University of Mississippi

eGrove

Honors Theses

Honors College (Sally McDonnell Barksdale Honors College)

2015

A Comparison of the Deaf Community and Hard-Of-Hearing Individuals on their Knowledge and Opinions of Cochlear Implants

Marian R. Bryant University of Mississippi. Sally McDonnell Barksdale Honors College

Follow this and additional works at: https://egrove.olemiss.edu/hon_thesis



Part of the Communication Sciences and Disorders Commons

Recommended Citation

Bryant, Marian R., "A Comparison of the Deaf Community and Hard-Of-Hearing Individuals on their Knowledge and Opinions of Cochlear Implants" (2015). Honors Theses. 637. https://egrove.olemiss.edu/hon_thesis/637

This Undergraduate Thesis is brought to you for free and open access by the Honors College (Sally McDonnell Barksdale Honors College) at eGrove. It has been accepted for inclusion in Honors Theses by an authorized administrator of eGrove. For more information, please contact egrove@olemiss.edu.

A COMPARISON OF THE DEAF COMMUNITY AND HARD-OF-HEARING INDIVIDUALS ON THEIR KNOWLEDGE AND OPINIONS OF COCHLEAR IMPLANTS

by	
Marian Rebecca Bryant	
A thesis submitted to the faculty of The University of Mississippi in partial fulfillment of the requirements of the Sally McDonnell Barksdale Honors College.	of
Oxford	
April 2015	
Approved by	y
Advisor: Dr. Rebecca Low	- re
Reader: Dr. Toshikazu Ikut	_ ta

Reader: Dr. Lennette Ivy

© 2015 Marian Rebecca Bryant ALL RIGHTS RESERVED

DEDICATION

This thesis is dedicated my parents, Lisa and Ray, who continuously guide and support me in all aspects of life. Thank you both for providing me with endless advice even when I did not want to listen. You have instilled me with a passion to learn and grow in all of my endeavors.

ACKNOWLEDGEMETS

First and foremost, I would like to thank my advisor, Dr. Lowe. Your continued guidance and support from the very start has made this thesis possible. You have pushed me to learn and made this experience thoroughly enjoyable. To Dr. Tossi, thank you for your persistent advice. Your insight throughout this process helped remarkably.

I would also like to thank the Sally McDonald Barskdale Honors College for providing me with a challenging, yet immensely rewarding, learning experience throughout the last four years.

ABSTRACT

MARIAN REBECCA BRYANT: A Comparison of the Deaf Community and Hard-of-Hearing Individuals on their Knowledge and Opinion's Of Cochlear Implants (Under the direction of Dr. Rebecca Lowe and Dr. Toshikazu Ikuta)

This thesis examined the opinions and knowledge of Deaf and hard-of-hearing individuals on cochlear implants. Previous research presented showed the controversial opinions on what was known about cochlear implants as a result of speculation in the Deaf community. This thesis consisted of surveying Deaf and hard-of-hearing individuals in order to have a better understanding of what is known about cochlear implants and the opinions that concur due to incorrect or correct knowledge. Thirteen subjects, including eight Deaf and seven hard-of-hearing individuals, completed the assessment. The results indicated that uncertainty about cochlear implants still remains; therefore, it is necessary to educate individuals on how cochlear implants benefit and work. This is essential to make informative decisions and form opinions surrounding cochlear implants and the Deaf community.

TABLE OF CONTENTS

LIST OF FIGURES AND TABLES.	vii
CHAPTER I: INTRODUCTION	1
CHAPTER II: LITERATURE REVIEW	10
CHAPTER III: METHODOLOGY	20
CHAPTER IV: RESULTS.	23
CHAPTER V: DISCUSSION	35
APPENDIX A: LETTER OF CONSENT	42
APPENDIX B: IRB APPROVAL	44
APPENDIX C: SURVEYS	45
REFERENCES	48

LIST OF FIGURES AND TABLES

FIGURE 1: COCHLEAR IMPLANT MECHANISMS	3
FIGURE 2. HEARING LOSS RANGES.	4
FIGURE 3. SOUND PICTORIAL AUDIOGRAM	5
FIGURE 4: OPINION 1 COMPARISON	24
FIGURE 5: OPINION 2 COMPARISON	25
FIGURE 6: OPINION 3 COMPARISON	25
FIGURE 7: OPINION 4 COMPARISON	26
FIGURE 8: OPINOIN 5 COMPARISON	27
FIGURE 9: FACT 1 COMPARISON	28
FIGURE 10: FACT 2 COMPARISON	29
FIGURE 11: FACT 3 COMPARISON	29
FIGURE 12: FACT 4 COMPARISON	30
FIGURE 13: FACT 5 COMPARISON	31

CHAPTER 1

INTRODUCTION

Most people never consider how critical normal hearing is to the development of spoken language. Depending on the onset of hearing loss, communication can be greatly affected. A person who is born with any degree of hearing loss is at risk for delay in spoken language that requires audio input for normal development. If hearing loss occurs, intervention to remediate the loss is critical for spoken language development. The most common intervention is hearing aids, which make sounds louder. Sometimes the hearing loss is too severe for even hearing aids to help; then, it may be necessary to use a different type of device called a cochlear implant. A cochlear implant is a device that replaces the damaged parts of the inner ear with an electronic device that allows a person to hear spoken language and environmental sounds. A person born Deaf will have substantial delays in spoken language, necessitating the reliance upon visual input. Access to spoken language is limited with little or no assistive listening devices, such as hearing aids or cochlear implants. A person with hearing loss may seek hearing aids or cochlear implants in order to have more access to spoken language and environmental sounds. Cochlear implants have significant effect on communication development, allowing a person to interact in a conversation using spoken language. Education in spoken language through therapy allows a person to learn and develop speech sounds. Still, a person can choose to continue using signs while learning spoken language.

A cochlear implant is a device that consists of an external and internal device. The device is surgically implanted through the cochlea; but, the remaining function, if any, of the cochlea is destroyed in the surgery process of implantation. Destroying the cochlea does no harm to the person. A deaf person fitted for a cochlear implant has no need for any function of the cochlea due to the cochlear implant. A cochlear implant works by bypassing the damaged portions of the ear that do not work, placing sound directly into the auditory nerve. A device on the outside of the head collects sound, sending it through the receiver, into the inner ear electrodes. The cochlear implant works to transform sound waves into a signal the brain can understand, a function normally performed by the hair cells in the cochlea in a person with normal hearing. Cochlear implants, however, do not provide a deaf person with normal hearing. Cochlear implants provide a person with speech understanding and environmental sounds, but cannot restore hearing completely (Shafer, 2007). The surgery is a simple and safe procedure, only requiring a hospital stay of approximately a day following the surgery. Yet, not all people are candidates for cochlear implants. A child who is a candidate to receive implants must have parents that are willing to work with the child to learn sounds and attend therapy nearly every day until skills are mastered. The ideal age for implantation is twelve months, so that the child can begin to learn sounds and language (Food and Drug Administration, 2014). A child must attend vigorous therapy after implantation in order to properly utilize sounds and develop language properly. Environmental sounds must also be learned in order to understand language (National Institute on Deafness and Other Communication Disorders, 2013). There are various degrees of hearing loss and only profound losses are considered for a person to be a candidate for cochlear implants.

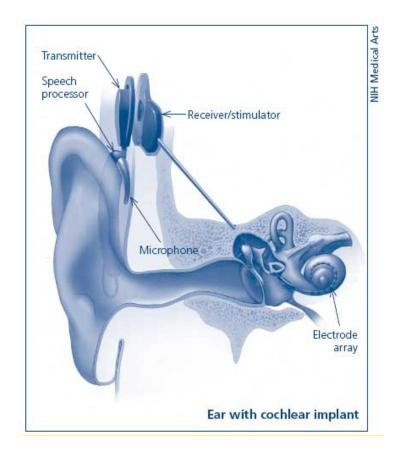
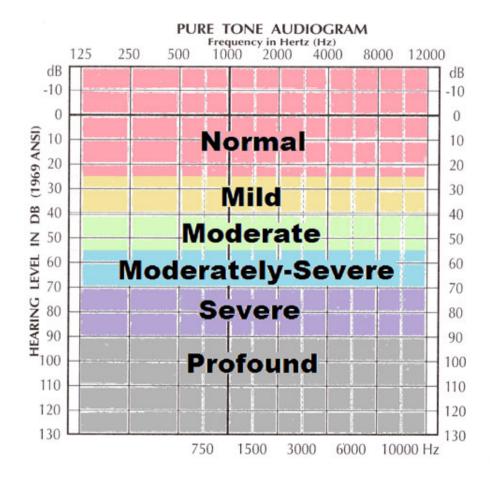


Figure 1. Cochlear Implant Mechanisms

(National Institute on Deafness and Other Communication Disorders, 2013)

Hearing loss is classified by categories, measured by units known as decibels. Decibels measure the level of sound intensity (loudness) at which a person can hear. Seven degrees of hearing are typically used to define the degree of hearing loss: normal hearing ranges from -10 to 25 decibels, a mild hearing loss ranges from 26 to 40 decibels, a moderate hearing loss ranges from 41 to 55 decibels, a moderately severe hearing loss ranges from 56 to 70 decibels, a severe hearing loss ranges from 71 to 90 decibels, and a profound hearing loss is 91 decibels or greater. A person is considered deaf if he or she has a profound hearing loss (Clark 1981).

