Pediatric Cochlear Implantation

The Parents’ Perspective

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Objective: To analyze parental views on cochlear implantation, before and in the years following implantation, to determine whether the results from the intervention met their expectations.

Design: Prospective longitudinal study to assess parental perspectives of an unselected group of children with cochlear implantation.

Setting: Tertiary referral pediatric cochlear implant center in the United Kingdom.


Intervention: A specifically designed questionnaire was administered to assess preimplant expectations and observed changes and concerns at 1, 2, and 3 years following implantation. Three key domains were evaluated: (1) communication with others, (2) listening to speech without lipreading, and (3) the development of speech and language.

Results: Preoperative expectations were met or surpassed at each of the follow-up intervals. In the area of communication, 35 (81%) parents expected a definite improvement preoperatively, and 3 years following implantation, 42 (98%) actually saw such an improvement. The respective numbers in the area of listening to speech were 15 (35%) and 38 (88%), and for speech development, 37 (86%) and 37 (86%). Speech development was the major area of concern at all intervals.

Conclusion: This study demonstrates the ability of cochlear implantation to meet or surpass parental expectations in 3 important outcome domains: communication, listening to speech, and the development of speech and language.


Cochlear implants represent the most important advance in the treatment of individuals with profound deafness in the last century. Although most of the hearing-impaired population can hear speech through acoustic hearing aids, many persons with profound deafness obtain no such benefit. The impact of such profound deafness is particularly great in early childhood, as it severely restricts the ability to develop spoken language. For these children, cochlear implants represent the only means of hearing speech and thus of developing meaningful oral communication abilities.

Parents are critical evaluators of their child’s well-being following a therapeutic intervention. Their perspective is critically important in the assessment of outcomes. The aim of this study was to analyze parental views on cochlear implantation, before and in the years following implantation, and to determine whether the results of the intervention met their expectations.

RESULTS

Parental expectations before implantation and the actual changes they perceived in their child following implantation are shown in Figures 2, 3, 4, 5, 6, and 7. Parents had high expectations in the fields of communication and development of spoken language (35 [81%] and 37 [86%] parents answered “certainly yes,” respectively), whereas their expectations in the area of listening to speech without lipreading were much lower (15 [35%] answered “certainly yes”).

Before the intervention, when asked about their expectation with regard to communication, 35 (81.4%) of 43 parents expected a definite improvement following implantation (“certainly yes”). One year following implantation, 38 (88%) par-
MATERIALS AND METHODS

A prospective longitudinal study was undertaken of the parents of a consecutive group of 43 children with profound deafness who underwent cochlear implantation. The parents were asked to complete questionnaires before cochlear implantation and at 1, 2, and 3 years following implantation. Twenty children (46.5%) were girls and 23 (53.5%) were boys. Age at implantation ranged from 2½ to 11 years (mean, 5.3 years). All children received a 22-channel cochlear implant (Nucleus; Cochlear Ltd, Lane Cove, Australia). After implantation, no child was lost to follow-up and all 43 parents completed the questionnaires annually during the study.

Each child underwent extensive medical, audiological, linguistic, and educational assessments to determine suitability for cochlear implantation. During this period, teachers of the deaf and speech and language therapists from the implant center made visits to the child's home and school. Parents were encouraged to seek the views of a range of sources, including adults with deafness and voluntary organizations for children with deafness. In addition, visit days for parents were organized by the implant center, enabling them to meet implant professionals and parents of children who had previously undergone cochlear implantation. Reading material was made available to parents and was supplemented by a videotape of the assessment procedure, hospital stay, and rehabilitation program. Information was also available for the child's siblings and peers, with coloring books for younger children and cartoon-type material for older children.

As no gold standard instrument existed for evaluating parental perspectives of cochlear implantation, a questionnaire was devised for this purpose (Figure 1). Having made the decision to proceed with implantation, parents were administered this questionnaire close to the time of surgery and completed it in writing.

The preimplant questionnaire asked parents to respond to questions about their expectations in 3 key domains: (1) communication with others, (2) listening to speech without lipreading, and (3) the development of speech and language. They were subsequently presented with similar questions at the 1-, 2-, and 3-year intervals following implantation. They were also asked to articulate specific concerns they may have had with regard to their child's progress. The format of the questionnaires was that of a 5-point Likert scale, including adults with deafness and voluntary organizations for children with deafness. In addition, visit days for parents were organized by the implant center, enabling them to meet implant professionals and parents of children who had previously undergone cochlear implantation.

