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Interpreter Access for the Deaf Community Before and During the COVID-19 Pandemic

Isabella C. Updyke-Welch
Portland State University

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Interpreter Access for the Deaf Community Before and During the COVID-19 Pandemic

By

Isabella Updyke-Welch

An undergraduate honor thesis submitted in partial fulfillment of the

requirements for the degree of

Bachelor of Science

in

University Honors

and

Psychology

and

Minoring in

American Sign Language

Thesis adviser

Tina Burdsall, PhD

Portland State University

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Abstract

It has been estimated that 1 out of every 20 Americans are Deaf or Hard of Hearing (HoH) (Mitchell, 2006).

More research is required to determine how people used ASL interpreters in medical settings, but ran into complications with the process of accessing accommodations and interpreters. There is a lack of research that outlines the Deaf community's preferences when it comes to interpretation options in medical settings. Additional research is required to determine what interpretation options would provide the most benefit and be the most accessible to members of the Deaf community, and all individuals with varying levels of hearing loss.

This thesis reviews current relevant research on the issues of interpreter access for members of the Deaf community, presents the results of a pilot study investigating the Deaf community's preferred interpretation options, as well as providing a template for a proposed future research study.

The pilot study used Likert Scale questions, but this thesis did not analyze the data or draw any conclusions because participation was too low due to the COVID-19 pandemic. The focus of this study changed to propose a future research study that follows the structure of the pilot study with some improvements and suggestions that could be used to create a relevant and repeatable research study.

Key Words: Deaf, Hard of Hearing, Deaf community, Communication, Interpreter Access, Medical field, Health Care, Hearing Loss, In-person Interpreter, American Sign Language (ASL), Accessibility.

Introduction

The Deaf community within the United States includes individuals who identify as Deaf, Hard of Hearing (HoH), or Deaf-Blind. “We use the lowercase deaf when referring to the audiological condition of not hearing, and the uppercase Deaf when referring to a particular group of deaf people who share a language – American Sign Language (ASL) – and a culture.” (Carol Padden and Tom Humphries, 1988 as cited in National Association for the Deaf, 2022).

The definition of Hard of Hearing (HoH) is complicated, and there is no universal definition. Identifying with deaf or HoH is not just about the audiological definition of the person’s hearing loss, it also includes how that person identifies their hearing loss and if they consider themselves as part of the Deaf community (Moore, M., Levitan, L., 2003). In this thesis, ‘deaf’ will be used when referring to the medical definition of deaf, and ‘Deaf’ will be used when referring to a group of people, the identity of being Deaf, or the Deaf community.

From a nationwide income survey in 2006 it has been estimated that 1 in 20 Americans are Deaf or HoH (Mitchell, 2006). Using census data collected from 2016-2020, it is estimated that 11,471,821 people in the United States have “hearing difficulty” (United States Census Bureau, 2020). The same census estimates that 321,525,041 people live in the United States, about 3.6% of the population has hearing difficulty. Although the percentage has dropped since 2006, this is still a significant number of people who are faced with the challenges that come with some form of hearing loss

The Johns Hopkins Bloomberg School of Public Health has estimated that “25.4 million people over the age of 12 in the United States have a mild hearing loss, and 12.8 million have a moderate or greater hearing loss.” They identified mild hearing loss as difficulty hearing softly spoken conversations, when people are speaking fast, and hearing conversations with

background noise present. Moderate or greater hearing loss is defined as when the individual struggles in those situations but may additionally struggle with normal conversations with no to little background noise (Goman, A., 2018).

This significant part of the American population has encountered problems with discrimination and inaccessibility of resources that are available to the majority hearing community. “Whether being denied rights to own property, to have children, or to drive a car, Deaf people have rarely been treated with the dignity that should come with being human.” (Bauman, HDL., 2004). While some individuals who are hard of hearing can still use their hearing while accessing resources like public healthcare, others who have more hearing loss or are deaf need interpreters who are fluent in English and American Sign Language (ASL) in order to receive the same quality of care.

American Sign Language (ASL), is the primary language used by members of the Deaf community in the United States. ASL is a visual language where hand movements, body movements, and facial movements are used to communicate. Prior to 1984, ASL was not considered an official language, and was dismissed by the hearing community. In 1984, linguist William Stokoe outlined the phonology of ASL and declared ASL an official language (Stokoe, 2005). ASL is now seen as a complete language with its own rules and grammar, and is even taught in many high schools to fulfill foreign language requirements.