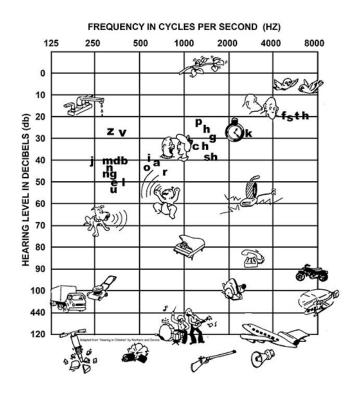


(Capital Region Otolaryngology Head and Neck Group, 2012)

Figure 2. Hearing Loss Ranges

Figure 2 shows the degrees of hearing loss, the decibel levels, and frequency levels, along with the letters and sounds that correspond with the levels of hearing. The degree describes the severity of the loss. Sound is produced in waves. The act of hearing takes place when these waves travel through air, resonating the hair cells and the cochlea. The shorter the wavelength is, the higher the pitch sounds. The longer the wavelength is, the lower the pitch sounds. Pitch is known as frequency; therefore, different sounds produce different frequencies, resulting in what is better known as varied pitches.

Decibels describe the intensity of the sound or how loud a sound can be. The more decibels, the louder the noise sounds.



(J.Northern and M.Downs, 2002)

Figure 3. Sound Pictorial Audiogram

Figure 3, known as the "families' sound audiogram," demonstrates the frequency and decibel levels at which certain objects sound. Hearing aids can help aid hearing to a certain degree. However, understanding language and environmental sounds are still greatly impacted without normal hearing and localization. Amplification is needed so that a person can properly function in the working and social environment, as well as safety purposes (i.e. traffic, fire, alarms, sirens). However, hearing aids cannot always give a person with profound loss access to the amount of amplification needed for spoken

language development, due to the degree of loss. Cochlear implants are recommended for those with hearing loss in the severe to profound area, which is 71 decibels or worse.

Permanent hearing losses can be caused by many different factors. A person can be born with a hearing loss or develop one from noise, age, ototoxic medicines (i.e. Lasix, aspirin, or certain antibiotics), injury to the head or ear, tumors in the ear, high fever, chicken pox, blood flow leading to the inner ear, and/or many other causes. The person must also have only inner ear and/or hair cell damage to the ear, no neurological damage or damage to the auditory nerves (American Speech-Language-Hearing Association, 2011).

Cochlear implants are not the only option for a deaf person in order to develop language. A person who is not treated for deafness must rely on American Sign Language, reading, writing skill, and other visual means in order to communicate. Cochlear implants provide children with the opportunity to learn spoken language from the time of early implantation. Levy (2007) argues that parents want children to share the same culture and share the same language as they do. A parent who cannot communicate properly with a child has a difficult time teaching the child and collaborating with the child at home. Since 90% of deaf children are born to hearing parents, parents have a difficult time letting their child be part of the Deaf culture (Levy, 2007).

The Deaf community, said to have its own culture, holds a controversial opinion on using cochlear implants. A culture is typically defined as a group of people sharing similar beliefs, values, language, and perspectives, differing from another group of people, which sets them apart (Banks, J.A., Banks, & McGee, C. A., 1989). Being "Deaf" is not the same as being "deaf." Deaf, with a capital "D", means that a person

uses American Sign Language, associates with the Deaf community, and is part of a Deaf culture (Dolnick, 1993). A Deaf person identifies himself as a linguistic minority rather than a person separated by a disability. A person who is deaf, lowercase "d" is part of the hearing world because he or she uses cochlear implants or other hearing assisted devices, a spoken language, and may not identify with the Deaf community (Dolnick, 1993). Deafness is not based on the degree of hearing loss, but rather the use of American Sign Language and identification with the Deaf community. Deaf people involved in the Deaf community share a language (American Sign Language), attend Deaf schools, have Deaf clubs, and share a unique history; therefore, Deafness strongly fits the definition of a culture (Sparrow, 2010). Deaf children become part of Deaf communities and culture by attending Deaf schools, clubs, and churches where other Deaf people gather (Hladek, 2007). Some people in the Deaf community may not accept individuals who do not have their same degree of deafness, or they will not fully accept a person who uses a device to hear such as a cochlear implant or does not properly use American Sign Language as part of their culture (Davis, 2006).

The Deaf community does not always have the resources, such as the easy ability to communicate with the hearing world, to relay the benefits of the Deaf world and to express the disadvantages of cochlear implants. This lack of communication is the reason the Deaf community's opinion is not often sought when hearing parents are making cochlear implant decisions for their children (Mauldin, 2012). Deaf adults consider "deafness" as an opportunity to be part of a unique Deaf culture (Ramsey, 2012). Some Deaf educators, Delost and Lashley (2000), believe that cochlear implants do more harm than good. These particular individuals state Deafness should not be treated as a

disability that needs medical attention. Depending upon the age of implantation, cochlear implants can alter a child's language development. Adjusting to cochlear implants and learning language at a school age can be challenging for professionals to locate the best learning environment for these children. Educating the deaf who are fit with cochlear implants has led to even more diversity in the deaf population (Archbold & Mayer, 2012). If Deaf schools decide to educate deaf students, those with cochlear implants or other hearing assisted devices, they are defying those in the Deaf community who oppose cochlear implants. The Deaf community believes that cochlear implants are leading to diminishing the Deaf community (Sparrow, 2010).

Deaf people have attitudes and perceptions of cochlear implants but may not have adequate knowledge of cochlear implants in order to make informed decisions regarding implantation. Most Deaf adults want to have a deaf child in order to ensure that their child will be a part of the Deaf community. Historically, Deaf community members want to build the Deaf community membership so that support, whether politically or culturally, will continue to grow in order to fight for Deaf rights, such as opposing cochlear implants (Anstey, 2002).

Most Deaf people shape their opinions about cochlear implants based on what other members in the Deaf community believe. There are no known videos in pure ASL explaining what a cochlear implant is and how it works. What exactly the Deaf community knows about cochlear implants is unknown. Chapter II describes current attitudes and perspectives Deaf people have about cochlear implants. Most Deaf adults argue that a deaf child even with hearing parents will benefit more from being part of Deaf culture rather than being deaf with a cochlear implant in the hearing world.

CHAPTER II

LITERATURE REVIEW

The Deaf community continues to be largely affected by the rising number of cochlear implant recipients (Johnston, 2004). Deaf people enjoy and value their rich culture and see no need to "fix" what some people see as a hindering disability (Dolnick, 1993). Hyde and Power (2006) discuss the perspective that many people view cochlear implants as a cure for "deafness." When using the terms "cure deafness," many Deaf adults say that deafness is seen by some to be a disability, rather than a cultural community based upon a common language. Hyde and Power purport, "perspectives on implants vary according to whether one adopts a 'medical/disability' or a 'social/ cultural' model of deafness." When weighing the risks and benefits of implantation, the authors suggested investigating both the cochlear implantation/spoken language development as well as involvement through the Deaf community and the development of American Sign Language for a child. Levy (2002) also described the common view of deafness as perceived by Deaf people. He stated that Deaf people feel that fitting deaf babies for cochlear implants demonstrates disrespect for Deaf adults. Trying to "fix" a deaf baby by fitting him or her with hearing aids or cochlear implants demonstrates that a Deaf life, one based upon a common language and set of values, is not fulfilling to the Deaf community. Levy also presented the belief that Deaf culture may diminish because of cochlear implants. Most often a deaf person or parent of a deaf child has to choose whether or not to allow his/her child to associate with the Deaf community and culture.

Deaf Perspectives on Cochlear Implants

Desai (2005) presented two perspectives on cochlear implants: (1) the perspective of implantation of Deaf adults and (2) the perspective from hearing parents of deaf children. Deaf adults claim that hearing technologies devalue the Deaf community by promoting the idea that people born deaf have a disability in need of remediation. Hearing parents of deaf children argue that they want their child to be able to make achievements in life to the best of their ability and that they cannot do so being deaf. The author stated that many times when exploring the option of implantation, hearing parents go directly to audiologists or other medical specialists but never seek the opinion of a Deaf adult who has thrived in the world. This can result in a lack of understandings for all available options a deaf person may have and all a Deaf person can accomplish.

