

■ An Assessment of Parents' Decision-Making Regarding Paediatric Cochlear Implants

■ Un examen du processus décisionnel des parents concernant l'implantation cochléaire pédiatrique

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Abstract

Parents of children with severe to profound hearing loss have to make a number of fundamental decisions for their children. These decisions include communication and amplification options. In particular, the parents must decide whether and when their child will receive cochlear implants, and whether these will be implanted unilaterally or bilaterally. The objective of this study was to describe the decision-making needs of parents making the cochlear implant decision for their children. Semi-structured interviews were conducted with eight parents and eight cochlear implant team members at a Canadian cochlear implant centre to document parental and clinician recollections and opinions of the decision-making process related to a unilateral or bilateral cochlear implantation. The results demonstrated that the decision to go ahead with a cochlear implantation was consistently based on the parents' preferences for spoken communication for their children. Parents reported satisfaction with the cochlear implant decision-making process. Two of eight parents felt that additional information on unilateral cochlear implantation risks and benefits should have been provided. Four of eight parents described how more information on the experiences of other families would have been helpful for their decision. Parental and clinical perceptions of the bilateral implantation decision were highly variable. All parents stated that additional information on bilateral cochlear implantation was needed. Based on the results of the interviews, it is concluded that there is a need for information and resources for bilateral cochlear implantation decision-making.

Abrégé

Les parents d'un enfant ayant une perte auditive de degré sévère à profond ont des décisions fondamentales à prendre pour leur enfant. Ces décisions comprennent des options de communication et d'amplification. Plus spécifiquement, ils doivent décider si leur enfant recevra un ou deux implants cochléaires et à quel moment. La présente étude visait à décrire les besoins des parents dans le processus décisionnel de l'implantation cochléaire pour leur enfant. Des entrevues semi-structurées ont été menées auprès de huit parents et de huit membres d'une équipe d'un centre canadien d'implantation cochléaire pour documenter ce dont se souviennent les parents et les cliniciens et leur avis concernant la décision menant à une implantation unilatérale ou bilatérale. Les résultats montrent que le fait de choisir l'implantation cochléaire était systématiquement fondé sur la préférence des parents pour la communication orale de leur enfant. Les parents ont dit être satisfaits du processus de décisions liées à l'implantation cochléaire. Deux des huit parents trouvent qu'ils auraient dû recevoir davantage d'information sur les avantages et les risques de l'implantation unilatérale. Quatre des huit parents ont dit qu'ils auraient trouvé utile d'avoir davantage d'information sur l'expérience d'autres familles avant de prendre leur décision. La perception des parents et des cliniciens concernant le choix de l'implantation bilatérale variait considérablement. Tous les parents ont précisé qu'ils

auraient eu besoin de plus de renseignements sur l'implantation bilatérale. Les résultats des entrevues mènent à la conclusion qu'il manque d'information et de ressources pour prendre des décisions dans le cas de l'implantation cochléaire bilatérale.

Key words: hearing loss, cochlear implants, needs assessment, decision making, audiology

Almost immediately after the diagnosis, the parents of children with bilateral, permanent, sensorineural hearing loss are required to make a number of fundamental decisions regarding the communicative rehabilitation of their child. These decisions involve use of the choice of amplification or cochlear implantation, and the communication approach for their child. Most of these parents have never experienced hearing loss, which may make the decisions more difficult and daunting (Northern & Downs, 1991). Their lack of knowledge regarding hearing loss, options for communication, and technologies for rehabilitation can be overwhelming for parents. They must absorb significant amounts of technical and scientific information during a period of grief about their child's hearing loss (Anagnostou, Graham, & Crocker, 2007; Kurtzer-White & Luterman, 2003). While the treatment team can provide parents with necessary information, the actual decision-making process is usually invisible to the professionals. A better understanding of the parents' process for decision-making may allow the cochlear implant team to reduce some of the parental stress and anxiety during this delicate and emotional time.

Family decisions about treatment vary depending on the severity and characteristics of the child's hearing loss. A child with any significant degree of bilateral hearing loss usually requires specialized early interventions in order to develop language (Samson-Fang, Simons-McCandless, & Shelton, 2000). A child with a severe to profound hearing loss may require considerable intervention in the form of amplification and aural rehabilitation in order to develop functional spoken communication. For these children, cochlear implants (CIs) are one of the available options. The criteria for CI use in children with significant hearing loss have expanded considerably since the initial approval of the device by the American Food and Drug Administration in 1990 (Candidacy Criteria, 2008). Originally used in older children with profound hearing loss, now children 1 year of age and even younger with severe to profound losses are routinely eligible for CIs (Thoutenhoofd et al., 2005). Because binaural hearing is important for sound localization and speech intelligibility in noise, bilateral implantations have become common in some paediatric centres (Berg, Ip, Hurst, & Herb, 2007).

When parents are considering cochlear implantation for their child, they are interested in the medical, speech and language, educational, and social outcomes of other users of the device. A systematic review of the effectiveness of unilateral paediatric cochlear implants reports that there are consistent benefits for children who use CIs rather than hearing aids in terms of hearing sensitivity levels and speech perception (Thoutenhoofd, et al., 2005). A recently published, multi-site study shows greater improvements in the language of children using CIs as compared to earlier evaluations of children using hearing aids (Moog & Geers, 2003). The evidence is less clear-cut regarding the relative benefits of CIs over hearing aids for children with residual hearing and children with comorbidities or congenital syndromes (Thoutenhoofd et al., 2005). Practices for the latter populations vary across CI centres.

There are risks associated with the CI surgery that may influence parental decision-making. Early studies estimated that 18% of CI surgeries were accompanied by some type of minor or major complication (Cohen, Hoffman, & Stroschein, 1988). The current estimates suggest that major complications range from 3 to 4% of CI surgeries (Tambyraja, Gutman, & Megerian, 2005). One major risk is the post-surgical complication of meningitis among children who have received an implant. Recent work has attributed the increased risk of meningitis, in part, to a particular positioner device that has since been withdrawn from the market (U.S. Food and Drug Administration, 2007; Biernath, et al., 2006). Vaccinations to prevent meningitis continue to be recommended for the entire CI recipient population. Facial nerve paralysis, vestibular problems, and risks associated with the use of a general anaesthetic are some of the other complications of CI surgery (Fayad, Wanna, Micheletto, & Parisier, 2003; Fina et al., 2003; Gysin, Papsin, Daya, & Nedzelski, 2000). Finally, once the CI surgery is undertaken, there is a high risk of losing the residual hearing in that ear (Bergeron, 2000; Boggess, Baker, & Balkany, 1989). Therefore, the parental decision to use a CI is typically irreversible.

