

**THE DEVELOPMENT OF A PRE-IMPLANTATION  
TOOL FOR RATING THE INDIVIDUALISED  
INFORMATION AND SUPPORT NEEDS OF  
PARENTS OF YOUNG COCHLEAR IMPLANT  
CANDIDATES**

BY ILOUISE LE ROUX

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SUPERVISOR: Dr Catherine van Dijk  
CO-SUPERVISOR: Talita van der Spuy

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## SUMMARY

<b>Title:</b>	The development of a pre-implantation tool for rating the individualised information and support needs of parents of young cochlear implant candidates
<b>Name:</b>	Ilouise le Roux
<b>Promotor:</b>	Dr Catherine van Dijk
<b>Co-promotor:</b>	Talita van der Spuy
<b>Department:</b>	Communication Pathology, University of Pretoria
<b>Degree:</b>	M. Communication Pathology

Cochlear implantation is a proven and accepted option for young children with profound hearing loss. Cochlear implantation requires a professional team which should inform, guide, support and collaborate with parents constantly throughout the process. Existing programs for children with hearing loss and their families are generally designed on the basis of what experts believe they should contain, rather than on what parents actually wish to receive, which may often lead to a mismatch between the professionals view and the parents' views of parental needs. In order to ensure that parental needs are appropriately addressed it is imperative that professionals investigate and understand the individual needs and desires of the parents with whom they collaborate. This can be managed by carefully tailoring information to their individual needs and presenting information in an accessible format at the time it is most appropriate and digestible.

The aim of this research study was to develop a pre-implantation tool to rate the individual support and information needs of parents of young cochlear implant candidates. Within the context of applied research, a qualitative descriptive intervention research design was used in the study. Ten parents of children with cochlear implants participated in a semi-structured interview to investigate their need for information and support during the pre-implantation phase of cochlear

implantation. Their responses were analysed and compared to relevant literature in order to develop the pre-implantation rating tool for parents of cochlear implant candidates.

The rating tool consists of ten areas for information and support. These areas are as follows: general, technical, surgery, social support, financial, communication options, education, outcomes, rehabilitation and parental role. Parents are able to rate which areas of information and support is important to them and what they would like to discuss with the professional involved. Parents are also encouraged to identify any area of information and support that is not included in the rating tool that they would want information on from the cochlear implant team.

This rating tool was evaluated by eight speech-language pathologist/audiologist working in six cochlear implant programmes in South Africa to determine the value of the rating tool. Positive responses were given about the adaptability of the tool to identify individual needs for support and information and the tool would be useful to guide speech-language pathologist/audiologists to identify needs of parents that should initially be addressed. Respondents agreed that the rating tool provides an opportunity to express parent's individual needs for information and support; that the tool correlates with a family centered approach and would be useful to include in cochlear implant programs. The majority of participants felt the rating tool possibly will be effective in identifying information and support needs of parents before cochlear implantation and respondents would be willing to implement the rating tool in their cochlear implant programme. The positive response from professionals working in the field of cochlear implantation validates the effectiveness of the rating tool.

**KEY WORDS:** children, cochlear implants, information needs, parents, pre-implantation, rating tool, support needs.

## OPSOMMING

<b>Titel:</b>	Die ontwikkeling van 'n pre-inplantering instrument om die individuele inligting en ondersteunings behoeftes van ouers van jong kogleêre inplantings kandidate te bepaal.
<b>Naam:</b>	Ilouise le Roux
<b>Promotor:</b>	Dr Catherine van Dijk
<b>Mede-promotor:</b>	Talita van der Spuy
<b>Departement:</b>	Kommunikasiepatologie, Universiteit van Pretoria
<b>Graad:</b>	M. Kommunikasiepatologie

Kogleêre inplantering is 'n beproefde en aanvaarde opsie vir jong kinders met 'n uitermatige gehoorverlies. Kogleêre inplanting vereis dat 'n professionele span ouers deur die proses inlig, lei en ondersteun. Huidige programme vir kinders met gehoorverlies en hulle gesinne, is oor die algemeen gebaseer op grond van inligting wat volgens kundiges belangrik is om in te sluit. Hierdie programme is nie noodwendig gebaseer op inligting ouers graag wil ontvang nie. Dit kan lei tot 'n verskil tussen die perspektief van professionele persone teenoor die van die ouer oor ouer- behoeftes aan inligting. Om te verseker dat ouers se behoeftes effektief aangespreek word, is dit noodsaaklik om dit te ondersoek en die individuele behoeftes van ouers te verstaan. Dit kan gedoen word deur inligting aan te pas volgens die individuele behoeftes van ouers en die inligting te verskaf in 'n toeganklike wyse op 'n gepaste tyd wanneer dit geskik is en die ouer die inligting kan prosessee.

Die doel van hierdie navorsing studie was om 'n pre-inplantering instrument te ontwikkel om die individuele behoeftes aan inligting en ondersteuning van ouers van jong kogleêre inplantings kandidate te bepaal. Binne die konteks van toegepaste navorsing is 'n kwalitatiewe beskrywings intervensie navorsingsontwerp gebruik. Tien ouers van kinders met kogleêre inplantings het deelgeneem aan 'n semi-gestruktureerde onderhoud. Die onderhoud het ouers

se behoefte aan inligting en ondersteuning tydens die pre-inplanterings fase van kogleêre inplantasie ondersoek. Die resultate is geanaliseer en vergelyk met relevante literatuur om sodoende die pre-inplantering bepaling instrument vir ouers van kogleêre kandidate te ontwerp.

Die instrument bestaan uit tien areas van inligting en ondersteuning. Hierdie areas is as volg: algemeen, tegnies, chirurgie, sosiale ondersteuning, finansieel, kommunikasie opsies, onderrig, rehabilitasie en ouer rol. Ouers kan bepaal watter areas van inligting en ondersteuning vir hulle belangrik is en wat hulle graag wil bespreek met die professionele persone betrokke by die kogleêre inplanting proses. Ouers word ook aangemoedig om enige area van inligting en ondersteuning te identifiseer wat moontlik nie ingesluit is in die instrument nie, maar wat hulle graag met die kogleêre span wil bespreek.

Agt spraak-taal patoloë/audioloë van ses kogleêre inplantings programme in Suid-Afrika het die instrument geëvalueer om die waarde daarvan te bepaal. Positiewe insette is gegee oor die aanpasbaarheid van die instrument om die individuele behoeftes vir inligting en ondersteuning te bepaal; dat die instrument betekenisvol is om die spraak-taal patoloog/audioloog te lei om die behoeftes van ouers te identifiseer en aan te spreek; dat die instrument ooreenstem met 'n familie- gesentreerde benadering en dat die instrument effektief ingesluit kan word in kogleêre inplantings programme. Die meeste deelnemers het aangedui dat die instrument effektief sal wees in die identifisering van inligting en ondersteunings behoeftes van ouers voor 'n kogleêre inplanting. Deelnemers het aangedui dat hulle bereid sal wees om die instrument te implementeer in hulle kogleêre inplantingsprogram. Die positiewe respons van spraak-taal patoloë en audioloë dui op die geldigheid en effektiwiteit van die instrument.

**Sleutelwoorde:** Bepaling instrument, kinders, kogleêre inplantings, inligtings behoeftes, ondersteunings behoeftes, ouers, pre-inplantasie.



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## CHAPTER 1

### INTRODUCTION AND ORIENTATION

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*"All our knowledge has its origins in our perceptions."-Leonardo Da Vinci*

#### **1.1 INTRODUCTION**

Cochlear implantation is an elective operation for those individuals who have profound sensory-neural hearing loss (Discolo & Hirose, 2002:114). A cochlear implant bypasses the dysfunctional cochlea and stimulates the auditory nerve fibres directly (Archbold, Sach, O'Neill, Lutman & Gregory, 2006:191). Cochlear implantation is a proven and accepted option for young children with profound hearing loss. More than 45 000 children have been implanted worldwide (Archbold et al, 2006:191), while in South Africa, the number of children with cochlear implants has grown to more than 400 (SACIG, 2010). Earlier age of implantation has emerged over the last few years largely as a result of newborn hearing screening that assists in earlier identification of hearing loss. Children as young as seven months are now considered candidates for cochlear implantation (Kaltenbrunn & Louw, 2005:22). Another motivation for earlier cochlear implantation is that children that receive cochlear implants at a younger age demonstrate earlier and improved spoken language development (Discolo & Hirose, 2002:114).

The process of cochlear implantation includes potentially stressful decision-making, irreversible surgery, and very intensive rehabilitation (Most & Zaidman-Zait, 2001:99). Firstly, parents must manage the process of deciding whether to choose a cochlear implant as the sensory aid for their child, later on they must deal with the anxiety and fear prior to and during the surgery, and finally parents must be dedicated to an extensive rehabilitation process (Zaidman-Zait & Most, 2005:130). Cochlear implantation requires a professional team which should

inform, guide, support and collaborate with parents constantly throughout this process (Most & Zaidman-Zait, 2001:100). The professional team involved in the pre-implantation phase typically consists of an Ear Nose and Throat (ENT) surgeon, an audiologist, a speech–language pathologist, a psychologist and educators for children with hearing loss (Ertmer, 2005:24). The ENT surgeon is involved in the pre- operative medical and radiological evaluations and later cochlear implant surgery. The audiologist assists in the hearing evaluations and hearing aid fittings as well as the mapping of the processor after the surgery. The speech-language pathologist evaluates the pre- and postoperative communication skills of the candidate. When the need exists, a psychologist performs psychological assessments and counselling. In some cases, social workers may be involved in the pre- implantation evaluation. In addition, educators for children with a hearing loss play an important role in providing information about school related issues and options available to the parents of cochlear implant candidates (Ertmer, 2005:25).

A child may be considered as a candidate for a cochlear implant when the child is diagnosed with a sensory–neural hearing loss of  $>90\text{dBHL}$  (Owens et al., 2006:361). Hearing aids are fitted and trailed for a period of three to six months. Children who fail to benefit from hearing aids are referred for consideration for a cochlear implant (Owens et al., 2006:362). The decision on whether a cochlear implant is necessary is made in a multidisciplinary setting. It relies on clinical, audiological and radiological evaluation (Owens et al., 2006:362).The clinical evaluation begins with a detailed history of the child’s hearing loss, language development, medical history, education history, availability of support services, family structure and support, communication style, cognitive ability and learning style as well as expectations of the family (Hellman et al., 1991:78). Audiological evaluation involves a battery of tests, depending on the child’s age, to assess the benefits of cochlear implantation (Owens et al., 2006:362). Radiological evaluation involves computed tomography (CT) and magnetic resonance imaging (MRI) of the temporal bones (Owens et al., 2006:362).Before implantation can

commence it is vital to make sure that parents understand and support the long-term commitment involved in the cochlear programme. They should be informed that without parental support the best functional outcome is unlikely to be achieved (Owens et al., 2006: 363).

Several different professionals on the cochlear implant program provide information and support. In a study on parents' perception three years after cochlear implantation, much emphasis was placed on the need of parents to obtain as much information as possible prior to implantation (Archbold et al., 2002:36). It has been established that the provision of adequate information leads to reduced parental stress (Edwards, MacArdle, Doney & Bellman, 2000:96). The areas of information include medical, technical, communication, and educational information (Most & Zaidman-Zait, 2001:106). Parents are given vast amounts of information during the pre-implantation selection process. The information is often given verbally and/ or in written forms. The information typically includes the following: what a cochlear implant is; how it works; how the speech processor works and is maintained; different processing strategies; how to cope with minor faults and guidelines on safety issues for cochlear implant users. This information is given to supplement information about how the cochlear implant programme is structured and managed, and what assessments are necessary in the pre-implantation phase of the cochlear implantation as well as rehabilitation that will follow after the cochlear implant (Edwards et al., 2000:97). Parents are often provided with contact numbers of schools for children with hearing loss. Financial issues are discussed as well as realistic expectations with regard to the expected outcomes of a cochlear implant.

It is reported that parents prefer to receive these types of information from several key professionals, preference given to information from the surgeon, audiologist and speech-language pathologist, and to a lesser extent, from the social worker and psychologist (Most & Zaidman-Zait, 2001:103). The aforementioned study reported on the needs of parents of cochlear implant

candidates. Parents reported on needs that were not addressed or lacked in the cochlear implant process. They indicated that they mostly lacked emotional support from the cochlear implant team members (Zaidman-Zait & Most, 2001:105). Emotional support referred to incidents where professionals calmed parents down during stressful situations, cared for parents, showed empathy, listened to parental concerns, expressed understanding for their situation, and encouraged them throughout the process of diagnosis, surgery and rehabilitation (Zaidman-Zait, 2007:221). Through the identification of such specific emotional needs of parents, it becomes possible and the responsibility on the part of the professional to address individual emotional needs of parents. It is important to remember that for all hearing parents who have a child who is deaf or hard hearing, the diagnosis represents a loss that must be grieved (Luterman, 2004:216). The variety of feelings experienced include: sadness, loss, guilt, anger, shock, despair, numbness and withdrawal (Anagnostou, Graham & Crocker, 2007:69). Numerous emotional, social, physical and economic stressors involved in raising a child with a hearing loss is also experienced by such parents (Feigin & Peled, 1998:20). Therefore there are continued efforts in the area of early intervention to focus on supporting parents rather than merely on providing services (Jean & DesJardin, 2003:392).

This approach of focusing on supporting parents rather than solely providing services is in accordance with the notion of family centred programmes, which serves as a tool to include family members in the cochlear implant process (Jessop, Kritzinger & Venter, 2007:47). The American Speech-Language-Hearing Association (ASHA) as well as the Health Professions Council of South Africa (HPCSA) advocates a continuous process of family focused service delivery (ASHA, 2008; HPCSA, 2007). The philosophy of family orientated programmes proposes that when professionals provide information and support to parents, it will empower parents to build collaborative partnerships and help parents adjust to the stressful situation of coping with a recently diagnosed child (Most & Zaidman-Zait, 2001:100). Existing programs for children with hearing

loss and their families are generally designed on the basis of what experts believe they should contain, rather than on what parents actually wish to receive, which may often lead to a mismatch between the professionals views and the parents' views of parental needs (Most & Zaidman-Zait, 2001:100).

The cochlear implant team members must therefore bear in mind that families are unique and vary in many ways. Each family's response to a child's hearing loss is different (Anagnostou et al., 2007:71). Parents may perceive the extra responsibilities of parenting a child with a hearing loss in very different ways (Jean & DesJardin, 2003:391). Individual families therefore have unique needs for information as well as the support provided by professionals.

This is especially true within the South African context with a population that is characterised by diverse social -economic, geographical, linguistic and cultural features (Louw & Avenant, 2002:146). Young cochlear implant candidates enter the cochlear implant programme from different socio-economic backgrounds. Children with poor social-economic environments encompass many challenges when faced with financial issues that accompany cochlear implantation and maintenance. Until recently, no state funding was available for cochlear implants in South Africa (Jessop et al., 2007:47). However, a few government hospitals have sponsored cochlear implants to underprivileged children in their communities (e.g. Universitas Hospital, Baragwanath Hospital and Pretoria Academic Hospital). Private funding for cochlear implants is also problematic, due to the decline in the percentage of medical aid contribution towards cochlear implants (Muller & Wagenfeld, 2003:58). More than half of the population in South Africa live in rural areas which have a negative impact on the accessibility to early intervention services (Van der Spuy, 2005:36). Cochlear implant teams serve families who speak one or more of the eleven official languages of South Africa. Professionals face a considerable language barrier due to the fact that very few professionals speak an African language (Louw & Avenant, 2002: 145). The diversity in socio -economic, geographical, linguistic and cultural features



within the South African population has a significant influence on the individual information and support needs of parents before cochlear implantation. However, as citizens of a world populated by a diversity of classes, genders, races and cultures; speech- language pathologists and audiologist should concern themselves with the everyday, lived experiences of most of the world's people (Kathard et al, 2007:7). The development and improvement of the profession should be guided by the scope of practice and the populations to be served in the unique South African context (Kathard et al., 2007:10) The policy changes in South Africa have provided a fertile conceptual resource to consider issues of social justice, equality and anti-discrimination (Kathard et al., 2007:6).

South Africa has seven main programmes with two of these that have satellite programmes performing cochlear implant surgery and providing counselling to this diverse population. These programmes are: The Tygerberg Cochlear Implant Programme in Cape Town with a satellite mapping programme in East London, the Pretoria Cochlear Implant Programme with a satellite mapping programme managed from the Ear Institute in Pretoria, the Military Cochlear Implant Programme in Pretoria, the Johannesburg Cochlear Implant Programme, the Durban Cochlear Implant Programme, the Port Elizabeth Cochlear Implant Programme and the Bloemfontein Cochlear Implant Programme (SACIG, 2008).

These programs provide services to the population characterised by diversity in socio-economic, geographical, linguistic and cultural features as discussed. South Africa is commonly referred to as the “rainbow nation” due to the broad diversity in race, culture and language characteristics of the population. When professionals of the cochlear implant programme deal with parents of different linguistic and cultural backgrounds, it complicates the process of providing information and support tailored to their individual needs.

## **1.2 RATIONALE**

It is of utmost importance to consider the diverse socio-economic, geographical, linguistic and cultural features when providing family centred cochlear implant services to South African parents. The ability to put oneself in the family's unique situation and to look from their perspective often provides a more realistic understanding of their concerns and needs, and results in a stronger partnership with the family (Johnson, Benson & Seaton, 1997:142).

In order to ensure that parental needs are appropriately addressed it is imperative that professionals investigate and understand the individual needs and desires of the parents with whom they collaborate (Christiansen & Leigh, 2002 in Most & Zaidman-Zait, 2001:100). Parents may have similar areas of information and support needs, but individual differences exist in the priority that these needs have for different parents. Many parents may feel overwhelmed by the extent and complexity of information provided about the cochlear implant process. This can be managed by carefully tailoring information to their individual needs and presenting information in an accessible format at the time it is most appropriate and digestible (Edwards, MacArdle, Doney & Bellman, 2000:104).

The rationale of the study is therefore that there is currently no pre-implantation tool locally available for professionals to identify and rate the individual support and information needs of parents of young cochlear implant candidates. A pre-implantation rating tool of these needs is required in order to ensure that parental needs are addressed according to the priorities of each family.

### **1.3 RESEARCH QUESTION**

The need evidently exists to approach each family on an individual basis, as each has their own needs for emotional support and information (Perold, 2001:54, Johnson et al., 1997:144, Louw & Avenant, 2002:145). The manner in which to identify these individual needs of families are being extensively researched internationally (Most & Zaidman-Zait, 2001:99, Archbold et al., 2006:191).

The question arises: how can the cochlear implant team ensure that they identify the information and support needs that are most important to the parents? Therefore, a rating tool should be developed that would be useful to South African cochlear implant programmes in considering the individual needs of parents as they receive their first pre-implantation session with their audiologist or speech- language pathologist (Anagnostou et al., 2007:82).

In order to meet the abovementioned requirements, the rating tool could be used by parents to rate their needs for information and support according to their individual priorities. The rating tool must be adaptable in order to rate the needs of every family that enters the pre –cochlear implantation process. The rating tool must be able to guide the professional to identify the specific type of information and support that is important to the family and the amount of information that they are ready to process. The focus of the rating tool must therefore be to identify and consider what information and support is most important to parents during the pre-implantation phase rather than what professionals believe is important to present to parents (Archbold, 2002:16).

The research question of the proposed study is therefore: **What tool can be used by the cochlear implant team to ensure that they identify the individual support and information needs of parents of young cochlear implant candidates?**

## **1.4. DIVISION OF CHAPTERS**

### **1.4.1 Chapter 1: Introduction and orientation**

Chapter one outlines the introductory orientation to the research study. An introduction of current research of the topic is described. The rationale for the study as well as the research question is formulated and explained within the context of the study field. All relevant concepts and terms related to the subject are defined and serve as a road map for the researcher.

### **1.4.2 Chapter 2: Literature review**

This chapter enfolds the theoretical component of the study. The concepts and constructs regarding the subject are included by means of a literature review. The focus of this chapter is to critically evaluate the existing research on the information and support needs of parents before the cochlear implantation of their child and to determine the value and relevance of these studies on the research project. The relevant areas that are critically discussed in this chapter are: The significance of early identification and intervention of hearing loss; the diagnosis of a hearing loss; early intervention; cochlear implantation in children; support needs of parents; information needs of parents and the South African context.

### **1.4.3 Chapter 3: Method**

The aim of chapter three is to describe the method of the research study. The research design, the main aim and sub-aims of the study are described and attributes to finding the answer to the research question. Within the context of applied research, a qualitative descriptive intervention research design was used in the study and data collection included the use of a semi-structured interview. A description of the participants, material and apparatus used and data collection, - recording and - analysis procedures are included in this chapter in such a way

that the reader or any other researcher will be able to duplicate the study exactly in every aspect.

#### **1.4.4 Chapter 4: Results and discussion**

Chapter four presents all the collected and processed data as research results and findings. These results as well as the results from the literature review served as basis of the construction of the rating tool. The rating tool is presented and discussed in this chapter. The results are followed by the discussion and interpretation of each finding according to the different sub-aims.

#### **1.4.5 Chapter 5: Conclusions and recommendations**

The results of each sub-aim are concluded in this chapter and the conclusions of the study are discussed based on the findings of the study. Clinical implications for the Bloemfontein Cochlear Implant Program, audiologists and possible cochlear implant candidates are discussed and are followed by a critical evaluation of the study. Recommendations regarding further research are indicated.

### ***1.5 DEFINITION OF TERMS***

The following terms are defined in order to clarify the meaning for this study.

#### **Cochlear implantation**

Cochlear implantation is an elective operation for those individuals who have a profound sensory-neural hearing loss (Discolo & Hirose, 2002:114). The cochlear implant bypasses the dysfunctional cochlea and stimulates the auditory nerve directly (Archbold, et al, 2006:191).

### **Early intervention**

Early intervention refers to the evaluation and treatment of neonates and young children that present with a confirmed risk for a developmental delay (Rossetti, 1996:21).

### **Information needs**

Information needs refers to what information parents require about the procedure and likely outcomes of cochlear implantation in order to make an informed decision (Archbold, Sach, O'Neill, Lutman & Gregory, 2008:120).

### **Pre- implantation**

Pre- implantation refers to the period between the diagnoses of the hearing loss to the time where cochlear implant surgery is performed. This involves the decision-making process where it is decided if a cochlear implant is the best sensory aid for a patient with a profound hearing loss (Most & Zaidman-Zait, 2001:99).

### **Post-implantation**

Post- implantation refers to the period after the cochlear implant surgery and includes rehabilitation and programming of the cochlear implant processor is performed.

### **Profound hearing loss**

Hearing loss that is greater than 90 dBHL is defined as profound hearing loss (Owens, 2006:361).

### **Support needs**

Emotional support referred to incidents where professionals calmed parents down during stressful situations, cared for parents, showed empathy, listened to parental concerns, expressed understanding for their situation, and encouraged

them throughout the process of diagnosis, surgery and rehabilitation (Zaidman-Zait, 2007:221).

## **1.6 ACRONYMS**

The following acronyms are used throughout the study and are clarified as follows:

**ABR:** Auditory Brainstem Response.

**AIDS:** Acquired Immunodeficiency Syndrome.

**ASHA:** America Speech and Hearing Association.

**ASSR:** Auditory Steady State Response.

**BCIP:** Bloemfontein Cochlear Implant Program.

**dBHL:** Decibel hearing level.

**EHDI:** Early detection and intervention.

**ENT:** Ear, nose and throat specialist.

**Hi- HOPES:** Home- Intervention- Hearing and language Opportunities Parent Education Services.

**HPCSA:** Health Professionals Council of South Africa.

**JCIH:** Joint Committee of Infant Hearing.

**OAE:** Oto- Acoustic Emissions.

**SACIG:** South African Cochlear Implant Group.

**UNHS:** Universal Newborn Hearing Screening.

## **1.7 CONCLUSION**

Cochlear implantation requires a professional team to inform, guide, support and collaborate with parents constantly throughout the process (Most & Zaidman-Zait, 2001:100). By providing information and support through focussing on

family's priorities and by engaging in an open process of assessing, listening and negotiating with families, professionals can create a relationship in which parents feel valued and through which professionals and parents develop a mutual respect and understanding of each other's values and perspectives (Eleweke et al., 2008: 200). It is of utmost importance to consider the diverse socio-economic, geographical, linguistic and cultural features when providing family centred cochlear implant services to South African parents. Each family is unique and should be regarded as an individual unit with its own values, beliefs, practices and needs (Louw & Avenant, 2002:145). As mentioned, the ability to put oneself in the family's unique situation and to look from their perspective often provides a more realistic understanding of their concerns and needs, and results in a stronger partnership with the family (Johnson, Benson & Seaton, 1997:142). In order to meet the abovementioned requirements, a rating tool could be used by parents to rate their needs for information and support according to their individual priorities. The focus of the rating tool should be to identify and consider what information and support is most important to parents during the pre-implantation phase rather than what professionals believe is important to present to parents (Archbold, 2002:16).

## **1.8 SUMMARY**

This chapter outlined the introductory orientation to the research study. An introduction on current research on the topic was described. An outline of the chapters was discussed and terms and definitions of concepts were provided. Cochlear implants have opened a new world for children with profound hearing loss as well as for their families. Parents who are in the decision-making process of cochlear implantation have unique needs for information and support provided by professionals. The question arises: What tool can be used by the cochlear implant team to ensure that they identify the individual support and information needs of parents of young cochlear implant candidates? A rating tool should be



developed that could be useful to the South African cochlear implant programmes in considering the individual needs of parents as they receive their first pre-implantation session with their audiologist or speech- language therapist (Anagnostou et al., 2007:82).

## CHAPTER 2

### YOUNG COCHLEAR IMPLANT CANDIDATES AND THEIR PARENTS: EARLY IDENTIFICATION AND INTERVENTION IN THE SOUTH AFRICAN CONTEXT

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*“Learn everything you can, anytime you can, from anyone you can  
-there will always come a time when you will be glad you did.”*

*- Sarah Cladwell*

#### **2.1. INTRODUCTION**

Hearing loss has been described as the most common childhood disability (Eleweke, Gilbert, Bays & Austin, 2008: 194). It is estimated that 718 000 infants are either born with, or acquire early-onset, permanent bilateral hearing impairment every year (Swanepoel, Störbeck & Friedland, 2009:1). This figure therefore suggests that almost 2000 babies are born daily with, or acquire permanent bilateral hearing loss around the world (Swanepoel, Störbeck & Friedland, 2009:1). Evidence indicates that the prevalence of permanent childhood hearing loss continues to increase through infancy (Eleweke, Gilbert, Bays & Austin, 2008:194).