The National Association of the Deaf (NAD) has posted two position statements regarding cochlear implants, one in 1991 and the most recent statement in 2000. The Food and Drug Administration (FDA) approved cochlear implants in 1990. The following year, NAD released a statement condemning the FDA's decision, proclaiming cochlear implants unethical and scientifically not safe (Audism Free America, 2009). The NAD did not support cochlear implants in 1991 based on three foundations: (1) scientifically, (2) ethically, and (3) procedurally. Scientifically, the NAD questioned cochlear implants scientifically due to lack of medical knowledge and potential risks at the time of surgery and in the future. Ethically, the NAD was concerned about the ethics of implantation because the Deaf community protested implantation devices saying cochlear implants stripped them of their culture and right to be Deaf. The NAD questioned the evidence on cochlear implants. Long-lasting benefits and risks were not

known, evidence regarding the child's quality of life, and educational success had not yet been measured on children with cochlear implants verses a Deaf child. The NAD reasoned that such an experimental surgery should not be tested on a child (National Association of the Deaf, 1991). The NAD called the surgery unethical because the benefits of belonging to the Deaf community are unknown by many parents making the decision for their child to receive cochlear implants. Procedurally, many in the Deaf community believe that parents of those seeking cochlear implants for their child do not consult with the Deaf community when making their decision. The NAD believes that if parents know other options for communication, such as learning American Sign Language, cochlear implants would not be necessary. The closing statement from the NAD stated that the FDA should not approve cochlear implants, research should be funded to weigh the risks and benefits of currently (then, 1991) implanted children, and implantations should be stopped in the country (Audism Free America, 2009). However, in 2000, the NAD released another statement regarding cochlear implants. This time, the NAD acknowledged that medical technology advancements, such as cochlear implants, are bringing about development in the deaf world. The NAD requested that parents seek well-informed options and that they take all perspectives into account when making a decision for a child. Options for a child included joining the Deaf community, attending a Deaf school, learning American Sign Language, and/or receiving cochlear implants. The NAD wanted parents to decide on an option that will benefit the child's life and education in the most successful way possible (National Association of the Deaf, 2000).

Deaf Perspectives on Parental Selection of Communication Methodology

Deaf people want individuals considering cochlear implants to recognize that the implants are not a "cure-all" or "magical fix" for deafness. Risks from the surgery and years of therapy must be considered before deciding on cochlear implants. Deaf adults without cochlear implants note that they adjust and are fully able to function daily, just like any hearing person, without cochlear implants (Moon, 2013). Still, deafness is considered by many in the hearing world to be a lonely life for those with the impairment, a life not capable of having the same opportunities of a hearing person. Deaf adults have argued that hearing parents of deaf children do not have the right to make such a life altering choice as a child receiving cochlear implants. Deaf culture should be taken into account when deciding if cochlear implants are necessary for a child, not just medical opinions and advancements; since deafness is not life threatening (Hyde & Power, 2000).

As Deaf culture advocates, Hintermair and Albertini claimed that cochlear implants confiscate a child's ability to enjoy their childhood and individuality. The two stated that cochlear implants involve surgery and endless hours of therapy; therefore, cochlear implants take away time from enjoying childhood. Many Deaf adults view their Deafness as a special and unique quality that has set them apart, and the use of cochlear implants may deny children the uniqueness and opportunities that a Deaf person could have as part of the Deaf community (Hintermair & Albertini, 2005). The majority of Deaf adults value the traditions and culture within the Deaf community. Many of these adults argued that if their parents had been given a choice of cochlear implants when they were a child, they would be happy their parents opted against implantation. These

individuals believe that if deaf babies could speak and reason for themselves, they would also decide to be part of the Deaf community in order to be a part of a rich culture, rather than having cochlear implants (Lane, 2005). In his article, Ramsey (2000) presented the decision process from a Deaf adult perspective. He stated Deaf adults purport that hearing parents of deaf children should always consult a Deaf adult prior to deciding what action should be taken with their child. In order to understand the daily tasks of a deaf person, Deaf adults think a hearing parent needs to consult with someone who has lived his or her life without hearing. A medical perspective should be evaluated alongside the expertise gained from a Deaf adult prior to making a decision about implantation.

Prior to 2000, the common perspective of cochlear implants can be characterized by Hartley Bressler, a Deaf family physician, who did not support the use of cochlear implants. He recognized the possibility of negative outcomes since the implantation is not successful for everyone. Bressler argued that deaf children who do not have a say in their parents' decision for cochlear implants should not be used for an experiment to gain knowledge in the medical field. Bressler said that many parents of his deaf children patients have not even spoken to a Deaf person to hear all options, especially the opinion of someone outside the medical field and part of the Deaf community (Swanson, 1997). The writings of Hagan and Wilson (2004) delve into the reasons Deaf adults do not support cochlear implants. Findings supported the fact that Deaf adults do not want to be "cured" of deafness and consider cochlear implant research as a waste of time.

Bender (2004) questioned whether or not parents of deaf babies have the right, according to the Fourteenth Amendment, to legally decide if cochlear implants should be implanted. Parents have a difficult decision to make regarding cochlear implants soon after learning that their child is deaf. Levy (2002) reasoned that Deaf parents should not wish for their children to be deaf. He acknowledged that the mainstream of parents want their child to be part of their same culture; nevertheless, choosing Deafness is not logical. Johnston, Smith, Benzies, Fitzpatrick, Angus, and Com (2009) questioned as to whether a parent, shortly after learning their child is deaf, has the stability to make such a life altering decision regarding another person's life? Oullete (2011) described a Deaf mother's public struggle in the court system in an attempt to prevent her two children from getting cochlear implants. Many in the Deaf community supported her decision; conversely, many hearing adults viewed her decision as child neglect.

Gale (2010) questioned 33 adults on cochlear implants and language usage, five being ASL advocates and of those five, three were deaf. In the study, all three deaf respondents strongly agreed with the following statements: the decision of cochlear implants is not as easy as deciding on eyeglasses, children should rightfully be allowed access to learn ASL, and visual language allows children to be successful in all communities. One respondent argued that the child should be able to choose the language, ASL or spoken English through cochlear implants, based on which one is more comfortable for them. Nowark (2006) asked if sign language could be culminating due to the implantation of cochlear implants. With a loss of sign language in children, the Deaf community could also face near extinction. Nowark quoted a psycholinguist at Northeastern University in Boston saying, "The idea of operating on a healthy baby

makes us all recoil. Deaf people argued that they use a different language, and through this language a different culture is derived, but there is certainly nothing wrong with them that needs fixing with a surgeon's scalpel. We should listen" (Nowark, 2006). The NAD (2008) supported that every person born deaf should have the opportunity to learn American Sign Language from a very young age in order to have a mode of communication within the Deaf community. Government funds should be made available in support of Deaf children learning sign language (National Association for the Deaf, 2008).

The decision of cochlear implants should lie in the hands of parents; however, parents should be well informed of all options. The government should not force cochlear implants onto deaf children, but should allow for research funding as a means to assist those who do want to implant their children or deaf adults later in life (Bruskey, 1995). Hyde, Punch, and Komesaroff's (2010) article included many interviews with parents debating cochlear implants for children. Most parents did not consult with a Deaf adult when weighing options. Of the parents who did consult the Deaf community, many received negative reactions from Deaf adults toward cochlear implants. One Deaf parent interviewed decided on a cochlear implant for her child. Deaf people want parents to receive an education on all options for a deaf child prior to deciding their course of action for their child. Harvey (2001), a therapist, presented his discussion with the parents of a deaf son debating cochlear implants. While trying to be neutral, Harvey eventually revealed that he supports Deafness over cochlear implants. Harvey believes a Deaf person is capable of being successful without cochlear implants and feels cochlear implants do not make a deaf person hear normally; therefore, cochlear implants still have

downfalls. Harvey's opinion coincides with the majority of the Deaf community on cochlear implants. However, in an interview conducted by Wheeler, Archbold, Gregory and Skipp (2007), Young students with cochlear implants were interviewed on their opinions of their cochlear implants. Most all were pleased with their parents' decision to provide them cochlear implants and would recommend cochlear implants to others.

Negative Perceptions on Cochlear Implants Due to Misinformed

Over the past few years, Deaf adults' harsh views on cochlear implants have lessened with the improvement of cochlear implants; yet, Deaf adults still want parents to study all options for a deaf child before deciding on cochlear implants (Hossain, 2013). Edwards (2005) used the Sound and Fury documentary to explain the historical aspect of cochlear implants in the Deaf community. Edwards argued that the hearing world is only informed of cochlear implants through the perspective of medical doctors, the hearing world, and those pushing for cochlear implants. The Deaf community's opinion on implantation is not well known. Also noted by one Deaf adult, a deaf person should have the opportunity to discover Deafness before being forced into cochlear implants.

John Christiansen and Irene Leigh (2004) examined the evolving parent and deaf community perspectives on pediatric cochlear implants based on two studies. According to the researchers, some parents of deaf children revealed the Deaf community's response when questioned about cochlear implants. Parents stated that some Deaf adults responded negatively, calling hearing parents who were considering cochlear implants for their children "child abusers." Other Deaf adults simply warned parents with caution, telling them to become knowledgeable on all possibilities for the child before making a

decision. A follow-up questionnaire at Gallaudet University was taken after the National Association of the Deaf published a new position statement regarding cochlear implants in 2000. Of the students questioned (Deaf, hard-of-hearing, and hearing), 54% of the Deaf students said that the University should not encourage more students with cochlear implants to attend the school, compared to the 34% of hearing and hard-of-hearing students.

According to Robert Sparrow, the conservation of Deaf culture is threatened by cochlear implants. Deaf adults argued that a Deaf person is capable of being successful without the help of cochlear implants. If hearing parents continue to fit deaf children with cochlear implants, the prominence of the Deaf culture may cease to exist (Sparrow, 2005). Kristin Knifton conducted a survey among 37 audiologists involved with students with cochlear implants. When asked about why students with cochlear implants joined schools for the deaf, 86.1% of audiologists responded by saying that deaf schools were good signing environments and 91.7% said the social environment was better compared to a hearing school (Knifton, 2009).

