Diaz, 2010). However, current research suggests that the visual hallucinations reported by Deaf people with schizophrenia could actually be sub-visual precepts (e.g., having the feeling that someone is communicating via ASL to them in their mind’s eye, perception of lips moving) and not true visual hallucinations that are reported by hearing people with schizophrenia (Landsberger & Diaz, 2010). Mental health clinicians may not be able to determine if language dysfluency is related to mental illness, deprivation of language, or both (Glickman, 2007).

Mental health treatment for the Deaf is a challenge and there have been several studies which focused on the Deaf in the inpatient mental health setting. Baines, Patterson, & Austen (2010) found that Deaf inpatients were likely to remain hospitalized for mental health twice as long as hearing peers. Explanations of these differences were possibly related to lack of appropriate rehabilitation services, lack of provision of outpatient services, and lack of appropriate community support (Baines et al., 2010).

An additional study regarding Deaf patients and inpatient mental health treatment was conducted by Hartman & Blalock (2011) who gathered retrospective information from a state mental health hospital database in Oregon using a case control study design. The Deaf or hard of hearing group had 22 people who had been hospitalized for mental health and matched them a hearing group that had similar age, length of hospitalization, gender, and behaviors that had a high potential of needing restraint and seclusion (Hartman & Blalock, 2011).

Hartman and Blalock (2011) found that the Deaf/hard of hearing group had a higher total number of seclusions/restraints and a higher monthly average of seclusion/restraints than the hearing group. Although the Deaf/hard of hearing group were more frequently restrained, the hearing group had a longer average length of restraint (i.e., spent more time being restrained) than the Deaf/hard of hearing group. The authors surmise that due to a lack of communication
between the staff and the Deaf patients that restraint was being used sooner with Deaf patients and that Deaf patients were able to calm themselves more quickly and were released from restraint quicker than the hearing patients (Hartman & Blalock, 2011).

Deaf people may not seek out mental health treatment or have knowledge about mental health illness for a variety of reasons. First, prior research regarding Deaf adult attitudes and beliefs about mental health practitioners and institutions revealed Deaf adults believed these practitioners and institutions were restrictive and prejudiced (Wright & Reese, 2015). This is similar to an earlier study that found Deaf people harbored expectations of authoritative or rejecting mental health practitioners (Wright & Reese, 2015). In addition to distrust of mental health providers, Deaf people do not know how to obtain mental health services and may have a general lack of knowledge regarding the availability of these services (Wright & Reese, 2015). Members of the Deaf community are likely to learn incorrect information about mental health issues from other members of the Deaf community because there are limited opportunities for the Deaf community to increase mental health literacy or become aware about service and educational resources (Mathos & Pollard, 2016). The Deaf community is often isolated from the plethora of educational materials that are in written English or auditory formats (Wright & Reese, 2015). In the Deaf community, it is common to share information between members in addition to providing advice, support, and informal counseling rather than seeking professional mental health treatments from hearing providers (Wright & Reese, 2015). Finally, there is limited access to evaluation or therapy for mental health disorders, case management, mobile therapy, group therapy, housing resources, and drug and alcohol treatment programs for the Deaf (Mathos & Pollard, 2016).

**Current Practices in Healthcare for Deaf Individuals**
**Medical Healthcare**

Currently, it appears that the majority of medical health providers are not providing culturally sensitive care. First, Sheppard (2014) found that a lack of communication occurred when Deaf patients attempted to receive medical care. These Deaf patients felt the health care encounters were meaningless and reported hospital settings and clinics as being scary and intimidating (Sheppard, 2014). Additionally, they reported the nurses and doctors as being impatient providers (Sheppard, 2014). Health care providers are not using appropriate body language with Deaf patients and heavily rely on the Deaf patient to lip-read a conversation or write notes back and forth in English for communication (Sheppard, 2014). Hearing providers may look around the room instead of maintaining eye contact with the Deaf patient. However, Deaf people rely on facial expression and eye contact for communication (Sheppard, 2014).

New graduates of health professions have been shown to have a lack of knowledge regarding culturally sensitive care for Deaf patients. A study of recent genetic counseling graduates found that 26% reported no Deaf awareness training and 51% reported a 60-120 minute training provided by instructors of the college (Nagakura, Schneider, Morris, Lafferty, & Palmer, 2014). Almost one third of the sample felt their training was inadequate and did not provide them with the knowledge to provide culturally sensitive care for Deaf patients (Nagakura et al., 2014). Additional research found similar results among medical students and reported that more than half of the students had no previous interactions with the Deaf culture, had little experience with medical sign language, and were not informed about ASL or Deaf culture (Lapinski, Colonna, Sexton, & Richard, 2015; Thew, Smith, Chang, & Starr, 2012). Nurses in Brazil reported little or no knowledge about the needs Deaf people have for adequate communication and stated they used mime, lip-reading, writing most frequently to communicate
with the Deaf person and rarely used drawing or a BSL interpreter (Machado et al., 2009).

Nurses in Greece had a lack of relevant knowledge and education regarding Deaf clients, but most expressed interest in attending an educational program (Velonaki et al., 2015). Finally, many members of the medical and scientific community view deafness from a pathological viewpoint and continue to suggest to the Deaf patient that they need to cure their deafness rather than accepting that a Deaf person may instead have pride as a member of Deaf culture and do not have a need for a “cure” (Thew et al., 2012; Landsberger et al., 2013). Deaf people may feel alienated which can lead to avoidance of health care, or seeking care at the last possible moment at the ER rather than participating in health promotion or prevention activities (Sheppard, 2014).

Inadequate assessment of Deaf patients is taking place within the healthcare setting. First, nurses are utilizing a numerical pain scale that can be misunderstood by Deaf patients and has not been normed for use among the Deaf community (Palese et al., 2011). Providers may not feel it is necessary to gauge the level of a patient’s proficiency in written English prior to providing an assessment tool to the Deaf patient which can result in inaccurate assessment. Pollard & Barnett (2009) found that Deaf adults (81% of whom had a college degree) demonstrated a risk for low health literacy and 32% of the sample were unable to comprehend health-related terms that people competent in health literacy understand. Because the majority of the sample had advanced degrees, it was believed that the general Deaf population is at even greater risk for low health literacy (Pollard & Barnett, 2009). Deaf people do not have access to educational tools that may help them attain adequate health literacy given that the majority of educational material is provided in written English or through auditory methods (Pollard & Barnett, 2009; Berman et al., 2013). The combination of these disparities makes it unlikely that a thorough and accurate assessment of the Deaf patient by a health care provider can be performed.
Nolan, Mathos, Fusco, & Post (2015) surveyed existing behavioral healthcare providers for the Deaf, Deafblind, or Hard-of-Hearing in the United States regarding structural and process domains of care. Nolan et al. (2015) found that 133 facilities served mainly adults, provided mental health services including therapy, assessments, and outpatient care to the Deaf population. The majority of facilities were integrated deaf/hard-of-hearing programs inside of a larger hearing persons’ program (n = 60), followed by a private practice (n = 44), freestanding clinic (n = 15), and training program (n = 14). Approximately 65% of the facilities served a single city, county, or multicounty region and over 40% of the facilities accounted for locations in New York, Pennsylvania, California, and Maryland while 18 states do not have any providers.

