

Coming to a Decision About Cochlear Implantation: Parents Making Choices for their Deaf Children

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This study combined quantitative and qualitative methods in a sequential approach to investigate the experiences of parents making decisions about cochlear implants for their deaf children. Quantitative findings from a survey instrument completed by 247 parents were extended and elaborated by qualitative findings from in-depth interviews with 27 of the survey respondents. Although parents used a variety of information sources when considering an implant, cochlear implant centers and doctors comprised their major source of information. Most parents found the decision-making process difficult and stressful, but a proportion reported finding the decision easy, believing that there was no other option for their child, and were keen for implantation to proceed as soon as possible. Implications for professionals working with families are discussed.

The introduction of universal newborn hearing screening in many industrialized nations means that most parents must now make decisions about cochlear implantation or other courses of action very early in the lives of their deaf children. The age at which implantation is commonly performed has reduced to as young as 6 months (Dettman, Pinder, Briggs, Dowell, & Leigh, 2007; Holt & Svirsky, 2008; Valencia, Rimell, Friedman, Oblander, & Helmbrecht, 2008) and recently to even younger ages in some centers (Birman, 2009; Lesinski-Schiedat, Illg, Heermann, Bertram, & Lenarz, 2004), the result of more common early

detection of deafness and technological advances. In addition, the implantation of older children continues, usually after children lose hearing due to illness or a degenerative hearing loss.

The variability among children's outcomes with cochlear implants means that it is difficult to accurately predict outcomes for an individual child (Hawker et al., 2008; Inscoe, Odell, Archbold, & Nikolopoulos, 2009; Pisoni, Conway, Kronenberger, Horn, & Henning, 2008). Parents must make decisions without any guarantees about the level of benefit their children will receive from having cochlear implants. Despite this, many parents have high expectations of the outcomes of cochlear implantation for their children (Christiansen & Leigh, 2002; Weisel, Most, & Michael, 2007; Zaidman-Zait & Most, 2005).

With the current trend to implant children with severe as well as profound losses, the decision-making process may become more complex for an increasing number of parents. In recent years, candidacy criteria have expanded to include children with useful residual hearing when using hearing aids. Studies have found gains in auditory skills for implanted children who had previously gained benefit from hearing aids for many years (Dettman et al., 2004; Dolan-Ash, Hodges, Butts, & Balkany, 2000; Fitzpatrick, McCrae, & Schramm, 2006). Parents and educators are increasingly seeking implantation for children who could be operationally defined as having a moderately severe to severe hearing loss (Eisenberg, Kirk, Martinez, Ying, & Miyamoto, 2004). Cochlear implant professionals

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have reported parents' requests for implants for children with useful residual hearing based on their assumptions that cochlear implants represent a better technology than hearing aids; these professionals found the assessment process and decision to implant particularly difficult in cases of children with substantial residual hearing (Fitzpatrick et al., 2009).

In addition, the increasing incidence of bilateral pediatric cochlear implantation, to date usually performed sequentially during two different surgical procedures (Ching, Massie, Van Wanrooy, Rushbrooke, & Psarros, 2009; Galvin, Mok, & Dowell, 2007; Scherf et al., 2007), means that many families face the need to decide about implantation for a second time. With simultaneous bilateral implantation of young children and infants now becoming a recommended option (Papsin & Gordon, 2008; Ramsden, Papaioannou, Gordon, James, & Papsin, 2009), it seems likely that parents in the future will need to decide whether to have their newly diagnosed deaf children implanted in both ears.

Hearing parents with a recently diagnosed deaf child generally find themselves negotiating a world previously unknown to them. After the diagnosis of their child's deafness, parents may be presented with, or need to seek out, a great deal of information about deafness and the educational, communication, and technological options for deaf children. Given the need to assimilate so much information at a time when they are likely to be experiencing heightened emotions, making decisions about cochlear implantation is often difficult and stressful for parents (Burger et al., 2005; Most & Zaidman-Zait, 2003; Spahn, Burger, Loschmann, & Richter, 2004; Weisel et al., 2007; Zaidman-Zait & Most, 2005). Despite the large amount of information parents may encounter, most hearing parents are exposed largely to a medical model of deafness and may not be presented with information about the social, cultural, and linguistic life of the Deaf community. It has been argued that, without access to all relevant information about the possible futures available to their children, parents are unable to make fully informed choices (Berg, Ip, Hurst, & Herb, 2007; Christiansen & Leigh, 2002; Hyde & Power, 2006; Young et al., 2006). Furthermore, the issue of informed consent for parents of deaf children

is multifaceted and complex (see, e.g., Hyde & Power, 2000, 2006; Young et al., 2006), but at the very least involves the autonomy of the individual making the decision and necessitates an extension beyond medical issues and "the promotion of knowledge and understanding ... rather than the provision of information per se" (Young et al., 2006, p. 329).

Personal decision making often has a strong affective component. Individuals are influenced by their emotional reactions, as well as their cognitive analysis of information, about the alternatives from which they need to choose; they are further influenced by their external circumstances, such as influences from other people, events, and environmental components (Kemdal & Montgomery, 1997). Li, Bain, and Steinberg (2004) pointed out that, in making decisions for their deaf children, parents are often influenced by their beliefs, values, and attitudes as much as by the information available to them. In their study, parents of children deemed eligible for cochlear implants were asked about their experiences of deciding about implantation for their children. Li et al. found that parents' decisions were strongly influenced by their values and beliefs as well as practical considerations and professionals' recommendations. The parents who chose not to have their children implanted placed significantly lower priority on their children's ability to speak rather than sign and on mainstream rather than bilingual (spoken language and American Sign Language) success. In interviews, some parents explained that they had become aware of an alternative that may provide their children with opportunities for development and a good life, through meeting signing deaf children and adults who appeared happy with their lives and did not desire cochlear implants. Other reasons for deciding against cochlear implantation included concerns about financial costs and the availability of services at their local schools.

