

5-1-2008

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Perspectives on Cochlear Implants

MSSE Master's Project

Submitted to the Faculty
Of the Master of Science Program in Secondary Education
Of Students who are Deaf or Hard of Hearing

National Technical Institute for the Deaf
ROCHESTER INSTITUTE OF TECHNOLOGY

By

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Student Signature

In Partial Fulfillment of the Requirements
For the Degree of Master of Science

Rochester, New York

May 22, 2008 (date)

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Abstract

Since their inception, the costs and benefits of cochlear implants (CIs) have been an area of considerable interest. Much of the discussion and published research, however, have focused on outcomes for children with implants; very little on adolescent and adult outcomes or the reasons why individuals choose to get implants (or not). Meanwhile, research on implant users typically only has included the "successful" users and the benefits of implantation, primarily with regard to speech and audition. Very little work has been published on mechanical failures of these devices or personal decisions to discontinue implant use. In general, the literature also has failed to address the socio-emotional effects of implantation. A few studies have addressed these issues among young children by asking their parents, but there is a need to examine the effects of implantation on adults and older children, who may be old enough to take part in the decision for implantation. This study involved interviews of college students who currently have cochlear implants or who had them previously but discontinued their use. Questions focused on satisfaction with their cochlear implants and reasons why some individuals choose to utilize them or not. The study has begun a longer-term consideration of socio-emotional aspects of cochlear implant use and satisfies recent calls from investigators to better understand implant non-users, a population typically omitted from research reports.

Introduction

Over the last two decades, the frequency of cochlear implantation has increased dramatically. The establishment of Universal Newborn Hearing Screening (UNHS) has resulted in many babies being identified earlier as having a hearing loss and receiving implants prelingually in parents' beliefs that CIs will provide full communication access and an easier life in a "hearing world." In an already variable deaf and hard-of-hearing community, CIs have increased the level of diversity in the population. The published literature has documented and tracked specific groups of cochlear implant users but has yet to address the true diversity of students receiving implants.

Although the literature has begun to address some of the issues surrounding CIs, much of the literature still focuses on the 'stars': children who have excelled using implants. But how is this 'success' measured? It could be their improved oral-aural language. Perhaps it is their improved academic achievement. With consideration for these factors, however, these 'star students,' may have done well in school even without their implants. While the literature primarily focuses on the successful outcomes of implants, it often fails to address the socio-emotional effects of implantation. And, given that many children are implanted prelingually, the few studies that have investigated socio-emotional outcomes necessarily have come from the parental perspective.

Although parental perceptions may offer some information about the immediate benefits of implantation, a closer examination of the child's perspective may yield insight into longer-term impacts such as (continued and consistent) usage and identity issues. It may be that some of these childhood users will become non-users, but their population size and the factors contributing to non-use are virtually unknown. Marschark, Rhoten, and Fabich (2007) discussed this problem in their review of the literature, noting that several investigators (e.g., Beadle et al., 2005; O'Donoghue, 2006) have criticized prior studies looking at literacy and academic achievement following cochlear implantation, as well as hearing, speech, and language studies more generally, because of shortcomings in their experimental methods. In particular, the results of many studies appear to be compromised by the exclusion of low

performers and individuals who have discontinued regular use of their implants (i.e. selection bias) (p. 277).

The goal of this research is to begin to identify the population of discontinued users and possible indicators for eventual non-use. According to Marschark (2007), over 85 percent of deaf and hard-of-hearing children are mainstreamed in public schools for at least part of the school day (p. 139). Those teachers will have far less experience (and comfort) working with children who have implants than will teachers of the deaf. Some of these teachers may face students who do not want to use their implants, just as they encounter children who do not want to wear their hearing aids or glasses in class, and not know how to handle the situation. It is important for parents and educators to be aware of and sensitive to potential issues so they are better equipped to address these kinds of issues. Non-users may also provide parents, teachers, and implant candidates with insight into the long-term implications of discontinued or intermittent use. Finally, consideration of non-users may provide a more complete understanding in a field where most of the information only comes from a part of the population that has received and is continuing to use implants. The current literature findings have focused on parental perceptions of CIs, most often investigating how parents navigate the journey from their child's candidacy to post-evaluation.

