

April 2019

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Kilgore, Tia (2019) "Exploring the Cochlear Implant Controversy: The Role of and Experience with Deaf Culture for Parents of Pediatric Cochlear Implant Users," *Ursidae: The Undergraduate Research Journal at the University of Northern Colorado*: Vol. 5 : No. 2 , Article 4.

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Exploring the Cochlear Implant Controversy: The Role of and Experience with Deaf Culture for Parents of Pediatric Cochlear Implant Users

Tia Kilgore

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Abstract: This project examined the relationships between pediatric cochlear implantation and Deaf Culture. More specifically, this research investigated how/if parents are educated about or exposed to Deaf Culture during the cochlear implant candidacy evaluation process, and what type of interactions (if any) the child or caregiver had with members of the Deaf community after the child received a cochlear implant. A short survey was distributed to caregivers of pediatric cochlear implantees. While the responses were varied, a majority of caregivers responded that Deaf culture was not an active piece of the CI candidacy process. Additionally, interactions with members of the Deaf community post implantation were mixed. This research substantiates that there is still some negative bias within the Deaf community against pediatric cochlear implantation. It is unclear if increased information regarding Deaf Culture options during the candidacy process might benefit families and encourage a more uniformly positive view of pediatric cochlear implantation.

Keywords: *cochlear implant, pediatric, Deaf Culture*

The advancement of modern medical technology often comes paired with opposing ethical responses- for example, embryonic stem cell research with pro-life sentiments, human genetic engineering with those opposed to “playing God,” and euthanasia with those who believe that doctors should “first, do no harm.” The cochlear implant debate is no exception. Modern technology in combination with medical advancements has allowed cochlear implants to restore hearing to individuals with significant degrees of hearing loss. Modern day cochlear implants are smaller than they have ever been before, have improved signal processing, and are FDA approved for implantation in adults and children as young as 12 months. However, while technology is continuing to advance and cochlear implants are becoming more common, there are individuals (especially in the Deaf community) who are opposed to the procedure, especially in children. This is largely due to the fact that they believe that it violates the rights of the child, and that it is the beginning of Deaf ethnocide.

The purpose of this study is to examine the relationship between pediatric cochlear implantation and the Deaf community. This research seeks to answer if exposure to and/ or knowledge of the Deaf community and culture impacts a parent’s initial decision to implant a

child; if/how the Deaf community is represented throughout the cochlear implant candidacy evaluation. In addition, it is of interest to know if pediatric implantees and/or their parents have had any positive or negative experiences with members of the Deaf community after receiving a cochlear implant.

COCHLEAR IMPLANTS

Overview of Cochlear Implant Function

Cochlear implants (CI) are surgically implanted devices designed to give the user access to sound via electrical stimulation. To be a candidate for a cochlear implant, a person must have a severe to profound sensorineural hearing loss (hearing loss related to the cochlea, the portion of the ear responsible for converting sound waves to electrical signals in both ears). The device is composed of both internal and external components. The external components are comprised of a microphone, speech processor, and a transmitter; the surgically implanted internal components are comprised of the receiver and electrode array. Sound waves are picked up by the microphone, where they are converted to a digital signal by the sound processor. The sound processor then sends the digital signals to the transmitter. The transmitter sends the signals across the scalp via FM radio waves to the

receiver, which is held flush to the transmitter using magnets. The receiver then sends the digital signals to the electrode array, which is implanted in the cochlea.

The electrode array then acts in place of the damaged hair cells within the cochlea, and sound representations are then sent to the brain via the auditory nerve fibers that are stimulated by the nearby activated electrodes. While the brain is then able to receive sound, it is important to note that a cochlear implant is not a cure for deafness. Improved access to auditory information does not equate to clear understanding of that information. The sound that the person is hearing is dramatically different than the sound that was actually presented, as it has been made into a digital version that the implant can transmit. Individuals with cochlear implants often require auditory (re)habilitation therapy to help train their brains to make sense of the new auditory information.

History of the Cochlear Implant

The first cochlear implants, like many medical technologies, were minimally successful. The first implant, placed by Charles Eyries and André Djourno in 1957, was a single electrode inserted into the cochlear nerve. The implant allowed the patient to hear some semblance of sound frequencies, but did not allow him to understand speech. Within a relatively short period of time, the electrode ceased function and was removed (Eisen, 2003).

The next attempt was made by American William House in 1961. House implanted a cochlear implant device of his own design, but difficulties with biocompatibility resulted in the need to explant the device (Blume, 1999). However, by the mid-1970s, the idea of cochlear implants began to really gain momentum, as well as the idea of pediatric implantation (the first children were implanted in France in 1977). In 1984, the 3M/House device became the first to gain approval from the Food and Drug Administration (FDA) for use in deaf patients 18 and older (Blume, 1999). This device, however, was only single channel, meaning all electrical

signals were sent to one place on the cochlea, regardless of their sound frequency. In 1984, Cochlear Corporation released the first multi-channel cochlear implant, called the Nucleus 22 (Brown et al., 2003). The multi-channel device allowed for greater frequency differentiation. This device was quickly approved by the FDA for use in adults, and the modern age of cochlear implants was born. FDA approval for use of cochlear implants in children followed by the end of the 1980s.