In a British study of parental perspectives of their children's cochlear implantation, the greatest area of agreement among the parent participants was that parents should have as much information as possible when considering implantation for their child (Archbold, Sach, O'Neill, Lutman, & Gregory, 2006). The study also found that those parents who placed the most importance on their children learning to talk and

participating fully in the hearing world had less difficulty making the decision than parents who placed less importance on these outcomes and who worried about whether their children would be part of the deaf or hearing world. It seems likely that the latter group of parents had knowledge of an alternative positive model of deaf life that made the decision about implantation less straightforward. These quantitative findings appear to reflect certain of the findings of the qualitative study by Li et al. (2004).

The decision-making process can be particularly difficult for parents whose children are borderline in their eligibility for implantation because of their relatively good speech development. In their study measuring stress in parents of deaf children, Burger et al. (2005) found a positive correlation between children's speech and comprehension capacity and parental stress at the time of the cochlear implant preexamination, suggesting that for these parents, the decision for implantation was not as clear-cut as for those parents whose children were showing little speech development. If it is clear that the child can gain no benefit from hearing aids and is unlikely to develop spoken language, the decision for cochlear implantation may seem the obvious choice to parents who dearly wish their child to develop speech and be as "hearing" as possible. Parents whose children show signs of speech development and are gaining some benefit from hearing aids are likely to find the decision more complex and stressful.

A large study conducted by the Gallaudet Research Institute (GRI) and reported by Christiansen and Leigh (2002) obtained quantitative data from 439 parents' responses to a questionnaire. Christiansen and Leigh also reported their findings from interviews with parents of 63 children with cochlear implants. Some of the findings from these studies are in regard to the parents' decision-making process. The authors reported that parents were largely motivated by a desire for their children to develop spoken language, that their major sources of information were medical and audiological professionals (with other families with implanted children also an important information source), and that they found the process of making the decision to implant difficult and stressful. Conversely, a British study of more than 200 parents'

perceptions of their children's cochlear implantation reported that the majority of parents found the decision straightforward and believed that their children had nothing to lose and everything to gain from a cochlear implant, with only a surprisingly few (9%) of the parents finding the decision difficult (Sach & Whynes, 2005).

In a small Australian study of 13 children and their parents, Spencer (2004) reported an association between higher spoken language achievement postimplantation and parents' reports of lengthy in-depth decision-making processes about implantation for their children. The qualitative findings from interviews with parents in the study by Spencer revealed an apparent association between lengthy decision making and later parental involvement with the child's habilitation and learning. The author suggested that parents who invest large amounts of time and effort in searching for information and making the decision about obtaining a cochlear implant are those parents who are likely to continue a high level of involvement in their children's postimplant rehabilitation. This high level of parental involvement has been found to contribute to the benefits gained by children from their cochlear implants (Geers, Brenner, & Davidson, 2003). Thus, it appears that the time parents invest in the decision-making process can be important to successful outcomes for children receiving cochlear implants. However, the emphasis currently placed on cochlear implantation occurring as early as possible may lead parents to feel that they have only a brief period in which to make their decision.

Professionals working with parents considering cochlear implants for their children face a difficult task ensuring that parents have a comprehensive understanding of the possible advantages and disadvantages of cochlear implants and can give fully informed consent if they decide to proceed with implantation for their children. Therefore, it is important to gain as full an understanding as possible of parents' perspectives and experiences related to making decisions about cochlear implantation for their deaf children. The current study is the first to use both quantitative and qualitative methods with a relatively large sample of parents to explore parental decision making in the Australian context. The findings reported here are

part of a large study investigating expectations and experiences of pediatric cochlear implantation in eastern Australia. This part of the study addressed the following questions:

- To what extent are parents' decisions on implantation based on informed choice and comprehensive advice?
- In addition to medical and audiological sources, what other organizations, people, and resources are involved in informing the decision-making process?
- What other elements of the decision-making process are there for parents?

Method

A mixed-method approach to data collection and analysis was used to enable the research questions to be addressed more fully and accurately than the use of a single approach would permit. The study combined quantitative and qualitative methods in a sequential approach in which one method is used to further explore and expand the findings of another (Creswell, 2003; Creswell & Plano Clark, 2007). Parental decision-making processes were measured by a quantitative survey instrument, followed by in-depth interviews with a subsample of parents in order to explain, extend, and elaborate on the survey data.

The Survey

We constructed a survey to gather background information and parents' perceptions of the information-gathering and decision-making processes they experienced prior to their children's implantation. The survey incorporated items and subscales used in the GRI study's survey (Christiansen & Leigh, 2002), enabling comparisons to be made with the findings of that major U.S. study.

The first section of the questionnaire sought background information and contained 30 questions covering family demographics, including household structure, postcode, and language used in the home, as well as information related to the child's hearing, including age of hearing loss occurrence and identification, age of cochlear implantation, presence of bilateral implantation, and the child's communication mode and educational setting.

The second section of the parent survey contained eight questions about parents' decision-making processes. Questions asked about the sources of information parents used while making the decision to have their child implanted; the length of time parents considered cochlear implantation before making their decision; their awareness of possible negative outcomes of implantation; and their satisfaction with the information, help, and support received from a range of professionals while making the decision. Parents were asked to rate their level of satisfaction on a 5-point scale, with 1 being *very dissatisfied* and 5 being *very satisfied*.

At the end of the survey, parents were invited to write an open-ended response to the question "if there is one central message that you would like to convey to us about the experiences you have had with your deaf child and his or her cochlear implantation, what would that be?"

The survey instrument was pilot-tested with a number of parents of children with cochlear implants and was reviewed by teachers of the deaf and other major stakeholders during ethics approval protocols.