Literature Review

Zaidman-Zait (2007) examined the emotional attributes and social connections of twenty-eight parents of children with cochlear implants. Parents were asked to describe their thoughts, feelings, and support mechanisms (such as social/professional services) in coping with diagnosis and the post-implantation rehabilitation process. Zaidman-Zait analyzed these descriptions to provide insight into how these situations helped shape parental views on CIs. Her study identified twenty categories of experiences that included identifying progress and success, intervention services, observing children with cochlear implants, and financial support. The top three experiences mentioned by all parents were

identifying progress and success, sharing experiences with other parents of children with CIs, and professionals' support. One category, "child's characteristics," addressed experiences related to attitudes and behaviors of the child, and only 33 percent of the parents described their child's positive attitude as helpful or beneficial to the parental coping process. Even those observations were based on children's outward behaviors, which may or may not reflect the inner feelings of the child.

Archbold, Lutman, Gregory, O'Neill, and Nikolopoulos (2002) also examined parental perspectives on CIs. Parents were asked to describe their own reaction to the process of cochlear implantation, their concerns, and future needs. The parents were given a list of seventeen open-format questions about their experiences pre- and post-procedure, such as "How would you describe your child before implantation?" and "Why did you decide to go ahead with the implant?" (p. 40). The prompts were administered randomly, and parents were asked to respond freely. This format allowed them to raise some socio-emotional impacts of implantation. The responses were analyzed for common thematic elements. One of the emergent themes was that parents noticed increased confidence and communication abilities in their child three years post-implantation. Improved confidence may also be a factor in successful long-term usage, but again it was reported through parental perceptions and should be substantiated by the implant users themselves.

Another study took a broader look at the whole family's ability to cope (Beadle, Shores, & Wood, 2000). The purpose of the study was to examine stressors affecting the families of children with implants. Parents were given 74 statements, separated into four sections. For the first section, *parental expectations*, respondents were asked to reflect back on their child before implantation and report their initial expectations. In the second section, *perception of outcome*, parents were given statements such as "Since implantation, my child can communicate better" and asked to rate those statements on a 10-point scale from "strongly agree = 10" to "strongly disagree = 1." In the third section, *parental reports of social support*, parents were asked to rate the level of "formal" and "informal" support they received from 5 different sources using the scale from "no support = 1" to "much support = 10." Last, parents

were asked to rate their child's *overall quality of life* after receiving an implant, from 1 to 10, with higher numbers meaning "better quality of life." Thus, this study, also, focused on the parents' perceptions of their child's behavior without taking into account the child's perspective.

A few studies in the literature, however, have begun to look at children's perceptions of cochlear implants. Nicholas and Geers (2003) addressed some of the socio-emotional aspects of young cochlear implant users. The study explored the psychosocial adjustment of children with cochlear implants and compared to the perspectives of their parents (p. 71S). The researchers selected 181 eight and nine-year-old children to participate in the study. All of the children were given a perceived self-competence task in which they viewed twenty-four pairs of statements, with accompanying drawings, and were asked to choose which of the statements best represented their experiences the majority of the time. For example, the child would see two statements, "This girl is very smart" and "This girl is not very smart" and a pictorial representation of each. The child then selected which statement best represented him/her most of the time. Parents were also asked to rate their child's adjustment using the Meadow-Kendall Social-Emotional Assessment Inventory for Deaf and Hearing-Impaired Students. Interestingly, the study found that children "reported high levels of perceived self-competence in all five areas of daily life" (p. 78S). Although the results suggest positive social adjustment outcomes in elementary school aged children, it is unclear whether these outcomes persist through the pressures of adolescence and young adulthood. Importantly, no correspondence was found between the parents' ratings and the children's self-reports, calling into question the validity of either the parents' or the children's evaluations. This finding suggests that a much more in-depth exploration into comparing children's perceptions with those of their parents is necessary. The results also indicate the importance of engaging children in discussions with their parents on perceptions of cochlear implant use.

