

Other Research

Issues of Contested Identity in the Adoption of Cochlear Implant Technology

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Abstract

This study investigates concerns about the efficacy, the ethics, and the psychosocial effects of implanting, in particular, very young children, with a prosthetic hearing device called a cochlear implant. In addition, it investigates the extent to which parents' decisions for or against implantation are influenced by the current implant debate. This is done within the framework of the parents' need to deal with the contest to their identity as a family which the birth of a profoundly deaf child brings. The study concludes that parents made implant choices based on the way in which they dealt with contested identity and that communication and social adjustment outcomes were either a direct or an indirect result of the decision they made.

Key Words

Cochlear implant; contested identity; post-structuralism; implant debate; Deaf culture

Introduction

Studies by some of the leading researchers (Carter & Hailey, 1996; Chute, Kretschmer, Popp, & Parisier, 1995; Geers & Moog, 1994) have demonstrated the benefits of cochlear implantation for adults and children. Despite this, however, serious questions have been raised by members of the Deaf community about the 'ethics' of implanting very young children. These issues have developed into a debate about whether or not parents and professionals are violating the right of Deaf culture to exist without threat to its future from what has been described by some, as reported by Balkany & Hodges, (1995), as the 'genocidal' effect of paediatric cochlear implantation.

In order to appreciate the full import of why an intervention which would appear to hold nothing but seemingly efficacious outcomes for the Deaf would be received with such mixed ambivalence, one needs to review the background from which these views are sourced. In part the issues revolve around the rather contentious issue of whether deafness ought to be viewed from the paradigm of a medical condition to be 'treated' using an invasive medical intervention or whether a paradigm shift is required which views the Deaf [the capital 'D' is significant since it distinguishes a group of people] as a cultural and linguistic minority, rather than viewing deafness - the condition - as a medical deviance. The 1993 position paper of the Canadian Association of the Deaf affirms that "[Implant surgery] perpetuates the view of deafness as a pathological condition" and the Danish Deaf Association in its position paper in the same year found "a lack of research into the sociological and psychological consequences of the surgery, and lack of information concerning Deaf culture on the part of parents" (Lane, 1994). The following research attempts to address some of those sociological and informational issues.

Contested Identity

The theory of contested identity is discussed in some detail by Hogan, (1998b & 1999). Hogan's work with deafened adults suggests that acquired deafness presents to the individual not only a change in physical condition, but also a contest to their identity as a

(hearing) individual because “[t]he lived experience of being deaf contests the notion that the world is hearing, a notion which follows the idea that because hearing and speech have traditionally dominated modes of communication, deaf people should also hear and speak. The experience of deaf people, in whatever form, contests Ableism” (p. 80).

The Post Structural model used in the current study is centered around communicative practice in which identity is performative. That is, when confronted with an identity crisis, people resolve it through what they do, who they do it with and, in this case, how they communicate (Corker, 1998; Hogan, 1999). For the group in this study, hearing and speech serve as the foundations in which language truly structures the performative and becomes the basis for re-establishing their ability to be associated with and participate in a phono-centric culture (Hogan, 1998a).

Method

Sampling and Participants

The type of information being sought in a qualitative research study such as this differs quintessentially from that which would be sought in a quantitative research study. This has important implications not only for the type of methodology, but also for the sampling strategy used to define and select both the type and size of the sample.

Patton (1990) suggests that a sampling strategy should be selected to fit the purpose of the study, the resources available, the questions being asked and constraints being faced. In the case of a quantitative study, where generalisable probabilities are being sought, probability sampling using large samples is a legitimate technique. However, because of its ability to deliver information-rich data in describing the lived experiences of participants, qualitative methodology was chosen for this study and a small, but representative sample of participants, was purposefully selected and studied in depth. Four adults (female) served as subjects for the study. Each subject was the mother of a prelinguistically deafened infant with a bilateral hearing loss and a better ear pure tone average (PTA) threshold of >90dB. Children’s ages ranged between 3-years- and 9-years-old. Because of their (traditional) role as primary caregivers, mothers (rather than fathers) were chosen.

