January 2018

Can You Hear Me Now: Being Deaf and Healthcare Experiences.

Jordan Blackaby
Eastern Kentucky University

Recommended Citation

Blackaby, Jordan, "Can You Hear Me Now: Being Deaf and Healthcare Experiences." (2018). *Online Theses and Dissertations*. 513.
https://encompass.eku.edu/etd/513

CAN YOU HEAR ME NOW: BEING DEAF AND HEALTHCARE EXPERIENCES

BY

JORDAN BLACKABY

THESIS APPROVED:

Chair, Advisory Committee

Member, Advisory Committee

Member, Advisory Committee

Dean, Graduate School

STATEMENT OF PERMISSION TO USE

In presenting this thesis in partial fulfillment of the requirements for a Master of Science degree at Eastern Kentucky University, I agree that the Library shall make it available to borrowers under rules of the Library. Brief quotations from this documents are allowable without special permission, provided that accurate acknowledgments of the source is made. Permission for extensive quotation from or reproduction of this document may be granted by major professor in (his/her) absence, by the Head of Interlibrary Services when, in the opinion of either, the proposed use of the material is for scholarly purposes. Any copying or use of the material in this document for financial gain shall not be allowed without my written permission.

Signature: JMB

Date: 12/ 20/2017

CAN YOU HEAR ME NOW: BEING DEAF AND HEALTHCARE EXPERIENCES

By

JORDAN BLACKABY

Bachelor of Science in General Health Studies
Minor: American Sign Language
Eastern Kentucky University
Richmond, Kentucky
2015

Submitted to the Faculty of the Graduate School of
Eastern Kentucky University
in partial fulfillment of the requirements
for the degree of
MASTER OF SCIENCE IN OCCUPATIONAL THERAPY
August 2018

DEDICATION

Thank you to my family who have always supported me in all aspects of my life. I could not have finished this without your help. And I also want to thank my friends who have laughed, cried and been with me through this whole process.

ACKNOWLEDGMENTS

I would like to thank my thesis chair, Dr. Christine Privott, for her ability to be open minded and fluid with my working style. Her patience and guidance through this process was invaluable in its completion. I would also like to thank the other committee members, Dr. Mary Ellen Thompson and Dr. Julie Baltisberger, for their comments and assistance over the course of this research project. I would like to thank the interpreters who volunteered their time and expertise to ensure the success of this project. And finally, I would like to thank my four Deaf participants who were willing to share their experiences with me as participants in this study.

ABSTRACT

The primary objective of the study was to examine how deaf culture impacts an individual’s experience in accessing healthcare. Research conducted by Montoya et al. (2004) found that the adult deaf population is severely underserved in the healthcare system. Sheppard and Badger (2010) found that it is important to also consider the deaf culture when evaluating a deaf patient. For this research, the Deaf community and culture will be explored to determine Deaf individuals’ experiences in healthcare. This study is a cross-language qualitative approach using narrative description to describe Deaf individuals’ and their experiences accessing healthcare. Data analysis was conducted with basic descriptive statistics and qualitative coding and thematic analysis. The researcher found that an individual’s experience is strongly influenced by their access to interpreters and the healthcare professional’s willingness to follow their preferred method of communication. The results will provide insight into the Deaf culture and their experiences in the healthcare system.

Keywords: Deaf, deaf culture, occupational therapy

TABLE OF CONTENTS

CHAPTER PAGE

I. Introduction 1

Literature Review 2

II. Journal Article Manuscript 12

References 24

APPENDICES

APPENDIX A. IRB Approval 27

APPENDIX B. IRB Approved Consent Form: Primary Participants 29

APPENDIX C. IRB Approved Consent Form: Key informant 32

APPENDIX D. IRB Approved Interview Guide 35

Chapter I

Introduction

The United States has a rich history of cultural diversity, founded on the principle that cultures from around the world are accepted and welcome to start a life in a free world. The U.S. is often seen as the melting pot of the world, a vast land full of diverse cultures and peoples (Shi. & Singh. 2015). The concept of culture is difficult to articulate, and many definitions have been created in an effort to explain its impact on individuals lives. According to the U.S Department of Health and Human Services (2017)

> Culture is often described as the combination of a body of knowledge, a body of belief and a body of behavior. It involves a number of elements, including personal identification, language, thoughts, communications, actions, customs, beliefs, values, and institutions that are often specific to ethnic, racial, religious, geographic, or social groups.

The Department of Health and Human Services goes on to further elaborate on cultural respect, explaining that in a healthcare setting it is vital to providing high quality healthcare to a wide range of patients (2017). Understanding and respecting an individual’s language and communication needs are important for providing culturally respectful care: this covers a wide range of individuals including those who are Deaf. While some healthcare providers do in fact provide culturally respectful care, the question arose, how does the Deaf communication and cultural barrier impact their access to healthcare?

Problem statement.

There are differences in how the deaf access healthcare compared to hearing individuals (Sheppard & Badger, 2010). The issue of health care in the U.S. is currently a controversial topic and one of political and social debate. For this study, the author looked at how being a member of the Deaf culture impacts experiences in the healthcare setting. Literature on being Deaf and utilizing healthcare is limited and lacks specific studies addressing individuals who are Deaf and their healthcare experiences.

Purpose statement.

The purpose of this qualitative study is to explore the Deaf community and culture, narratively, to better understand their healthcare experiences.

Significance.

The significance of this study is to shed light on the specific barriers Deaf individuals experience as they engage in the U.S. healthcare system for their own healthcare. Because members of the Deaf culture need access to healthcare, it is important for healthcare professionals to fully understand consumers of healthcare who are deaf and ways to provide these services.

Literature Review

Scholarly literature on Deaf culture and healthcare utilization is limited and lacking in specific research studies addressing these elements. Key search terms of *deaf culture* and *access to healthcare* were used to frame the study. This literature review is organized by the two main categories, Deaf culture and healthcare concerns, each with sub-categories, discovered in the course of the literature search to provide the best study context for readers.

Deaf Culture: pretext to healthcare.