Bilateral implants have recently become available in many paediatric cochlear implant centres, although not yet universally in Canada. The research indicates that there are benefits for patients receiving bilateral stimulation compared to the use of a single CI, demonstrated on measures of speech recognition in noise and sound localization (Brown & Balkany, 2007; Ching, van Wanrooy, & Dillon, 2007; Murphy & O'Donoghue, 2007; Schafer & Thibodeau, 2006). New guidelines for patient selection and other position papers have also recently been published (William House Cochlear Implant Study Group, 2008; Perreau, Tyler, Witt, & Dunn, 2007). The addition of the bilateral implantation option further complicates the parental and clinical decision-making process. Recent audiology and otolaryngology literature has discussed the need for additional evidence of bilateral CI effectiveness above and beyond the improved speech recognition in noise and sound localization (Berg et al., 2007; Gregoret, 2003).

Parental cochlear implant decision-making

Publications from around the world have described the challenges parents face in deciding on cochlear implantation for their children (Sorkin & Zwolan, 2008; Sach & Whynes, 2005; Li, Bain, & Steinberg, 2004; Incesulu, Vural, & Erkam, 2003; Most & Zaidman-Zait, 2003; Peters, 2000; Steinberg, et al., 2000). Incesulu et al. (2003) report that 81% of parents responding to a survey indicated that the CI decision was the most difficult aspect of the implantation process for them. Most and Zaidman-Zait (2003) also describe the high parental stress during the implantation decision-making process and the specific parental needs for information to aid in the process.

In contrast, Sach and Whynes (2005) of the UK report that most of the 216 interviewed families found the decision regarding implantation to be straightforward. They did, however, describe the overall stress for families undergoing cochlear implantation. A very recent survey of parents in the US indicates that those who chose the CI for their child felt that they lacked "comprehensive and bias-free" information when making the decision (Sorkin & Zwolan, 2008).

The medical decision-making literature makes a distinction between preference-sensitive and effective decisions (Wennberg, 2002). In medical decision-making, a decision is considered preference-sensitive when the available evidence indicates that there are several available choices that carry both harms and benefits. In such a scenario, the personal beliefs and preferences of the patient may affect his or her perception of the relative weight of the harms and benefits of an intervention. The patient's care must therefore acknowledge these preferences (O'Connor, Legare, & Stacey, 2003; Wennberg, 2002). This is in contrast to effective care. In an effective care scenario, the benefits of a treatment clearly outweigh possible harmful treatment effects. Based on findings in the pertinent literature, the CI decision appears to be preference-sensitive.

When individuals are faced with making preference-sensitive decisions, they can experience increased decisional conflict. Decisional conflict is the state of uncertainty about the best course of action (O'Connor, 1995). Previous CI studies have not referred to, nor measured, the decisional conflict in parents making the CI decision. They also have not contextualized the CI decision within the broader medical decision-making literature.

The literature indicates that there is variability in the decision-making process across geographical regions, cultural backgrounds, and CI centres (Sorkin & Zwolan, 2008; Sach & Whynes, 2005; Li, Bain, & Steinberg, 2004; Incesulu, Vural, & Erkam, 2003; Most & Zaidman-Zait, 2003; Peters, 2000; Steinberg, et al., 2000). However, even within an individual CI centre, families may experience very different forms and levels of decisional conflict and emotional stress. The reported stress may be due to uncertainty about possible risks and benefits. The parents may be uncertain or conflicted in their values regarding communication approaches (e.g., oral or sign language)

that may be linked to the CI decision. They may feel that they have inadequate information about their options, or feel under pressure from clinicians or other family members. Having a better understanding of the CI decision-making process may identify a way to reduce parental stress during this process or to meet any specific information needs that are identified. There is currently no available literature on parental perceptions of the bilateral CI decision.

Purpose

The present study was undertaken to investigate the decision-making process and the needs of parents regarding unilateral and bilateral CIs. Research objectives were to explore:

- (a) The parental and clinician perceptions of the unilateral and bilateral decisions: How did parents and clinicians perceive different options with regards to their respective advantages and disadvantages?
- (b) The parents' and clinicians' perceptions of their knowledge, values and expectations, as well as the support and resources available to them during CI decision-making.
- (c) The parents' recollections of the manifestations of decisional conflicts and their contributing factors during the decision-making process.
- (d) The need for a formal decision aid to support parents and clinicians in the cochlear implant decision-making process.

Framework

The Ottawa Decision Support Framework (ODSF; O'Connor et al., 1998) was chosen as the framework to guide the needs assessment in the present study. A schematic overview of the ODSF is presented in Figure 1. This framework is appropriate for decisions that "(1) are stimulated by a new circumstance, diagnosis, or developmental condition, (2) require careful deliberation because of the uncertain and/ or value-sensitive nature of the benefits and risks, and (3) need relatively more effort in the deliberation stage than the implementation stage" (O'Connor et al., 1998, p.268). The paediatric cochlear implementation decision meets each of these criteria. The ODSF depicts how a family's decisional needs and decisional quality influence each other. Decisional needs include (a) elements of the decision, such as timing, stage, and leaning, (b) decisional conflict, (c) knowledge and expectations, and (d) values. Decision support can be used to address decisional needs to improve the quality of decisions.

Method

Participants and recruitment

A sample of parents at various stages of decision-making were recruited. Eligible participants included parents whose children were (a) were currently assessed for CI candidacy, (b) were awaiting surgery, or c) had undergone surgery within the last 2 years, and had used