Tucker (1998) made note of how Deaf adults express feelings toward cochlear implants while using American Sign Language by saying, "The hatred with which Deaf culturists view cochlear implants is expressed in the ASL sign for a cochlear implant, which contains a two-fingered stab to the back of the neck, indicating a 'vampire' in the cochlear" (Tucker, 1998).

Some Deaf people carry specific attitudes toward cochlear implants. Attitudes are developed from experiences. When opinions are reinforced, people form a set attitude, which turns into a belief about a specific subject, such as cochlear implants. Groups of

people that share a similar culture, such as the Deaf community, tend to carry the same attitude because they typically share the same experiences. In order to change a person's opinion, one must focus on the direction, intensity, and salience of the attitude. A person trying to change another's attitude must target a message the audience finds interesting; otherwise, the direction of the message is lost. The intensity of the person's attitude towards a subject will change how easily the viewpoint is influenced by a differing argument (Putnam, 2007). For example, if a Deaf person has a strong attitude towards cochlear implants, his or her opinion will be difficult to change; but, if that Deaf person is unsure about cochlear implants, more knowledge may be the key to changing a negative attitude into a supportive attitude. Most Deaf people are directly affected by the debate regarding cochlear implants; therefore, salience may prove to be the most difficult characteristic when trying to change an attitude. The majority of Deaf people feel strongly about Deafness. As a result, attitudes are not easily altered (Swanson, 1997).

Lack of Tutorials in American Sign Language (ASL) for Cochlear Implants

The majority, mostly all, cochlear implant tutorial videos are in English spoken language. Cochlear implant companies have produced videos informing those interested in learning more about products. However, these videos are in spoken English language with a closed caption option. Therefore, a deaf person has a difficult time fully understanding the information being presented since there are no ASL informative videos. As a result of no formal educational training, deaf people do not have the ability to completely understand and learn about cochlear implants. Therefore, the purpose of

this study is to test the effects of an educational program informing Deaf people about cochlear implants on the knowledge base and attitudes of the Deaf.

The research questions are as follows:

- 1. What do individuals in the Deaf community or with a severe to profound hearing loss know about cochlear implants?
- 2. Do individuals' opinions march past research showing negative perceptions of cochlear implantation of the Deaf?
- 3. Does an informative video on cochlear implants change Deaf adults opinions and knowledge of cochlear implants?

CHAPTER III

METHODOLOGY

Participants

Participants of this project were recruited from the Oxford, Mississippi, Tennessee, and Alabama Deaf communities through social media methods. Eligible participants included those 18 years of age or older and classified as Deaf or hard-of-hearing with a profound to severe hearing loss. Fifteen subjects completed the surveys, eight Deaf and seven hard-of-hearing. There were no other inclusion or exclusion criteria for participation.

Survey

This assessment was completed in two different processes. This chapter will discuss those two processes for gathering information and the results from both. Initially, subjects were presented a questionnaire regarding personal information and two five-question surveys to assess their knowledge on cochlear implants and examine their opinions regarding the use of cochlear implants. All surveys were classified by an identification number. Upon completion of the initial survey, a PowerPoint presentation was presented to instruct and clarify factual evidence about the use and implantation of cochlear implants. The presentation encompassed all of the information assessed on the knowledge survey. The information was presented in English, the subjects' second language, and was translated by an interpreter to American Sign Language, the subjects'

first language. Both the video and surveys were presented in this manner. Following the presentation the subjects completed the same two surveys about their knowledge and opinions on cochlear implants. The re-surveying was completed in order to cognize if the participants' knowledge of cochlear implants improved after learning accurate information about the implants rather than relying on myths previously assumed about cochlear implants. The purpose was also to assess if any opinions regarding cochlear implants changed after being informed about the medical, physical, and sociological aspects about cochlear implants. However, due to a low number of participants, only two subjects, another route was taken to gather additional data.

Subjects were recruited to complete the same two surveys over the internet by email due to low participation for the initial presentation. Subjects with a severe-to-profound hearing loss or those considered deaf completed the survey. The survey was only presented one time, and no teaching presentation was given to the subjects.

Therefore, those using American Sign Language as their primary language had to complete the surveys in English, their second language. In conjunction with the two surveys, participants of both trials were also asked basic personal information.

Participants completed a nineteen-question survey regarding opinions and knowledge on cochlear implants. The surveys are replicated in Appendix C. The first five questions of the survey served to identify the subject's basic information, including the following: age, gender, length of deafness or hearing loss, primary language, and number of deaf children, if any. The next five questions served to reveal the subject's opinion on cochlear implants. Following the opinion questionnaire, subjects completed a cochlear implant fact survey. This survey was intended to gauge the knowledge of those who were both

Deaf and hard-of-hearing about cochlear implant candidacy, surgery, outcomes, and therapy. The subject was presented with five statements, all of which were true. However, the subject was asked to answer by one of the following: true, false, or do not know. At the end of the survey, participants, if willing, were allowed to comment further regarding the subject matter.

Risks and IRB Approval

This study was approved by the Institutional Review Board at the university of Mississippi (IRB Protocol # 14-042) prior to the initial recruitment of participants. No risks were anticipated while participating in this survey?

CHAPTER IV

RESULTS

Two people completed the survey in person and thirteen completed the surveys online. In total, eight subjects were Deaf and seven had a severe to profound hearing loss, but considered themselves hard-of-hearing. Six of the eight Deaf subjects were born deaf and use American Sign Language to communicate. One of the Deaf subjects was born deaf and received cochlear implants at the age of four. One of the Deaf subjects developed deafness late in life; therefore, his primary language is English. All subjects who classified themselves as "Deaf," were part of the Deaf community. The eight hardof-hearing subjects utilize English and oral lip-reading as a primary language. When the subjects were asked how many of them knew recipients of cochlear implants, all responded with at least one, ranging to twelve or many. This question was asked in order to see if knowing versus not knowing someone with cochlear implants would affect the subjects' knowledge and/or opinions on the matter. Participants were asked if they had children and, if so, if any were deaf. One Deaf subject responded having two Deaf children. All other subjects either had no children or had hearing children. Only one Deaf person responded having another Deaf family member. One hard-of-hearing subject responded having a Deaf family member. These questions concluded the personal questionnaire portion of the assessment.

The following section will include all participants' initial responses to the opinion questions. Subjects were presented with five questions and were asked to mark whether

he/she agreed, disagreed, or remained neutral on the subject. Question 1 asked if cochlear implant surgery is too risky because of the proximity to the brain. This opinion statement was presented in order to ascertain if subjects were aware of what the surgery actually entails, and in what way their opinions were about the surgery. 50% of Deaf subjects agreed that the surgery was too risky, 37.5% disagreed, and 12.5% were neutral. 71% of hard-of-hearing subjects did not think that cochlear implant surgery is too risky. 29% of subjects were neutral on riskiness, and none agreed. Figure 4 shows these results.

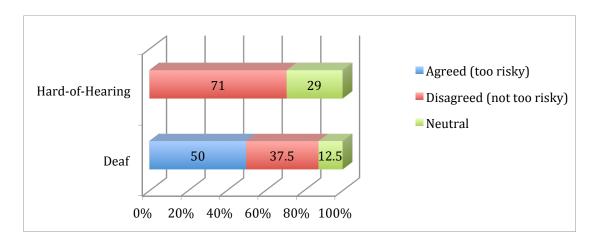


Figure 4. Opinion: Cochlear implant surgery is too risky because it is so close to the brain.

Subjects were then asked if cochlear implant candidates should wait until they are old enough to make their own decision about whether or not they want to wear a cochlear implant. This statement was presented due to conflicting research previously discussed. The debate of whether or not parents should implant an infant has been an ongoing issue. 50% of Deaf subjects agreed, 25% were neutral, and 25% disagreed. Of those that were

hard-of-hearing, 14% agreed, and 86% disagreed, saying that the choice should be in the caregiver's hands. Figure 5 represents the results.

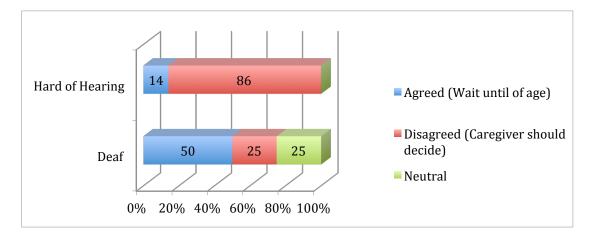


Figure 5. Opinion: Cochlear implant candidates should wait until they are old enough to make their own decision about whether or not they want to wear a cochlear implant.

Subjects were asked if they thought cochlear implants would limit a person's lifestyle, such as not being able to swim or play sports, making it wise not to wear one. Researchers reported that if a child has a cochlear implant, he or she will never be able to participate in an activity like swimming; conversely, researchers state that this is not true. The exterior portion of the cochlear implant is taken off just like hearing aids and glasses. Of the Deaf subjects, 25% agreed that cochlear implants would limit a person's lifestyle, 25% were neutral, while 50% disagreed. Only 14% of the hard-of-hearing subjects agreed with the lifestyle limitation question, while 86% disagreed.