It is important to explain the difference between the word deaf and *D*eaf. The capitalization of the [d] has a strong impact on what the word means to Deaf individuals. When members of the Deaf community state they are deaf, the [d] is capitalized. O'Brian and Placier (2015) state, "the 'd' refers to the physical condition, 'disability' or 'pathology' of deafness. It indicates that something is broken, that the ability to hear is impaired… In contrast, 'D' denotes people who consider themselves members of Deaf culture or the Deaf community" (p 321). To facilitate a greater understanding of Deaf individuals' experiences, there must be an understanding of their culture and community. For this paper, the author will purposefully use Deaf when referring to the culture and community.

Individuals experiencing life events are influenced by several factors, such as the physical environment and culture. Culture is defined as "the learned, shared and transmitted values, beliefs, norms and lifetime practices of a particular group that guides thinking, decisions and actions in patterned ways." (Andrews & Faulkner, 2004, p.20). An individual's culture plays a large role in their perception of the world around them and how they experience events. Like other cultures around the world, the American Deaf culture is rich in art, literature, and shared values. According to Ladd and Lane (2013), Deaf culture plays an important role in creating what is called Deaf ethnicity, which also creates a sense of belonging and community. There are four domains considered part of the Deaf culture: 1) audiological (being deaf or hard of hearing), 2) linguistic (the use of a form of sign language), 3) social (interacting and following the sociocultural norms) and 4) political actions (Holcomb, 2013). Holcomb (2013) goes on to state “American Sign Language (ASL) is one of the most distinctive marks of Deaf culture” (p.7). Someone who is more involved socially and fluent in ASL can be more strongly rooted in the culture rather than someone who does not know ASL. Many Deaf individuals consider themselves to be bilingual knowing both English and ASL (Holcomb, 2013). As with others who are bilingual, Deaf individuals’ fluency in both languages can vary, thus impacting interaction with others. This is especially important to consider when they access healthcare and communicate with their healthcare providers.

Language.

A unifying aspect of the Deaf community and a strong part of the culture is the language. ASL is a deeply valued part of the culture. It is difficult to assess how many deaf/hard of hearing individuals use ASL. Estimates are from five hundred thousand to one million using ASL as their primary language for communication (Montoya et al., 2004). A common misconception is that ASL is a broken form of English, and it is often seen as a primitive form of communication comprised of mostly gestures. Montoya et al., (2004) state “With its own unique vocabulary, idioms, grammar, and subtle nuances, American Sign Language (ASL) is a language in its own right. It is different from English” (p. 314). Language plays a critical role in passing on different traditions, rituals, norms or values and most importantly language allows for social interaction among the members of a specific culture (Ladd & Lane, 2013). Many Deaf American’s consider themselves to be bilingual, using both English and ASL in their day to day activities. Over the years there have been several misconceptions about ASL. As the years have passed, ASL has undergone rigorous study and is now accepted by the majority of linguistics, as a legitimate language (Holcomb, 2013). Like any language, ASL has its own grammatical structure, phonology, morphology, syntax and discourse (Liddell, 2003). Understanding that ASL is an important part of the Deaf culture and that it is not a form of broken English is vital to having proper communication with Deaf individuals.

Being a part of the Deaf culture allows for a sense of congregation; it provides many with a type of societal support that facilitates communication, interaction between likeminded individuals and practicing skills important to succeed in everyday life. Members of the Deaf community feel a deep sense of belonging because of their shared language. Holcomb writes (2011) "American Deaf people are noted for their strong sense of pride, and their fierce protective rights of independence, self-determination and the right to use a signed language." (p.3). ASL is a gateway for them to access the hearing world, a world that would have otherwise been cut off from them. Having access to easy communication, information and creating a positive sense of identity are key aspects of being a part of the community (Ladd & Lane. 2013).

Deaf and the Hearing.

Like with many cultures, the Deaf culture is not without adversity. Members of the Deaf community have faced oppression for years. Until as recent as the 1970's many Deaf individuals were viewed as, less than human because they were unable to speak (Bauman, 2004). Years of oppression has created distrust towards hearing individuals, specifically towards healthcare officials. Recently the term *audism* has been coined by those in the Deaf community. It is important to mention that much of the literature noted audism as a concept. Eckert and Rowley (2013) defined audism as, "a schema of audiocentric assumptions and attitudes that are used to rationalize differential stratification, supremacy, and hegemonic privilege" (p. 105). This phenomenon appears when hearing individuals distrust a deaf person’s ability to function in society because they are unable to hear. A common example of this is when a hearing person assumes that someone who is deaf is unable to drive, or complete simple tasks such as crossing a street or going to the store, because they are unable to hear. Audism is similar to other forms of prejudice like racism, sexism and ableism. Deaf individuals who experience audism, may be discriminated against or excluded in various social activities because of their inability to hear. Many members of the Deaf culture do not view themselves as disabled instead they view themselves as a linguistic ethnic minority. (Holcomb, 2011) This view is at odds with many professionals in healthcare settings.

Healthcare Environments

General healthcare.

The American healthcare system has been a controversial topic of politicians and the American people for many years. With the enactment of the Affordable Care Act (ACA) the majority of American’s have access to healthcare. The three primary goals of the ACA are; to make health insurance more affordable and available to more people, expand the federal insurance program Medicaid to over more adults below the poverty level, and support newer and more innovative healthcare delivery methods to help reduce costs of general healthcare (CMS, 2017). An acceptable healthcare delivery system requires two things to be considered effective: availability and cost effectiveness. First, it should be available to all citizens so that they may obtain the needed services (Shi. & Singh, 2015). With the implementation of the Affordable Care Act more American’s are getting access to healthcare. Although there is still a portion of Americans who are without healthcare the number is slowly decreasing. The next thing that an acceptable healthcare delivery system needs, is that the services must be cost effective and it must meet quality standards that have been established (Shi. & Singh, 2015). In recent events the ACA and state governments have been working to reduce costs of healthcare for everyone (U.S. Centers for Medicare & Medicaid Services, 2017). Insurances are no longer allowed to decline someone due to a pre-existing condition, such as being deaf. The recent changes in healthcare are important to keep in mind when exploring how Deaf individuals access healthcare.

Being deaf and healthcare.

In the United States health and healthcare are strongly influenced by the medical model. This model defines health as an absence of disease, therefore implying that a person's optimum health exists only when they are free of any illness (Shi. & Singh. 2015). The medical literature on being deaf appears to focus on the physical limitations, of lack of hearing. Being deaf is viewed as a condition that needs to be corrected (O'Brien & Placier, 2015). Because of this, members of the Deaf community distrust medical professional. General access to healthcare, using interpreters, and misdiagnoses are examples of Deaf individuals concerns when accessing healthcare.