Survey Participants

Parents of children with cochlear implants in three eastern states of Australia participated in the study. The number of surveys received from parents was 250. Three surveys were excluded from analysis due to missing data, thus the total number analyzed was 247.

Mothers comprised the large majority (88.3%) of respondents, whereas 10.1% were fathers and 1.6% were "others" (two of whom were the child's grandmother, one the child's foster parent, and one the child's stepfather). Most of the parents were hearing (96.7%), 2.8% were hard of hearing, and one parent (0.4%) was deaf. Although 9.7% of parents indicated that English was not their first language, only 4.0% reported that English was not the language they used most each day.

Of the 247 surveys analyzed, 49.4% reported on a male child. The mean age of the children was 9.42 years, with a range of 0.67–25.0 years. Most of the children (92.7%) had a profound hearing loss pre-implantation and 6.9% had a severe loss. For the

majority of the children (68.4%), hearing loss had occurred at or before birth. Another 19.0% had lost their hearing between the ages 0.25 and 6 years ($M = 1.73$ years, $SD = 1.26$). A further 12.6% of parents reported that they did not know when their child's hearing loss occurred. Fifty-five parents (22.3%) indicated that their children's hearing loss had been identified soon after birth. Of the remaining 191 respondents (77.3%), their children's deafness was identified between the ages of 0.08 and 8.00 years ($M = 1.43$ years, $SD = 1.27$). One quarter of the parents (25.3%) reported that their children had additional difficulties or disabilities.

Families' postcodes were used to ascertain socioeconomic status (SES). Each postcode was assigned to 1 of the 10 decile positions according to the Index of Relative Socioeconomic Advantage and Disadvantage, which ranks areas on a continuum of social and economic advantage to disadvantage (Australian Bureau of Statistics, 2008). Most parents lived in areas ranked in the highest deciles: 75.1% lived in areas ranked in the top five deciles.

Interviews

We aimed to conduct follow-up interviews with approximately 10% of parents who completed surveys. Almost 80% of the survey respondents agreed to be contacted for an interview. Thus, we needed to make a selection of parents to contact and invite to be interviewed. In keeping with the aims and qualitative approach of this phase of the study, sampling was purposeful. Purposeful sampling is designed to select information-rich cases likely to best illuminate the questions being investigated and yield insights and in-depth understanding, rather than empirical generalizations (Patton, 2002). We sought to include a range of parents in terms of location (metropolitan, regional, and rural), current age of child, age of child at implantation, and the type of educational setting the child attended, so that there would be structured representation across the range of situations of families.

We interviewed 27 parents. Although we attempted to arrange interviews with several fathers, only one interview with a father eventuated; the other interviewees were all mothers. One interviewee was deaf; the others were hearing. Five of these parents had two

children with cochlear implants, and so, the number of children discussed in the interviews was 32 (16 girls and 16 boys). Two of the children attended early intervention centers, 19 were in primary school, 10 were in high school, and 1 was in the workforce. The children's age ranged from 1 year 8 months to 25 years. Five of the children had been implanted before the age of 1 year, 18 between the ages of 1 and 3 years, 5 between the ages of 3 and 12 years, and 4 between the ages of 12 and 17 years. Three of the children no longer used their cochlear implant.

Interviews were conducted over the telephone and most lasted around 1 h. Most of the interviews were conducted by the second author, who has a background and training in counseling, and a further six interviews were conducted by a research assistant experienced in interviewing and given training specific to this project's interviews. The interviews were semi-structured, incorporating an initial list of questions serving as a guideline only, allowing unanticipated information to emerge (McCracken, 1988). Questions relating to decision making were "what was it like for you to make the decision for your child to have a cochlear implant?" and "how easy or difficult was it for you to find the information that you needed?" with further questions added to probe or clarify particular answers as seemed necessary during the course of each interview.

All interviews were audiotaped, with the parents' prior consent, and transcribed in full for analysis. The interview data were analyzed according to the constant comparative method (Glaser & Strauss, 1967; Lincoln & Guba, 1985). Analysis involved the coding of data in order to generate categories, with the constant comparison of units of data in order to discover similarities, differences, patterns, and consistencies of meaning that identified themes. As a validity check, a selection of interview transcripts was reviewed and coded by an informed academic external to the research team (Creswell & Plano Clark, 2007). The interview analysis was facilitated by the use of the NVivo 8 computer program.

Procedure

Approval for the project was gained from the Human Research Ethics Committees of the universities, state

government departments of education, early intervention centers, and hospitals with cochlear implant clinics involved in the study. Cochlear implant clinics, early intervention centers, and the education departments facilitated distribution of copies of the survey to the families of implanted children on their databases. Parents were informed of the option of completing and submitting the questionnaire online. All survey and interview data were collected in 2008.

Quantitative Results

Desire for Oral Communication

In their responses to the question “what was the main reason for deciding on a cochlear implant for your child,” most parents indicated that their predominant reason was “development and use of child’s speech and hearing,” with 73.0% choosing this response. Communication within the family was chosen by 7.0%, child’s safety/environmental awareness by 3.7%, convenience in daily activities by 2.0%, and concern for child’s self-image by 0.8%. Three parents (1.2%) chose the response “child’s expressed desire to have cochlear implant.” A further 12.3% chose the response “other” and specified reasons such as “broader educational options,” “thought it was the best option for my child’s future and development,” and “to assist her to participate in a broader community throughout life.”

Another question asked parents “when you were considering the cochlear implant, how did you most want your child to communicate in his or her life?” Most respondents (87.0%) indicated that they wanted their child to use speech and hearing, and 12.1% wanted their child to use a combination of speech and sign. No parents indicated that they had wanted their child to use Australian Sign Language (Auslan) only or Signed English only. The two parents (0.8%) choosing “other” as their response specified “however it was best for him” and “just normal like other child.”