In regards to private practitioners, 81.8% reported accepting private insurance and 50% reported they provide services for non-insured individuals, while less than one half of private practitioners reported accepting Medicaid or Medicare (Nolan et al., 2015). This is an important finding because many mental health services are not deemed necessary and are left to state discretion on whether or not to provide them. Psychiatrist services are mandatory, but psychologists, clinical social workers, case management, and outpatient mental health services are optional (Nolan et al., 2015). The highest percentage of office-based services were mental health screening and assessment (73.7%) and outpatient counseling (77.4%) while the majority of community-based services were case management (59.4%) and behavioral management (42.9%) (Nolan et al., 2015). There were only nine community treatment teams (CTT) or assertive community treatment (ACT) services fluent in ASL. Behavioral health referrals to vocational rehabilitation centers occurred at 78.6% of training programs, 72.7% of private practices, and 71.7% of integrated programs. Freestanding clinics collaborated with case managers (100%), schools (93.3%) and other Deaf organizations (100%) within the community
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to support Deaf outreach. The researchers reported that despite fervent recruitment efforts to locate providers that treat Deaf patients with mental health illness, there are not enough services across the country to adequately meet the needs of the population (Nolan et al., 2015).

Finally, the healthcare system as a whole is not providing licensed ASL interpreters to Deaf patients when requested or to Deaf caregivers that may be responsible for taking care of a sick child who can hear (Ferguson & Liu, 2015). There are many settings where it is difficult for a Deaf patient to get an ASL interpreter such as the pharmacy, at a primary care visit, and at the ER (Ferguson & Liu, 2015; Middleton et al., 2010). Potential reasons for the lack of qualified ASL interpretation is cost, lack of qualified interpreters, or lack of knowledge on the part of the health care facility regarding the ADA law.

Mental Healthcare

Only 2% of Deaf people with a mental illness are receiving care (Wilson & Schild, 2014). Despite the increase in access to mental health services via telehealth and videoconferencing, there are still disparities in access to and quality of mental health care as well as differences between specialist versus non-specialist treatment programs (Fellinger et al., 2012). An example of this is that Deaf patients in psychiatric units stay twice as long as their hearing counterparts due to a lack of services once they are discharged (Fellinger et al., 2012). Additionally, providers in primary care are not adequately screening Deaf people for mental health disorders. Sheppard (2014) found that Deaf people reported their medical providers had not asked them about feelings of depression or suicide attempts during the course of the visit. Additionally, there are a limited number of psychiatrists, psychologists, counselors, and social workers that specialize in serving the Deaf population (Mathos & Pollard, 2016).
There appear to be age related differences among mental health care practices between older and younger Deaf patients that mental health professionals should consider when providing culturally sensitive care. In a cross-sectional study of 173 Deaf participants that attended a conference for the Florida Association of the Deaf, the subjects were grouped into either 18-34 years (i.e., “young adult”), 35-54 years (i.e., “middle adult”), 55-65 years (i.e., “older adult”), and 66+ years (i.e., “elderly adult) and surveyed regarding perspectives and preferences for existing mental health services for Deaf adults (Feldman & Gum, 2007). Although there were no differences between the groups regarding preferred age, gender, and hearing status (i.e., Deaf or hearing) of the mental health professional, the results of the study found differences regarding preference for a signing practitioner. Specifically, younger adults were slightly more open to the use of an interpreter. All Deaf adults of all ages preferred a mental health professional who could communicate in ASL and sparsity of signing mental health practitioners was listed as a barrier to treatment (Feldman & Gum, 2007). Additionally, older adults were less aware of existing mental health services, less trusting of mental health professionals, and less likely to know which provider to see for mental health services (Feldman & Gum, 2007). Mental health practitioners should be aware of potential differences in the Deaf person with mental illness related to age.

There have been some efforts to create task forces to address the mental health disparities that affect the culturally Deaf. An example is the “Daylight Project” that was a task force by the Colorado Commission for the Deaf and Hard of Hearing which created a Standards of Behavioral Health Care guide that suggested best practice for communication access and clinical practice where Deaf people are concerned (Mathos & Pollard, 2016). Task force efforts attempt to fix the problem before it occurs. This is in contrast to the reactive efforts after Deaf consumers brought forth law suits when they had experienced inequities in states such as Pennsylvania
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(Mathos & Pollard, 2016). After the wake of a lawsuit, advocates, providers, lawyers, and program planners attempt to improve the public mental health services for the Deaf but it may not create long-lasting change (Mathos & Pollard, 2016)

**Interventions for Communication Barriers at the Provider Level**

Communication has been reported in the literature as a major barrier that Deaf patients encounter when accessing medical and mental healthcare. Interventions need to be implemented to overcome these barriers. There have been evidence-based interventions which focused on alleviating the communication barrier that involves the healthcare provider.

**Assessment of Communication Level of the Deaf Patient**

When a Deaf patient arrives at a clinic visit for medical or mental healthcare, it is important to assess what mode of communication works for the patient. Additionally, the healthcare provider needs to be able to determine the level of communication fluency the patient is exhibiting. Ferguson & Liu (2015) reported that a literacy assessment coupled with effective communication is essential when working with Deaf people to ensure safe medication use and optimal health outcomes.

A large, cross-sectional study of d/Deaf people in the United Kingdom was conducted to determine the communication preferences of this group during medical consultations (Middleton et al., 2010). Just over 1,000 people returned the survey via postal mail. During everyday life, 11% of the participants used BSL, 70% used speech, and 17% used a mixture of BSL and speech. When asked about communication preferences during a clinic visit, 50% of the BSL users preferred to have a healthcare visit with a BSL interpreter present while 43% wanted to have the visit directly with a healthcare professional that had BSL proficiency. Only 7% stated they would be accepting of a visit using spoken language as long as the provider had adequate
Deaf cultural competence and knew about lip-reading/speech-reading (Middleton et al., 2010). As was noted in this study, it appears that sign language users vastly prefer either a sign language interpreter, or a provider who utilized sign language to communicate (Middleton et al., 2010).

Assessment of communication level is particularly important for mental healthcare providers. Horton (2010) recruited 102 Deaf consumers who had schizophrenia or schizoaffective disorder to determine if sign language ability uniquely contributed to levels of functional status over and above cognition and social cognition. Horton (2010) found that functional status was positively correlated with linguistic ability such that superior linguistic ability was significantly associated with higher levels of functional outcome. Additionally, a multivariate regression that included linguistic ability, cognition, and social cognition as related to functional outcome found that 43% of the variance in functional outcome could be explained by all three variables and of that 23% was explained by linguistic ability alone. Fellinger et al. (2012) reported similar findings. Deaf people with a low level of language ability also tended to have more psychosocial difficulties and that those with high levels of language had the same incidence of psychosocial difficulties as their hearing peers. It is critical to assess use of language, communication behavior, and cognitive functioning to avoid misdiagnosis of a person’s mental state (Fellinger et al., 2012). Finally, standardized tests and measures of mental health that are normed off of hearing individuals are not valid for use in the Deaf population (Fellinger et al., 2012). The average level of written English of the Deaf is at the 4th grade level. Each Deaf person is unique in level of ASL fluency (Cabral et al., 2013).

Cabral et al. (2013) found that Deaf people reported an ‘internal stigma’ associated with thoughts about mental health care providers in that hearing mental health clinicians were seen as having more knowledge about mental illness than Deaf or hard of hearing mental health
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clinicians. Deaf people with mental illness reported wanting peer support from another Deaf
person due to the similar language and sometimes wanted to communicate with another person
with mental illness (Cabral et al., 2013). The Deaf clients pointed out that a peer support group
was not as effective because Deaf people have differing ASL capabilities and therefore need
more therapists who can communicate in ASL. Additionally, the term ‘recovery’ was not
understood by the majority of Deaf people in the study due to lack of literacy capacity or lack of
education about mental health and illness (Cabral et al., 2013). Finally, some Deaf people
connected the concept of ‘recovery’ with the sign for ‘get better’ or ‘improve’ and had an idea
that the recovery process is possible but hard.