Currently, three major cochlear implant manufacturing companies produce devices that are FDA approved. These manufacturing companies are Medical Electronics (MED-EL), Cochlear Corporation, and Advanced Bionics Corporation.

CLINICAL EVALUATION PROCESS

The cochlear implant surgery is preceded by an in-depth, multidisciplinary evaluation process.

Audiologic Testing

All candidates for cochlear implantation must go through extensive audiologic testing, in order to assess whether or not they have the FDA required type and degree of hearing loss. It is also important to show that the individual does not receive much benefit from alternative amplification devices (i.e. hearing aids). This information is obtained by an audiologist. This testing involves a hearing evaluation to test the patient's air and bone conduction hearing thresholds. In addition, a patient's speech understanding is tested with and without hearing aids. Some centers also offer balance testing, to help determine the best ear for implantation. Since vertigo can be a side effect of cochlear implant surgery, it is helpful to know if there is already a vestibular weakness on one side.

Medical Testing

Medical testing involves an otolaryngologist and/or physician, and can include: (a) patient history; (b) surgical history; (c) head and neck examinations; and/or (d) MRI or CT scans. There is also the potential for genetic testing, depending on the age of the patient and location of the clinic

(not all cochlear implant clinics offer genetic testing). The purpose of the genetic testing is to help physicians understand the cause of the hearing loss, as well as to assess whether or not there is a potential for any other health problems to affect the cochlear implant surgery. In addition, there may also be a standard physical in order to assess whether or not a patient is healthy enough to undergo surgery.

Speech-Language Evaluation

This piece of the evaluation is designed to determine the development of speech and language skills in young children. This is performed by a speech-language pathologist. Often, parental questionnaires are used for very young children who are less likely to provide reliable behavioral results. In addition to projecting the potential benefit of implantation, this evaluation also looks at the current level of the patient's speech and language ability, and serves as a baseline for post-operative speech and language rehabilitation.

Emotional and Developmental Evaluation

This part of the cochlear implant evaluation process looks at the emotional and developmental readiness of the patient to receive an implant. This piece of the process can be performed by any number of professionals, ranging from psychologists to occupational therapists. This evaluation attempts to address any parental or patient concerns regarding implantation, to assess whether or not a patient is emotionally ready to handle not only the implant surgery but the life changes that will come afterwards, and prepare the patient for what follows in terms of rehabilitation post-implantation¹.

FACTORS CONTRIBUTING TO SUCCESSFUL AUDITORY AND SPEECH OUTCOMES WITH COCHLEAR IMPLANTS

Age at Implantation

There are many factors that can affect the amount of benefit a cochlear implant can provide, the most important perhaps being age of implantation (for children). This is primarily due to critical or sensitive periods for development of the central auditory nervous system as well as speech and language skills. Initially, only adults were FDA eligible for cochlear implantation. However, as time has passed, cochlear implant candidacy criteria have broadened to include children 12 months of age and older to be implanted. Parents of children with severe to profound hearing loss are encouraged to implant as early as possible in order to take advantage of brain plasticity, and critical periods of auditory, speech, and language development. One of the measures used to determine auditory abilities is the Categories of Auditory Performance (CAP) test. Children are tested on a scale of zero (no awareness to environmental sound) to seven (can use the telephone with a familiar talker). Govaerts et al., (2002) found that a child implanted older than four years of age will very rarely reach normal CAP levels. A child who is implanted at two to four years of age will likely reach normal CAP levels, but will take three years or so to reach that level. A child who is implanted before the age of two is extremely likely to reach normal CAP levels, as early as three months post-implantation. The benefits of early implantation was reinforced in 2002, when the speech perception abilities of 36 prelingually deaf children were evaluated. Children who were implanted before the age of three were found to have higher levels of speech perception abilities (Baumgartner et al., 2002). While several of these studies were done on children with now outdated cochlear implant technology, the notion that

¹ Information in this section is drawn heavily from cochlear implant evaluation information sheets from the Dallas Ear Institute (*Cochlear Implant Process*, n.d.) and

Helen DeVos Children's Hospital (*Cochlear Implants: Pre-Implant Evaluation*, n.d.).

earlier implantation yields maximal benefits and outcomes continues to be found in the literature. For example, Nicholas and Geers (2007) found that children implanted between 12-18 months had significantly higher language levels than children who were implanted at later ages, even if they had been using the implant for the same amount of time. Geers, Nicholas, and Moog, (2007) found that children implanted between ages one and two had very comparable receptive vocabulary abilities when compared to hearing children of the same age.

Age at Onset of Deafness and Neuroplasticity

It has also been suggested that the age at which deafness occurs plays a factor in the speech and auditory outcomes of cochlear implantation patients, in order to take advantage of early brain plasticity and development. This idea has been supported by the research of Sharma and colleagues who have looked at the development of the auditory pathways before and after cochlear implantation. Based on auditory evoked potential testing, children implanted prior to age three show normal development trajectories post implantation, while children implanted between three and a half and seven years sometimes showed normal trajectories, and children implanted later than age seven never showed normal trajectories (Sharma et al., 2005).

