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The Deaf Experience in a Hearing Medical World

Sarah Kaylynn Lykins
Eastern Kentucky University

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THE DEAF EXPERIENCE IN A HEARING MEDICAL WORLD

By

Sarah K. Lykins, OTS

Thesis Approved:



Chair, Advisory Committee



Member, Advisory Committee



Member, Advisory Committee



Dean, Graduate School

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Date 6/23/16

The Deaf Experience in a Hearing Medical World

By

Sarah K. Lykins, OTS

Bachelor of Science

Eastern Kentucky University

Richmond, Kentucky

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DEDICATION

This thesis is dedicated to my mother Cynthia Wilson for always encouraging me to push further in my education until I reach my ceiling, and I will always keep reaching.

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I would like to thank my major professor, Dr. MaryEllen Thompson, for her guidance and patience. I would also like to thank the other committee members, Dr. Karen Petronio and Dr. Shirley O'Brien, for their comments and assistance over the past year. I would like to express my thanks to my husband, Chris, for his understanding, love, and patience during those times when I felt there was no end in sight. His encouragement made me push forward and stick with it until the end. I would like to thank the immediate members of my family for their encouragement and making me the person I am today: my mother Cynthia Wilson, my siblings Victoria and Andrew, and my grandparents Gary and Kay Wilson.

ABSTRACT

Background: The purpose of this narrative study was to understand personal experiences of a Deaf individual when communicating with healthcare professionals, to describe personal feelings regarding challenges and successes experienced during healthcare interactions, and express the need for culturally competent healthcare providers with increasingly diverse populations.

Method: The participant interviewed is a member of the Deaf community, uses American Sign Language (ASL), and had multiple decades of major medical treatments. The study was conducted using a semi-structured method with a certified interpreter (CI) present to interpret and was audio and video recorded to account for all aspects of the signed language.

Results: There were a total of 5 narratives and 4 major themes found throughout the interview. In addition, a section of other important information as stated by the Deaf participant was added to better explain the viewpoints of the participant. Results demonstrate the importance of including a certified interpreter to facilitate comprehension and understanding by Deaf individuals during medical treatments.

Conclusion: Utilizing a person's native language gives them the opportunity to be fully involved and competent when making important health decisions. Culturally competent healthcare professionals are needed as populations continue to grow in diversity in order to provide all clients with satisfying care.

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Chapter 1 Literature Review

Purpose

The purpose of this narrative study was to understand the personal experiences of a Deaf individual when communicating with healthcare professionals in order to recognize challenges and successes that occur during healthcare interactions and to develop a better understanding of the Deaf populations' needs when communicating in the healthcare field. This study looks to promote the importance of cultural competency regarding communication styles and client needs in the healthcare field. In this study, medical treatment is generalized to include things such as doctor visits, making appointments, extreme or emergency procedures, and therapy.

Narrative Analysis

Narrative studies differ from other types of qualitative research in that it focuses on the story of an individual, group, or organization (Cresswell, 2007). A narrative is unique due to the emphasis on sequence and consequence within the story (Reissman, 2008). It describes events occurring in an organized and connected manner that can be analyzed with meaning (Reissman, 2005). Though there are multiple methods to evaluate data using narrative analysis, the one specifically used in this study is called thematic analysis (Huberman & Saldana, 2013). Thematic analysis finds similar themes and ideas that resonate across multiple events in one or more person's story, with the themes coming strictly from participant's interviews (Reissman, 2005). It is vital that studies using narrative analysis describe data collected using a story format.. Though narrative analysis may not be suitable for many studies, the story format followed the norms of the language used by the Deaf participant.

Understanding the Population

The deaf population can be defined as a medical classification, as a disability, and as a culture, yet each of these categories refers to different groups of people. Deafness, in medical regards, refers to anyone with a specific level of hearing loss and includes up to 13% of Americans (Annual Report, 2014). This often includes persons categorized as hard of hearing as well, but the specific data defining one population to another is very difficult to uncover. Often, the population who have hearing issues is grouped together under one umbrella, although there may be multiple types of problems or levels of hearing loss involved. According to Steinberg, there is an estimated range between 100,000 and 1 million deaf individuals in the United States, showing the umbrella of the diagnosis (2006).

Lastly, the cultural definition of Deafness, which uses a capital D, defines a true culture and community involving its own language, norms, and history (Sheppard, 2014). The individual within the big 'D' deaf group often are born deaf into a family where being deaf is more common than hearing, and deafness is welcomed as a norm versus a problem. This group does not believe their lack of hearing ability is a disability. Instead, they are proud of their culture and heritage (Sheppard, 2014). The primary language used in this culture is sign language, which is relative to the geographical location of the population, changing for different countries, and even uses its own slang terms specific to smaller communities. In the United States, American Sign Language, or ASL, is the general language used, which is a visually focused language utilizing the hands, body, and facial expression to convey meaning (Padden & Padden, 2009). This language is

unique in many ways, especially in that normal conversations are often told in a story format.

Deafness qualifies as a disability according to the American Disability Act of 1990, meaning it can create barriers to daily occupations (Gribois & Nosek, 2001). The term disabled is one that often sparks controversy among members of the Deaf population due to the opposing viewpoints regarding the term (Sheppard, 2014). Members of the Deaf population (as opposed to deaf with a small 'd') would say they are not disabled. They are capable of completing almost all, if not all, of the same types of activities that hearing people do without any issue. Opposing the view of independence and ability, some may believe that the use of an interpreter to communicate with hearing individuals deems as a help with everyday activities and by using this assistance, the deaf population is disabled (Gribois & Nosek, 2001). This argument is one that has persisted since the passage of the Americans with Disability Act in 1990.

The deaf population is one with a long history of struggle, growth, and overcoming adversity. The era of time focused upon in this research article pinpoints historical events involving Deaf culture starting from the 1970s. The pivotal event during this time was *Deaf President Now* occurring at Gallaudet University in 1988. *Deaf President Now* was a protest involving students, faculty, and Deaf community members demanding to have their school president be a true representation of their population (Armstrong, 2014). Prior to this movement, only hearing personnel had been President of the school and *Deaf President Now* showed the importance of true representation of a population. It gave the U.S. a look at how Deaf individuals are capable of creating change. *Deaf President Now* involved other policy changes on the campus, but the

biggest change was the new national awareness of the deaf population and an understanding of their skills and abilities (Armstrong, 2014).

U.S. Historical Context

From the 1970s until the 2000s, the United States has seen an array of changes in multiple contexts, creating the current complex system of today. Changes seen vary from political and legislative, to medical advances, and even encompass our country's changing viewpoints on the value of diversity. While there are too many to discuss individually, the three major areas of change focused on during the contextual era include the general concentration towards equality, the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990.