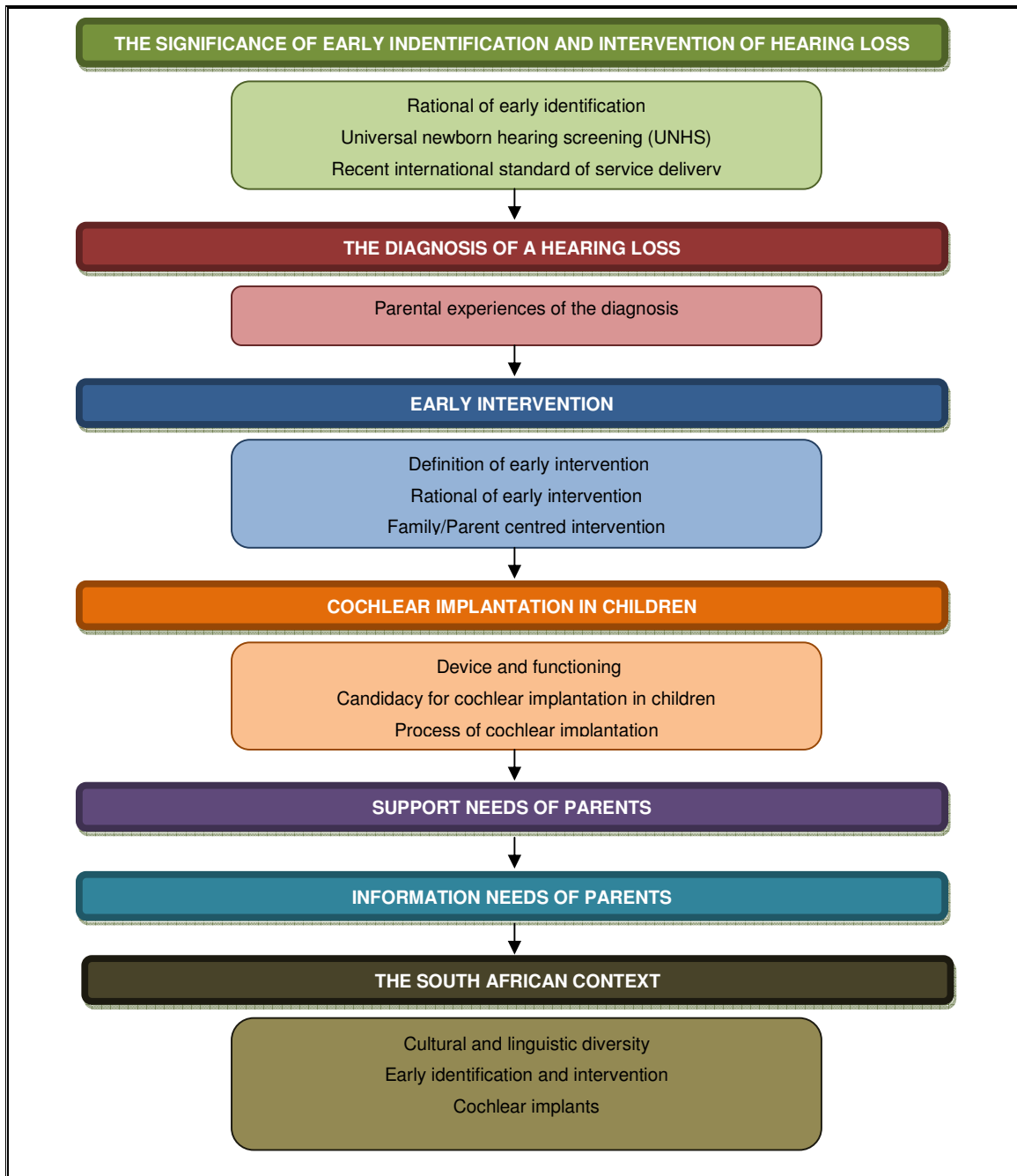
The impact of hearing loss in infancy and early childhood is profound. This is because virtually every aspect of communication and language learning is subserved by early access to phonology of speech and the effects of an inability to access phonological inputs are pervasive (Niparko & Blankenhorn, 2003: 267). Congenital hearing loss is associated with delayed language, learning, and speech development early in life as well as low educational and occupational performance in adulthood (Keren, Helfand, Homer, McPhillips & Lieu, 2002: 855). In a study on the economic burden of hearing impairment, it has been estimated that severe to profound hearing loss of pre-lingual onset is expected to have an expenditure of approximately one million dollars over the lifetime of an individual that society must carry (Durieux- Smith, Fitzpatrick & Whittingham, 2008: 1).

The continued development and improvement in technology in early identification, diagnosis and intervention is giving hope to families and children with hearing disabilities. The development of modern diagnostic and audiologic methods significantly decreases the age limits for diagnosis and management of congenital or acquired pre-lingual deafness (Profant, Kabatova & Simkova, 2008:369). Due to universal newborn hearing screening (UNHS) and early hearing detection and intervention (EDHI) programs, both the age of identification of hearing loss and age at entrance into intervention programs are dropping from an average of a two-year age level to within the first few months of life (Yoshinaga-Itano, 2003:252).

The influx of young infants identified with hearing loss through successful hearing screening programs has established a need for amplification resources for infants within the first 12 months as the use of amplification is commonly the first step in treating hearing loss (Gabbard & Schryer, 2003:236). Cochlear implantation has been called the modern miracle and is now firmly established as an effective option for children with severe and profound hearing loss (Müller & Wagenfeld, 2003: 57). Over the past few years, cochlear implantation at a younger age has emerged. Children as young as seven months are now considered as candidates for cochlear implantation (Kaltenbrunn & Louw, 2005:22).

Cochlear implantation requires a professional team to inform, guide, support and collaborate with parents constantly throughout the process (Most & Zaidman-Zait, 2001:100). By providing information and focussing on the family's priorities and by engaging in an open process of assessing, listening and negotiating with families, professionals can create a relationship in which parents feel valued and it can also promote the development of mutual respect and understanding of each other's values and perspectives (Eleweke, Gilbert, Bays & Austin, 2008:200). It is for these reasons that the aim of this research is to develop a pre-implantation tool to rate the individual support and information needs of

parents of young cochlear implant candidates. The aim of this chapter is to describe the relevant theoretical concepts of early diagnosis, intervention and cochlear implants defined by recent literature. These concepts and themes form a basis for the planning of the execution of this study. Theoretical concepts that are applicable for this study are set out in Figure 1.



**Figure 1:** Outline of theoretical concepts discussed in literature study

## ***2.2 THE SIGNIFICANCE OF EARLY IDENTIFICATION AND INTERVENTION OF HEARING LOSS***

### **2.2.1. Rational of early identification**

The rational of early identification of hearing loss is based on three important factors. Firstly, one of the most identifiable reasons is that hearing loss is described as the most common childhood disability (Eleweke, Gilbert, Bays & Austin, 2008:194). Secondly, it is a recognised fact that unidentified hearing loss leads to irreversible language, speech and cognitive delays, with far-reaching social and economic ramifications (Swanepoel, 2004:36). The third reason is that there are far-reaching positive outcomes associated with early identification of hearing loss in infants (Yoshinaga- Itano, 2001:62).

Between one and two children per 1000, live births have a moderate or greater bilateral permanent hearing loss (Grill, Uus, Hessel, Davies, Taylor, Wasem & Bamford, 2006: accessed 7 /7/2009). Since screening using high-risk criteria, fails to identify 50% of children with a hearing loss, the Joint Committee of Infant Hearing (JCIH) (1994), endorsed the National Institute of Health consensus statement (NIH, 1993) goal. Whereby it is recommended that all infants be screened during the first three months of life (Durieux- Smith, Fitzpatrick & Whittingham, 2008:1).

Children with congenital hearing impairment benefit from early detection and management of their hearing loss. The neurological development of auditory pathways requires acoustic stimulation in the first 18 months of life (Grill et al, 2006). There is compelling evidence that children born with hearing loss who have been identified and begun intervention by six months of age will have significantly better language development than their peers who were identified at an older age only (Gabbard & Schryer, 2003:236). Early identification and intervention thus has an impact on the quality of life of a child.

A study by Yoshinaga-Itano and Gravel (2001:63) summarises the most compelling outcomes associated with early identification as follows:

- Children with early-identified hearing loss who receive appropriate intervention services demonstrate significantly better language, speech, and social emotional development than later identified children.
- Early identified children who received intervention have language development similar to their nonverbal cognitive development.
- The better the language development, the less parental stress there is, and the better personal-social development of children.
- In general, children with early identified hearing loss tend to have better speech development as a result of better language development.

Numerous investigators have documented the validity, reliability and effectiveness of early identification of infants with hearing loss (JCIH, 2000:798). Early identification has been made possible through the development of modern diagnostic and audiologic methods as well as the implementation of universal newborn hearing screening (Profant, Kabatova & Simkova, 2008:369).

### **2.2.2 Universal Newborn Hearing Screening (UNHS)**

There has been remarkable growth in early hearing loss identification, diagnosis and intervention programs during the past 15 years (Swanepoel, Louw & Hugo, 2007:321). The issue of efficacy of early identification and early intervention has been of great concern to the medical profession and policy makers due to the advent of universal newborn hearing screening (Yoshinaga-Itano, 2003:252). In 1993, the National Institute of Health consensus statement stated that all infants must be screened during the first three months of life (Durieux- Smith et al., 2008:2). In 2000, the Joint Committee on Infant Hearing (JCIH) endorsed UNHS and promoted early detection and intervention (EHDI) for infants with hearing loss (JCIH, 2000:798). A direct result of these programs is that both the age of

identification of hearing loss and age at entrance into intervention programs are dropping from an average of a two year age level to within the first few months of life (Yoshinaga-Itano, 2003:252).

Technological advancements in Audiology have made early detection of hearing loss a viable and practicable option (Theunissen & Swanepoel, 2008: 24). Newborns are screened by one of two objective test of auditory function, namely: automated auditory brainstem responses (ABRs) or evoked oto-acoustic emissions (OAEs) (Samsang-Fang, Simons- McCandless & Shelton, 2000:77). Both automated ABRs and OAEs provide non-invasive recordings of physiologic activity underlying normal auditory function and have been successfully used in UNHS and these procedures are described as the only reliable method of newborn hearing assessment (JCIH, 2007: 9).

UNHS is not only focussed on the early detection of a hearing loss in infants but also on early intervention that is managed through early hearing detection and intervention (EHDI) programs. The goal of EHDI programs is to maximise the linguistic and communicative competency and literacy development of children who are hard of hearing or deaf (JCIH, 2000: 798). These early intervention programs are to be family-centred, interdisciplinary, are culturally sensitive, and should build on informed choices for families (JCIH, 2000:798). Hearing screening is thus only one critical component of the EHDI program.

UNHS has made a remarkable difference in the lives of children with hearing loss and their families. It was possible with later-identification of hearing loss for children to develop strong language, speech, auditory, and social-emotional skills. However, the likelihood of successful communicative outcomes was significantly increased from a 35% likelihood of success to a 80% probability for children with significant hearing loss and no additional disabilities born in hospitals prior to, as compared to after, the establishment of universal newborn hearing (Yoshinaga-Itano & Thomson, 2008:14).

### **2.2.3. Recent international standard of service delivery**

Neonatal hearing screening programs are currently being implemented in all 51 states of the USA, with 41 states reportedly screening 90% or more of all live births (Theunissen & Swanepoel, 2008:24). Other countries such as the United Kingdom, Australia, Austria, Taiwan, Belgium, Canada, Japan, Sweden, Spain and Germany are developing and implementing UNHS/ EDHI programs (Yoshinaga- Itano, 2003:252).

It is thus clear that neonatal hearing screening is increasingly becoming the golden standard of early identification of hearing loss in infants around the world. Fair and Louw (1999:15) describes four components of service delivery in early intervention. These components consist of (1) screening programs, (2) in –depth diagnostic evaluation, (3) delivery of intervention services and (4) the management of these components.

1. The JCIH position statement (2000) was revised in 2007 in order to provide updated principals and guidelines for early hearing detection and intervention programs (JCIH, 2007:1). The principles of early detection and intervention services are a physiologic measure no later than 1 month of age.
2. All infants who do not pass the initial screening should have the appropriate audiologic evaluations to confirm the presence of hearing loss no later than 3 months of age.
3. No infants with confirmed hearing loss should receive early intervention services any later than 6 months of age.
4. The EHDI system should be family centred with infant and family rights and privacy guaranteed through informed choice, shared decision making, and parental consent. Families should have access to information about all intervention and treatment options as well as counselling regarding hearing loss.



5. The child and family should have immediate access to high-quality technology including hearing aids, cochlear implants, and other assistive devices when appropriate.
6. All infants and children should be monitored for hearing loss in the medical home. Appropriate professionals should provide continued assessment of communication development to all children with and without risk indicators for hearing loss.
7. Professionals knowledgeable about hearing loss should provide appropriate interdisciplinary intervention programs for infants with hearing loss and their families. Intervention programs should recognise and build on strengths, informed choices, traditions, and cultural beliefs of the family.
8. Information systems should be designed and implemented to interface with electronic records and should be used to measure outcomes as well as to report the effectiveness of EHDI services at the patient, practice, community, state and federal levels (JCIH, 2007:5).

The above mentioned principles represent the ultimate outcomes of successful early identification and early intervention of infants with a hearing loss. The 2007 guidelines were developed to update the 2000 JCIH position statement principals and to support the goals of universal access to hearing screening, evaluation and intervention (JCIH, 2007:5). It is the responsibility of speech-language pathologist and audiologist to strive towards applying these principals while working with families who are going through a difficult time of dealing with the identification and diagnosis of their child's hearing loss.

## **2.3. DIAGNOSIS OF HEARING LOSS**

### **2.3.1. Parental experiences of the diagnosis**

Identification of hearing loss through universal newborn hearing screening programs have brought about a significant change in how and when parents learn about the possibility that their child may have hearing loss (Kurtzer- White & Luterman, 2003:233). Information about possible hearing loss is given at a vulnerable time in the family's life, when mothers are recovering from birth, parents and siblings are reworking their identities and roles in relation to the newest member, and emotional recourses are focused on establishing critical parent-infant connections (Kurtzer- White & Luterman, 2003:233).

It is also important to mention that more than 95% of children with hearing loss are born to hearing parents that have no previous experience and knowledge of raising a child with hearing loss (Eleweke, Gilbert, Bays & Austin, 2008:191). The realisation that a child has a hearing loss causes stress in families who have had little contact with people with hearing loss and who know little about the implication of a hearing loss (Feher- Prout, 1996:155).

The diagnosis of deafness in a child can be best understood in terms of loss (Luterman, 1997:75). Such a diagnosis in a child or infant can be emotionally devastating to parents (Eleweke, Gilbert, Bays, & Austin, 2008:191). It is important to remember that for all hearing parents who have a child who is deaf or hard hearing, the diagnosis represents a loss that must be grieved (Luterman, 2004:216). Several investigators have equated the diagnosis of disability and hearing impairment in a child to an experience similar to death for parents (Kurtzer- White & Luterman, 2003:233). This is why parents need time and space to mourn their loss just as if they had experienced death of a loved one (Luterman, 1997:73). The variety of feelings that parents experience during and shortly after the diagnosis includes: sadness; loss; guilt; anger; shock; despair; numbness as well as withdrawal (Anagnostou, Graham & Crocker, 2007:69).

Another response that arises very quickly in the grief process is the feeling of inadequacy (Luterman, 1997:74). There are numerous emotional, social, physical and economic stressors involved in raising a child with hearing loss (Feigin & Peled, 1998:20). Parents tend to want to turn over responsibility of their child to a professional in order to ensure a good result (Luterman, 1997:74). It is the responsibility of speech-language pathologist/audiologist to support the development of informed, independent as well as empowered families (ASHA, 2008).

## **2.4 EARLY INTERVENTION**

### **2.4.1. Definition of early intervention**

Early intervention refers to the evaluation and treatment of neonates and young children that present with a confirmed risk for a developmental delay (Rossetti, 1996:21). Early intervention with regard to hearing loss in children are characterised by a family-centred approach, culturally responsive practices, collaborative professional–family relationships, strong family involvement, developmentally appropriate practices, interdisciplinary assessment, and community-based provision of services (JCIH, 2007:18). The role of the audiologist in early intervention includes the timely fitting and monitoring of amplification devices, in addition to education and counselling for families in their ongoing participation in the child’s development. Audiologists furthermore provide direct rehabilitation services to infants and their families and also participate in the assessment of cochlear implant candidacy (HPCSA, 2007:8).

### **2.4.2 Rationale for early intervention**

Early intervention aims to prevent or at least reduce the negative consequences of childhood hearing loss and strives to enable children to participate in society through technology and rehabilitation (Fitzpatrick et al., 2008:39). The issue of

efficacy of early intervention has been of great concern to the medical profession and policy makers due to the advent of universal newborn hearing screening (Yoshinaga-Itano, 2003:252).

The rationale for early intervention is based on the positive research outcomes associated with early intervention services. It is estimated that children with hearing loss born in UNHS hospitals and who receive intervention before six months of age have a 80% probability of having language development within the normal range (Yoshinaga-Itano, 2003:253). Research indicated that children with early intervention initiated in the first twelve months of life have greater language abilities than those with early intervention initiated later than twelve months of age (Yoshinaga-Itano, 2003:255).

Parents of children who were identified early and receive early intervention, report benefits that extend beyond traditional communication outcomes (Durieux-Smith, et al., 2008:9). As described by parents, these benefits include early access to hearing, no regret about missing the hearing problem, and no sense of urgency to catch up in language development. Parents also place great value on the family-centred care provided in early intervention programs (Durieux-Smith, et al., 2008:9).

### **2.4.3 Family/parent centered intervention**

Family centered care is advocated as an important characteristic of best practices for infant hearing health services, from identification through to the intervention process (Fitzpatrick, Angus, Durieux-Smith, Graham & Coyle, 2008: 39). The American Speech-Language- Hearing Association (ASHA) as well as the Health Professions Council of South Africa (HPCSA) advocate a continuous process of family focused service delivery (ASHA, 2008; HPCSA, 2007).

It is for this reason that these early intervention programs are also referred to as parent-infant programs in some literature, as a result of their benefits to parents

and young children with hearing loss (Eleweke et al., 2008:194). It has been proposed that an intervention approach that values partnerships with families and promotes self-efficiency in parents may result in higher rates of follow-through, greater participation in early intervention, and improved outcomes for children with hearing loss (Fitzpatrick et al., 2008:39).

The philosophy of family orientated programmes proposes that when professionals provide information and support to parents, it will empower parents to build collaborative partnerships and help parents adjust to the stressful situation of coping with a recently diagnosed child (Most & Zaidman-Zait, 2001:100). Despite the recent attention accorded to UNHS, relatively little emphasis has been placed on parent's views of their needs after the detection of hearing loss and the service models needed to address them (Fitzpatrick et al., 2008:39).

A child's parents are considered as the ultimate decision-making authority in the management of the child (Eleweke et al., 2008:195). It is thus vital that parents be involved in the entire process from the diagnosis of the hearing loss through to the rehabilitation. Parental involvement can be defined as the quality of family participation in early intervention (DesJardin, Eiesenberg & Hodapp, 2006:183). The focus of many programs is on the child's disability and not on the needs and wishes of the parents (Eleweke et al., 2008:201). Existing programs for children with hearing loss and their family are generally designed based on what experts believe they should contain, rather on what parents actually wish to receive, which may often lead to a mismatch between the professional's views and parents' views of parental needs (Most & Zaidman-Zait, 2001:100). Thus, successful early intervention programs should not only focus on the child's needs, but also on the needs of the family system in which the child is nurtured (Eleweke et al., 2008:194.)

## **2.5 COCHLEAR IMPLANTATION IN CHILDREN**

### **2.5.1. Device and functioning**

Cochlear implants provide children with severe to profound hearing loss greater access to sound and improvement in their auditory skills, speech understanding, and oral linguistic development (McJunkin & Jeyakumar, 2009:1) The cochlear implant bypasses the dysfunctional cochlea and stimulates the auditory nerve directly (Archbold et al., 2006:191). It thus provides direct stimulation of the residual spiral ganglion cells of the cochlear nerve by bypassing the destroyed hair cells (Marsot- Dupuch & Meyer, 2001:119).

The cochlear implant device consists of two components. The externally worn components include a speech processor and an ear- level microphone, placed behind the ear and worn like a hearing aid. In addition to the behind the ear devices, body worn processors are also available. The microphone is connected to a transmitter (Marsot- Dupuch & Meyer, 2001:120). The internally implanted components consist of a receiver/stimulator coil, fixed firmly beneath retro auricular soft tissues within a well drilled-out area of the temporal squama. This transmitter has a transducer coil coupled across the skin by a magnet disk with a receiver coil. An electrode array is inserted into the scala tympani of the basal turn via the round window or via a cochleostomy. (Marsot- Dupuch & Meyer, 2001:120).

The functioning of the cochlear implant device can be described as follows: The sound waves received by the external microphone are transduced into electric signals. These electric signals are then digitally encoded by an external speech processor, and then transmitted as electromagnetic waves across the skin by a transducer to the receiver which reconverts radio waves into elementary electric signals to stimulate sequentially each electrode of the implanted electrode array. Therefore, this multi-channel device provides a complex sound analysis similar to

the physiological analysis of sound in normal hearing patients (Marsot- Dupuch & Meyer, 2001:120).

### ***2.5.2 Candidacy for cochlear implantation in children***

Cochlear implantation is a proven and accepted option for young children with profound hearing loss. To date, more than 80 000 children have undergone cochlear implantation world-wide (Archbold, et al., 2008:121). In South Africa the number of children with cochlear implants has grown to over 400 (SACIG, 2010). This increase is mainly due to newborn hearing screening that assists in the earlier identification of hearing loss. Children as young as seven months are now considered as candidates for cochlear implantation (Kaltenbrunn & Louw, 2005:22). Another motivation for earlier cochlear implantation is that children that receive cochlear implants at a younger age demonstrate earlier and improved spoken language (Discolo & Hirose, 2002:114).

The selection of candidates for cochlear implantation remains one of the most difficult phases in the cochlear implantation process, especially when it concerns children. Candidacy criteria for cochlear implants have consistently broadened. Early guidelines for cochlear implants restricted use to post-lingual deafened adults with profound hearing loss who exhibited no open-set speech recognition skills and did not benefit from hearing aids (Yuelin, Bain & Steinberg, 2004: 1028). Eligibility requirements have since shifted to include children, toddlers as well as infants (Yuelin et al., 2004:1028).

The referral for consideration of cochlear implant candidacy is summarised as follows by Owens et al (2006:362):

The referral criteria for children younger than 5 years include:

- Bilateral sensory-neural hearing loss of >90 dBHL at 2 kHz and 4 kHz.
- Click ABR thresholds at 90 dBHL
- No minimum age of referral.

- Children with additional needs will always be considered.
- Parental/Guardian consent for referral obtained.

The referral criteria for children 5 years and older include:

- Children with sudden onset or progressive hearing loss.
- Bilateral sensory- neural hearing loss of > 90dBhl at 2 kHz and 4 kHz.
- Children whose primary form of communication is speech.
- Children with additional needs will always be considered.
- Parental/Guardian consent for referral obtained.

After a child is referred for a cochlear implant, general criteria may require the child to: have bilateral, profound hearing impairments; wear well-fitted hearing aids for a period of three to six months; and show little or no benefit from amplification (Ertmer, 2005:24). In extenuating situations, such as incidents of ossification in the cochlea, children younger than 12 months have also received cochlear implants. In some cases, children who have severe hearing loss with poor aided speech perception ability may also be accepted for implantation (Ertmer, 2005:24). The decision on whether a cochlear implant is necessary is made in a multidisciplinary setting and relies on clinical, audiological and radiological evaluation (Owens et al., 2006:362).

### ***2.5.3 Process of cochlear implantation***

The cochlear implant process includes potentially stressful decision-making, irreversible surgery, and very intensive rehabilitation (Most & Zaidman-Zait, 2001:99). Firstly, parents must manage the process of deciding whether or not to choose the cochlear implant as the sensory aid for their child, later on they must deal with the anxiety and fear prior to and during the surgery, and finally parents must be committed to an extensive rehabilitation process (Zaidman-Zait & Most, 2005:130). Cochlear implantation requires a professional team to inform, guide, support and collaborate with parents constantly throughout this process (Most &



Zaidman-Zait, 2001:100). The professional team involved in the pre-implantation phase typically consists of an Ear Nose and Throat (ENT) surgeon, an audiologist, a speech–language pathologist, a psychologist and educators for children with a hearing loss (Ertmer, 2005: 24).

A clinical evaluation of a cochlear implant candidate begins with a detailed history of the child's: hearing loss; language development; medical history; education history; as well as availability of support services; family structure and support; expectations of the family; communication style; cognitive ability and learning style (Hellman et al., 1991:78).

The Ear Nose and Throat (ENT) surgeon is involved in the pre-operative medical and radiological evaluations as well as in later cochlear implant surgery. The clinical evaluation begins with a detailed history followed by physical examination. Otological history includes age of onset of hearing loss, continued risks for further hearing loss and information on concurrent ear problems (Owens et al., 2006:362). The examination involves a general review of the child's fitness for surgery (Owens et al., 2006:362). Radiological evaluation involves computed tomography (CT) and magnetic resonance imaging (MRI) of the temporal bones (Owens et al., 2006:362).

The role of the audiologist is to conduct thorough audiologic evaluations to identify those children in whom an implant will produce functional hearing (Owens et al., 2006:362). Audiological evaluation involves a battery of tests depending on the child's age, to assess the benefits of cochlear implantation. In children undergoing evaluation it is necessary to establish a baseline hearing threshold to monitor outcome (Owens et al., 2006:362). The audiologist assists in the hearing evaluations and hearing aid fittings. A hearing aid trial is undertaken irrespective of the level of hearing loss to establish if hearing augmentation is sufficient (Owens et al., 2006:362). Followed by a failed hearing aid trial, a battery of audiological tests are undertaken depending on the child's age, to

assess the benefits of cochlear implantation. After the cochlear implantation, audiologists are involved in the mapping of the processor.

The speech-language pathologist evaluates the pre- and postoperative communication skills of the candidate. The pre-implantation assessment includes investigating areas such as the demographic details of the child, medical and radiological conditions, language and speech abilities, multiple handicaps or disabilities, family structure and support, educational environment, the availability of support services, expectations of the family and the child with a hearing loss, cognitive abilities and learning style (Nikolopoulos, Dyar & Gibben, 2004:128).

Additional assessments that may take place pre-operatively are psychological assessments and counselling performed by a psychologist. Educators for children with a hearing loss can play an important role in providing information about school related issues and options to the parents of cochlear implant candidates (Ertmer, 2005:25-31).

It is important to describe the role of the parent in the cochlear implant process. It is the parent who seeks medical advice on the child's behalf. The parent authorizes the procedure, by providing legal consent for the child to undergo surgery for a non-life threatening condition. Parents also potentially play a major role in the rehabilitation of the child following implantation; this requires an investment of time, effort and resources (Sach & Whyne, 2005:401). Before implantation can commence it is vital to make sure parents understand and support the long-term commitment involved in the cochlear program and that without parental support the best functional outcome is unlikely to be achievable (Owens et al., 2006:363).

## **2.6. SUPPORT NEEDS OF PARENTS**

Hearing parents of a child with hearing loss have to assume a new set of responsibilities- a role not anticipated and for which such parents had very little or no preparation (Eleweke et al., 2008:192). There are numerous emotional, social, physical and economic stressors involved in raising a child with hearing loss (Feigin & Peled, 1998:20). Parents are concerned about whether their child will be able to use speech, speak normally, go to school, obtain employment and have a family (Eleweke et al., 2008:191). Cochlear implantation affects the entire family and has a dramatic impact on parents' marriage, siblings, employment and financial issues as well as further family planning (Sach & Whynes, 2005:403). It is evident that parents experience a lot of stress and anxiety during the process of cochlear implantation of their child. The stressful nature of cochlear implantation is evident in mother's expression of their need for emotional support during the process (Most & Zidman- Zait, 2001:106). As mentioned, the parents ultimately decide whether a cochlear implant is the best sensory aid for their child. During the decision making process parents may experience a range of feelings including fear, a sense of urgency, anxiety, insecurity, frustration and intimidation (Duncan, 2009:39). It should be emphasised that cochlear implantation arouses many hopes and expectations that are not always realistic (Most & Zaidman- Zait, 2001:100). Sensitive counselling that has a high degree of listening and emotional support can help families with productive decision-making (Luterman, 2004 in Duncan, 2009:39). Families that receive information and support from professionals and other parents are best able to deal successfully with these reactions and emotions (Eleweke et al., 2008:191).

Although the importance of providing emotional support to parents is stressed in the literature, parents often indicate that they lack emotional support from the cochlear implant team members (Zaidman-Zait & Most, 2001:105). Emotional support refers to incidents where professionals reassured parents during stressful situations, cared for parents, showed empathy, listened to parental

concerns, expressed understanding for their situation, and encouraged them throughout the process of diagnosis, surgery and rehabilitation (Zaidman-Zait, 2007:221). Support services are flexible forms of assistance that enhance a family's ability to care for their child who has hearing loss (Eleweke et al., 2008:191). The need that parents have to meet other parents of children with cochlear implants is a form of social support (Most & Zaidman- Zait, 2001:107). The encounter with other parents from similar backgrounds who face comparable problems provides support, alleviates feelings of isolation, and offers models and strategies for coping (Most & Zaidman- Zait, 2001:107). Through the identification of these specific emotional needs of parents, it becomes possible as well as a responsibility on the part of the professional to address these individual emotional needs of parents. This leads to continued efforts in the area of early intervention to focus on supporting parents rather than merely on providing services (Jean & DesJardin, 2003:392).