Parental expectations regarding improvements in listening to speech without lipreading were more conservative (35% expected a definite improvement ["certainly yes"]). Therefore, the postoperative percentages (74% in the first year and 88% in the third year who saw such an improvement [Figure 3]) revealed a general improvement beyond parents' expectations. Figure 6 reveals that this difference (35% vs 88%) is attributed to parents who had low expectations in this area and who saw a definite improvement after implantation.

A definite improvement in the development of speech and language was expected preoperatively in 37 (86.0%) of 43 patients. At the follow-up intervals (1 and 3 years after implantation), the respective numbers of parents who saw such an improvement were 35 (81%) and 37 (86%) (Figure 4). Although speech takes several years to develop, the postoperative outcomes seem to have met preoperative expectations. However, Figure 7 reveals that, although before implantation no parent responded with "mostly no" or "certainly no," such responses were found 3 years following implantation, although the percentage is small (2 parents [4.6%]). These parents' children are now known to have language learning problems (one following meningitis and the other congenitally) and have
not developed spoken language. However, they continue to elect to wear their implant system for environmental sound identification in their teenage years. The concerns of parents with regard to the progress of their children are illustrated in the Table (1 and 3 years after implantation). Speech development remained the major area of concern at all intervals.

**COMMENT**

Parental expectations relating to the success of cochlear implantation are considered so important that decisions about postponement, rejection, and selection of children for implantation have been based on these expectations. In a psychological and social approach to different disabilities, Wright indicated that “sometimes the wish that all will be well is so strong as to lead to unrealistic expectations of marked improvement and even-
change in the ability to hear. Therefore, if parents are not clearly counseled about the limitations of the intervention and the need for their involvement in their child's rehabilitation, their disillusionment could easily result in nonuse of the implant system by their child. Thus, thorough counseling is important in cochlear implantation and especially with regard to children, in whom there is a need for prolonged rehabilitation for several years before the full potential of the implant is realized.

Although the role of the parents is essential in all the stages of cochlear implantation, only one article in the literature, to our knowledge, has addressed the parents' perspective with regard to pediatric multichannel cochlear implantation. This survey found that advantages and disadvantages expected by parents preoperatively were consistent with those reported by parents whose children had used their cochlear implant for 1 to 3 years. However, their results are considerably weak-
ened by the relatively small number of subjects and the nonlongitudinal design of the study, with different parents participating at the various intervals (only 1 parent participated at all intervals).

The present prospective and longitudinal study assesses the parents' perspective of an unselected group of children with cochlear implants. There were no exclusions and no losses to follow-up. Therefore, all subjects who reached the 3-year interval had participated in all the previous intervals.

The results suggest that the outcome of cochlear implantation satisfied parental expectations. This was true even in the difficult area of speech and language development. Many critics of cochlear implantation doubted whether these children would ever obtain material benefits in these domains. Nevertheless, speech and language remained the most frequent area of concern at all intervals. This is not surprising, given that speech development in children with profound deafness is an extremely gradual process that may typically take more than 3 years to develop, especially in the youngest children.

In the area of listening to speech without lipreading, the results revealed a general improvement beyond parents' expectations (15 [35%] expected a definite improvement, but 32 [74%] and 38 [88%] saw a definite improvement in the first and third years, respectively). This difference was attributed to parents who had low expectations in this area and saw a definite improvement in the follow-up intervals. On the other hand, some parents who had high expectations in this area were more conservative at the follow-up intervals. This highlights the crucial importance of continued parental counseling to ensure that expectations are maintained within reasonable limits.

The level of parental satisfaction compared favorably with that of similar studies done for other interventions (strabismus surgery in children, 85%; tonsillectomy, >90%). It is difficult to compare these interventions directly with pediatric cochlear implantation. However, the literature with regard to parental satisfaction following any kind of surgery is limited, and there is thus a compelling need to involve parents more in outcomes assessment. It is now becoming more widely accepted that any new method of treatment should engage the public in discussion about what a national health service should provide and who should decide it. Moreover, it has also been suggested that repeated evaluation of patients' (or parental) views should become an integral part of routine health care.

The high level of parental satisfaction found in the present study may be attributed to the success of the intervention in restoring hearing combined with the comprehensive counseling before implantation and its maintenance during the years following implantation. The satisfaction of parents is an important benchmark in evaluating pediatric procedures, and this study demonstrates the ability of cochlear implantation to meet or surpass parental expectations following the intervention.

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REFERENCES