If one was to look at historical changes and movements occurring near the 1960s and 1970s in the United States, the numerous subpopulation groups working towards equality could not be overlooked due to the vast number of them. Major changes were finally occurring during this time promoting change towards equality and fairness for populations other than Caucasian males. These changes include civil rights, women's rights, and disability rights. The Civil Rights Movement occurred to try to end discrimination, segregation, and mistreatment towards the African American community (Civil Rights, 2009). Women's rights also have movement during this era, where feminism focused on women gaining equal pay, rights, and reproductive freedom (Freeman, 1995). Disability rights were changed consistently with the passing of the Rehabilitation Act of 1973 and the Americans with Disabilities Act. These changes demonstrate how during this period in the U.S., advocacy for one's self and one's community was vital.

The Rehabilitation Act of 1973 was designed to establish guidelines that reduce and/or eliminate discrimination specifically in the workplace. This act had many areas of focus that involved federal changes to funding and training programs that would allow for individuals with disabilities to be employed in different areas, including federal jobs (Rehabilitation Act, 1973). In addition, this act promoted the importance of vocational rehabilitation services for individuals with severe disabilities, allowing this population to receive services that could help them to reach personal goals of employment. While the Rehabilitation Act of 1973 created an awareness to discrimination in the workplace and created laws preventing further discrimination, this only pertained to the workplace. While it was the first major piece of legislation to promote equality for the disabled population, it only addressed a small fraction of issues occurring for the population. Other issues faced in daily life were not addressed until about fifteen years later.

After the Rehabilitation Act of 1973 created a change in employment standards for the disabled community, in 1990 the Americans with Disabilities Act (ADA) was passed. The ADA went further to protect against discrimination and assist the disabled community in other areas of daily life. This law requires reasonable accommodations from employers for employees with disabilities as well as requiring public buildings, sidewalks, and transportation to be accessible for all persons (Grabois & Nosek, 2001). Accessibility and accommodations includes means of communication, such as an interpreter or text-to-speech device. The ADA was put into place to ensure that all individuals who needed services, accommodations, and adaptations would have access to these things, so a list of mental and physical conditions were compiled in conjunction with the Equal Employment Opportunity Commission. Conditions listed include a range

of disabilities from post-traumatic stress to deafness, and do not require that the disability be permanent or extremely severe (Grabois & Nosek, 2001). It is important to remember that reasonable accommodations refer to modifications or adaptations that must be made in order for a person to be able to complete a daily occupation, but at a reasonable cost to the employer or community entity. Examples of these adaptations may include a ramp at a doorway, larger size font used on visual materials or signs, sign language interpreters, or creating lower curb access to cross the street.

The Profession of Sign Language Interpreting

It is unclear when in time sign language interpreting transformed from an interaction between two individuals to an official valued profession. However, literature shows that by the 1970s the interpreter profession was finally recognized as a valued service in the community (Grabois & Nosek, 2001; Solow, 2014). One can assume that major factors influencing this increase in value and recognition involve the implementation of the Rehabilitation Act of 1973 and Deaf President Now at Gallaudet University in 1988 (Armstrong, 2014; Rehabilitation Act, 1973). Interpreting for the deaf as a profession has grown immensely over time, assisting in the interpretation of various languages used all over the world. Individuals are currently required to complete a Bachelor's degree, must pass the National Interpreter Certification exam, and adhere to the requirements of the Registry of Interpreters for the Deaf, Inc. (Registry of Interpreters, 2015). With the growth of the profession, major organizations such as the National Association of the Deaf and the Registry of Interpreters for the Deaf, Inc. collaborated to create a professional code of conduct in order to provide specific expectations and philosophies for certified interpreters to follow within their practice

(Registry of Interpreters, 2015). This code of conduct primarily discusses the importance of confidentiality, professionalism, conduct, respect for consumers, and respect for colleagues. A review of the literature found that while the code of conduct has many main topics, some interpreters personalize the ways in which each of these topics are integrated into their interactions with clients, creating four identified roles: conduit, advocate, manager, and professional (Hseih E, 2008). Research shows a consistent outcome regarding the use of certified interpreters in medical settings; the best means of communication between Deaf clients and hearing healthcare professionals requires the use of a certified interpreter (Barrett, 2002; DiPietro, Knight & Sams, 1981; Rouse & Barrow, 2015). Deaf clients found that the most important factors involved with using an interpreter were that the individual must have high quality interpreting skills and the interpreter actively works to build rapport with the Deaf client (Chong-Hee Lieu et al., 2007). In order to not seem “robotic” or “non-thinking” with their interactions between the Deaf and hearing communities while interpreting, interpreters use verbal and nonverbal strategies to reinforce the provider-client relationship and continue to build rapport (Hseih E, 2008).

Medical Interactions with the Deaf Population

As stated previously, members of the Deaf community use ASL, as their primary means of communication within the community. This language utilizes a combination of body language and facial expressions, and gestures of the hands to convey meaning (Culture Clues, 2012). Due to the contrast between the languages used by hearing healthcare professionals, which is primarily spoken English, and ASL used with the Deaf community, communication difficulties commonly arise during interactions between

these two groups (Chong-Hee Lieu et al, 2007; Halder, 2012). These difficulties often come from different needs within each of the communities, Deaf and medical, which create different types of barriers between the individuals and often leave the Deaf client with mostly negative perspectives of the healthcare field (Sheppard, 2014; Steinberg et al, 2002; Steinberg et al, 2006).

Medical personnel working with clients who are Deaf may have difficulty understanding their client's perspective due to their belief that they are following medical procedure or protocol for their facility. The two cultures, medical and Deaf, have different needs that are often conflicting with each other in healthcare settings. For example, Deaf individuals often require another person to be in the room during their medical appointments in order to have someone assist with communication, which can range from a family member or friend to a certified interpreter; yet healthcare professionals must follow the Health Insurance Portability and Accountability Act (HIPAA) in order to keep records and identifiable information confidential (HIPAA, 1996). Healthcare professionals may find it difficult to comply with HIPAA completely with the second person in the room, and it may hinder their ability to communicate successfully (Meador & Zazove, 2005). In addition, the quality of communication may be poor when using certain types of interpreting tools or poor quality interpreters. While using an interpreter with ASL may be the best way to communicate, healthcare professionals using visual guides or drawings can help Deaf clients understand medical procedures, terminology, or some small level of communication (Solow, 2014; Steinberg et al, 2006). Some research articles found that Deaf clients felt using a certified interpreter was the only way to communicate properly with a Deaf client in order to reach

a positive outcome (Barrett, 2002; DiPietro, Knight & Sams, 1981). Multiple pieces of literature describe experiences of Deaf individuals interacting with healthcare professionals as very negative with similar experiences such as there being a lack of quality communication due to use of spoken or written English and a lack of information regarding medical procedures. Many Deaf clients felt as though healthcare providers did not like the Deaf community (Sheppard, 2014; Steinberg et al, 2002; Steinberg et al., 2006). Interpreters who did not interpret quickly or communicated poorly with healthcare professionals can make a Deaf client look unintelligent and cause negative future interactions (DiPietro, Knight & Sams, 1981; Rouse & Barrow, 2015).