Length of Time Making the Decision

Parents indicated how long they had considered the cochlear implant as an option before making the decision to have their child implanted. The majority (60.9%) indicated that they had considered the option

for less than 3 months before making their decision. A further 27.5% had taken between 3 and 6 months, 7.7% had taken between 7 and 11 months to decide on an implant, and 3.9% reported taking 1 or more years, with the longest time taken to make the decision reported as 13 years.

Sources of Information

Parents were asked who had been the first person to suggest a cochlear implant for their child. The most frequently reported category was audiologists (40.9%), followed by Ear, Nose, and Throat specialists (ENTs; 23.1%). Another 8.3% of respondents indicated that a pediatrician had first suggested the implant, and 1.7% indicated their general practitioner. Thus, medical practitioners had suggested an implant for 33.1% of respondents. Teachers were indicated by 10.7% of parents, and family members and friends were indicated by 4.1% and 1.7% of parents, respectively. Several parents chose the “other” option (9.6%), and nearly all these parents said that they themselves had first suggested an implant, writing comments such as “myself, I actively sought it.” Some also wrote that they had seen media reports about cochlear implants, for instance “I saw the TV commercial they had years earlier and wanted the same for my child.”

Respondents were asked to indicate which information sources they used in making their decision from a list 13 possible sources. They were asked to check all that applied and also to mark with an asterisk the one source that was most important to their decision. Most parents indicated that they had used multiple sources of information. The most frequently used sources were audiologists and cochlear implant program staff, both of which received responses from 70% of parents. ENTs were indicated by 54.7% of parents, pediatricians by 21.1%, and general practitioners by 16.2%. Another major source of information for parents was other families with implanted children: 55.5% of parents had obtained information from parents of children with cochlear implants and 36.0% from children with cochlear implants. Early intervention centers were an information source for 38.1%, and teachers for 29.1%, of respondents. Printed literature was a source of information for

42.9% of parents, and the Internet for 27.5%. Relatively few parents had used Deaf organizations (17.8%) or deaf adults with a cochlear implant (10.9%) as information sources. Parents who checked “other” (8.1%) most commonly reported their own research, family members, and media reports as sources of information.

Not all parents responded to the request to mark with an asterisk the one source of information that they considered to be most important to their decision. As shown in Table 1, of the 154 parents (62.3%) who did this, the most commonly chosen information source was cochlear implant programs, followed by parents of children with cochlear implants and children with cochlear implants. Deaf organizations and adults with cochlear implants were nominated as the most important information source by one parent each.

A further question asked parents if they had received information from people with personal experience of deafness such as deaf adults and parents of children who either successfully used or had discontinued using cochlear implants. Respondents were asked to check all items that applied. The largest proportion of parents (63.2%) reported receiving information from parents whose children successfully used cochlear implants. Some parents had received information from deaf adults: 18.9% from deaf adults opposed to childhood cochlear implantation, 15.3% from deaf adults supportive of childhood cochlear

implantation, and 12.0% from deaf adults who neither strongly opposed nor strongly favored childhood cochlear implantation. A small proportion (7.2%) had obtained information from adults, or parents of children, who had discontinued using their cochlear implants. Some parents (23.1%) indicated that they had obtained information from none of these people.

Satisfaction With Professionals

Parents indicated a generally high level of satisfaction with the information, help, and support they received from professionals and service providers when they were making the decision about a cochlear implant for their children, with 90.5% (the sum of the *satisfied* and *very satisfied* responses) satisfied with the implant clinic and 85.2% satisfied with audiologists. Furthermore, 79.6% had been satisfied with early intervention or school teachers and 69.8% with doctors.

Awareness of Potential Negative Outcomes

A question asked respondents the extent to which they had been made aware of potential negative outcomes of cochlear implantation for their children in five areas. A large majority of the parents indicated that they had been made aware of possible medical/health-related negative outcomes (87.9%) and of possible auditory/audiological negative outcomes (80.2%). Fewer had been made aware of potential negative language-related (68.8%), social (51.4%), and psychological (45.7%) outcomes.

Stress Involved in Making the Decision

A question on the survey asked parents about the strength of their agreement, on a 5-point scale, with the statement “the decision to give my child a cochlear implant was extremely stressful for me.” Almost half of the parents indicated that the decision was extremely stressful (27.9% agreed and 20.1% strongly agreed) and 38.9% disagreed that it was extremely stressful (29.1% disagreed and 9.8% strongly disagreed).

Qualitative Results

The findings from the interview data provided illustration and elaboration of the quantitative findings, the

Table 1 Information source most important to parents ($N = 154$)

Information source	Frequency	%
Implant program	50	32.5
Parents of children with implants	22	14.3
Children with cochlear implants	15	9.7
Early intervention center	20	13.0
Ear, Nose, and Throat specialists	15	9.7
Audiologist	11	7.1
Teachers	7	4.5
Pediatrician	4	2.6
Internet	2	1.3
Printed literature	1	0.6
Adults with cochlear implants	1	0.6
Deaf organizations	1	0.6
Other	5	3.2

narratives told by parents adding detail and depth about their decision-making experiences.

Sources of Information

It was apparent from the qualitative findings that many parents had invested a great deal of time and effort in seeking out information from various sources. As these two comments show, parents often used their initiative to actively research all that they needed to make this decision on behalf of their child:

I went everywhere and asked everyone as much as I possibly could. I asked parents, I got on the Internet, searched through all the stuff, actually had a bit of a sample of what it might sound like to them. Tried to research as much as I possibly could and at times, there were doubts about whether to go ahead with it. It's not an easy decision to make.

Basically, I'd say I was the main driving force and I was able to source a range of information and decide which ones to accept and which ones not to accept. We got a lot of different viewpoints At conferences I read lots of papers, I looked at articles on the Internet—by that stage I was actually studying to be a teacher of the deaf so I had lots of access to a lot of good quality information.