Multiple barriers exist that make it difficult for the deaf to access healthcare. Drainon et al., breaks it down into three main categories: structural barriers, such as insurance policies transportation, communication with providers and time constraints; financial barriers and personal/cultural barriers (2006). The structural barrier of provider poor communication means individuals face personal, cultural barriers such as misconceptions, insufficient knowledge and insensitivity to their identity and individualistic needs. Many physicians do not have the knowledge or background to appropriately provide linguistically and culturally competent care for Deaf patients (Hoang, Laltousse, Nakaji, & Sadler, 2011). In contrast, Deaf individuals typically do not see themselves as disabled. These barriers reinforce the distrust many Deaf people feel towards healthcare providers, and create a reluctance to go to the doctor or a medical facility. This can lead to a greater risk of preventable illnesses. Members of the Deaf culture also participate in *reporting back*, or telling others about what you are doing and where. It can be something as trivial as telling someone you are going to check on food in the kitchen, or that you are going to a new doctor. This phenomenon is an important part of the sharing of information. (Holcomb, 2011) Mistrust of healthcare professionals can be spread through social interactions and may exacerbate the problem even more.

Use of interpreters.

A major healthcare concern is the use, or rather misuse of interpreters in a healthcare setting. According to a study done by Olson and Swabey (2017) many physicians rely on lip reading and writing to communicate with their deaf patients. This is an unreliable and potentially dangerous method of communication. Lip reading is a considerably difficult task and as few as thirty percent of the English language can be properly understood through this method (Hoang et al., 2011). Writing is also an unreliable source of communication. According to Montoya et al., the median reading comprehension of deaf high schoolers is roughly fourth grade (2004). This is below the national average which is a fifth grade reading level, and significantly lower than the average written healthcare material which is a tenth grade reading level (National Partnership for Women & Families, 2009). Under the American's with Disabilities Act (ADA) medical professionals are required by law to provide an interpreter for their deaf patients (National Association for the Deaf 2017) However due to misunderstandings of the law many do not provide one. When an interpreter is provided there may continue to be barriers in communication such as problems when translating speech patterns like idioms, or misunderstanding the content/intention of the sentence (Montoya et al., 2004). Sheppard and Badger conducted a study asking deaf individuals how they communicate with their healthcare providers. The focus of the study was examining communication problems with healthcare providers, and the use of interpreters in different healthcare settings. Sheppard and Badger (2010) stated that “Healthcare was described as embarrassing and frustrating. While all prefer an interpreter present for most healthcare, eight expressed that an interpreter was unwelcome when seeking mental health.” (p. 786). While interpreters are required to keep all medical information confidential, having an extra person in the room can make some deaf individuals reluctant to share information with their doctors. This can be especially true for small towns where the number of interpreters are limited and the Deaf patient may have to rely on the interpreter for other services.

The Deaf culture’s distrust of healthcare professionals, lack of interpreters and poor communication styles, and limited access to resources, create several barriers for Deaf individuals accessing healthcare. It is important to examine the social and cultural impact that impacts a Deaf individual’s healthcare experiences. A person’s cultural identity has a profound impact on their health and should be taken into consideration when treating a patient (Munoz, 2007). The primary objective of this research study is to fully understand Deaf culture related to perceptions of the healthcare accessibility. The secondary objective of this research study is to fully understand Deaf culture and the impact of these healthcare experiences on daily life.

Theoretical Lens - Kawa River Model

The U.S. current healthcare system is commonly accepted to be built upon a medical model, with a distinct fixation on the idea that curing physical problems will improve well – being – neglecting other aspects of the patient such as culture and religious views. There is also a lack of cultural safety in the health service field. Brown and Stoffel (2011) state "the concept of cultural safety extends notions of cultural sensitivity or cultural competency, which often ignore the power dynamics between those providing and those seeking services, particularly marginalized populations" (p. 443). The Kawa model is a culturally safe model occupational therapists consider when working with clients (Brown & Stoffel, 2011). This model considers an East Asian worldview and looks at how different contextual influences can impact imbalance in the client's life (Brown & Stoffel, 2011). The model provides a visual reference with five key elements for both clients and the healthcare providers. The first element is Mizu, or water. The water is a representation of life energy or the person's movement through their lifetime. The other parts of the model can impede or help the water move down through the river. The second element is Kawa no suki heki**,** or the river side wall. This represents the environment, society, and the physical contact that impacts the flow of the Mizu. The third element is Iwa, or rocks which represents different circumstances in one's life (mental illness or a physical disability for example). The fourth element is Ryuboku, or drift wood. This represents attributes of a person such as values, culture, personality, and relationships. Ryuboku can represent both positive and negative features in a person life and impede or assist the flow of the Mizu. The final element of the model is the Sukima - or space in between the obstacles. Kawa presents it as the role of the health practitioner in filling in the spaces and moving around the obstacles to help treat the patient in a comprehensive manner; considering all of the different aspects of the person's river.

The Kawa river model is a deep and comprehensive look at individuals and how they view life and the obstacles present, while allowing both the client and practitioner to find a way through them. The model is individualistic and varies from person to person and is aligned with notions of cultural differences. For example, some deaf individuals may view their inability to hear as a rock or driftwood impeding life flow, while others may view it as the river side wall - always with them in their journey through life.

Chapter II

Journal Article Manuscript

Methods

This cross-language study used an ethnographic, narrative, approach to examine the experiences Deaf individuals and access to healthcare. ASL was the cross-language of choice and the researcher used interpreters to translate interviews during data collection. The narrative aspect of the research design was used to describe experiences and stories from the participants; the ethnographic approach explored their Deaf culture in relation to healthcare access.

Participants

Before participants could be purposefully recruited, approval was granted by the Eastern Kentucky University, Institutional Review Board (IRB). After several attempts because of difficulty obtaining consensus on where and how the interpreters fit into the research design, the IRB was approved. The cross-language design meant that the interpreters would not be interviewed themselves, but only provide skills as a *certified interpreter*. The researcher assigned the title of *Key Informant* to the interpreters and the Deaf participants were assigned *Primary Participant*. The Primary Participants and Key Informants were recruited through a snowball-like sampling (word of mouth and referrals).