Other Factors

In addition to factors such as age at implantation and onset of deafness, one of the main factors contributing to successful auditory and speech outcomes is the mode of communication used post-implantation. Research has shown that in pediatric cochlear implant users, those who are immersed in strictly oral communication after implantation had better rates of spoken word development than those whose parents used a mixed method of communication (oral and sign language) after implantation (Kirk et al., 2000).

Finally, it has also been suggested that there may be some factors that influence speech and auditory capabilities after implantation, such as socioeconomic status. Gerard and colleagues

found that in a study of 89 children, the 36 children with low socioeconomic status had low APCEI scores (a scale evaluating 5 different language components) compared to the children with medium or high socioeconomic status. In addition, these 36 children had slower rates of improvement and never reached the performance level of the children in the high socioeconomic status category (Gérard et al., 2010).

THE DEAF COMMUNITY

Prior to the 1800s, the Deaf community (written with an upper case “D” to denote pride in deafness) did not exist in America. Deaf people were seen as people with an incredible, insurmountable disability and were placed into the lower rungs of society. They remained socially and physically isolated from the larger community. Deaf people were often poor and destitute, as employment options were few. Some children born to wealthy parents were sent to study abroad in foreign deaf schools, but were often considered outcasts by society as well.

However, the founding of the first American deaf school (called an “asylum” at the time) in Hartford, Connecticut, in 1817 brought about the beginning of a much brighter period for deaf individuals. For the first time in American history, larger groups of deaf people were brought together to seek education. The asylums were typically residential schools, which made school administrators responsible for all aspects of a deaf child’s upbringing; religious, social, ethical, and educational standards were set and enforced by these schools, rather than the child’s parents. In deaf asylums, children began to communicate with each other using hand signs, which allowed them to leave a world of isolation for the first time. This led to a development of a fledgling Deaf culture, where these children could share stories, histories, and desire for change.

Over time, the sign language used by children in deaf asylums grew and became more complex. Deaf culture itself mirrored this growth and complexity. In 1864, the first post-secondary school for the deaf was founded, the Columbia Institution for the Deaf and Dumb and Blind (later

called Gallaudet University). These children who had grown up developing this sign language then began to teach in these asylums or at the post-secondary level. Deaf community truly began to emerge with the development of sign language, deaf associations, religious services, and sense of community. This development unnerved some within the hearing world, who then tried to eradicate use of sign language by enforcing strictly oral communication and education.

While eradication of sign language was certainly an issue, it did not really begin to take effect until the Second International Congress on Education of the Deaf in Milan in 1880. This congress decreed that oral communication was to be the only method of communication used in classrooms and banned the use of sign language (Berke, 2014). In addition to attempting to eradicate sign language, it was also becoming more and more common to attempt to eradicate deafness in general, the most extreme case being Nazi Germany. In order to create the perfect race, those deemed “undesirable” (deaf individuals included) were forcibly sterilized in order to prevent the trait from spanning generations. Forcible sterilization of deaf individuals also took place in America, but to nowhere near the degree of Nazi Germany (Kaebler, 2014).

The Deaf community and identity did not die out as intended. They fought back by forming associations such as the National Association of the Deaf (NAD), founded in 1880. The purpose of the NAD was to encourage and promote the use of sign language and to have the interests of the Deaf community represented on a national scale.

While sign language was still banned in the classrooms, it was still being utilized by children and adults in educational arenas. They continued to pass down stories, the history of their culture, and pride in the Deaf identity. While a dark time in Deaf history, the Deaf community was gaining strength and had a unified goal: to be recognized as a minority who were proud to be deaf.

By the beginning of the twentieth century, this idea of a Deaf identity continued to develop, but the Deaf community was still under heavy fire.

Inside and outside of the classroom, deaf students were forced to learn how to communicate orally via strict usage of lip reading. Sign language inside the classroom was still strictly prohibited, and there was a rising fear that Deaf people would suffer the loss of their language.

By the middle of the twentieth century, social bonds in the Deaf community began to weaken. Deaf individuals were eventually displaced from the unifying jobs that they had had during World War 2, which gave them less ability to socialize. Children were encouraged to become mainstreamed into the hearing classroom due to the Rehabilitation Act of 1973, which forbid discrimination based on disability. Technological advancements in the 1960s and 1970s such as captioned television and the Teletypewriter (TTY) phone (a phone allowing the language to be typed rather than spoken) allowed deaf individuals to interact more easily with the hearing world. This led to a decline in the face-to-face interaction of the Deaf community, when just 50 years earlier, it had been a central part of the Deaf identity.

When things seemed quite grim concerning the continuation of the Deaf community and its culture, passion was revived with the Deaf President Now movement in 1988, which called for the election of the first Deaf president to Gallaudet University. This movement inspired the Deaf community to remember their history and sparked a feeling of empowerment in deafness. Deaf President Now was a period of change for Deaf people in the United States in the later 20th century.