Wheeler, Archbold, Gregory, and Skipp (2007) also addressed the children's perspectives on implantation. They interviewed 29 British, deaf youth with cochlear implants, asking questions in several areas including: "deafness and your implant," "other people," and "friends." Several common

themes emerged: using the technology, making the decision to implant, communication, identity, education, and advice to others. The participants were reported to be fairly straightforward in demonstrating their feelings on implantation, although many of their responses reflected the auditory need/benefit outcomes rather than personal feelings. The participants also described being left out of the decision-making process because they were too young to take part. All of these students were consistent implant users and, as in most studies, the authors did not include discontinued users in their sample, address whether or not the children will continue to use their implants, or ask if the participants considered discontinuing use.

In a larger British study Ray, Wright, Fielden, Cooper, Donaldson, and Proops (2006) gave participants questionnaires to determine their usage or non-usage of their CIs. Their study included 423 participants; 172 youth (age 9 to 16) and 251 adults (age 21 to 64), who were mailed a brief paper questionnaire about their implant experiences, including questions about time spent using the device, usefulness, expectations, and feelings of depression. The results showed that only 1.89 percent of participants reported being non- or intermittent users. Among adults, non-usage outcomes were typically the result of audiological difficulties (perceived lack of benefit, tinnitus, and infections). Younger limited (or non-) users, however, cited peer pressure and embarrassment, among several socio-emotional themes, as the direct cause for intermittent use or total discontinuation. The authors, however, did not address these findings in their discussion, instead focusing on the medical complications in the older non-users. Additionally, young adult non-users between the ages of 17 and 20 were not included in the sample; perhaps overlooking a group who may have had socio-emotional adjustment difficulties similar to the youth. These limitations further suggest that more research is needed to determine the typicality of the findings of Wheeler et. al. and Ray et. al. Is there a possibility that once these children reach young adulthood they will discontinue using their implants despite the perceived benefits and outcomes during adolescence?

Method

Participants

The participants were recruited through “word-of-mouth” and paper advertising. Ten deaf and hard-of-hearing students volunteered to participate in the study; six males and four females. All of the participants were deaf or hard-of-hearing undergraduate students attending Rochester Institute of Technology (RIT). Based on self-reporting, five of the participants currently used a cochlear implant, and five had discontinued use. The average age of the participants was 22 years old. The average age of implantation was 9.25 years old. Table 1 provides basic demographic information on the participants in the study including gender, age at the time of the study, the age at which they first received an implant, the number of implants currently used by each participant, how long they used or had been using their implant, and whether they would have the implant procedure again.

Table 1: Demographic Information of Cochlear Implant Users and Non-Users

Participant Number	Gender	Current Age (yrs.)	Number of Cochlear Implants (currently in use)	Age Received 1st Implant (yrs.)	Self-Reported Length of Time Using Implant (yrs.)	Would you have the same procedure again?
1	male	22	1	5	17	Yes
2	male	22	0	12	4.5	no
3	female	23	1	21	2	yes
4	male	22	0	7	10.5	yes
5	male	22	0	6	6.5	no
6	male	18	0	4	12	no
7	male	20	0	13	4	no
8	female	23	1	18	3	yes
9	female	23	1	4	19	yes
10	female	20	1	2.5	17.5	yes

Procedure

Participants were interviewed in quasi-random order based on their availability. In advance, students were informed that the study would take approximately 45 minutes to complete and that they would be videotaped giving their responses. Immediately prior to the interview, participants completed

a paper demographic questionnaire. Using a semi-structured interview format, all participants were asked questions about their involvement in the decision to receive their implant, to offer their views on deaf adults getting implants, and to describe situations in which they felt positively and negatively about having an implant. Non-users were asked five additional follow-up questions on their decision to stop using their implant and whether they have reconsidered their decision (Appendix I). To ensure confidentiality, participants were identified only by number. Upon completion of the interviews, the researcher reviewed the videotapes repeatedly to identify common themes.

Results

The following section presents each question posed during the interview and a summary of the responses given.

How involved were you in the decision to get an implant?