Duncan (2009:41) suggests the following recommendations for improving ways associated with supporting parents in the cochlear implant decision-making process:

- Professionals should remember that parents of young children with hearing loss need time to manage their feelings. The amount of time each family needs varies and is difficult to determine. Above all, professionals should not rush the decision making process.
- Professionals should engage the parents in discussions and should determine their ambitions, aspirations and desires for their child. Professionals must become aware of the family's values.
- Professionals must display clear, open, harmonious beliefs, expectations and assumptions.
- Professionals have to have necessary skills in recognising emotions, beliefs and knowledge integral to decision-making processes. This is essential to facilitate successful parental readiness for decision-making.

- Professionals should provide parents with impartial, comprehensive, written and spoken information presented free of jargon and in a judicious manner. This pathway to parental knowledge must be transparent and systematic, yet flexible enough to respect the individual family needs.

## **2.7 INFORMATION NEEDS OF PARENTS**

While cochlear implantation is an increasingly routine provision for profoundly deaf children in many countries, parents still require information about the procedure and likely outcomes in order to make an informed decision (Archbold et al, 2008:120). Much emphasis is placed on the need of parents to obtain as much information as possible prior to implantation (Archbold et al., 2002:36). Providing information that is clear, relevant and timely is a very important part of any healthcare service (Edwards et al., 2000:96). It has been established that the provision of adequate information leads to reduced parental stress (Edwards et al., 2000:26). The areas of information include medical, technical, communication, and educational information (Most & Zaidman-Zait, 2001:106). More specific information needs relates to hearing loss- specific information and therapy related information as well as prognosis information (Fitzpatrick et al., 2008:44).

Parents are given vast amounts of information during the pre-implantation selection process. They need as much as possible information during the pre-implantation selection process, in order to ensure that it is understandable, considering that parents need to make a decision that involves an irreversible, invasive procedure (Most & Zaidman-Zait, 2001:106). The information is often given verbally and/or in written form. The information typically includes the following; what a cochlear implant is, how it works, how the speech processor works and is maintained, different processing strategies, how to cope with minor faults and guidelines on safety issues for cochlear implant users. This information is coupled with information about how the cochlear implant program is organised

and managed, and what assessments are necessary in the pre-implantation phase of the cochlear implantation as well as rehabilitation that will follow the cochlear implant (Edwards et al., 2000:97). Parents are often provided with contact numbers of schools for children with hearing loss. Financial issues are discussed as well as realistic expectations with regard to the expected outcomes of a cochlear implant. It is reported that parents prefer to receive these types of information from several key professionals, mostly the surgeon, audiologist and speech-language therapist- and to a lesser extent, from the social worker and psychologist (Most & Zaidman-Zait, 2001:103). Cochlear programs are structured in various ways. General information, technical information, costs, surgery, mapping, rehabilitation, emotional support, educational systems and instruction to family and educational staff are mostly provided through private talk and to a lesser extent through group meetings, written material or formal lectures (Most & Zaidman-Zait, 2001:105). Written information routinely given to children and parents in a cochlear implant program includes: information sheets on audiological/cochlear implant terms, comments of parents of children who have received implants, using the speech processor, cochlear implant programming strategies, processor fault finding, do's and do not's with your cochlear implant, colour brochures from cochlear implant processors and booklets aimed at children up to seven years (Edwards et al., 2000:106). Parents indicate that they prefer information given through private talk with the surgeon, audiologist and speech-language pathologist during the period before the decision to undertake the surgery is made (Most & Zaidman-Zait, 2001:105). Professionals on a cochlear implant team serve as case managers who serve as coordinators of services and provide the child and family with essential information (Most & Zaidman-Zait, 2001:108).

The literature indicates that several factors affect the provision of information to parents by service providers. These factors include (Eleweke et al., 2008:201):

- Communication difficulties.
- Lack of common base knowledge by parents and professionals.

- Differences in professionals understanding of ‘models’ and conceptions of disability, causality and prognosis.
- Family member’s unfamiliarity with the professional’s vocabulary and jargon.

These factors can have the following adverse consequence such as: persistent misconceptions and superstitious beliefs about the cause of the disability, ignorance of what can be done to help the child with such a disability and ‘shopping around’ for a remedy due to misconception that a cure can be found (Eleweke et al., 2008:201). In cochlear implantation the same factors can affect the provision of information to parents and the consequences reflect the above mentioned misconceptions with regard to the outcome of cochlear implantation.

The cochlear implant team members should focus on the fact that families are unique and they vary in many ways. Archbold et al (2008) reported that parents needs are varied and may not conform to the expectations of others, including the implanting teams (Archbold et al., 2008:121). Each family’s response to a child’s hearing loss is different (Anagnostou et al., 2007:71). Parents may perceive the extra responsibilities of parenting a child with hearing loss in many different ways (Jean & DesJardin, 2003:391). Individual families therefore have unique requirements of the information and support provided by professionals. Research studies demonstrate that although parents are typically satisfied with the quality of intervention services, certain gaps in how information is delivered need to be addressed to meet consumer preferences (Fitzpatrick et al., 2008:46). By providing information and focussing on families priorities and by engaging in an open process of assessing, listening and negotiating with families, professionals can create a relationship in which parents feel valued and through which professionals and parents develop mutual respect and understanding of each other’s values and perspectives (Eleweke et al., 2008:200).

## **2.8 THE SOUTH AFRICAN CONTEXT**

### **2.8.1 Cultural and linguistic diversity**

Hearing loss remains a silent epidemic, unnoticed in developing countries (Swanepoel et al., 2007:321). More than 90% of the estimated 718 000 infants born annually with congenital or early onset permanent hearing loss reside in developing countries where environmental risks are more prevalent and early identification programs are extremely uncommon (Swanepoel et al., 2009:2). This is especially true within the South African context with a population that is characterised by diverse socio-economic, geographical, linguistic and cultural features (Louw & Avenant, 2002:146). The socioeconomic barriers that influence accessibility to intervention services include; poverty, transportation problems, violence, crime, malnutrition and unemployment (Van der Spuy & Pottas, 2008:30). The majority of South Africans (80-85%) are served by the public health sector, which utilize only 39% of the country's total health expenditure. This is in stark contrast to a wealthy minority, (15-20% of the population), which make use of private health care services that constitute 61% of the total health expenditure (Swanepoel, Ebrahim, Joseph & Friedland, 2007:2). More than half of the households living in poverty are in rural areas where remittance and state social grants are relied on as the primary sources of income (Swanepoel, 2004: 118).

Linguistic diversity is extremely evident in South Africa, as a country with 11 official languages. The diversity in language and culture in South Africa, together with the growing awareness and recognition of such diversity presents a challenge to speech-language pathologist and audiologist in the early intervention service delivery to young children with hearing loss (Louw & Avenant, 2002:145). Cultural diversity has a profound effect on the way in which families and professionals relate cross-culturally and participate together in early intervention programs (Louw & Avenant, 2002:146).



There is increasing awareness that differences, across and within cultural-linguistic groups, need to be accounted for (Louw & Avenant, 2002:145). Speech- language pathologists and audiologist cannot assume that the families whom they serve share their own basic ideas and beliefs regarding disabling conditions and interventions. These differences make it vital that professionals develop cultural competence and become committed to honouring cultural diversity through the services provided to families of young children with hearing loss (Louw & Avenant, 2002:145).

### **2.8.2. Early detection and intervention**

Early Hearing Detection and Intervention (EHDI) programs are consistent with South African primary healthcare priorities and should form an integrated part of services to infants and young children (Swanepoel, et al., 2007:323). Despite the proven benefits of early identification and intervention of infant hearing loss, the vast majority of infants with hearing loss have no prospect of early identification because they are born in developing countries around the world (Swanepoel et al., 2009:1). The total lack of Early Hearing Detection and Intervention (EHDI) services in the Sub- Saharan Africa can be attributed to several factors including; a high burden of infectious diseases, restricted resources and the lack of tertiary education for audiologists or other hearing health care specialists (Swanepoel et al., 2009:2). It is not surprising therefore, that early identification of permanent non-life threatening disabilities such as hearing loss has not received the necessary advocacy, support, and resource allocation in a country such as South Africa (Theunissen & Swanepoel, 2008:24).

The National Government pledged to the philosophy of early identification followed by appropriate interventions in the White Paper on an Integrated Disability Strategy, 1997. However, the implementation for childhood hearing loss is still lacking (Theunissen & Swanepoel, 2008:24). The HPCSA in accordance with the JCIH has been advocating early detection and intervention for infants

with hearing loss (HPCSA, 2007 & JCIH, 2007). Unfortunately, such implementation is still lacking (Theunissen & Swanepoel, 2008:24).

Due to the lack of legislation and awareness regarding infant hearing loss, the initial detection in South Africa remains primarily passive. This results in an average age of diagnosis of almost two years with enrolment in intervention programs at over two and a half years, which means the critical periods of intervention before 6-9 months of age is not accessed (Swanepoel et al., 2009:2). Currently, no more than 7.5% of public hospitals provide some form of infant hearing screening and less than 1% provide universal screening (Swanepoel et al., 2009:2). Unfortunately there are no surveys, to date, documenting the status of early identification of hearing loss in the private health sector nationally (Swanepoel et al., 2009:3). Approximately 90% and more of babies born in South Africa do not have the prospect of early detection of hearing loss despite a reasonably established health care infrastructure compared to other Sub-Saharan African countries (Swanepoel et al., 2009:3).

Early intervention services, which are the cornerstone for attaining optimal outcomes in infants with hearing loss, historically have not been widely available or accessible in South Africa (Swanepoel et al., 2009:3). Intervention services is often not accessible due to lack of awareness of services, limited funds to access services, and limited or no access to transportation due to the geographical location of the centre-based program (Störbeck & Pittman, 2008:37). Apart from a few centre- or school based programs spread across the country, very few programs has been available to cater for the unique needs of infants with hearing loss (Swanepoel et al., 2009:3). The Hi-HOPES (Home- Intervention- Hearing and language Opportunities Parent Education Services) was launched in 2006 in Gauteng province. Hi-HOPES was started in order to enhance the range of current services being provided by medical professionals in South Africa in order to complete the vision of truly successful EHDI program for the entire country (Störbeck & Pittman, 2008:37).

### **2.8.3. Cochlear implantation**

The field of cochlear implants has seen a steady growth in South Africa with several centres now providing these services around the country (Swanepoel, Störbeck & Friedland, 2009:3). As mentioned, over 45 000 children have been implanted world-wide (Archbold et al., 2006:191) and in South Africa the number of children with cochlear implants has grown to over 400 (SACIG, 2010).

The high cost of the device, surgery and follow-up services remain an obstacle in a limited resourced context such as South Africa (Swanepoel et al., 2009:3). Young cochlear implant candidates enter the cochlear implant program from different socio-economic backgrounds. Children with poor socio-economic environments encompass many challenges when faced with financial issues, which accompany cochlear implantation and maintenance. Until recently, no state funding was available for cochlear implants in South Africa (Jessop et al., 2007:47). However, a few government hospitals have sponsored cochlear implants to underprivileged children in their communities (e.g. Universitas Hospital (Free State), Baragwanath Hospital (Gauteng) and Steve Biko Hospital (Gauteng). Private funding for cochlear implants is also problematic, due to the decline in the percentage of medical aid contribution towards cochlear implants (Muller & Wagenfeld, 2003:58).

More than half of South Africa's population live in rural areas. These conditions have negative impacts on the accessibility of early intervention services (Van der Spuy, 2005:36). Cochlear implant teams have to serve families who speak one or more of the eleven official languages of South Africa, with English often not being their primary language. Professionals face a considerable language barrier because very few professionals speak an African language (Louw & Avenant, 2002:145). The diversity in socio-economic, geographical, linguistic and cultural features within the South African population has a significant influence on the individual information and support needs that parents receive before cochlear implantation. Due to meagre schooling and limited access to printed information,

many mothers from low-income families are disorientated and confused about what to expect relative to normal developmental norms of their children (Louw & Avenant, 2002:145). This lack of knowledge places caregivers at a disadvantage and they may feel incompetent to articulate their needs and this can also cause a sense of bewilderment and detachment in families which may in turn lead to poor compliance and possible withdrawal from programs (Louw & Avenant, 2002: 47).

The cochlear implant programs in South Africa serve a population that is characterised by diversity in socio-economic, geographical, linguistic and cultural features as previously discussed. South Africa is commonly referred to as the “rainbow nation” due to the broad diversity in race, culture and language characteristic of the population. When professionals of the cochlear implant program interact with parents of different linguistic and cultural backgrounds, these diversities complicate the process of providing information and support tailored to their individual needs.

It is of utmost importance to consider the diverse socio-economic, geographical, linguistic and cultural features when providing family centred cochlear implant services to these South African parents. Each family is unique and should be respected as an individual unit with its own values, beliefs, practices and needs (Louw & Avenant, 2002:145). The ability to put oneself in the family’s unique situation and to look from their perspective often provides a more realistic understanding of their concerns, needs, and results in a stronger partnership with the family (Johnson et al., 1997:142).

In order to ensure that parental needs are properly addressed it is imperative that professionals investigate and understand the individual needs and desires of the parents with whom they collaborate (Christiansen & Leigh, 2002 in Most & Zaidman-Zait, 2001:100). It is important that any information given to parents reflect the reality of the experience as fully as possible. Studies that only use questionnaires designed by professionals may overlook some issues that are

important to parents (Archbold et al., 2008:121). As mentioned, parents needs vary greatly and may not conform to the expectations of others, including the implanting teams (Archbold et al., 2008:121). Professionals need to involve parents of children with hearing loss in the development, evaluation and delivery of the range of information that they wish to receive (Eleweke et al., 2008:203). Parents may have similar areas of information and support needs, but individual differences exist with regard to the priority that these needs have to different parents. Many parents may feel overwhelmed by the extent and complexity of information provided about the cochlear implant process. This is unless it is carefully tailored to their individual needs and is presented in an accessible format at the time it is most appropriate and acceptable (Edwards et al., 2000:104). It is also important to know that information and support needs change over time (Eleweke et al., 2008:204). Information should not be overwhelming, this is important because parents must understand the information (Eleweke et al., 2008:193). Minchom et al (2003) reported that parents identified key areas in which service development should improve for families of children with a hearing loss. In this study parents commented that professionals should develop a better manner of identifying parental needs (Minchom, Shepherd, White, Hill & Lund, 2003:102).

## ***2.9 CONCLUSION***

Cochlear implantation requires a professional team to inform, guide, support and collaborate with parents constantly throughout the process (Most & Zaidman-Zait, 2001:100). By providing information and support through focussing on family's priorities and by engaging in an open process of assessing, listening and negotiating with families, professionals can create a relationship in which parents feel valued. This can also facilitate the development of a relationship in which professionals and parents have mutual respect and understanding of each other's values and perspectives (Eleweke et al., 2008:200). It is of utmost importance to consider the diverse socio-economic, geographical, linguistic and

cultural features when providing family centred cochlear implant services to South African parents. Each family is unique and should be regarded as an individual unit with its own values, beliefs, practices and needs (Louw & Avenant, 2002:145). The ability to put oneself in the family's unique situation and to look from their perspective often provides a more realistic understanding of their concerns, needs, and results in a stronger partnership with the family (Johnson et al., 1997:142).

## **2.10 SUMMARY**

The aim of this chapter is to describe the relevant theoretical concepts of early diagnosis, intervention and cochlear implants defined by recent literature (See Figure 1). Each concept is defined and discussed according to recent and relevant literature. In order to determine parental needs for information and support during the pre-implantation phase of cochlear implantation, it is important to have knowledge of the status of hearing loss in children, the identification and intervention that is available to these patients and their parents. These aspects serve as the background for cochlear implantation. Cochlear implantation is part of early intervention services provided to children with hearing loss. It is important to provide cochlear implantation in a family or parent centred approach. The need for cochlear implantation programs, which can provide information and support according to the unique needs of the family, was highlighted during the discussion of the literature concepts. It is even more apparent through the discussion of the South African context with many challenges faced by professionals serving parents with young children who receive cochlear implantation.

## CHAPTER 3

### METHOD

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*"The art and science of asking questions is the source of all knowledge."- Thomas Berger*

#### **3.1. INTRODUCTION**

Cochlear implantation is an elective operation for children with a bilateral moderate to profound sensory neural hearing loss (Discolo & Hirose 2002:114). The latest statistics show that over 400 children in South Africa have received cochlear implants (SACIG, 2010). Research shows that comprehensive information and support before the cochlear implantation of their children is a necessity for parents (Archbold et al., 2006:191). The initial information session in cochlear implant programmes generally focuses on information and support that experts believe is important, rather on what parents have indicated they actually wish to receive. This may often lead to a mismatch between the views of the professionals and that of the parents in terms of their specific needs (Most & Zaidman- Zait, 2001:100). The need clearly exists to approach each family on an individual basis, as each has its own emotional and information needs (Louw & Avenant, 2002:145; Perold, 2001:54). Therefore it is clear that a rating tool should be developed to identify the individual needs of parents. The aim of the study was to develop a pre-implantation tool to rate the individual support and information needs of parents of young cochlear implant candidates. This chapter provides a description of the research method that was used to investigate the above mentioned aim of the research. The main as well as sub-aims of the study, as well as the research design, are discussed followed by a description and discussion of the four phases of the research.

## **3.2. RESEARCH AIMS**

The research aims are pursued in order to answer a research question. The main research aim as well as the sub-aims of the study are as follows:

### **3.2.1. Main aim of the study**

The main aim of this study was to develop a pre-implantation tool to rate the individual support and information needs of parents of young cochlear implant candidates.

### **3.2.2. Sub-aims of the study**

The sub-aims of this study were as follows:

1. To identify retrospectively the information and support needs of parents of young children with cochlear implants.
2. To compile a pre-implantation rating tool to determine individualized information and support needs of parents of young cochlear implant candidates.
3. To determine the value of the pre-implantation rating tool for cochlear implant teams.

## **3.3. RESEARCH DESIGN**

Research design refers to the overall research approach or strategy taken. Within the context of applied research, a qualitative descriptive intervention research design was used in the study. Qualitative studies focus on describing and understanding a phenomenon from the participants' point of view (Leedy & Ormrod, 2005:94). In the research study the focal point was to determine parental perspectives and their individual needs for information and support.

The study was descriptive in the information gathering phase through literature review and semi- structured interviews. Descriptive studies examine a situation



as it is (Leedy & Ormrod, 2005:179). The main use for descriptive studies is to give service providers and planners information that will help them design services (Katzenellenbogen, Joubert & Abdool Karim, 1999:66). Semi-structured interviews were used and analyzed to describe the needs of parents and contribute to the design of the research rating tool. The clinical value of the rating tool was evaluated by professionals with the use of an evaluation form.

Within the context of applied research, an intervention research study was conducted. Intervention research (not to be confused with assessment research) is defined as studies carried out for the purpose of conceiving and creating innovative human services approaches to prevent problems or to maintain quality of life (De Vos, Strydom, Fouche & Delport, 2005:394). A study that systematically designs and develops interventions is one of the studies that are subsumed under intervention research (De Vos et al., 2005:394). Intervention is defined as an action taken by a researcher to enhance or maintain the functioning and well-being of an individual, family, group, community or population (Schilling, 1997 in De Vos et al., 2005:394). In this research study the researcher aimed to provide a rating tool that could be used by South African cochlear implant programs in order to enhance the functioning and well-being of the parents that are involved in cochlear implantation.

### **3.4. PARTICIPANTS**

The participants involved in phase one of the research study consisted of parents of children with cochlear implants, while those in phase two were speech-language pathologists/audiologists that are involved in the pre-implantation phase of young cochlear implant candidates. Parents of children with cochlear implants were involved in the semi-structured interviews. The speech language therapists/audiologists were involved in the determination of the value of the research rating tool.

### 3.4.1 Participant selection criteria

Selection criteria were established in order to identify appropriate participants that conform to the requirements of the study.

Participant selection criteria is an important part of the preparation of the study. It ensures that the research question can be answered with validity. The participant selection criteria for parents are set out in **Table 1** below:

Table 1 Selection criteria for parents	
Criteria	Justification
Participants had to be <b>parents</b> or <b>primary caregivers</b> of children who are cochlear implant recipients.	The study focused on the parental needs and not significant others that play a role in the child's life. A primary caregiver is a person who takes primary responsibility for meeting a child's needs, but does not receive remuneration and cares for the child with the consent of a parent, guardian, or custodian of the child (Department of Welfare, 1997).
Participants had to be parents or primary caregivers of children who are <b>cochlear implant recipients</b> of the <b>Bloemfontein Cochlear Implant Programme (BCIP)</b> at Universitas Hospital in Bloemfontein.	To ensure that uniformity between the participants existed and to ensure that information was easily available logistically to the researcher, who has access to the BCIP.
The children of the participants had to be <b>12 years of age or younger</b> at the time of data collection.	The study was executed to determine the needs of parents of young children with cochlear implants. Young children refer to children before the adolescent phase whose parents play the primary role in the decision making process when considering a cochlear implant. After the age 12 years adolescence starts (Owens, 2001).
Children of the participants had to be <b>using</b> their cochlear implant for at <b>least a period of one year and not</b>	The participants had to be adapted to the usage of the cochlear implant by their children. Participants should have been in a position to reflect back on the time before the cochlear implant



<p><b>longer than 5 years.</b></p>	<p>surgery. Since the research depended on parents to recall past events, the children must not be implanted longer than 5 years in order to recall pre-implantation needs as accurately as possible.</p>
<p>Participants had to be proficient in either <b>English or Afrikaans.</b></p>	<p>The participants had to be able to complete the structured interview in Afrikaans or English. The participants had to comprehend the questions and answer the questions appropriately. The majority of implanted clients of the BCIP are able to speak and comprehend English or Afrikaans although it is not necessarily their first language. The researcher is only proficient in these two languages.</p>

The selection criteria for the speech–language pathologists/audiologists are described in **Table 2**.

<b>Table 2 Selection criteria for speech-language pathologists/ audiologists</b>	
<b>Criteria</b>	<b>Justification</b>
<p>Participants had to be a <b>qualified speech-language pathologist/audiologist</b> with a degree in Communication Pathology or the equivalent and be registered at the Health Professional Council of South Africa (HPCSA) as a speech language therapist and/or audiologist.</p>	<p>A qualified speech-language pathologist/audiologist is a prerequisite of the South African Cochlear Implant Group in order to work on a Cochlear Implant team. It was thus appropriate to include them in the research.</p>
<p>Participants had to be <b>members</b> of one of the seven Cochlear Implant Programmes in South Africa.</p>	<p>This ensured that participants play an active role in the pre-implant stage of cochlear implantation and was able to make meaningful and relevant insight contributions with regard to the rating tool. This was done according to their experience in working with parents.</p>
<p>Participants had to be proficient in</p>	<p>The evaluation form was compiled in English and the participants</p>

<b>English.</b>	had to be proficient and literate in English in order to comprehend the statements and instructions and to provide appropriate responses.
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### 3.4.2 Participant selection procedure

The selection of participants was determined by their characteristics according to purposeful convenient sampling. The researcher had access to the Bloemfontein Cochlear Implant Team by working with the team for two and half years before the commencement of the research study. The following procedures were followed to select the participants during each phase of the study:

- A letter to the Head of the BCIP was compiled and permission was obtained in order to approach the program's clients and to gain access to the clients' records (see Appendix A).
- Participants that met the selection criteria as set out in **Table 1** and **Table 2** were selected by the researcher to take part in the study. The selected participants were informed about the research project by means of personal contact, electronic mail or telephonically. Participants were informed about the nature, purpose, content and implications of the study in written format. Parents who wished to participate in the semi- structured interviews of the study completed an informed consent letter (see Appendix B). Speech- language pathologists/audiologist that indicated that they wanted to participate in the research completed a letter of consent (see Appendix C).

### 3.4.3. Sample size

The sample size used in a research study should closely reflect or represent the study population in order to generalize results to the larger population (Katzenellenbogen et al., 1999:74). Due to the small population of children with cochlear implants associated with the BCIP, ten parents who comply with the selection criteria were included as participants for this study. This amounts to ten

out of 19 (68%) of the total parent population of the BCIP. Eight speech-language pathologist /audiologists who complied with the selection criteria were included as participants for this study. This study was therefore concerned with detail and in-depth analysis and purposeful convenient sampling was used to select the participants. Purposeful convenient sampling involves the selection of people that are readily available and for a specific purpose due to the fact that they represent diverse perspectives on an issue (Leedy & Ormrod, 2005:206). Based on logistic motives and the accessibility to the BCIP, the researcher conveniently used the clients of the BCIP. This sample is part of non-probability sampling.

### 3.4.4 Description of the sample

The profile of the participants involved in the research study is compiled in

**Table 3.**

Table 3 Description of the sample	
Total number of participants	18
Total number of parent or caregiver participants	10
Total number of speech therapists/audiologists	8
Number of children with cochlear implants	11
Age of children with cochlear implants	9 years and younger
Gender	Male and Female
Race	Black, Colored and White
First language	Afrikaans, Portuguese and isiXhosa
Duration of cochlear implant use	Less than 5 years
Age of parents	25-39 years

**Table 3** provides a summary of the participants included in the research study. A detailed description and discussion of the participants is provided in Chapter 4.

### **3.5 DATA COLLECTION**

Data was collected using the following instruments and apparatus:

#### **3.5.1 Data collection instruments**

A semi- structured interview and evaluation form were the chosen methods for data collection in this study and are described in the following discussion.

##### **3.5.1.1 Interview schedule**

The purpose, justification and design of the semi-structured interview are described in the following section. The interview schedule can be seen in Appendix D.

##### ***Purpose of the semi- structured interview:***

The purpose of the semi-structured interview was to collect information regarding the individual information and support needs that parents required before the cochlear implantation of their children.

##### ***Justification for the use of a semi-structured interview:***

An interview schedule is a written questionnaire to guide the interviewer to gain the desired information (De Vos et al., 2005:296). Interviewing is the predominant mode of data collection in qualitative research (De Vos et al., 2002:292). Within the context of applied research, a qualitative descriptive intervention research design is used in the study. The descriptive nature of the study is complimented by the use of semi- structured interviews due to the fact that semi- structured interviews gain a detailed picture of a participant's belief about a particular topic (De Vos et al., 2002:292). Since there are a limited amount of participants available for the study, in-depth and detailed analysis was performed on their responses through the use of semi- structured interviews. The focus of the study was to put oneself in the family's unique situation and to look from the family's perspective which often provides a more realistic understanding of their concerns

and needs and results in a stronger partnership with the family (Johnson et al., 1997:142). Interviews can be defined as attempts to understand the world from the participant's point of view, to unfold the meaning of people's experiences and to uncover their lived world prior to scientific explanations (De Vos et al., 2002: 292).

### ***Format and content of the semi-structured interview***

An interview schedule is a written questionnaire to guide the interviewer to gain the desired information (De Vos et al., 2005:296). The interview schedule format consists of two sections: Section A and section B.

The first section of the interview was designed to gather biographical information on the participants and their children. The section consists of three pages and 22 closed ended questions were asked. Section A of the semi-structured interview was used to gather data, such as names, ages, gender and language of the participants in order to provide an accurate description of the sample. The same information was gathered with regard to the children of the participants. In addition the history with regard to the children's hearing loss and cochlear implantation was also gathered to validate the selection criteria for the research study. The questions in Section A were presented to the participant, but responses were also verified through the use of the information file of the BCIP.

Section B consisted of 2 pages with five types of questions: an opening question, an introductory question, a transitional question, seven key questions and three closing questions. The questions are all open ended questions to allow the participants to express their views freely (De Vos et al., 2002:303). The key questions have been selected according to the central themes of information and support needs of parents during the pre-operative stage of cochlear implantation. The justification for the inclusion of each key question is described in **Table 4**.