Inclusion criteria for the Primary Participants were: 1) age 18 – 80 years, 2) speak American Sign Language (ASL) or Pidgin Sign Language (PSE), 3) self-report that they are deaf or hard of hearing, and 4) self-report they have seen a medical professional (as defined by the participant) within the past last 2 years. For participant inclusion purposes, the individuals' experiences accessing healthcare was critical: The participants' diagnoses were not. Other demographic factors such as gender and ethnicity were not relevant to the subject population. Inclusion criteria for the Key Informants were: 1) age 18 - 80 years, 2) self-reported fluency/or certification in ASL or PSE interpretation, and 3) willingness to participate in the study. Upon initial IRB approval, it was not yet determined if the Key Informants would be certified interpreters: All key informants who eventually volunteered for the study were certified interpreters.

Primary Participants and Key Informants were provided Informed Consent forms and explanations of confidentiality were discussed with the researcher before the interviews began. Five primary participants agreed to participate in the interviews; however, due to scheduling conflicts, the fifth participant was dropped leaving a total of four Primary Participants. Participants' ages ranged from 26 to 67, and two males and two females. There were three Key Informants who volunteered their time to interpret the interviews.

Data Collection

Data was collected via semi-structured interview protocol with open ended questions to ensure Primary Participants were able to expand and narrate their experiences. The interviews took place on Eastern Kentucky University (EKU) campus in a location of the Primary Participants' choosing. The interviews varied in time with the shortest being ten minutes and the longest 35 minutes. Part of one interview was lost when the researcher attempted to download the cross-language video (videotape of interpreter and client during interview) to the computer - roughly two to three minutes of interview. This was documented on the transcript and considered during the data analysis process. Each video was recorded with the researcher's password-protected phone camera: the camera focused on the Primary Participant as they were interviewed by the researcher using interpreter services. The interviews were transcribed verbatim by the researcher.

Because this was a cross - language approach, the interpreters' words were transcribed, and it was noted when the interpretation did not directly align with what the Primary Participants signed. One Primary Participant and Key Informant asked to see the transcription to ensure correct interpretation**.** The interview was comprised of five open-ended questions, with several prompts allowing for fluidity in the interviews. Once interviews were completed, each Primary Participant was assigned an anonymous number to ensure confidentiality in disclosing the results.

Data Analysis

Data analysis began with five repeated readings and review of each of the four transcripts and across all transcripts four times, ensuring to mark where the Key Informant (interpreter) was filling in the spaces with different phrases. This allowed the researcher to discern the Primary Participants' responses. For example, the Key Informants would fill in silence or take time to think while interpreting and use the phrase "you know" even though the Primary Participant did not sign this during their response(s).

Open coding resulted in certain word clusters and the words were marked, categorized, and grouped together. Once coding was completed, a primary theme emerged and with three secondary themes. The primary theme, *Interpreting Services*, was supported with the secondary themes of *Education of Healthcare Professionals, Oppression*, and *Quality of Care*. The resultant themes were analyzed within the context of the Kawa River Model to begin to understand the participants' Deaf culture and healthcare stories as they navigate the "river" of healthcare.

The results are also anonymously represented by the initial [I] for Key Informant and a number [1-4] for each Primary Participant. This is to reinforce the cross-language design of the Key Informants *interpretation* of the Primary Participants responses.

Rigor

To maintain and support validity and rigor, the researcher reflexively journaled throughout the study; this allowed researcher bias(es) to be identified and set aside during the study. Other steps were also taken to ensure trustworthiness: Member checking of interview data, peer debriefing to ensure themes were consistent with the data, and documenting each step or the data collection process.

Results

Primary Theme

This primary theme of Interpreting Services comprised most, if not all, of the emergent data. All participants' discussed interpreting and the impact on healthcare experiences. Four transcripts contained a derivative of the word interpreting, forty-nine times. The biggest contributing factor to a positive or negative experience in a health care setting was access to interpreting services based on the data collected in this study. Not only was having access to an interpreter a determining factor but being able to choose how the service was delivered also contributed to the overall experiences.

Throughout the interview Participant I1 discussed how having access to interpreters that she trusted was difficult to find. She mentioned that there was a limited pool to select from in this area making it difficult to find a specific one for certain more private doctors' visits. Participant I1 stated "But we need to have an interpreter there [in reference to a healthcare setting] so um, the importance is trust and confidence". Trusting that the interpreter would keep information confidential was a concern, as well as finding one that she didn't know. Participant I1 also discussed how she must plan her visits to a healthcare facility around the availability of an interpreter. Using the Kawa model and based on her responses, it appears that interpreting services for this individual would be considered Ryuboku or drift wood. Drift wood does not always have to be a negative aspect of someone's life, requiring an interpreter and have that bridge for communication appears to both help the flow of Participant I1's mizu or water as well as hinder it.

Other participants such as I2 and I3 mentioned interpreting services as well but did not go as in depth in their experiences or opinions. Participant I3 briefly discussed how having interpreters at during a healthcare visit allowed him to make more comprehensive decisions about his healthcare. Participant I3's interview was the shortest and provided limited amount of data. Participant I2 discussed how he preferred an interpreter but was less inclined to wait for one and would prefer to write back and forth with his doctor or use a video phone service to talk with his doctor. Participant went into more detail about his experiences with interpreters but due to technical errors some of his interview recording was lost. Therefore, what he discussed in that portion will not be considered in the results. Like Participant I1 he stated "if you bring an interpreter in you never really know what's going to happen. You have to learn to trust that interpreter if they're going to follow the code of ethics and if they're going to be confidential with that information.". Trusting an interpreter and having established a rapport with said interpreter during a doctor's visit appears to be a significant factor in contributing to whether the experience is positive or negative. Again, like the Participant I1, I2 appears to consider interpreting services to be Ryuboku, and something healthcare professionals needs to work around and with to ensure a comprehensive and positive healthcare experience.

Participant I4 mentioned that her experiences in healthcare were about 50/50 positive and negative, depending on who the interpreter was. She expressed frustration with the limited pool to choose her interpreters from. Of all the participants I4 went the most in-depth about her experience with interpreting services and her dissatisfaction with them. Participant I4 stated

> "I know what interpreters are qualified that I want in the healthcare profession, and it seems some do not meet my needs linguistically and are not accustomed to highly educated academic deaf person with skills such as mine. They're not used to voice interpreting for me. So they may dumb down so to speak, so I have to meet the needs of the interpreter rather than be able to be myself and ask the questions I need at the level I normally would so, and so in that sense there is a low quality of interpreting services."