While a Deaf client may request a certified interpreter for his or her appointment, another tool has come into use in recent years called Video Remote Interpreting (VRI) (Power & Power, 2010). VRI may be more convenient for healthcare facilities to use, since it involves having the Deaf client to sign with an interpreter through a video WIFI connection. There are multiple companies working to create a system that both hearing and Deaf individuals can use to communicate together, but there are often difficulties and complication that one would experience using an open WIFI network such as dropped calls, pixilation of the picture, and frozen screens (Meador & Zazove, 2005; Wilson & Schild, 2014). In part, due to these issues, the clients who are Deaf found the system to be difficult, of low quality, and more confusing than helpful (Steinberg et al., 2006).

Communication Barriers between Medical Personnel and Non-English Speaking Clients.

Hearing healthcare professionals in the U.S. most likely communicate using the spoken English language with their hearing clients. With the increasing level of diversity

among healthcare clients, the idea of culturally competent care has become a key component of creating a positive experience for clients. Part of that care involves working with clients that speak a language other than English. When healthcare professionals work with clients that communicate using a different language, it is vital that the two work together in order to find the best means for high quality communication, most likely involving a competent interpreter of that language in order to prevent possible client harm (Quan, 2010). In addition, being sure that individuals involved in interpreting, whether they are certified or not, are of good quality to promote positive communication and build rapport (Chong-Hee Lieu et al., 2007). Learning the client's preferred method of communication gives the healthcare professional an idea of where to begin (Culture Clues, 2012). In 1990, the ADA was put in place in order to prevent discrimination of individuals who are in need of assistance to complete everyday activities (Grabois & Nosek, 2001). The ADA requires healthcare facilities to provide a sign language interpreter to any client who may need one in order to be involved in their personal healthcare. By a healthcare facility not providing appropriate interpreters for their clients, there is a high possibility of a malpractice case occurring due to damages from poor communication (Quan, 2010).

Clients who do not communicate using the English language, and do not have an interpreter present, may experience communication barriers with English speaking healthcare professionals. This may result in these clients suffering from misdiagnosis, medication mismanagement, delay and ineffective service delivery, and other ethical considerations (Brogan, Adriaenssens, & Kelly, 2014). In order to prevent these healthcare disparities, healthcare facilities have opportunities to utilize skilled interpreters

and educate their workers on ways to become more culturally competent. One program, called VOCAL-Medical, combines pertinent information regarding a specific culture as well as a “beginners” course of the language used in that culture. This program is one way for healthcare facilities to educate their professionals about increasingly common client cultures to promote cultural competency, build rapport with new clients, as well as provide better care to those clients (Brogan, Adriaenssens, & Kelly, 2014).

Occupational Justice and Marginalization

Though many individuals work daily to promote the concept of occupational justice among the public or experience it first hand, one may not be familiar with the term if they are not an occupational scientist or a member of the occupational therapy field. One way of defining occupational justice would be promoting fairness, equity, and empowerment to enable opportunities for participation in occupations for the purposes of health and quality of life (Durocher, Rappolt, & Gibson, 2014). For occupational therapists who work with clients to promote independence and participation in valued activities, the topic of occupational justice is of great importance. For the field of occupational therapy, the American Occupational Therapy Association created a framework that outlines each aspect of client care called the Occupational Therapy Practice Framework (OTPF). According to the OTPF, occupational justice refers to the “Access to and participation in the full range of meaningful and enriching occupations afforded to others, including opportunities for social inclusion and the resources to participate in occupations to satisfy personal, health, and societal needs” (OTPF, 2014 page S43). To most individuals, participating in everyday activities such as a job, an education, and managing one’s health is something that occurs without a second thought.

Unfortunately, some individuals are not given the right to participate in these activities and therefore experience occupational injustice, “any undue limitation on a person’s freedom to have or to pursue meaningful occupational engagement in society” (Durocher, Gibson, & Rappolt, 2014, page 432). Occupational injustice may occur to an individual due to discrimination of his or her race, gender, or other characteristics that associate them to any particular group. It is important to remember that a group’s identity does not mean each person in the group is the same, and we as healthcare professionals must allow each person’s preferences and choices to define them as an individual (Baillard, 2014). Another type of situation that may occur that is similar to occupational injustice is occupational marginalization. Occupational marginalization occurs in situations where individuals or groups may not be given the choice to participate in valued occupations, and may be relegated to those that are less prestigious or allow little choice or control in the matter (Durocher, Rappolt, & Gibson, 2014). This exclusion from participation is typically based on “invisible” norms and expectations about who should participate in certain occupations.

Chapter 2

Journal Article

Abstract

Background: The purpose of this narrative study was to understand personal experiences of a Deaf individual when communicating with healthcare professionals, to describe personal feelings regarding challenges and successes experienced during healthcare interactions, and express the need for culturally competent healthcare providers with increasingly diverse populations.

Method: The participant interviewed is a member of the Deaf community, uses American Sign Language (ASL), and had multiple decades of major medical treatments. The study was conducted using a semi-structured method with a certified interpreter (CI) present to interpret and was audio and video recorded to account for all aspects of the signed language.

Results: There were a total of 5 narratives and 4 major themes found throughout the interview. In addition, a section of other important information as stated by the Deaf participant was added to better explain the viewpoints of the participant. Results demonstrate the importance of including a certified interpreter to facilitate comprehension and understanding by Deaf individuals during medical treatments.

Conclusion: Utilizing a person's native language gives them the opportunity to be fully involved and competent when making important health decisions. Culturally competent healthcare professionals are needed as populations continue to grow in diversity in order to provide all clients with satisfying care.

Introduction

In the United States, up to 13% of the population has some level of hearing loss or is considered medically deaf (Annual Report, 2014). The Deaf population can be viewed as under this umbrella definition but can also be considered a cultural community instead of a medical diagnosis. The cultural definition of Deafness, which uses a capital D, defines a true culture and community involving its own language, norms, and history (Sheppard, 2014). The individual within the big D deaf group often are born deaf into a family where being deaf is more common than being hearing, and deafness is seen as a norm versus an impairment. This group does not believe their lack of hearing ability is a disability and is instead proud of their culture and heritage (Sheppard, 2014). The primary language used in this culture is sign language, which is relative to the geographical location of the population, unique to different countries, and even uses its own slang specific terms within smaller communities. In the United States, American Sign Language (ASL) is the general language used, which is a visually focused language utilizing the hands, body, and facial expression to convey meaning (Padden & Padden, 2009). The Deaf community is known as one of the many subpopulations in the United States, with their own history, culture norms, and language.