**Table 4 Justification for inclusion of key questions**

Key question	Justification for inclusion of question
Tell me about the <i>challenges</i> surrounding the decision-making process before the cochlear implantation?	According to literature the cochlear implant process includes stressful decision making (Most & Zaidman-Zait, 2001:99). The answers to this question provided the researcher information with regard to challenges that parents experience during the pre-operative phase of cochlear implantation that be useful to include in the information and support tool.
Looking back to that time period before the cochlear implantation, what were your specific <i>needs for information</i> at that stage?	Much emphasis is placed on the need of parents to obtain as much information as possible prior to implantation in order to make an informed decision with regard to cochlear implantation (Archbold et al., 2002:36). The aim of the study was to retrospectively identify the information needs of parents. The information gathered from this question contributes to the compliment of the pre-implantation rating tool.
What were your specific <i>needs for support</i> and counselling at that stage?	According to literature the stressful nature of cochlear implantation is evident in mother's expression of their need for emotional support during the process (Most & Zaidman- Zait, 2001:106). The aim of the study was to retrospectively identify the support needs of parents. The information gathered from this question contributes to the compliment of the pre-implantation rating tool.



<p>If you could decide on the <i>most important area of information</i> that parents need to know before cochlear implantation what will it be?</p>	<p>Parent's needs are varied and may not conform to the expectations of others, including implanting teams (Archbold et al., 2008: 121). This question was asked to evaluate the different and unique needs of parents with regard to the kind of information that they feel is of utmost importance to families.</p>
<p>If you can select the <i>most important form of support</i> that parents need before cochlear implantation what will it be?</p>	<p>This question was asked to evaluate the different and unique needs of parents with regard to the kind of support that they feel are of utmost importance to families.</p>
<p>How can the cochlear implant team <i>assist</i> parents more effectively during the pre-implantation phase with regard to providing information and support to parents?</p>	<p>Existing programs for children with hearing loss and their family are generally designed on the basis of what experts believe they should contain, rather on what parents actually wish to receive, which may often lead to a mismatch between the professionals views and parents' views of parental needs (Most &amp; Zaidman-Zait, 2001:100). Parents should be provided with opportunities to improve the service that cochlear implant programs provide. The answers from this question provided parents the opportunity to express themselves on service delivery. One of the focal points of this study was to facilitate in the more effective service delivery to parents.</p>
<p>How will you feel about it, if parents are <i>given a choice</i> before implantation to identify the type and amount of information and support they need?</p>	<p>Professionals need to involve parents of children with hearing loss in the production, evaluation and delivery of the range of information that they wish to receive (Eleweke, et al., 2008: 203). Since the tool would be evaluated by professionals, it was important for the parents to provide insight on their perspective with regard to aim of the pre-implantation information and support tool.</p>

### **3.5.1.2 Evaluation form**

The evaluation form was provided to the speech-language pathologists/audiologist in order to assess the rating tool in order to determine the clinical value. The participants received the proposed rating tool (Appendix E) as well as the evaluation form (Appendix F).

#### ***Purpose of evaluation form:***

The purpose of the evaluation form was to determine the clinical value of the rating tool by speech language pathologist/audiologists that are working with families in the pre-implantation phase. Professionals in the field have the correct authority to determine whether this rating tool could be useful to cochlear implant programmes.

#### ***Justification for the use of an evaluation form:***

Evaluation can be broadly described as the general process of weighing or assessing the value of something (De Vos et al., 2002:374). Evaluation is an ever-present fact of life and therefore the issue of evaluation is not whether it should be done but rather how evaluation should take place (De Vos et al., 2002:374).

The main aim of the research study was to develop a pre-implantation tool to rate the individual support and information needs of parents of young cochlear implant candidates. The information that was gathered through a thorough literature review as well as information from the semi-structured interviews were used to compile the pre-implantation rating tool. In order to determine the clinical value of the rating tool, an evaluation form was designed for professionals in order to rate their viewpoints on different aspects of the pre-implantation rating tool.

The decision to include a critical evaluation form in the study was motivated by the possible outcomes it would provide. These outcomes include:

- To determine the clinical value of the pre-implantation rating tool.
- To determine the practical utilization of the pre-implantation rating tool by cochlear implant programmes.
- To identify further areas of improvement of the pre-implantation rating tool.
- To contribute to the reliability and validity of the research study.
- To determine further research needs for the implementation of the pre-implantation rating tool.

***Format and content of the evaluation form:***

The evaluation form consists of six statements that the professionals had to rate on a scale from one to three. A rating scale is valuable when an attitude of phenomenon of interest needs to be evaluated on a continuum (Leedy & Ormrod, 2005:185). A Likert scale was used in the evaluation form. This scaling consists of breaking up a continuum into a collection of response categories (De Vos et al., 2002:194). A numeric ordinal scale was used where participants was asked to rate each statement of a scale that included numeric values of 1 (Do not agree), 2 (Agree) and 3 (Strongly agree).

Key areas that were evaluated were: adaptability of the tool, guidance, opportunity to express needs, family centeredness, effectiveness and usefulness of the rating tool. Participants were offered an opportunity to provide comments to an open ended remark for further suggestions and comments with regard to the rating tool. The statements and justifications for inclusion are described in the **Table 5**.

Table 5 Statements and justification included in the evaluation form	
Statement	Justification for inclusion of the statement
The tool is <b>adaptable</b> to identify the individual information and support needs of parents before cochlear implantation.	To determine the main purpose of the tool for the identification of the individual information and support needs of parents. The adaptive nature of the pre-implantation rating tool was a requirement for the effectiveness of the tool.
The tool would be useful to <b>guide</b> the speech language therapist/audiologist to identify what information and support is most important to the specific family and what issues should be addressed initially.	Professionals need guidance to determine what is important to parents vs. what they wish to communicate to parents (Archbold, 2002:16). This statement evaluates the ability of the tool that assisted in that need of professionals.
Parents are provided with an <b>opportunity to express</b> their individual needs for information and support to professionals on the cochlear implant team.	The literature indicates that several factors affect the provision of information to parents by service providers. These factors include (Eleweke et al., 2008:201). Communication difficulties, lack of common base knowledge by parents and professionals, differences in professionals understanding of 'models' and conceptions of disability, causality and prognosis and family members unfamiliarity with the professionals vocabulary and jargon. The statement evaluates the ability of the tool to address these factors.

<p>The tool correlates with a <b>family centred approach</b> to early childhood intervention services.</p>	<p>It has been proposed that an intervention approach that values partnerships with families and promotes self- efficiency in parents may result in higher rates of follow- through, greater participation in early intervention, and improved outcomes for children with hearing loss (Fitzpatrick et al., 2008: 39) This statement evaluates the accordance of the tool with a family centred approach to early intervention services.</p>
<p>The tool may be <b>effective</b> to identify the individual information and support needs of parents before cochlear implantation.</p>	<p>The effectiveness of the tool to identify the individual information and support needs of parents before cochlear implantation is of utmost importance to determine the aim of the tool as well as contributing to the overall clinical value of the research study.</p>
<p>The tool may be <b>useful to include</b> in similar cochlear implantation programmes.</p>	<p>This statement provides information for the further use of the pre-implantation tool in cochlear implant programs in South Africa.</p>
<p>Please indicate any further suggestions:</p>	<p>Professionals were given the opportunity to provide further comments and suggestions that was not covered by the six statements.</p>

**Table 5** provides an overview of the statements included in the evaluation form that participants had to rate in order to determine the clinical value of the rating tool. Justifications for the inclusion of the statements are included in **Table 5**.

### 3.5.2. Data collection equipment

The following data collection equipment was used to conduct the research.

- An Olympus VN-7800 PC digital voice recorder was used in the interview to record the participant's responses for further analysis.
- Windows Media Player was used as a storage system for audio recordings of the interviews.
- An external microphone was connected to the recorder to enhance the quality of the recordings.

The description of the data collection equipment and the justification for the use is set out in **Table 6**.

<b>Table 6 Data collection apparatus and justification</b>	
<b>Data collection apparatus</b>	<b>Justification</b>
Olympus VN-7800 PC digital voice recorder	The semi-structured interviews were recorded in order to analyze the information gathered during the interview and to contribute to the validity of the data recording procedure. Digital voice recorders provide a good sound quality.
Windows Media Player	Research data should be stored for a minimum of 15 years. Therefore Windows Media Player was used to transfer the digital recording onto a CD that serves as back-up for data storage.
External microphone	An external microphone was used as a noise canceling device to improve the sound quality of the digital recording and to assist in analysis of the recorded data.

### **3.6. PILOT STUDY**

A pilot study was conducted before the main study and is described below.

#### **3.6.1 Aim of the pilot study**

Conducting a pilot study is an important aspect in the planning and evaluation of the research material. The aim of the pilot study was to determine whether the relevant data can be obtained from the participants (Royse, 1995:172 in De Vos et al., 2002:337). The pilot study further assisted the researcher in accuracy and reliability of administering the methods and procedures of the study as planned. Thus, a pilot study was conducted prior to the data collection to determine whether the questions in the interview schedule were appropriate, easy to understand and efficient to obtain accurate results.

#### **3.6.2 Participant of the pilot study**

Due to the limited amount of participants available to the research study, it was decided not to use one of the identified parents for the pilot study as participation in the pilot study would exclude the participant from the main study. A parent that compared well with the selection criteria as set out in section 3.4.1, but whose child was implanted more than 5 years ago, was identified.

#### **3.6.3 Material for the pilot study**

A semi-structured interview was conducted with the participant in the pilot study in order to assess the content, wording and clarity, as well as the appropriateness of the questions. The participant of the pilot study was able to comment on the wording of the questions, the sequence of questions, possible redundant questions and missing or confusing questions (De Vos et al., 2005:210). The audio recorder was also used during the interview in order to test the clarity of the sound that was recorded.

### **3.6.4 Procedures of the pilot study**

The respondent of the pilot study was personally contacted telephonically to request participation in the pilot study. The aim of the pilot study was discussed and thereafter an appointment date was set. A letter of informed consent stating the purpose of the pilot and main study was given to the participant. After signing the letter of informed consent, the interview, according to the semi-structured interview schedule, was conducted. The participant was expected to critically evaluate each question. Every comment and recommendation was taken in consideration in order to make appropriate adjustments to the interview schedule.

### **3.6.5 Results of the pilot study**

By testing the nature of questions in the interview schedule during the pilot study, the researcher was able to make modifications in order to improve the quality of interviewing during the main investigation (De Vos et al., 2002:337).

It was determined that approximately 30 minutes was required for the completion of each interview. The sound quality from the digital voice recording was very clear. Changes to the interview schedule mostly included the simplification of wording, language and providing examples. The duration of implant use was deleted as it was an unnecessary question because the answer could be calculated from the answer to the question about the date of activation of the cochlear implant. The adapted interview schedule was used in the main study.



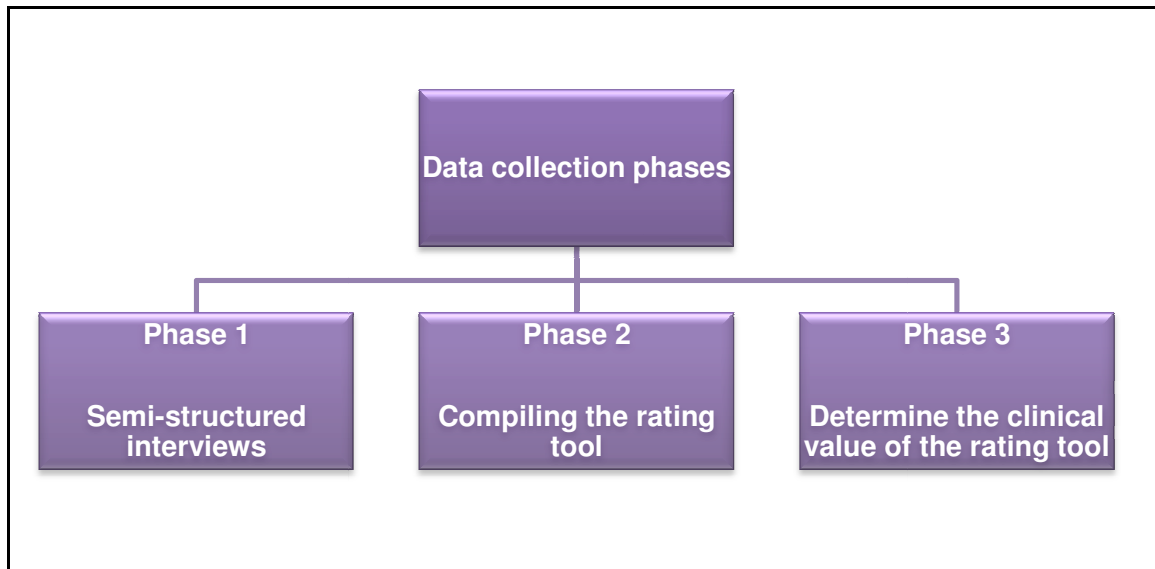
### **3.7 DATA COLLECTION AND DATA RECORDING PROCEDURES**

The data collection of the research study was performed in four phases.

#### **3.7.1 Overview of data collection steps**

- The head of the BCIP, Prof. Claassen was contacted and permission was obtained to include clients from the BCIP in the research study (Appendix A).
- Ethical Clearance was obtained from the Research and Ethics Committee of the University of Pretoria to conduct the study (Appendix G).
- Parents who adhered to the selection criteria were identified from the BCIP client list.
- Selected participants were contacted telephonically in order to determine willingness to participate in the study.
- A date that suited the participant was arranged for the data collection procedures. The participant was only required to meet the researcher once.
- On the arranged date the participant met the researcher, and a written letter of consent was signed by the participants (Appendix B).
- The semi-structured interview followed after informed consent was obtained. The duration of the interview was approximately 30 minutes.
- The interview was recorded with an Olympus VN-7800PC digital recorder and the interview was then transcribed via Windows Word 2005.
- Speech-language pathologist/audiologists were contacted via electronic mail (email) and the informed consent letter (Appendix C), the rating tool (Appendix E) as well as an evaluation form was sent to them via email (Appendix F).
- Once they had evaluated the rating tool they were requested to send the evaluation form back to the researcher via email.

The different phases of the data collection procedures are set out in the following Diagram 1:



**Diagram 1: Data collection phases**

The data collection consisted of three phases as illustrated in Diagram 1 and discussed as sequencing of data collection procedure.

### **3.7.2 Sequencing of data collection procedure**

- Phase 1: Interview parents who have been through the process of cochlear implantation to identify their individual information and support needs during the pre-implantation phase of cochlear implantation.
- Phase 2: Compile rating tool using information gathered through the semi-structured interviews in Phase 1 in combination with relevant literature on the subject. This pre-implantation rating tool aims to be implemented in the identification of the individual information and support needs of parents of young cochlear implant candidates in the pre-implantation phase of cochlear implantation.

- Phase 3: Determine the value of the research rating tool. This is carried out by speech-language pathologist /audiologists of cochlear implant programs completing an evaluation form.

The different data collection procedures are discussed in more detail and are presented as follows:

### **3.7.3 Phase 1 Data collection procedures for the semi-structured interview**

The purpose of the semi-structured interviews was to collect information regarding the prevalent information and support needs that each individual parent had before the cochlear implantation of their children.

Semi-structured interviews are defined as those structured around areas of particular interest, while still allowing considerable flexibility in scope and depth (De Vos et al., 2005:292). A semi-structured interview involves the implementation of a number of predetermined questions that are asked in a systematic and consistent order, but the interviewer is permitted to probe far beyond the answers to their prepared questions (Berg, 1998:61). The key questions of the interview schedule were selected according to the themes from the literature review.

The semi-structured interview was followed after informed consent was obtained from the participant (Appendix B). The researcher discussed the interview schedule with the participant; the participant could then choose what particular question he/she wishes to answer at specific stages, allowing the participant a strong role in determining how the interview proceeded (De Vos et al., 2005:297). The interview took approximately 30 minutes to complete. The researcher and participant were seated at a desk across from one another in a quiet environment. The researcher asked the participants a few open-ended questions in order to encourage the participant to express his/her thoughts, experiences

and feelings that related to the research question. The answers to the open-ended questions were recorded by means of writing the response down on the interview schedule recording form. An audio recorder was used as a back-up strategy for data recording and to enable transcription of the recorded data. The results of the interview was analyzed and utilized in the next phase of the research namely the development of the rating tool.

#### **3.7.4 Phase 2 Data collection procedures for the construction of the rating tool**

The data collected from the semi-structured interview in combination with relevant literature formed the basis on which the construction of the rating tool was designed (Appendix E).

#### **3.7.5 Phase 3 Data collection procedures to determine the value of the rating tool**

The rating tool was sent via email to the speech-language professionals serving on different cochlear implant teams in South Africa that are involved in the pre-implantation phase of young cochlear implant candidates. These professionals rated the tool according to the value it will have in determining parents individual needs for information and support during the pre-implantation phase of cochlear implantation. The speech-language pathologist/audiologists determined the value of the tool by rating different aspects of the tool using a rating scale. They also had the opportunity to make further suggestions and comments (see Appendix F).

### **3.8 DATA ANALYSIS**

The audio recorded information obtained from the semi-structured interviews was transcribed. The transcribed data from the semi-structured interviews was

analyzed by identifying themes according to the sub-aims of the study (Silverman, 2001:13). Content analysis was used as the technique to analyze the data. Content analysis is a technique for making inferences by systematically and objectively identifying special characteristics of messages (Berg, 1998:224). The analyzed results from both the data collection method and the literature review was then interpreted together in order to obtain the answer to the research question by developing the rating tool. The presented sub-aims were used to guide the analysis and presentation of the information. The analyzed data enabled the researcher to identify common themes and trends and was discussed according to the sub-aims. The comparison of the findings between the various participants was not significant, because of the small sample that was used. The findings and interpretations of the data is presented in tables, graphs, charts and figures.

### **3.9 ETHICAL CONSIDERATIONS**

“Ethics is a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offer rules and behavioral expectations about the most correct conduct towards respondents and other researchers” (De Vos et al., 2005:57). Ethical principles are of such immense importance, it should be internalized in the personality of the researcher to such an extent that ethically guided decision making becomes part of his/her total lifestyle (De Vos et al., 2005:57).

Anyone involved in research needs to be aware of the general agreement of what is proper and improper in scientific research (De Vos et al., 2005:56). Ethical issues in research are described in four categories, namely informed consent, protection against harm, confidentiality and honesty with professional colleagues (Leedy & Ormrod, 2005:101).

A research proposal was submitted to the Research Committee of the Department Communication Pathology at the University of Pretoria, as well as to the Research Proposal and Ethics Committee of the Faculty of Humanities in order to obtain ethical clearance. This is to ensure that the research study is ethically sound. Ethical clearance was obtained before any fieldwork was conducted (See Appendix G).

**Informed consent** was obtained from all the participants: parents of children with cochlear implants (Appendix B), speech therapists/audiologists (Appendix C), as well as the head of the Bloemfontein Cochlear Implant Program (Appendix A). Although the participants are parents of children with cochlear implants, the children themselves were not directly involved in any of the procedures for the research project. The principle of informed consent was incorporated into the study by means of providing an informed consent letter to the participants (Appendix B & C). Obtaining informed consent implies that all possible or adequate information regarding the goal of the research, the procedures that will be followed during the investigation, the possible advantages and dangers which respondents may be exposed to, will be explained to the respondents (De Vos, 2005:59). Participants were informed that participation in the study was voluntary and if they agreed to participate they had the right to withdraw at any time during the research project without any negative consequences (Leedy & Ormrod, 2005:101).

**No physical or emotional harm** was foreseen to participants in the research study, as an interview was conducted by a qualified professional in the field of cochlear implantation.

The conditions of **confidentiality** apply in the research study with regard to the collection of data by means of audio recordings and face-to-face interviews. The use of the audio recorder was explained to the participants and they were free to reject any recording being made if they so wish. In order to protect the privacy of

the participant, they were informed of their right to refuse to be interviewed and to refuse to answer any question they wish. The confidentiality of the participants was assured by making an active attempt to remove any element that may indicate the participants' identities (Mouton, 2001:244). Confidentiality also includes to the information gathered from participants (Mouton, 2001:244). The information shared during the semi-structured interviews was kept confidential by removing identifiers and by randomizing the responses.

The researcher respects the ethical concept of ***honesty towards professional colleagues***. The researcher is qualified to perform the semi-structured interviews due to the registration at the Health Professions Council of South Africa (HPCSA) as a speech-language pathologist/audiologist. The researcher reported the findings in a complete and honest fashion, without misleading procedures or intentionally misleading others about the nature of the findings (Leedy & Ormrod, 2005:102). Ethical guidelines acted as the foundation of this research project.

### **3.10 VALIDITY AND RELIABILITY**

Validity and reliability of the research project is important throughout the research process. *Validity* refers to the extent to which a measure reflects the concept it is intended to measure (De Vos, 2005:160). Validity consists of two parts: if the instrument actually measures the concept in question and if the concept is measured accurately (De Vos, 2005:166). Validity was ensured in the study by completing a thorough literature study before the interview schedule was compiled to ensure that relevant as well as research based questions were included. A pilot study took place before the semi-structured interviews to critically evaluate the application and accuracy of each question. The interviews were recorded and transcribed verbally; this contributed to the validity of the responses. The transcribed data was cross-checked with the audio recording by

the research supervisor in order to ensure that an accurate representation was transcribed and to reduce any element of bias. The language of the semi-structured interviews was adapted to eliminate any uncertainty and confusion of concepts. The results from the semi-structured interviews were correlated with the results from the literature study. Professionals evaluated the pre-implantation rating tool in order to determine its clinical value. The evaluation of the tool contributed to the content validity of the instrument.

*Reliability* of a measurement instrument refers to the extent to which it yields consistent results when the characteristics being measured have not changed (Leedy & Ormrod, 2005:93). Inter-test reliability was eliminated because all the semi-structured interviews were conducted by the researcher and not by different interviewers. The same interview schedule was used for each participant. Reliability was also ensured by selecting participants that are proficient in Afrikaans or English. As a result, misinterpretation of responses was eliminated by not translating questions and answers in another language.

### **3.11 CONCLUSION**

The initial information session in cochlear implant programmes generally focuses on information and support that professionals believe is important, rather on that what parents have indicated they actually wish to receive. This may often lead to a mismatch between the views professionals hold and that of the parents in terms of their specific needs (Most & Zaidman- Zait, 2001:100). The need clearly exists to approach each family on an individual basis, as each has its own emotional and information needs (Louw & Avenant, 2002:145; Perold, 2001:54). It is thus clear that a rating tool should be developed to identify these individual needs. The aim of the study was to develop a pre-implantation tool to rate the individual support and information needs of parents of young cochlear implant candidates. The method followed to develop the pre-implantation rating tool for



parents of cochlear implant candidates has been discussed in detail in this chapter. The procedures, material and equipment used are reliable and could be repeated in the same sequential order when the study is conducted by other researchers. The rating tool was developed to identify individual needs of parents for information and support during the pre-implantation of cochlear implants. A clinical evaluation of the rating tool by professionals working in the field of cochlear implants in South Africa merited the validity and reliability of the rating tool. Ethical guidelines formed the foundation of this research project and participants were well informed of the ethical considerations that were made throughout the research.

### **3.12 SUMMARY**

This chapter provides a throughout discussion of the research aims, the research design, participant selection criteria, data collection instruments and equipment, the pilot study, data collection procedures, data analysis, ethical considerations as well as the validity and reliability of the study. The chapter aimed to discuss the logical planning of the method used to gather the data for analysis and to explain the different phases of the research project. The method described was suitable to obtain reliable and valid results to address the main aim of the study. The chapter ends with a conclusion and summary.

## CHAPTER 4

### RESULTS AND DISCUSSION

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*“Tell me and I’ll forget, show me and I may remember, involve me and I’ll understand.” – Chinese Proverb*

#### **4.1 INTRODUCTION**

The field of cochlear implants has seen a steady growth in South Africa with several centres now providing services around the country (Swanepoel et al., 2009:3). To date, more than 45 000 children have received implants worldwide (Archbold et al., 2006:191). In South Africa, the number of children with cochlear implants has grown to be more than 400 (SACIG, 2008). It is of utmost importance to consider the diverse socio-economic, geographical, linguistic and cultural features when providing family centred cochlear implant services to South African parents. Each family is unique and should be regarded as an individual unit with its own values, beliefs, practices and needs (Louw & Avenant, 2002:145). The ability to put oneself in the family’s unique situation often provides a more realistic understanding of their concerns and needs. This may lead to a stronger partnership with the family (Johnson et al., 1997:142). It is therefore necessary to approach each family on an individual basis, as each has their own needs for emotional support and information (Perold, 2001:54; Johnson et al. 1997:144; Louw & Avenant, 2002:145).

The main aim of this study was to develop a pre-implantation tool to rate the individual support and information needs of parents of young cochlear implant candidates. This tool will assist parents and professionals in identifying the family’s unique needs for information and support prior to cochlear implantation for their children.

The aim of this chapter is to describe the results gathered from the semi-structured interviews, to compile the rating tool and to discuss the results from the evaluation of the rating tool by professionals.

## ***4.2 RESULTS AND DISCUSSION***

The results are presented according to the sub-aims of the study outlined in Section 3.2.2. The data collection consisted of three phases as illustrated in Diagram 1. The discussion begins with a description of the participants that were included in the semi-structured interviews. The semi-structured interviews were conducted during phase one of the data collection.

### **4.2.1. Description of participants**

The responses to the questions asked in Section A of the semi-structured interviews during phase one of the data collection procedures are summarised and presented in **Figure 2** and **Figure 3** below.