Participant I4 also elaborates on how having a highly qualified interpreter helps make the healthcare experience positive. On several occasions Participant I4 mentions how she would bring her own interpreters to use to ensure that she is receiving the quality care that she needs. Based on her responses it seems that requiring interpreting services during healthcare settings varies from being Ryuboku, to Iwa or rocks. Sometimes as mentioned above, the interpreter is a rock, or a circumstance that she must work around to gain access to healthcare, and other times it is drift wood, slowly flowing down her river.

Each participant discussed both positive and negative experiences with interpreting services, making it the primary theme when accessing healthcare. However, there were secondary themes that emerged, all of which come back to or related back to the primary theme in some way he secondary themes that emerged are discussed next: these themes critically support the meaning of Interpreting Services.

Secondary Theme

Educating health care professionals.

Most of the participants' discussed participating in some aspect of education with their healthcare professionals about being Deaf. Participant I4 stated,

> One big impact on my life is constantly educating society at large about the Deaf community, their misconceptions, and misperceptions thinking it's a disability and just hearing loss. Overlooking the huge factor that we are just a community with a language that is a minority, with a culture and behaviors and our own norms. So that impacts my life daily, having to constantly educate people.

Participant I1 stated that they hoped, through this study, healthcare providers will be educated on the importance of being able to meet the needs of the patient by listening to what they want in healthcare. Participant I4 also spoke to the need to educate healthcare providers on the importance of qualified interpreters and how vital interpreters are to facilitating effective communication.

Oppression.

The concept of oppression was present in all four participants' interviews. Participant I4 conveyed "we face frustrations, oppressions, those sorts of things, um are all embedded into our culture as well and are parallel to any other minority." Three participants discussed new technology such as Video Remote Interpreting(VRI). VRI is a program that is used through an IPAD or Tablet and allows the doctor to call an interpreter through the video screen. It is being used to replace interpreters and many in the Deaf community do not like using it but are forced to use it anyway. Participants I1,I2, and I4 felt their needs were not being met during their time in a healthcare setting. For example, Participant I4 stated "they're [the interpreters] not used to voice interpreting for me. So, they may dumb down so to speak, so I have to meet the needs of the interpreter rather than be able to be myself and ask the questions I need at the level I normally would." Later in the interview, Participant I4 expressed the frustrations of not having a say in the interpreters' who come in and who are there during emergency or unplanned visits. Another participant, I1, discussed how sometimes the doctors were reluctant to provide an interpreter at all because they were unwilling to pay for the service. Participant I1 discussed an experience when she was young and required surgery,

> I didn't know what was going on. I had no idea… but there was no interpreter my family didn't tell me when it was going on you know…And as I look back I realize that was a terrible experience not good. Ah I didn't know what was going on with my own body. With you know, inside what was happening.

This experience was echoed by Participants I3 and I4. Participant I3 also explained how frustrating it is when there isn't an interpreter present: He explained how difficult it is to be in an appointment with your doctor and not know what was going on until after the fact.

Quality of care.

The third secondary theme that emerged was Quality of Care. All the participants discussed the quality of their care and heavy dependence on the quality of the interpreting service provided. Three of the participants, I1, I2, and I4, shared that when VRI was being used they felt the quality of their care decreased. Participant I1 stated,

> But hospitals, VRI, um, I would not recommend it. I’m just a little perturbed about it. Its oh I want to save money, I want to get this and uh, that perspective doesn’t work. It’s frustrating to me, which is more important, saving money or the patients. That’s what it boils down to.

Participant I4 went on to say, “We don’t have full access to healthcare services in that sense, because there needs to be a filter of a systematic use for patients, we are very vulnerable at that point.” Participant I4 related that they would only go to doctors recommended by others in the Deaf community because those doctors are more likely to meet their needs, and allow an interpreter there - thus providing a higher quality of care.

Discussion

The emergent primary and secondary themes indicate that for this study, Deaf culture, in the form of reliance upon interpreters, plays a critical role in Deaf individuals’ healthcare experiences. Healthcare professionals who are culturally aware and willing to use interpreters provided better experiences for the participants. The importance of language and communication as factors of the Deaf culture and at minimal, accounting for satisfactory access to community services such as healthcare, cannot be underestimated.

It could be argued that members of the Deaf culture would view their language, ASL, as Kawa Ryuboku (drift wood) - language nuances that float along their own river through most of their lives. Further analysis using Kawa is the idea that oppression, which also impacts quality of care for these participants', could be the rocks in their rivers – the obstacles that make up the healthcare "walls" erected in the community. Healthcare providers, including occupational therapists, and who are an integral part of the healthcare environment, should be looking for strategies of working around the rocks and using the drift wood to their clients' advantage. For healthcare services to be adequate and effective for the Deaf culture, healthcare providers should look for the Sukima, or the "language interpretation" space between the education, oppression, and quality of care "rocks". This will help providers' deliver the most comprehensive treatment possible for this population.

In summary, this researcher's bias prior to beginning the study included a belief that interpreting services would play a significant role in a Deaf person's healthcare experience (based on her experiences with the Deaf culture). The results of this study, conducted with great attention to researcher bias and accurate and appropriate cross-language procedures, appear to support this belief, the participants' feel they must educate healthcare providers on the importance of interpreters – not just providing interpreters. The participants' also feel oppressed when they are denied the right to choose their interpreters or when they are denied access to services because the doctors do not want to provide interpreters. A direct relationship emerged: The quality of their healthcare experiences relies heavily on the quality of the interpreters and doctors' willingness to listen to their needs.