Language Concordant Providers

Access to ASL interpreters is legally mandated, but there may be times when it is
appropriate for a provider to communicate with the Deaf patient directly in ASL. A quantitative
cross-sectional study of 89 Deaf participants aged 50-75 years old across the United States was
investigated to determine if the language utilized by the provider (i.e., ASL providers were
named “language concordant providers”; providers who did not use ASL were called “language
discordant providers”) had an impact on the Deaf person’s use of preventative services.
Respondents who reported that their provider was language concordant were 4.55 more times
likely to report receiving a flu vaccination than those with a language discordant provider
(McKee, Barnett, Block, & Pearson, 2011). Similarly, the language concordant provider group
was 3.42 times more likely to report receiving a higher number of preventative services over the
last year than the language discordant group (McKee et al., 2011). In the language discordant
provider group, 17.2% of Deaf clients reported receiving either none or one preventative service
within the last year, 41.4% reported receiving two preventative services, and 41.4% reported
receiving three or more preventative services. In the language concordant provider group, only 3.2% of the Deaf clients reported receiving either none or one preventative service within the last year, 32.3% reported two preventative services, and 64.5% of the group reported receiving three or more preventative services within the past year (McKee et al., 2011).

As previously mentioned, in mental health, language concordant providers are particularly necessary because Deaf people report they would prefer to have a provider that can use ASL and would not want an ASL interpreter due to privacy reasons (Sheppard & Badger, 2010). Interpreters and the Deaf people they serve form close relationships and the Deaf client may feel awkward sharing personal information about their mental health. Additionally, the Deaf community is tightly knit and there is a high level of fear regarding gossip spreading around the community and Deaf people see the interpreter as a potential source of gossip even though their job requires confidentiality (Sheppard & Badger, 2010). Young Deaf people are more willing to use ASL interpreters for mental health services than older Deaf people (Fellinger et al., 2012). Deaf participants in the Cabral et al. (2013) study stated that more ASL proficient counselors are needed for the optimal care of Deaf people with mental health illness. Finally, inaccessibility to mental health services for the Deaf population is largely related to the lack of culturally and linguistically competent providers (Wilson & Schild, 2014). A provider needs a strong foundation in mental health issues amongst the Deaf population, proficiency in ASL, and understanding of biological, developmental, vocational, legal, educational, cultural, and social components of the Deaf (Wilson & Schild, 2014).

When the term “language concordant provider” is mentioned, an image of a hearing person who uses ASL to communicate with a Deaf patient may come to mind due to the assumption that many health care or mental health care providers are from the hearing
population. However, a Deaf provider and Deaf patient combination also provides a language concordant situation. For example, in 1999, lead nurses and senior clinicians from the United Kingdom National Services for Mental Health and Deafness came together with the English National Board for Nursing and Midwifery and established the first Deaf People’s Access to Nursing Project (DPANE) (Sharple, 2013). This project had the goal of providing functionally equivalent mental health services for Deaf people. In order to do that, Deaf health professionals needed to be trained in roles where they could directly work on a clinical level with Deaf patients (Sharple, 2013). By 2006, there were eight Deaf, signing, qualified mental health nurses on the Nursing and Midwifery council registry which is similar to registered nurse (RN) status in the United States (Sharple, 2013). As of 2012, the number of Deaf qualified nurses rose to 10 in the United Kingdom (Sharple, 2013). Sharple (2013) conducted a qualitative study of the viewpoints of five nurses who had gone through the program and maintained their anonymity. The nurses reported that for their Deaf clients, BSL was a resource to the clients, was preferable to receiving nursing care in spoke language, and provided a way to support minority language users and promote inclusion and diversity within the healthcare setting. However, if the institution where the Deaf nurse worked did not have a culture that supported this diversity, it made it difficult for the nurse to feel accepted with nursing peers, administrators, and other hospital staff (Sharple, 2013). The Deaf nurses also reported that they were able to empower and advocate for the Deaf patients in ways that hearing nurses could not because the hearing nurses are not a part of the minority group that has been marginalized (Sharple, 2013). One Deaf nurse reported negotiating with psychiatrists to provide an interpreted assessment for a client and another Deaf nurse taught Deaf children how to use the power of communication to engage with the world around them (Sharple, 2013). In order to be successful, the Deaf nurses
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had to figure out how to manage linguistic, professional, gender, and community power issues and at the same time remain clinically proficient and culturally sensitive (Sharples, 2013).

Telehealth/Use of Video Relay Services

Studies have shown that the use of ASL through telehealth with Deaf individuals is linguistically equivalent to a face-to-face interaction in a scenario when specific directions were given using both methods and in addition allows a patient to be seen at more regular intervals, for a longer appointment duration, and there were annual savings on travel costs for both the Deaf person and the provider (Wilson & Schild, 2014). In regards to VRS services, Deaf people reported utilizing this service when interacting with pharmacists after picking up their prescriptions and going back home to make the call as was reported in the Ferguson & Liu (2015) study. This interaction went smoother if the pharmacist was knowledgeable about how to accept a VRS call, communicate on the call, and could take the time to answer all questions (Ferguson & Liu, 2015). There is a lack of outcome studies utilizing telehealth in mental illness of Deaf people, therefore it is unknown if the treatments provided via telehealth are as successful as those provided face-to-face.

Ways to Communicate with the Deaf Patient

In general, there have been some suggested ways to communicate with a Deaf person that would be more accepted by the Deaf culture. In the Palese et al. (2011) study, some Deaf participants thought it was appropriate to use a family member as a mediator for communication, while others felt that they wanted to communicate independently. Using written communication with pen and paper was not an effective method of communication due to lack of correlation between signed language and written language (Palese et al., 2011). Lip reading, slow speaking, and other methods to try to communicate with a spoken language were not effective, mainly
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because lack of adequate lighting, or the opposite situation where there was too much light which decreased visibility (Palese et al., 2011). Finally, having a sign language interpreter is useful for some Deaf patients, however if the Deaf person has intravenous access in a place where they cannot move their hands effectively, the level of communication they are able to express using sign language will be limited (Palese et al., 2011).

Fellinger et al. (2012) highlight additional recommendations on how to interact with Deaf patients based on a review of the literature. The most important thing to do is ask the Deaf patient regarding his or her preferred method of communication and if it is ASL, obtain a qualified interpreter. When engaging with the patient, maintain eye contact as this is considered polite in Deaf culture and a main way of communicating. Do not rely solely on lip-reading for communication due to the increased risk of ineffective communication using this method. When speaking, ensure that the Deaf person has the best possible view of your face that is not directly in front of a light source and speak in simple language using short sentences. Avoid vague terms, over enunciating, and speaking overly slowly. Communicate first and then act because doing both of these at the same time can cause confusion. Realize that it takes more time to communicate effectively with Deaf clients and schedule adequate time for an appointment. Check for comprehension via return demonstration and do not ask the patient if he or she understood because nodding “yes” does not equal comprehension (Fellinger et al., 2012).

If written information is created and given to a Deaf patient such as instructions for medication use and details regarding medication action and side effects, it must be appropriately adapted for a Deaf audience. Suggestions made by the Deaf individuals in the Ferguson & Liu (2015) study were 1) bigger writing on medication bottles including larger print for warnings 2)
making the wording for warnings simple and clear 3) print the information with pictures to highlight warnings and dosing schedule and 4) use list format, not paragraphs for information.

