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Breaking the sound barrier: exploring parents' decision-making process of cochlear implants for their children

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ABSTRACT

Objective: To understand the dynamic experiences of parents undergoing the decision-making process regarding cochlear implants for their child(ren).

Methods: Thirty-three parents of d/Deaf children participated in semi-structured interviews. Interviews were digitally recorded, transcribed, and coded using iterative and thematic coding.

Results: The results from this study reveal four salient topics related to parents' decision-making process regarding cochlear implantation: 1) factors parents considered when making the decision to get the cochlear implant for their child (e.g., desire to acculturate child into one community), 2) the extent to which parents' communities influence their decision-making (e.g., norms), 3) information sources parents seek and value when decision-making (e.g., parents value other parent's experiences the most compared to medical or online sources), and 4) personal experiences with stigma affecting their decision to not get the cochlear implant for their child.

Conclusion: This study provides insights into values and perspectives that can be utilized to improve informed decision-making, when making risky medical decisions with long-term implications.

Practical implications: With thorough information provisions, delineation of addressing parents' concerns and encompassing all aspects of the decision (i.e., medical, social and cultural), health professional teams could reduce the uncertainty and anxiety for parents in this decision-making process for cochlear implantation.

1. Introduction

Three hundred and sixty million people worldwide are deaf or hard-of-hearing, and 32 million of these individuals are children [1]. Since 1984, individuals have had the option of getting cochlear implants. According to the Food and Drug Administration (FDA), approximately 324,200 people globally have received these implants, including about 58,000 adults and 38,000 children in the United States [2].

A cochlear implant is a surgically implanted device designed to help individuals who are sensorineurally deaf to perceive varying levels of sound. The device works by connecting a nerve-stimulating electrode to the inside of the cochlea, which is the hearing nerve [3,4]. It has been called "the first man made device that successfully interfaces with the human brain" [5,p. 1837]. In combination with therapy, it can restore a great deal of hearing [6].

The benefits of getting a cochlear implant are maximized when the surgery is performed before the age of five years old [3,4]. In 2000, the FDA lowered the age eligibility for implantation to one-year-old because it is safest to receive the implant at a younger age [7]. Since early implantation leads to better results and fewer complications [8–10], parents feel pressure to make this decision.

Research has focused on the multiple perspectives of the d/Deaf community. d/Deaf (with both the lowercase and capital "d") is used to refer to and to be inclusive of different understandings of deafness. Lower case "deaf" refers to deafness as a medical and pathological matter, while "Deaf" denotes a linguistic trait and cultural identity [20]. This semantic distinction reflects the two dominant viewpoints: 1) the 'd'eaf community, which tends to be more pro-cochlear implant [11,48], and 2) the 'D'eaf community, which tends to be more critical about the cochlear implant [12–14,47].

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Extant research covers the technological history and medical implications of cochlear implants, but it overlooks the important role parents have in making this decision for their child(ren). This is particularly challenging because the implants vary widely in outcomes and effectiveness [15]. In addition to medical risks, such as injury to the facial nerve, meningitis and tinnitus [16] individuals are also prone to social and psychological risks [46]. Research focuses on the clinical, ethical and cultural ramifications of undergoing this risky and sometimes stigmatized surgery [17–19], but less has been focused on the social processes and communicative components leading up to this decision. Therefore, the aims of this qualitative study are to identify: A) what factors parents consider when making the decision, B) to what extent parents' communities and networks influence their decision-making, C) which information sources parents seek and value when making this decision, and D) what personal experiences they have with stigma that may or may not affect the perception of information about this risky medical procedure. Combined, these four components will provide a lens through which we can better understand the decision-making process, each of which comes with a set of unique pressures, norms and motivations.

2. Methods

2.1. Participants

Study participants included 33 parents of d/Deaf children. The sample included parents who at one point considered the cochlear implant for their child(ren) and decided for or against the cochlear implant. Participants were recruited through Schools for the Deaf across the United States, as well as through the American Society of the Deaf. All the participants of the study were mothers. Of the participants, eight were recruited via snowball sampling. Twenty-five of the participants were hearing, five of the participants were d/Deaf and had no cochlear implant(s), and three of the participants were d/D and had a cochlear implant(s) (Table 1).

2.2. Data collection

The Institutional Review Board at the author's affiliating University approved this project. The author with the help of her two research assistants mapped out potential schools and d/Deaf organizations that could help with the recruitment of participants. Some of the Schools for the Deaf required the completion of confidentiality forms, which the author completed. They emailed and/or phone-called Schools for the Deaf across the United States and reached out to national organizations such as the American Society for Deaf Children to see if they would be willing to post the recruitment letter on their website, any weekly e-blast, or refer us to any other organization that would help reach out to parents. The two research assistants prepared for this project, conducting literature reviews and having weekly meetings with the author as part of their research assistant requirements. Additionally, the two research assistants had a month of preparation for making phone calls to schools, as they practiced with the author. People interested in participating in the study were encouraged to contact the author directly to schedule an interview. Participants were also recruited through snowball sampling.

Data were obtained from in-depth semi-structured interviews conducted by the author. The author obtained verbal informed consent from the participants by reading a written informed

Table 1
Sociodemographic information about participants.

Participant (n)	Sex of participant	Participant description being hearing or d/Deaf	Age/sex of child	Cochlear implantation of child	State of recruitment
1	F	Hearing	5/Son	Bilateral cochlear implants	Michigan
2	F	Hearing	12/Daughter	Cochlear implant	Ohio
3	F	Hearing	15/Son	No implant	Ohio
4	F	Hearing	4/Son	Cochlear implant	New York
5	F	Hearing	3/Daughter	Bilateral cochlear implant	California
6	F	Deaf/no Implants	15/Son and 12/daughter	No implants	New York
7	F	Hearing	12/Son	Cochlear implant	Michigan
8	F	Deaf/no Implant	4/Daughter	Cochlear implant	Massachusetts
9	F	Hearing	7/Son	No implant	New York
10	F	Hearing	2/Daughter	No implant	New York
11	F	Deaf/no Implant	7/Daughter	No implant	New York
12	F	Hearing	6/Daughter	No implant	Ohio
13	F	Hearing	15/Daughter	Cochlear implant	Ohio
14	F	Hearing	15/Son	No implant	California
15	F	Hearing	3/Son	Cochlear implant	California
16	F	Hearing	6/Daughter	No implant	California
17	F	Deaf/no Implant	2/Daughter	Cochlear implant	California
18	F	Hearing	12/Daughter	Bilateral cochlear implants	Arizona
19	F	Hearing	4/Son	Cochlear implant	Massachusetts
20	F	Hearing	3/Son	No implant	Michigan
21	F	Hearing	8/Daughter	Cochlear implant	New York
22	F	Hearing	12/Daughter	Cochlear implant	Massachusetts
23	F	Hearing	11/Son	Cochlear implant	Massachusetts
24	F	Hearing	4/Son	Cochlear implant	New York
25	F	Deaf, cochlear implant	13/Daughter	Cochlear implant	Rochester
26	F	Deaf, no implant	7/Son	Cochlear implant	New York
27	F	Hearing	17/Son	No implant	Arizona
28	F	Hearing	9/Daughter	No implant	New York
29	F	Hearing	11/Daughter	Cochlear implant	Ohio
30	F	Deaf, cochlear implant	8/Son	No implant	New York
31	F	Hearing	3/Son	Cochlear implant	Massachusetts
32	F	Hearing	5/Son	Cochlear implant	Ohio
33	F	Deaf, cochlear implant	11/Daughter	No implant	Michigan

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