Limitations

There were several limitations to this study; the small sample size of only four, Primary Participants means that the results cannot be generalized. The Primary Participants were also recruited from one university and all of them earned or were working on a college degree which may have altered the results since their experiences may be different from those who do not participate in higher education. There were also several Key Informants who assisted with the study. For consistency, one Key Informant could allow for more uniform interpreting procedures for data collection and analysis. Additionally, it may be more rigorous to recruit two Key Informants (interpreters) who come together to the interviews to ensure accuracy in the interpretation. This study was also limited in that the Primary Participants only discussed their healthcare experiences and thus narrowing the full narrative possible of the views of the Deaf culture in areas of their life

Implications for Occupational Therapy

The Kawa model is an occupational therapy based theory that uses a top down approach to therapy. This approach is client centered and begins by looking at the client as a whole, or the big picture. Through this theoretical lens an occupational therapists (OT) can gain a more elaborate and in depth perspective of their client, it also allows for the OT's to incorporate a more cultural perspective when helping Deaf clients. When an OT begins working with a client they typically examine and define client factors that are relevant and valuable to their interventions. Through the Kawa model OT's are able to look at various physical aspects of the clients and find where their individual circumstances fit in the clients river. OT's can also look at other client factors such as values, and beliefs which incorporate aspects of the Deaf culture. Based on the results of this study, incorporating a Deaf client's values and beliefs into their treatment are vital to ensure that the client receives the most comprehensive treatment possible.

This study found that Deaf clients are required to educate professionals, face daily oppression, and overall have a decreased quality of care. As OT's it is important to teach Deaf clients how to self-advocate. The Occupational Therapy Frame work lists self-advocacy as a intervention, and defines it as "advocacy efforts undertaken by the client, which the practitioner can promote and support." (AOTA, p. S30). The OT can encourage their client to utilize different techniques to manage and reduce oppression, effective communication techniques in educating healthcare professionals. By doing these things a client can increase the quality of care that they receive. When addressing the issues found through this study, OT's support and facilitate different client occupations such health management and maintenance, social participation, self-advocacy, and care of others. It is the role of the OT, or any healthcare provider, to work with the client and find out more than just their physical limitations. The Kawa model explains that it is the job of the healthcare professional to find the spaces in between the rocks and the drift wood, and use that space to help the client find the highest level of success (Brown & Stoffel, 2011)

References

American Occupational Therapy Association. Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy, 62,* 625-683.

Andrews, G., & Faulkner, D. (2004). A glossary of terms for community healthcare and services for older persons (Vol. 5). Kobe, Japan: WHO

Bauman, H. h. (2004). Audism: exploring the metaphysics of oppression. *Journal Of Deaf Studies & Deaf Education*, 9(2), 239-246. doi:10.1093/deafed/enh025

Brown, C., & Stoffel, V. C. (2011). *Occupational therapy in mental health: a vision for participation*. Philadelphia: F.A. Davis Co.

Drainoni, M., Lee-Hood, E., Tobias, C., Bachman, S., Andrew, J., & Maisels, L. (2006). Cross- Disability experiences of barriers to health-Care access. Journal of Disability Policy Studies, 17(2), 101-115.

Eckert, R., & Rowley, A. (2013). Audism: A theory and practice of audiocentric privilege. Humanity & Society, 37(2), 101-130.

Hoang, L., LaHousse, S., Nakaji, M., & Sadler, G. (2011). Assessing deaf cultural competency of physicians and medical students. Journal of Cancer Education, 26(1), 175-182. doi:10.1007/s13187-010-0144-4

Holcomb, T. K. (2013). Introduction to American deaf culture. New York: Oxford University Press.

Kim, M. (2012). Intertextuality and narrative practices of young deaf students in classroom contexts: A microethnographic study. Reading Research Quarterly, 47(4), 404-426. doi:10.1002/RRQ.029

Ladd, P., & Lane, H. (2013). Deaf ethnicity, deafhood, and their relationship. Sign Language Studies, 13(4), 565-578.

Liddell, S. (2003). Grammar, gesture, and meaning in ASL. Cambridge: Cambridge University Press

Montoya, L. A., Egnatovitch, R., Eckhardt, E., Goldstein, M., Goldstein, R. A., & Steinberg, A. G. (2004). Translation Challenges and Strategies: The ASL Translation of a Computer-Based, Psychiatric Diagnostic Interview. Sign Language Studies, 4(4), 314-344

Moores, D. (2001). Educating the deaf : Psychology, principles, and practices(5th ed.). Boston: Houghton Mifflin.

Muñoz, J. (2007). Culturally responsive caring in occupational therapy. Occupational Therapy International, 14(4), 256-280.

National Association for the Deaf. (2017, July 11). Americans with Disabilities Act. Retrieved October 22, 2017, from https://www.nad.org/resources/civil-rights-laws/americans-with- disabilities-act/

National Partnership for Women & Families . (2009). Health Literacy & Plain Language Overview [Pamphlet]. Washington DC: National Partnership for Women & Families

O'Brain , C. A., & Placier, P. (2015). Deaf Culture and Competing Discourses in a Residential School for the Deaf: “Can Do” Versus “Can't Do”. Equity & Excellence in Education, 320-338. doi:10.1080/10665684.2015.1025253

Sheppard, K., & Badger, T. (2010). The lived experience of depression among culturally Deaf adults. Journal Of Psychiatric & Mental Health Nursing, 17(9), 783- 789. doi:10.1111/j.1365-2850.2010.01606.x

Shi, L., & Singh, D. A. (2015). Delivering healthcare america: A systems approach (6th ed.). Burlington, MA: Jones & Bartlett Learning