An especially important finding by Zazove, Mcador, Reed, & Gorenflo (2013) regarding the English comprehension of a sample of 106 Deaf adults highlights the need for provider to adequately assess the English comprehension of each Deaf patient. The subjects with higher communication and greater healthcare visit satisfaction scores were also more likely to have a higher English comprehension score. Therefore, increasing the English reading level of Deaf people might help improve communication, but in the meantime if communication in English is happening between a healthcare provider and a Deaf patient it is critical that providers use the level of English that is at the patient’s reading level (Zazove et al., 2013).

**Interventions for Assessment Techniques and Screening**

Ensuring thorough and adequate assessment of the Deaf is challenging. Interventions need to be instituted to ensure assessment data that is gathered is accurate. The following findings were highlighted in the research regarding more effective screening tools and assessment techniques when working with the Deaf population.

**Iowa Pain Thermometer**

When assessing the level of pain that a culturally Deaf person has, it is important to use a scale that is most understood by this population. Palese et al. (2011) found that Deaf people stated the Iowa Pain Thermometer was more understood than the traditional numerical pain assessment scale. As with any assessment tool, it is imperative to provide education regarding the scale prior to use in the communication format that is best understood by the client. After the education is provided, the client should be asked to explain what they understood so that further clarification can be provided if the initial teaching was not successful (Fellinger et al., 2012).
**Newest Vital Sign**

Assessment of the health literacy level of a Deaf person is a priority to obtain when planning interventions to increase level of health literacy. However, an assessment tool to determine health literacy in the Deaf patient had not been created or tested. McKee et al., (2015) created an instrument called the ASL Newest Vital Sign (ASL-NVS) that was designed to determine the level of health literacy a Deaf person has and if they are at risk for having inadequate health literacy. The sample consisted of 166 Deaf ASL users aged 40-70 from Rochester, NY. The ASL-NVS was found to have criterion validity and test-retest reliability and was found to be a useful tool in gauging health literacy of Deaf ASL users (McKee et al., 2015).

**Assessment Tools for Mental Health**

Mental health assessments generally include the use of self-report assessment tools to determine the presence of mental illness. However, these scales have not been tested and validated for the Deaf population. A study in the United Kingdom had a goal of translating three well-known mental health assessment tools for the hearing population into British Sign Language (BSL) and validating these scales in the British Deaf population (Rogers et al., 2012). The first scale, the Patient Health Questionnaire (PHQ-9) is a 9 item scale that measures depression levels and has been found to have good test-retest reliability in the hearing population. The second scale, the Generalized Anxiety Disorders (GAD-7) scale is a 7 item scale that measures presence of a generalized anxiety disorder and was found to have good reliability as well as criterion validity amongst the hearing population. Finally, the Work and Social Adjustment Scale (WSAS) investigated five items related to work and social functioning and had an internal reliability ranging from 0.79-0.94 in a hearing population. Rogers et al., (2012) translated the assessments into BSL, and asked Deaf people over age 16 years to complete the
mental health assessments online and received 136 respondents. The majority of the sample had not had a mental health difficulty in the past 12 months (n = 88), while the remainder of the sample had some mental health difficulties in the previous 12 months (n = 25) (Rogers et al., 2012). Internal reliability was good for all three measures that had been translated into BSL. A potential difference between the Deaf and hearing population was found in that the hearing population showed only one component of depression, while the concept of depression within the Deaf population had two distinct facets (Rogers et al., 2012). This study demonstrated the feasibility of translating standardized mental health assessments into signed language for the use of assessing mental health of a Deaf person (Rogers et al., 2012).

A more recent study by Rogers, Evans, Campbell, Young, & Lovell (2014) investigated a general, not diagnosis specific measure called the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) that can be used for determining global well-being as well as risk to self and others. This measure was translated into BSL and 136 participants provided data online. The researchers also provided an English version of the scale for d/Deaf people to complete. The results of this measure found that for the English version of scale, the non-risk scores had excellent internal reliability, but the risk and functioning domains when completed by a Deaf person had lower internal reliability than when compared the BSL version. This suggests that it may not be feasible to gather accurate data from Deaf populations in an English written format and that it would be better to use a scale that has been translated into BSL and normed on the Deaf population (Rogers et al., 2014).

**Interventions for Increasing Health and Mental Health Literacy in the Deaf**

Research has shown that Deaf people are at risk for low levels of health literacy (McKee et al., 2015; Yao et al., 2012; Hickey et al., 2013). In addition, Deaf people are at risk for
misunderstanding mental illness or the concepts related to mental health (Cabral et al., 2013; Sheppard & Badger, 2010). Interventions are needed to increase literacy in the mental health and medical health for the culturally Deaf population.

Adaptation of Educational Materials for the Deaf Population

Several research studies have attempted to assess the efficacy of ASL educational videos to increase health knowledge in Deaf people for specific disease processes. Zazove, Meador, Reed, Sen, & Gorenflo (2012) investigated cancer prevention knowledge amongst Deaf people from Michigan and had 195 adults over age 18 complete the baseline survey and post-test survey. Participants were randomized to either a control group that viewed a video program with voice, text, and graphics on a computer or an intervention group that viewed the same program with an ASL interpreter and captions throughout the video. Follow up surveys were conducted immediately post-test, and again at one month and six months after the intervention. Zazove et al., (2012) found that the treatment group and control group both significantly increased knowledge after the video but the difference between the groups was not statistically significant. Additionally, the presence of an ASL interpreter and captions in the interventions group did not improve long-term knowledge because there were no differences in knowledge between the control and experimental group at one or six months after the study. The overall study population (both groups combined) yielded a significant long-term increase in knowledge of cancer-related prevention measures (Zazove et al., 2012).

Yao et al. (2012) aimed to increase cervical cancer knowledge, after study participants viewed the educational video that was created by the investigators. Both Deaf and hearing groups increased their knowledge in each of the three knowledge areas; the group of Deaf women had a larger increase in knowledge than the hearing group. Interestingly, at the post test,
the hearing and the Deaf groups had the same level of knowledge which suggests that although the Deaf women had less knowledge prior to education, they were able to bridge the knowledge gap and become as educated as their hearing peers after viewing the educational video in ASL.

This study provided strong evidence for the lack of knowledge regarding cervical cancer among Deaf women when compared to hearing women in two important ways. First, the group of hearing women served as a control group, and the sample size of both groups was adequate for statistics to be performed. Secondly, the researchers created the knowledge surveys based on the information taught in the video and described in detail how the questions were created, including the process of making the language at a grade level that could be understood by the respondents.

In a similar study, Hickey et al. (2013) hypothesized that women who were Deaf ASL users and viewed an educational video in ASL about breast cancer would gain increased knowledge about breast cancer immediately after viewing the video. Two months after viewing the video, Hickey et al. (2013) also believed the Deaf women would be able to retain that knowledge to a high degree. Immediately after viewing the ASL video about breast cancer, the participant scores on breast cancer knowledge significantly increased (Hickey et al., 2013). Two months after the viewing of the video, participants still showed significantly increased breast cancer knowledge when compared with baseline, although the scores did drop to some degree (Hickey et al., 2013). The information presented in the video was complex in nature; the participants only viewed it once, and were still able to retain the information two months later, which suggests that the ASL format was successful in educating the Deaf participants about breast cancer for long term memory retention.