Historically, multiple populations in the United States have worked towards equality and the discontinuation of discrimination since the 1970s (Armstrong, 2014). *Deaf President Now* was one of the first major events to occur that brought national attention to the skills and abilities of the Deaf population in recent decades. The protest took place in 1988 with students, faculty, and community members demanding to have a Deaf individual as president of Gallaudet University. Other movements towards equality

during this time include the Civil Rights Movement, Disability Rights, and Women's Rights (Freeman, 1995; Civil Rights, 2009). From these movements promoting self-advocacy and awareness, multiple pieces of legislation came to pass. In 1973, the Rehabilitation Act was established to create guidelines eliminating discrimination of the disabled population in the workplace, as well as promote and fund training programs that would assist these individuals in being employed in federal jobs. It also shined a spot light on the importance and need of vocational rehabilitation services that help prepare severely disabled individuals with skills needed in the workforce (Rehabilitation Act, date). In 1990, the Americans with Disabilities Act was passed which took a much broader approach to ending discrimination in other areas of the community. The ADA not only requires employees to create reasonable accommodations for their employees that may need some level of assistance to perform their designated job skills, but also required these accommodations of the public transportation service, public buildings, and other places involving the completion of daily occupations (Grabois & Nosek, 2001). One specific example of these accommodations would be the requirement of public facilities to provide an interpreter for a Deaf person.

It is unclear when in time interpreting transformed from an interaction between two individuals to an official valued profession. However, literature shows that by the 1970s the interpreter profession was finally being recognized as a valued service in the community (Gribois & Nosek, 2001; Solow, 2014). Sign language interpreting as a profession is one that has grown immensely over time and is involved in assisting in the interpretation of various spoken languages for Deaf individuals all over the world. Now, individuals are required to have a Bachelor degree and must pass the National Interpreter

Certification exam and adhere to the requirements of the Registry of Interpreters for the Deaf, Inc. (Registry of Interpreters, 2015). With the growth of the profession, major organizations such as the National Association of the Deaf and the Registry of Interpreters for the Deaf, Inc. collaborated to create a professional code of conduct in order to provide specific expectations and philosophies for certified interpreters to follow within their practice (Registry of Interpreters, 2015). Research found a consistent outcome can be found regarding the use of certified interpreters in medical settings; the best means of communication between Deaf clients and hearing healthcare professionals requires the use of a certified interpreter (Barrett, 2002; DiPietro, Knight & Sams, 1981; Rouse & Barrow, 2015). Deaf clients found that the most important factors involved with using an interpreter were that the individual must have high quality interpreting skills and that the interpreter actively worked to build rapport with the Deaf client (Chong-Hee Lieu et al., 2007).

This research study examines the experiences had by a Deaf individual at healthcare facilities and her ability to communicate with her healthcare providers. Due to ASL being a visual language that is very different from English, along with the cultural norms and customs of each population being very different, communication barriers can easily occur (Sheppard, 2014). Healthcare professionals following confidentiality requirements and using equipment for specific procedures may create a disconnect in communication due to the different areas of focus in medicine compared to that of the Deaf community and use of ASL. A common means of communication between healthcare providers and Deaf clients would be to write notes back and forth, but since English and ASL are not similar, and English may not be the Deaf client's first language,

it is important for the healthcare provider to realize the possible miscommunications that can occur using this method (Chong-Hee Lieu et al, 2007; Culture Clues, 2012; Halder, 2012;). Even clients who use a spoken language other than English felt that when they were able to have a certified interpreter present during their appointments, they could clearly understand the content and could ask questions as needed, creating an overall positive experience (Sheppard, 2014; Steinberg et al, 2006). Clients that are Deaf or do not speak English that had negative experiences commonly felt the quality of communication was very poor. They did not receive enough information regarding medical procedures, and some even felt the healthcare team had a negative view of the Deaf community (Sheppard, 2014; Steinberg et al, 2002; Steinberg et al, 2006). Health care providers understanding the needs of clients using a different language than their own is a key part is providing quality health care to these individuals, which can set the stage for a positive environment for the client and build rapport with the Deaf community (Sheppard, 2014).

Though many individuals work daily to promote the concept of occupational justice among the public or experience it first hand, they may not be familiar with the term if they are not a member of the occupational science or occupational therapy fields. One way of defining occupational justice would be being oriented to promoting fairness, equity, and empowerment to enable opportunities for participation in occupations for the purposes of health and quality of life (Durocher, Rappolt, & Gibson, 2014). To most individuals, participating in everyday activities such as a job, an education, and managing one's health is something that occurs without a second thought. Unfortunately, some individuals are not given the right to participate in these activities and therefore

experience occupational injustice, “any undue limitation on a person’s freedom to have or to pursue meaningful occupational engagement in society (Durocher, Gibson, & Rappolt, 2014 page 432).” Occupational injustice may occur to an individual due to discrimination of his or her race, gender, or other characteristics that associate them to any particular group. It is important to remember that a group’s identity does not mean each person in the group is the same, and we as healthcare professionals must allow each person’s preferences and choices to define them as an individual (Baillard, 2014). Another type of situation that may occur that is similar to occupational injustice is referred to as occupational marginalization. Occupational marginalization occurs in situations where individuals or groups may not be given the choice to participate in valued occupations, and may be relegated to those that are less prestigious or allow little choice or control in the matter (Durocher, Rappolt, & Gibson, 2014). This exclusion from participation is typically based on “invisible” norms and expectations about who should participate in certain occupations.

Methods

Narrative Analysis.

In qualitative research, there are many methods to analyze data and learn from participants (Cresswell, 2007). Narrative analysis puts emphasis on the story being told within an interview and looks to describe events through sequences, consequences, and connection to meaning as told by the participant. Narrative analysis requires the researcher to immerse their self in the story or stories told by the participant. By doing so, key aspects of the narrative are highlighted and memoed, breaking down the narrative(s) to find the inner themes and ideas that resonate across multiple stories

(Reissman, 2005). When using narrative analysis, the researcher should consider multiple aspects while reading and analyzing the stories such as the plot(s), cultural resources involved in the stories, and participant reflection on their narrative.