Like the Deaf President Now movement, the advancement of technology also helped re-strengthen the Deaf community, when ironically, it had threatened to tear it apart not much earlier. The birth of the World Wide Web and communication avenues such as email and blogging have helped repair broken social bonds over the last few decades. For example, Deaf individuals use avenues such as YouTube or interactive video to communicate via sign language in real time. Deaf people are able to

once again interact easily and efficiently, bringing rise to modern Deaf community.

The modern American Deaf identity is one of pride and empowerment. Their endurance throughout many years of hardship and persecution is a powerful testament to their desire to preserve their history and culture. Communicating largely by American Sign Language (ASL), they are now a population of people who proudly proclaim to the world that they are Deaf, and take no shame in that fact. No longer do they hide in the shadows, but have come forth boldly in order to make their voices heard².

THE COCHLEAR IMPLANT CONTROVERSY

Cochlear implantation in adults does not currently cause much controversy within the Deaf community. In the past it has been viewed negatively by many, giving rise to the ASL sign of a snake bite when referencing cochlear implants. However, modern views by major Deaf associations are attempting to take a more positive approach. Part of the idea of empowerment is confidence in the ability of an adult to make their own decisions, and the collective Deaf community tends to support this decision, regardless of the outcome (*NAD Position Statement on Cochlear Implants*, 2000). This same sentiment, however, does not typically apply to pediatric cochlear implantation, thus spurring the development of this research project.

Arguments Opposing Pediatric Cochlear Implantation

Lack of Understanding

One of the largest arguments opposing pediatric cochlear implantation is the suggestion that parents who choose to have their children implanted are often not fully informed about the procedure—alternate options, physical risks of the surgery, benefits and drawbacks, and long-term rehabilitation commitments (*NAD Position*

Statement on Cochlear Implants, 2000). People using this argument often suggest that parents are not provided with an unbiased representation of what this surgery is and what it means for their child.

Pediatric Cochlear Implantation is the Beginning of Deaf Ethnocide

It is also argued that pediatric cochlear implantation is the beginning of a mass Deaf ethnocide. If deaf children (who are essential to the continuation of Deaf culture and are the future leaders of the Deaf culture movement) are implanted, it is feared that they will stop identifying as deaf (even though the cochlear implant itself does not take away a child's 'deafness'). If they stop identifying themselves as deaf, then as more and more children are implanted, Deaf culture will become non-existent (Balkany, Hodges, & Goodman, 1996; Ida, 2004; Sparrow, 2005). The use of sign language in America will decline, and eventually, there will be no such thing as Deaf.

Pediatric Cochlear Implantation is a Violation of a Child's Rights

One of the largest arguments against pediatric cochlear implantation is the idea that it violates the bodily autonomy of a child. As some view cochlear implantation as an elective surgery, they argue that it is a violation of the child's right to choose the world with which they identify (hearing or deaf). In addition to the loss of bodily autonomy, it is also suggested that children who undergo cochlear implantation also lose the right to identify with a particular group of people, either hearing or Deaf. It is argued that cochlear implantation creates a "hybrid" population who are neither hearing nor deaf, and therefore, do not belong to any large collection of people, forcing them to live in isolation from both worlds (Ida, 2004). A deaf child could grow up to choose to be implanted, but a child who is implanted at an early age has no choice but to continue the rest of

² This section draws heavily from Powell-Williams, (2008) discussion on the history of the emergence of deaf culture, taken from her dissertation.

their life being implanted, unless they have an additional surgery to reverse the original implantation procedure. At this point, any residual hearing that the child may have had would likely have been destroyed in the surgical procedure, eliminating their right to an alternative hearing device, such as a hearing aid (*NAD Position Statement on Cochlear Implants*, 2000). Following this line of reasoning, pediatric cochlear implantation violates the child's right to choose. While this argument becomes more irrelevant with a child who is older and able to express their wishes, the approval of earlier implantation ages has brought this argument to the forefront of the cochlear implant debate. It should also be noted that current advances in surgical technique have made it possible to preserve residual hearing in more individuals (Brown et al., 2010).

Viewing of Deafness as a Disability

Voiced almost as frequently as the violation of the child's rights is the argument that deafness is not a disability. If deafness is not a disability, then there is no point to cochlear implantation (*NAD Position Statement on Cochlear Implants*, 2000). People in the Deaf community argue that their deafness is not a disability, but simply the way that they were born—no different than being born blonde or brunette, for example.

Arguments Supporting Pediatric Cochlear Implantation

Similarly, there are also various arguments that the medical community tends to offer in support of pediatric cochlear implantation. Proponents of pediatric cochlear implantation tend to feel just as strongly about its importance as those who are opposed feel about its potential harm.

