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## Case Report

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# The Right Not to Hear: The Ethics of Parental Refusal of Hearing Rehabilitation

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**Objective:** To explore the ethics of parental refusal of auditory-oral hearing rehabilitation.

**Study Design:** Case study with medical ethical discussion and review.

**Methods:** Two young brothers present with severe-to-profound congenital sensorineural hearing loss. The parents, both of whom have normal hearing and work as sign language interpreters, have decided to raise their children with American Sign Language as their only form of communication. They have chosen not to pursue cochlear implantation nor support the use of hearing aids.

**Discussion:** This case raises significant questions concerning whether hearing rehabilitation should be mandated, and if there are circumstances in which parental preferences should be questioned or overridden with regard to this issue. In addition, legal concerns may be raised regarding the possible need to file a report with Child Protective Services. Although similar cases involving the Deaf community have historically favored parental rights to forego hearing rehabilitation with either cochlear implantation or hearing aids, we explore whether conclusions should be different because the parents in this case are not hearing impaired.

**Conclusions:** The ethics of parental rights to refuse hearing rehabilitation are complex and strikingly context-dependent. A comprehensive appreciation of the medical, practical, and legal issues is crucial prior to intervening in such challenging situations.

**Key Words:** Pediatric ears, otology.

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### CASE STUDY

J.M. is a 3-year-old male with profound congenital sensorineural hearing loss secondary to a heterozygous connexin 26 mutation, originally detected after a failed newborn hearing screen. He has no significant comorbidities, nor any evidence of cognitive disability. His otherwise-healthy 8-month-old brother carries the same mutation and has profound sensorineural hearing loss, also diagnosed shortly after birth. Their mother and her partner are not hearing impaired, but both have hearing-impaired relatives and grew up with hearing-impaired parents who communicated with them via sign language.

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The parents, both of whom are sign language interpreters, have decided to raise their children with American Sign Language (ASL) as their only form of communication. They have chosen not to pursue cochlear implantation or hearing aids and desire to assimilate their children into Deaf culture, with exclusive use of ASL for communication. Even though both parents are hearing, they are very much integrated with and identify with the Deaf community. Like many members of the Deaf community, they are philosophically opposed to cochlear implants. They feel that ASL is the appropriate choice of communication for deaf individuals. Because both parents are fluent in ASL, they felt that they could provide their children with an appropriate communication environment.

### INTRODUCTION

This article focuses upon the ethics of cochlear implantation as they relate to the profoundly hearing impaired children of hearing parents. We will review the interface between Deaf culture and advocates of hearing rehabilitation, and the legal issues that arise from this conflict. We focus our discussion upon the unique ethical questions raised by the fact that the parents are not hearing impaired, and describe our decision-making process in this challenging clinical situation.

## CONFLICT WITH THE DEAF COMMUNITY

The term *deaf* (with a lower case “d”) refers to individuals who have profound hearing loss and are unable to effectively use oral communication without amplification or other means of hearing rehabilitation, such as cochlear implants. *Deaf* (with an upper case “D”) has a more specific implication. The Deaf culture represents a community of individuals that share the same language (ASL), customs, and values and essentially reject the notion that hearing impairment represents a disability. Being Deaf is highly valued within the culture, and some expectant Deaf parents hope to have Deaf children with whom they can share their language, culture, and unique experiences.<sup>1</sup>

According to the United States Food and Drug Administration (FDA), approximately 188,000 individuals worldwide have received cochlear implants (CIs) as of April 2009.<sup>2</sup> The current FDA criteria for pediatric implantation are as follows:<sup>3</sup>

- 12 months and older
- severe to profound sensorineural hearing loss in both ears
- limited benefit from hearing aids
- lack of auditory development progress
- score of less than 30% on age-appropriate word lists (if applicable)

Children with profound sensorineural hearing loss who receive CIs before 24 months of age demonstrate better speech, language, and auditory development compared with children who are implanted after 24 months or never implanted.<sup>4–6</sup> This appears to be due to a critical window of neurologic plasticity during normal development. Individuals with connexin 26 mutations, such as our index patients, have higher success with CIs compared to other implanted children.<sup>7</sup> Familial support and commitment, as well as an educational environment emphasizing oral/aural communication, also contribute to successful outcomes with a CI.<sup>4</sup>