The majority of the students reported that they were involved in the decision making process. Some were not a part of the process either because they were too young, or because their parents wanted to make the final determination. Several of the participants described visiting other families where one or more members of the family had an implant. A few of the non-users reported that they saw friends with an implant and that was the initiating factor in getting them to consider an implant. All of the participants reported their parents making a strong effort to investigate the technology and discussing options with professionals before going ahead with the procedure.

Do you view using your implant(s) as a choice?

All of the participants saw having and using (or not using) their implant as a personal choice. Users and non-users both reported that parents strongly encouraged use, but over time most parents became less insistent and allowed each of them to make the decision to continue (or discontinue) use. One

student stated that he felt he should have had the choice to stop using his implant, but the choice was taken away from him. He was pressured by his classroom interpreter and speech therapist to keep using his implant even after he told them it was not beneficial.

As a child, did you see any deaf adults with implant(s)?

Responses among the participants were split. Some students recalled visiting a deaf adult or seeing a friend at school with an implant. Two students reported that after seeing a deaf adult with an implant, they decided against having the procedure at that time. For others, they were the only ones in their community with an implant.

How do you feel about the number of faculty and staff getting implants?

Users felt strongly encouraged by seeing faculty and staff with implants. It added to their sense of connection and belonging. They reported feeling “like everyone else.” Users and non-users agreed that getting an implant is an individual decision and they are fine with the number of adults getting implants. One user noted that she was “not okay” with seeing young children with implants because it suggests that the child was not part of the decision-making process.

Tell me about a time when you were happy that you have/had an implant.

Most of the participants were able to recount at least one positive experience with their implant. Students cited the first time they heard and recognized an environmental sound, like a car turn signal, or someone banging on the desk, as being helpful and exciting. One non-user mentioned that at his 14th birthday party he was able to hear the “Happy Birthday” song for the first time. Only one student could not recount at least one positive experience associated with his implant.

Tell me about a time when you felt negatively (embarrassed, awkward) about having an implant.

All of the participants recounted at least one negative experience. Among non-users, one student described developing severe and repeated headaches after a few years with his implant. Another non-user described being “tattled on” by his interpreter when he refused to wear his implant in class. Several users cited feeling isolated and not having a social life because of their implant. They felt different from their classmates.

Do you feel different about wearing your implant here (at RIT/NTID) than when you were in high school?

All of the students described feeling different about their usage (or non usage) choices at RIT compared with high school. Many cited feeling like they did not “fit in” in high school. Going to speech therapy and auditory therapy made their schedules and social lives difficult. In several cases, students stated that he/she was the only one in high school with an implant even among other deaf students. Upon arriving at RIT/NTID, users felt more connected and part of the community. Participants cited that other users understood what they went through from candidacy through aftercare which made them feel more accepted. Additionally, the flexibility and variety in communication on campus allowed them to be more comfortable in their identity as an implant user. Similarly, non-users cited that the environment at RIT/NTID allowed them the freedom to communicate in ASL and they do not feel that they have to use their implants. All of the students reported that they have oral friends and strong Deaf culture friends because the community encourages it.

How do you decide when to use your implant(s)?

Most users reported using the device all of the time, except when the device was damaged, or during a severe headache. One user stated that she has had to remove the device during tests because she finds she is extremely sensitive to background noise. Another user reported she cannot wear her implant in her apartment because her implant is also very sensitive to environmental noise. Four of the non-users

reported they used the device consistently in the past. Only one non-user reported intermittent use, usually only during speech therapy sessions.

In what situations do you use your implant(s)?

Users cited using their implant in just about every situation from one-on-one communication to sporting events. Several of the users said they “can’t live without it,” and “had a hard time” when a device broke and it could not be used.

Have you ever considered not using your implant?

The majority of the users said “no, never.” One user said she was curious about the idea of non-use, but after one situation where her implant broke, she realized that she would never stop using it long-term.

The users also agreed that the communication environment at RIT/NTID has allowed them the flexibility to remove the external portion of the device if they choose, yet for the most part they prefer to wear it consistently.

Overall, would you say your cochlear implant experience was positive or negative?