To organize these ideas within the research, thematic analysis assists the researcher in identifying themes and ideas that come strictly from the participant's story (Reissman, 2005). This analysis method within narrative breaks down stories into characters, plots, the setting of the story, as well as reflective statements from the participant. This method was chosen because of the connection of storytelling in American Sign Language. In ASL, the language format is frequently that of a story, often providing a story as an example of a situation or emotion instead of using single words (Padden & Padden, 2009). By using this method, the ideas of the participant are explained using their own words. Due to the participant in this study being Deaf and using ASL, the closest interpretation of her words and thoughts are the interpreter's English version of the participant's stories. Any quotes or phrases used in the study come from the certified interpreter but are the closest representation of Anne's words available.

Participant Information

The Deaf participant is a Caucasian female in her mid-forties and will be referred to as Anne (participant's pseudonym). She was deaf at birth and comes from a predominately deaf family. At the age of twelve, she was involved in a serious auto accident resulting in ongoing, significant medical experiences. The interpreter is a Caucasian female and is a certified interpreter who received her Bachelor of Science degree in ASL and English Interpretation. Both Anne and the interpreter are acquainted with the researcher through educational interactions on a university's campus. Anne was

purposefully recruited due to the researcher's knowledge of her highly active medical history over a significant period of time, and Anne's self-identification as a member of the Deaf community. The certified interpreter used was also purposefully recruited due to having a long-standing rapport with Anne.

Data Collection

In order to understand the depth of a Deaf individual's experience with healthcare professionals overtime, a semi-structured interview was conducted with a single Deaf participant and a certified interpreter. The study was approved by the Institutional Review Board at a university in the central southeast portion of the United States. E-mails inviting participation in the research study were sent to both Anne and the interpreter in order to obtain virtual confirmation. Once interest in participation was received, both participants were given a written form of consent in the presence of the researcher. This allowed Anne to ask any questions to the researcher using the certified interpreter, and both signed the forms.

The interview was audio taped and videotaped in order for the researcher to utilize and understand all aspects of Anne's stories, including body language, facial expressions, and other movements that contributed to her stories. Due to the language barrier between researcher and Deaf participant, it is important to remember that all quotes, phrases, and questions from the Anne are an interpretation of her actual language choice (ASL) as told by the interpreter and are the best English representation of her thoughts. The interview lasted an hour and fifteen minutes and was conducted on the university's campus in an area familiar to both the participant and the interpreter. The interview was voiced in English and signed by the interpreter using ASL. Open-ended

questions were asked of Anne and statements were used to allow her to share all aspects of her personal experience, as she felt comfortable. During the interview, some questions asked by the researcher did not make sense when being interpreted so the researcher had to alter the manner in which the question was asked. This often came from a difference between the languages or the meaning of a phrase changing through its interpretation (Solow, 2014). The researcher deferred to the interpreter's best judgment on when questions needed to be altered for better understanding. The interview concluded with multiple areas of reflection by the Anne, opportunities for her to ask questions of the researcher, and a final opportunity for Anne to add any further comments she wished to convey.

Data Analysis

The researcher transcribed the interview word for word. The interpreter reviewed the transcribed interview to clarify areas of confusion and to ensure the data collected was the best interpretation of Anne's story. The interpreter was also consulted for further clarification of events in the stories. The interpreter checked for clarification of events with Anne. After completing the member check, the researcher reviewed the transcription by highlighting important aspects of the interview and used memoing to keep notes of connections between stories. Using thematic narrative analysis, themes and codes within stories developed and defined multiple separate narratives as well as themes that resonate throughout each of the stories. The qualitative coding tool HyperRESEARCH was used during this process in order to break down codes relating to the themes and narratives throughout the interview.

Results

A total of five key narratives and four major themes were found. The five narratives were stories of experiences Anne had involving healthcare professionals throughout major events in her life: Burn Narrative, Childbirth Narratives (three), and Hospitalized Child Narrative. The four themes found were ideas or experiences discussed in each of the narratives: The importance of high quality interpreters; The conflict between Deaf culture and medical procedure; The importance of self-advocacy; and Marginalization and occupational injustice occurring due to communication barriers.

Narratives

Burn Narrative.

The first and most important narrative discussed by Anne was the description of how her medical experiences began which occurred in the summer of 1981. The narrative described an accident involving her family's car, which caught on fire, and caused the death of one of her sibling. During the accident, Anne was severely burned over most of her body, including her hands, and was rushed to the nearby hospital for treatment. Once at the hospital, no interpreters were present and teachers from a nearby school for deaf children were used for means of communication when available. Due to the severity of her injuries, Anne was placed in a special medical bed that moved constantly to relieve pressure from her injuries. The movement of the bed often forced her to look at the ground or other places that did not allow for any type of communication with others. This narrative described Anne being moved to a hospital further from her family, and described multiple experiences of communication barriers between the hearing healthcare professionals and herself or other Deaf family members. In order to

communicate with the staff to indicate her needs or express pain she had to try to teach the staff to sign while her hands were burned. While the incident occurred over thirty years ago, she continues to this time to require surgeries and other medical procedures because of the level of damage that was done to her body.

The main characters involved in this narrative consist of Anne, her family, medical personnel, other clients, and teachers from the Deaf school. The setting of the narrative included two different hospitals far from her home, which meant family was often not available to be present during her procedures. One reflective statement from this narrative that describes Anne's feelings during this experience would be:

I was trying to tell him I was in pain, so when they would do the IV, I would move trying to convey it was painful and the doctor would get angry with me and we didn't have any kind of rapport in order to communicate so I was very frustrated.

Childbirth Narratives.

The second, third, and fourth narratives depicted her experiences with different levels of interpreters during the births of her three children and showed how quality of communication can help or hinder medical experiences. The first child's birth took place in the early 1990s in the maternity ward of a hospital. Though the Americans with Disabilities Act had been put into place, there were not yet certified interpreters available. Instead, a woman that worked for the health department, was involved with WIC, and had deaf parents interpreted for her. While the narrative is very short and somewhat vague about what she experienced, it clearly describes an overall positive experience working with this woman. Anne felt the quality of communication was very good and

made her feel very comfortable throughout the entire process. The specific characters involved in this narrative include Anne, medical personnel, and the woman who interpreted. One reflective statement describing her experience would be: “I went to birthing classes, and they interpreted for me for that, that was my first child so that worked out nicely.”