Because most people that Deaf people interact with do not know ASL, there is a continual need for ways to communicate between hearing and Deaf people. Often this communication is through writing, having a family member with them who can communicate in both ASL and English (English, A., n.d), or even a child. Relying on the child, especially an underage child, is both legally and ethically wrong. (Finch, C., 2020). These unofficial forms of

interpretation can be riddled with problems especially when discussing emotional or complex concepts. Family members may volunteer to interpret, but this does not allow patients to speak frankly with healthcare providers and violates confidentiality laws.” (Scheier, D., 2009) In order to provide official interpretive services, a certificate is needed from the Registry of Interpreters for the Deaf (RID), (Registry of Interpreters for the Deaf (RID), Inc. n.d). This certificate does not provide education on interpretive services for specialty fields such as medical or legal interpretive services. There are not many Undergraduate programs that specifically prepare future interpreters for a specialization of interpreting in medical settings. Because of this scarcity, many interpreters will do the normal RID certification but then seek out further educational programs like workshops, online instruction, and mentorship (National Consortium of Interpreter Education Center (NCIE). n.d.)

In the majority hearing community that uses spoken English to communicate, many members of the Deaf community often struggle to access resources and support. Bauman, HDL,, (2004) outlines the discrimination of Deaf people, also called Audism. Bauman stated three definitions of the word Audism, “1. The notion that one is superior based on one’s ability to hear or behave in the manner of one who hears. 2. A system of advantage based on hearing ability. 3. A metaphysical orientation that links human identity with speech.”

The quality of medical care will decrease with a lack of quality communication, of which interpretation is necessary for individuals who do not speak English as their first or primary language. In their book, *Communicating with your doctor, Rx for Good Medical Care*, Dr. J Alfred Jones and Gerald Phillips outline the different aspects of doctor and patient communication. While discussing the barriers to effective medical relationships they state that, “The most effective doctor-patient relationships are characterized by patients that

understand some technical language and can ask productive questions.” (Dr. Jones, A., and Phillips, G., 1988. p17).

In January of 2020, the global pandemic of the COVID-19 virus began. The first known cases were in China, but in March of 2020 there were documented cases of Americans who did not have travel histories, indicating that within-community transmission had been happening outside of the hospital containment zones for travelers who came back to the US and got sick (David, C., Peter, M., 2020).

As of March 17th 2022, the Center for Disease Control (CDC) released statistics of how many Americans were affected by the COVID-19 pandemic. According to the CDC there have been 82,522,948 total cases of COVID-19, 997,468 total deaths, 16,571 current hospitalizations, and 257,942,199 Americans have at least one dose of a COVID-19 vaccination (Centers for Disease Control and Prevention [CDC], 2022).

As a response to COVID-19 numbers rising rapidly, all healthcare facilities had to make immediate emergency changes to accommodate sick patients. Medical care staff, particularly nurses at Intensive Care Unit level (ICU), were in high demand at most medical facilities (Retzlaff, K., 2020). Chen, R., et al. conducted the first large-scale study of trauma and burnout responses from nurses working during the COVID-19 pandemic. They found that high levels of nurses were having symptoms of trauma including trouble sleeping, anxiety about more disasters happening in the future, nervous and fearful behavior was experienced during unexpected events, and experienced feelings of irritability, anger, and unhappy thoughts and memories connected with the COVID-19 pandemic (Chen, R., 2021). Communication between medical providers and the Deaf community can be challenging under the best of circumstances, and the COVID-19 pandemic just caused more issues.

The COVID-19 pandemic has disproportionately affected those individuals with disabilities in the workforce, medical care, and daily lives (Chang, M., & Lipner, S., 2020). There has been research done that concluded that communication was more difficult, and public announcements about the virus during the COVID-19 pandemic were often not as accessible to the Deaf and Hard of Hearing. Research has shown that those who are deaf were 4.6 times more likely to report difficulty accessing the public information around COVID-19 than those who are hearing (Panko, T., et al. 2021). This could have led people to engage in activities that put them at risk of contracting COVID-19, or caused them to avoid going to see medical providers when they needed to.