All of the users reported having very positive experiences associated with their implant. They really felt successful with their speech and auditory perceptions. With one exception, the users all said that they would have the procedure again because they see the benefit and they want to hear. Users that received their implants prior to age five also said they were grateful to their parents for going through the whole process and making the decision for them. Non-users’ responses were divided. A few said their implant experience was very negative and they would never try it again. Others said that even though they did not benefit from the device, they still enjoyed some aspects of having an implant, such as listening to music, or being able to hear environmental sounds.

Why did you stop using your implant(s)?

Non-users reported several reasons for discontinuing use. A few said that the device stopped working properly, but they did not investigate why. Others said that the device was useful for environmental sounds, but really did not help their speech perceptions or speech production in any situation. One non-user reported he felt like a different person with his implant, isolated and introverted, whereas he felt more open and sociable without it.

If you could go back, would you make the same decision?

All of the non-users reported being satisfied with their decision to stop using their implant. They also reported at present, as non-users, if they could go back, they most likely would not have had the surgery.

How did you tell your parents about your decision to stop using your implant (if you did)?

Most of the students reported not having a specific conversation with their parents about their decision to discontinue. Instead, several of the non-users reported progressively decreasing their usage over time until they stopped wearing the device all together. One participant reported that once he started attending a deaf school, he abruptly stopped using his device, and being that the school had a strong Deaf community his parents just accepted the decision. Another participant reported that after cycling through several speech therapists, he informed the last one that he really did not want to use the device, at which point the speech therapist called home and told his parents. Neither his parents nor the speech therapist gave him the details of their conversation, but after that he was allowed to stop using the implant and stop attending speech therapy.

How long did you use your implant before you decided to stop?

Non-users self-reported using their implant on average about six to seven years. All of the non-users reported using their implant for at least four years before making the decision to discontinue.

Have you reconsidered your decision?

Non-users reported that they were fine with their decision to stop using their implant. Only one participant said that he may consider going back to using his implant in the future, because he did like the benefit of being able to hear environmental sounds.

Discussion

Participants who discontinued using their cochlear implants reportedly did so because they really did not benefit from the device. According to Dr. Linda Spencer, researchers working with children have noticed that:

Trends [towards non-use] seem to relate to age of implantation, and non-use spikes in adolescent years. Other factors [determining usage or non-usage] are whether implant recipients were in a supportive environment and to some level the amount of benefit they got (personal communication, April 29, 2008).

The present results, however, do not support this observation. With one exception, the majority of the participants reported consistent usage through middle school and high school. The non-users received their implants prior to, or very early in adolescence and continued to use their implant until they began college, whereas the users were either younger than 5 or over 18 at the time of implantation. In addition, all of the non-users reported receiving full support from family and friends pre- and post-implantation, even when they made the decision to discontinue. All of the students reported getting some benefit from using CIs in recognizing environmental sounds, yet most the discontinued users reported little or no benefit in their own speech production and in the classroom, group discussion, social events, or one-on-one settings; arguably the most important situations. Thus it appears that for these non-users, the lack of benefit was the principal deciding factor.

Several of the students reported taking an active role in the decision-making process of getting an implant, four of the non-users made the choice to discontinue use. In contrast, all of the users who reported that their parents made the decision for implantation were still using the device. Therefore, it appears that being involved in the decision making process, does not ultimately result in a consistent usage outcome. Among users, when asked if they would have the medical procedure again, most said they would because they saw the benefit. For example, participants said “Yes, I want to hear” and “Yes! I love the device and how it works. It’s very effective compared to hearing aids.” Conversely, only one discontinued user said that he would consider having the surgery again in the future. Hence, for the users the benefits of the device were great enough to warrant going through the original procedure again; suggesting a high level of satisfaction. Non-users generally were not satisfied, however, and therefore would be unlikely to go through the procedure again.

Interestingly, all of the self-reported discontinued users in the study were male. Several questions arise from this finding. Is there a real difference between men and women learning to use the device or was the finding the result of the small sample size? Is it easier for women to hide their implant because of their longer hair and therefore more inclined to keep using it? Could it be that the men were less patient with the rehabilitation process (speech therapy) compared to women? Several men reported something unknown “went wrong” with their implants. Did the men have some internal auditory difficulty that prevented them from benefiting from the device? These questions merit further examination.

