

Review Article

A Cut Too Far? Cochlear Implants and Division among the Deaf

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Abstract

An operation that restores the sensation of sound to a deaf child struggling to integrate within the hearing world would appear to be an excellent application of surgical skill. But when the candidate has grown up within a Deaf family, the offer of surgery may be perceived by parents as an intrusive manipulation upon the body of their child and a threat to their relationships, mode of communication, and the future of the Deaf community. This dilemma has created opposing and vehemently defended viewpoints within the UK and US Deaf communities.

Keywords

- Cochlear implants
- Deaf culture
- Deaf controversy
- Deaf education

INTRODUCTION

Last summer, the BBC broadcast a television documentary about the families associated with a Deaf football club [1]. One of the main themes was that of a young lady, fluent in British Sign Language, preparing for a cochlear implant. She wanted to have greater access to the hearing world whereas her mother was terrified that she would no longer be part of the family, lose her first language, and become marginalized from both hearing and signing communities. The arguments between mother and daughter epitomized the wider and unresolved tensions that have been expressed within Deaf communities on both sides of the Atlantic.

BENEFITS AND PROBLEMS

Potentially there is much to be gained from restoring hearing to deafened infants and young people. Only 1% of deaf children read at an appropriate level on leaving school [2], and many find it difficult to socialize as they struggle to understand the thoughts and feelings expressed by others [3]. Significant educational measures can improve considerably following cochlear implantation [4], but may not match the achievements of their hearing peers as they function as hard of hearing children rather than hearing [5]. Many Deaf adolescents, able to mix with hearing friends, express satisfaction with their implant [6]. The acquisition of oral skills can vary following implantation, with good results when the procedure is performed at an early age. However, the interaction between parents and child is shown to be a significant factor [7], making it imperative to take seriously the concerns of parents, especially those who are Deaf.

The potential educational and social benefits of implantation may not seem as obvious to Deaf families when encountering objections such as those cited by Action on Hearing Loss [8] and

the blogcochlearwar.com. Among possible problems listed are sign language delays while waiting for surgery and the inability to predict any level of improvement following the operation. Opponents claim that intensive rehabilitation may spoil signing, and that recipients cannot actually 'hear' but become aware of noises they must learn to decode, with any attempts at speech being coarse and degraded. This creates anxiety among parents that children might be left without any effective communication, isolated between hearing and non-hearing communities.

All commentators are aware of the practical limitations following the procedure. Implants must be removed for bathing and swimming; wearers must avoid contact sports and activities that generate an electrostatic charge, such as playing with plastic slides, balls or balloons. People with cochlear implants cannot pass through passport control, nor have an MRI scan, as the magnetic field can scramble the electronics.

CONTROVERSY

Since cochlear implants first became available, strong opposition emerged from within the Deaf communities based on issues deeper than practical considerations and educational achievement. In the 1990s, objections were stated and public demonstrations took place, as cochlear implantation became more common with an apparent momentum growing towards operations. A view expressed within the US Deaf community was that doctors, the FDA, and the companies who manufactured the devices, had not properly consulted Deaf people, were pressurizing their young, and 'fast tracked' those waiting for implants to the disadvantage of other Deaf adults and children. Some were offended, not only by a procedure thought to be 'cruel and painful', but by the underlying inference that their lives needed enhancing, aggravated by an incessant stream of media

stories that referred to cochlear implants as so-called 'miracle cures' for deafness. There was also growing concern about the potential health risks of cochlear implantation, including meningitis, cerebrospinal fluid leaks, wound infections, facial nerve damage, and balance problems [9].

Perhaps well-meaning advocates of implantation were unaware that such fears are rooted in the deeply emotive issue of communication and identity that has fermented within Deaf culture for more than 200 years. Identity within Deaf communities is perceived in terms of whether a person uses speech or sign language as their primary means of communication, allowing people to align with either the hearing majority or a signing subculture. This identification is likely to form early, and will be dependent upon the style of communication used at home. When the child attends Deaf school, the emerging identity may be confirmed or subverted according to the school's preference for learning through speech or signing.