The necessary use of face masks during the COVID-19 pandemic for protection for provider and patient, disproportionately negatively affected those who are Deaf or Hard of Hearing. Some individuals use lip-reading techniques in medical settings, but facial expressions are also used linguistically in American Sign Language for grammar and punctuation (Grossman, R., and Kegl, J., 2006). While clear masks were available, only one brand was approved by the FDA as safe in medical settings (Safe 'N' Clear, 2022).

How health care facilities provided interpretation changed due to COVID-19. “In-person sign language interpreters are being switched to remote interpreting roles during the COVID-19 pandemic to conserve personal protective equipment and reduce their risk. Remote interpreting can be supplied by existing hospital staff interpreters, contracted community based medical interpreters, or video remote interpreting agencies” (McKee, M., et al., 2020). There is no current research reviewing how the changes in available interpretation options affected the Deaf and Hard of Hearing (as of May 20, 2022).

This thesis will address the question of how the COVID-19 pandemic has affected members of the Deaf community within the West Coast of the United States when utilizing interpreter services while receiving care from the health care system.

Literature Review

There has been a vast amount of research done surveying ASL interpreters, and some research done surveying workers in the medical field, on their perspectives and experiences working with members of the Deaf community (Hommes et al., 2018)(Iezzoni, 2004). Although the process of using interpreter services can be analyzed from interpreters and medical staff, the research cannot be as effective a tool in studying the problems and improving the system because it unintentionally excludes research directly surveying members of the Deaf community.

Discrimination against individuals with a disability in medical settings is against federal law due to the Americans With Disabilities Act (ADA) of 1990. It is discriminatory not to offer appropriate “qualified interpreters or other effective methods of making aurally delivered materials available to individuals with hearing impairments” (Americans with Disabilities Act, 1990). Because of this law, all medical facilities legally have to provide certified medical ASL interpreters.

Many healthcare providers, including physicians, nurse practitioners, and advanced practice nurses, were not educated on the ADA laws that it is the provider’s responsibility to provide interpreters. It is also the responsibility of the healthcare provider to bear the cost of any interpretation services. This can lead to situations where the deaf/HoH individual does not have the necessary interpreter because the healthcare provider did not provide one. Or the healthcare

provider opted to not hire an interpreter, because of their lack of education on the ADA laws. Lack of quality interpretation can also lead to medical accidents based on mis-communication.

Hommel et al., (2018) surveyed certified ASL interpreters to identify their perspectives on the barriers that members of the Deaf community face when receiving health care. Their research identified several common problems with communication and reviewed the different ASL interpretation options that are usually available. It has been found that when Deaf and HoH patients were able to access their preferred interpretation method, that communication was easier for both the patient and the doctor (Hommel et al., 2018). It is critical to identify the Deaf community's preference for different ASL interpretation options and find ways to make those options more reliably accessible and available.

Methods

Originally this thesis was focused on conducting primary research. Due to the research difficulties created by the COVID-19 Pandemic, the research focus and question had to be altered away from collecting primary data. The thesis goal has been reframed to design a robust study that I hope to complete in the future, using the pilot study as a model.

The pilot study was approved by the Portland State University's Institutional Review Board (IRB). All materials including promotional material, email drafts, consent forms and survey questionnaires were included in the IRB application and are included in Appendices A-C.

The pilot survey research was a cross-sectional survey of Deaf, Hard of Hearing, and Deaf-Blind individuals. The criteria for participation in the research was that participants be adults over the age of 18, who identify as Deaf, Hard of Hearing, or Deaf-Blind, live on the West

Coast of the United States of America, and have received medical care within two years before the pandemic and accessed care during the pandemic.

The survey structure and questions were based on two previous survey research studies, one surveying ASL interpreters (Hommes et al., 2018), and the other interviewing deaf and Hard of Hearing individuals (Iezzoni et al., 2004). The survey primarily asked Likert scale questions with a five point scale from never, rarely, sometimes, often, and always. There were also multiple-choice and fill-in-the-blank questions. To allow anonymous online responses, the website Qualtric was used to create the survey, and links to the survey were distributed by poster, email, posted on online sites, as well as given to ASL professors at Portland State University and professional ASL interpreters. The study relied on the snowball effect to spread the survey to members of the Deaf community.

The survey started with acquiring consent, then asked demographic information of ethnicity, age, how they identify their hearing loss (Deaf, Hard of Hearing, Deaf-Blind), if they have congenital deafness, or acquired deafness through injury or illness, or due to aging, and at which age they became deaf. The original demographic information collected from the pilot study would have been used in the data analysis, but since the focus of this thesis has changed, the demographic information is now not pertinent to the thesis.