System-Wide Interventions for Effective Care of Deaf Patients
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The population of Deaf people who use ASL as a primary mode of communication are part of a rich culture. Research has shown that if providers are not culturally sensitive during care that Deaf patients can feel alienated and more likely to seek care at the ER instead of participating in health prevention or promotion (Sheppard, 2014). Of new graduates in the health care professions, most report limited or no training in cultural sensitivity in regards to Deaf culture (Lapinski et al., 2015; Nagakura et al., 2014; Thew et al., 2012; Velonaki et al., 2015). To address this systemic issue, interventions at the level of the health care profession college student have been supported by research to increase exposure to cultural sensitivity awareness when working with Deaf patients.

Acquisition of Cultural Sensitivity in Health Care Providers

In order to provide care that is functionally equivalent to the care that a hearing person is able to receive with ease, providers must obtain a high level of cultural sensitivity. The definition of culture is an integrated pattern of human behavior that includes thoughts, actions, beliefs, customs, language, and institutions of ethnic, racial, social, or religious groups (Nagakura et al., 2014). Lapinski et al. (2015) created a cultural competency training program for osteopathic medical students that included a workshop about Deaf culture and teaching of medically relevant terms in ASL. Thirty-three second year medical students who were between the ages of 18 and 25 years old participated in the study and the majority of the subjects had little to no prior interaction with the Deaf culture or knowledge of ASL (Lapinski et al., 2015). Prior to the intervention, the students rated themselves on confidence level when working with Deaf patients and took an ASL vocabulary quiz. Additionally, they participated in a seven minute recorded simulation that portrayed a scenario with a Deaf patient and two separate graders utilized a rubric and provided scores on mastery of educational concepts, professionalism, and interpersonal skills.
during the encounter. The intervention component included four hours of basic medical ASL that was taught by an undergraduate child of a Deaf adult (CODA) and the goal was to increase the medical students’ cultural sensitivity with the Deaf community. Besides ASL, additional information was taught during the workshop and included listening the stories of members of the Deaf community, legal issues regarding providing care for Deaf patients, examples of how to navigate a healthcare visit for a Deaf patient, effective communication with the Deaf, and etiquette in the Deaf culture followed by a question and answer session (Lapinski et al., 2015). A posttest evaluation was completed two weeks after the workshop and included the same content as the pretest. The medical students improved in all areas as evidenced by statistically significant increases in ASL vocabulary, the standardized patient encounter, and the student self-confidence rating regarding level of confidence when working with a Deaf patient when comparing pre-workshop and post-workshop scores (Lapinski et al., 2015). The results of this workshop suggest that the medical students were able to increase their confidence level and short-term knowledge regarding working with the Deaf population by attending a single workshop, however it is unknown whether that information will be retained on a long-term basis.

At the University of California, San Diego School of Medicine, a fellowship was created and funded by the National Cancer Institute to train a small cohort of medical students in Deaf culture and ASL within the scope of cancer control in order to create medical partners for the Deaf community who were advocating for improved access in healthcare (Hoang, LaHousse, Nakaji, & Sadler, 2011). The overall program was four years long and consisted of two parts: 1) a Deaf culture training (DCT) program and 2) reinforcement and practicing their skills through research and clinical rotations in the Deaf community. The training program occurred over the first two years of medical school and included mastery of a curriculum of self-paced reading
materials regarding Deaf culture, six quarters of ASL classes, and one summer at Gallaudet
University where the students participated in an ASL immersion program at the campus. After
the training program, the students continued to practice ASL, gave workshops to the Deaf
community about health promotion topics, completed a mandatory research project on a topic
related to the Deaf community, and completed a fourth year clinical rotation in the Deaf
community. In order to retain the student’s participation in the program and as compensation for
the extra workload, the students received an $8,000 stipend for each year they were involved
with the program. To test whether the DCT medical students had more knowledge than other
medical students and faculty members at the medical school, a 28-item survey regarding Deaf
culture was given to these groups of individuals at the school and group percentages of the
amount of correct responses were compared. The DCT medical students were found to have a
significantly higher overall mean knowledge score than the faculty and the medical students who
did not participate in the program. For example, 95.5% of the DCT students correctly identified
that it was not appropriate for a physician to ask the nurse who has taken several semesters of
ASL classes to interpret for a consultation while 45.5% of the faculty members and 39.5% of the
non-DCT students knew the right answer. The entire DCT group knew that the Deaf patient had
a right to be provided with an interpreter by the practitioner while 70.2% of faculty and 64.9% of
non-DCT students knew this information. The most striking finding was that 84.6% of the DCT
group knew that only 30% of the English language can be accurately lip-read by a Deaf person
while only 17.1% of the faculty and 13.5% of the non-DCT students had an understanding of this
fact (Hoang et al., 2011). This research supported the idea that cultural sensitivity training
programs are effective in increasing the knowledge base of medical students to include relevant
information about the Deaf culture.
Another cultural sensitivity training program called the Deaf Strong Hospital (DSH) was created in Rochester, NY and implemented with 99 first year medical students in 2011 (Thew et al., 2012). Members of the local Deaf community also participated in the program and acted out a scripted scenario that mimicked an actual health care encounter where there was a potential for misdiagnosis or mistreatment as a consequence of common barriers that Deaf patients experience during a healthcare visit. The medical students participate in a role reversal exercise where they play the role of a patient and they can only communicate with the health care providers (who are Deaf and do not speak) using gestures, ASL, notes written in English, or finger spelling. The student progresses through four different stations including a doctor’s office, emergency room, psychiatrist, and a pharmacy. At one of the stations, there is an ASL interpreter that can be utilized for communication where the student can compare the difficulties that can occur without the presence of the interpreter versus the ease of communication with the interpreter. At each station, the student must wait for his/her name to be finger-spelled (i.e., “Called”) which imitates the experience of most Deaf people in waiting rooms every day. At the end of simulations, there is a small-group debriefing session. This program has been conducted since 2006 more than 90% of participants have stated that they “agree” or “strongly agree” that the DSH helped increase the knowledge regarding importance of linguistic, cultural, and communication issues when delivering healthcare to Deaf patients. Almost 80% of the 2011 group of DSH medical students described the program as interesting, thought-provoking, and frustrating in a positive way (Thew et al., 2012). Long-term feedback regarding the DSH program was collected from prior participants who reported they continue to use knowledge from the program to work with Deaf patients and other non-English-speaking patients, acknowledged the benefit of having an interpreter, and reported a need for knowing proper
etiquette when utilizing an interpreter such as talking directly to the patient and using nonverbal cues to therapeutically connect with the patient (Thew et al., 2012). Although they did not compare the level of cultural sensitivity gained by the DSH students with non-DSH students, the researchers stated a need for this comparison in the future and concluded the program was successful in teaching cultural sensitivity regarding Deaf patients to first year medical students (Thew et al., 2012). This program model was also implemented a pharmaceutical school in Rochester, NY and attempted to educate first year pharmacy students regarding Deaf culture (Mathews, Parkhill, Schlehofer, Starr, & Barnett, 2011). Similar results were obtained at the conclusion of the training program and 97% of the students reported that they agreed or strongly agreed that the program would likely impact attitudes and behaviors in future encounters with people who are non-English-speaking in the healthcare setting (Mathews et al., 2011).

A study of genetics counselors in the United States who were less than five years post-graduation participated in a cross-sectional survey which asked questions about levels of cultural sensitivity for Deaf culture (Nagakura et al., 2014). Participants were grouped into genetics counselors who had received Deaf awareness training (DAT) while the other group of genetics counselors had not received DAT. The scores on Deaf culture and deafness knowledge as well as scores on the attitudes towards Deaf people scale were statistically similar between the DAT and non-DAT groups. However, the majority of the DAT group reported the training they received regarding deafness and Deaf culture was 1-2 hours in length. This suggests that the training the DAT group received may have not been enough to significantly increase the measures of cultural competency necessary to provide competent care to the Deaf community (Nagakura et al., 2014). Another research study regarding attitudes of genetic counselors regarding Deaf culture found that those people who have deaf/Deaf friends were more likely to indicate more positive attitudes
towards d/Deaf people (Enns, Boudreault, & Palmer, 2009). This finding suggests that exposure to the Deaf community can have a positive effect on the attitude a provider has regarding the d/Deaf.