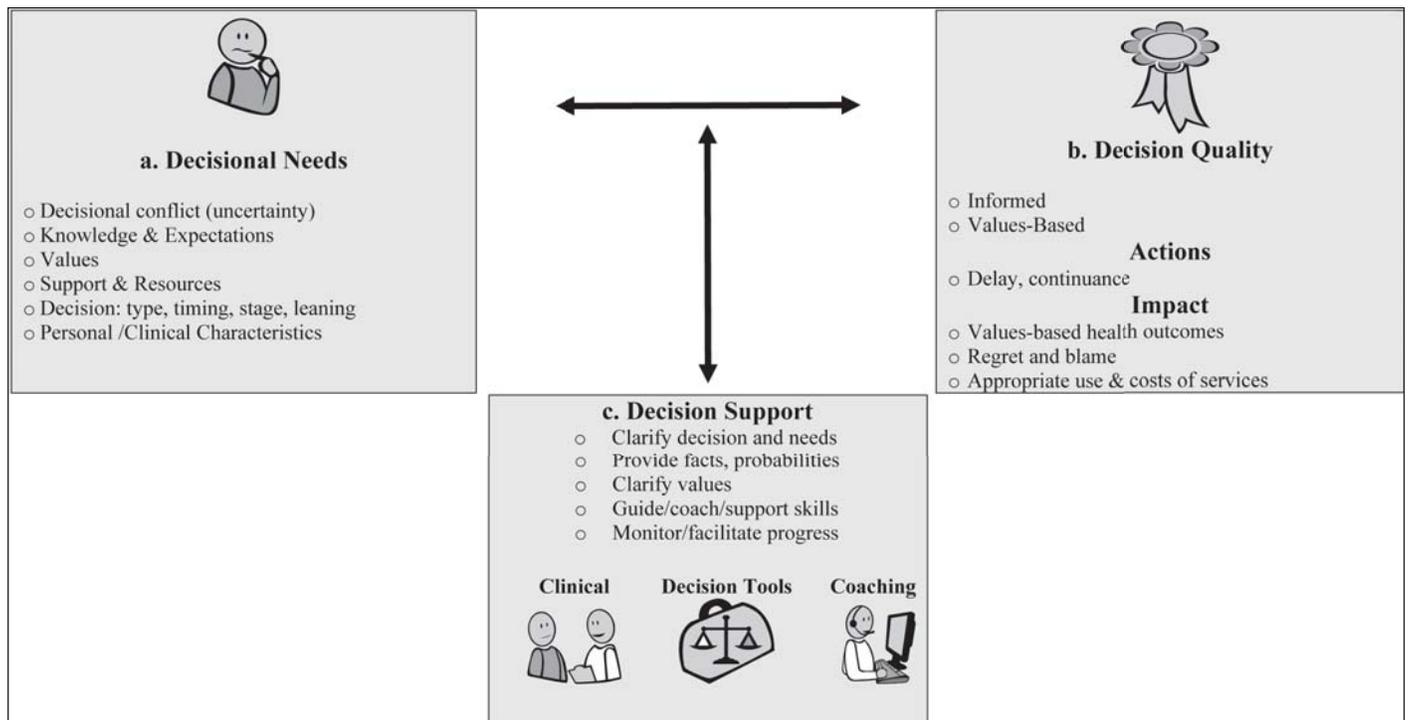


Figure 1. Ottawa Decision Support Framework

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their implants for at least 6 months. All families had to speak and understand English because the interviews were conducted in English.

The hospital CI clinicians were also invited to participate. The potential participants included audiologists, rehabilitation therapists, a psychologist, a social worker, and a CI surgeon. Consent for participation was obtained from each participant prior to study commencement. Ethical approval for the study was received from the Children's Hospital of Eastern Ontario and the University of Ottawa, Research Ethics Boards.

Interview procedure

A semi-structured interview guide was developed based on the standard needs assessment questions of Jacobson and O'Connor (2006). The open ended questions were guided by the ODSF. Interview questions for parents and professionals focused on (a) reactions and decisions surrounding the identification of their child's hearing loss, (b) the options available to them, (c) the perceived benefits and risks associated with their options, (d) manifestations of decisional conflict (uncertainties), (e) knowledge and expectations, (f) values, (g) support and resources including usual roles in decision making, (h) patient

characteristics such as age of identification and etiology, (i) barriers and facilitators in receiving decision support; and (j) potential strategies for over-coming barriers. See the appendix for a copy of the interview guide used with parents. While there was only a single open-ended question on bilateral implantation, this sparked considerable discussion and additional follow-up questions were asked depending on parent responses.

The parent interviews lasted between 30 and 60 minutes and were conducted at a mutually agreeable location, either in the parents' home or at the clinic. The clinician interviews lasted about 30 minutes and were held at the clinic. The interviews were audio recorded and transcribed. The clinical characteristics of the children undergoing the CI implantation were obtained during the interview.

Analysis and interpretation

A mixed methods approach was used in analysing the data. This approach seeks to use both qualitative and quantitative research methods to answer research questions (Tashakkori & Teddlie, 2003). The interview data from the parents and clinicians were analyzed together. Frequencies and counts were used where appropriate to describe

structured, quantifiable responses that corresponded to the answer templates in the interview guide. A deductive coding strategy based on the ODSF was used to analyze the content of the open-ended responses. Similar items were grouped together based upon the elements in the ODSF. Nuances in the responses were qualitatively explored based on the clinical characteristics, such as the child's age at the diagnosis of the hearing loss, the aetiology, the presence of co-existing health issues, and the current status in the implantation process (pre- or post-implant). Due to the exploratory nature of the research and the small sample size, no statistical analysis could be undertaken to formally quantify the effect of these factors on parental responses.

Results

Characteristics of participants

Seven families participated in the interviews. From these seven families, eight parents or guardians of eight children took part in the study. Four children had already received a unilateral CI, one had received bilateral implants, and three were awaiting their surgery for a unilateral implant. At the time of the interview, the children were between 1 and 5 years of age. Two of the eight children had co-existing health issues at the time of diagnosis. One was recovering from meningitis and the other had a congenital health concern. Half of children were candidates for CIs upon diagnosis and the remaining four children had hearing losses that progressed to make them CI candidates. Two of the children had auditory neuropathies. Four of the children were only children. Two of the children had a sibling with hearing loss in a family of two children. Two of the children were the only child with a hearing loss in a family of two children.

One of the children was identified with a hearing loss after 18 months of age following medical referral, one child had meningitis as an infant, and six were identified through newborn hearing screening programs. All children used auditory-verbal therapy (AVT) as their primary communication approach. An effort was made to seek out families who had declined CI surgery. However, the families who were identified declined participation in the interview. Eight of the ten CI team members participated in individual interviews. The CI team members came from a range of disciplines with a wide range of experience in CI.

Identification of hearing loss and early decision-making

The responses of parents and guardians to the identification of hearing loss varied depending on the co-occurrence of other health issues at the time. Parents of children ($N = 6$) with no co-occurring health issues described the uncertainty and shock associated with the diagnosis:

"We were shocked. It was very painful. We just couldn't believe it. My wife was crying. It was a horrible experience." [parent of 3-year-old]

"At the beginning, when we found out about our child it was really hard for us. We didn't know what to do and where to go and how things were going to work for him in the future. We didn't know anything about if he's going to go for sign language or going to go for only hearing aids, or that. We didn't know anything. We didn't know what the hell's going on." [parent of 1-year-old child]

Parents who had children that suffered from meningitis and postnatal health problems ($N = 2$) described less shock at the identification of hearing loss than parents of children without co-occurring health concerns:

"Because he had other health issues at birth, I guess we kind of took it as a grain of salt. We were just really grateful that he made it through because he wasn't expected to live, and I figure if he had to have some sort of incapacity, I'd prefer the hearing to the eyesight. So I don't think we were ever in shock about it. I don't remember being in shock, anyway." [parent of 4-year-old child]

Parents and clinicians were asked to describe some of the decisions that had to be made following the identification of their child's hearing loss. Both groups identified the communication approach as the first decision that parents have to make. The parents made a distinction between using an aural/ auditory-verbal approach or sign language with their child. They did not describe struggling with the communication approach decision and all chose an auditory-verbal approach for their children. Other decisions named by both parents and clinicians included whether to use a hearing aid, the decision to undergo cochlear implantation, the type of implant or manufacturer to choose, when to proceed with the implantation, and the decision for a parent to return to work or stay at home to teach their child.