CIs are strongly opposed by many members of the Deaf community. Many Deaf individuals claim that CIs have not definitely proven efficacious and argue that proceeding with implantation exposes individuals to surgical risks without proven benefit. Additionally, efforts to treat hearing loss are seen by some as a threat to the Deaf culture. Leaders of the Deaf culture have associated CIs with “child abuse” and “cultural genocide” because they can lead to implanted children leaving Deaf society.<sup>8</sup> Some contend that these two arguments are inherently contradictory.<sup>9</sup>

A disability is defined when a “specific function is impaired, there is reduced ability below efficiency, or a limitation of functional ability occurs with reference to the patient’s age/gender group.”<sup>10</sup> Credible sources affirm disparities between hearing and nonhearing individuals. The average reading level of a Deaf adult is at the third- or fourth-grade level,<sup>11</sup> and the average Deaf adult’s income is 30% lower than the general population mean.<sup>12</sup> Moreover, the Deaf community is one of the largest beneficiaries of funding from the Americans with

Disabilities Act (ADA). In many ways, this dichotomy defines the debate between the hearing and Deaf worlds.

The preponderance of the established medical and surgical community accept that CIs have the ability to manage a disability that carries significant morbidity, and thereby increase available opportunities for education, employment, and personal relationships among profoundly hearing-impaired children.<sup>13</sup> Given the limited window of opportunity for efficacious cochlear implantation early in a child’s life, waiting for a child to mature in order to make his/her own decision about implantation prevents him/her from achieving the greatest potential benefit.<sup>4–6</sup> That said, parents are frequently encouraged to temporarily defer surgery in order to fully appreciate its magnitude and implications and to prepare for the necessary rehabilitation thereafter; deferring surgery for years or indefinitely would typically be discouraged. In practice, parents frequently assent to implantation of children at young ages and allow their children to make autonomous choices—to use or discontinue the use of the implant—once they reach an appropriate age. Our index case raises the issue of whether certain non-life threatening medical decisions should be questioned in these situations.

## LEGAL AND ETHICAL CONTEXT

As a fundamental ethical principle, parents are granted the right to raise their children according to their own morals and values and to make independent decisions with regard to their children’s health and well-being. Non-emergent medical procedures in minors, such as CIs, require the consent of a parent or legal guardian. It is expected that the parent’s decision is based on the child’s autonomy (i.e., respect for self-determination) and beneficence (i.e., concern for well-being).<sup>14</sup> When a child is suspected of being neglected or maltreated, it is the responsibility of Child Protective Services (CPS), state-funded organizations, to intervene in order to preserve the best interest of the child.<sup>15,16</sup> Efforts to simultaneously rehabilitate the family, adequately meet the physical and emotional needs of the child, and preserve an autonomous family dynamic are often undertaken. If the parents are legally deemed unable to adequately meet the needs of the child, parental rights can be terminated.<sup>16</sup>

CPS defines child neglect as “harm or threatened harm to a child’s health or welfare by a parent, legal guardian, or any other person responsible for the child’s health or welfare.”<sup>17</sup> More specific to our case at hand, medical neglect is perceived as “the failure to seek, obtain, or follow through with medical care for the child, with the failure resulting in or presenting risk of death, disfigurement, or bodily harm or with the failure resulting in an observable and material impairment to the growth, development, or functioning of the child.”<sup>18</sup>

According to Michigan State Law, CPS has the responsibility to investigate and respond to any complaint of child abuse and/or neglect. By this same law, mandated reporters (i.e., physicians, nurses, social workers, audiologists, psychologists, or other professionals

who have contact with children) are required to report any cases of suspected child abuse/neglect. To protect against underreporting, mandated reporters are legally protected from lawsuits that may be lodged against them for nonmalicious, erroneous reports. Conversely, mandated reporters who fail in this duty may be held civilly liable for damages caused and may be charged with a criminal misdemeanor.<sup>16</sup>

One relevant case has been decided in Michigan courts. The foster parent of two profoundly hearing-impaired children petitioned the Court to proceed with cochlear implantation over the objections of their Deaf biological mother, whose custody was temporarily revoked for unrelated reasons. The Court rejected the foster parent's request but stated that surgery was likely in the best interest of the children, and would be permissible if the biological mother's custody rights were permanently revoked.<sup>19</sup> The case did not comment upon parental responsibilities to provide hearing rehabilitation in general.