Communicative Value

Deaf individuals can communicate easily with sign language, if both parties are both speakers of sign language. However, the majority of hearing Americans cannot speak American Sign Language. Exact numbers for ASL are not known, but statistics from Gallaudet University suggest

that there are anywhere from 500,000 users to 2,000,000 users nationwide (Harrington, 2010). This only constitutes .1 to .6 percent of the current United States population (Schlesinger, 2013). Therefore, it is argued that since the majority of Americans are unable to communicate using sign, the ability for most cochlear implant users to gain oral communication abilities allows them to communicate more easily with the vast majority of the population.

Child's Environmental Safety

It is argued that the ability for a child to hear sounds related to their environment improves their overall health and wellbeing. For example, if a child is outside playing with a ball that rolls into the street, the ability to hear if a car is coming is a paramount piece of their ability to safely retrieve that ball. Therefore, any hearing ability that a child gains due to the cochlear implant allows them to be more aware of their surroundings, thus making him or her safer.

The Paradox of Delaying Implantation

One of the main arguments opposing pediatric cochlear implantation is that of violation of a child's bodily autonomy. As discussed previously, proponents of this argument claim that cochlear implantation should be delayed in order for the child to be able to choose. However, the later a child receives an implant, the less effective the implant is in overall speech and language benefits. Therefore, a child should be implanted as early as possible in order to attain the best possible outcome in regards to oral communication (see above section: Age at implantation).

Conclusion

While there is a rather large body of research that looks at the various factors parents consider when contemplating a cochlear implant for their child (Fitzpatrick, Jacques, & Neuss, 2011; Hardonk et al., 2010; Hyde, Punch, & Komesaroff, 2010; Li, Bain, & Steinberg, 2004) there is no research directly examining how the Deaf community affected or impacted parents' decisions (if at all). In addition, there is no research that looks at whether or not parents of

implanted children (or the children themselves) had any kind of interaction with the Deaf community after implantation. While it is possible that the parents themselves are deaf, a large majority of children who are born with hearing loss are born to hearing parents. Therefore, this study was designed to determine if the Deaf community affects a parent's decision to implant their child via the information the parents receives prior to implantation, if the Deaf community is represented through the cochlear implant evaluation process, and whether the child or parent had any positive or negative interactions with members of the Deaf community after receiving the cochlear implant.

METHODS

Study Design

The project was centered around an electronic survey, and was designed using Qualtrics. This survey was largely multiple choice in nature; however, one question was open-ended.

Survey Materials and Procedures

The survey used in this study was modeled after two surveys used in other research studies, the Survey of Parents of Pediatric Implantees (Christiansen & Leigh, 2014) and a survey focusing on the evaluation process that cochlear implant clinics use in their candidacy process (Berg, Ip, Hurst, & Herb, 2007). It was decided to adapt two other surveys largely because these surveys had already been used successfully in other research. The questions and their answers were tailored slightly to fit the scope of this research, but the general integrity of the questions remained similar. Two additional questions were designed to determine whether parents or their children had any interaction with members of Deaf culture post-implantation. Finally, there was one open-ended question in which parents were able to write general comments or elaborate on any survey responses. The survey had a total of 19 questions.

The survey for this study reviewed three aspects of the implantation process. First, it asked questions regarding the decision-making process

of a primary caregiver (for example, how they first heard of implants and where they found information regarding implantation). These questions were designed to assess whether knowledge of/from the Deaf community affected a parent's decision to pursue implantation for their child. Next, it asked questions regarding the clinical evaluation process (for example, who was on the implant team and if they were given information regarding the Deaf community). Finally, it asked whether they or their child had any interactions with Deaf culture post-implantation, and whether these interactions were positive, negative, or neutral.

The data was collected via Qualtrics. A short informational paragraph was written to describe the survey and who should take it, and then participants were provided a link to the survey. It was not an open survey, but was link-specific to prevent random participation.

When opening the survey, participants first saw an informed consent page. It described the purpose of the survey, the procedures, the risks involved, the compensation received, and how to contact the researcher with any questions. The participant was unable to enter the survey until he or she read and gave consent to participate.

Participants

The only source of data was survey responses from parents or primary caregivers of pediatric cochlear implantees. Accessing this population was somewhat challenging as cochlear implantation is a medical procedure, and medical records cannot be released freely. Therefore, the survey was first distributed electronically to two popular cochlear implant support groups via Facebook (Cochlear Implant Experiences and Parents of Children with Cochlear Implants). In addition, the survey was also distributed to a few of the research mentor's acquaintances who are well connected with potential participants; these acquaintances work for cochlear implant manufacturers, are audiologists who work with cochlear implant users, and/or are cochlear implant users themselves. These individuals were asked to either take the survey themselves (if they

were eligible), or provide potential participants with an electronic link to the survey.

Of the 102 individuals who opened the survey link, 92 individuals (90%) consented to participate in the study. Six participants (7%) of the 92 were then deemed ineligible due to the fact that they were not a primary caregiver of a child with a cochlear implant. Therefore, a total of 86 participants were surveyed. Not every participant answered every question, but on average, questions had a response rate of 80 (93%).