Velonaki et al. (2015) found that nurses who reported a lower level of self-efficacy in working with Deaf clients were also more likely to report that they have avoided providing care for Deaf patients. An increased level of self-efficacy was positively correlated with the amount of contact that nurses had with members of the Deaf community. Finally, when nurses reported they had received relevant education regarding Deaf culture, they were also more likely to have a higher level of knowledge regarding the Deaf. These findings suggest that when nurses receive education regarding the Deaf community and have contact with Deaf people that these behaviors can contribute to improved knowledge and care of these patients.

Recent literature regarding interventions to increase the level of cultural sensitivity of mental health providers was not discovered during the literature search. However, Wright & Reese (2015) state, “Many counselors receive no exposure to deaf clients or Deaf culture in their training; for those mental health clinicians who do obtain experience, exposure to deafness is often pathologically oriented” (p. 284). Mental health providers may also benefit from receiving cultural sensitivity training regarding Deaf culture so that they are more aware of the appropriate ways to provide for functionally equivalent care.

Summary

Improving the accessibility of medical and mental healthcare for Deaf people is a complex issue with many components. A review of the literature determined that lack of communication, lack of appropriate assessment techniques, low health and mental health literacy, and lack of cultural sensitivity among healthcare providers were the largest barriers for
HEALTHCARE AND MENTAL HEALTH FOR THE DEAF

the Deaf in receiving functionally equivalent care. Both qualitative and quantitative studies have been performed to determine interventions that may be appropriate during the scope of medical and mental healthcare with the Deaf. There is not an abundance of literature on this topic in regards to randomized control trials, however, in some cases there were several small studies that found similar results which would bolster the believability of the findings. For example, improving the cultural sensitivity of health care providers is strongly supported in the literature and is one way to improve healthcare provider interactions with the culturally Deaf (Hoang et al., 2011; Lapinski et al., 2015; Mathews et al., 2011; Nagakura et al., 2014; Thew et al., 2012; Velonaki et al., 2015).

Conclusion

There are many barriers that Deaf people face when they access the medical and mental health care systems in the United States. If something is not done to improve the system, Deaf people will continue to experience life as a marginalized minority group with low health literacy, high rates of illness and inadequate therapeutic management of disease. Interventions to target the provider, the Deaf person, or the overall health systems have been conducted and suggest evidence-based interventions that can improve care for Deaf patients.
CHAPTER THREE

The goal of this thesis was to create best practice recommendations to improve healthcare and mental health services for Deaf clients by overcoming barriers that currently exist. Chapter two reviewed research regarding current practices among care providers when working with Deaf clients and investigated interventions that have been used to increase the ability of the care provider to effectively work with the Deaf. Chapter three will identify best practice recommendations that are informed by existing evidence and focuses on the most effective ways to improve provider abilities when working with Deaf clients.

Purpose

The purpose of these evidence informed recommendations will be to increase the quality and accessibility of care by training providers with the knowledge necessary to provide appropriate services for Deaf clients. Research suggests that improving provider knowledge regarding Deaf culture, communication between Deaf clients and providers, and assessment techniques when working with Deaf clients can allow Deaf people to receive services that are more accessible and relevant to their needs. The primary goal is to enhance the knowledge, skills, and attitudes of providers regarding the culturally Deaf population. It is the hope that one day, the field of healthcare will achieve equal access for Deaf clients in medical and mental health care and sustain these improvements.

Target

Although there are barriers to equal access noted at the provider level, client level, and system-wide, the target of interventions will focus on providers that may come into contact with Deaf clients in the medical or mental healthcare setting. Studies have indicated that barriers exist at the provider level regarding cultural sensitivity, communication, assessment. These
barriers are roadblocks to equally accessible healthcare for Deaf clients. In order to increase the accessibility and quality of medical and mental healthcare for the Deaf, the evidence-based recommendations must address these areas at the provider level.

**Interventions**

The interventions delineated in Table 1 utilize evidence-based data in order to improve provider abilities when caring for Deaf clients. The research included in this table focuses on the findings that appeared to be the most effective and provide long-term provider improvement.
<table>
<thead>
<tr>
<th>Year</th>
<th>Study</th>
<th>Level</th>
<th>Evidence</th>
<th>Component</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>Reilly et al.</td>
<td>Level II</td>
<td></td>
<td>Best Practice Recommendations for Improving Provider Care of Deaf Clients Education Providers</td>
</tr>
<tr>
<td></td>
<td>LaPlante et al.</td>
<td>Level III</td>
<td></td>
<td>Cultural Sensitivity Training</td>
</tr>
<tr>
<td>2014</td>
<td>Wilson &amp; Schilid</td>
<td>Level II</td>
<td></td>
<td>Use cultural sensitivity training</td>
</tr>
<tr>
<td>2013</td>
<td>Zazou et al.</td>
<td>Level I</td>
<td></td>
<td>Supportive Sensitivity Training</td>
</tr>
<tr>
<td>2015</td>
<td>Ferguson &amp; Liu</td>
<td>Level I</td>
<td></td>
<td>Cultural Sensitivity Training</td>
</tr>
<tr>
<td></td>
<td>Fehlinger et al.</td>
<td>Level I</td>
<td></td>
<td>Cultural Sensitivity Training</td>
</tr>
</tbody>
</table>

Table 1
HEALTHCARE AND MENTAL HEALTH FOR THE DEAF
who can directly sign with the client are preferred in mental health settings

- Clinicians should determine language level of the client and educate at the level of the client
- Written instructions must be adapted and include larger print for medication warnings, simple and clear language, use of pictures and bullet format versus paragraph form
- Communication techniques include maintaining eye contact, speaking slowly, adequate lighting, communicating first and then acting, requesting a return demonstration to determine if education was understood, eliminating use of lipreading and pen/paper communication, allowing adequate time for communication, and avoiding speaking too loudly, too slowly, or using complicated terms

### Communication Assessment Techniques

<table>
<thead>
<tr>
<th>Level V</th>
<th>Fellinger et al., 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level VI</td>
<td>Ferguson &amp; Liu, 2015</td>
</tr>
<tr>
<td>Level VI</td>
<td>Cabral et al., 2013</td>
</tr>
<tr>
<td>Level VI</td>
<td>Middleton et al., 2010</td>
</tr>
</tbody>
</table>

- Advanced practice nurses will be trained on how to assess Deaf clients for language fluency
- A simulation will be performed to assess the nurse's ability to accurately determine language fluency of a Deaf client
- A literacy assessment coupled with effective communication can help ensure Deaf clients are using medications safely and have optimal health outcomes
- When determining language fluency, it is preferred to use an ASL
Evaluation - Outcome Measure has been validated. Clinical Outcomes in Routine Evaluation (COURTE) has been validated for use in the British Deaf population.

The British Sign Language versions of the Patient Health Questionnaire (PHQ) and Generalized Anxiety Disorder Scale (GAD-7) are now validated for use with the Deaf. The Deaf Sign has shown good reliability and validity when used with these tools.

Rogers et al., 2012

Level I

Advanced practice nurses will be educated on how to select assessment tools that have been validated for use with the Deaf population.