Failure of a parent to provide or obtain adequate services to ensure the health and well-being of his/her child may result in the child being removed from the home and possible termination of parental rights.<sup>15,16</sup> The State of Michigan has exercised this policy in multiple cases that did not involve potentially life-threatening or emergency conditions. In one case, parents consistently failed to participate in the medical, educational, and physical therapy appointments of their child who suffered from hydrocephalus and cerebral palsy.<sup>20</sup> Another case involved a family of three children, all with chronic medical problems including juvenile diabetes, poor eyesight and hearing deficits, and a genetic kidney condition. The parents were unwilling or unable to comply with the recommended medical regimens and missed numerous scheduled appointments.<sup>21</sup> In these cases, the parents were deemed unable to provide the necessary care that the children needed, resulting in the termination of parental rights.

According to the Michigan case law cited above, failure to attend medical appointments and to provide a child with the resources necessary for maintenance of health and happiness are grounds for initiation of legal proceedings, even in cases in which parents may have thought they were acting in the best interest of the child. It therefore seems reasonable to question parental choices in relation to our index case. In practice, the degree of harm caused by not proceeding with cochlear implantation must be critically examined. Despite good-quality evidence that stresses the importance of early implantation, CI remains an invasive procedure for a chronic condition that is not life-threatening. We are not aware of any cases of cochlear implantation being legally mandated for a child against the will of a legal guardian.

## **UNIQUE CONSIDERATIONS OF THE INDEX CASE**

To our knowledge, this is the first published discussion and report of hearing parents refusing CIs for

children against medical recommendations. Although similar cases involving the Deaf community have historically favored parental rights to forego hearing rehabilitation with either CIs or hearing aids, there is a question concerning whether the debate is fundamentally different because the parents can hear.

The fact that the parents can hear allows them to appreciate the advantages of functional hearing for both safety and communication. Furthermore, they can also appreciate the educational advantages functional hearing provides. Given that a small minority of the population is severely hearing impaired,<sup>2</sup> deafness places affected individuals at a clear disadvantage in communicating with the hearing community that is not ASL-fluent. Hearing parents trained in ASL have access to both the hearing and the Deaf worlds, and are therefore better able to anticipate the limited opportunities available outside of the Deaf world for individuals who lack the ability to communicate effectively. Of course, the counterargument would contend that the advantages of complete assimilation in Deaf society outweigh potential negatives. Although actions that compromise a child's growth and development define medical neglect when the refusal of an intervention is life threatening, it seems reasonable to place more accountability on our index parents, as they are in a position to more fully realize the implications of their decision than can Deaf parents.

Although no physical harm is being inflicted by refusing CI surgery, the ability to hear not only has communicative and functional value, but also gives rise to auditory pleasure and improved safety.<sup>9</sup> Medical evidence suggests that impairment in intellectual and social growth and development may be compromised without hearing rehabilitation among profoundly hearing-impaired children.<sup>13</sup> Hearing parents who deny their children this opportunity may thus be functionally limiting their children's academic, professional, and social potential. In a culture in which parents desire to provide their children with more opportunities than what they themselves have experienced, refusing a well-tolerated procedure that offers one's children hearing rehabilitation and all of the benefits thereof, is apparently contradictory to this societal principle.

Although the parent's proficiency in ASL provides them with more access to the Deaf culture than most hearing individuals, the Deaf culture will always remain partially inaccessible to them: unlike their two sons, they have a choice and can seamlessly transition from the Deaf to the hearing community. Although some might argue that granting their children the ability to fully assimilate in the Deaf world is inherently beneficial, placing their children in a community of which they will always remain outsiders may be detrimental to the parent-child relationship and may potentially foster estrangement, alienation, and even resentment.