Data Analysis

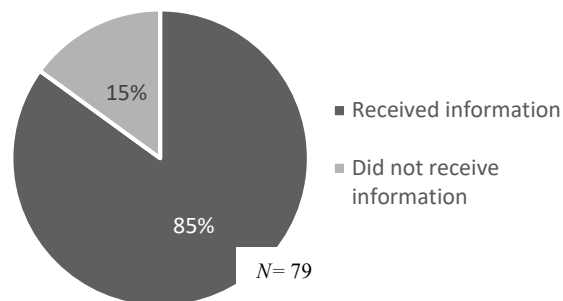
Due to the fact that this study was largely exploratory, survey responses were analyzed using descriptive statistics. Responses were analyzed using the SPSS data program. The survey was broken up into three sections for analytical purposes: pre-implantation (questions focused on whether parents received and/or used information from Deaf culture in the decision to pursue implantation for their child), clinical evaluation (questions focused on whether the Deaf community was represented in the medical evaluation process), and post-implantation (questions focused on interactions of implantee and caregiver with the Deaf community after implantation).

RESULTS

Pre-Implantation Period

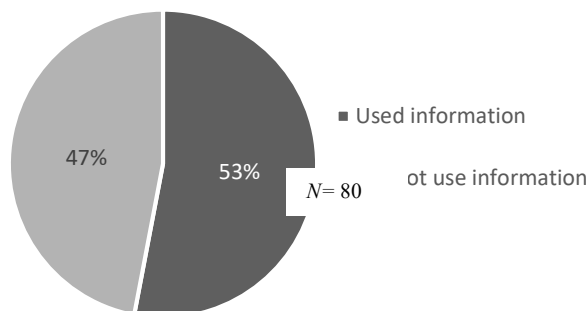
As stated above, questions in this time period revolved around a caregiver’s initial decision to pursue implantation for their child. The majority of caregivers (40%) were informed of their child’s deafness at birth, and most (47%) chose to implant their child between the ages of one and two. Prior to their child’s implantation, the majority of caregivers reported receiving information from Deaf adults regarding the procedure (both in support of and opposed to implantation), as shown in Figure 1.

Figure 1. Amount of caregivers that received information regarding Deaf culture prior to their child’s implantation.



However, while most caregivers reported that they did receive information regarding Deaf culture, the number of those who actually utilized this information in their decision-making process declined (see Figure 2).

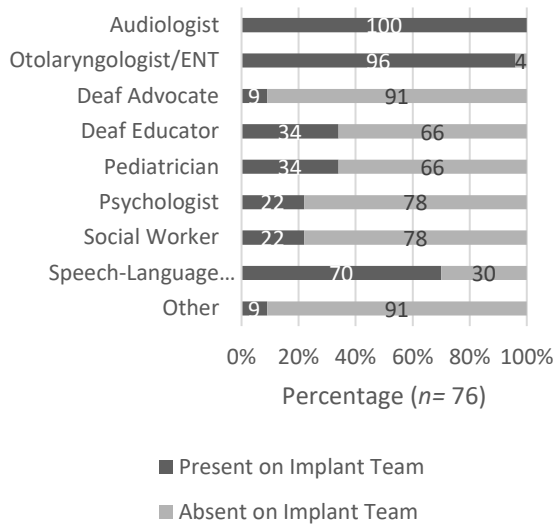
Figure 2. Amount of caregivers that utilized information from Deaf culture in their decision to pursue implantation for their child.



Clinical Evaluation Period

First, caregivers were asked which professionals were present on their child’s implant team. As shown in the table below, a Deaf Advocate or Deaf Educator was present on the team only 43% of the time (see Figure 3). In the “other” category, caregivers listed the following professionals: geneticists, pediatric neurologists, auditory verbal therapists, and developmental pediatricians

Figure 3. Graph representing how often a specific professional was present or absent on the cochlear implant team.



In addition, caregivers also reported that there was a lack of discussion regarding Deaf culture/perspective during the medical evaluation. Of 77 respondents, 49 (64%) stated that there was no discussion of Deaf culture. Twelve (16%) noted that when Deaf culture was discussed, the audiologist took on this role, and only two (3%) stated that they discussed Deaf culture and perspective with a Deaf advocate.

Despite an apparent lack of Deaf representation during the evaluation process, 62 of 77 respondents (81%) still reported feeling thoroughly informed regarding all of their alternative communication options at the time of the implant surgery (options such as sign language and hearing aids). Twelve (16%) caregivers felt that they were fairly well informed, while only 3 (4%) felt minimally informed.

Also included in this section was a question designed to assess how important (important, neutral, or not important) caregivers felt each of the professionals present on cochlear implant teams were to the team overall. If a particular professional was not present, they were asked to indicate how important they feel they would have been. However, this question was not analyzed

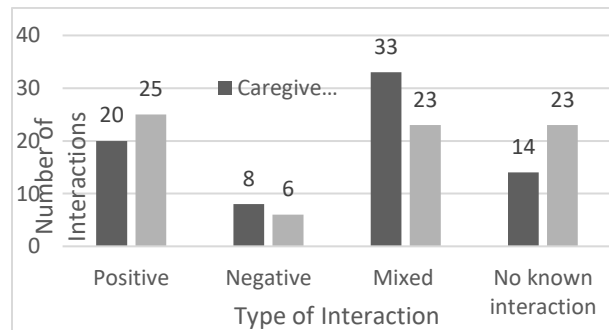
due to the fact that an unknown error prevented it from showing once the survey was made public.