Introduction of cochlear implants

When asked when and how the topic of CIs was first introduced to them, the parents provided varied answers. The parents of the four children that were initially diagnosed with profound hearing loss stated that the topic had been introduced at the time the diagnosis was shared. The parents with the four children with progressive hearing loss stated that the topic had been introduced a year or later after the initial diagnosis. Some parents had felt shocked when the clinicians had suggested a CI while others had been relieved:

"It actually came as a bit of a surprise to us because [my child] now wears a hearing aid and a cochlear implant, and so he had both ears equipped with hearing aids, and he was making progress, and we were getting language... So it was a little of a set-back emotionally." [parent of 3-year-old child]

"I kind of just heard from other parents in the department, like seeing them in the waiting room, and chatting about it. Their kids may have had hearing aids but now they had a cochlear implant, and now it's much better. So, we had a positive image right away from that because the parents were like, 'Oh, yeah. No more feedback, no more... you know... they can hear so much better.' Well, I think as his hearing

Table 1*Perceived Advantages and Disadvantages of Available Options as Described by Parents and Clinicians*

Cochlear Implant Option		Hearing Aid Option		Sign Language Option	
Advantages	Disadvantages	Advantages	Disadvantages	Advantages	Disadvantages
<ul style="list-style-type: none"> - Greater exposure to speech and language at early age - Consistent with hearing family's culture - Potential for the child to use spoken communication - Potential for the child to communicate with larger community - Possible removal later if child chooses sign language - Cost of device is covered compared to hearing aids 	<ul style="list-style-type: none"> - Surgical risk - Increased risk of Meningitis - Making a decision for a child that might have made a different decision - Reduced possibility of using newer technology - Challenges of repairs, device failure, programming - Cosmetic issues of external and internal device - Travel and time for fitting and programming 	<ul style="list-style-type: none"> - No surgical risk - Consistent with hearing family's culture - Ability to hear the child speak - Possible removal later if child chooses sign language - No loss of residual hearing 	<ul style="list-style-type: none"> - Less speech and sound exposure from greater distances - Slower speech and language development than with CI - Challenges of feedback, hearing aid repairs 	<ul style="list-style-type: none"> - No surgical risk - Consistent with signing family's culture - A small, warm cultural community available to child 	<ul style="list-style-type: none"> - Child enters a culture unfamiliar to hearing family and friends - Entire hearing family needs to acquire a new language - Living in a minority culture - Fewer employment/ educational options available - Limited opportunity to chose oral communication after childhood

started getting worse, we felt frustrated, so when it was first brought up with us, I think we kind of felt happy because, in a way, it was not... we weren't happy that it was getting low like that, but we were happy that we were going to have another option because we were getting frustrated." [parent of 2-year-old child]

The parents and clinicians reported that the professions most likely to be involved in first discussing the CI with families were the audiologists and auditory-verbal therapists working with their children. Five out of the eight parents received information from other families in the clinic waiting room and the internet before discussing the CI with their clinicians.

Options available

When asked about their options regarding the CI decision, half of the parents perceived their decision as a choice between a CI and hearing aids. Of these parents, all

had children with hearing losses that had progressed from severe to profound over time. The other half of parents perceived their decision as a choice between a CI and sign language. These parents had children with profound losses as a result of genetic losses, auditory neuropathies, and meningitis. The clinicians varied little in their perceptions of the options.

Five of the eight clinicians perceived parental decisions as a choice among three options: CI, hearing aids, or sign language. One clinician perceived the two options: CI or hearing aids. The remaining two clinicians perceived two different options: CI or sign language.

Perceived advantages and disadvantages of options

After identifying the available options, the parents and clinicians were asked to list some of the perceived advantages and disadvantages of each. Table 1 provides a

summary of the advantages and disadvantages that were generated by the parents and clinicians. All parents reported that the CI option was most consistent with their family's communication culture and linguistic backgrounds.

The clinicians' perceptions of parents' choices were consistent with parent's views. This consistency between the CI choice and the families' communication culture was the perceived benefit of the CI option:

"Most of the hearing impaired children are born into hearing families where spoken language is the language of the home whether or not there are other children. So, in terms of ease of natural language simulation in most families it would come through speaking. So, I mean, there would be an understanding in sign language that the parents are going to be learning a new language system. And then, also hopefully, to have other friends and extended family getting involved with communication systems as well. If sign language is the language at home for a particular family, I would think that that would be the natural option for those families." [clinician]

Two of the eight parents commented on their qualms making a decision for their child in light of the uncertainty that their child might later disagree with their decision. However, they felt that they were making the best decision for their family at the present time:

"We had concerns in having to make a decision for a child who might have made a different decision later... It is always possible later on to have the devices removed if she chose that later, and we wouldn't have had the opportunity, necessarily, to have the same opportunity to get [speech and language] results." [parent of 2-year old child]

In this study, most families found it difficult to perceive any benefits of sign language. All families had chosen AVT as their primary communication approach and were enrolled in a program. Seven parents reported that sign was not a fit for their family. However, one parent wished that the family had the option to communicate to their child in sign language. However, the parent realized that this would have been inconsistent with the AVT philosophy. The benefits regarding sign language that are listed in Table 1 were all derived from clinicians' interview data.

Manifestations of decisional conflict

The responses to the structured question on feelings during the cochlear implant decision-making process are summarized in Figure 2. The parents were also given an opportunity to expand and comment further.

The parents reported feeling most concerned about what could go wrong: *"They make a hole in the bone, so there's no protection here only more... only that piece of equipment there."* Another concern was that their child would not benefit sufficiently from the cochlear implant: *"I was worried that it wouldn't work. I was really worried but at the same time that wasn't something that would stop us from trying the cochlear implant."*

Parents did not report delaying the decision, wavering between choices, feeling uncertain about what was important, or dwelling excessively on the decision. All

parents emphasized that they were confident that the CI decision was the appropriate decision for their family:

"Even though I didn't grow up with anyone with a hearing loss I knew it wasn't something I wanted my son to do. I want to hear the words, 'I love you mom,' I want to be able to just communicate and be able to tell him when his back is to me, 'Can you go get your shoes?'" [parent of 3-year-old]

Factors contributing to decisional conflict

When asked which factors had contributed to decisional conflicts, neither parents nor clinicians felt that parents were unclear about what was important to them or that they lacked the skills to make the CI decision. Figure 3 presents the responses to the structured question. The parents and clinicians responded similarly on most items. However, four of the eight parents felt that they had lacked information on the choices that other families had made regarding CIs. Only one clinician of eight perceived this as a possible gap in the information provided to families. In general, the clinicians reported that they consistently linked families with each other to provide mutual support and share information. One of the interviewed parents commented as follows:

"We wanted to know how it worked for other people, and we weren't that well connected to a lot of families. I had requested all along to be connected with families, and that never happened. I did it on my own. And I think that's one thing that every family should have that ability to connect very quickly, and it took us a while." [parent of 2-year old]

Clinicians and parents also varied slightly on their perception of pressure in decision-making. Parents did not report feeling pressure to choose the CI option. Four of the eight clinicians reported that parents might feel pressure to make the decision to go ahead with cochlear implantation:

"We never pushed the parents into getting the implant, but it depends on how that's worded. You know, and I'm not there to see the [other team members], how they actually provide the info, but there might be a bit of solid pressure." [clinician]

Perception of others' opinions, practices, support, and pressures

Parent participants reported that the individuals most likely to be involved in the CI decision were the audiologists, auditory-verbal therapists, and the CI surgeon. The parents valued the team approach to the CI process. Individuals outside of the CI team were not named as stakeholders in the decision-making. When asked about the influence that extended family members might have on the process, most parents said that there was little such influence.

When clinicians and parents were asked to describe the decision-making dynamic that they had or were experiencing, both parents and clinicians reported equally that it was either a shared decision or that the clinic team members provided support for them to make the decision themselves. No parent reported that the decision was made for them by clinicians.

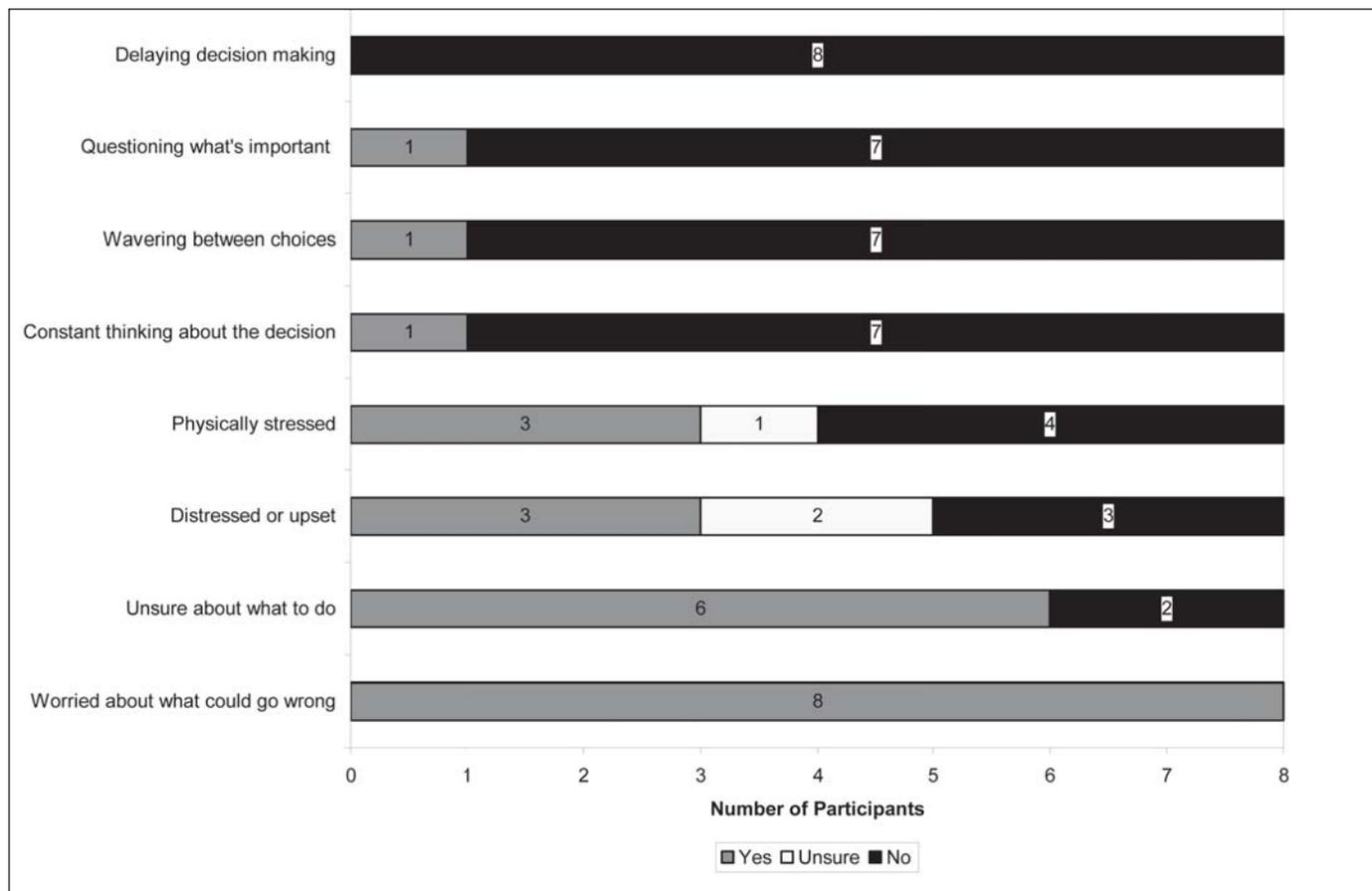


Figure 2. Parent responses to structured questions regarding reported behavioral manifestations of decisional conflict about the cochlear implant decision-making process.

Resources in the decision-making process

Families and clinicians were asked about the type of information they accessed to make a decision and which additional resources they perceived as potentially beneficial. Most families felt that the clinicians provided them with adequate information on the treatment options and the associated risks and benefits. The parents also commented on their need to seek additional information on their own to supplement in the information from the clinic. This was often accomplished through the internet or by meeting families who had already experienced the CI process. Five parents reported meeting with other families before they made their decision or before they had the surgery. They all spoke highly of this contact with other families: "If I hadn't talked to those families I did talk to, I would have felt at a real loss for not knowing things. And having that ability to contact them was huge." The other three parents did not have the opportunity to meet other families. They indicated that they would have liked to have the interactions with others who have made similar decisions for their children.

Meeting with the surgeon to hear about the risks and benefits of the CI surgery was also mentioned as an important source of information for parents:

"The meeting with the physician before the surgery, that was obviously key. That was a really big one for us. To actually talk to the guy who was going to do this, and to find out whatever we can about success, failure, problems, all that kind of stuff." [parent of 2-year-old]

In terms of the appropriate format for sharing information, all parents and clinicians agreed that counselling from a health professional, information pamphlets, books, videos, and the internet were useful ways of helping with their decision-making. All participants were uncertain of the value of support or discussion groups for families making the same decision. Most parents suggested that it might be useful for some families but that they would be unlikely to use a support group.

When asked about who should disseminate the information, there were some variations in the responses.