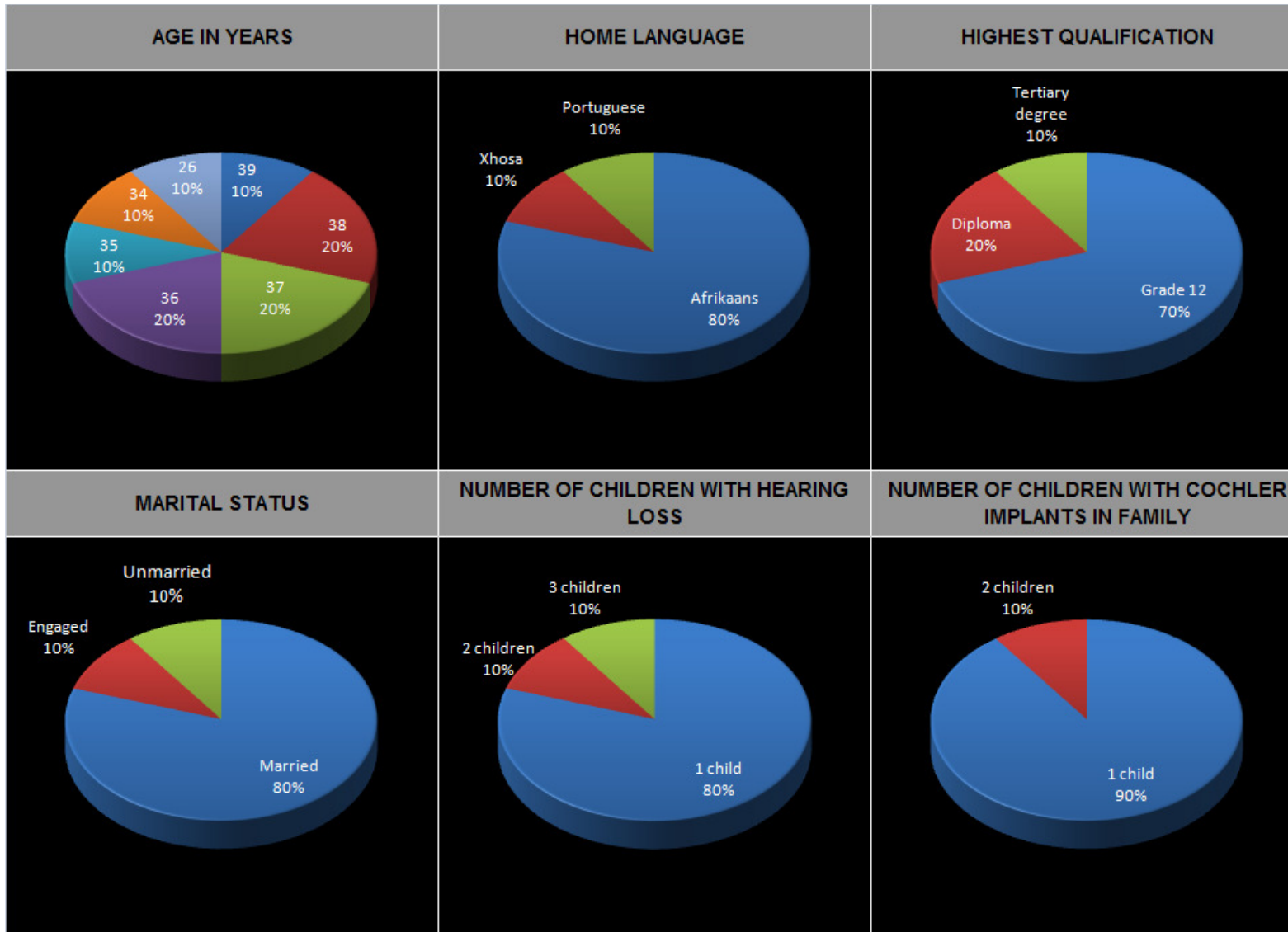


Figure 2 Description of participants included in the semi structured interviews (n=10)

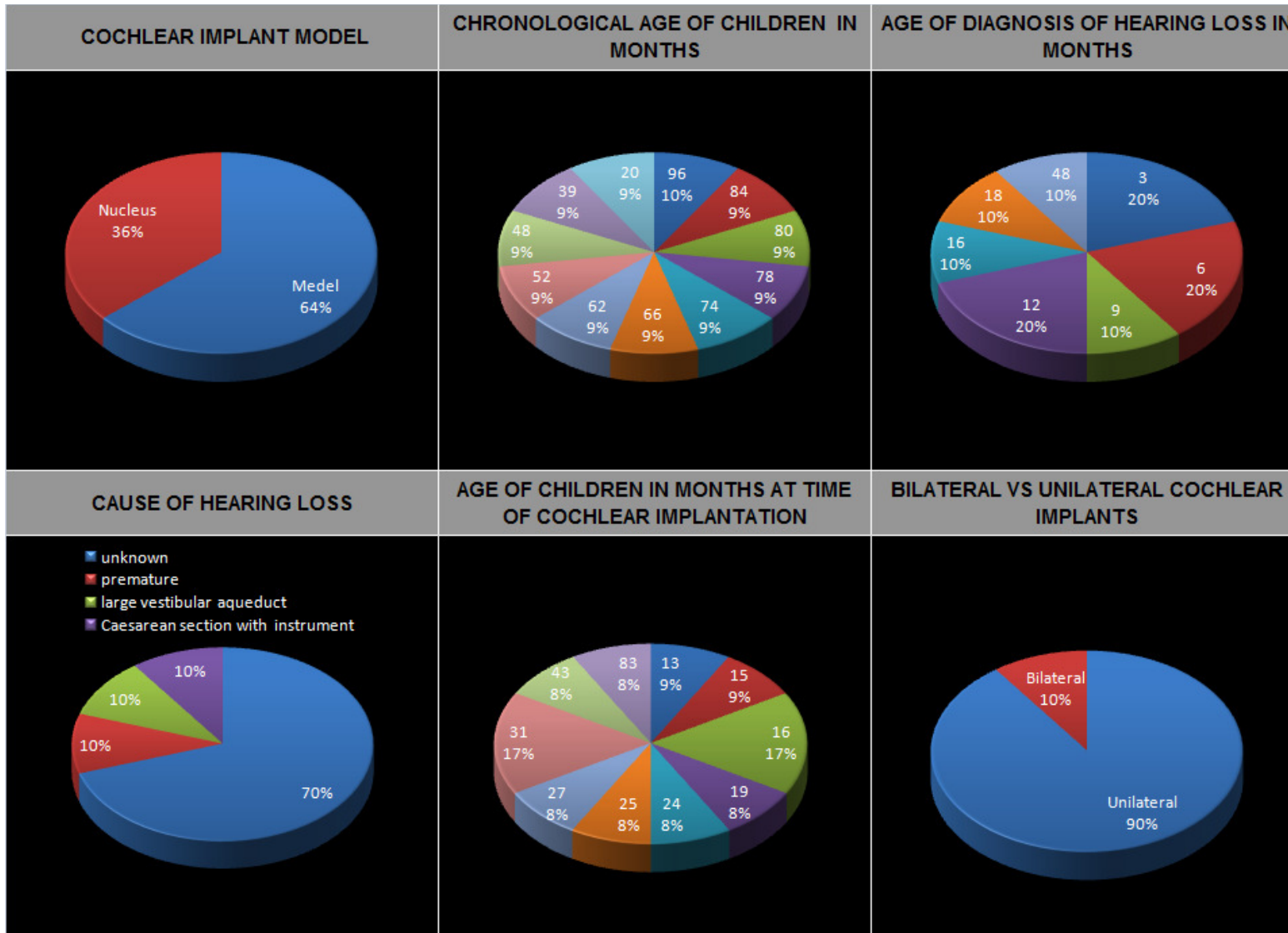


Figure 3 Description of the children of participants included in the semi-structured interviews (n=10)

As presented in **Figure 2**, the mean age of participants that took part in the semi-structured interviews was 30 years (range is 26-39 years). Over 90% of the participants were in their thirties. The majority of the participants' home language was Afrikaans (80%). This correlates with the demographic area and the racial groups included the study. The main home language spoken in the Free State is SeSotho (64,4%), spoken by the most Africans and Afrikaans (11,9%), spoken by the most Whites and Coloureds in the Province (Statssa, 2004:19). The respondent whose home language is isiXhosa is fluent in Afrikaans and thus the interview was conducted in Afrikaans. The Portuguese participant was able to speak English and the interview was therefore conducted in English. The participants also represented various racial groups, with 70% of participants being White, 20% Coloured and 10% Black. The Black population in this study are from previously disadvantaged communities and therefore are from a lower income group than other respondents. According to Statistics South Africa, the Black population generally earns seven times less than the White population in general (Statssa, 2005/2006:27). This statistic is reflected in cochlear implant programmes, where Black and Coloured populations often cannot afford the high costs associated with cochlear implantation. This inequality in socio-economic status of different population groups in South Africa makes the sample used in this study unrepresentative of the South African population and results should be generalized with caution. This limitation should be taken into account in the analysis of the results as well as the application of the rating tool that was designed. The majority of the participants obtained Grade 12 as their highest qualification (70%) while 30% obtained a tertiary qualification. With regards to marital status, 80% of the participants are married, 10% are engaged and 10% are single. The majority of participants had only one child with a hearing loss (80%). One participant had two children in her family with a hearing loss and another parent had three children with a hearing loss where two of her three children received cochlear implants.

**Figure 3** provides a description of the children of participants included in the semi-structured interviews. With regard to cochlear implant models used, 64%

of the participants' children were implanted with Medel devices, while 36% were implanted with Nucleus devices.

The mean age of the children was 63 months (range was 20-96 months). The mean age of diagnosis was 13 months (age of diagnosis ranged between 3-48 months). Sixty percent of participants children were diagnosed with a hearing loss within the first year of life. A study conducted in the Western Cape, South Africa indicated the age of diagnosis for severe or profound hearing loss to be between 11 and 17 months (Van der Spuy et al., 2008:33). This correlates with the findings in this study since all the children had severe to profound hearing loss. However, the age of diagnosis of participants children does not correlate with the mean age of diagnosis of 23 months in the study by Van Der Spuy and Pottas, (2008: 33). A possible reason for the earlier age of diagnosis in this study may be because two of the families had older children with hearing loss and therefore the younger sibling was tested at an earlier age due to the family's knowledge of hearing loss. The child that was diagnosed at three months was born prematurely and a hearing test was done before the child was discharged from Neonatal Intensive Care Unit (NICU). For most of the participants the cause of their child's hearing loss was unknown (70%). An unknown cause for hearing loss is common (Pichard, 2004:226). The mean age of implantation in this study was 26 months (age of implantation ranged between 13-83 months). Of the 11 children who received cochlear implants, only one child had a bilateral implantation. This may be due to the high cost associated with cochlear implantation and the limited financial contribution that medical aids are willing to make (Müller & Wagenfeld, 2003:59). Another contributing factor may be the fact that more than 85% of the population of South Africa rely on the public health sector (Swanepoel et al., 2009:2). There is limited funding available to the public health sector and high cost associated with the device, surgery and follow –up services of bilateral cochlear implantation. This leads to bilateral implantation as rare option for cochlear implant candidates.

### ***4.3 SUB-AIM 1: Retrospective identification of information and support needs of parents of young children with cochlear implants***

During the semi-structured interviews in phase one of the data collection process, participants were asked to reflect back on the pre-implantation phase of their child's cochlear implant. Responses from the participants who were Afrikaans speaking were translated into English. Transcripts of the semi-structured interviews are presented in Appendix H. Amendments were made to responses that were grammatically unclear, in order to clarify the meaning to the reader. The responses were categorised according to themes identified in the questions of the semi-structured interviews. These themes were selected by the researcher in order to categorise the responses in a structured manner. The following themes were identified and the results of the semi-structured interviews are discussed accordingly:

1. Challenges experienced during the decision making process,
2. Information needs,
3. Support needs,
4. Main need for information and support,
5. How to effectively assist parents with information and support,
6. Perception on giving parents a choice regarding the amount and type of information and support that they wish to receive.

The responses from participants guided the researcher on what themes to include in the development of the rating tool that was developed to identify the information and support needs of parents during the pre-implantation phase of cochlear implantation.

#### **4.3.1. Challenges experienced during the decision making process**

Challenges that participants experienced during the decision making process were discussed in order to determine the effect of the pre-implant phase on parents and to identify factors that cochlear implant teams should take into account when working with families during the decision making process.



**Table 7** contains excerpts from the interview and illustrates the emotional challenges that participants experienced during the decision- making process.

<b>Table 7 Emotional challenges during the decision making process</b>
"...we felt pressured to make a decision immediately regardless of the fact that we did not have all the information..." Participant 1
"...I was scared..." Participant 2
"... it was chaotic time..." Participant 3
"...it was an emotional stressful time..." Participant 3
"...it is a big change and shock to absorb..." Participant 6
"To accept (older child's name) is deaf. That was very difficult." Participant 8

**Table 7** illustrates that participants often experienced the decision- making process involved in choosing a cochlear implant as sensory aid for their child as stressful. Parents felt pressurised to make a decision and report that what made this decision even harder was that often they were still in the process of accepting such a diagnosis, while a decision had to be made. The stressful nature of the decision-making process is well described in the literature (Agnagnostou et al., 2007:71; Eleweke et al., 2008:191; Most & Zaidman-Zait, 2001:99; Zaidman- Zait & Most, 2005:130). Universally, children are identified at an earlier age with a hearing loss (Yoshinaga-Itano, 2003:252). Most parents are presented with a diagnosis that is unexpected and as a result of the diagnosis, the future for their child is uncertain, unpredictable and ambiguous (Kurtser- White & Luterman, 2003:233). At the time of diagnosis, or closely following, parents are presented with a large amount of technical information. They need to make decisions about a broad range of options such as educational, language and sensory aids and this decision-making process can be emotional and challenging (Kurtser-White & Luterman, 2003:233). The emotional challenges that parents experience during the decision-making process is important to take in consideration when professionals work with parents. Professionals should be sensitive to the emotions experienced by parents in order to build a relationship of trust and understanding. Professionals should be trained in counselling skills in order to support parents during the decision-making process (JCIH, 2007:5).

The major challenge that parents reported on was the financial implications that the cochlear implant entailed. **Table 8** lists some of the parents remarks regarding these financial challenges.

<b>Table 8 Financial challenges during the decision making process</b>
"...it is going to cost thousands of Rands but it is the best for you child so you must do it." Participant 1
"The worst is that it is expensive..." Participant 2
"...the finances are the most important...that was a challenge..." Participant 5
"Definitely the finances. You know your child is hearing impaired where you are going to find the money?" Participant 6
"...everyone told you immediately it was a lot of money..." Participant 6
"...funding to make it possible..." Participant 7

As presented in **Table 8**, the financial implications of funding a cochlear implant and rehabilitation services, required after the cochlear implant, is a great concern to parents (Sach & Whynes, 2005:403). With a vast majority of South Africans (approximately 85%) relying on the public health sector, the high cost of the cochlear implant device, surgery and follow-up services has remained an obstacle in South Africa (Swanepoel et al., 2009:3). It is thus important for professionals to recognise that apart from the emotional stress parents experience during the decision-making process, parents face immense financial challenges as well and this places additional burden on the parents and the family system. The challenges that parents face during the decision-making process gives a clearer perspective of the stressful nature of cochlear implantation that professionals should take into account when working with parents. Cochlear implant teams should give parents thorough information with regard to the financial implications of a cochlear implant and provide options that they could consider or investigate in order to plan financially for the cochlear implantation.

### 4.3.2. Need for information

Participants' need for information was varied and some reported unique needs. The following themes were identified from the responses obtained by the semi-structured interviews with regard to participants' need for information. Quotes from the participants concerning their need for information are provided in **Tables 9 to 14**.

**Table 9** below illustrates the need for information on the effectiveness of cochlear implants with the quotes from participants.

<b>Table 9 Need for information on the effectiveness of cochlear implants</b>
"I only wanted to know if my child will hear after the operation." Participant 2
"I wanted to know will it work." Participant 5
"It is going to work for him?" Participant 8

The statements of the participants as depicted in **Table 9** illustrate the need for information on the effectiveness of cochlear implants. Some respondents merely wanted to know whether the cochlear implant will work and if their child will be able to hear with the device. Parents seek reassurance that their decision on a cochlear implant is the right choice. According to Johnston and colleagues (2008: 175), a key concern for parents is that their child would not benefit sufficiently from the cochlear implant. It is thus important to provide parents with information on the benefits as well as effectiveness of cochlear implants in all children with severe to profound hearing loss. Parents could be provided with the latest statistics and information regarding success rates of cochlear implantation by the specific cochlear implant centre.

Participants' statements about the need for information on other children with cochlear implants are provided in **Table 10**.

<b>Table 10 Need for information about other children with cochlear implants</b>
"We wanted to know about other children ... how they are progressing with their cochlear implants." Participant 5

“Testimonials from other parents...” Participant 7

“...want to see somebody with children like that... I wanted to see somebody with a cochlear implant.” Participant 8

Participants had a great need for information about other children who have undergone cochlear implantation. Parents wanted to know about other children, see other children, hear testimonials and even meet other children with cochlear implants. One of the most important factors in the decision-making process is to witness the success of the device in other children and to get in contact with their parents (Perold, 2001:49). This reflects the need for mutual support and the opportunity to share information on behalf of parents (Johnson et al., 2008:175). It is important for families to know that they are not the only family that has to go through cochlear implantation and that it has been successful in other children. Professionals should thus provide information on other children with cochlear implants and offer opportunities for parents to meet and get in contact with other families whose children received cochlear implants.

Participants indicated a need for information on the outcomes of cochlear implants. Their responses are presented in **Table 11**.

**Table 11 Need for information on outcomes**

“In the long run, how is it going to work for her?” Participant 5

“How will his future look? This was the biggest issue for us.” Participant 6

“...what is the outcome en how fast we can expect what...” Participant 9

**Table 11** reflects parents’ need for information on what is expected of the cochlear implant and what are the outcomes of children with cochlear implants. Given the majority of parents have no previous experience of hearing loss, it is not surprising that they tend to be anxious about their child’s future (Eleweke et al., 2008:193). Edwards and colleagues (2000:102) reported that one of the most important sources of information during the assessment phase of the cochlear implant is the need for more detailed information on possible outcomes of cochlear implantation, parents do not

want to hear “*don’t expect too much*”. Professionals should thus be able to ensure that parents have realistic expectations prior to the surgery in order to prepare them for future outcomes.

Participants report fears and concerns about the surgery. **Table 12** contains accounts from parents in this regard.

<b>Table 12 Need for information on surgery</b>
“The toughest part for me was to go through surgery.” Participant 10
“...how long will she be in theatre, what are they going to do...” Participant 3
“...show us where they going to make the cut...” Participant 4

**Table 12** illustrates the need for information on the surgery procedure. Edwards et al. (2000:102) reported that a key source of information during the pre-implantation phase of the cochlear implant is the need for more information about the operation, for example what the incision will look like, what a real cochlear implant looks like and what the surgery involves. The surgeon involved in the cochlear implant programme should thus provide sufficient detail and information about the surgery and procedures involved in cochlear implantation.

Participants indicated a need for information on financial issues. **Table 13** outlines some of their comments about finances.

<b>Table 13 Need for information on financing a cochlear implant</b>
“Obviously financial information, if we can afford it, the batteries etc.” Participant 10
“How much will it cost...?” Participants 3

As previously mentioned, the financial implications of funding a cochlear implant and the rehabilitation services required after the cochlear implant, is a great concern to parents (Sach & Whyne, 2005:403). A need exists in care related to funding of sensory aids, such as cochlear implants. This remains a barrier to optimal service delivery to parents of children with hearing loss

(Fritzpatrick, 2008:43). Parents should thus be thoroughly informed about the financial implications and funding options for a cochlear implantation. Funding of cochlear implantation should be advocated at medical aids as well as in the public health sector in South Africa.

The following excerpts are unique needs of individual parents and are depicted in **Table 14**.

<b>Table 14 Unique needs for information</b>
Functioning of a cochlear implant: "We wanted to know how it works." Participant 6
Statistics of effectiveness of a cochlear implant: "...what is the success rate...how many children speak...what percentage is able to function normally...what percentage of are able to go to a mainstream school..." Participant 1
Procedure if the cochlear implant is not functioning: "...if she is not able to hear with the implant, are they going to remove it?" Participant 2
Different manufactures of cochlear implant processors: "We wanted to know about different types of cochlear implants." Participant 4
Internet websites: "I went on the internet....I did my own research..." Participant 7

According to research on parents' needs of children with cochlear implants, they need extremely diverse information on the cochlear implant process (Most & Zaidman- Zait, 2001:106). The remark on the use of the internet can be highlighted since literature suggests that websites references and links are essential to give to parents (Eleweke et al., 2008:204). The internet has become an important source of information for parents of children with hearing loss (Eleweke et al., 2008:204). Clinicians should provide guidance for parents to limit access to unscientific and misleading information on the internet. It is of utmost importance to take these unique needs for information into account when working with parents and thus a tool to identify these unique needs would be very valuable.

### 4.3.3. Need for support

Parents commented on their need for support as well as on the need for sources of support during the process of cochlear implantation. The following themes were identified through analysis of the semi- structured interviews. Responses are summarised in **Table 15**.

<b>Table 15 Need for support</b>
<p>Need to meet parents of children with cochlear implants:</p> <p>“...to meet other parents whose children received cochlear implants to share their experience...” Participant 1</p> <p>“...we wanted to meet people who went through the process...” Participant 4</p> <p>“...to talk to people who actually went through this...” Participant 7</p>
<p>Reassurance from the therapist:</p> <p>“...I wanted to know from the people that deal with the implants .....reassurance that it is going to be ok; she will be able to hear....” Participant 3</p>
<p>Guidance:</p> <p>“...you want somebody to come and tell you what to think, for go for the operation or not...” Participant 8</p>
<p>Information as support:</p> <p>“...we wanted more in terms of outcomes... what happens before the operation and what happens after the operation...” Participant 9</p> <p>“...information, we wanted as much information, whether it was negative or positive, we wanted to know what to expect...” Participant 10</p>
<p>Support providers:</p> <p>“...Dr gave us information and support....” Participant 9</p> <p>“...My collages gave support...” Participant 2</p> <p>“...My speech therapist gave support...” Participant 2</p> <p>“...At her school, people encouraged you...” Participant 5</p> <p>“...family helped us...family support was important to us...” Participant 6</p>

**Table 15** illustrates the different needs for support. Parents’ need for emotional support are of utmost importance during the pre-implantation phase of cochlear implants. Parents reported that they mostly lacked emotional support from professionals during the decision-making process (Most & Zaidman- Zait, 2001:105). The participants responded similarly to respondents in a study by Most and Zaidman- Zait, (2001). One participant

stated: *“I just felt that the emotional support was absent. You have to cope on your own. I personally feel that they should address the emotional issues more...” Participant 1.*

A necessity for parents is to meet other families whose children received cochlear implants. The request to meet other parents has been described in the literature as an “emotion- focused” coping strategy (Most & Zaidman- Zait, 2001:107). Parents often seek out peers to validate and manage their feelings towards their child’s condition and the encounter with other parents from similar backgrounds who face comparable problems provides support, alleviates feelings of isolation, and offers models and strategies for coping (Most & Zaidman- Zait, 2001:107). Cochlear implant centres should provide opportunities for families to meet other parents who have been through cochlear implantation.

Emotional support refers to incidents where professionals’ calm parents during stressful situations, care for parents, show empathy, listen to parental concerns, express understanding for their situation, and encourage them throughout the process of diagnosis, surgery and rehabilitation (Zaidman-Zait, 2007:221). This is evident in the participants need for reassurance and guidance from a professional.

The support provided by professionals, correlates with the study of Most and Zaidman-Zait, (2001) that reported that parents preferred to receive information and support from several key professionals, mostly the surgeon, the audiologist and the speech- language therapist. Professionals should recognise of the emphasis placed on emotional support during the pre-implantation process. Parents should be provided with resource options such as access to support groups, psychologists and parents that have been through the cochlear implant process. Professionals should draw on good counselling skills to address these emotional needs for support of parents (Duncan, 2009:39).



#### 4.3.4 Main need for information and support

Participants were asked to articulate what they thought was the most important information and support to give to parents before a cochlear implant. The participants' responses reflect the most important information and support to give to parents. Their accounts are presented in the **Table 16**.

<b>Table 16 Main need for information and support</b>	
<b>Main need for information:</b>	<b>Main need for support:</b>
<ul style="list-style-type: none"> <li>Statistics on success rate of cochlear implants: "To know if it will work...." Participant 1</li> </ul>	<ul style="list-style-type: none"> <li>To meet other parents: "...who were in the same situation..." Participant 1</li> </ul>
<ul style="list-style-type: none"> <li>Information on phases of cochlear implantation: "...how is it done, what happens after the surgery..." Participant 2</li> </ul>	<ul style="list-style-type: none"> <li>Reassurance: "...to not be afraid..." Participant 2</li> </ul>
<ul style="list-style-type: none"> <li>Information on rehabilitation after surgery: "Your work does not stop after the surgery. It is hard work..." Participant 3</li> </ul>	<ul style="list-style-type: none"> <li>Speech Therapist guidance: "...to have a speech therapist that can support them before the implant..." Participant 3</li> </ul>
<ul style="list-style-type: none"> <li>Impact of a cochlear implant: "...impact of the cochlear implant...how will it have an effect on my child?" Participant 4</li> </ul>	<ul style="list-style-type: none"> <li>Communication: "Communication...an open line for communication..." Participant 4</li> </ul>
<ul style="list-style-type: none"> <li>The future of children with cochlear implants: "...to understand that what is done is done for the future of your child..." Participant 5</li> </ul>	<ul style="list-style-type: none"> <li>Information: "...to provide information and talk about it..." Participant 5</li> </ul>
<ul style="list-style-type: none"> <li>Financial implications of cochlear implants: "Definitely the financial implications...maintenance of the device..." Participant 6</li> </ul>	<ul style="list-style-type: none"> <li>Uphold: "Definitely to uphold us." Participant 6</li> </ul>
<ul style="list-style-type: none"> <li>Probability of failure of cochlear implantation: "That cochlear implant sometimes does not work.... I had hoped...and that was not how it should have been..." Participant 7</li> </ul>	<ul style="list-style-type: none"> <li>24/7 availability of support: "There should be 24/7 call centre, a call line..." Participant 7</li> </ul>
<ul style="list-style-type: none"> <li>Time constraints: "...you cannot wait..." Participant 8</li> </ul>	<ul style="list-style-type: none"> <li>Timely decision making: "...when they find the problem they must do it.</li> </ul>

	Because it is better than wait, much better...” Participant 8
<ul style="list-style-type: none"> <li>Functioning of cochlear implants: “...functioning of the cochlear implant, because that is unfamiliar to everyone...” Participant 9</li> </ul>	<ul style="list-style-type: none"> <li>Empathy: “...most important to have empathy with the parents...” Participant 9</li> </ul>
Speech therapy guidance before implantation: “...to attend speech therapy beforehand to teach your child...” Participant 10	Emotional and financial: “I think emotionally and financially because you want that kind of support.” Participant 10

The unique needs that different participants have are prominent in **Table 16**. It should be noted that ten participants gave ten different responses to the question in both their needs for information and for support. This illustrates the uniqueness of families. Cochlear implant team members should focus on the fact that families are unique and they vary in many ways. Archbold *et al.* (2008:121) reported that parents needs are varied and may not conform to the expectations of others, including implanting teams. Louw and Avenant (2002:145) referred to the South African population with the following statement: “*Each family is unique and should be regarded as an individual unit with its own values, beliefs, practices and needs.*” It is important to take note of these individual needs and to put oneself in the family’s unique situation. This provides a more realistic understanding of the family’s concerns and needs, which results in a stronger partnership with the family (Johnson et al., 1997:142). The responses in **Table 16** clearly indicate the need to identify the family’s unique needs for information and support during the pre-implantation phase. This clearly illustrates the need to develop a tool to identify these needs.

#### **4.3.5 Guidelines from participants for more effective service delivery**

Participants were asked to provide guidelines or suggestions for cochlear implant teams for more effective service delivery of information and support during the pre-implantation phase. The participants’ suggestions are presented in **Table 17**.

**Table 17 Guidelines for effective service delivery**

<ul style="list-style-type: none"> <li>• More emotional support:            “I personally feel that hospital should address the emotional aspect more...” Participant 1            “I think if they could start a group...a support group for parents...” Participant 4            “I think they should continue to motivate...” Participant 7</li> </ul>
<ul style="list-style-type: none"> <li>• Information on what can be expected:            “After the operation what can be expected and what not to expect” Participant 2            “I think they should provide reading material in terms of what is involved in the pre-implant phase en in the post-implant phase...” Participant 9.            “To know exactly what is going to happen, what is needed...to explain the financial impact clearly...” Participant 9</li> </ul>
<ul style="list-style-type: none"> <li>• Less information:            “Actually, I had too much information. I don’t think it is always necessary to have so much information.” Participant 3</li> </ul>
<ul style="list-style-type: none"> <li>• Internet:            “...if you have internet and email, you have to receive news headlines on the latest technology...” Participant 7</li> </ul>
<ul style="list-style-type: none"> <li>• Timely decision making:            “I think they should choose and help the baby quickly...not waste time” Participant 8</li> </ul>

The issues raised by participants in **Table 17** gave valuable insight that cochlear implant teams could use in areas of improvement in their service delivery. It should be observed that the majority of suggestions to improve service delivery centered on the need to provide more emotional support and information to parents.

Although the importance of providing emotional support to parents is stressed in the literature, parents often indicate that they lack emotional support from the cochlear implant team members (Zaidman-Zait & Most, 2001:105). Sensitive counselling with a high degree of listening and emotional support can expedite the parents acceptance and move them from denial into productive decision makers (Duncan, 2009:39).

The need for information on outcomes is important to parents during the pre-implantation phase (Edwards et al., 2000:102). Professionals need to provide parents with impartial, comprehensive, written and spoken information,

presented to them jargon free and in a judicious manner on all aspects of cochlear implantation including potential outcomes in children (Duncan, 2009:41).

The need for less information indicates the uniqueness of families. Many families may feel overwhelmed by the extent and complexity of information provided about cochlear implants, unless it is carefully tailored to individual needs and presented in an accessible format at an appropriate time (Edwards, et al., 2000:104). Information therefore needs to be flexible enough to respect individual family needs (Duncan, 2009:40).

In a study by Fitzpatrick et al. (2008:45) the internet emerged as an important access point for parents, however, several families expressed that this source is not sufficiently supported and maximized by professionals. Parents rely heavily on the internet for information and therefore a list of recommended websites should be provided to parents to gain reliable information on cochlear implants (Fitzpatrick et al., 2008:45).