However, even for parents so obviously keen to make an informed decision based on the information they researched, it could be an emotive moment such as witnessing their child's difficulty or another child's experience that finally decided them on the implant. One mother explained that, after her extensive researches, "the thing that really tipped me over" was "a really poignant moment for me" when, having taken her son to play at a kindergarten friend's house, she saw him unable to hear and be understood by the friend in a simple exchange and realized that, although he had good language proficiency,

If he can't hear well enough what a friend is saying and he can't speak clearly enough for them to understand him, it's going to be a shitty life So I thought, well, we want to go for this cochlear implant.

Six of the 32 children discussed in the interviews had been implanted between 10 and 14 years before

the interviews were conducted. Some of the parents of these children said that it had been difficult to find adequate information to help them in their decision making, whereas parents whose decision was more recent (particularly those of the 17 children implanted no more than 6 years before) mentioned the availability of more sources, including the Internet. Information sources most frequently mentioned by parents were the cochlear implant center, parents of other children who had implants, and teachers of the deaf at their child's school or early intervention center. Although cochlear implant centers were a predominant source of information for the parents interviewed, some of the parents perceived this information as being one-sided or limited in some way. Several parents said that they had been given a lot of information about cochlear implants from medical and audiological perspectives but had wanted to know about how an implant might affect other aspects of their children's lives. This parent, whose child had been implanted 5 years earlier, explained:

I would have liked more information on the emotional point of view, and a family point of view, just about, like, the deaf community. I guess the only information we were offered was from the medical point of view from the cochlear implant clinic.

Some parents said that they would not have been receptive to hearing about potential negative outcomes. One said "you tend to block out anything that you don't want to know about," and another explained:

I felt that I wasn't pressured into a cochlear implant but I certainly didn't feel I was given negatives either, but I probably wouldn't even want to listen, it was like, I've made up my mind quite clearly.

Frequently, parents talked about the help they gained from meeting other families with children with cochlear implants, talking to the parents about their experiences, and seeing the results that other children had achieved, as this mother described:

I'd spoken to other people, and I'd seen other children with the cochlear implant so I made my decision sort of based on, if it worked, it was going to help her.

Very often, these parents met the other families through attending an early intervention center. These centers were clearly a major source of information and support for families, both from the professional staff and from interactions with other parents and deaf children. However, some families who did not have access to an early intervention center spoke about the efforts they made to find and contact other families and arrange to visit them. Most of these parents had met only one other family with a child with a cochlear implant before making their decision.

Contact With the Deaf Community or Organizations for Deaf People

Reflecting the small numbers of survey respondents who had obtained information from the Deaf community or Deaf organizations, few of the parents interviewed said they had met any deaf adults. For parents who had wanted to explore all options for their children and had sought out the Deaf community, the decision was not necessarily easier once they had done so. Five of the parents interviewed said they had sought contact with deaf people, and all reported being aware of negative attitudes among the Deaf community toward the option of cochlear implantation for children.

I was really quite tortured by it [making the decision] because we had a fair bit of contact with the Deaf community and had spoken to people who were against cochlear implants. And ... because of my contact with the Deaf community and the reading I had done, I really didn't know whether when she was an adult, she was going to say "I didn't want that." I felt like I had to make that fairly important decision for her ... it was very hard to make.

All too often parents, in their struggle to find information and to make the best decision for their child, felt caught between two opposing sides—in one parent's words, "those that are for the implant and those that are against." This mother described the difficulty of deciding under such conditions:

We had hearing people telling us we were neglecting our child if we didn't go with the implant, and

on the other side we had the Deaf community saying that it was a form of abuse if we implanted our child. I had many tears and many a sleepless night, changed my mind that many times, my husband changed his mind and for quite a few months it was a really stressful time, and there was no way around that. In hindsight I don't think we could have done it differently, but yes it was stressful, fearful.

The only deaf parent in our study described a mixed, but largely supportive, response from deaf friends toward the decision she and her husband made to implant their child:

Most of our friends have said, good on you, it's your decision, nothing to do with us, good on you. But a few of our friends said, why are you doing that, and were a little bit critical of us. A few said, good on you for being brave, wonderful, good on you for giving it a go. So that's the variety of response.

"No Other Option"

Not all the parents interviewed had found it difficult to make the decision for an implant. In some cases, parents had been clear in their desire to try an implant for their child, and these parents frequently talked about there being "no other option." If their child was unable or unlikely to gain useful audition from hearing aids, these parents felt that an implant was the only avenue for their children to develop hearing and speech and thus to communicate in the same way as their families. For these parents, the decision was easier than for parents whose children had the potential to benefit from hearing aids, as this mother explained:

I thought with our first child, well with our second child as well, because they were profound, they had a profound loss, there was really no other option, you know. You are going to try everything you can to try and get to the same method of communication that you as parents have, so for us it wasn't a case of, it's not like our kids had borderline hearing and we were all making a big decision. It was our last straw at getting

communication like my husband and I. If that didn't work, well we had signing. So that's how we came to that decision.

Some of the comments that parents wrote on the survey expressed similar views:

Without the cochlear implant my child would be using sign language as she is profoundly deaf. Our decision on a cochlear implant was not a difficult one because we wanted our child to speak and knew this was the only option for her.

Some parents said that they pushed to have the implant as quickly as possible, sometimes, in the view of professionals, prematurely. This mother, whose child received an implant at four and a half months, described her desire to have the implant as soon as possible:

Because he didn't react I just went, right, I want to investigate implants ... I brought it up with them [the audiologists] ... They were suggesting he'd need a bit longer before they referred us to [the implant center]. I said we'd already been and we are waiting for a date, a date for next week. They thought we were rushing it too much.

In contrast, this mother felt that there had been pressure on her to implant her child, writing on the survey about her feeling of not having made a decision at all:

My daughter had meningitis and was then implanted almost immediately. I did not decide to have her implanted. I was just told that it was going to be done. Because it was so rushed, I felt that we weren't given information on the procedure, future therapy and rehabilitation or expected outcomes. I feel that we were left in the dark regarding any options or choices.