Rogers et al., 2014

Level III

Most standardized assessment tools are not validated for use with the Deaf.

Nzimke et al., 2015

Level III

The average English Language comprehension of the Deaf state order to avoid misdiagnoses of mental health disorders. The Deaf client regarding language in the deaf client rewording language in order to assess the ability of interpreter for accurate communication.

Thermometer for Deaf clients introduced to use the Iowa Pain Thermometer for Deaf clients rather than the numerical pain rating scale.

Advanced practice nurses will be instructed to use the Iowa Pain Thermometer for Deaf clients.

Education Regarding Assessment Tools for the Deaf
<table>
<thead>
<tr>
<th>Year</th>
<th>Level</th>
<th>Authors</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>VI</td>
<td>Wilson &amp; Shield</td>
<td>Supported the training of Deaf signing in Britain, the Government has provided funding for this.</td>
</tr>
<tr>
<td>2013</td>
<td>VI</td>
<td>Sheppard &amp; Badger</td>
<td>Peer mental health providers currently receive a small proportion of these types of training.</td>
</tr>
<tr>
<td>2013</td>
<td>VI</td>
<td>Caperell et al.</td>
<td>Don’t people prefer providers who can communicate in ASL?</td>
</tr>
<tr>
<td>2013</td>
<td>VI</td>
<td>Sherpes</td>
<td>Access to providers who use ASL to preventative services.</td>
</tr>
<tr>
<td>2011</td>
<td>III</td>
<td>Micken et al.</td>
<td>People are more likely to receive treatment if their providers are fluent in ASL.</td>
</tr>
</tbody>
</table>

**Best Practice Recommendations for Recruiting Providers with ASL Skills**

- Encourage ASL as a second language for college students who are pursuing careers in healthcare.
- Encourage those in these fields to become trained in ASL.
- Educate patients about the benefits of ASL-trained providers.
- Increase the number of providers.
- Language concerning providers.

---

<table>
<thead>
<tr>
<th>Level</th>
<th>Year</th>
<th>Authors</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>III</td>
<td>2012</td>
<td>Zazove et al.</td>
<td>Knowledge of ASL is not effective in increasing health care.</td>
</tr>
<tr>
<td>III</td>
<td>2013</td>
<td>Hickey et al.</td>
<td>Knowledge was seen among women viewed in educational video.</td>
</tr>
<tr>
<td>III</td>
<td>2013</td>
<td>Yu et al.</td>
<td>Increase in knowledge was also seen months later.</td>
</tr>
</tbody>
</table>

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**Educational Materials for the Deaf**

- Appropriate resources for the deaf.
- Instruction on how to find appropriate materials.
- Advanced practice nurses until the availability.

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**Educational Materials for Deaf Clients**

- Educational materials for deaf clients.

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**Education Regarding Selection of Care**

- Selection of care providers.
- English and other language wishes in the deaf British.
- English and other language needs in the deaf British.
Note: Level of evidence based on Melnyk & Fineout-Overholt (2011)

Results
nurses in mental health with positive
Summary

The proposed best practice recommendations are designed to be implemented in the college setting where students are being trained in medical and mental healthcare. The college setting is also a perfect place to continue research that will benefit the health and mental health outcomes for Deaf people. Implementation of these evidence-based practices will increase the proficiency of care providers when they are working with Deaf clients which will in turn improve health and mental health outcomes for Deaf clients. Research has shown that improving proficiency of providers can increase equal accessibility to health care and mental health services for Deaf clients (Mckee et al., 2015; Fellinger et al., 2012).
CHAPTER FOUR

Implementation and Evaluation

The following chapter will provide the roadmap for implementing the best practice recommendations and evaluating whether or not these interventions have changed the behavior of healthcare and mental healthcare practitioners when providing care to culturally Deaf patients. The study will follow the PDSA methodology which was created by Walter Shewhart and later modified by his student W. Edwards Deming (Deming.org, 2016). There are four steps in this model which are performed in sequence and repeated infinitely in order to strive for continual improvement. The first step involves determining a purpose, hypothesis about what will happen, and defining the desired outcome. Next, the plan is implemented in practice using a small number of people. Third, outcomes are monitored which provides information about progress, success, problems and opportunities for improvement. Finally, during the “Act” step, the results of the research can be integrated into practice if the goal has been met, or the knowledge gained can be used to adjust the methods or goal and the cycle repeats again (Deming.org, 2016).

Plan

During the first step of the PDSA cycle, it is necessary to formulate a plan from which the study will proceed (Deming.org, 2016). Important components of a good plan include a clear purpose for the study, an educated hypothesis about what is likely to occur based on prior research findings, and a clear definition of what a successful outcome looks like as a result of the evidence-based recommendations. The barriers that culturally Deaf people face in order to receive healthcare and mental healthcare occur at the level of the provider, at the level of the individual Deaf person, and at the system-wide level. This project will focus on the provider
level since the University of Arizona is educating a large number of healthcare and mental health professionals and will likely interface with a Deaf client at some point in their career.

**Purpose.** The purpose of the best practice recommendation intervention is to increase the knowledge, skills, and attitudes of healthcare and mental health care professionals prior to the completion of their college education. Specifically, health care and mental health care providers will gain knowledge regarding Deaf culture and how to overcome barriers when working with culturally Deaf clients. Research suggests that improving provider knowledge regarding Deaf culture, communication, and assessment techniques when working with Deaf clients can allow Deaf people to receive services that are more accessible and relevant to their needs.

**Hypothesis.** Implementing best practice recommendations while training the next generation of medical and mental health provider will have positive effects for culturally Deaf patients. First, increasing the knowledge and skills of nurse practitioners at the University of Arizona College of Nursing will improve assessment and communication techniques of practitioners when working with Deaf Clients. Secondly, educating these providers about Deaf Culture will change provider attitudes by increasing their awareness of Deaf culture norms which, in turn will increase the cultural sensitivity of services they provide to Deaf clients. Finally, once trained, providers will have increased confidence levels when working with Deaf clients.

**Desired Outcome.** The goal is to prepare nurse practitioners for interacting with Deaf clients in their chosen specialty. Preparing providers will tackle some of the barriers that Deaf clients encounter at the provider level when attempting to access mental health or medical healthcare services. Overall, the hope is that decreasing the number of barriers Deaf people encounter can improve access and functional equivalence of medical and mental health services.
Additionally, once the project has shown effectiveness, it would also be performed with undergraduates in the areas of nursing, medicine, mental health, pharmacy, and public health.

Do

The “Do” phase of the PDSA cycle includes performing an intervention or change to gain improvement in the system (Deming.org, 2016). One of the main components of the initial PDSA cycle is ensuring the first cycle is a small iteration of change. This way, the iterations that follow can be larger if the interventions are successful, or modifications can be made if the interventions did not meet the goals. The initial PDSA cycle will involve interventions with a small group of students from the College of Nursing at the University of Arizona. At the start of the school year, all Nurse Practitioner students take part in a week of training at the college, which is a perfect time to include this group of students in an intervention.

Participants. The participants in the initial cycle will be doctoral level Nurse Practitioner students in their first through fourth years. The Nurse Practitioner specialties that will be represented include: family practice, adult-gerontology acute care, pediatric, and psychiatric mental health. All participants have completed an undergraduate degree in Nursing or have both the undergraduate and Master’s level degree in Nursing. The majority of the program is online, however during a week in August, all students come together at the college to start off the academic year.