Findings

Ten people participated in the pilot study but only four answered all the questions. Although this did not provide enough data to analyze, there were some trends that were visible in the demographic information. All participants selected the demographic 'white' as well as 'Deaf' instead of hard of hearing or Deaf-Blind. Three participants selected that they became Deaf

before the age 3, and the fourth participant selected above 40. The pilot study used the snowball method of distributing surveys, and for the snowball method to work there needs to be a lot of data to analyze, otherwise there are issues with representation of the population. This is shown in the similar demographic answers from four responses.

What I learned about creating my survey was how easy it is for survey questions to be confusing for participants, especially if the main population does not use English as their primary language. For any future research, before sending out a national level survey, the researchers should have groups of people who identify as Deaf and use ASL as their primary language to approve the survey questions. For the qualitative interviews, the future researchers should provide access to video interpreters for all participants.

Limitations of the Pilot Survey

The low participation levels in the pilot survey can be attributed to several factors, from internal problems with the survey that will be changed in future research, to external problems that were caused by the location and timing of the survey, as well as the pandemic. Before the COVID-19 pandemic, there were social events and organizations that hosted events in the Deaf community. All in-person activities were disrupted by stay-at-home orders and restrictions about how many people can be in one room.

Discussion

Using the pilot survey as a guide for designing a future longitudinal design research project requires that some changes be taken into consideration. The outline and structure of a future research project will be laid out and supported with the results from the pilot survey. The

actions of the future research will be divided into a national level survey, and in-depth qualitative interviews.

The first wave would consist of a nationwide online survey that will be structured to collect and analyze data to create a set of questions for the in-depth qualitative interviews.

The population of future research should focus on individuals that identify as Deaf. The pilot study only received responses from those who identify as Deaf. There may be cultural changes that could occur between 2022 and the year the future research is conducted. Future researchers can make a more educated decision about what population to survey when the time comes and they have a better understanding of the current Deaf culture, and have more input and involvement from Deaf community.

Future research populations will be affected by how the research will be accessed by the community. The pilot study struggled with participation from members of the Deaf community; participation can be improved for future research with some modifications. The online and anonymous nature of the survey creates a survey format that would be accessible to most of the population in the United States. The pilot survey only distributed the questionnaire to members of the Deaf community who lived on the West Coast of the United States (Oregon, Washington, and California). To increase participation and create a larger data pool, future research will be distributed to as many states within the United States of America as possible to increase the population size. Since the laws around ADA (Americans with Disabilities Act) are on the federal level, expanding the size of the survey to other states is not a problem.

To have more success with distributing the survey, future research should reach out to prominent Deaf organizations, as well as Universities to advertise the survey. Gallaudet University, and National Technical Institute for the Deaf (NTID) would be great Universities to

work with in the future. The National Association of the Deaf (NAD), and the National Black Deaf Advocates are examples of great organizations that future research can use to help distribute a survey. Organizations may be different when the future research occurs, so the researchers will contact the leading organizations that have strong connections to the Deaf community. This will increase the amount of people the researchers can advertise the survey too, and increase the diversity of participants.

The second wave of research will be qualitative interviews either distributed by sending interview questions over email, or setting up interpersonal or video interviews. The questions for the interviews will be created based on the results from the national survey. Qualitative interviews can give richer understanding of personal experiences and allow the researcher to ask probing questions which can help the researchers to get information on specific answers or subjects. Using a national level online survey that will use Likert scale questions paired with qualitative interviews can give future researchers a rich collection of data to analyze.

Conclusion

A large percentage of the population within the United States identifies as Deaf, Hard of Hearing, or Deaf-Blind and use American Sign Language as their primary form of communication. Those who need interpretation while receiving medical care often run into issues accessing the correct accommodation. The lack of accessibility to preferred interpretation options can have a detrimental effect on the quality of the medical care given, so it is important to research what the actual preference on interpretation options are for the Deaf community and make them accessible.

This thesis looked at the research on the subject and applied relevant findings into a pilot study that will then be a model for more indepth future research. The goal of the pilot study as well as any future research, was expanding knowledge about the accommodation needs of those with hearing loss, the legal responsibilities of medical facilities, and advocating for more accessible access to the prefered interpretation options for the Deaf community.