In an interview, she explained further:

I didn't realize there was an option, it was like, she had meningitis, she's from a hearing family, she gets implanted. And I said OK. I didn't even know what an implant was ... They rang up and made an appointment or whatever or gave me the number, go there and she'll get an implant. OK, whatever, so that was it, so I went there, I had an

appointment with the professor and straightaway it was "this is what we do, this is what we'll do, here you go, here's the hospital date." OK!

This mother was made aware of the need for speed because of the risk of ossification of the cochlea in meningitis cases, and although she is happy with the outcomes of her daughter's implantation, she expressed amazement at how little she knew at the time of implantation and how the decision seemed to be in other people's hands.

The Deaf Family's Experience

Although most parents in the study clearly valued speech and hearing and had a strong desire for their children to develop oral communication and participate fully in the hearing world, the only deaf parent in the study expressed different values and explained how these values had affected her decision making about a cochlear implant for her young daughter. This mother and her husband, also deaf, were not initially in agreement; at first she did not want the implant:

I was worried about [our child] losing her Deaf identity; that was my biggest worry ... I didn't want to change any of the Deaf values that I hold strongly and dearly in my family.

However, her husband was in favor of his daughter having an implant:

He felt he wanted to open up the world for her more, he wanted to give her those opportunities and the possibility of integrating in the hearing world using spoken language and listening, and also to be able to use Auslan to mix in the Deaf community and with family.

The mother explained how her husband's point of view became more tenable to her as she considered potential opportunities for and limitations to her daughter's future:

She could, you know, fit in with the hearing world, she could develop the confidence on her own, she could do all those things without an implant, but what if she turned around at say 11 or 12 and said "all my deaf peers have got cochlear implants and have been implanted from a young age and they

can speak and hear well because of the implant and I can't, I haven't been given that opportunity, so why did you limit me?"

This comment, and similar ones made by hearing parents, indicates that many parents were acutely aware of the responsibility of making a decision for their child that would profoundly affect that child's future life.

Children's Involvement in Making the Decision

Where possible, parents involved their deaf children in the decision. Six of the parents interviewed had children who received their cochlear implant between 7 and 16 years old, an age when their opinions and wishes were taken into consideration. They had all used hearing aids; in some cases, their hearing had degenerated, and in others, their hearing level was such that implantation had not been considered earlier, but a relaxation of eligibility criteria and advances in cochlear implant technology meant that an implant had become an option. For the children aged from about 10 years, the parents described the decision as being largely in their children's hands. For instance, the parent of a 16-year-old girl, an Auslan user with both deaf and hearing friends who wanted to be able to hear her hearing friends better, explained:

It was a joint decision with [our daughter], she initiated the process At school they were talking about cochlear implants, and she came home one day and said she'd like to find out a bit more about it. So I said, we can contact the clinic and have an assessment made, if you'd like that, or just go down for some conversation, which we did, and over the course of 2007 we went down for information, for testing, for a number of tests, and then [our daughter] came to the decision that she'd like to have the cochlear [implant]. And that was also with my husband and myself, we felt we were more informed.

It was clear from the qualitative data that these decisions were extremely difficult for most parents and, in many cases, for the young people also. Parents worried about the timing when their children were approaching particularly important periods in their

schooling, such as moving from primary to high school or into their final years of high school. They were concerned that, although there were potential gains from having an implant, there were possible losses as well. One young person worried about the possibility of not being able to play contact sport; several others were concerned about the look or the aesthetics of the cochlear implant. Meeting another child with an implant was often the deciding factor for these young people. This parent of a boy who had been able to use hearing aids throughout his childhood years and whose hearing diminished when he was twelve explained:

He was very anti it [the implant], although he was depressed and he couldn't hear anything and he was retreating and isolated, he was worried about what he'd look like, he used the word "robot" quite a lot. And we weren't prepared to push him into it. I think he was only thirteen, so basically we left the decision up to him. And a family came up to visit us . . . and their daughter, she was eleven at the time I think, and she had an implant. He just watched in amazement, that she could talk and follow the conversation and things like that . . . and he said to us that night, "I think I'll have it." We were happy, because he was very auditory and very verbal and it seemed like a big ask to go into a different form of communication at that age.

For one family, the decision was particularly difficult because their 16-year-old son still had usable residual hearing and gained benefit from his hearing aids for his severe hearing loss. Widening candidacy criteria made him eligible for an implant, which he was keen to have. His parents worried that an implant would jeopardize his low frequency hearing; his mother described the situation as "a quandary. What do we do? Do we risk losing the low tones and the way he uses the hearing aids to go to a cochlear [implant]?" The parents tried to ensure that his expectations were realistic:

Well I think being a teenage boy that they, especially at that age, they are looking for solutions, and they are looking for a chance to be normal. And so even though you arm them with all of the facts, and you are really open with them, and tell

them all the difficulties that they could experience, and in fact in some ways I think we really highlighted the difficulties he was going to have, he saw cochlear [implants] through rose-colored glasses.

Discussion

The quantitative findings showed that cochlear implant programs played a predominant role in the information parents used to make the decision about having their children implanted and that doctors, particularly ENTs, were also important to parents' decision making. It is not surprising, therefore, that parents were made aware of potential negative medical and health-related outcomes to a far greater extent than they were made aware of other potential negative outcomes that could be involved in cochlear implantation, in the areas of social and psychological outcomes particularly. This was reflected in the qualitative findings. In the interviews, parents spoke of the cochlear implant center being their major source of information; however, some parents considered the information from this source to be one-sided and circumscribed. It did not satisfy their desire to know about the implications of cochlear implantation and alternative options for their children's social and emotional well-being, education, and family relationships. Audiologists were also an important source of information; however, the data do not indicate to what extent these audiologists were associated with cochlear implant programs or worked with other audiological services used by deaf infants and children.