Interventions. A one-day workshop will be included during the week of training at the college which specifically focuses on learning how to work with Deaf patients. The workshop will include the themes of cultural sensitivity, communication, communication assessment techniques, assessment tools for the Deaf, and selection of educational materials for Deaf clients. The cultural sensitivity component will include exposure to a panel of culturally Deaf adults,
written materials, and a simulation with a standardized Deaf patient. During the simulation, participants will be instructed to determine the communication level of the patient, determine which type of communication the person prefers, and determine the diagnosis of the patient. The psychiatric mental health nurse practitioners will have a patient with a mental health diagnosis, while all other specialties will interact with a Deaf client with a medical diagnosis. There are many studies that have supported the use of interactive exposure to Deaf people to increase the cultural sensitivity of providers (Lapinski et al., 2015; Hoang et al., 2011; Velonaki et al., 2015; Nagakura et al., 2014; Thew et al., 2012; Mathews et al., 2011; Machado et al., 2009; Enns et al., 2009; Wright & Reese, 2015).

A lecture regarding assessment of communication preference of the Deaf client as well as communication strategies when caring for Deaf patients will be provided during the training. This intervention is based on the research that found a literacy assessment coupled with effective communication can help Deaf clients increase health knowledge and have optimal health outcomes (Ferguson & Liu, 2015). Several studies have also found that there are appropriate ways to effectively communicate with a Deaf client (Fellinger et al., 2012; Zazove et al., 2013; Palese et al., 2011; Wilson & Schild, 2014). An additional lecture will cover assessment tools for the Deaf including the Iowa Pain Thermometer for pain assessment in Deaf clients (Palese et al., 2011), Newest Vital Sign to assess level of health literacy (McKee et al., 2015), and the Patient Health Questionnaire, Clinical Outcomes in Routine Evaluation – Outcome Measure, Generalized Anxiety Disorder Scale, and Work and Social Adjustment Scale for use in assessment of a Deaf client (Rogers et al., 2012; Rogers et al., 2014). Finally, the workshop will include a lecture regarding where providers can find appropriate educational materials for Deaf clients. Providers will be educated about needs of the Deaf for educational materials in ASL and
to limit the use of educational materials in written English (Yao et al., 2012; Hickey et al., 2013; Zazove et al., 2012).

**Timeline.** At the start of the day, students will fill out a baseline survey regarding personal knowledge of Deaf culture and attitudes about working with Deaf clients. Then, the students will participate in the standardized simulation with a Deaf patient which will be video recorded for later review. A member of the Deaf community will serve as an actor for the simulation. The simulation will take 20 minutes and participants will be graded on whether or not they were able to accurately determine the communication need of the client, the level of language that the patient has, and the diagnosis. The simulation is open-ended in that the student can use any method of communication with the client that they wish. If they ask for an ASL interpreter at any time, one will be provided. The Deaf actor will also fill out a survey after each interaction with a student and rate the student on different measures such as effectiveness of communication, comfort level the Deaf client had with the interaction, and overall grade of the interaction as a whole.

After the simulation, the remainder of the day will include the lectures described above, and a panel of Deaf community members who will explain Deaf culture and specific experiences they had in the healthcare or mental healthcare setting. At the end of the day, the students will perform a follow-up simulation similar to the first one, and complete the same surveys they filled out in the morning to determine if change has occurred as a result of the interventions.

**Study**

In the “study” phase of the PDSA cycle, the objective data that was collected during the “do” phase will be analyzed to determine if a statistically significant change has occurred and if the desired outcome has been met. Has progress been made towards the goal? If not, what are the
opportunities for improvement to achieve the goal? Does the study protocol need to be adjusted in order better achieve the goal? Additionally, how feasible is the study protocol long term? These are the kinds of questions that need to be answered during the “study” phase of the PDSA cycle.

**Monitoring Outcomes.** Pre-test and post-test knowledge and attitudes was collected in the form of surveys and videotaped interactions assessed skills that the nurses had with the standardized Deaf patient. The survey data will be logged into a spreadsheet and statistical analysis software will be used to test for statistically significant differences between baseline and post-intervention data. The videotaped interactions will be coded by four coders who have been trained on how to code the specific outcome measures of “communication need of the client”, “patient level of language”, and “patient diagnosis”. Additionally, coders will be able to comment regarding communication strategies employed by each student during the interaction. In order to reduce coder bias, a coder will not be able to code both the baseline and post-intervention video of the same student. In order to determine reliability of the coding, each video will be coded twice and the level of agreement will be calculated. If the level of agreement is below 90%, the principal investigator will meet with both coders to solve the discrepancy. The results of the statistical analyses will be used to determine what, if any, changes occurred. This will provide the necessary information to adjust the plan prior to the next PDSA cycle.

**Changing the Plan.** If significant changes in the student population have occurred during the cycle which meet the stated goal, then the plan will not need much adjustment prior to the second iteration of the PDSA cycle. However, it is likely that some adjustments will need to be made in order to improve the training for all participants and ensure that the training is able to inform the students to the point where they feel confident in working with Deaf clients, that the
Deaf client feels their needs were met during the interaction, and that the attitudes regarding Deaf culture have improved from baseline. The goal of this phase of the cycle is to use the data to make adjustments to the plan so that continual improvement is achieved and the training becomes better over time. Once the data is compiled and analyzed, it will become clear which changes need to be made in order to efficiently improve the program.

Act

During the “Act” phase of the cycle, the results of the data analysis will be reviewed and integrated in a revised study plan. Theoretically, the revised study plan will be an improvement from the first iteration of the plan and the training program can get even closer to the study goals after the second iteration. The PDSA model includes as many cycles necessary to attain the goal, all of which are informed by the results achieved during the current cycle. Some research has used the PDSA model as a theoretical guide, but only had one iteration of a PDSA cycle. The authors of the PDSA model are clear in stating that more than one iteration is needed in order to continually improve (Deming.org, 2016).

Next Steps. One of the goals of this research is to be able to educate and train all health care and mental health students at the college level which includes doctors, nurses, pharmacists, counselors, and public health students. Once the training program has met the goals with a smaller group of nursing students, it will be time to implement the plan on a larger scale to the population of students listed above through another PDSA cycle. The University of Arizona has interdisciplinary trainings that exist to involve and educate all students that work in the medical field. These interprofessional exercises not only train students on specific challenges in the medical field, they also provide a time for students to learn what other disciplines have to offer. There was one exercise in particular that was two hours long and involved patients with
disabilities. Unfortunately, there were a wide range of disabilities present, so it made it difficult for the students to specifically learn about the needs of the culturally Deaf. Additionally, research suggests that in order to effectively learn about the Deaf population, the training needs to last longer than two hours (Nagakura et al., 2014). This platform may pose an opportunity for a longer, more in depth interdisciplinary training related to culturally Deaf clients at the university level in the near future.

**Summary**

Culturally Deaf people encounter many barriers when attempting to access medical or mental health services. The healthcare system in the United States is not adequately addressing these barriers and Deaf people are not receiving care that is functionally equivalent to the care that hearing people receive. Providers who encounter Deaf people are unsure how to best provide care and may have biased attitudes toward Deaf people due to lack of knowledge regarding Deaf culture. Deaf people are also unable to access education in their native language of ASL which could increase their health literacy and assist them in achieving better health. All of these barriers will continue to exist and hinder the health of this vulnerable population of Americans if action is not taken. The research training program outlined in this thesis is a summation of best practice recommendations which are informed by prior research. Utilizing the Plan, Do, Study, Act model of continuous quality improvement will ensure that medical professionals at the college level receive necessary training on how to provide functionally equivalent care to the culturally Deaf population prior to their entrance into the workforce. Improving the services for culturally Deaf people is necessary in order to assist this vulnerable population in achieving optimal health.
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