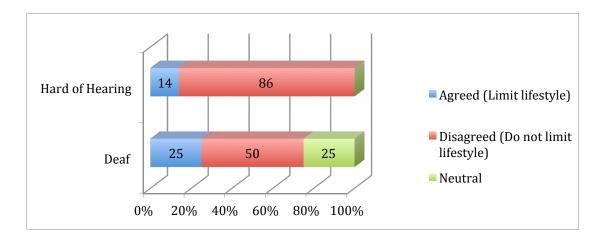


Figure 6. Opinion: Cochlear implants will limit a person's lifestyle (cannot plat sports or swim, etc.), so it is wise not to wear one.

The next question stated that once a Deaf person gets a cochlear implant, he/she cannot be part of the Deaf Community because they are forced to speak. Researchers deem that because a person learns speech sounds and environmental sounds, a person with cochlear implants can no longer be a part of the Deaf Community (Gale, 2010). Some hold the opinion that a person who is born deaf will always be classified as Deaf; therefore, that person can be apart of the Deaf community whether he or she does or does not have a cochlear implant. None of the Deaf subjects agreed with this opinion, 12.5% were neutral, 87.5% disagreed. Of the hard-of-hearing subjects, 14% agreed and 86% disagreed. Figure 7 represents the previous statistics.

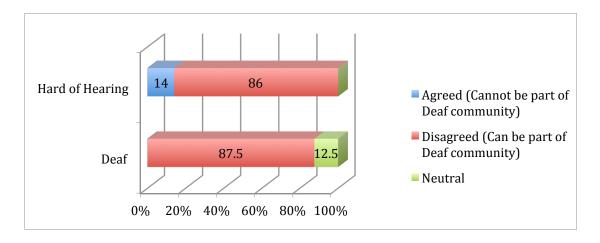


Figure 7. Opinion: Once a deaf person gets a cochlear implant, he/she cannot be part of the Deaf Community because they are forced to speak.

The final opinion question stated that if all Deaf people were currently being implanted with cochlear implants, American Sign Language and the Deaf culture would diminish. Research suggests that there is a speculation that as the number of deaf people receiving cochlear implants rises, there will be a direct correlation of a decrease in American Sign Language and the Deaf culture (Johnston, 2004). This opinion statement was presented to see if these subjects feel the same way. Of the Deaf subjects, 12.5% agreed, 62.5% disagreed, and 25% were neutral. Of the hard-of-hearing subjects, 14% agreed, 72% disagreed, and 14% were neutral.

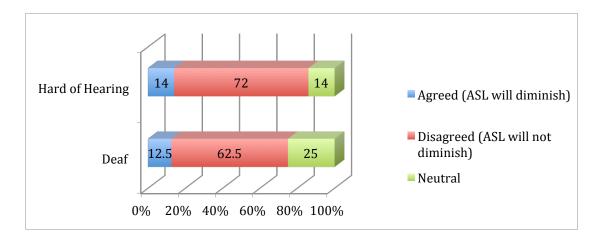


Figure 8. Opinion: If all deaf people are currently being implanted with cochlear implant, American Sign Language and the Deaf culture will diminish.

These five questions concluded the opinion portion of the assessment.

The following section will discuss the results from the knowledge portion of the assessment. The first question stated that cochlear implant surgery is an ear surgery and has similar risks as any other ear surgery. This statement was presented to see if subjects know the accurate risks of cochlear implant surgery. 75% of the Deaf subjects marked this statement true, 12.5% false, and 12.5% neutral. 57% of the hard-of-hearing population thought the statement was true, and 43% thought the statement was false.

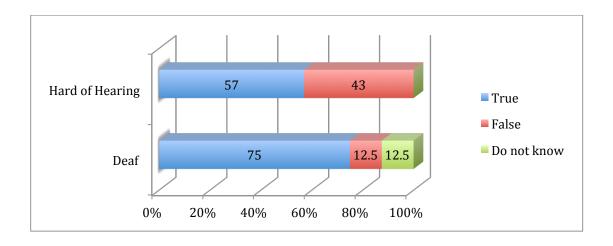


Figure 9. Fact: Cochlear implant surgery is an ear surgery and has similar risks as any other ear surgery.

The next fact presented was that cochlear implants are most effective the younger one is implanted. Research in early intervention has proven that the earlier one is implanted, the better the success rate. 37.5% of the Deaf subjects marked true, 37.5% false, and 25% said they do not know if this is true or false. Of the hard-of-hearing subjects, 43% marked true, 28.5% false, and 28.5% marked do not know. The figure below shows these results.

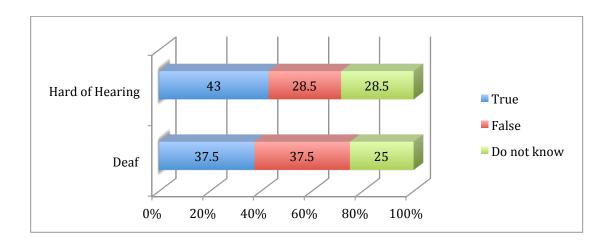


Figure 10. Fact: Cochlear implants are most effective the younger one is implanted.

The next statement said that children who wear cochlear implants can do as much as other children who do not wear implants, such as play sports, swim, or water ski. As previously stated, those with cochlear implants do not undergo lifestyle limitations due to implants. Of the Deaf subjects, 50% marked true, 25% marked false, and 25% responded that they did not know if children's lifestyle's with cochlear implants would be limited

compared to other children without cochlear implants. Hard-of-hearing subjects marked 100% true.

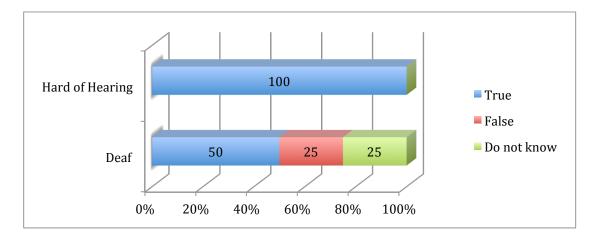


Figure 11. Fact: Children who wear cochlear implants can do as much as other children who do not wear implants (play sports, swim, water ski, etc.).

Subjects were then presented with the following statement: after a person has surgery he/she can still choose to sign as well as develop listening skills and spoken language.

Both the Deaf and hard-of-hearing subjects all responded with 100% true, agreeing that a person can still sign, as well as learning spoken language, after implantation.

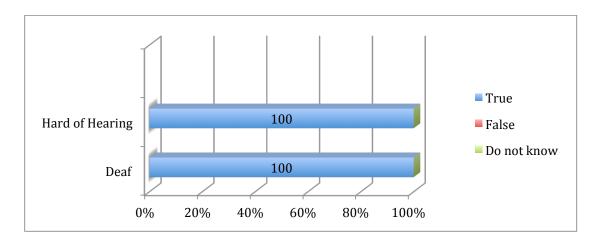


Figure 12. Fact: After a person has surgery, he or she can still choose to sign as well as develop listening skills and spoken language.

The final fact stated that not every person who is Deaf is a good candidate for cochlear implants. Research previously discussed illustrated that some people believed that any person was eligible to receive a cochlear implant; however, this is far from true. 87.5% of the Deaf subjects marked true, while 12.5% did not know whether this statement was true or false. Though, 100% of the hard-of-hearing subjects marked true, agreeing with this statement.

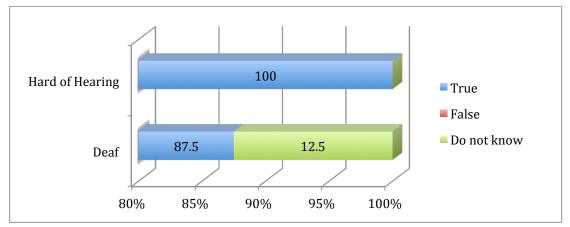


Figure 13. Fact: Not every person who is deaf is a good candidate for cochlear implants.

After completing the survey, subjects were then asked to leave any comments he/she wished regarding cochlear implants or the Deaf community. One of the Deaf subjects classified himself as Deaf, as well as having cochlear implants. He stated that he was implanted as a baby, a decision made by his parents. He also noted that his parents' decision to have him implanted was the best decision for him. He stated that he has been able to be a member of both the hearing world and the Deaf community, simply by turning on and off his cochlear implants. However, another Deaf subject, a member of the Deaf community, stated parents should not implant a baby, but should allow the child to make the decision later in life. This subject would not have wanted cochlear implants. The subject also stated that only a person who is deafened later in life who already knows how to speak English should be provided implants. Another Deaf subject commented on the concern of doctors performing the surgery and the expensive cost of cochlear implants. This participant stated that doctors should interview Deaf patients on their opinions of cochlear implants in order to improve and promote reasons for implantation; thus, increasing the degree of trust that Deaf people have with the doctors. The subject commented on the costly financial aspect of cochlear implants. Often times, insurance does not cover the entirety of the surgery, making costs a burden on families and clients. The patient also noted that doctors should assist in developing financial options or making cochlear implants more cost efficient due to their high cost and lack of medical insurance coverage for these devices. Two other Deaf subjects disclosed concern with cochlear implants because of fellow Deaf friends who did not have success with cochlear implants; therefore, reducing their support for implantation in others. A hard-of-hearing

subject, diagnosed at age four, received one cochlear implant at age sixteen. However, this subject found the cochlear implant to be unsuccessful and was no longer using the device. One of the hard-of-hearing subjects stated that he did not agree with implanting a child. This subject also mentioned that if the parents make the decision to have implants for a child, those parents should also allow the child to learn both spoken English and American Sign Language, while also becoming involved in the Deaf community.