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Appendix A. Consent Form

Survey about how interpreter services have been utilized in during the pandemic

Isabella Updyke-Welch from Portland State University's Honors college is conducting a research study on how the COVID-19 pandemic has affected how interpreter services are being utilized in health care settings by members of the Deaf community. I am conducting this research to fulfill the requirements for my Bachelors of Science degree in Psychology, minor in American Sign Language, and the requirements from the Honors college; under the direction and mentorship of Dr. Burdsall.

Who can be a participant in this study?

Participants have to be at least 18 years old to participate. We are looking for individuals who identify as Deaf, Hard Of Hearing, or Deaf Blind, and live in the one of the following West Coast states of the United States of America: California, Oregon, or Washington.

What am I asking of you?

If you decide to take part in this project, you will take a survey about how you have utilized interpreter services while receiving medical care, both 2 years before the pandemic and during the pandemic. This survey will take you about 15 minutes to complete.

Why have you been asked to take part in this study?

Because your experiences can help inform how Interpreter services are being used, and how they can be improved in the future.

What are the risks and what is being done to protect you?

This survey will be anonymous, and will not document your name. The survey is asking demographic questions about ethnicity, and age. There is a small risk that you will feel uncomfortable answering some of the questions. You can skip uncomfortable questions. Any information from the survey will be presented as data that represents groups of people, not individual answers, so it will not be possible for readers to know who is connected to which answers.

What will you gain by taking part in this study?

You will not gain anything directly by taking part in this study. However, if you participate you may be helping us learn more about how interpreter services are being utilized in health care settings, and so help improve interpreter options for those in the future.

Any Questions?

If you have any questions about this study, this survey, or my final paper, please contact *Isabella Updyke-Welch* at icu@pdx.edu. If you have any concerns about your rights as a research

participant, please contact the chair of the Human Subjects Committee of Portland State University about your rights as a research participant. Portland State University, Cramer Hall, Room 111, 1721 Broadway Ave., Portland OR 97201, Telephone: 503-725-4288; Email: hsrrc@lists.pdx.edu

Please keep a copy of this letter for contact information if you have any questions.

Appendix B. Flier

Isabella Updyke-Welch

Dr. Burdsall

Portland State University

Presents

ASL Interpreter Access Survey

Survey Research looking for participants

Starting on 1/1/2022

What is this survey for?

-We are looking at how interpreter services have been utilized by the Deaf community when receiving medical care both before and during the COVID-19 pandemic. The research will focus on how the pandemic has affected access to interpreter services, and how we can improve future accessibility to the medical field.

Why participate?

-Your unique and valuable perspective might help shape future access to interpreter services.

Who can participate?

-Members of the Deaf community who identify as: Deaf, Hard of Hearing, or Deaf-Blind.

-Are 18 years of age or older

-Live or spend most of their time in the West Coast states (Oregon, Washington, and California) of the United States of America

-Has received medical care more than once in the past 4 years

This is a single survey that will take about 15 minutes to complete. We really appreciate your voluntary participation in this research.



Isabella Updyke-Welch

Email: lcu@pdx.edu

Appendix C. Email Draft

Hello,

My name is Isabella Updyke-Welch, and I am a senior honors student at Portland State University, working towards a Bachelor of Science in Psychology with a minor in American Sign Language. As a requirement for my graduation, I am doing an honors thesis on interpreter services for the Deaf community in medical settings, under the supervision of Dr. Burdsall.

We are asking members of the Deaf community who are 18 years old or older, identify as Deaf, Hard of Hearing, or Deaf-Blind, and have received medical care more than once in the past 4 years to fill out a 15 minute anonymous online survey. The survey will not be collecting names or any identifying information and has been approved by the IRB board at Portland State University.

The survey is looking at how interpreter services have been utilized by the Deaf community when receiving medical care both before and during the COVID-19 pandemic. The research will focus on how the pandemic has affected access to interpreter services, and how we can improve future accessibility to interpreter services within the medical field.

This link (https://portlandstate.qualtrics.com/jfe/form/SV_ctDbZQdg0jGpH82) will take participants to a website called 'Qualtrics' where they can fill out the survey. Please forward this email to anyone who you think would be interested in participating in this research study.

If you have any concerns or questions, please email me at icu@pdx.edu.