The birth of her second child occurred in 1993 and showed a very different experience along with poor quality of communication. The characters involved in the story include Anne, her husband at the time, her sister-in-law, and medical personnel. There was no actual interpreting individual present for this narrative. The narrative described how both she and her deaf ex-husband attempted to understand and communicate with hearing medical doctors. Because of the difficulty of this task, her sister-in-law was pulled in to try to assist with communication between the two groups. Once the birthing process began, the sister-in-law had to leave the room due to health code standards at the time. This added to the barrier regarding communication, and the couple attempted to read the lips of the doctors in order to understand what was going on. Then, due to the need for a cesarean section the doctors wore masks over their face, which took away the ability to lip read, creating even more of a barrier to communication. Procedures, such as an epidural, were done without any means of explanation and the tubal ligation requested by the Deaf participant was not done at all. Anne shared many reflective statements regarding this narrative such as: “And I was just frightened, I didn’t know if it (epidural) was going to hurt my baby or if it was going to hurt me. So the second birth was a terrible experience.” and “The second child I didn’t have that [an interpreter] and it was horrible.”

Due to the tubal ligation not occurring after the second birth as requested, Anne's third child came as a surprise the next year. The characters in this narrative include Anne, her husband, medical personnel, and a teacher from the School of the Deaf. The setting of the story was the maternity ward of a hospital near her home. During the third birth, the "interpreter" was very skilled and knowledgeable creating a positive experience for Anne. While the person interpreting was very helpful, the ADA had been in place for four years at the time and still she had not seen a professional interpreter. She described the experience of this birth as relatively positive and reflects upon her experience stating: "...a teacher at the School for the Deaf [interpreted] and that communication went well with the birth and everything."

Hospitalized Child Narrative.

The last of the key narratives found refers back to after Anne's second child was born. It described the experience of her child being in the hospital for two months due to medical issues and her interactions with the hospital staff. The characters involved in this narrative include the sick child, Anne, nursing staff, and a "better than nothing" interpreter. This narrative took place in the children's unit of a hospital over a two-month period. The narrative described nurses in charge of her daughter's unit telling Anne that the child needed to be closer to the window for them to check on, because they felt a Deaf parent would not be able to properly care for their child since they could not hear the baby crying. Anne described a special light system she used that notified her if her child was crying. She attempted to tell the nurses that she could take care of her child, but they did not listen to her. Anne often found the nurses so busy they did not notice children crying on the unit floor and she would let them know. After being in the

hospital for multiple days a woman who knew sign language was brought in to assist with communication, yet her skill set actually created more of a problem between the hearing staff and Anne. The “better than nothing” interpreter portrayed Anne in a negative way due to her poor skill set, by making Anne sound unintelligent or by interpreting interactions inappropriately. Due to that experience, Anne explained how she sometimes used her children, who are hearing, to interpret for her during other medical experiences. Many reflective statements were shared during this narrative including: “So, the doctors and nurse thought it was my ignorance, the way she was voice interpreting for me wasn’t me, it was her skill as an interpreter and she was not doing a good job”

Themes

The importance of high quality interpreters

The first theme identified throughout the narratives is the importance of high quality interpreters. The literature reviewed recognizes the value of interpreting services starting the in 1970s. Interpreting has grown from requiring certifications to four-year degrees with opportunities of to specialize or receive Master’s degrees in various advance training areas such as law or medical terminology. The relevance and need for experienced and highly qualified interpreters continues to grow in this culturally diverse day and age (Armstrong, 2014; Gribois & Nosek, 2001; Registry of Interpreters, 2015; Solow, 2014).

Throughout the narratives, Anne experienced many types of interpreters that demonstrate a range of skill level and training. Since the narratives occurred both before and after the ADA was in place, it would be expected that she would experience different levels of interpreting over the almost 4 decades she discusses in her interview. In her

narratives, Anne discussed multiple types of interpreters such as family members, friends, teachers of the Deaf school, and certified interpreters. For example, the narrative involving her second child's hospitalization demonstrates that a person titled as interpreter does not mean quality communication or interpreting is occurring. The skill set of the interpreter influences the quality of communication and overall experience had by the participant. Using highly qualified interpreters is vital for positive working communication between members of the Deaf community and those who speak English. Many reflective statements were made regarding this theme throughout the major narratives including:

After about three or four days we finally ended up getting an interpreter in there but they weren't a certified interpreter so their sign skills weren't great and she was not doing a good job, but it was reflected on me as my intelligence.

Marginalization and occupational injustice occurrence due to communication barriers

The second theme identified is the marginalization and occupational injustice occurring during healthcare interactions due to communication barriers. Marginalization and occupational injustice occurred when the communication barriers kept the participant from actively participating in her own healthcare as well as parenting, and prevented her from having the best possible care. Anne discussed multiple accounts throughout the major narratives and other aspects of her interview in which she or other family members were left in the dark regarding possible healthcare decisions and were not given the opportunity to voice concerns or ask questions regarding treatment. In the hospitalized child's narrative, Anne is treated as if she is incapable of caring for her own child due to

being Deaf. The staff at the hospital moved the baby closer to the window so they could keep a better eye on her, but in actuality, the nurses become too busy to care for each baby. During this narrative, Anne helps the nursing staff telling them when a baby was crying, proving her ability to be aware of not only her baby but all children in that area even if she is Deaf.

Marginalization was discussed in one narrative where Anne had specifically requested a female interpreter for a gynecological appointment, but the agency used by that facility sent a male interpreter. She experienced multiple encounters with interpreters, interpreting companies, and healthcare facilities that did not provide her with adequate interpreting services and would not allow her to use a preferred interpreter during healthcare interactions. The ADA requires facilities to provide interpreters as “reasonable accommodation,” meaning the quality of the interpreter must be at a point where there are able to assist the Deaf client in a positive manner. When contracting companies send interpreters for clients, it is vital that the interpreter is appropriate for the job, have good rapport with the client, and does not create an awkward or uncomfortable experience for their client. This can refer to aspects of the client’s care such as gender specific appointments or having someone that understands their medical history if it is complicated. Many reflective statements were made regarding this theme throughout the major narratives including: “I want a female interpreter for this particular gynecology appointment and they will send a male interpreter. How do you address this thing once the person is sitting there? That is awkward.”

The conflict between Deaf culture and medical procedure

The third theme found throughout all the narratives is the conflict between Deaf culture and regulations for medical procedures, or medical culture. The conflict experienced between the medical and Deaf cultures showed the different areas of need and focus for both groups. While communication needs were of high importance for Anne during the birth of her second child, the medical professionals focused on following healthcare precautions to keep all personnel involved the safest during the procedure. For Anne, communication during this experience would have required either her sister-in-law to be present to interpret or the removal of the facial masks of the staff so Anne and her husband could lip read, but both of these options went against standard health precaution techniques during the time. This disconnect created a rift between the participant and the healthcare providers, making quality communication impossible. While both groups were trying to follow the norms of their culture, it created more barriers for good communication between client and healthcare provider. Having competency about another culture's needs prepares one for interactions that may be difficult or different than the healthcare providers' norm, such as having another person in the room or allowing for extra time during communication due to differences in phrasing or word meanings between the languages.