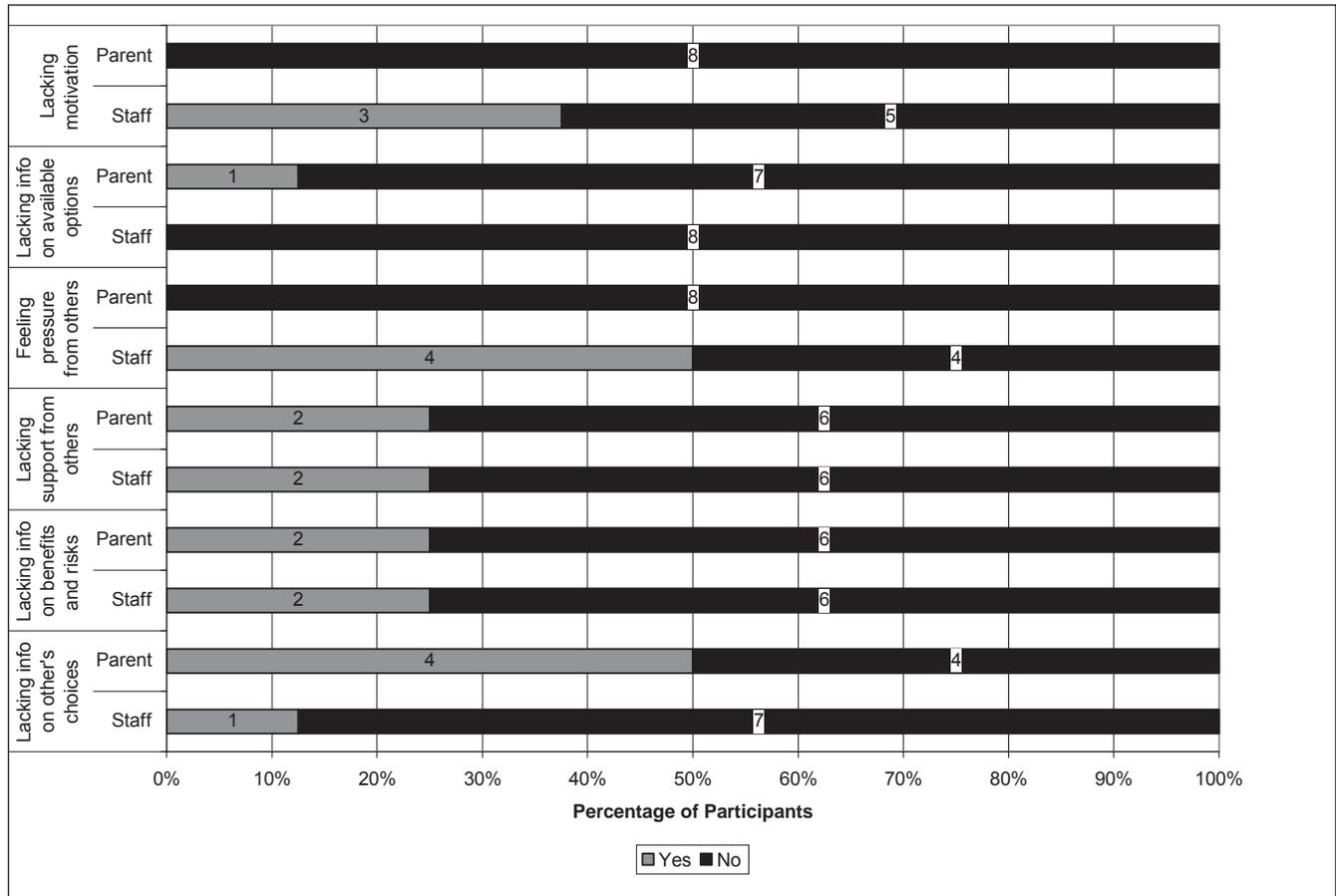


Figure 3. Clinicians' and parents' responses regarding what makes the cochlear implant decision difficult.

There was general agreement that the government and health societies and non-profit groups had only a small role to play in the development of resources for families. All clinicians and parents agreed that information materials should be prepared by medical staff and researchers. One clinician summarized the current challenge in providing unbiased research information:

"Preferably, I'd like nice unbiased research. Although, in reality, I mean, that's kind of difficult to still find, and a lot of the information that's available... and a lot of the research has been sponsored by one of the companies or the other, and so giving decent advice information sometimes is a little difficult." [clinician]

Four of the clinicians felt that CI manufacturers should create the information pamphlets, but the other four clinicians noted that this could result in biased information for families. While some parents ($N=3$) felt that the information should not come from CI manufacturers because of potential bias, other families felt that the manufacturers had a role to play in providing information.

Half of the parents felt that parents of children with CIs should help prepare information materials. This echoes the request for additional resources regarding the experiences of other families who have chosen CIs for their children. Clinicians did not feel strongly about parents' participation in preparing information.

Bilateral cochlear implantation

There was uncertainty and variability when participants were asked about their perceptions of the bilateral CI option for their child. The parents and some clinicians discussed (a) their perceptions of the bilateral decision, benefits, and risks. (b) their pre-disposition to the bilateral cochlear implantation decision, and (c) some of the barriers to decision-making.

Perceptions of the bilateral cochlear implant decision. There were differences in the parent and clinician perceptions of the benefits and risks associated with bilateral implantation. In contrast to the benefits from unilateral implantation that all parents were unanimous about, only one parent brought up the additional benefits of a bilateral

CI, such as such as an improvement in sound localization and hearing in noise. The other parents brought up their concerns regarding the perceived risks of a second CI. One parent reported concern about a second surgery:

"They suggested that we should do two because her right ear is not good, but still, I don't want to do that now, because this is her first one... because it's her brain. It's head surgery. It scares me." [parent of a 4-year-old child]

Parents did not report that the increased risks of meningitis and mastoiditis associated with the second surgery influenced their decision. However, a clinician commented that she was uncertain that parents fully understood the risks associated with the second surgery:

"Then we start talking about binaural implantation. I have a feeling that somehow, people are hiding their heads, putting their head in the sand. They're not really paying attention to those potential risks. If I had a child who was deaf, I don't know if I'd go for a binaural implant. I'd go for the first one, and I'd accept the risks. And you can't judge what people decide to do, but there is this feeling that they want the success, and they don't necessarily grasp the risks. The parents who have been through the case of mastoiditis, and meningitis have actually been quite brave about it, and have freely accepted those events, but I think we've been lucky." [clinician]

Pre-disposition to the bilateral cochlear implantation decision. Half of the interviewed parents expressed a great interest in receiving a second implant as soon as possible for their child:

"Now that I see that [the first cochlear implant] does work and I've been talking to different people about getting a second one it is something that we definitely want for our children. I feel like they should have that opportunity to have the direction finding [sound localization]." [parent of a 3-year-old].