Overall, it appears that students who benefited greatly in their auditory perceptions and speech production from the device are still using it, whereas non-users discontinued because they only achieved minimal benefit. Having little or no benefit in understanding speech outweighed gaining access to environmental sounds and was not enough to justify continued use. Both users and non-users reported satisfaction with their decision to use (or not to use) their implant. All participants stated being

comfortable with their identities has a users or non-users. Additionally, in this sample, age of implantation and length of use did not determine usage or non-usage outcomes.

Limitations

This is only a pilot study, but the results are consistent enough to warrant further examination with a larger sample. Gerard O'Donoghue, an internationally recognized implant surgeon in Nottingham, England, has recognized the importance of further research in this area:

Most implant studies are not typical or representative. Too much of the CI literature is based on these top-end performers. Let's drill down to understand what went 'wrong' and what it is we can all learn and do better" (personal communication, April 29, 2008).

In addition, several other questions remain. Does the level of benefit generally determine usage, as was the case in this sample of college students? In this study, participant responses reflected the auditory need and benefit outcomes rather than personal feelings, similar to the findings in Wheeler et. al. Are there other reasons for non-usage? Are there socio-emotional or cultural reasons that may not be evident in such a small group? All of the students, users and non-users, recounted at least one situation where they felt negatively about having an implant; is one such event enough to make young adults (or others) stop using their implants? Is there a real gender difference resulting in men being more likely to discontinue use, and if so, why? Future studies in this area may yield some insight into these unanswered questions.

References

- Archbold, S.M., Lutman, M.E., Gregory, S., O'Neill, C., & Nikolopoulos, T.P. (2002). Parents and their deaf child: their perceptions three years after cochlear implantation. *Deafness and Education International*, 4, 12-40.
- Beadle, E., Shores, A.I., & Wood, E. (2000). Parental perceptions of the impact upon the family of cochlear implantation in children. *Annals of Otolaryngology, Rhinology & Laryngology (Suppl. 185)*, 109 (12), 111-114.
- Marschark, M. (2007). *Raising and Educating a Deaf Child: A comprehensive guide to the choices, controversies, and decisions faced by parents and educators*. New York: Oxford University Press.
- Marschark, M., Rhoten, C., Fabich, M. (2007). Effects of Cochlear Implants on Children's Reading and Academic Achievement. *Journal of Deaf Studies and Deaf Education*, 12, 269-282.
- Nicholas, J. & Geers, A. E. (2003). Personal, social, and family adjustment in school-aged children with a cochlear implant. *Ear and Hearing*, 24, 69S-81S.
- Ray, J. Wright, T., Fielden, C., Cooper, H., Donaldson, I., Proops, D.W. (2006). Non-users and Limited Users of Cochlear Implants. *Cochlear Implants International*, 7, 49-58.
- Wheeler, A., Archbold, S., & Gregory, S. (2007). Cochlear implants: The young people's perspective. *Journal of Deaf Studies and Deaf Education*, 12, 303-316.
- Zaidman-Zait, A., (2007). Parenting a child with a cochlear implant: A critical incident study. *Journal of Deaf Studies and Deaf Education*, 12, 221-241.

Appendix I: Interview Questions

All Participants:

How involved were you in the decision to get an implant?

Follow-up: Do you view using your implant(s) as a choice?

As a child, did you see any deaf adults with implant(s)?

Follow-up: How do you feel about the number of faculty and staff getting implants?

Tell me about a time when you were happy that you have/had an implant.

Tell me about a time when you felt negatively (embarrassed, awkward) about having an implant.

Do you feel different about wearing your implant here (at RIT/NTID) than when you were in high school?

How do you decide when to use your implant(s)?

In what situations do you use your implant(s)?

Have you ever considered not using your implant?

Overall, would you say your cochlear implant experience was positive or negative?

Non-Users:

Why did you stop using your implant(s)?

If you could go back, would you make the same decision?

How did you tell your parents about your decision to stop using your implant (if you did)?

How long did you use your implant before you decided to stop?

Have you reconsidered your decision?