Deaf clients may use a variety of communication styles and languages to communicate but the most commonly used in the United States is American Sign Language, ASL, which is a visual language that uses gestures, facial expressions, and body language to portray meaning. ASL and spoken English are very different, especially in grammar, use of space, use of verb tense, and pronouns. With the different

languages being used also come different communication styles. Anne described an interaction where an English-speaking healthcare professional where he was attempting to explain a medical procedure by drawing pictures instead of writing it out in English. Anne stated how this picture helped her to understand what he was trying to say much better than any written note she had received before. It is important for hearing healthcare professionals to remember that a Deaf person may not be able to read or understand written English since it may not be their first language. Anne made many reflective statements regarding this theme throughout the major narratives one in particular would be:

Are you talking about...surgeries? We just did not communicate at all. Nobody made any effort. My mother would just say, "Ok" and sign the paper and they would take me back and we didn't understand a thing about what was going on.

The importance of self-advocacy

The last theme identified throughout the entire interview with Anne is the importance of self-advocacy. Anne demonstrated self-advocacy through multiple narratives by creating opportunities for communication when interpreters were not available. During her hospital stay as a child after the accident, she taught medical staff basic ASL signs in order to tell them she was in pain and to have any ability to communicate at all. She described experiences with a family who's child was also sick and in the hospital the same time as Anne. Anne volunteered to look after the child while the family was away to help them not feel so nervous about leaving. The family learned sign language in order to communicate with her and thank her for watching their child. She also demonstrated the importance of self-advocacy by standing up for herself as a

mother when the nurses felt she could not take care of her own child because of being Deaf.

Anne made the point throughout her narratives to describe the importance of advocating for personal rights as well as those for the entire Deaf community. Some facilities still are not adhering to the requirements put in place by the ADA, which is providing reasonable accommodation for Deaf clients by providing interpreters. Anne described multiple occasions where she had to explain her rights to have an interpreter, or to have an in-person interpreter instead of the Video Relay Interpreting system. When discussing advocacy, Anne talked about how the community works together to find healthcare facilities that work well with the Deaf population, and they share their experience with others in order to make sure the Deaf community is receiving the best possible care. When asked how Anne would handle a situation where a facility is not willing to provide an interpreter, she stated the following:

I would talk to them very kindly and explain the situation about my rights and my communication in a very positive light and get them examples, for instance if you provide a wheelchair ramp for people in a wheelchair why would you not provide an interpreter for a deaf person?

Other Importance Topics

During the interview with Anne, she discussed multiple other topics she felt were important for the interviewer to know and share that were not directly related to main narratives and themes. One of which is her lack of ability to feel feminine due to the medical equipment necessary for her to remain healthy and mobile. Due to her medical history and continuing need for medical treatments, she must wear special orthotic shoes

in order to be able to walk. Anne hopes that one day she will be able to find orthotic shoes that also allow her to feel attractive.

Another topic discussed is the need to recognize the importance and use of Certified Deaf Interpreters (CDI). CDI are interpreters that are Deaf that have completed the requirements to be certified to interpret. These individuals can interpret alongside a hearing certified interpreter when working with Deaf individuals needing a more native form of the language. They use a highly visual mode of ASL that Deaf individuals can connect to and understand more due to ASL being the CDI's first language. This method is often used during court cases or other situations of high importance to ensure the Deaf individual is given the best ability to communicate and understand the interaction between them and hearing individuals.

Lastly, Anne felt it important to share her views on the Video Relay Interpreting system (VRI) being currently used in a variety of settings. VRI is a way to use technology to communicate with a certified interpreter through an online video system. Anne described how healthcare personnel seem to believe VRI is a solution if certified interpreters are unavailable in person. Her experiences using the system have all been very negative. She described a story in which a friend of hers displayed symptoms of a heart attack and when arriving at the hospital there were no interpreters available. The staff attempted to have the friend use the VRI system, but due to multiple technological issues his symptoms worsened and there was no means of communication for over an hour. Once a certified interpreter arrived in person, they were able to communicate, find out he was not having a heart attack, and leave the hospital after completing all required paperwork in less than an hour. Some specific examples of issues Anne has experienced

with the VRI system included: the WIFI going down; the interpreter being frozen on the screen; the picture pixelating or not being clear; and overall poor ability for communication through the video system. A reflective statement by Anne about these topics is as followed: “So the struggles [of needing an interpreter] have not stopped, they are still there, they are just different.”

Discussion

Analysis of the participant’s interview revealed various narratives and themes demonstrating the importance of quality communication and cultural competence when the Deaf community interacts with healthcare professionals. When looking specifically at Deaf culture and interpreting, these major themes can easily be found throughout each of the narratives discussed as well as in other important topics described by Anne during the interview. One idea repeated throughout the research found in the literature as well as Anne’s experiences is that high quality skills and experience play a key part in the quality of communication and the creation of rapport between Deaf clients and interpreters (Chong-Hee Lieu et al., 2007). When comparing Anne’s experiences with various communication options, she believes the use of a certified and experienced interpreter is the best way to promote quality communication between hearing and Deaf individuals. She stated from her past experiences that doctors who drew pictures helped her to understand the concepts better than writing notes back and forth. This is similar to the research found regarding the use of visual aids and it’s assistance in communication of difficult medical topics (Solow, 2014; Steinberg et al, 2006). Both Anne and Deaf individuals from other research share the belief that using a certified experienced interpreter is the best possible way to have high quality communication with hearing

individuals (Barrett, 2002; DiPietro, Knight & Sams, 1981; Sheppard, 2014; Steinberg et al, 2002; Steinberg et al, 2006). When interpreters are not present, misunderstandings, such as the tubal ligation not being done, increase with Deaf clients. Anne had similar feelings regarding the use of VRI systems as the literature (Meador & Zazove, 2005; Steinberg et al, 2006; Wilson & Schild, 2014). She does not feel the VRI system is worth being used ever in healthcare facilities, especially regarding emergencies due to the extreme stress and confusion she experienced in the narrative described in the “Other Important Topics” sections. When asked what Anne felt the best solution to the VRI difficulties would be in those situations, her response was: “The interpreter! They just need to provide the interpreter.”