The comment on timely decision making, suggests that the participant felt that the cochlear implant team should make the decision to implant or not to implant in a timely fashion. In a study by Perold (2001:49) mothers expressed anger and disappointment that their child had not been referred earlier for cochlear implantation and it became evident that referrals for cochlear implantation should be made as soon as it becomes evident that the child is not deriving meaningful benefit from hearing aids. This is not considered to be the role of the professional. A child's parents are considered as the ultimate decision making authority in the management of a child (Eleweke et al., 2008:195). Cochlear implantation decision making should be shared by the parents and professionals and be managed in a timely fashion (JCIH, 2007:5).

#### 4.3.6 Perception on giving parents a choice regarding the amount and type of information and support that they wish to receive

Participants were asked how they would feel if parents are given a choice in the amount and type of information they wish to receive before the cochlear implantation.

The overall response was positive with eight participants providing positive feedback. Two participants felt unsure about how they would feel given options to choose information and support. Accounts from participants are provided in **Table 18**.

<b>Table 18 Perception on giving parents a choice regarding information and support</b>
"...I think they do not focus enough on what the parent of the deaf child needs...it is too much..." Participant 1
"I think they can choose because it differs from person to person what type of information you want". Participant 3
"You don't know what to ask. If there were a list that could inform you what are available, then you could go through it and communicate what you do not know." Participant 4
"That wonderful, then you can decide..." Participant 7
"I think it is important to have all the information available but parents should still have a choice" Participant 9
"After your child gets the cochlear implant then you want to know more things." Participant 8.

According to responses as provided in **Table 18**, the option to choose information and support received, provides the opportunity for parents to communicate their needs, illustrate a form of respect for individual differences, limit information overload and provide time to process information. One participant felt that she did not want a great deal of information before the cochlear implant. This participant indicated that she would prefer more information after the cochlear implantation.

These individual comments of the participants are similar to other findings in the literature. Many parents may feel overwhelmed by the extent and complexity of information provided to them about the cochlear implant

process, unless it is carefully tailored to their individual needs and is presented in an accessible format at the time it is most appropriate and digestible (Edwards et al., 2000:104). It is also important to know that information and support needs change over time (Eleweke et al., 2008:204). It is of utmost importance that information should not be overwhelming so that parents can assimilate it (Eleweke et al., 2008:193). Minchom et al. (2003:102) reported on key areas that parents identified in which service development should improve for families of children with hearing loss. Parents commented that professionals should develop better means of identifying parental needs.

The need clearly exist for the development of a rating tool that would be useful to South African cochlear implant programmes in considering the individual needs of parents as they receive their first pre-implantation session with an audiologist or speech- language therapist (Anagnostou et al., 2007:82). By investigating the responses of the participants in the semi-structured interviews several important areas of information and support were identified. These needs will be taken into consideration in the next aim of compiling a pre-implantation rating tool to determine individualized information and support needs of parents of young cochlear implant candidates.

#### ***4.4 SUB- AIM 2: A pre-implantation rating tool to determine individualized information and support needs of parents of young cochlear implant candidates.***

During phase two of the data collection procedure the responses gathered from the semi-structured interviews, together with relevant literature were used to compile a pre-implantation rating tool to determine individualized information and support needs of parents of young cochlear implant candidates.

The rating tool is presented in **Figure 4** as well as in Appendix E. A brief discussion on the content of the rating tool follows.



**Figure 4 The pre-implantation rating tool for parents of cochlear implant candidates**

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Child's name: \_\_\_\_\_  
Date: \_\_\_\_\_  
Name of parent: \_\_\_\_\_

Dear Parent:  
Many parents of young children who are in the decision phase and pre-implantation phase of cochlear implantation have specific needs for information and/or support. Listed below are some of the needs frequently identified by parents. It would be helpful if you could check the topics below which you wish to receive information on or to discuss with a member of our cochlear implant team. At the end of the rating scale there is a place for you to add other areas not included on this list.

If you choose to complete this form, the information you provide will be kept confidential. If you would prefer not to complete the survey at this time, you may keep it for future needs.

Please rate the following ten categories according to your specific needs. Rate the categories from 1-5, indicating 1 indicates the most important area that you want your therapist to pay attention to and 5 the least important area for you.

Rating Scale				
1	2	3	4	5
Most important	Very important	Moderately important	Not that important	Least important

1. General	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
The criteria for cochlear implantation candidacy.				
The alternatives to cochlear implantation.				
The effectiveness of cochlear implantation in children.				
The impact of delaying cochlear implantation for my child.				
The phases of the cochlear implant process.				
About bilateral (both ears) cochlear implantation.				

2. Technical	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
About the components and functioning of a cochlear implant.				
About the different kinds of cochlear implants and their advantages and disadvantages.				
Information on how the cochlear implant will fit in with future technology.				
Troubleshooting and failure of the functioning of the cochlear implant.				
Mapping/programming of the cochlear implant.				
Internet resources on cochlear implantation.				
About hearing tests before and after cochlear implantation.				

3. Surgery	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
About the surgical procedure.				
About the risks of surgery.				
About meningitis risks with regard to cochlear implantation.				
About magnetic resonance imaging (MRI).				
The duration of hospital stay after the cochlear implantation surgery.				

4. Social Support	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like:</b>				
To meet other parents whose child received a cochlear implant.				
To know the availability of support services for children with cochlear implants and their families.				
Someone outside my family to talk to about my child.				
When and how to communicate with cochlear implant team members				
To be part of a support group of parents of children with a hearing loss.				
To receive emotional support.				

5. Financial	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
The cost of the cochlear implant.				
The maintenance costs involved in cochlear implantation.				
The medical aid contribution to cochlear implantation and rehabilitation.				
Surgical and hospital costs involved in cochlear implantation.				
The rehabilitation costs involved in cochlear implantation.				
The mapping costs involved in cochlear implantation.				
About financial support for cochlear implantation.				

6. Communication options	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
About the Auditory -Verbal approach.				
About Sign Language.				
About the Oral approach.				
About Total Communication.				
About the Deaf culture.				

7. Education	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
About educating my child in a signing school.				
About educating my child in a mainstream school.				
About educating my child in a school for children with hearing loss.				
About educational options for my child immediately after receiving a cochlear implant.				

8. Outcomes	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
The factors that influence outcomes of children with cochlear implants.				
The variability of auditory performance that can exist in children with cochlear implants.				
Basic outcomes that can be expected after cochlear implantation.				
The variability of speech and language development that exists in children with cochlear implants.				
Outcomes for children with additional challenges or disabilities.				

9. Rehabilitation	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
About speech therapy after cochlear implantation.				
Additional rehabilitation resources.				

10. Parental role	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
The time commitment to obtain results from the cochlear implant.				
The parental commitment we have to make for scheduled appointments.				
My responsibility in the maintenance of the device.				
The parental responsibility for implant use at home.				
The parental commitment to be accessible to advanced medical care and technical services.				
The commitment to rehabilitation-, therapy- and home programmes.				

Please list other topics of information that you feel would be helpful to receive or discuss:  
\_\_\_\_\_  
\_\_\_\_\_

Thank you for your time.  
We hope this form will be helpful to you in identifying the services that you feel are important at this stage. We are committed to assist your family in its individual needs.

#### 4.4.1 Discussion of the Rating tool

The pre-implantation rating tool for parents of cochlear implant candidates as outlined in **Figure 4**, was developed in order to aid the clinician in prioritising the wealth of information that has to be shared with parents of a cochlear implant candidate by identifying the most important areas of information and support that the parents require. Once the parent has completed the form, the team can focus on what is important to the specific family at that particular time and not overburden them with too much information.

The initial division of the rating tool identifies the child, the parent and the date on which the first rating is done. A brief explanation to the parents follows the biographic information. This explanation to parent explains the aim of the rating tool and provides instructions for the parent to follow. The second part of the rating tool offers the parent the opportunity to systematically go through the different areas of information and rate the importance of that area. Parents are able to select if they would wish to receive information or not. Parents are also able to identify if they would prefer information on a particular topic at a later stage.

The pre-implantation rating tool for parents of cochlear implant candidates consists of ten areas for information and support. These areas are as follows:

1. General
2. Technical
3. Surgery
4. Social support
5. Financial
6. Communication options
7. Education
8. Outcomes
9. Rehabilitation
10. Parental role

The ten areas of information and support were identified during the analysis of the semi-structured interviews in Section 4.3 and are supported by literature



(Berg et al., 2007:25; Deconde & Johnson, 1997:443; Eleweke et al., 2008:193; Fitzpatrick et al., 2008:44; Minchom et al., 2003:100; Most & Zaidman-Zait, 2001:113; Pollard, 1996:20). A brief description of each of these ten areas of information and support is discussed.

1.General: The topics included in the general area relates to general audiological information with regard to cochlear implantation. Berg et al. (2007:18) identified the following areas of information that is included in the rating tool: Criteria for cochlear implant candidacy, alternatives to cochlear implantation as well as the impact of delaying cochlear implantation. According to research, it is important to discuss alternatives to cochlear implantation with families (Berg et al., 2007:18; Pollard, 1996:20). The need to know about the effectiveness of the cochlear implant process was indicated by participants during the semi-structured interviews.

2.Technical: Berg et al. (2007:18) identified the following important technical areas in providing informed consent for parents: Accessibility to future technologies, different types of cochlear implant devices and mapping procedures. Knowledge of the device itself constitutes to reasonable expectations (Pollard, 1996:20). Parents want access to information and the internet has emerged as an important access point for parents (Fitzpatrick, 2008: 45). Fitzpatrick (2008:45) suggests giving parents a list of recommended internet sites to research in their own time. These areas correlates with responses during the semi- structured interviews where participants indicated a need to know about the appearance, functioning and mapping of cochlear implants as well as internet resources for cochlear implants.

3.Surgery: Knowledge pertaining to surgical risks is necessary to discuss with cochlear implant candidates and their families (Pollard, 1996:20). There are five types of medical/surgical information to discuss with parents: Meningitis risks, MRI compatibility, anaesthesia risks, medical risks, surgical risks such as facial nerve damage (Berg et al., 2007:17). All these areas were included in the rating tool. During the semi-structured interviews it was clear from the

responses that the surgery involved in cochlear implantation was a great concern to participants and they needed thorough information on the surgery.

4.Social support: In a study by Fitzpatrick, (2008:42) on parents' needs, following identification of childhood hearing loss, all the respondents pointed out the value of emotional support. Parents indicated their need for support in the semi-structured interviews as well as the manner in which they needed support. This was included in the rating tool for example, the need to meet other families with children who had received a cochlear implant and information on the availability of support services. In a study by Minchom et al., (2003:95) on the service needs of children with a hearing loss and their families, respondents indicated the need for more contact with other parents. Parent support groups or access to parental input seem to fulfil several needs, including knowledge sharing, practical information, prognostic information and hope (Fitzpatrick, 2008:44). For some parents, support groups also filled an emotional support need beyond what could be offered by psychosocial providers in health care (Fitzpatrick, 2008:44).

5.Financial: Estimations about the financial cost of surgery as well as the maintenance cost of cochlear implantation is important to give to parents (Most & Zaidman-Zait, 2001:113). The semi- structured interviews clearly indicated the financial concerns of families and therefore the financial information needs that was stated was included in the rating tool for example the medical aid contribution and rehabilitation costs.

6.Communication options: Parents indicate a need for unbiased information about intervention options/approaches (Minchom et al., 2003:95). It is important to provide parents with information on various communication options/intervention approaches. (Eleweke et al., 2008:193). Communication options that were included are: Auditory- Verbal approach, Sign language, Oral approach and Total Communication. Deaf culture was also included as an option for parents who feel the need (Berg et al., 2007:18).

7.Education: The need exists to provide parents with information on different options for education (Eleweke et al., 2008:193). The education options correlate with the communication options and include signing, mainstream and education in a school for children with hearing loss.

8.Outcomes: Parents often indicate a need for forming realistic expectations about cochlear implant outcomes (Minchom et al., 2003:95). Discussing communication outcomes with parents constitutes to reasonable expectations (Pollard, 1996:20). The need to receive information on outcomes of children with cochlear implants was clearly stated during the semi-structured interviews. Parents have the opportunity to ask about factors that influence outcomes with cochlear implants, the variability of speech and language development that exist in children with cochlear implants and the outcomes for children with additional challenges and disabilities.

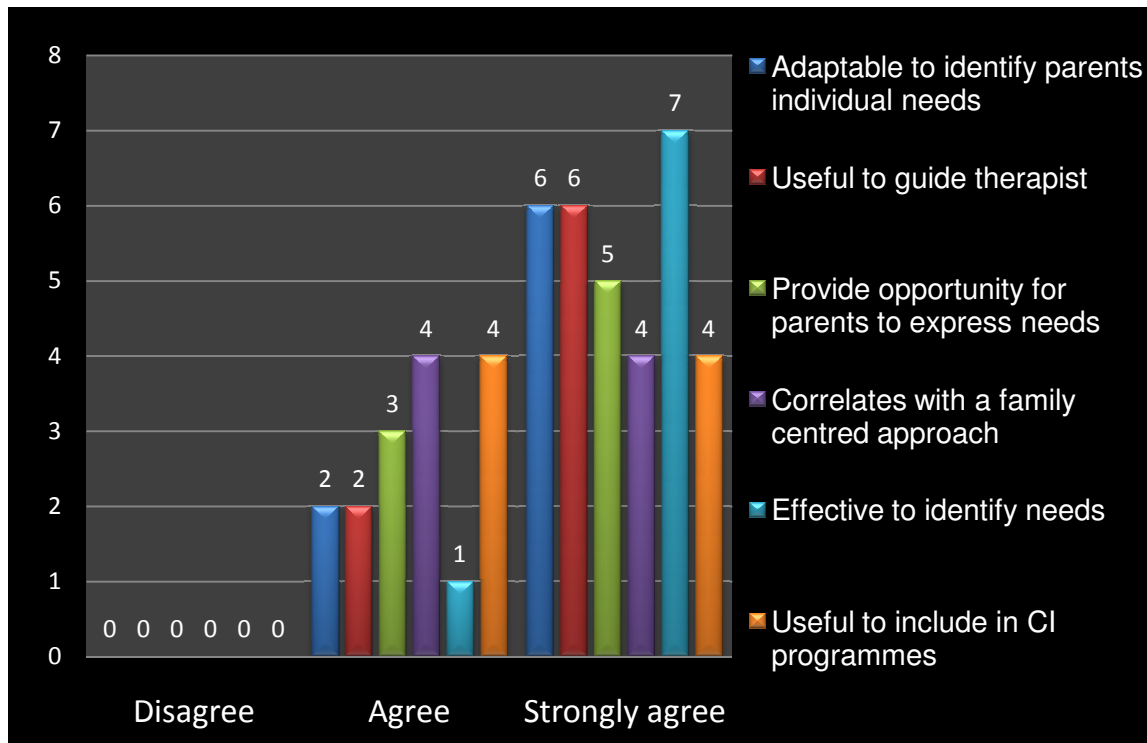
9.Rehabilitation: As mentioned, parents often indicate a need for unbiased information about rehabilitation options (Minchom et al., 2003:95). Rehabilitation forms an essential part of cochlear implantation and parents should have the opportunity to receive information on rehabilitation resources during the pre-implantation phase of cochlear implantation.

10.Parental role: It is of utmost importance to provide information to parents that will ensure their active participation in programs (Eleweke et al., 2008:196). Four types of parental role information are included namely: the need for time commitment to obtain maximum results, parental to scheduled appointments and maintenance of the device, the responsibility for carryover of implant use at home, and parental commitment to be accessible to advanced medical and technical services (Berg et al., 2007:18).

At the end of the rating tool parents have the opportunity to write any further information they wish to receive. This provides the opportunity to identify unique needs for information that was not mentioned in the rating tool.

#### ***4.5 Sub- Aim 3: Value of the pre-implantation rating tool for cochlear implant teams***

The pre-implantation rating tool for parents of cochlear implant candidates (Appendix E) was sent to 14 speech-language pathologist/ audiologist that are currently working in cochlear implant teams in South Africa. These participants were asked to evaluate the rating tool by completing a clinical evaluation form (Appendix F). The clinical evaluation formed part of phase three of the data collection procedure. The clinical evaluation forms contained six statements that participants had to rate by using the following scale: 1 (Disagree), 2 (Agree) and 3 (Strongly Agree). From the 14 evaluation forms that were sent out eight were returned (51% return rate). Forms were returned from six main cochlear implant programmes in South Africa, namely: Bloemfontein Universitas hospital cochlear implant unit (Free State), Durban cochlear implant programme (Kwazulu-Natal), Johannesburg cochlear implant programme (Gauteng), Pretoria cochlear implant programme (Gauteng) and Tygerberg Hospital –University of Stellenbosch cochlear implant Unit (Western-Cape). The responses from clinicians are therefore representative of cochlear implant programmes in South Africa. The responses from the clinical evaluation are presented in **Figure 5**.



**Figure 5 Clinical evaluation of the rating tool for parents (n=8).**

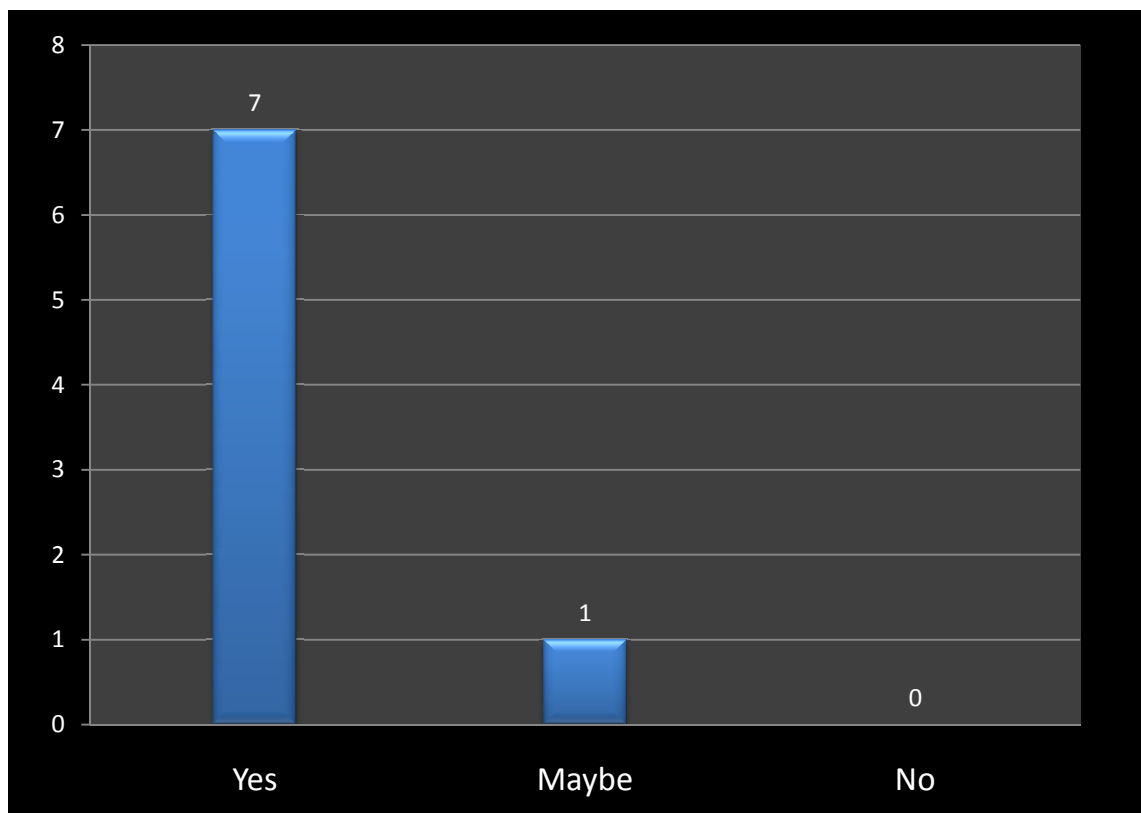
**Figure 5** clearly illustrates an overall positive clinical evaluation of the pre-implantation rating tool for parents of cochlear implant. The majority of participants (n=6) strongly agreed that the rating tool was adaptable to identify individual information and support needs of parents before cochlear implantation. In order to ensure that parental needs are properly addressed it is imperative that professionals investigate and understand the individual needs and desires of the parents with whom they collaborate (Christiansen & Leigh, 2002 in Most & Zaidman-Zait, 2001:100). The rating tool thus provides an opportunity to identify parents individual needs.

One of the prerequisites of the rating tool was that it should be able to guide the professional to identify the specific type of information and support that is important to the family and the amount of information that the family is ready to process. The focus of the rating tool therefore has to be on identifying and considering which information and support is most important to parents during the pre-implantation phase rather than what professionals believe is important to present to parents (Archbold, 2002:16). The majority of participants (n=6) strongly agreed that the tool would be useful to guide speech-language

pathologist/audiologists to identify the needs of parents that should initially be addressed.

Five of the participants strongly agreed that the tool provides an opportunity to express parents individual needs for information and support. Family centred care is advocated as an important characteristic of best practices for infant hearing health services from the identification through the intervention process (Fitzpatrick et al., 2008:39). Half of the participants strongly agreed that the rating tool correlates with a family centred approach and would be useful to include in cochlear implant programmes. The majority of participants (n=7) felt the rating tool may be effective in identifying information and support needs of parents before cochlear implantation.

**Figure 6** illustrates the number of participants that would wish to use the rating tool in their cochlear implant programmes.



**Figure 6** Willingness to use rating tool in cochlear implant programs (n=8).

As illustrated in **Figure 6**, the majority of participants (n=7) indicated that they would like to use the tool in their programme. Not one participant indicated

that they would not like to use the rating tool in their cochlear implant programme. The overall positive responses from participants indicate that pre-implantation rating tool for parents of cochlear implant candidates may have clinical value for cochlear implant teams in South Africa to identify parent's individual needs for information and support.

Participants had an opportunity to indicate further suggestions and comments. All the accounts from participants' responses are provided in **Table 19**.

<b>Table 19 Suggestions and comments on the rating tool for parents (n=8).</b>
<p><b>Comments:</b></p> <p>“The tool provides parents of young CI candidates with the opportunity to not only make their informational needs known but also help them to become more aware of all the different facets (or categories) which are involved in cochlear implantation. The tool may also serve as a checklist for team members in their pre- and post implantation counselling.”</p> <p>“The tool covers all the areas of cochlear implantation that need to be discussed before cochlear implantation.”</p> <p>“It guides the therapist to immediately discuss issues that are of importance to the family and not what the therapist might think is burning issues to a particular family.”</p> <p>“Addressing the needs of the family first and foremost, will often lead to effective communication between the therapist/CI team and family, will set the ground for a trustworthy relationship with the therapist/CI team, as well as enhancing the commitment from the family.”</p> <p>“The tool can help the family better understand the CI –process, their roles within the process, the financial implications and what the phrase <i>life long commitment</i> from the family entails.”</p> <p>“It will guide team members what should be discussed during pre-op counselling sessions; indicate which areas need more counselling in a specific family; empower parents and give them a feeling of good service delivery; help the families to hopefully have realistic expectations.”</p> <p>“This could be a very useful tool but the information is not ordered in a sequence way that would indicate the process of cochlear implantation. On the other hand some parents arrive with information already Googled on the internet, so in that way it would be useful for the</p>



professional to find the areas where they still need more information and help.”

“I think it is a good tool- the audiologist/therapist will need to ensure that all the relevant information is given to the parent even if it is initially not priority for them (before the operation).”

“I think this tool is very useful in all CI programs as it allows parents to express their counselling needs, and it also may provide them with ideas regarding areas of intervention that they may not have thought about prior to the process. I think it would also assist with the bonding process between professional and parent.”

“I hope this tool becomes available nationwide.”

<b>Suggestions:</b>	<b>Implementation of suggestions:</b>
<p>“I would suggest that the rating tool should be handed out after the first counselling /information sharing session to the parents. They need to have some idea of what it is all about and then specify the specific areas that they would need more information on.”</p>	<p>Cochlear implant teams can choose at what moment during the pre-implantation phase they want to utilize the rating tool for parents. This should be done according to the needs of the family.</p>
<p>“Although the content of the rating scale is very comprehensive, a few language inaccuracies (grammatical, word choice and consistency of word use) may lead to unnecessary confusion.”</p>	<p>Professional language and grammatical editing was done after suggestions from professionals were implemented to eliminate language inaccuracies.</p>
<p>“Will add to outcomes section: Information about basic outcomes that can be expected after cochlear implantation.”</p>	<p>This suggestion was implemented in the outcomes section of the rating tool by adding: “Basic outcomes that can be expected after cochlear implantation.”</p>
<p>“Maybe add to Education section: School placement/Educational options for my child immediately after receiving CI.”</p>	<p>This suggestion was implemented in the education section of the rating tool for parents by adding: “About educational options for my child immediately after receiving a cochlear implant.”</p>



<p>“Not to be used with all patients, should be adapted according to the educational level/development of the parents.”</p>	<p>The majority of participants (n=6) strongly agreed that the rating tool was adaptable to identify needs of parents. However, further research studies should be done to investigate the effectiveness of identifying the needs of parents with different educational levels.</p>
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Participants’ comments were overall optimistic as seen in **Table 19**, and their comments underscore the aim of the rating tool in achieving to identify individual needs of parents to improve service delivery to families. The comments correlate with the results of the statements that participants rated where many comments were made about to the ability of parents to express their needs and to guide the therapist. Valuable suggestions were made and taken into consideration in the final draft of the rating tool. The need exists to tailor counselling to meet particular needs and to adapt the type and extent of counselling to meet the changing needs of parents over time (Perold, 2001:42). The pre-implantation rating tool for parents of cochlear implant candidates may thus be part of beginning this tailoring process.

#### **4.5 CONCLUSION**

The main aim of this study was to develop a pre-implantation tool to rate the individual support and information needs of parents of young cochlear implant candidates. This was achieved through three sub-aims. The first sub-aim was to identify retrospectively the information and support needs of parents of young children with cochlear implants. This aim was achieved by conducting semi-structured interviews with ten participants who expressed their individual needs for information and support during the pre-implantation phase of cochlear implantation of their child. Several key areas of information and support needs were identified. Through the analysis of the results from the semi- structured interviews, parents individual differences in their need for information and support became evident. Ten different families highlighted ten different topics of information and support that they felt was the most

important needs to address. The information gathered from the semi-structured interviews were used with relevant literature to compile a pre-implantation rating tool to determine individualized information and support needs of parents of young cochlear implant candidates (Sub- aim 2). The pre-implantation rating tool for parents of cochlear implant candidates was developed. The rating tool consists of ten areas for information and support. These areas are as follows: general, technical, surgery, social support, financial, communication options, education, outcomes, rehabilitation and parental role. Parents are able to rate which areas of information and support is important to them and what they would like to discuss with the professional involved. Parents are also encouraged to identify any area of information and support that is not included in the rating tool that they would want information on from the cochlear implant team. The pre-implantation rating tool for parents of cochlear implant candidates was sent out to speech-language pathologist/audiologist who are currently working in the field of cochlear implants in South Africa to determine the clinical value of the pre-implantation rating tool for cochlear implant teams (Sub-aim 3). A total of eight participants from six main cochlear implant programmes completed the clinical evaluation. Positive responses were given about the adaptability of the tool to identify individual needs for support and information; that the tool would be useful to guide speech-language pathologist/audiologists to identify needs of parents that should initially be addressed. Respondents agreed that the rating tool provides an opportunity to express parents individual needs for information and support; that the tool correlates with a family centred approach and would be useful to include in cochlear implant programs. The majority of participants felt the rating tool possibly will be effective in identifying information and support needs of parents before cochlear implantation and respondents would be willing to implement the rating tool in their cochlear implant programme. The positive response from professionals working in the field of cochlear implantation validates the effectiveness of the rating tool. This may be the start of addressing the need to tailor counselling to meet particular needs and to adapt the type and extent of counselling to meet the changing needs of parents over time (Perold, 2001:42).

## **4.6 SUMMARY**

The aim of this chapter was to describe the results gathered from the semi-structured interviews, to compile the rating tool and to discuss the results from the evaluation of the rating tool by professionals. The results of this study were presented according to the sub- aims of the research and the phases of the data collection procedure. Responses from the semi-structured interviews are provided in table format in this chapter. The pre-implantation rating tool for parents of cochlear implant candidates was developed in order to identify the individual preferences for information and support before a cochlear implantation. The rating tool was presented and discussed. The clinical value of the rating tool was outlined.

## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

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*“Knowledge is not enough: we must apply. Willing is not enough: we must do.”*  
- Johann Wolfgang van Goethe

#### **5.1 INTRODUCTION**

Cochlear implantation is often referred to as the modern miracle and is now firmly established as an effective option for children with severe and profound hearing loss (Müller & Wagenfeld, 2003:57). Earlier age of cochlear implantation has emerged over the last few years. Children as young as seven months can be considered as candidates for cochlear implantation (Kaltenbrunn & Louw, 2005:22). Cochlear implantation requires a professional team to inform, guide, support and collaborate with parents constantly throughout the process (Most & Zaidman-Zait, 2001:100). By providing information and focusing on the family’s priorities and by engaging in an open process of assessing, listening and negotiating with families, professionals can create a relationship in which parents feel valued and through which professionals and parents develop a mutual respect and understanding of each other’s values and perspectives (Eleweke, Gilbert, Bays & Austin 2008:200). Cochlear implant team members should focus on the fact that families are unique and they vary in many ways. Parental needs may vary greatly and may not conform to the expectations of others, including implanting teams (Archbold et al., 2008:121). In order to ensure that parental needs are properly addressed it is imperative that professionals investigate and understand the individual needs and desires of the parents with whom they collaborate (Most & Zaidman-Zait, 2001:100). The need evidently exists to approach each family on an individual basis, as each family has their own needs for emotional support and information (Johnson et al., 1997:144; Louw & Avenant, 2002:145; Perold, 2001:54). The manner in which to identify these individual needs of families are being extensively researched internationally (Archbold. et al., 2006:191; Most & Zaidman-Zait, 2001:99). It is for this reasons that the aim of this research was to develop a pre-implantation tool to

rate the individual support and information needs of parents of young cochlear implant candidates.

The aim of this chapter is to present a conclusion to the research problem by describing the crux of each sub-aim and by critically evaluating the study.

## **5.2 CONCLUSIONS**

The conclusions are discussed according to the sub-aims of the study and the results drawn from the information gathered through the semi-structured interview and clinical evaluations performed in the research study.

### **5.2.1 Information and support needs of parents of young children with cochlear implants**

During the semi-structured interviews parents were asked to reflect back on the pre-implantation phase of their child. A semi-structured interview was used, where the participants were asked to identify key areas of information and support needs. This was used in the development of the pre-implantation rating tool for parents of cochlear implant candidates. The following themes were selected and the results of the semi-structured interview are discussed in the following order:

- **Challenges experienced during the decision-making process**

From the statements, it became clear that participants experienced the decision-making process as stressful. Parents felt under pressure to make a decision while in the process of accepting the diagnosis of the hearing loss. The stressful nature of the decision-making process is well described in the literature (Agnagnostou et al. 2007:71; Eleweke et al., 2008:191; Most & Zaidman- Zait, 2001:99 Zaidman- Zait & Most, 2005:130). When professionals work with parents they have to consider the emotional challenges that parents experience during the decision-making process. Professionals should receive training in counselling skills to support

parents during this time. The biggest challenge parents reported was the financial implications that the cochlear implant entailed. Cochlear implant teams should give parents sufficient information with regard to the financial implications of a cochlear implant and provide options that they could consider or investigate in order to plan financially for the cochlear implantation. Through the analysis of the statements about challenges experienced during the decision-making process, it became evident that financial issues had to be included as a category in the rating tool. Thus, the following statements were included in the *financial category* of the rating tool:

- The cost of the cochlear implant.
- The maintenance costs involved in cochlear implantation.
- The medical aid contribution to cochlear implantation and rehabilitation.
- Surgical and hospital costs involved in cochlear implantation.
- The rehabilitation costs involved in cochlear implantation.
- The mapping costs involved in cochlear implantation.
- About financial support for cochlear implantation.

- **Information needs**

Participants' need for information was varied and some had unique needs. Parents expressed the need for information on: the effectiveness of cochlear implants; other children with cochlear implants; outcomes with cochlear implant; surgery and financial issues. Unique needs for information included; the functioning of a cochlear implant, statistics of effectiveness of a cochlear implant, procedure if the cochlear implant is not functioning, different manufactures of cochlear implant processors and Internet websites where they could search for information. It is of utmost importance to take these unique needs for information into account when working with parents and thus a tool to identify these unique needs would be very valuable. The information needs that parents identified were therefore included in the development of the rating tool. Participants' needs were divided into different categories according to areas of information. Participants' specific needs were included in combination with relevant literature. The following statements were included in different categories:

- *General Information:*
  - The criteria for cochlear implant candidacy.
  - The alternatives to cochlear implantation.
  - The effectiveness of cochlear implantation in children.
  - The impact of delaying cochlear implantation for my child.
  - The phases of cochlear implant process.
  - Bilateral (both ears) cochlear implantation.
- *Technical Information:*
  - About the components and functioning of a cochlear implant.
  - About the different kinds of cochlear implants and their advantages and disadvantages.
  - Information on how the cochlear implant will fit in with future technology.
  - Troubleshooting and failure of the functioning of the cochlear implant.
  - Mapping/programming of the cochlear implant.
  - Internet resources on cochlear implantation.
  - About hearing tests before and after cochlear implantation.
- *Surgical Information:*
  - About the surgical procedure.
  - About the risks of surgery.
  - About meningitis risks with regard to cochlear implantation.
  - About magnetic resonance imaging (MRI).
  - The duration of hospital stay after cochlear implant surgery.
- *Communication options Information:*
  - About the Auditory-Verbal approach.
  - About Sign language.
  - About the Oral approach.
  - About Total Communication.
  - About the Deaf culture.
- *Education Information:*
  - About educating my child in a signing school.
  - About educating my child in a mainstream school.

- About educating my child in a school for children with hearing loss.
- About educational options for my child immediately after receiving a cochlear implant.
- *Outcome Information :*
  - The factors that influence outcomes of children with cochlear implants.
  - The variability of auditory performance that can exist in children with cochlear implants.
  - Basic outcomes that can be expected after cochlear implantation.
  - The variability of speech and language development that exists in children with cochlear implants.
  - Outcomes for children with additional challenges or disabilities.
- *Rehabilitation Information:*
  - About speech therapy after cochlear implantation.
  - Additional rehabilitation recourses.

Unique needs for information was taken into account with the development of the rating tool by including an option for parents to write any further needs that was not covered in the ten categories of the rating tool.

- **Support needs**

Parents commented on their need for support and sources of support that they received during the process of cochlear implantation. Parents identified the following needs for support; the need to meet other parents with children with cochlear implants, reassurance from the therapist, guidance, information as support as well as certain support providers such as therapists and surgeons. Emotional support needs of parents are of utmost importance during the pre-implantation phase of cochlear implants. Professionals should draw on good counselling skills to address these emotional needs for support from parents. The support needs expressed by participants were included in



the category of social support in the rating tool for parents. Therefore, the following statements were included:

*Social support:*

- To meet other parents whose child received a cochlear implant.
- The availability of support services for children with cochlear implants and their families.
- Someone outside my family to talk about my child.
- When and how to communicate with cochlear implant team members.
- To be part of a support group of parents of children with a hearing impairment.
- To receive emotional support.

- **Main need for information and support**

Participants were asked to articulate what they thought was the most important information and support to provide to parents before a cochlear implant. The unique needs of different participants are prominent in the responses received to the question to identify the most important information and support to give to parents before a cochlear implantation of their child. It is important to note that ten participants gave ten different responses to the question regarding their needs for information as well as for support. The responses of the participants clearly indicate the need to identify families' unique needs for information and support during the decision-making process and thus the development of an instrument or tool to identify these needs would be very valuable to cochlear implant teams. In order to identify the unique needs of parents that might not be included in the different categories in the rating tool, an open answered option for parents to write any further needs was included. A rating scale based on 1 as most important and 5 as least important was included at every category of information and support needs to allow parents to indicate their most important needs.

- **How to effectively assist parents with information and support**

Participants were asked to provide guidelines of suggestions for cochlear implant teams for more effective service delivery of information and support

during the pre-implantation phase. The following suggestions were made; more emotional support from the cochlear implant team, more information on what can be expected, less information to digest initially, provision of internet resources and timely decision-making by the team. Sensitive counselling with a high degree of listening and emotional support should be applied in cochlear implant programmes in order to expedite the parents acceptance and move them from denial into productive decision makers (Duncan, 2009: 39). Professionals need to provide parents with impartial, comprehensive, written and spoken information presented free of jargon and in a judicious manner on all aspect of cochlear implantation including potential outcomes in children (Duncan, 2009:41). Information therefore needs to be flexible enough to respect individual family needs (Duncan, 2009:41). These factors, namely; support, expected outcomes and internet recourse were included in the pre-implantation rating tool for parents of cochlear implant candidates. The rating tool also aims to provide parents the opportunity to indicate the amount of information that they feel ready to digest. The pre-implantation rating tool for parents of cochlear implant candidates aims to aid the professional to address the individual needs of parents.

- **Perception on giving parents a choice regarding the amount and type of information and support that they wish to receive**

Participants indicated how they would feel if parents were given a choice concerning the amount and type of information, they wish to receive before the cochlear implantation. The overall response was positive with eight participants giving positive responses to the option of being given a choice. According to the participants the option to choose the information and support they wish to receive offers them the opportunity to communicate their needs, illustrate a form of respect for individual differences, limit information overload and provide time to process information. It is foreseen that the pre-implantation rating tool for parents of cochlear implant candidates offers the opportunity for parents to choose the amount and type of information they wish to receive before the cochlear implantation of their child.

By investigating the responses of the participants in the semi-structured interviews, ten important areas of information and support were identified. These needs were taken into consideration and included as discussed in the next aim of compiling a pre-implantation rating tool to identify individualized information and support needs of parents of young cochlear implant candidates.

### **5.2.2 Development of a pre-implantation rating tool to determine individualized information and support needs of parents of young cochlear implant candidates**

The pre-implantation rating tool for parents of cochlear implant candidates (See Appendix E) was developed in order to aid the clinician in prioritising the wealth of information that has to be shared with parents of a cochlear implant candidate by identifying the most important areas of information and support that the parents require. Once the parent has completed this form, the team can focus on what is important to the specific family at that particular time and not overburden them with too much information.

The initial division of the rating tool identifies the child, the parent and the date on which the first rating is to be conducted. A brief explanation to the parents follows the biographic information. The explanation to the parent explains the aim of the rating tool and provides instructions for the parent to follow. The second part of the rating tool provides the parent the opportunity to systematically go through the different areas of information and rate the importance of that area to them. They are able to select whether they would wish to receive information or not. They are also able to identify if they would like information on a particular topic at a later stage.

The pre-implantation rating tool for parents of cochlear implant candidates consists of ten areas for information and support. These areas are as follows: General, technical, surgery, social support, financial, communication options, education, outcomes, rehabilitation and parental role.

These ten areas of information and support were identified during the analysis of the semi-structured interview in Section 4.3 and are supported by literature (Berg et al., 2007:25; Deconde & Johnson, 1997:443; Eleweke et al., 2008:193; Fitzpatrick et al., 2008: 44; Minchom et al., 2003:100; Most & Zaidman-Zait, 2001:113, Pollard, 1996:20.).

The rating tool may be a valuable asset to cochlear implant teams in the pre-implantation phase of cochlear implantation. It would benefit both the parent and the professional to express their needs for information and support during the decision-making process and guide the therapist on what individual needs parents may have.

### **5.2.3 The clinical value of the pre-implantation rating tool for cochlear implant teams**

The pre-implantation rating tool for parents of cochlear implant candidates, was send to speech-language pathologist/ audiologist that are currently working in cochlear implant teams in South Africa. These participants indicated the clinical evaluation of the rating tool by completing a clinical evaluation form (Appendix F). Eight responses were received from six cochlear implant centres in South Africa.

Participants' responses clearly indicated that the pre-implantation rating tool for parents is:

- Adaptable to identify parents individual needs for information and support during the pre-implantation phase of cochlear implantation.
- Useful to guide the professional to identify the specific type of information and support that is important to the family.
- Valuable as it provides parents an opportunity to express their individual needs for information and support.
- In accordance with a family centred approach of intervention services to children with a hearing loss and their parents.

- Effective in identifying information and support needs of parents before cochlear implantation.
- Useful to include in cochlear implant programmes with the majority of participants indicating that they would like to use the tool in their programme.

Participants' overall comments were optimistic and their comments underscore the aim of the rating tool in achieving to identify individual needs of parents to improve service delivery to families. Valuable suggestions were made and taken into consideration in the final draft of the rating tool.

The clinical evaluation of the rating tool clearly indicated the possible value that this could have in identifying the individual information and support needs of parents of children who are in the decision-making process of cochlear implantation in South Africa.

### ***5.3 CLINICAL IMPLICATIONS***

The results of this research study firstly indicate that parents of children with cochlear implants have unique needs for information and support. This was illustrated by the fact that ten different participants identified ten different areas of information and support that they regarded as most important to give to parents before the cochlear implantation of their child.

The research thus indicates the need for an individualized approach to identify and consider what is important to the unique families that enter the cochlear implant process. This is especially true within the South African context with a population that is characterised by diverse social, economic, geographical, linguistic and cultural features (Louw & Avenant, 2002:146). The need for a rating tool to identify these needs of parents is clear.

The pre-implantation rating tool for parents of cochlear implant candidates was developed in this study. This rating tool provides an opportunity for

parents to express their unique needs for information and support in the pre-implantation phase of cochlear implantation. The rating tool is adaptable in order to rate the needs of families that enters the pre –implantation process. The rating tool is able to guide the professional to identify the specific type of information and support that is important to the family and the amount of information that they are ready to process. The focus of the rating tool is therefore to identify and consider what information and support is most important to parents during the pre-implantation phase rather than on what professionals believe is important to present to parents (Archbold et al., 2002:16).

The clinical value of the pre-implantation rating tool for parents of cochlear implant candidates was evaluated on a small scale by professionals working in the field of cochlear implants in South Africa. However, the responses received, was from the six main cochlear implant programmes in South Africa. Their responses was overwhelmingly positive with the majority (n=7) indicating that they would use the pre-implantation rating tool for parents of cochlear implant candidates in their cochlear programmes. The research can thus be directly applied and be used in the clinical setting in South Africa. The pre-implantation rating tool for parents of cochlear implant candidates can thus be used in different cochlear implant programmes throughout South Africa.

#### ***5.4 EVALUATION OF THE RESEARCH STUDY***

A reflection on the positive and negative aspects of the research study is important to gain insight on the information and support needs of parents of young cochlear implant candidates as they enter the decision making process of cochlear implants.

The main strength of this study was that this was the first study of this kind to be conducted in the South African cochlear implant programme setting. The

results obtained reflected the uniqueness of the population that cochlear implant programmes face in South Africa.

The study provided a glimpse into the unique information and support needs of the population of parents that enter cochlear implant programmes in South Africa. The research aimed to develop a rating tool in order to identify these unique information and support needs of parents. A practical clinical tool that could be implemented and used in cochlear implant programmes was developed. A clinical evaluation of the rating tool was done in order to ensure that it would be useful in the clinical setting of cochlear implant programmes in South Africa.

As there is few research studies done on how to identify and address the unique needs of parents of cochlear implant candidates this study also contributes towards knowledge in the field.

The main weakness of the study lay in the small sample size of the participants. The majority of participants were white Afrikaans (n=6) speaking participants from the Free State, this is not representative of the population in South Africa. However, this sample included the majority of the parents of the Bloemfontein Cochlear Implant Programme with children who received cochlear implants. Identification of parents needs through semi-structured interviews were not the main aim of the research study and merely identified some of their needs and demonstrated that parents needs are unique and varied. Participants responses were compared to literature of similar research performed in different parts of the world to evaluate the validity of the responses.

The clinical evaluation of the pre-implantation rating tool for parents of cochlear implant candidates was also done by a small sample of professionals. However, this sample was representative of six cochlear implant programmes in South Africa. It would have been interesting given enough time to do a clinical evaluation of the pre-implantation rating tool for parents by not only professionals but also parents themselves.

## **5.5 RECOMMENDATIONS FOR FURTHER RESEARCH**

The following recommendations are made for further studies:

- Further studies to determine the clinical value of the rating tool by parents of cochlear implant candidates during the pre-implantation phase.
- Studies that determine the adaptability of the pre-implantation rating tool for parents of different cultural background and socio-economic groups in South Africa.
- Comparative studies that determine parent's satisfaction with the manner that they were able to express their need for information and support with and without the use of the pre-implantation rating tool for parents.
- Translating the pre-implantation rating tool for parents in the official languages of South Africa.

## **5.6 CLOSING STATEMENT**

Cochlear implantation requires a professional team to inform, guide, support and collaborate with parents constantly throughout the process (Most & Zaidman-Zait, 2001:100). Providing information and support by focusing on families priorities and by engaging in an open process of assessing, listening and negotiating with families. Professionals can create a relationship in which parents feel valued and professionals and parents can develop mutual respect and understanding of each other's values and perspectives (Eleweke et al., 2008:200). It is of utmost importance to consider the diverse socio-economic, geographical, linguistic and cultural features when providing family centred cochlear implant services to South African parents. Each family is unique and should be regarded as an individual unit with its own values, beliefs, practices and needs (Louw & Avenant, 2002:145). The ability to put oneself in the family's unique situation and to look from their perspective often



provides a more realistic understanding of their concerns and needs, and results in a stronger partnership with the family (Johnson et al., 1997:142). The pre-implantation rating tool for parents of cochlear implant candidates may be one of the first steps to achieve that goal.

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## 8. APPENDICES

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- Appendix B: Informed consent letter to parents
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## **Appendix A**

***Letter to obtain permission of head of the Bloemfontein cochlear implant programme***



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1908 - 2008



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Humanities  
Dept of Communication Pathology  
Tel: +27 12 420 2814  
Fax : +27 12 420 3517  
Email: catherine.vandijk@up.ac.za

Prof A .J. Claassen  
Head: Bloemfontein Cochlear Implant Programme  
Dept Otolaryngology Universitas Hospital  
University of the Free State  
9301

10 September 2008

Dear Prof. A.J. Claassen,

**PERMISSION TO CONDUCT A RESEARCH PROJECT INVOLVING PARENTS OF CHILDREN FROM THE BLOEMFONTEIN COCHLEAR IMPLANT PROGRAMME (BCIP)**

As a master's student in Communication Pathology at the University of Pretoria, I need to conduct a research project in fulfilment of my postgraduate degree. The title of the study is: The development of a pre-operative tool for rating the individualized information and support needs of parents of young cochlear implant candidates.

The aim of this study is to develop a tool to rate the individual support and information needs of parents of young cochlear implant candidates. The tool will guide the professionals on the cochlear implant team to identify the specific type of information and support that is important for the family to receive, the amount of information that they feel ready to process and the manner in which they wish to receive the information and support. The focus of the tool is identify and consider what information and support is important to parents during the pre-implantation phase rather than what professionals believe is important to present to parents. The results of the research project may benefit South African cochlear implant programmes directly by contributing to a more parent-centred programme.



I hereby request permission to involve parents and professionals of the Bloemfontein Cochlear Implant Programme (BCIP) in the study and to have access to their records. The parents will be requested to partake in a semi-structured interview. A speech-language therapist/audiologist on the team will be asked to evaluate the value of the rating tool.

It is planned that participant selection will be performed in June 2009 and the semi-structured interview will be carried out during July 2009. The evaluation of the instrument will be conducted in November 2009.

Participation in this study is voluntary and participants have the right to withdraw from the study at any time without any negative consequences. Confidentiality will be maintained throughout the course of this study and information will only be utilised if we have each participant's expressed prior consent.

The information and results of this research project will be available in the format of a thesis at the library of the University of Pretoria as well as in a possible article for publication in an academic journal. All raw data will be stored in hard copy for 15 years before it will be destroyed.

Please inform me of any additional information required. You are kindly requested to complete the attached form and return it to me at your earliest convenience.

Kind regards,

Louise Le Roux

**M. Communication Pathology Student**

Dr Catherine van Dijk

**Research Supervisor**

Professor Brenda Louw

**HEAD: DEPT COMMUNICATION PATHOLOGY**



Please complete the form below

Dear Mrs Le Roux

I hereby give permission for you to make use of parents of the Bloemfontein Cochlear Implant Programme in the research project and have access to their records as set out in the letter. Please ensure that the participants are aware that participation in the study is on a voluntary basis.

Kind regards,

  
\_\_\_\_\_  
Prof. A.J. Claassen  
Head: BCIP

10/10/08  
\_\_\_\_\_  
Date

## **Appendix B**

### **Informed consent letter to parents**





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1908 - 2008



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA  
Faculty of Humanities

Department of Communication Pathology

10 September 2008

Dear Parent,

**Permission to participate in a research project that aims to develop a pre-operative tool to rate the individual support and informational needs of parents of young cochlear implant candidates.**

I am currently a master's degree student in Communication Pathology at the University of Pretoria. The title of my proposed study is: *The development of a pre-operative tool for rating the individual information and support needs of parents of young cochlear implant candidates.*

The aim of this research is to develop a pre-operative tool to rate the individual support and informational needs of parents of young cochlear implant candidates. The instrument aims to determine what is important to parents with regard to information and support before cochlear implantation.

You are hereby invited to participate in this study. You will be asked to participate in a semi-structured interview. It will be expected of you to answer questions about the type of information and support you needed before the cochlear implantation of your child as well as the type of information and support you think other parents will need to receive before cochlear implantation. The semi-structured interview will take place at a time that will suit you and the interview will take not longer than 40 minutes. There are no risks involved for participants.

Your willingness to participate in the study will contribute to the results that may be used to:

- raise awareness of professionals on the cochlear implant team such as speech-language therapist/audiologists about information and support needs of parents before cochlear implantation;
- relieve the stress parents experience before cochlear implantation;
- and contribute to a more parent centred cochlear implant programme.

This information may contribute to a better service delivery and enhanced client satisfaction for parents that are in the process of cochlear implantation for their children.

Participation in this study is voluntary and participants have the right to withdraw from the study at any time without any negative consequences.

Universiteit van Pretoria  
Pretoria, 0002

Telefoon : 00 27 12 420-2814  
Faksimile : 00 27 12 420-3517

catherine.vandijk@up.ac.za  
www.up.ac.za



Confidentiality will be maintained throughout the course of this study. No personal information will be made available to any one except the researcher.

The information and results of this research project will be available in the format of a thesis at the library of the University of Pretoria. The results obtained in this study may also be published as an article in an academic journal. All raw data will be stored in hard copy for a period of 15 years before it will be destroyed. A summary of the results will be made available to you on your request.

If you require any further information you are welcome to contact me: Ilouise le Roux at 0824090534

Should you decide to participate in the research project, you are kindly requested to complete the attached form and return it to me.

Yours sincerely,

**Ilouise le Roux**

**M.Communication Pathology student/ Speech-language therapist & Audiologist**

**Dr Catherine van Dijk**

**Research Supervisor**

**Professor Brenda Louw**

**HEAD: DEPT. COMMUNICATION PATHOLOGY**



Please complete the form below

Dear Ilouise le Roux,

I hereby declare myself willing to participate in the proposed study as set out in the letter. I am aware that my participation is totally voluntary and that I may withdraw at any time.

Please send/ not send (circle option) me a summary of the results of the research.

Kind regards,

\_\_\_\_\_

Name

\_\_\_\_\_

Date



10 September 2008

Geagte Ouer,

**Deelname aan 'n navorsingsprojek wat handel oor die ontwikkeling van 'n instrument om ouers se individuele inligtings en -ondersteuningsbehoefes te meet voor die kogleëre inplantering van hul kinders.**

Ek is tans besig met 'n meestersgraad in Kommunikasiepatologie aan die Departement Kommunikasiepatologie van die Universiteit van Pretoria. Die titel van my projek is: *Die ontwikkeling van 'n pre-operatiewe instrument om die individuele inligting en -ondersteunings behoeftes van ouers van jong kogleëre inplantings kandidate te meet.* 'n Deel van die studie behels dat inligting bekom word in die vorm van onderhoude met ouers.

Die doel van hierdie navorsingstudie is om 'n pre-operatiewe instrument te ontwikkel wat die individuele behoeftes ten opsigte van inligting en ondersteuning te meet van ouers van jong kogleëre inplantasie kandidate. Die instrument het dus ten doel om te bepaal wat belangrik vir ouers is ten opsigte van inligting en ondersteuning voor kogleëre inplantasie.

Ek nooi u graag om aan hierdie projek deel te neem. U sal gevra word om deel te neem aan 'n eenmalige semi- gestruktureerde onderhoud. Met hierdie onderhoud sal u gevra word oor die tipe inligting en ondersteuning wat u nodig gehad het voordat u kind 'n kogleëre inplanting ontvang het asook die tipe inligting en ondersteuning wat u dink ander ouers nodig het om te ontvang voor kogleëre inplantasie. Die onderhoud sal plaasvind op 'n tyd wat vir u geleë sal wees en behoort nie langer as 40 minute neem nie. Daar is geen risiko vir deelnemers aan hierdie navorsing nie.

U deelname aan hierdie sal bydra tot die resultate wat gebruik kan word om:

- kogleëre spanlede, soos spraakterapeute en audioloë bewus te maak van die inligting en ondersteunings behoeftes van ouers voor die inplantasie;
- die spanningsvolle tyd van die pre-inplantasie tydperk vir ander ouers te probeer verlig;
- en 'n bydrae te maak tot 'n meer ouer-gesentreerde kogleëre inplantingsprogram.



Hierdie inligting mag bydra tot beter dienslewering en verhoogde klient-bevrediging vir ouers met 'n kind wat in die proses 'n kogleëre inplantering is.

U deelname aan hierdie studie word hoog op prys gestel. Deelname is vrywillig en u het die reg om enige tyd sonder enige negatiewe gevolge van die studie te onttrek.

Algehele vertroulikheid sal ten alle tye deur die verloop van hierdie navorsing gehandhaaf word. Geen persoonlike inligting sal vir enige iemand buiten die navorser beskikbaar wees nie.

Die inligting en resultate wat in hierdie studie verkry word sal in die vorm van 'n navorsingsverslag by biblioteek van die Universiteit van Pretoria beskikbaar wees. Bevindings waartoe daar in die studie gekom word, sal ook moontlik as 'n artikel in 'n akademiese tydskrif gepubliseer word. Alle rou data sal in harde kopie vir 'n periode van 15 jaar geberg word, waarna dit vernietig sal word. 'n Opsomming van die resultate sal op versoek aan u beskikbaar gestel word.

Indien u enige verdere inligting verlang kan u my gerus skakel: Ilouise le Roux by 082 409 0534.

Indien u besluit om wel aan hierdie studie deel te neem, versoek ek u vriendelik om die aangehegte vorm te voltooi en aan my te oorhandig.

Vriendelike groete,

**Ilouise le Roux**

**M. Kommunikasiepatologie student/ Spraak-taalteapeut en Oudioloog**

  
namens Dr C van Dijk  
**Dr Catherine van Dijk**

**Studieleier**

**Professor Brenda Louw**

**HOOF: DEPT KOMMUNIKASIEPATOLOGIE**



Voltooi asseblief die vorm op die bladsy.

Ilouise le Roux,

Hiermee verklaar ek myself gewillig om aan die studie soos in meegaande brief uiteengesit, deel te neem. Ek is ten volle bewus dat my deelname op 'n vrywillige basis geskied en dat ek op enige stadium mag onttrek van die studie.

Ek wil graag/ wil nie (omkring asb) 'n opsomming van die resultate ontvang na afloop van studie.

Vriendelike groete,

\_\_\_\_\_

Naam

\_\_\_\_\_

Datum



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## **Appendix C**

### ***Informed consent letter to professionals***



26 March 2010

Dear speech- language therapist/ audiologist,

**Request for your participation in a research project that aims to develop a pre-operative rating tool**

I am a master's degree student in Communication Pathology at the University of Pretoria. The title of my proposed study is: *The development of a pre-operative tool for rating the individualized information and support needs of parents of young cochlear implant candidates.*

The aim of this research is to develop a pre-operative tool to rate the individual support and informational needs of parents of young cochlear implant candidates. The instrument intends to determine what is important to parents with regard to information and support before cochlear implantation.