The rehabilitative efforts after implantation are complex. Extensive time, effort, and resources are required for a previously nonhearing patient to master spoken language comprehension and expression.<sup>22</sup> A situation in which a Deaf parent foregoes hearing

rehabilitation for his/her nonhearing child may be reasonable because the Deaf parent may not be able to fully appreciate the benefits of and opportunities facilitated by CI despite extensive discussion thereof. More importantly, the parent may be inherently incapable of participating in the necessary aural–oral rehabilitation for their implanted child. Mandating CI among hearing-impaired children of Deaf parents might then potentially require removing the child from the home in order for them to maximally benefit from implantation, which is one reason why this has not been recommended. However, this is not applicable to our index case; both parents are available to participate fully in hearing rehabilitation. An implanted child who has a hearing parent available to him/her on a consistent and reliable basis has immense opportunity for hearing rehabilitative success.<sup>22</sup> Moreover, given their fluency in ASL, our index case parents could even choose to raise their children bilingually should they desire to do so.

Healthcare providers have a responsibility to patients to provide competent care and to facilitate autonomous decisions.<sup>23</sup> This involves a careful and forthright discussion of all risks, benefits, and alternatives of any proposed interventions. Still, providers should make recommendations, even if these suggestions are in conflict with the family's beliefs or values. Such suggestions can, and often are, made out of concern for the child's well-being and are not meant to be accusatory in nature. The difficulty lies in determining the extent of boundaries and the continuum that should be used to act in the best interest of a child.

## RESOLUTION

Returning to the index case, the obvious question involves how best to counsel the parents. Although it is not our intent to discredit the beliefs/values of either the parents or of Deaf culture in general, the interests of the children supersede. Although ASL is a vibrant language and valid form of communication, preventing children from receiving auditory input and developing oral communicative skills will indelibly impact their lives and limit their potential. Although the parents may believe that they are acting in the best interest of their children, their actions may compromise their children's growth and development. As such, there is a moral and professional obligation to educate parents about the relevant medical facts, and assist in their decision-making. In this case, it behooves clinicians to strongly recommend consideration of cochlear implantation despite opposing parental preference.

Assuming that the parents choose not to follow this path, clinicians must consider the possibility of reporting neglectful behavior to CPS. Failure to seek or obtain necessary medical care for a child that result in the impairment in growth, development, and/or function defines medical neglect. Unfortunately, the "necessity" of the intervention and the resultant "impairment" are highly subjective, and individual providers must make these conclusions on a case-by-case basis, without the

benefit or availability of formal guidelines or legal precedent to specifically guide their decision.

The ethical dilemma faced by the involved clinicians prompted formal review by the medical center's Ethics Committee. Despite mixed opinions during this discussion, the overall committee consensus was that there was not an ethical imperative to mandate implantation against parental wishes. The medical center's Child Protection Team also evaluated the case and deferred their decision-making to the medical center's legal experts given their uncertainty. State and case law were subsequently reviewed by an attorney in the Compliance Office, and in her opinion, the case did not meet the legal threshold required to file a CPS report. As a result of the input from all involved sources, a formal CPS report was not filed. The involved medical personnel instead counseled the parents to strongly consider implantation. In such complicated cases, the involvement of legal counsel and ethics consultation can be invaluable and is encouraged in all cases in which clinicians are faced with difficult choices that require ethical and/or legal expertise.

## CONCLUSION

The ethics of parental rights to refuse hearing rehabilitation are complex and strikingly context-dependent. A comprehensive appreciation of the medical, practical, ethical, and legal issues is crucial prior to intervening in such challenging situations. Although a definitive decision-making process does not exist, healthcare providers and families should form a partnership in order to meet the best interests of the patient and family. In certain cases, professional and legal obligations may intercede, although these circumstances may be quite difficult to define explicitly, and often depend upon clinicians' individual assessments.

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