Each participant’s child was a student at a school or pre-school for deaf children in Victoria, Australia, and participants were subdivided into two categories: those who had chosen in favour of an implant for their child, and those who had considered an implant, but decided against implantation for their child. Three of the children have been implanted and one has not. The non-implanted subject provided an opportunity to study an outlier to the adoption pattern. Table 1 is a description of the participants who, for the purpose of this study and to protect their identity, have been given pseudonyms:

Table 1
Participants’ Statistics

Mother’s Pseudonym	Child’s Gender	Child’s Age	Implanted	Age at Assessment	Age Implanted
Lynda	male	3 years 10 months	Yes	20 months	21 months
Ann	female	6 years 9 months	Yes	15 months	19 months
Kate	female	8 years 9 months	Yes	7 years	7 years 2 months
Mary	male	3 years 10 months	No	2 years 8 months	2 years 10 months

Design and Procedure

The project was designed as a qualitative study around the framework of Post Structuralism with particular emphasis on the theme of Contested Identity as postulated by Hogan (1998b & (1999). A semi-structured interview schedule was developed from issues emerging from the literature which had either not been previously investigated or required further investigation. Each interview took approximately 50 minutes, was conducted in the individuals home environment, and was recorded on audio tape. These recordings were later transcribed and participants' responses were thematically analysed using inductive techniques. Grounded theory techniques as outlined by Glasser and Strauss (1967) were used to develop a theory of contested identity for families facing the issues of cochlear implantation for the young deaf children.

Results and Discussion

Issues of Contested Identity in Communication Methodology Decisions

The birth of a child with a hearing defect shatters a family's sense of normalcy and, unlike other forms of disability, creates a cultural dissonance between the child and the other family members (Jamieson, 1995). It is in an attempt to make sense of this dissonance that parents set out, initially, to redefine their understanding of what is "normal." In doing so, they make a series of choices in an attempt to redefine their understanding of what is "normal." Although communication issues are related to implant decisions, they are essentially a means to an end - the reconstruction of the child - not the end in themselves. Despite comments such as "[s]igning was not really an option for us" (Lynda) and "[w]hen they explained to us that basically it was a signing option or an implant option, we went with the implant" (Ann), these decisions are essentially cultural/social decisions, not (initially at least) communication decisions. This is not because communication decisions are unimportant, but rather because without already having made decisions about cultural identity, communication decisions are made in a vacuum and are therefore meaningless (Ladd, 1991).

Vindication for the theoretical framework of this paper can be seen in the responses of the participants as they make decisions in favour of oral communication because oralism facilitates the remaking of their cultural identity as a hearing family. Hogan, (1999) comments:

Language constitutes people as very specific types of actors. The governance of deafness is about shaping behaviour so that the code rules and values of hearing culture and the systems, technologies and networks that sustain it, can be secured and upheld in very specific ways (p.79).

Participants' interpretation of the crisis they face in contested identity is through the filter of their understanding of normality. When faced with a choice of a communication method with which they associate normality, and one which speaks of something which is "other than" normal, their response, in an attempt to make sense of their loss of identity, is to remake the child in terms of their understanding of normality.

Implant decisions are associated with notions of normalcy

In answering a question about the influence of communication on implant decisions, all mothers of implantees responded in terms of its effect on maintaining, or to be more correct, reclaiming normalcy (where "normal" is associated with having hearing). Each one suggested, either directly or indirectly, that possible communication outcomes had influenced their decision by virtue of the fact that in seeking to reclaim the "normalcy" of a hear-

ing, speaking family, the choice must, of necessity, be for oral outcomes. These are delivered in turn by positive implant outcomes because for an implant child since "being able to communicate is resolved. Ah, not resolved, but stands a better chance, um, being a normal part of family and society...my view was, a signing child I meet to compare with say [my child] um, to me sounded like a wild beast and I just thought I do not know how you could choose that" (Ann).

Negative implant decisions seek to resolve contested identity from the child's perspective

Mary also has a desire for her child to be "normal," although she uses the term cautiously requesting that it be placed in inverted commas, but her response to the normalization process is quite different from the implantees. Her interpretation of "normal" is couched in terms of her child's ability to "do" the normal things one would expect a little boy to "do" without the limitations and perceived stigma of a mechanical device. She comments, "It stops him. I hate this word 'normal' but it stops him growing up like other - like 'normal' children because you know, it's just - there's this pack they have got to carry around all the time" (Mary). For her then it is not so much the decision about desired communication outcomes which drives implant decisions, as is the case for implantees, as it is the decision not to implant which sets in motion an inevitable communication outcome.