The four parents who were still at the decision-making stage responded that they were uncertain about what they would choose for their child:

"Everybody has a different reaction to doing it. I'm kind of, I'm cautious by nature, so I'm kind of, 'Well, let's see if this is a good thing to do,' as opposed to, 'Yeah, I want to have him have that bilateral.'" [parent of a 3-year old]

One clinician also expressed her perception of parental uncertainty about the bilateral CI decision:

"Not all parents will want two implants for their kids, and that's fine. We've got... I think the decision-making is, it's going to be more variable. But we'll have to respect that. I know some parents have told me, 'Well, we're going to get one, and we'll wait until something better comes up for the second one,' or, 'Nope. We'll go for two because I've read that two is better than one, and we've got two hearing aids, we want two implants.' It depends on the parent." [clinician]

Barriers to bilateral cochlear implantation decision making. Many of the parental comments revealed barriers to bilateral cochlear implantation decision-making. In particular, they focused on their perceived lack of knowledge about the bilateral procedure. One parent who had been

actively seeking bilateral implants for her children expressed her interest in having more research available to support her family's decision:

"Even with the bilateral, we believe that it's best for them, I do wish that there was more research stating exactly, 'These are the advantages,' or, 'Hearing will improve in these ways.' The research aspect, I wish there was a lot more out there." [parent of a 2-year-old]

Another parent and a clinician expressed similar requests for additional information and support for the bilateral decision:

"I know we don't have enough experience with two implants now to have a lot of data on it, so I don't feel comfortable enough with the counselling and all because it's not there." [clinician]

"People are going ahead and doing this, they've got to line up [the bilateral information] just the same way they should line up the cochlear implant information. So that parents who are even thinking about it know that there's a resource they can go to and start looking at that." [parent of 3-year-old]

Another parent voiced concerns regarding the difficulty in making decisions for her young son without his involvement:

"We now see that bilateral implantation is possibly another decision we have to make in his lifetime. We actually hope that it will be in his lifetime as opposed to ours, but I also feel that I would like him to be able to make the decision. He's had it done once where we made the decision for him as the parent, but I like would like him, with whatever life experience he's had at that point to be able to decide whether or not he wants to do it. I would feel better about it." [parent of 3-year-old]

In making the decision for unilateral implantation, parents consistently reiterated their comfort with the decision for the CI. However, there was more uncertainty among parents with regard to the bilateral CI.

Discussion

Identification of hearing loss and early decision-making

The parents' description of the initial shock and grief about the diagnosis of hearing loss was consistent with other literature on the topic (Anagnostou et al., 2007; Kurtzer-White & Luterman, 2003). The current study identified differences in the magnitude of the parental reaction to the diagnosis depending on the child's co-existing health issues. There is no specific literature on the parental reactions to a diagnosis of hearing in parents of children with complex co-morbidities. This may be an area for further inquiry.

The families did not describe struggling with the decision about the communication approach for their child. Li et al., (2003) reported similar results in their survey regarding the attitudes, beliefs, and values of 83 parents of children with various levels of hearing loss. They reported that the second most influential factor in deciding

about the communication modality, after the degree of a child's hearing loss, was the parents' desire to use spoken communication with their child. As all the children in the current study were CI candidates or recipients with severe to profound losses, the degree of hearing loss did not differentiate between the parents in this study.

Perception of the Cochlear Implant decision

All parents emphasized that the perceived risks associated with the CI implantation were acceptable in relation to the value that they attributed to oral communication with their child. These findings were consistent with a study that examined the influence of parental values on the CI decision-making (Li et al., 2004). That study examined families from a variety of deaf communication programs: oral, sign, and total communication programs. In the 50 families that participated, 33 children proceeded with the CI surgery while the other 17 children did not. Among the 17 families who decided against the CI, the authors found that their attitude toward communication could be used as a statistical predictor for their final decision. The authors emphasized that a CI is often emotionally loaded for some families. Identifying the value that parents place on oral rather than manual communication may be important in identifying those parents who will have difficulty with the CI decision-making process.

Options available

In this study, the parents of children who had begun AVT and were already progressing in their oral language development before the CI decision arose, did not perceive sign language as a viable option. In contrast, the families that had to make the CI decision immediately after their child's diagnosis perceived the decision as being a decision between CIs and sign language. The different perception of treatment options suggests that the parents of children with an early diagnosis chose the communication approach together with the CI.

Many of the advantages and disadvantages of the options listed by participants were consistent with previous findings in the literature (Sach & Whynes, 2005; Incesulu et al., 2003; Kluwin & Stewart, 2000). The primary perceived advantage of the CI option was the increased opportunity for speech and language exposure. This was followed by hopes for improved communication skills and becoming a member of the larger hearing community. It is a specific oddity of the Canadian context that a CI is fully covered by the public health care system while hearing aids are only partly funded. This was noted by one of the clinicians as an apparent benefit to parents. The influence of cost on the CI decision was not explored in the present study but may be of interest for future research.

The parents' qualms about making the CI decision for a child who might later resent that decision had been noted as a stress factor by Sach and Whynes (2005). In the survey by Incesulu et al. (2003), 6 of the 25 participating parents reported concern about later blame from their children. Parents in the current study explained that this

concern was alleviated by the fact that their children could still have the CI removed if they so chose.

Manifestations of decisional conflict

Like other studies, results of this study indicated that the parents were confident about the CI choice. Nevertheless, preparing to undergo surgery and the entire CI process was a stressful event for the families (Incesulu et al., 2003; Most & Zaidman-Zait, 2003). Identifying ways to adequately address and reduce this stress should be both a research and clinical priority.

Perception of others' opinions, practices, support, and pressures

Information about other families' decisions was reported to be the single most helpful piece of support for the CI decision. This is in agreement with the results of previous studies (Incesulu et al., 2003, Most & Zaidman-Zait, 2003). The discrepancy between parents' and clinicians' perceptions of what constituted adequate information on the decisions of other families should be noted. Notwithstanding the small sample size in the present study, it might be worthwhile to explore additional ways to put parents in touch with other families to share information and emotional support (Most & Zaidman-Zait, 2003).

Apart from the contact to other families, the contact with audiologists, auditory-verbal therapists and surgeons was perceived as important during the decision-making process. The multi-disciplinary team provides an important support mechanism for parents of children with hearing loss (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008; Most & Zaidman-Zait, 2003).

Resources to Make Decisions

The need for additional information is often closely associated with the particular clinical profile of a child. In this study, the parents of children with auditory neuropathy and children with progressive loss requested additional information and resources for decision-making. Kluwin and Stewart (2000) interviewed 35 families who had undergone cochlear implantation with their children. They identified that most families were satisfied with the information they received. However, eight families felt that they would have liked more information on the surgery and rehabilitation process. While the majority of parents appeared content overall with the available resources, there may be a need for more information for some families. Based on a series of case studies, Neuss (2006) described families' search for information before deciding for the CI. The results were similar to the current study. Most parents stated that they supplemented the information from clinicians with additional research on the internet or with discussions with other parents.