The proportion of parents using the Internet as an information source was not especially high, at 27.5%. However, some parents had been seeking information for making decisions some years ago, when Internet use was not so widespread. It is likely that the Internet will continue to become an increasing source of parents' information about cochlear implants as parents of young children are used to accessing information in this way. However, the available information may not be comprehensive. Researchers investigating the Web-based information accessible to parents of deaf children emphasized that little information beyond early intervention possibilities was available (Porter & Edirippulige, 2007; Zaidman-Zait &

Jamieson, 2004). In particular, Zaidman-Zait and Jamieson found little or no coverage of education and communication approaches on relevant Web sites.

Both the quantitative and the qualitative findings indicated that some parents' main knowledge about cochlear implants at the time of their children's diagnosis of deafness had come from media reports, usually on television. It is of concern if parents are prompted to seek implants for their children by media reports, which are often superficial in their coverage of the issues involved and tend to portray cochlear implants as a miracle restoring hearing to deaf children (Komesaroff, 2007; Power, 2005). The growing prevalence of implantation for children and the public perception of cochlear implants as a "cure" for deafness mean that parents may be faced with family, friends, and acquaintances, suggesting that parents must be neglectful if they do not choose implants, and as early as possible. Parent-to-parent mentoring programs such as those developed by parent associations in Australia can be valuable in providing more informed and balanced, yet personalized, perspectives to parents.

Parents certainly valued information from other parents whose children had cochlear implants and wanted to know about the experiences and outcomes of these children. Slightly over half of the parents surveyed had obtained information from parents of children with implants and more than one third from children with implants themselves, and this was reflected in the qualitative findings. Similarly, the GRI study reported 57% of parents having used children with cochlear implants as an information source (Christiansen & Leigh, 2002), and other studies have reported the high value parents placed on the information, personal experiences, and emotional support they gained from contact with families whose children had cochlear implants (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008; Most & Zaidman-Zait, 2003; Zaidman-Zait, 2007). The importance of learning from other families can be seen in the popularity of online support groups established by parents in recent years, such as Hands and Voices in the United States (<http://www.handsandvoices.org>) and Aussie Deaf Kids in Australia (<http://www.aussiedeafkids.org.au>), which are active

forums for parents to share views, experiences, and information.

Previous research has shown that parents want as much information as possible when they are making their decision and throughout the different stages of the cochlear implantation process (Archbold et al., 2006; Christiansen & Leigh, 2002; Most & Zaidman-Zait, 2003). In the current study, the majority of parents interviewed emphasized the importance of gaining sufficient information, and many devoted a great deal of time and effort to finding information, meeting other families with children who had cochlear implants and, in some cases, seeking out Deaf community members. However, a few parents expressed a different view. These parents tended to decide quickly, usually because they felt that an implant was the only way their child would gain communication through speech and hearing, and thus, the only option for their child and for them as a family. This finding may explain the almost 40% of survey respondents who reported that they did not find coming to a decision stressful. These findings are consistent with previous studies reporting that making a decision was easier for parents who believed their children would not develop speech without an implant (Burger et al., 2005) and who placed the most importance on their children speaking rather than signing (Archbold et al., 2006; Li et al., 2004). However, our findings did not reflect the very low proportion of parents who found the decision problematic in the study by Sach and Whynes (2005) in England.

The interviewees who decided relatively quickly had been keen for their children to have the implant as soon as possible. The quantitative findings indicated that, in considering the option of cochlear implantation for their children, most parents had taken a relatively short amount of time before deciding: 60.9% had taken less than 3 months and a further 27.5% had taken between 3 and 6 months. These findings indicate a shorter decision-making time than those of families in the GRI study, which reported that approximately 25% of parents took less than 3 months and another 25% took between 3 and 6 months (Christiansen & Leigh, 2002). In light of Spencer's (2004) finding of higher language achievement in children associated with parents' lengthy decision making, it may be that

parents (and those advising them) need to be aware that they can take the necessary time to make their decision. In any event, it is important that such a major decision should not be rushed (Duncan, 2009). The increasingly young age at which infants are being implanted in many centers means that parents who feel a strong sense of urgency about gaining the envisaged benefits of implantation for their children may seek to have their infants implanted within short periods of time after their child's deafness is identified. This may preclude allowing time for hearing aids to be fully trialed, for the infant to be old enough for behavioral audiology tests to be conducted, or for all possible options to be fully considered.

It appears from both the quantitative and the qualitative findings that most parents had little contact with the Deaf community or organizations of or for deaf people during the time they were making the decision about implantation for their children. The small number of parents interviewed who had made contact with members of the Deaf community said that they found this contact stressful because of the strength of opinion they encountered against implantation, and at the same time felt pressure from hearing people that they would be failing their children if they did not go ahead with the implant. It is difficult for parents, particularly at a time of heightened emotion and worry about their child's future, to make such a major decision in the face of strongly polarized opinions.

Models of decision making generally consider that decisions consist of four basic elements: initial options, alternatives or choices; values, encompassing worth, utility, and attractiveness; uncertainties; and possible outcomes (Pierce & Hicks, 2001). For many of the parents in this study, the decision about whether or not to implant their deaf children seemed scarcely to contain more than one initial option or alternative. These parents used terms such as "no other option" because they believed that cochlear implants were the only means to their children being able to communicate in a hearing world using hearing and speech. Thus, they gave little consideration to possible alternatives or were they universally encouraged to consider alternatives. It was clear from both the quantitative and the qualitative findings that parents' values

and attitudes were a driving force in their decisions; parents overwhelmingly valued the development of hearing and speech and chose cochlear implantation for their children as a means to develop communication through hearing and speaking. It was apparent from the qualitative findings that parents placed great importance on their children sharing their own social, cultural, and linguistic traditions. Almost all the parents interviewed spoke of wanting their children to be able to communicate with family and friends, take their place in the hearing world, and have broad opportunities in life, and saw the cochlear implant as providing hearing and subsequent spoken language development and, therefore, a means to those ends. This option held the highest attractiveness for parents. In the context of medical decision making among patients, Pierce and Hicks (p. 270) pointed out that “the attractiveness of one option may prevent the patient from accurately appraising other relevant information.” It seems to be the case that the parents who made their decision quickly because they saw cochlear implants as “the only option” for their children did not fully appraise alternative approaches apart from information related to implantation.