Although Mary's choice to resolve contested identity by not implanting secures her goal by a route which is different from the implantees, the principle of performative identity in communicative practice is still applied thereby affirming its application as a general practice. Mary's responses suggest that had it been possible, she would have in fact opted for an implant. She states "because we had another acoustic omissions test done that showed the cochlea had deteriorated even though the audiogram had not changed, we thought we had better check [an implant] out." (Mary). Having done so, however, it was discovered that due to other mitigating factors, the child was not a suitable candidate. With this information, Mary then opts for the next best thing choosing to resolve the dissonance of her contested identity by remaking the family in the protocol of Deaf Culture and adopting a performative practice in which the whole family learns to sign. In doing so, Mary uses exactly the same discourse as the implantees in describing her desire for normalcy despite the fact that she defines it differently and uses a different performative practice and ultimately achieves the same end, the regaining of, from their perspective, normalcy.

As already mentioned, for Mary "normal" has quite different connotations to those placed upon it by families who decide to implant. She deals with her sense of contested identity not by trying to remake the child to fit her understanding of normalcy, but by remaking her understanding of normalcy to fit the child. In fact, her attempts to reinvent her understanding of normalcy are so radical that the whole family has learned to sign. This is more than a token effort to try to establish some kind of relationship with the child. It is in fact a radical paradigm shift for the family in an effort to understand the world from the child's point of view.

Conclusions and Recommendations

Findings in this study are presented in the context of their being an adequate preliminary disclosure of a discourse which warrants further study into the issues of contested identity and the competing notions of normalcy presented earlier in the paper. With this in mind, the following conclusions can be drawn.

Parents in this study interpret normality differently. For some normality is associated with a state of being wherein to "be" normal means to "be" like others. For others, normality is associated with a state of doing wherein the ability to "do" as others "do" is more important than it is to "be" like others. There appeared also to be a gender related issue with

the concept of "doing" or "being," which is worthy of further research.

Participants made implant decisions based on the extent to which they consider that being normal outweighed doing normally or vice-versa. These decisions were grounded in their need to resolve the issues of contested identity.

Participants made differing decisions about implantation according to the way in which they chose to resolve the contest to their identity as a family, which the birth of a profoundly deaf child brings. Hogan (1999) previously used the principles of contested identity to explain the social identity processes which are engaged by deafened adults as they attempt to reconstruct their identity as hearing impaired people. This study has attempted to apply those same principles of social engagement as they are observed in parents of congenitally deaf children.

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References

- Balkany, T. J., & Hodges, A. V. (1995). Misleading the Deaf community about cochlear implantation in children. In G. Clark & R. Cowan (Eds.), *International Cochlear Implant, Speech and Hearing Symposium Melbourne, 1994. Annals of Otolaryngology, Rhinology and Laryngology* 106, 148-149.
- Carter, R., & Hailey, D. (1996). *Economic evaluation of the cochlear implant (Centre For Health Program Evaluation: Working Paper 44)*. Victoria, Australia.
- Chute, P. M., Kretschmer, R. E., Popp, A. L., & Parisier, S. C. (1995). Cochlear implant performance in a deaf child of deaf parents: A case study. In G. Clarke & R. Cowan (Eds.), *International Cochlear Implant, Speech and Hearing Symposium Melbourne, 1994. Annals of Otolaryngology, Rhinology and Laryngology* 106, 316-318.
- Corker, M. (1998). *Deaf and disabled, or deafness disabled?* Buckingham, UK: Open University Press.
- Geers, A. E., & Moog, J. S. (1994). Spoken language results: Vocabulary, syntax and communication. *The Volta Review*, 96(5), 131-147.
- Hogan, A. (1998a, September). *Contested identity*. Personal communication: Faculty of Health Sciences, University of Sydney.
- Hogan, A. (1998b). The business of hearing. *Health*, 2(4).
- Hogan, A. (1999). Carving out a place to act - acquired impairment and contested identity. In M. Corker & S. French (Eds.), *Disability Discourse* (pp. 79-91). Buckingham, PA: Open University Press.
- Jamieson, J. R. (1995). Interactions between mothers and children who are deaf. *Journal of Early Intervention*, 19(2), 108-117.
- Ladd, P. (1991). The modern deaf community. In S. Gregory & T. Hartley (Eds.), *Constructing deafness*. Milton Keynes, UK: Open University Press.
- Lane, H. (1994). The cochlear implant controversy. *WFD News*, 2 (3), 22-28.
- Lane, H. (1997). Construction of deafness. *The disability studies reader* (pp. 153-171). New York: Routledge.
- Patton, M. J. (1990). *Qualitative evaluation and research methods*. (second ed.). London: Sage.