Anne discussed the importance and connection between U.S historical events and occupational justice throughout her narratives, these connections can be seen throughout literature. The ADA was passed in 1990 and required businesses and facilities to provide reasonable accommodations to individuals with disabilities (Grabois & Nosek, 2001; Rehabilitation Act, 1973). This includes a Deaf individual’s need for an interpreter to communicate with their healthcare professionals. During the interview, Anne recalled not having her first experience with a professional interpreter until 1997 or 1998, and still encounters facilities that do not supply professional interpreters to Deaf clients demonstrating the current level occupational injustices being experienced by this population (Durocher, Gibson, & Rappolt, 2014; Grabois & Nosek, 2001). Anne continues to experience occupational marginalization when facilities will not provide an interpreter and she must try to understand written English regarding her health even though ASL and English are completely different languages (Durocher, Rappolt, &

Gibson, 2014). As Anne explained about her experience with written English in healthcare facilities: “If I have to depend on solely on written English I’m not going to understand these forms.” Overall, any individual who does not speak English deserves high quality care and health care professionals must work to find the best means of communication (Baillard, 2014; Durocher, Rappolt, & Gibson, 2014).

The last group of themes discussed involved the communication problems had between healthcare professionals and clients that are Deaf or do not speak English. No matter the language used by clients, it is vital to educate healthcare providers about the importance of quality communication and advocate for the clients who use different languages (Brogan, Adriaenssens, & Kelly, 2014; Steinberg et al, 2006). Healthcare providers are in charge of creating good care for their clients and doing all they can to make sure clients’ rights have not been infringed upon. Anne strongly feels her lack of proper representation and interpretation at different healthcare facilities was wrong and advocates for the Deaf population by informing facilities of their responsibility to following the ADA. It can easily be seen that both Anne and other members of the Deaf community would agree that clients need to feel they are important and properly cared for when working with medical staff no matter their language (Barrett, 2002; Quan, 2010). When asked about the differences between her experiences communicating with health care professionals, Anne stated: “There was a tremendous difference in them providing an interpreter and, realizing that my health was important and it was important I understood all what to do and how to take care of myself.”

Trustworthiness

The trustworthiness of this research study was tested using multiple methods to ensure credibility including member checking, expertise of the thesis committee, review of interpretation by an experienced researcher, and personal reflection. Member checking with the interpreter and the participant occurred during the data analysis process. This allowed the interpreter to review sections of the transcript for accuracy and possible ambiguities and to clarify with Anne on some minor points. Lastly, personal reflection and thesis committee review ensured the removal of personal biases or assumptions made by the researcher or committee members throughout the analysis process. In addition, one of the committee members is a certified interpreter and a linguist, providing insight into both these important areas of the subject matter.

Limitations

Limitations for this study are that this narrative study revolves around a single Deaf participant's life experiences communicating with healthcare professionals. Though the concepts may be generalizable, personal experiences are unique to each individual and therefore might not transferable to other members of the Deaf community. The researcher conducted a single interview with Anne and the certified interpreter, reducing the amount of possible data collected. Purposeful recruitment provided the researcher with a participant with decades of experience communicating with healthcare professionals, yet limited the perspective to that of a Caucasian female from the southeastern area of the USA. In future research regarding this topic, it would be important to consider including a more diverse background of perspectives such as race, geographical area, gender, and age.

Implications to Occupational Therapy (OT)

In occupational therapy, the focus is on helping clients complete valued daily occupations while working with a wide variety diagnoses in an array of settings. Therefore it is important for occupational therapists to understand and value quality communication and assist clients experiencing communication barriers. Anne experienced occupational injustice because of her inability to pursue valued Instrumental Activities of Daily Living such as health management and maintenance and child rearing. A difference in native language does not mean one should be marginalized. Others engaging with the client should work to better understand their native culture and learn about their preferred language. It is important for healthcare providers to attempt communication in any way that can assist clients in participating in their care, such as drawing pictures instead of using written English as stated in Anne's experience and supported in the literature (Steinberg et al, 2006; Solow, 2014).

Part of the OT profession involves advocating for our clients and teaching them about their rights regarding level of care, among many other things. As occupational therapists, it is vital to remain familiar with the changing legislation regarding the rights of their clients and what is best for their care overall. Occupational therapists are not only required to advocate for clients, but it is also important teach OT clients what their rights are and how to advocate for themselves. In addition, occupational therapists should educate other healthcare professionals on the value of quality communication with clients and the ways it can affect other areas of their care.

Lastly, the terms occupational marginalization and occupational injustice refer to "any undue limitation on a person's freedom to have or to pursue meaningful

occupational engagement in society” (Durocher, Gibson, & Rappolt, 2014).

Occupational therapists work to facilitate their clients’ ability to participate in valued occupations. A language barrier could cause marginalization, or exclusion from involvement due to a lack of resources, creating a situation where the individual feels trapped. As healthcare professionals, occupational therapists are available to help educate communities in a way that reduces marginalization, encourages the importance of cultural competency, and promotes involvement in valued occupations.

Conclusion

In conclusion, research shows that members of the Deaf community often experience occupational injustice and marginalization with medical care due to communication barriers with hearing healthcare professionals. Though the ADA has been in place since 1990, members of this community still encounter facilities that do not follow legislation because they find it inconvenient or expensive. Utilizing certified interpreters is one way to assist the Deaf community, but it is important to remember this concept is one that can be generalized to all clients communicating with healthcare professionals using different languages. Providing resources for these clients, as well as understanding the frustration and difficulty that come with these experiences is one way to assist these individuals in order to find the best means of quality communication. It is vital for all healthcare professionals to consider, how are we able to provide our client the best practices of our field if we do not try understanding their culture and work to create a positive and valued means of communication?

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APPENDIX A:
Interview Questions

Research Study Interview Questions Semi-Structured Interview

Start by explaining who I am, who interpreter is, main purpose of interview, and expected length of time. Ask if any questions starting at the beginning.

Can you tell me about your life as a Deaf individual, starting anywhere you feel comfortable? (Age of onset of deafness? Experiences in medical centers? When moved to Richmond KY area?)

Have you experienced any medical issues or medical life events, either related to/not related to your deafness? (Describe medical experiences, personal feelings about medical situations, what occurred during that medical experience)

Have you received any medical services in or around the Richmond, KY area? If so, what types of facilities were they (without mentioning specific names)? examples: urgent clinic, emergency room, general practitioner's office. (Probe about type of care received and communication with medical staff)

TYPE OF LANGUAGE:

What are your feelings about how healthcare professionals communicate with people who are deaf?

Were you able to use your sign language in these facilities? If not, how did you communicate with the healthcare professionals?

How did this make you feel and why?

CHALLENGES:

If you feel there are some specific challenges you have faced communicating with healthcare professionals, what were they?

What are some ways these challenges could be alleviated or resolved?

What are some ways that medical facilities could be more deaf friendly?

SUCSESSES:

What are some specific helps you have had communicating with healthcare professionals? (successes, positive experiences)

What are some ways you have seen/experienced facilities being deaf friendly?

CONCLUSIONS- Thank for participation, Ask if any other questions, reassure safety of info.