An alternative that did not appear to be part of the information-giving process for most of the parents was the option of bilingual outcomes, with both Auslan and English being learned and used. The great majority of parents seemed to see these two languages as separate options and not in any complementary manner. There was an embedded assumption that implantation would lead to spoken language outcomes only, with signing seen as a possible backup. However, the use of a sign language and the objectives of cochlear implantation may not be incompatible and can both be realizable (Christiansen & Leigh, 2002; Moores, 2008/2009; Watson, Hardie, Archbold, & Wheeler, 2008), and, indeed, some of the families later came to embrace the use of signed communication in their implanted children’s lives, as we report elsewhere (in preparation). In this context, it may be important for information about sign language and the Deaf community to be more accessible to families both before and after their children’s implantation, and for parents to be made aware that choice of a communication mode need not be an either/or option. From our find-

ings, organizations with expertise in and knowledge of bilingualism for deaf people do not seem to have been widely accessed by parents. Clearly, organizations that promote the full range of communication and educational options (including bilingual education) and offer nonbiased information and nonjudgmental support to families of deaf children have a valuable role to play, particularly in the early stages of families’ decision making about cochlear implantation. A key challenge for professionals is the need to gently challenge and expand parents’ assumptions during the “on-going process of constructing the meaning of deafness for themselves” (Young, 2002, p. 6). This assumes that those professionals themselves have knowledge of the possible futures for deaf people and the way in which speech and hearing, fluency in sign language, and Deaf community membership are interwoven in the lives of many deaf adults.

Our interview findings indicated that parents found it very difficult coming to a decision on implantation for children with residual, aidable hearing. This result is consistent with reports in the literature following the recent move toward a widening of candidacy criteria to include such children (Burger et al., 2005; Fitzpatrick et al., 2009). In cases such as the 16-year-old boy who had a strong desire to have an implant and who had useful residual hearing that would be lost with implantation, families face particular difficulties in coming to a decision. Given the uncertainty of the potential benefits and drawbacks, it is a challenging task for adolescents, who are at a particularly sensitive time in their social and emotional development, to weigh up the pros and cons of implantation.

Advances in technology in recent years have seen developments in hearing aids as well as in cochlear implants. Advances in microcircuitry since the 1980s have led to digital programmable hearing aids that provide many advantages over the older analog aids, such as their ability to analyze incoming sounds and adjust loudness based on preset parameters, detect softer speech sounds and raise their loudness, and reduce amplification of background noise. In addition, their reduced size means that they are often less noticeable, and therefore more appealing to many wearers, than hearing aids used to be (Ackley & Decker, 2006). There was evidence in our interviews of

a demand for candidature by some parents of infants and by some teenagers with hearing loss in the severe range and with useable residual hearing, potentially placing pressure on audiologists and cochlear implant centers. With the greater proportion of childhood hearing loss being moderate or mild rather than severe or profound, will there be continued pressure for implants for children with less than severe hearing losses who may well be more suited to using hearing aids? The matter is of particular concern where benefits from hearing aids can be provided more cheaply, less invasively, and perhaps with less stress and fewer rehabilitation demands on families.

The retrospective nature of the parents' responses about the experiences involved in their decision making prior to their children's implantation could have the potential to be affected by recall bias. However, other researchers have found that most parents had detailed and accurate recall of significant events such as the diagnosis of their children's deafness even many years later (Gregory, Bishop, & Sheldon, 1995; Watson & Gregory, 2005). Certainly, we found in the interviews that parents, in telling their stories of discovering their children's deafness and coming to a decision about implantation, vividly recalled their experiences, thoughts, and feelings in the period leading to their children's implantation.

As parents self-selected to participate in this study, they may not be representative of the whole group of parents of children with cochlear implants in eastern Australia. It is not possible to know if responding parents differed from nonresponders in demographic characteristics. However, the breakdown of socioeconomic level by respondents' postcodes indicated that three quarters of families lived in areas included in the five highest deciles ranking socioeconomic advantage and disadvantage (Australian Bureau of Statistics, 2008). Thus, the views of families from low socioeconomic backgrounds may not be fully represented. It is possible that parents in the lowest SES categories are hindered in responding to surveys of this nature, not having the time or resources to do so. The parents who completed the survey may have been better resourced financially and personally than the whole population of parents whose children have cochlear implants. It may be that parents of lower SES have different experien-

ces in reaching a decision about cochlear implantation for their children and may find it harder to access information. Future research that includes the full diversity of families is desirable.

Conclusions

An important factor in coming to a decision about cochlear implantation is the gathering of information and the quality and diversity of the information gathered. From our findings, it appeared that information was often limited and that some parents made their decision with a sense of urgency about having their children implanted. There is no doubt that cochlear implantation has provided greater access to sound and the development of spoken language than was previously possible for many profoundly deaf children. However, the benefits of cochlear implants should not overshadow the seriousness and difficulty of the decisions that parents must make on behalf of their deaf children (or that deaf children and adolescents are faced with themselves). These decisions are major and complex and involve issues, concepts, and options that are likely to be completely new to hearing parents of recently diagnosed deaf children. It is essential that parents have the time they need to consider fully these major decisions and have ready access to objective, impartial, and nonjudgmental information and ongoing support.

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