Another hard-of-hearing subject agreed that those born deaf should begin learning sign language as early as possible in order to acquire language; therefore, if a cochlear implant does not work for the child, that child will already have another language to rely upon. Two of the hard-of-hearing subjects noted an unease concerning the age in which one receives a cochlear implant. Both of these participants noted that adults deafened later in life might receive more benefit from cochlear implants having already learned spoken language. These comments concluded the assessments for those taking the surveys online, as well as two subjects discussed in the following paragraph.

Two subjects, both members of the Deaf Community, completed the same process as stated above, and their results are included in those specified above as well. However, these two subjects also viewed a presentation regarding the workings of cochlear implants, the surgical implantation process, myths about cochlear implants, and interviews from those involved in the Deaf community, as well as the hearing world. This survey was presented in English; still, all information was translated into American Sign Language, which was the subjects' native language. The same surveys were then again given to the subjects to assess any changes in opinions and/or knowledge of cochlear implants after watching the presentation. Subject 1's responses on the cochlear

implant facts survey did not differ after watching the presentation. Subject 2's responses did vary on three out of the five factual questions. The first statement, cochlear implant surgery is an ear surgery and has similar risks as any other ear surgery, subject 2 first answered "do not know"; but, after the presentation, subject 2 answered that this statement was true. The second statement on which subject 2's response differed was on the statement that children who wear cochlear implants can do as much as other children who do not wear implants, such as play sports, swim, or water ski. Subject 2 first answered that this statement was true, and changed to "do not know." On the statement, not every person who is deaf is a good candidate for cochlear implants, subject 2 changed from answering "false" to "do not know." Subjects then again answered the cochlear implant opinion questions. Subject 1 remained the same, with the exception of one statement after the presentation. Subject 1 initially answered "neutral" to the statement that read, "Once a deaf person gets a cochlear implant, he/she cannot be part of the Deaf Community because they are forced to speak. After the video, subject 1 then answered, "disagree" to the previous statement. Subject 2's answers varied on three opinion statements following the presentation. Subject 2 changed from "neutral" to "agree" on the statement that cochlear implant surgery is too risky because of the proximity to the brain. For the statement that read, "cochlear implant candidates should wait until they are old enough to make their own decision about whether or not they want to wear a cochlear implant," subject 2 changed from "disagree" to "neutral." The final opinion that changed for subject 2 was the statement that read that cochlear implants would limit a person's lifestyle, such as not being able to play sports or swim, so it is wise not to wear one.

Subject 2 first disagreed with this statement, but later agreed with this statement after the presentation. The implications of this research will be discussed in the following chapter.

CHAPTER V

DISCUSSION

The purpose of this study was to discuss and interpret the perspective that some researchers, hard-of-hearing individuals, Deaf individuals, and others involved in the hearing community hold regarding cochlear implants. In previous research, Levy (2000) noted how Deaf people feel about being Deaf. He stated that it is a way of life, not needing to be "fixed" by something such as a cochlear implant. However, others, such as hard-of-hearing individuals and researchers, that are not part of the Deaf community, hold different views on cochlear implants (Desai, 2005). The goal of this study was as follows:

- What do individuals in the Deaf community or with a severe to profound hearing loss know about cochlear implants?
- Do individuals' opinions march past research showing negative perceptions of cochlear implantation of the Deaf?
- Does an informative video on cochlear implants change Deaf adults opinions and knowledge of cochlear implants?

The questionnaire consisted of two parts so that the researcher could understand what the participant knew about cochlear implants. If the subject did not know correct facts, opinions could be affected. The first survey consisted of the opinion portion of the

assessment. The first opinion presented stated that cochlear implant surgery is too risky due to its juxtaposition to the brain. More Deaf subjects agree with this statement compared to hard-of-hearing subjects by a difference of 21%. However, on the matching knowledge question stated, 66% of total subjects marked that cochlear implant surgery has no more risks than any other ear surgery. The correct information was known by the majority of the subjects on this statement; yet, one has to question the Deaf rationale of the riskiness of the surgery. One assumption could be that although the subject knows the potential risks, he or she still does not want to undergo those risks of the surgery.

The second opinion presented concerned the age of consent for cochlear implants. Audism Free America stated in 2009 that cochlear implantation in children should be illegal. This opinion matches the one previously held by the National association of the Deaf (NAD) in 1991 (Audism Free American, 2009). Both organizations agreed that a caregiver did not have the right to implant an infant, and a child should be given the opportunity to Deaf until an appropriate age to decide on his or her own to be implanted. Although the NAD altered this opinion in 2001 and became more open to infants being implanted, some in both the Deaf community and outside the Deaf community still believed that infants and children should not be implanted. According to the survey, half of the Deaf subjects agreed that parents should not implant children. Hard-of-hearing subjects disagreed by 86%, saying that parents should be able to implant a child if they wish to do so. Cochlear implants are in fact more effective the younger one is implanted (Maudlin, 2012). Language skills and environmental sounds are more easily mastered when a infant is implanted at twelve months; therefore, waiting until the child can decide on his or her own can potentially hurt the child if that child decides to receive cochlear

implants (FDA, 2014). The fact presented along with this opinion stated that cochlear implants are more effective the younger one is implanted. Subjects' answers varied drastically on the results. Over half of the total subjects marked either false or do not know. This proves a lack of knowledge in this area. If subjects knew that cochlear implants would be more effective if implanted as an infant, opinions of whether the parent should implant the child might change.

The next opinion stated that cochlear implants would limit a person's lifestyle. Some Deaf individuals think that a person with a cochlear implant cannot enjoy the same activities as a person without implants; however this is not true. In activities such as swimming, water sports, etc., all one has to do is take the processor and outside magnetic receiver off so that it is not submerged in water for a long period of time. The majority of both Deaf and hard-of-hearing subjects disagreed, 50% and 86% respectively, that cochlear implants would not limit a person's lifestyle. For the factual portion regarding lifestyle limitations, half of the Deaf subjects correctly marked that no limitations would take place after receiving cochlear implants, while all hard-of-hearing subjects also marked true. This statement contradicts previous research stating that the majority of the Deaf subjects have the impression that lifestyle limitations take place after implantation.

The opinion of involvement in the Deaf community after implantation is highly debatable, especially in the Deaf community. As a survey previously taken at Gallaudet University stated, the majority of Deaf students thought that those with cochlear implant should not attend Gallaudet. However, approximately two-thirds of hard-of-hearing students that attended Gallaudet University stated that those with cochlear implants should feel welcome to attend the school (Christiansen and Leigh, 2004). This survey is

in conflict with the previously stated survey, showing that 87.5% and 86% of the Deaf and hard-of-hearing subjects, respectively, think that a person can still be apart of the Deaf community and attend functions and places, such as Gallaudet University, after receiving a cochlear implant. Subjects agreed that a person could concurrently use sign language and learn spoken language. The fact that correlated with this opinion stated that after a person has surgery, he or she can both sign and learn spoken language. All subjects, both Deaf and hard-of-hearing, agreed with this statement.

As recent as 2008, the NAD expressed that all children born deaf should learn American Sign Language, regardless of whether or not that child receives a cochlear implant. One researcher even stated that allowing those with cochlear implants to receive an education at a school for the deaf would defy the Deaf community (Sparrow, 2010). According to this study, an overwhelming amount, 62.5% of Deaf subjects and 72% of hard-of-hearing subjects, did not agree with the opinion that Deaf culture will diminish due to a rise in cochlear implants. This conflicts previous research, stating that those in the Deaf community do not feel that their culture or language is threatened because of cochlear implants.

The final fact presented indicated that not every person is a suitable applicant for cochlear implants. As the National Institute on Deafness and Other Communication Disorders stated in 2013, motivation to learn spoken language, environmental sounds, attend therapy many days a week, and parents who are willing to work with the child at home all go into consideration before a child can be approved for a cochlear implant. According to the survey, subjects, both Deaf and hard-of-hearing, understood the

candidacy requirements, with 87.5% of the Deaf subjects marking true and 100% of hardof-hearing subjects marking true for this statement.

Of the two subjects that took the surveys again after watching an informative presentation, little to no improvements were made when testing their knowledge base on cochlear implants. Some answers went from true to false, some went from true to unsure, some from false to unsure, and some from false to true. This resulted in the conclusion that all answers could be guesses. Some could originally just be agreeing with the statements in an attempt to get the questions correct. On the answers that went from false or unsure to true, could show that the informative video worked in some ways to provide an educational background.