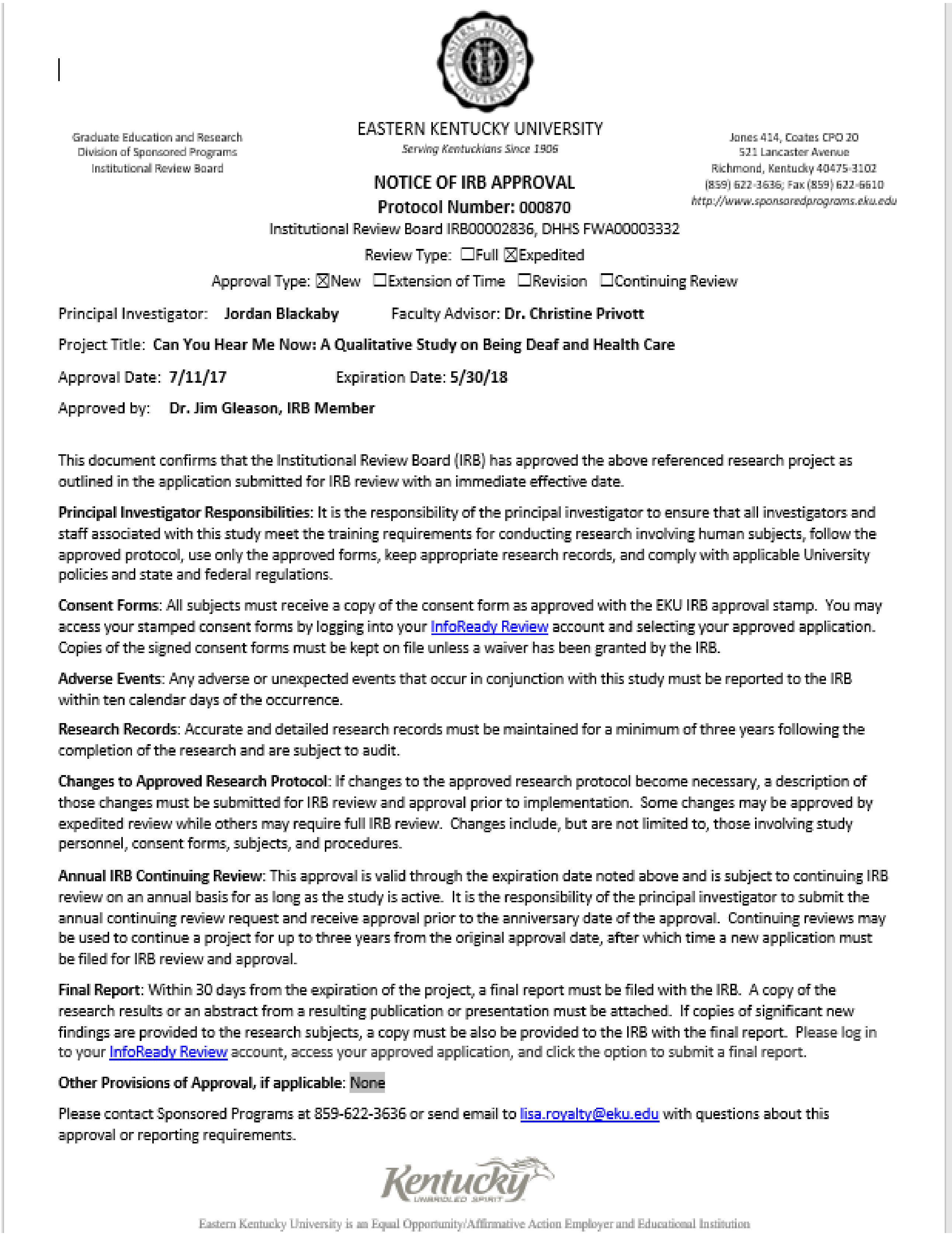
Steinberg, A., Barnett, S., Meador, H., Wiggins, E., & Zazove, P. (2006). Healthcare system accessibility : Experiences and perceptions of deaf people. Journal of General Internal Medicine, 21(3), 260-266. doi:10.1111/j.1525-1497.2006.00340.x

U.S. Centers for Medicare & Medicaid Services (CMS) (Ed.). (2017). Affordable Care Act (ACA) - HealthCare.gov Glossary. Retrieved October 22, 2017, from https://www.healthcare.gov/glossary/affordable-care-act/

U.S Department of Health and Human Services. (2017, February 15). Cultural Respect. Retrieved October 24, 2017, from https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/cultural-respect

APPENDIX A

IRB Approval



Graduate Education and Research
Division of Sponsored Programs
Institutional Review Board

EASTERN KENTUCKY UNIVERSITY
Serving Kentuckians Since 1906

Jones 414, Coates CPO 20
521 Lancaster Avenue
Richmond, Kentucky 40475-3102
(859) 622-3636; Fax (859) 622-6610
http://www.sponsoredprograms.eku.edu

NOTICE OF IRB APPROVAL

Protocol Number: 000870

Institutional Review Board IRB00002836, DHHS FWA00003332

Review Type: ☐Full ☒Expedited

Approval Type: ☒New ☐Extension of Time ☐Revision ☐Continuing Review

Principal Investigator: **Jordan Blackaby** Faculty Advisor: **Dr. Christine Privott**

Project Title: **Can You Hear Me Now: A Qualitative Study on Being Deaf and Health Care**

Approval Date: **7/11/17** Expiration Date: **5/30/18**

Approved by: **Dr. Jim Gleason, IRB Member**

This document confirms that the Institutional Review Board (IRB) has approved the above referenced research project as outlined in the application submitted for IRB review with an immediate effective date.

Principal Investigator Responsibilities: It is the responsibility of the principal investigator to ensure that all investigators and staff associated with this study meet the training requirements for conducting research involving human subjects, follow the approved protocol, use only the approved forms, keep appropriate research records, and comply with applicable University policies and state and federal regulations.

Consent Forms: All subjects must receive a copy of the consent form as approved with the EKU IRB approval stamp. You may access your stamped consent forms by logging into your InfoReady Review account and selecting your approved application. Copies of the signed consent forms must be kept on file unless a waiver has been granted by the IRB.

Adverse Events: Any adverse or unexpected events that occur in conjunction with this study must be reported to the IRB within ten calendar days of the occurrence.

Research Records: Accurate and detailed research records must be maintained for a minimum of three years following the completion of the research and are subject to audit.

Changes to Approved Research Protocol: If changes to the approved research protocol become necessary, a description of those changes must be submitted for IRB review and approval prior to implementation. Some changes may be approved by expedited review while others may require full IRB review. Changes include, but are not limited to, those involving study personnel, consent forms, subjects, and procedures.

Annual IRB Continuing Review: This approval is valid through the expiration date noted above and is subject to continuing IRB review on an annual basis for as long as the study is active. It is the responsibility of the principal investigator to submit the annual continuing review request and receive approval prior to the anniversary date of the approval. Continuing reviews may be used to continue a project for up to three years from the original approval date, after which time a new application must be filed for IRB review and approval.

Final Report: Within 30 days from the expiration of the project, a final report must be filed with the IRB. A copy of the research results or an abstract from a resulting publication or presentation must be attached. If copies of significant new findings are provided to the research subjects, a copy must be also be provided to the IRB with the final report. Please log in to your InfoReady Review account, access your approved application, and click the option to submit a final report.