The parents' preferences for information in brochure format as well as on the internet was consistent with a national survey on the decision-making needs of Canadians (O'Connor, Drake et al., 2003). In addition, like the respondents in the national survey, the parents

and clinicians interviewed in this study preferred that the materials be created and disseminated by medical and health-care specialists. In an examination of the internet resources available to parents making decisions about unilateral cochlear implantation for their children, Zaidman-Zait and Jamieson (2004) found that the majority of articles available for parents were from medical departments, consumer organizations, CI manufacturers, and health care providers. The researchers qualitatively evaluated the information provided on these websites and concluded that the available evidence for parents was neither peer-reviewed nor evidence-based, and that the creators of the sampled websites rarely referred parents to research that is available in the public domain. A recent survey of parents by Sorkin and Zwolan (2008) found a perceived lack of bias-free information on CI.

Bilateral Cochlear Implantation

The parental responses to the question of bilateral CIs indicated that the decision was more difficult than for the unilateral CI. The parents were uncertain about the potential benefits and about the value of these benefits to their child or their family. At the time of this study, bilateral CIs were relatively new to this clinical setting and did not constitute the standard of care. In contrast to the unilateral CI, the value that the parents placed on the second CI does not appear consistent. The bilateral procedure may have been perceived as elective because a second device provides secondary improvements in sound localization and speech intelligibility compared to the speech and language development associated with a CI.

As the bilateral clinical treatment option was relatively new, parents and clinicians perceived a lack of information and resources. These findings indicate a need to develop more information in user-friendly formats to support families in their deliberations of the bilateral CI option.

Planning for decision-support

Including patients in decisions about their health by providing research information is an important component of knowledge translation (Holmes-Rover et al., 2001; Coulter, 1997). Based on the results of this study, a knowledge translation tool to help families increase their knowledge about cochlear implantation prior to and during their decision-making would appear beneficial. The need for such a tool was pronounced for the bilateral CI decision. One approach to translating knowledge for health-care consumers is through the use of patient decision aids (O'Connor & Edwards, 2001). Decision aids are "tools designed to help people participate in decision making about health care options. They provide information on the options and help patients clarify and communicate the personal value they associate with different features of the options" (International Patient Decision Aid Standards, 2008).

Decision aids can be particularly helpful in situations where a choice between two or more treatments options is available and no clear standard of care is available based

on evidence (O'Connor & Edwards, 2001). They have been shown to improve the decision-making quality and process, to decrease anxiety, and to create more realistic expectations of outcomes (O'Connor et al., 2002). Currently, no decision aid exists for the decision to undergo paediatric unilateral or bilateral cochlear implantation (Cochrane Inventory of Patient Decision Aids, 2008).

Limitations

By interviewing only parents after their CI decision there would have been potential for the parental perceptions to have been influenced by recall bias, decisional regret, and parents' need to appear content with their decision. This was addressed by including interviews of parents involved in prospective decision-making. We attempted to purposefully sample families who had chosen not to undergo cochlear implantation but these families chose not to participate.

The sample size for this study was relatively small. As only 20-24 children are implanted each year in the study CI centre, only 30-36 children were eligible to participate based on the inclusion criteria. The participant pool was further reduced because approximately 20% of the population in this clinic was French speaking and the interviews were only conducted in English. During the interviews, similar themes emerged from the parents indicating that sufficient data saturation was achieved even with the small sample.

Some demographic information was not collected from the participants. This included socioeconomic status, family support, and immigration status. These factors may also have had an impact on the decision-making of families. The clinical characteristics that were included and explored in the study (i.e., child's age at identification, co-existing health issues, and aetiology of hearing loss) could not be generalized to the entire population of families due to the small sample size in this study. Future research should explore the influence of all of these factors in a larger sample of families.

Only a single CI site was included in this study. This centre has a strong emphasis on auditory-verbal therapy as the dominant treatment option for children and families. Families and clinicians from other centres may have different perceptions of the CI decision-making process.

Conclusions

The interviewed parents reported that their decision to undergo cochlear implantation for their children with severe to profound hearing loss was related to the value that their family placed on oral communication. Comprehensive information on the risks and benefits associated with cochlear implantation should be offered to all families. Parents also benefit from their interactions with, and the support offered by, families who have already made their choice. While the choice for a single CI appeared to be a value-based and presented little decisional conflict, the situation was more complex for parents contemplating a bilateral CI. Bilateral CI decision-

making should be addressed systematically in future research to further understand and support parents of children with bilateral severe to profound hearing losses.

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Appendix: Cochlear Implant Needs Assessment Semi-Structured Interview Guide

- 1) Can you tell me about the first few days and weeks after you found out about your child's hearing loss? What were the most important decisions that you faced early on?
- 2) Let's focus on the cochlear implant decision. How were you introduced to the topic of cochlear implants?
- 3) Can you describe your experience in making the decision to implant or not?
- 4) How did you feel when you had to make this decision? Were you:
 - unsure about what to do worried what could go wrong distressed or upset
 - constantly thinking about the decision wavering between choices or changing your mind delaying the decision
 - questioning what is important to you feeling physically stressed—tense muscles, racing heartbeat, difficulty sleeping
- 5) What made this decision difficult to make? Were you?
 - lacking information about options, pros and cons lacking information on the of benefits and harms
 - unclear about what is important to you lacking information on what others decide feeling pressure from others
 - lacking support from others not feeling ready to make a decision lacking the ability to make this type of decision
- 6) Thinking about the cochlear implant decision, which options were there for your family?
- 7) What do you see as the main advantages and disadvantages of these options?
- 8) Who was most involved in helping you make this decision?
- 9) Thinking about the clinic staff you encountered, how were they usually involved in making this decision? Did they:
 - make the decision for you, share the decision with you,
 - providing support or advice for you to make the decision on your own
- 10) How did you go about making such a decision? Did you:
 - get information on choices get information on how likely the choices are consider how important choices are,
 - get information on how others decide find ways to handle pressure get support from others
- 11) What helped you to make this decision?
- 12) What gets in the way of making this decision?
- 13) What else is needed?
- 14) I will list possible ways to help people with decisions, which ones do you think may be useful for you?
 - Counseling from health practitioner Discussion groups of people facing the same decisions,
 - Information materials If yes, type of medium----> booklets, pamphlets videos CD ROMS Internet
 - other, specify _____
- 15) Who do you think should prepare information about this decision?
 - health societies expert medical and health practitioners government consumer associations
 - cochlear implant companies
- 16) Bilateral cochlear implants are now emerging as an option for children with bilateral hearing loss. Is there anything you would like to add about this issue?