Post-Implantation Period

For this time period, caregivers were asked what kinds of interactions they or their child had (if any) with members of the Deaf community after their child was implanted. Caregivers were to describe these interactions as positive, negative, mixed, or non-existent.

The majority of caregivers noted that their child had only positive interactions with members of the Deaf community, followed closely by those who noted that their child had either mixed or no interactions (see Figure 4). Only 6 caregivers (8%) responded that their child had only negative interactions. In contrast, caregivers reported most frequently that they themselves had mixed interactions with members of the Deaf community. Caregivers were slightly more likely than children to have only negative interactions, and reported a lesser likelihood of having no interactions with the Deaf community.

Figure 4. Table representing the type and number of interactions with Deaf community reported by caregivers.



Other Findings

In addition, caregivers were also asked how they would describe their child (hearing, deaf, or both) both before and after implantation. Of 80 responses, 62 caregivers (78%) described their child as deaf, 9 (11%) described their child as hearing, and 9 (11%) described their child as both hearing and deaf prior to implantation. Alternatively, of 79 responses, only 20 caregivers (25%) still described their child as deaf post-implantation. Forty-four caregivers (56%) then

described their child as both hearing and deaf, and 15 caregivers (19%) described their child as hearing after receiving the implant.

Parents were also asked to describe how they felt about the implant after their child received it. Of 77 responses, 47 caregivers (61%) responded that they wished that they would have, or could have, gotten their child implanted sooner. 28 respondents (36%) said they were happy their child received the implant at the time that he/she did. Only one caregiver (1%) said that wished they would have waited, in order to allow their child to be part of the implant decision. Two respondents chose the “other” option. One responded that they would have liked to have gotten their child implanted sooner, but that they got their child implanted as soon as their state and insurance allowed them to. Due to the fact that this respondent said that they would have liked to have implanted their child sooner, their response was moved into the first category for analytical purposes. The other respondent said that their child was a candidate at age four when she developed a profound hearing loss, but were reluctant to have their child undergo elective surgery until age seven, when their child lost all residual hearing. Finally, no caregivers chose that they regretted the decision to implant their child.

Themes

The following are common themes that were extracted from the caregivers’ responses to the open-ended question at the conclusion of the survey. The primary researcher and the research mentor read through the open-ended questions separately and chose themes based on the frequency of ideas presented in the caregiver responses. These lists were then compared, and themes were chosen if they were present in both lists. The only exception was the environment theme, which was not present on both lists. Upon further discussion, it was decided that the theme occurred frequently enough throughout the responses to be included with the other common themes present in both lists.

Knowledge of Sign Language

Of 18 open-ended responses that expanded on the kinds of interactions caregivers and implanted children had with members of the Deaf community, nine (50%) of these caregivers stated in some way that they believed the positivity from the Deaf community was related to either their ability or their child’s ability to use sign language. One caregiver stated, “I’ve had both positive and negative experiences, primarily, I believe, because I sign a bit myself (although my implanted child does not). I’m also always so very careful when I meet Deaf adults, because of my fear of backlash”.

Environment

A number of the open-ended responses also indicated that children encountered negative reactions in school and social settings. One caregiver wrote, “The deaf and [hard of hearing] teacher that worked [with] my daughter at school gave my daughter her opinion about cochlear implants prior to our surgery. We always wanted this to be her decision. She was born severe to profound bilaterally and this changed her mind for over a year because the teacher told her they were bad and she would hate it and the way everything sounded”. Another wrote, “Most people have been supportive in the deaf community. However, our child has had negative comments at a signing deaf camp ‘you are talking too much - your voice is going to run out’ or at the school for the deaf sport's club: ‘You speak well but you don't know basic aspects of Deaf Culture, like the ABC stories, etc.’ Some kids have told her that she's not a "real" deaf person. But on the whole, most people we meet have been very welcoming - I think that's because she also signs”.

Online Versus Offline Presence.

Numerous caregivers also noted that their negative encounters came from members of the online Deaf community. One caregiver wrote, “I’ve found that most big-D Deaf people we encounter and get to know in person are open and welcoming of my daughter, regardless of their thoughts about CIs. A handful are not, there are several aides and an ASL teacher at my daughter's

former school (before she was mainstreamed at 1st grade) who didn't hide their disapproval. There is some bullying of kids with CIs by Deaf kids, likely reflecting of their parents' dislike of CIs. But by far, the worst encounters have been online, where there is a small but very active campaign against CIs that takes a very nasty turn whenever possible. Unfortunately, this is all that many parents see, and so they immediately dismiss all of Deaf culture with [these] horrible people in mind."