Many factors impacted the results of this study. Depending on the number of people the subjects knew with cochlear implants could have an impact on how the subject feels about cochlear implants, as well as the success rate for those with implants. If a subject knew a person that did not respond well to cochlear implants, that subject could have biased opinions about whether or not others should be fitted. Whether or not and to what degree a person is involved in the Deaf community could have also affected the results. If peers or friends in the Deaf community do not support cochlear implants, a subject could also be influenced to have the same opinions without any other background knowledge. Education level of the subject could influence the subjects' opinions. Some subjects could be well educated, knowing more about cochlear implants compared to others. This could improve the knowledge statistics, and the opinion portion could, therefore, be affected, compared to those who have no or little previous knowledge of cochlear implants. If the subject had children, Deaf, hard-of-hearing, or normal hearing,

could also affect the results. In most situations, caregivers want to speak the same language and share the same culture as their child (Levy 2007). Therefore, those subjects with children could potentially have differing views due to wanting to share the same language with their child. Additionally, age of deafness onset could impact the results as well. Those who are deafened later in life might have a differing opinion than those born deaf, though all are considered deaf. The way the survey questions were asked could potentially skew the results, as well. All the statements on the knowledge survey were in fact true. If the statements were to be mixed, some false and some true, different results could have occurred.

This study should be expanded in order to have more data to compare to past research. Perhaps a different type of educational teaching for the Deaf community and hard-of-hearing subjects could result in a better understanding of cochlear implants.

More subjects would allow for more data comparison as well. Additionally, including Deaf subjects, hard-of-hearing subjects, normal hearing subjects, and parents of those debating implantation for a child would result in a viewpoint from many angles. Once Deaf subjects and hard-of-hearing subjects know the true facts about cochlear implants, informative decisions and opinions can be formed. The Deaf community requests parents to do the same: know all perspectives before deciding to implant a child, that way an informative decision can be made.

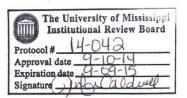
This thesis was designed to measure what Deaf and hard-of-hearing individuals know about cochlear implants and their opinions about different aspects of cochlear implants. Overall, the surveys contradicted some aspects of previous research, while agreeing with others. The inconsistency demonstrates a need to continue researching and

educating those involved in the Deaf community, hard-of-hearing individuals, parents considering cochlear implants for a child, doctors promoting cochlear implants, and all involved with the aspects of hearing.

APPENDICES

Appendix A

Consent Form



Consent to Participate in an Experimental Study

Title: Test the effects of an educational program informing Deaf people about cochlear implants on the knowledge base and attitudes of the Deaf

Investigator
Marian R. Bryant
Undergraduate Student
The University of Mississippi
(228) 223-6376

Advisor
Rebecca Lowe, Au.D.
Department of Communication Sciences and Disorders
304 George Hall
The University of Mississippi
(662) 915-7574

☐ By checking this box I certify that I am 18 years of age or older.

Description ☐ We are conducting this study to determine the knowledge base and opinions of Deaf adults on cochlear implants. We are asking that you participate in filling out surveys in order to gain more information. The first survey will assess your knowledge on cochlear implants through five multiple-choice questions. The second survey will evaluate your opinions on implantation. There are no right or wrong answers on this second survey. You will then be presented with information on cochlear implants in American Sign Language. Following the presentation, you will complete the same two surveys to assess whether your knowledge or opinions changed with the information we gave you.

Risks and Benefits Because this is an innocuous study, we do not think that there are any risks. You may be better informed about cochlear implants after reviewing the information.

Cost and Payments ☐ The assessment will take approximately an hour to complete. There are no other costs for helping us with this study.

Confidentiality \(\) We will not put your name on any of your tests. A number and your age will identify your surveys. Materials and surveys will be stored securely and confidentially in a locked cabinet.

Right to Withdraw ☐ You are not required to take part in this study. If you begin the study and decide that you do not want to finish, please inform Marian Bryant or Dr. Lowe in person, by letter, or by text. The letter may be sent to the Department of Communication Sciences and Disorders, 304 George Hall, The University of Mississippi, University MS 38677. You may text (662) 832-3137 to inform us that you no longer want to participate in the study. Whether or not you choose to participate or to withdraw will not affect your standing with the University, and it will not cause you to lose any benefits to which you are entitled. The researchers may terminate your participation in the study without regard to your consent and for any reason, such as protecting your safety and protecting the integrity of the research data.

UM Protocol #14-042

IRB Approval

This study has been reviewed by The University of Mississippi's Institutional Review Board (IRB). The IRB has determined that this study fulfills the human research subject protections obligations required by state and federal law and University policies. If you have any questions, concerns, or reports regarding your rights as a participant of research, please contact the IRB at (662) 915-7482.

Statement of Consent

I have read the above information. I have been given a copy of this form. I have had an opportunity to ask questions, and I have received answers. I consent to participate in the study.

Signature of Participant	Date
Signature of Investigator	Date

NOTE TO PARTICIPANTS: DO <u>NOT</u> SIGN THIS FORM IF THE IRB APPROVAL STAMP ON THE FIRST PAGE HAS EXPIRED.

UM Protocol #14-042

Appendix B

IRB Approval Letter



9/10/2014

Ms. Bryant Communication Sciences and Disorders University, MS 38677 Dr. Lowe Communication Sciences and Disorders University, MS 38677

IRB Protocol #:

14-042

Title of Study: Senior Thesis: Test the effects of an educational program informing Deaf people about cochlear implants on the knowledge base and attitudes of the

Deaf

09-10-14

Approval Date: Expiration Date:

09-09-15

Dear Ms. Bryant:

This is to inform you that your application to conduct research with human participants has been reviewed by the Institutional Review Board (IRB) at The University of Mississippi and approved as Expedited under 45 CFR 46.110, Category 7.

Research investigators must protect the rights and welfare of human research participants and comply with all applicable provisions of The University of Mississippi's Federalwide Assurance 00008602. Your obligations, by law and by University policy, include:

- Research must be conducted exactly as specified in the protocol that was approved by the IRR
- Changes to the protocol or its related consent document must be approved by the IRB prior to implementation except where necessary to eliminate apparent immediate hazards to participants.
- Only the approved, stamped consent form may be used throughout the duration of this research unless otherwise approved by the IRB.
- A copy of the IRB-approved informed consent document must be provided to each participant at the time of consent, unless the IRB has specifically waived this requirement.
- Adverse events and/or any other unanticipated problems involving risks to participants or others must be reported promptly to the IRB.
- Signed consent documents and other records related to the research must be retained in a secure location for at least three years after completion of the research.
- Submission and approval of the Progress Report must occur before continuing your study beyond the expiration date above.
- The IRB protocol number and the study title should be included in any electronic or written correspondence.

If you have any questions, please feel free to contact the IRB at (662) 915-7482 or irb@olemiss.edu.

Jennifer Caldwell, Ph.D.

Senior Research Compliance Specialist

OFFICE OF RESEARCH AND SPONSORED PROGRAMS

100 Barr Hall | Post Office Box 1848 | University, MS 38677-1848 | (662) 915-7482 | Fax: (662) 915-7577 | www.olemiss.edu

Appendix C

Subject Information Questionnaire

Cochlear Implant Opinions and Quiz

What is your age?	
Gender: Male or Female	
How long have you been deaf?	_
Primary Language:	
How many people do you know with cochlear implants?	
How many of your family members are deaf?	
If you have children, how many are deaf?	Hearing?

Cochlear Implant Opinion Survey

Cochlear Implant Opinions

1. Cochlear implant surgery is too risky because it is so close to the bra	1.	Cochlear implant	surgery is to	oo risky beca	use it is so	close to the brai
--	----	------------------	---------------	---------------	--------------	-------------------

- a. Agree
- b. Neutral
- c. Disagree
- 2. Cochlear implant candidates should wait until they are old enough to make their own decision about whether or not they want to wear a cochlear implant.
 - a. Agree
 - b. Neutral
 - c. Disagree
- 3. Cochlear implants will limit a person's lifestyle (cannot play sports or swim, etc), so it is wise not to wear one.
 - a. Agree
 - b. Neutral
 - c. Disagree
- 4. Once a deaf person gets a cochlear implant, he/she cannot be part of the Deaf Community because they are forced to speak.
 - a. Agree
 - a. Neutral
 - b. Disagree
- 5. If all Deaf people are currently being implanted with cochlear implants, American Sign Language and the Deaf culture will diminish.
 - a. Agree
 - b. Neutral
 - c. Disagree

Cochlear Implant Fact Survey

Cochlear Implant Facts

1. Cochlear implant surgery is an ear surgery and has similar risks as any other ear surgery.
a. True
b. False
c. Do not know
 2. Cochlear implants are most effective the younger one is implanted. a. True b. False c. Do not know
3. Children who wear cochlear implants can do as much as other children who do not

- 3. Children who wear cochlear implants can do as much as other children who do not wear implants (play sports, swim, water ski, etc.).
 - a. True
 - b. False
 - c. Do not know
- 4. After a person has surgery they can still choose to sign as well as develop listening skills and spoken language.
 - a. True
 - b. False
 - c. Do not know
- 5. Not every person who is Deaf is a good candidate for cochlear implants.
 - a. True
 - b. False
 - c. Do not know

REFERENCES

- Anstey, K. W. (2002). Are attempts to have impaired children justifiable? *Journal of Medical Ethics*, 28(1), 286-288. Retrieved from http://jme.bmj.com/content/28/5/286.full.pdf
- Archbold, S., & Mayer, C. (2012). Deaf Education: The Impact of Cochlear Implantation?. *Deafness & Education International*, 14(1), 2-15. doi:10.1179/1557069X12Y.0000000003
- Audism Free America. (2009). Retrieved from http://audismfreeamerica.blogspot.com/2009/06/nads-1991-position-statement-on.html
- Bender, D. G. (2004). Do fourteenth amendment considerations outweigh a potential state interest in mandating cochlear implantation for deaf children?. *Journal of Deaf Studies and Deaf Education*, *9*(1), 104-111. Retrieved from http://jdsde.oxfordjournals.org/content/9/1/104.full.pdf
- Brusky, A. E. (1995). Making decisions for deaf children regarding cochlear implants: the legal ramifications of recognizing deafness as a culture rather than a disability . *Wisconsin Law Review*, 1-6.

