

Ursidae: The Undergraduate Research Journal at the University of Northern Colorado

Volume 5
Number 1 2015 Research Excellence Awards
Winners and Finalists

Article 11

January 2015

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Recommended Citation

Kilgore, Tia (2015) "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. 1, Article 11.

Available at: <https://digscholarship.unco.edu/urj/vol5/iss1/11>

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

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Abstract: Approximately 90% of children born deaf have hearing parents. Many of these parents seek cochlear implants for their children. However, while current position statements from the National Association of the Deaf are somewhat positive, pediatric cochlear implantation has previously been very controversial amongst members of the Deaf community. Deaf individuals feel that hearing parents are not fully informed about and do not consider Deaf Culture for their children. This research had two goals: to investigate if parents are informed about or consider Deaf Culture during the cochlear implant candidacy evaluation process, and to examine the interactions (if any) the child or caregiver had with members of the Deaf community after the child's implantation. An 18-question survey was distributed to parents of cochlear implantees using two cochlear implant Facebook groups and the research advisor's personal connections. A total of 84 respondents completed the survey. Of those respondents, 64% reported there was no direct discussion of Deaf Culture during their child's evaluation. However, 85% reported receiving some information about Deaf Culture prior to implantation, but only 53% reported utilizing this information in their decision making process. Finally, caregivers reported mixed reactions from the Deaf community. Several interesting themes emerged from their open-ended comments, including the role that the relationship between the Deaf individual and child played in the interactions. Additionally, reactions tended to be more negative from the online Deaf community. While this research does support that the majority of parents may not be directly educated by professionals on the implant team about Deaf Culture options for their child during the implant evaluation process, and a large number are not considering Deaf Culture in their decision making process, respondents question whether Culture is more directly related to the child's deafness, or the "hearing culture" of the family he/she is born into.