Families with Deaf Parents and Children with Cochlear Implants

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Abstract: 1993 marked the beginning of cochlear implantation in deaf children of deaf parents in Germany. Ever since, the situation of these children and their parents has been a major subject of research at the Chair of Education for the Deaf and Hearing Impaired at the University of Munich. Beginning in 2000, the research project has evolved into a number of subprojects or modules and currently comprises 7 completed modules and another in progress, the results of which are presented, with focus on the family situation.

Keywords: Children with cochlear implants, parents with hearing impairment, family situation, research programme, Deaf Community, CODA

RESEARCH BACKGROUND

1993 marked the beginning of cochlear implantation in deaf children of deaf parents in Germany [1]. At this time, cochlear implant (CI) provision for such children was nevertheless controversial and subjected to much criticism by members of the Deaf community on the one hand and much scepticism on the other hand by the inexperienced medical and educational carers who cast doubt on the success of post CI rehabilitation for children whose parents were themselves deaf.

One particular case of the first CI implants for deaf children of deaf parents involved a family who, encouraged by the grandparents, requested surgical cochlear implantation for both their children, at the time aged 2 and 6 years. For social reasons, the surgeon also advised implantation for the parents. The rationale was to create a homogeneous situation for both children and parents, although it was assumed right from the start that CI for the parents would be of limited benefit [2].

Within a short time reports on several other cases in German speaking regions were documented, whereby deaf children or children with severe hearing impairment of parents with the same disabilities received cochlear implants [3, 4]. The age of the children documented by Wittasek [4] were 6 and 8 years at the time of implantation. The child described by Bastian [3] in Switzerland was 7 at the time of implantation.

These cases initiated a research project at the Ludwig Maximilian University of Munich in the year 2000, which is still in progress, having evolved into a vast number of subprojects or modules.

THE RESEARCH PROGRAMME

The research commenced with the preliminary studies in the year 2000 (Table **1**). Promoted by external funding, the first project began in 2001. The first publication on the subject appeared in 2004 [5]. To date (2019), 7 Modules are complete and another is in progress. Each module took between one and three years to complete.

Selected results from various modules will be presented, highlighting the investigation results governing the family situations (Module V). Modules II to V and VII were funded by external sources, enabling the hiring of a project worker. Module VI falls within the framework of the Bachelor studies, comprising case studies.

MOTIVE FOR INITIATING THE RESEARCH PROGRAMME

Deaf parents or parents with severe hearing impairment are more relaxed about the condition of their deaf child than hearing parents. They can use sign language to communicate with their child right from the start and are aware through experience that a Deaf person can still have a fulfilling and enriching life in spite of deafness.

At the start of the research programm, cochlear implantation was rejected by the Deaf community, who considered it a threat to their culture and sign language. As scientists, it was of interest to determine why deaf parents or parents with severe hearing loss, contrary to the sceptical majority of deaf and hearing impaired (DHH), nevertheless opted for implantation. Further, the development of these children was of

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Table 1: Research Programme "Deaf Parents and Children with CI"

Module	**I**	**II**	**III**	**IV**
subject	Deaf parents and CI children	Deaf parents and CI children (pilot study)	Information on CI for the Deaf	Vocabulary development (in spoken and sign languages) in CI-children of deaf parents
Research subject	Deaf parents and CI-children	Deaf parents	Deaf adults	CI-children of deaf parents
duration	since 2000	2001-2004	2006-2009	2010-2013
Module	**V**	**VI**	**VII**	**VIII**
subject	Family situation of deaf parents with CI-children	Young adult CI wearers	"CI for children" in other languages	Preschool and school inclusion of CI-children of deaf parents
Research subject	Families	adult CI-wearers from childhood with deaf parents	(translations: Russian, Turkish, Greek, English, Czech, Slovakian, Polish)	included CI-children of deaf parents
duration	2010-2013	since 2011	2011-2018	

particular interest: does the development correspond more to the development of deaf children or hearing children? And: how will these children behave later? What will hearing achieve for them? How will the hearing and language in CI children of parents with severe hearing impairment develop? Will cochlear implanted children of deaf parents continue to act like CODAs (Child Of Deaf Adults)?