There remains within Deaf culture, the painful repercussions of the massive split in Deaf education resulting from the 1880 Milan Congress that triggered an international campaign to eradicate sign language, seen as primitive and subhuman, and to compel the non-hearing, regardless of ability, to learn to read lips and use speech. This in turn, caused the adoption of a medical model that saw Deaf people as 'ill' or 'broken' and who needed to be 'cured' or 'fixed' [10]. The subsequent reaction of Deaf communities against such assumptions ensured the survival of signing, and with time, became the language of choice for many.

Generations of Deaf people, therefore, have been concerned about the continuity of family relationships and community integrity that rely upon an identity based on signing as opposed to speech. They resent the dismissal of Deaf language and a culture that emphasizes a rich visual and social experience rather than acknowledge the limitations of silence presumed by a hearing majority, and object to the notion that they must be able to hear and speak to lead productive lives. Thus the advent of cochlear implants unintentionally re-ignited the historic fear that young people would be taken out of their community and stripped of their identity through being made to hear and speak.

Paddy Ladd has gone further, describing the procedure as a form of 'oralist colonialism' and drawing a political analogy, notes that the National Union of the Deaf made legal objections by attempting to apply UN Genocide Legislation [11]. In 2007, the controversy had become so fierce and occupied so much web space that the US based blog deafnotes.com banned cochlear implant comments as "heavy, space-consuming, bitterly argued and endlessly discussed" setting up its sister website cochlearwar.com for those who wished to continue the strident debate, typified by emotive posts that speak of "bitter feelings", "ideological splits", "shaken up families", "child abuse", and the "Ghettoising of the Deaf".

Such views represent strength of feeling largely overlooked by health providers. Many contributors understand that the majority of deaf children are born to hearing parents who wish to communicate by speech if possible and integrate them into the hearing majority. There is also a general acceptance of older people who have never learned to sign choosing cochlear

implants, or who have gradually lost their hearing and can sign who choose to be part of both hearing and signing communities. The most vociferous attacks are reserved for Deaf parents who choose to have implants for their own children, thus diminishing the culture of which they are a part. The fear is expressed that older Deaf people, including members of their own families, risk becoming alienated from a younger generation who will try to hear, cannot sign and whose primary cultural identity is with the majority hearing world rather than the sign language minority within which they have grown up.

CONCLUSION

It is estimated that 840 babies are born in the UK each year with significant deafness, the overwhelming majority to hearing parents for whom cochlear implantation would be a desirable possibility. There are 20 000 severely deaf children under the age of 15, over half of whom were born deaf. Only 210 children and 185 adults receive cochlear implants in the UK annually, making a total population of 10 000 implanted people in the UK compared to 96 000 in the USA [12].

People with implants remain a minority within the deaf community, despite the hearing majority perceiving the procedure as a 'miracle cure' [13]. In recent years, much more tolerance has been shown towards young cochlear implant users and their parents, with Deaf organizations advocating implantation as an option for any child born deaf or who loses hearing later in life with a memory of sound. Writers from Gallaudet claim the debate has become more balanced since official guidelines were revised in 1995 emphasizing the provision of 'informed choices' for children [14]. The Deaf University, formerly very much at the heart of the controversy, now has its own cochlear implant information center.

Although greater acknowledgement of the educational merits of implantation exists within the Deaf community, particularly when children continue to learn signing [15], care should be taken by health providers and educationalists. In extolling the benefits, they need to be open about potential problems, bearing in mind the considerable anxieties shared by many Deaf parents. Such fears may be exacerbated by views expressed within the family or wider sub-culture. The continuity of signing should be advocated, not just for educational reasons, but also to allay the fear that Deaf young people will lose touch with their community following the procedure.

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