Other Provisions of Approval, if applicable: None

Please contact Sponsored Programs at 859-622-3636 or send email to lisa.royalty@eku.edu with questions about this approval or reporting requirements.

Kentucky
UNBRIDLED SPIRIT

Eastern Kentucky University is an Equal Opportunity/Affirmative Action Employer and Educational Institution

APPENDIX B

IRB Approved Consent Form: Primary Participants

Consent to Participate in a Research Study

Can You Hear Me Now: A Qualitative Study On Being Deaf And Their Health Care Experiences.

I am a graduate student at Eastern Kentucky University, and I am conducting an interview for my Occupational Therapy Master's thesis. I am researching the culture of being Deaf in the health care system. My goal is to gain a greater understanding of the experiences Deaf adults have while utilizing America's health care system.

During the interview, you will be asked to answer some questions as to what being deaf means to you and how that impact your experiences in the health care system. The interview will be video recorded for later reference. An interpreter will be provided to assist in the interview process as I am not fluent in ASL or PSE. The interview will take place at the Department of OS/OT Research Center, this location is design specifically for interviews and videotaping. Should this location not be acceptable to you or the interpreter then a mutually determined public sites on or near campus such as a reserved room in the Eastern Kentucky University (EKU) Library will be used. This interview was designed to be approximately 30 minutes in length. However, please feel free to expand on questions asked or talk about related ideas. Also, if there are any questions you would rather not answer or that you do not feel comfortable answering, please say so and we will stop the interview or move on to the next question, whichever you prefer. To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

All the information will be kept confidential. I will keep the data in a secure place. Only I and the faculty supervisor on my research team will have access to this information. Upon completion of this project, all data will be destroyed or stored in a secure location.

Participant's Agreement:

I am aware that my participation in this interview is voluntary. I understand the intent and purpose of this research. If, for any reason, at any time, I wish to stop the interview, I may do so without having to give an explanation.

The researcher has reviewed the individual and social benefits and risks of this project with me. I am aware the data will be used in presentation on Eastern Kentucky universities Research day and paper that will be publicly available at the Eastern Kentucky University. I have the right to review, comment on, and/or withdraw information prior to the presentation and papers submission. The data gathered in this study are confidential with respect to my personal identity unless I specify otherwise.

If I have any questions about this study, I am free to contact the student researcher (Jordan Blackaby at jordan_blackaby3@mymail.eku.edu or through phone at 859-620-5677) or the faculty adviser (Dr. Christine Privott OTR/L at christine.privott@eku.edu or through phone at 859-622-6326)   If I have any questions about my rights as a research participant, I am free to contact Lisa Royalty the Research Compliance Coordinator. (Lisa.Royalty@eku.edu , 859-622-3636)
I have been offered a copy of this consent form that I may keep for my own reference.

I have read the above form and, with the understanding that I can withdraw at any time and for whatever reason, I consent to participate in today's interview.

______________________________________ ______________

Participants signature Date

APPENDIX C

IRB Approved Consent Form: Key Informants

Consent to Participate in a Research Study

Can You Hear Me Now: A Qualitative Study On Being Deaf And Their Health Care Experiences.

I am a graduate student at Eastern Kentucky University, and I am conducting an interview for my Occupational Therapy Master's thesis. I am researching the culture of being D/deaf in the health care system. My goal is to gain a greater understanding of the experiences deaf adults have while utilizing America's health care system.

You are being invited to participate in this study because of your self-reported fluency in ASL or PSE interpretation. Your participation in the study will allow me to communicate with the primary participants during an interview. The interview will take place at the Department of OS/OT Research Center, this location is designed specifically for interviews and videotaping. Should this location not be acceptable to the interviewee or yourself, then a mutually determined public sites on or near campus such as a reserved room in the Eastern Kentucky University (EKU) Library will be used. The questions in the interview will relate the primary participants experiences in the health care system. This interview was designed to be approximately 30 minutes in length but it can go longer depending on the participant's responses. If at any time, you feel uncomfortable interpreting for the primary participant you are welcome to stop the interview. To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

All the information will be kept confidential. I will keep the data in a secure place. Only I and the faculty supervisor on my research team will have access to this information. Upon completion of this project, all data will be destroyed or stored in a secure location.

Participant's Agreement:

I am aware that my participation in this interview is voluntary. I understand the intent and purpose of this research. If, for any reason, at any time, I wish to stop the interview, I may do so without having to give an explanation.

The researcher has reviewed the individual and social benefits and risks of this project with me. I am aware the data will be used in presentation on Eastern Kentucky universities Research day and paper that will be publicly available at the Eastern Kentucky University. I have the right to review, comment on, and/or withdraw information prior to the presentation and papers submission. The data gathered in this study are confidential with respect to my personal identity unless I specify otherwise.

If I have any questions about this study, I am free to contact the student researcher (Jordan Blackaby at jordan_blackaby3@mymail.eku.edu or through phone at 859-620-5677) or the faculty adviser (Dr. Christine Privott OTR/L at christine.privott@eku.edu or through phone at 859-622-6326) If I have any questions about my rights as a research participant, I am free to contact Lisa Royalty the Research Compliance Coordinator. (Lisa.Royalty@eku.edu , 859-622-3636)

I have been offered a copy of this consent form that I may keep for my own reference.

I have read the above form and, with the understanding that I can withdraw at any time and for whatever reason, I consent to participate in today's interview.

____	________________
Participants signature	Date

APPENDIX D

IRB Approved Interview Guide

Can You Hear Me Now: A Qualitative Study On Being Deaf And Their Health Care Experiences.

Interview Protocol

Date

Interviewer: Jordan Blackaby OTS

Location:

Informed Consent: Y N

1.) Describe what being d/Deaf means to you? Especially with accessing your own healthcare? (probe: physically, emotionally, socially?)

2.) Please describe the type/kind of healthcare services you typically access and use. (prompts: medical, health and well-being, caregiving)

3.) Describe a positive that may have been meaningful to you when you interacted with a healthcare provider. (probe: one that was meaningful, stood out,)

4.) Describe a negative experience that may have been meaningful to you when you interacted with a healthcare provider.

5.) 6.) Can you describe further how you feel about your experiences as a d/Deaf person accessing healthcare services in your community?

6.) Where and how do you get information about our current healthcare system? (prompts: family, friends, community members, media