Since we at the Chair of Education of the Deaf and Hearing Impaired do not carry out implantations, we adopt a neutral position. Regarding the implantation procedure.

RESULTS OF THE PILOT STUDY (MODULE II)

This study (2001 – 2004) primarily focussed on why deaf parents or parents with severe hearing loss opted to have their child fitted with a cochlear implant, at a time when the procedure was highly controversial. The results were based on guided interviews with the D/HH parents of cochlear implanted children.

The following reasons were divulged in the interviews:

- Better chances for the child´s future
- Decline in the number of `classical` deaf children at schools for the hearing impaired (since most hearing parents of D/HH children opted for cochlear implantation)
- Anticipated (integrative or inclusive) schooling close to home
- The value of hearing
- Facilitated language acquisition
- Fear of later reproach from their child for not opting for CI in childhood and thereby depriving him/her of the chance to hear

"My child should have it better than the parents" was not seldom [6, 7].

RESULTS OF OTHER MODULES

The results of the research modules presented in Table **1** indicate that the wishes and hopes of parents are for the most part fulfilled. The 5 year follow up and aftercare monitoring in the first decade of the 21 century highlights the fact that almost all children implanted in early childhood (first years of life) were attending inclusive schools, i.e. regular schools, with a command of both sign and spoken language.

In the meantime, deaf parents and parents with severe hearing impairment have a head start over hearing parents regarding information. Every hearing impaired parent will know what a cochlear implant is all about whereas a hearing parent first has to come to terms with the diagnosis of hearing disability in their child before turning their attention to the possibility of cochlear implantation. This means that for CI provision, children of parents with severe hearing disability are no longer second in line to those of hearing parents.

For the majority of hearing parents, CI is the "method of choice", enabling their child to enter their (hearing) world, resulting in a closer bond. Deaf parents or parents with severe hearing impairment, on the other hand, are governed by completely different criteria in their decision making; for these parents a CI means placing their child in a world they are not familiar with and are apprehensive about creating a distance or losing them [8].

EXAMINATION OF THE FAMILY SITUATION

To determine whether CI provision of a child affects the family situation or structure, families where at least one child of parents with severe hearing disability was fitted with a CI were closely examined [9].

The Family System Test (FAST)

The family situation was established using the FAST procedure employed in psychology as well as by means of interviews with both hearing impaired parents and their CI children.

The family system test consists of a board divided into 81 fields with wooden coordinators (1/1 to 9/9). The participant is requested to portray the family, using the wooden figures. This provides an insight into both the individual and family setup. Analysis of the cohesion – defined as the emotional bond between family members – is based on the distance between the family members- neighbouring fields representing maximal coherence (closeness) and greater distances the opposite.

Research Participants

13 families agreed to participate, including 13 mothers and 11 fathers (two of the fathers being away on business). The age of the parents was between 26 and 49 years. A total of 23 children were involved, 16 of whom were fitted with CIs.

Using the family system test, the parents were requested to perform 2 tasks:

Task 1 (to be performed by both parents together):

"Could you please place your family members on the board. As well as the core memberyou and your children-you can include others. I am interested in all members of the family who play a role in your daily lives; the ones who are important on a daily basis" (Busch 2013, 127).

Task 2 (to be done by each parent separately):

"Your child has a problem at school/nursery school, e.g. a spat with other children. You want to help. Who is involved in finding a solution?" [9, p. 217].

Results of the Family Tests

The main results are:

- At least one hearing contact person is closely involved with the core family
- Fewer close ties are primarily due to greater geographical distances.
- The post CI family situation remains the same as the pre CI.
- Emphasis is placed on independent, uninfluenced decision making for cochlear implantation. Interference by (hearing) family members in this decision is met with reactance.
- When problems arise, the families rarely consult other (hearing) family members or contact persons outside the core family. Instead they turn to a sign interpreter for help or consult the teacher or child carer in person.

Supplementary Interviews

Guided interviews were conducted with both hearing impaired parents and CI children as from 8 years. These interviews helped to provide a more comprehensive picture of the family situation. According to preference, the interviews were conducted either in sign or spoken language, with the help of an interpreter for German sign language.

The interviews with the parents focused on the subject of CI, family life, (communication, interaction) child development, family daily routine and hopes for the future.