- Christiansen, J. B., & Leigh, I. W. (2004). Children with cochlear implants changing parent and deaf community perspectives. Retrieved from http://o-archotol.jamanetwork.com.umiss.lib.olemiss.edu/article.aspx?articleid=647451
- Davis, L. J. (2006). Deafness and the riddle of identity. *The Chronicle Review*, *53*(19), B6. Retrieved from http://www.odec.umd.edu/CD/ABILITY/DEAF1.PDF
- Desai, J. (2005). Falling on deaf ears. Science & Spirit, (1), 50.
- Delost, S., & Lashley, S. (2000). The cochlear implant controversy. Retrieved July 2, 2008, from http://www.drury.edu/multinl/mnlprint_new.cfm?ID52442&NLID5166.
- Dolnick, E. (1993, September). Deafness as culture. *The Atlantic*. Retrieved from http://courses.washington.edu/intro2ds/Readings/Deafness as culture.pdf
- Edwards, R. R. (2005). Sound and Fury; or, Much Ado about Nothing? Cochlear Implants in Historical Perspective. *Journal Of American History*, *92*(3), 892-920.
- Gale, E. (2010). Exploring perspectives on cochlear implants and language acquisition within the deaf community. *Journal of Deaf Studies and Deaf Education*, *16*(1), 121-139. Retrieved from http://0-

e_oxfordjournals.org/cgi/reprint/16/1/121.pdf

Hagan, P., & Wilson, C. (2004). Falling on deaf ears. New Scientist, 183(2462), 36-39.

- Harvey, M. A. (2001). Does god have a cochlear implant. *Journal of Deaf Studies and Deaf Education*, 6(1), 70-81. Retrieved from http://jdsde.oxfordjournals.org/content/6/1/70.full.pdf html?sid=df540013-ce26-41f7-b1df-02c854a92b5d
- Hintermair, M., & Albertini, J. A. (2005). Ethics, deafness, and new medical technology.

 *Journal of Deaf Studies and Deaf Education, 10(2), 184-192. Retrieved from http://jdsde.oxfordjournals.org/content/10/2/184.full.pdf html?sid=b889d1af-c40c-45e9-b56c-4c2ab2fee810
- Hladek, G. (2007). Cochlear implants, the deaf culture, and ethics. *Ohio University*.

 Retrieved from http://www.ohio.edu/ethics/2001-conferences/cochlear-implants-the-deaf-culture-and-ethics/index.html
- Hossain, S. (2013). Cochlear implants and the deaf culture: A transhumanist perspective.

 H, Retrieved from http://hplusmagazine.com/2013/11/12/cochlear-implants-and-the-deaf-culture-a-transhumanist-perspective/

- Hyde, M., & Power, D. (2006). Some ethical dimensions of cochlear implantation for deaf children and their families. *Journal of Deaf Studies and Deaf Education*, 11, 102-111. Retrieved from http://0-jdsde.oxfordjournals.org.umiss.lib.olemiss.edu/content/11/1/102.full.pdf html
- Hyde, M., & Power, D. (2000). Informed Parental Consent For Cochlear Implantation Of
 Young Deaf Children: Social And Other Considerations In The Use Of The
 'Bionic Ear'. Australian Journal Of Social Issues (Australian Council Of Social
 Service), 35(2), 117-127.
- Hyde, M., Punch, R., & Komesaroff, L. (2010). Coming to a decision about cochlear implantation: Parents making choices for their deaf children. *Journal of Deaf Studies and Deaf Education*, *15*(2), 162-178. Retrieved from http://jdsde.oxfordjournals.org/content/15/2/162.full.pdf
- Johnston, T. A. (2004). W(h)ither the deaf community. *American Annals of the Deaf*,

 148(5), 358-375. Retrieved from

 http://muse.jhu.edu/journals/american_annals_of_the_deaf/v148/148.5johnston.ht

 ml
- Johnston, J. C., Smith, A. D., O, A., Benzies, K., Fitzpatrick, E. M., Angus, D., & Com, B. (2009). The development and piloting of a decision aid for parents considering

sequential bilateral cochlear implantation for their child with hearing loss. *Volta Review*, *109*(2-3), 121-141. Retrieved from http://listeningandspokenlanguage.org/uploadedFiles/Connect/Publications/The_Volta_Review/VOLTA109n2-3.pdf

- Lane, H. (2005). Ethinicity, ethics, and the deaf-world. *Journal of Deaf Studies and Deaf Education*, 10(13), 291-310. Retrieved from http://jdsde.oxfordjournals.org/content/10/3/291.full.pdf html?sid=b889d1af-c40c-45e9-b56c-4c2ab2fee810
- Levy, N. (2002). Reconsidering cochlear implants: the lessons of Martha's Vineyard. *Bioethics*, 16(2), 134-153.
- Levy, N. (2002). Deafness, culture, and choice. *Journal of Medical Ethics*, 28(1), 284-285. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1733648/pdf/v028p00284.pdf
- Levy, N. (2007). Must publicly funded research be culturally neut? . *American Medical Association*, 9(2), 140-142. Retrieved from http://virtualmentor.ama-assn.org/2007/02/oped1-0702.htmlral

- Mauldin, L. L. (2012). Parents of deaf children with cochlear implants: A study of technology and community. *Sociology Of Health And Illness*, *34*(4), 529-543. doi:10.1111/j.1467-9566.2011.01401.x
- Moon, A. (2013, November 17). The cochlear implant controversy. *Daily Kos*. Retrieved from http://www.dailykos.com/story/2013/11/17/1256259/-The-Cochlear-Implant-Controversy
- National Association of the Deaf. (2000). NAD position statement on cochlear implants. http://www.nad.org/issues/technology/assistive-listening/ cochlear-implants.
- National Association of the Deaf. (2008). Position statement on American Sign Language.http://www.nad.org/issues/american-sign-language/position-statement-american-sign-language-2008.
- National Institute on Deafness and Other Communication Disorders (2013). Cochlear Implant Fact Sheet.http://www.nidcd.nih.gov/staticresources/health/hearing/FactSheetCochlearImplant.pdf
- Nowak, R. (2006). Ear implant success sparks culture war. (This week) (deaf community uncertain about cochlear implants). *New Scientist*, (2579), 16.

- Oullette, A. (2011). Hearing the deaf: Cochlear implants, the deaf community, and bioethical analysis. *Valparaiso University Law Review*, 45(3), 1247-1270.

 Retrieved from

 http://www.heinonline.org/HOL/Page?handle=hein.journals/valur45&div=37&?&collection=journals
- Ramsey, C. L. (2000). Ethics and culture in the deaf community response to cochlear implants. *Seminars in Hearing*, *21*(1), 75-86. Retrieved from https://o-www.thieme-connect.com.umiss.lib.olemiss.edu/ejournals/pdf/10.1055/s-2000-6827.pdf
- Shafer, K. (2007). Cochlear implants: For the deaf or for the hearing. *Prick of the Spindle*, *I*(1), Retrieved from http://www.prickofthespindle.com/nonfiction/1.1/shafer_cochlearimplants.htm
- Sparrow, R. (2005). Defending Deaf Culture: The Case of Cochlear Implants. *Journal Of Political Philosophy*, 13(2), 135-152. doi:10.1111/j.1467-9760.2005.00217.x
- Tucker, B. (1998). Deaf culture, cochlear implants, and elective disability. *Hastings Center Report*, 28(4), 6-14.
- Wheeler, A., Archbold, S., Gregory, S., & Skipp, A. (2007). Cochlear implants: The young people's perspective. *Journal of Deaf Studies and Education*, 12(3), 303-

- 316. Retrieved from http://jdsde.oxfordjournals.org/content/12/3/303.full.pdf html?sid=fe80337f-2db9-4c58-bd4e-8147816ff73f
- Sparrow, R. (2010). Implants and ethnocide: Learning from the cochlear implant controversy. *Disability and Society*, *25*(4), 455–466. Retrieved from http://www.codaaustralia.com/wp-content/uploads/2012/02/Implants-and-Ethnocide.pdf
- Swanson, L. (1997). Cochlear implants: the head-on collision between medical technology and the right to be deaf. *Canadian Medical Association*, *157*(7), 929-932. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1228221/pdf/cmaj_157_7_929.pdf