Parental Desire for Children to Interact with Hearing Family and Culture

Finally, some caregivers also noted that they wanted to have their child have the ability to interact with the hearing world, and specifically their hearing family, (only one survey respondent was deaf, the rest were hearing). One parent responded, "I have come to believe that my daughter's deafness, caused by abnormal inner ear anatomy issues, is not the same as being born with blue eyes, will significantly impact how she learns and interacts with the world, which is hearing, and she belongs to her hearing family FIRST, not the Deaf culture. When she was still very young, I was told over and over that she was one of "them" and I "owed" it to her to give her "her culture." I became guilty and felt like a foreigner in my own daughter's life. But she is the last of 5 siblings and 14 cousins, and she "acts" hearing although she is profoundly deaf. Culture isn't something you can teach a person, culture is what you live with the people you live with. I can't give her Deaf culture [because] that's not my culture. She needs the CI's to fully participate in the life she has with her hearing family."

DISCUSSION

At this point in time, the National Association of the Deaf attempts to present a stance of neutrality from the Deaf community regarding pediatric cochlear implantation, by saying that they respect the right of the *educated* parent to decide the proper course of action when considering implantation for their child. This is a more positive outlook than has been previously held. Therefore, this study was designed in order

to determine the current relationship between pediatric cochlear implant users and the Deaf community. To define this relationship, this research examined whether the Deaf community affected a caregiver's initial decision to pursue implantation, whether or not the Deaf community was represented throughout the medical evaluation process, and what interactions (if any) the pediatric implant user and their caregiver experienced post-implantation.

Results indicated that while the majority of caregivers received information regarding the Deaf community prior to implanting their child, only about half actively used this information in their decision to pursue implantation for their child. Additionally, it was found that Deaf advocates were present on the child's implant team and that Deaf culture was discussed less than half the time, yet most parents still felt like they were fully informed of all of their child's communication options. Finally, results indicated that pediatric implantation is still not viewed neutrally, when applied to real life scenarios. Bearing all these things in mind, the relationship between the Deaf community and pediatric implant users is still complex.

It was apparent that although Deaf culture does not play a large role in the evaluation process, most caregivers received information in some way regarding the Deaf community prior to implantation; therefore, the Deaf community does play a role in a caregiver's overall decision making process. This is in opposition to the current NAD position statement, which presents the idea that parents are generally unaware of the Deaf community and alternative communication options, and lack overall knowledge of what cochlear implantation entails.

Regarding the idea that pediatric cochlear implantation is the beginning of Deaf ethnocide (presented by researchers such as Balkany, Hodges, & Goodman, Ida, and Sparrow), this research indicates that it is more likely that implantation creates a hybrid culture. This notion of an isolated hybrid culture, presented by Jonathan Ida in 2004, is not what these results

indicated. While most caregivers did indeed report feeling that their child was both hearing and deaf post-implantation, none reported regret regarding their child's implantation. This lack of regret would suggest that their child is able to interact at an acceptable level in the hearing world. Similarly, many parents reported positive interactions with the Deaf community when their child knew sign language, suggesting that the implanted child is also able to interact acceptably in the Deaf world.

This study was subject to several limitations. First, survey research in general does not garner the highest return rate. Therefore, it is possible that survey responses are not necessarily indicative of the whole population of potential participants. The responses gathered may have also been subject to a response bias—the caregivers who responded to the survey may have a completely different experience than those who chose to not complete the survey. It is essential to keep in mind that it is difficult to find parents and caregivers who had extreme experiences with either the cochlear implantation process and/or implantation itself, further deepening the potential for response bias. Finally, survey research lacks detail and depth, making it difficult to draw absolute conclusions.

This research was largely exploratory, and was designed to be a platform for which further research could stem. First and foremost, it is imperative that further research be completed in order to garner a more complete picture of the complex relationship between the Deaf community and pediatric implant users. This research came from the viewpoint of the caregiver, but it is also important and necessary to complete research based on the viewpoints of members of the Deaf community itself. It is also recommended that further research be done in order to provide more information regarding the central themes that emerged from the open responses. For example, are there perhaps correlations between the age of the child and the type of interaction? Is the Deaf community instigating these interactions without prompting from parents, or are they in response to parental

outreach? Questions following those lines of thought were beyond the scope of this research, but are important nonetheless. Finally, and perhaps the most vital avenue to pursue, is that of further exploration into implanted children's self-identification post-implantation. Do they view themselves as hearing, deaf, both, neither, or perhaps something else?

CONCLUSION

As stated previously, the relationship between the Deaf community and pediatric cochlear implant users remains complex, with this study attempting to begin to uncover what exactly this relationship entails. The information indicated can be used to challenge the idea that Deaf culture plays no part in the cochlear implant process, which is a central argument to those opposed to pediatric implantation. In addition, the results of this study also challenge the idea that parents are largely uneducated about Deaf culture prior to implantation. The experiences of the caregivers represented in this study help present a more complete picture of the cochlear implant controversy, which can in turn, be beneficial for parents of future potential pediatric implantees. Finally, the experiences of these caregivers can also be used by the medical community to notice and correct where there are information gaps in the cochlear implant process, with specific regards to information pertaining to Deaf culture.

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