From the analysis of the interviews, one could deduce that cochlear implantation had been performed between the first and third year of life. The parents mostly opt for a unilateral implantation first but there were 3 cases of bilateral implantation performed in one operation. At the time of the interviews all children were bilaterally implanted. In retrospect, the parents would not act differently-only perhaps shorten the time between the right and left ear implantation procedures.

According to the parents, there was a change in family routine following CI provision of the children but no undue stress. In most cases, the children had no problems adapting to the integrative situation. This meant that they were no longer dependent on external intervention or visits and could receive remedial support within the framework of school or kindergarten curricula. Additional appointments are only necessary after early implantation and do not pose a problem regarding family routine.

At the toddler stage, parents desire more provision in the sense of time and space, so that the child can simply enjoy being a child. Any change in the inner family situation was anticipated positively. The parents expressed their appreciation of the chance to optimise the development potential for their chid. Supportive assistance by persons outside the core family are welcomed rather than perceived as interference. Criticism is levelled more at the treatment and care at the clinics governing the implantation procedures. Particularly distressing for the parents is the pressure often exerted by doctors forcing them to opt for CI provision. They complain that the medical staff lack the necessary expertise and communication skills in issues relating to deafness and sign language.

Interviews with the Children

Interviews with the children were only possible in 4 cases because all others were not yet 8 years- the required starting age for the interviews. At 8 children have a basic understanding and avoidance of too much reflection during the interviews was more or less guaranteed. These interviews also began with the feedback on CI, followed by school, family life, speech development, leisure and hopes for the future. From the responses one could also deduce that they too found the situation hugely enriching in that they had access to both deaf and hearing worlds.

They also implied that they needed a certain amount of time to adapt to sign language at home after a long day at school using the spoken language. They proved however that they were able to use appropriate register in various situations. In cases where the CI child had hearing siblings, it was observed that the relationships were definitely improved following implantation. Inclusive schooling of these children proved successful. Especially appreciated was the possibility to attend a school close to home, rather than the long journeys to special schools for the hearing impaired. Inclusion in the hearing circle of friends was a positive experience; sport clubs were also instrumental for communication in the spoken language. If communication problems arose (e.g. during leisure time activities), the children could turn to their family for support and comfort. The circle of friends included other CI children of D/HH parents. These friends, however, often lived far away which means they had less contact with each other.

Summary of the FAST Results and Interviews

Taken together, the results of the FAST testing and interviews highlight the importance of *independent* decision making on the part of the parents. CI provision for their children is not something they rush into. The whole process of decision making proves to be emotionally stressful whereas the new CI situation does not have a negative influence on family life. Rather, the family dynamics is often improved and the situation is seen as a bonus for hearing grandparents or siblings. The (hearing impaired) parents strive to win over the acceptance of their decision by those in the Deaf community who are averse to the whole idea of CI.

DO CI CHILDREN BEHAVE LIKE CODAs?

The interviews with the children and adolescents suggest that the children behave like CODAs [10]. When the parents do not understand what is being said, the children speak slowly, repeat and reinforce with sign language. They are proud of this skill and according to [9] feel positive about taking on the role of interpreter for their D/HH members of the family. If there is a hearing sibling, then they are quite happy to let this member of the family do the interpreting.

OUTLOOK

Since 1993, the number of cochlear implantations in children of D/HH parents has risen continuously. A further increase is predicted. The decision for or against CI provision lies solely with the parents. An independent decision taken by the parents, without any external influence, is instrumental in the success factor.

A supplementary interview with (to date) nine adolescents (from 18 onwards), all of whom underwent cochlear implantation in childhood, (Module VI), revealed that no persons would want to have missed the opportunity and were happy that their parents had made the right decision for them, notwithstanding that these young persons received their CIs relatively late, at an average age of 9 years. In 6 cases, encouraged by other CI classmates, it was the personal wish of the child to be fitted with a C. One person was influenced by his teacher and in 2 cases-the brothers mentioned at the beginning of this article- it was the (hearing) grandparents who took the initiative whereby the older brother insisted he had also played a role in the decision making. The younger brother was at the time of the implantation just 2 years old (see above).

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