I would like to invite you to participate in this study. You will be asked to partake in the evaluation of the rating tool to determine the value thereof. The proposed rating tool will be provided to you as well as an evaluation form that will be used to determine the value of the tool. You will also have the opportunity to make any further comments and suggestions about the rating tool. There are no risks involved for participants.

Your willingness to participate in the study will contribute to the results that may be used to:

- raise awareness of members on the cochlear implant team such as speech-language therapist/audiologists about information and support needs of parents before cochlear implantation;
  - reduce the stress parents experience before cochlear implantation;
  - contribute to a more family centred cochlear implant programme.
  - and determine the clinical value of the tool.
-





This information may contribute to better service delivery and enhanced client satisfaction for parents that are in the process of cochlear implantation for their children.

Participation in this study is voluntary and participants have the right to withdraw from the study at any time without negative consequences.

Confidentiality will be maintained throughout the course of this study. No personal information will be made available to anyone except the researcher.

The information and results of this research project will be available in the format of a thesis at the library of the University of Pretoria. The results obtained in this study may also be published as an article in an academic journal. All raw data will be stored in hard copy for 15 years before it will be destroyed. A summary of the results will be made available to you on your request.

If you require any further information you are welcome to contact me: Ilouise le Roux at 0824090534

Should you decide to participate in the research project, you are kindly requested to complete the attached form and return it to me.

Sincerely,

Ilouise le Roux  
M. Communication Pathology Student/ Speech language therapist & Audiologist

Dr Catherine van Dijk  
Research Supervisor

Dr Maggi Soer  
ACTING HEAD: DEPT. COMMUNICATION PATHOLOGY



**Please complete the form below:**

Dear Ilouise le Roux,

I hereby declare myself willing to participate in the proposed study as set out in the letter. I am aware that my participation is totally voluntary and that I may withdraw at any time.

Kind regards,

\_\_\_\_\_

Name

\_\_\_\_\_

Date

Would you like to receive a summary of the research findings? YES/ NO (please circle)

## **Appendix D**

### ***Interview schedule***

## ***Afdeling A: Agtergronds inligting***

### **Algemene inligting:**

#### *Inligting met betrekking tot die ouer :*

- A1. Naam:
- A2. Van:
- A3. Geboortedatum:
- A4. Geslag:
- A5. Huistaal:
- A6. Adres:
- A7. Hoogste kwalifikasie:
- A8. Huwelikstatus:
- A9. Hoeveelheid kinders:
- A10. Hoeveelheid kinders met gehoorverlies:
- A11. Hoeveelheid kinders met kogleieëre inplanting:

#### *Inligting met betrekking to die kind:*

- A12. Naam:
- A13. Van:
- A14. Geboortedatum:
- A15. Oorsaak van gehoorverlies:
- A16. Hoe oud was jou kind toe hy gediagnoseer is met 'n gehoorverlies?
- A17. Hoe was jou kind toe hy 'n kogleieëre inplanting ontvang het?
  - A17.1 Eerste oor: \_\_\_\_\_ A17.2 Tweede oor: \_\_\_\_\_
- A18. Datum van die kogleieëre inplanting:
  - A18.1 Eerste oor: \_\_\_\_\_ A 18.2 Tweede oor: \_\_\_\_\_
- A19. Datum van aktivering van die kogleieëre inplanting:
  - A19.1 Eerste oor: \_\_\_\_\_ A19.2 Tweede oor: \_\_\_\_\_
- A20. Watter tipe kogleieëre inplanting is geinplanteer?
- A21. Watter tipe spraakprosesseerder gebruik jou kind?

## **Afdeling B Ouers se behoefte aan inligting en ondersteuning**

### **1. Openings vraag:**

Vertel my hoe gaan dit met (kind se naam)?

### **2. Inleidings vraag:**

Hoe het jy uitgevind dat jou kind 'n gehoorverlies het?

### **3. Oorgangsvraag:**

Hoe het jy te wete gekom van 'n kogleêre inplanting vir 'n kind met 'n gehoorverlies?

### **4. Kern vrae:**

- Vertel my van jou uitdagings wat jy ervaar het tydens die besluitnemingsproses voor die kogleêre inplanting operasie?
- As jy terugdink na die tyd voor die kogleêre inplantering, watter behoefte het jy gehad aan inligting?
- Wat was julle as ouers se behoeftes rondom ondersteuning?
- As jy kon die belangrikste area van inligting wat ouers benodig voor die kogleêre inplantering kan uitsonder, wat sal dit wees?
- As jy die belangrikste vorm van ondersteuning aan ouers kon uitsonder, wat sal dit wees?
- Hoe kan die kogleêre span ouers meer effektief bystaan met inligting en ondersteuning tydens die pre- inplanterings fase?
- Hoe sal jy daarvoor voel as ouers 'n keuse gegee word voor die kogleêre inplantering oor die tipe en die hoeveelheid inligting en ondersteuning wat hulle benodig?

### **5. Afrondingsvrae:**

- **Reflektiewe vraag:**

Van alles wat ons nou bespreek het, wat dink jy is ouers se grootste behoefte rakende inligting en ondersteuning voor 'n kogleêre inplanting?

- **Opsommende vraag:**

Het ek alles wat gesê is korrek opgesom?

- **Finale vraag:**

Is daar iets belangrik wat jy nog sou wou byvoeg?



## Interview schedule

### ***Section A: Biographical Information***

#### **General information:**

##### *Information of parent:*

- A1. Name:
- A2. Surname:
- A3. Date of birth:
- A4. Gender:
- A5. First language:
- A6. Address:
- A7. Highest qualification:
- A8. Marital status:
- A9. Number of children:
- A10. Number of children with hearing loss:
- A11. Number of children with cochlear implant:

##### *Information of child with cochlear implant:*

- A12. Name:
- A13. Surname:
- A14. Date of birth:
- A15. Cause of hearing loss:
- A16. How old was your child when he/she was identified with a hearing loss?
- A17. How old was your child when he/she received a cochlear implant?
- A17.1 First ear: \_\_\_\_\_ A17.2 Second ear: \_\_\_\_\_
- A18. Date of implantation of cochlear implant:
- A18.1 First ear: \_\_\_\_\_ A18.2 Second ear: \_\_\_\_\_
- A19. Date of activation of cochlear implant:
- A19.1 First ear: \_\_\_\_\_ A19.2 Second ear: \_\_\_\_\_
- A20. What type of cochlear implant was implanted?
- A21. What type of speech processor does your child wear?

## ***Section B Parental Needs for information and support***

### **1. Opening question:**

Tell me how is (child's name) doing?

### **2 Introductory question:**

How did you first discover that your child has a hearing loss?

### **3. Transitional question:**

Where did you hear about cochlear implantation for children with a hearing loss?

### **4. Key questions:**

- Tell me about the challenges that you experienced surrounding the time of decision-making process before the cochlear implantation?
- Looking back to that time period before the cochlear implantation, what were your specific needs for *information* at that stage?
- What were your specific needs for *support* and counselling at that stage?
- If you could decide on the most important area of information that parents need to know before cochlear implantation what will it be?
- If you can select the most important form of support that parents need before cochlear implantation what will it be?
- How can the cochlear implant team assist parents more effectively during the pre-implantation phase with regard to providing information and support to parents?
- How will you feel about it, if parents are given a choice before implantation to identify the type and amount of information and support they need?

### **5. Closing Questions:**

- **Reflective Question:**



From everything mentioned up to now, what would you consider to be the greatest need for parents for information and support before cochlear implantation?

- **Summary Question:**

Did I sum up everything that we discussed correctly?

- **Final Question:**

Is there anything important that we haven't discussed?



## Appendix E

***Rating Tool: The pre-implantation rating tool for parents of cochlear implant candidates***



**The pre-implantation rating tool for parents of cochlear implant candidates**

Le Roux & Van Dijk 2010  
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Child's name: \_\_\_\_\_  
Date: \_\_\_\_\_  
Name of parent: \_\_\_\_\_

Dear Parent

Many parents of young children who are in the decision-making phase and pre-implantation phase of cochlear implantation have specific needs for information and/or support. Listed below are some of the needs frequently identified by parents. It would be helpful if you could check the topics below which you wish to receive information on or to discuss with a member of our cochlear implant team. At the end of the rating scale there is a place for you to add other areas not included on this list.

If you choose to complete this form, the information you provide will be kept confidential. If you would prefer not to complete the survey at this time, you may keep it for future needs.

Please rate the following ten categories according to your specific needs. Rate the categories 1 to 5, indicating 1 as the most important area that you want your therapist to pay attention to and 5 the least important area for you.

Rating Scale				
1	2	3	4	5
Most important	Very important	Moderately important	Not that important	Least important

1. General	No	Yes	Maybe at a later stage	Rating (1 to 5)
<b>I would like to know:</b>				
The criteria for cochlear implantation candidacy.				
The alternatives to cochlear implantation.				
The effectiveness of cochlear implantation in children.				
The impact of delaying cochlear implantation for my child.				
The phases of the cochlear implant process.				
About bilateral (both ears) cochlear implantation.				

2. Technical	No	Yes	Maybe at a later stage	Rating (1 to 5)
<b>I would like to know:</b>				
About the components and functioning of a cochlear implant.				
About the different kinds of cochlear implants and their advantages and disadvantages.				
Information on how the cochlear implant will fit in with future technology.				
Troubleshooting and failure of the functioning of the cochlear implant.				
Mapping/programming of the cochlear implant.				
Internet resources on cochlear implantation.				
About hearing tests before and after cochlear implantation.				



<b>3. Surgery</b>	<b>No</b>	<b>Yes</b>	<b>Maybe at a later stage</b>	<b>Rating (1-5)</b>
<b>I would like to know:</b>				
About the surgical procedure.				
About the risks of surgery.				
About meningitis risks with regard to cochlear implantation.				
About magnetic resonance imaging (MRI).				
The duration of hospital stay after the cochlear implantation surgery.				

<b>4. Social Support</b>	<b>No</b>	<b>Yes</b>	<b>Maybe at a later stage</b>	<b>Rating (1-5)</b>
<b>I would like:</b>				
To meet other parents whose child received a cochlear implant.				
To know the availability of support services for children with cochlear implants and their families.				
Someone outside my family to talk to about my child.				
When and how to communicate with cochlear implant team members.				
To be part of a support group of parents of children with a hearing loss.				
To receive emotional support.				

<b>5. Financial</b>	<b>No</b>	<b>Yes</b>	<b>Maybe at a later stage</b>	<b>Rating (1-5)</b>
<b>I would like to know:</b>				
The cost of the cochlear implant.				
The maintenance costs involved in cochlear implantation.				
The medical aid contribution to cochlear implantation and rehabilitation.				
Surgical and hospital costs involved in cochlear implantation.				
The rehabilitation costs involved in cochlear implantation.				
The mapping costs involved in cochlear implantation.				
About financial support for cochlear implantation.				

<b>6. Communication options</b>	<b>No</b>	<b>Yes</b>	<b>Maybe at a later stage</b>	<b>Rating (1-5)</b>
<b>I would like to know:</b>				
About the Auditory –Verbal approach.				
About Sign Language.				
About the Oral approach.				
About Total Communication.				
About the Deaf culture.				



7. Education	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
About educating my child in a signing school.				
About educating my child in a mainstream school.				
About educating my child in a school for children with hearing loss.				
About educational options for my child immediately after receiving a cochlear implant.				

8. Outcomes	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
The factors that influence outcomes of children with cochlear implants.				
The variability of auditory performance that can exist in children with cochlear implants.				
Basic outcomes that can be expected after cochlear implantation.				
The variability of speech and language development that exists in children with cochlear implants.				
Outcomes for children with additional challenges or disabilities.				

9. Rehabilitation	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
About speech therapy after cochlear implantation.				
Additional rehabilitation resources.				

10. Parental role	No	Yes	Maybe at a later stage	Rating (1-5)
<b>I would like to know:</b>				
The time commitment to obtain results from the cochlear implant.				
The parental commitment we have to make for scheduled appointments.				
My responsibility in the maintenance of the device.				
The parental responsibility for implant use at home.				
The parental commitment to be accessible to advanced medical care and technical services.				
The commitment to rehabilitation-, therapy- and home programmes.				

Please list other topics of information that you feel would be helpful to receive or discuss:

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Thank you for your time.

We hope this form will be helpful to you in identifying the services that you feel are important at this stage. We are committed to assist your family in its individual needs.



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## Appendix F

*Evaluation form for speech-language pathologists/audiologists*





- Would you like to use this tool in your program?                      Yes/      No./  
    Maybe

Please motivate your answer:

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Please indicate any further comment or suggestions:

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## Appendix G

*Letter of ethical clearance from the University of Pretoria*



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Faculty of Humanities  
Research Proposal and Ethics Committee

1 June 2009

Dear Dr van Dijk

**Project:** The development of a pre-operative tool for rating the individualized information and support needs of parents of young cochlear implant candidates

**Researcher:** I le Roux

**Supervisor:** Dr C van Dijk

**Department:** Communication Pathology

**Reference number:** 22071289

Thank you for the well written application you submitted to the Research Proposal and Ethics Committee, Faculty of Humanities.

I have pleasure in informing you that the Research Proposal and Ethics Committee formally **approved** the above study on 28 May 2009. The approval is subject to the candidate abiding by the principles and parameters set out in her application and research proposal in the actual execution of the research.

The Committee requests you to convey this approval to Ms le Roux

We wish you success with the project.

Sincerely

**Prof. Brenda Louw**  
**Chair: Research Proposal and Ethics Committee**  
**Faculty of Humanities**  
**UNIVERSITY OF PRETORIA**  
**e-mail: [brenda.louw@up.ac.za](mailto:brenda.louw@up.ac.za)**

Research Proposal and Ethics Committee Members: Prof P Chiroro; Dr M-H Coetzee; Dr JEH Grobler; Prof KL Harris; Ms H Klopper; Prof E Krüger; Prof B Louw (Chair); Prof A Mlambo; Prof G Prinsloo; Mr C Puttergill; Prof H Stander; Prof E Taljard; Dr J van Dyk; Prof C Walton; Mr FG Wolmarans

**Appendix H**  
***Transcripts of interviews***

## Onderhoud 1 met ouer A

### I: Hoe het jy uitgevind jou kind het 'n gehoor verlies?

Ouer A: Haar ontwikkeling was normaal, sy het op 4 en 'n half maande gesit, 7 maande gekruip, sy het op 10 en 'n half maande geloop. Hierna 13 maande het ek gevra maar hoekom praat sy nie, want al die ander ontwikkeling is normaal, maar sy het nooit spontaan 'n poging aangewend om spontaan te praat nie, soos om mamma of baba te sê nie, sy het die hele tyd na goed gewys. Toe bel ek die baba kliniek en 'n afspraak gemaak vir haar 18 maande inspuiting. Toe praat ek met die een kliniek suster en sê ek is baie bekommerd oor (kind se naam) want dit kom vir my voor sy wil net nie praat nie toe sê sy party kinders praat maar bietjie laat en hulle het tog deurlopend van geboorte vir (kind se naam) gesien. Ek was self nie seker of is daar 'n gehoor probleem is en of sy maar net 'n stadige prater nie. En aanvanklik het ons gedink ons sal dit weer aanspreek op 18 maande. En terwyl ons daar gesit het, het die kliniek suster gesê sy tel op dat (kind se naam) nie reageer as sy praat nie en dat sy sou voorstel dat ons haar vat na 'n oudioloog toe. Toe het sy voorgestel (oudioloog se naam), ons het hom gebel en binne twee weke 'n afspraak gekry en toe is sy getoets in (hospitaal se naam) en toe het hy bevind sy het 'n gehoorverlies.

### I: En hoe of waar het julle toe gehoor van 'n kogleêre implanting?

Ouer A: Weet jy ons het maar aanvanklik by (oudioloog se naam), na aanleiding van die gehoortoets wat hy gedoen het, het hy gesê sy het 'n verskriklike gehoorverlies, so hy is nie doodseker of gehoorapparate vir haar gaan werk nie. Maar die kriteria is dat hulle eers moet gehoorapparate dra en dan 'n klomp toetse ondergaan en dan 'n kogleêre implanting en toe het hy gesê ons moet kontak maak met Prof Claassen by Universitas Hospitaal vir die kogleêre implanting maar hy sal intussen haar verslag en toets na hulle toe stuur. Toe het ons gebel vir 'n afspraak toe het ons vir Prof Claassen toe nou gaan sien. En vandaar af het ons toe nou verder gegaan.

### I: Sê vir my wat was vir jou uitdagings of goed wat julle moeilik ondervind het tydens daardie besluitnemingsproses vandat jy Prof Claassen gesien het tot en met die operasie. Wat kan jy van daardie tydperk onthou?

Ouer A: Weet jy Ilouise, wat aanvanklik moeilik was, is dat ons baie gedruk gevoel het vir tyd in die eerste plek omdat ons laat uitgevind het van haar gehoorverlies. En omdat as Prof Claassen hulle kon sou hulle die volgende week die operasie wou gedoen het, hulle het baie, en dit is aan ons verduidelik hoe vinniger die implanting gedoen word want taalontwikkeling moet voor 3 jaar plaasvind ens. Maar ons het baie gedruk gevoel om onmiddellik 'n besluit te maak alhoewel ons nie presies al die inligting gehad het nie. Vir hulle het die heelyd gegaan oor dis haar gehoorverlies, dit is baie erg die gehoorapparate werk nie vir haar nie so toe laat ons implant, maar nie regtig verduidelik presies hoe die implanting in die eerste plek werk nie, dit is nou van Prof Claassen se kant af, en die tweede plek presies soos dit gaan soveel duisende rande kos maar dit is die beste vir jou kind so jy moet dit doen. Dis soos ons gevoel het, ek dink nie dit is soos wat hulle wou oorkom nie, maar dit is soos wat jy gedruk gevoel het jy moet die besluit nou dadelik maak, want jy het nie tyd om daarvoor te dink en jy gaan deur al hierdie emosies van jy het 'n dowe kind te werk nie, jy moet nou net hierdie implanting doen en dan gaan alles fine wees. En dit was aanvanklik baie moeilik. En ons wou weet hoekom sou die gehoorapparate nie werk nie, toe is (kind se naam) vir 'n Pedo toets. Dit is mos in daardie klankdigte kamer, om te kyk wat hoor sy presies met die gehoorapparate of dit wel vir haar geskik is of nie. Wat hulle toe bevind het dit is nie. Toe gaan sy vir 'n scan vir haar oortjie, dit was baie erg, dit was ongelooflik erg, die gehoortoets ook want hulle gee vir hulle (medikasie se naam) om te slaap. En aanvanklik as hulle daardie goed inkry dan huil hulle, dit was (kind se naam) se reaksie daarop gewees. Jy druk haar vas om dit vir haar te gee en dan het sy dit nou uiteindelik in dan begin dit werk, die oomblik wat sy voel sy verloor beheer, dan gaan sy aan die skree, sy skree die hospitaal se dak af en vir my en vir haar pa dat jy nie weet waar jy is nie. Totdat sy uiteindelik aan die slaap is, en dan doen hulle die toets. En dit was, dit is hartverskeurend, ek sal in my lewe vir geen ouer toewens nie, want jy raak so emosioneel in daardie situasie want sy besef sy verloor beheer, sy besef sy gaan nou slaap dat skree aanmekaar, en jy weet naderhand nie wat om te doen nie.



Toe het sy gegaan vir die MR scan om te kyk hoe haar binne oortjie lyk dis toe ons teruggestuur is na Prof Claassen toe, toe het (Spraaakterapeut se naam) by Universitas Hospitaal vir ons verduidelik wat is 'n kogleëre inplanting, en hoe werk dit maar nog steeds jy verstaan nie al die tegnologie en al die terme nie en jy het nog steeds twyfel in jou hart of as jy hierdie inplanting gee, gaan dit werk. Gaan sy kan praat? Hoe lank gaan dit vat? Hoe presies werk hierdie apparaat? Hoe is hy aanmekeer gesit? Waar kom dit vandaan? Jy weet daardie tipe vra, vra jy nog steeds alle tyd, deurentyd vir jouself. En toe is Deon se toets, die toets in die klank digte kamer, die scan alles by Prof Claassen en toe het hy weer vir ons gesê sy is 'n geskikte kandidaat. Die terapeute het basies die finansiële deel vir ons verduidelik en min of meer na die beste van hulle vermoë verduidelik wat is 'n kogleëre apparaat en hoe werk dit Maar nog steeds twyfel jy.

**I: Wat wou jy weet , wat se inligting wou jy gehad het. Jy het nou gesê jy wou seker goed wou jy geweet het...**

Ouer A: Ek wou geweet het, behalwe dat daar al baie kogleëre inplantings gedoen is wou ek weet, wat is die persentasie of wat is die success rate as ek dit so kan stel. Kinders wat kogleëre inplantings het, hoeveel van hulle praat? Hoeveel van hulle is in staat om te volle te kommunikeer? Watter persentasie in staat om normaal te funksioneer? Watter persentasie is in staat om hoofstroom skool toe te gaan? Hoe vorder hulle terwyl hulle in die hoofstroom skool is? Hoe lank nadat die inplanting gedoen is gaan sy begin praat? Hoeveel werk is daaraan verbonde? Wat kan ons as ouers doen om dit makliker te maak?

Toe is ons na Karel Du Toit toe verwys wat toe nou met ouerleiding en spraakterapie begin het. Mens is nog steeds, en weet jy Louise dis nog steeds 'n geval van die kind kan nie praat nie, ma jy as ouer moet ook geleer word om met die kind te laat praat. Ek het gevoel die terapeute het nie vir my genoegsame inligting gegee om my as ouer toe te rus om na die beste van my vermoë (kind se naam) toe te rus om te praat nie.

**I: En wat, in daai tyd, watter behoefte het jy en jou man gehad aan ondersteuning, watter ondersteuning wou jy gehad het?**

Ouer A: Miskien om met ander ouers gepraat het wat kinders het wat kogleëre inplantings het om hulle ervarings en hoe hulle dit reggekry het om hulle kinders te laat praat en te vorder om daai inligting te kon deel jy weet om uit ander ouers se oogpunt uit te kon agterkom maar dit gaan werk. Dis nie net die terapeut en die professor en die ENT wat so sê nie, dit gaan regtig werk. En die moontlikheid dat dit gaan goed werk is daar. Ek dink net daar is te min interaksie en te min inligting uitruil tussen ouers wat kinders het wat 'n gehoorgestremdheid het, hetsy of hulle 'n kogleëre inplanting dra of 'n gehoorapparaat. Dit voel vir my so almal is so soort van alleen in hulle stryd. Al hoe jy regtig met ander ouers in aanraking kan kom is ma deur die terapeute want jy weet nie van ander ouers wat met so 'n probleem worstel nie. Totdat jy self in daardie situasie is. En dit voel van die hospitaal se kant af en die terapeute se kant af het hulle nie regtig genoeg gedoen om ons in kontak te sit met ander ouers wat in dieselfde situasie is nie.

**I: So jy dink die belangrikste inligting wat jy wou weet is meer statistieke van hoe die kogleëre inplanting werk...**

Ouer A: Ja en of dit gaan werk want jy twyfel nog steeds of hulle vertel vir jou van hierdie apparaat en hoe wonderlik dit is, maar jy het heeltyd die twyfel in jou hart van of sy of dit haar in staat gaan stel om te kan praat.

**I: En jou belangrikste behoefte aan ondersteuning, as jy een kon uitsonder sal dit wees om met ander ouers te praat...**

Ouer A: Ja wat in die selfde situasie reeds was of nog steeds is wat vir jou kon sê my kind is so lank terug ingeplant en weet jy dit werk. Jy weet die twyfel oor of dit gaan werk of nie.

**I: Hoe dink jy as jy dit nou kon oor doen en jy kon raad gee vir die kogleëre inplantingspan wat sou jy sê hoe kan hulle meer effektief om beter inligting en beter ondersteuning te gee in daardie besluitnemingsproses?**

Ouer A: Ek weet dit is baie aan baie tydgebonde, ek het baie begrip daarvoor maar dat hulle tydens die evaluasie die emosionele kant ook sal kans gee, ja om die ouers kans te gee om berusting te kry bedoelende dat dit is hierdie skok vir jou en skielik is jy alleen, jy sien nie regtig iemand of praat met iemand wat ten volle begrip het vir die emosionele verbonde aan jy het nou net uitgevind jou kind jou kind is doof nie. En weet jy Ilouise dit is, jy kan nie die emosies daarom vir iemand in woorde beskryf nie, daardie ongelooflike hartseer, jy weet nie wat volgende gaan gebeur nie, dit is nie regtig wat jy vir jou kind wil hê nie, dit is nie wat jy vir jouself wil hê nie, maar jy is nou in hierdie situasie en jy moet jy moet nou daarmee deal maar dit is net asof daar was nie regtig iemand wat jou help om daarmee te deal nie. Hulle verwys jou nie na 'n sielkundige of 'n berader enige iemand toe net om daai emosionele pyn ook deur te werk nie. Jy het heeltyd hierdie emosionele pyn en worsteling dan word jy voor hierdie klomp keuses te staan gebring van sy moet 'n kogleêre inplanting kry, sy kry (medikasie se naam), sy skree die hospitaal se dak af, jy weet daai klas van ding. Dit maak dit uiters moeilik. Nou dink almal maar jou kind is net doof, wat is nou so erg daaraan maar dit is so erg dink ek. soos vir enige ouer wat uitvind hulle kind het 'n gestremdheid, ek dink vir 'n ouer wat uitvind haar kind het Downs Sindroom is dit net so erg, of vir 'n ouer wat uitvind haar kind is blind, is dit net so erg.

Ek voel net die emosionele ondersteuning was nie daar nie. Jy mos maar soortvan self cope en verwerk. Ek persoonlik dink die hospitaal moet die emosionele meer aanspreek. Die ouers kans gee of verwys na iemand toe wat saam met hulle deur daardie emosies kan werk, dan hanteer jy die inligting wat hulle vir jou gee en die besluite wat jy moet neem, dink ek bietjie makliker. In ons geval was daar iemand, ek het onmiddellik vir my man gesê, ek gaan nie hier deur kom nie, ek het berading nodig en daar was iemand na wie ek kon gaan, een van my vriendinne is 'n berader en sy het my nou deur die emosies gehelp. Maar as ek haar nie gehad het nie, sou dit honderd keer moeiliker en erger gewees het en ek sou dit nie so maklik aanvaar het en deur dit alles kon werk en so maklik en vinnig besluite kon neem soos wat ek in staat was om te doen nie, want dit is aanvanklik te oorweldigend vir jou as ouer, jy wil nie gekonfronteer word van al hierdie besluite van inplantings, en hoeveel dit gaan kos en hoe hard jy gaan werk om hierdie kind te laat praat nie. Jy net hierdie stil plekkie hê waar jy kan deurwerk hoekom is hulle doof, wat het nou eintlik gebeur ens. Van my kant as ouer sou ek sê hulle moet meer terapie of berading vir die ouers emosioneel ook gee, om dalk deur die trauma te werk, dan sal die besluite dalk makliker wees en vinniger plaasvind.

**I: (ouer se naam) sê nou jy kon by die inplanting span aankom en hulle sê hier is 'n lys van onderwerpe wat ons bespreek bv. Hier is finansies, hier is ondersteuningsdienste, kontak met 'n ander ouer, wil jy berading sien, en hier is hoe 'n inplanting werk, en jy kan self kies en sê weet jy vandag wil ek net weet hoe kan ek kontak maak met ouers en het julle vir my 'n nommer van iemand wat ek kan sien. Dink jy jou ervaring so anders gewees het as 'n terapeut gefokus het op dit wat jy nou nodig het voordat hulle met die ander areas aangegaan het?**

Ouer A: Ek dink dit sou Ilouise dat as hulle eerste die emosionele rondom die skok en die trauma van jy het nou net uitgevind jou kind is doof en dan al hierdie ander inligting gegee het, en dan gesê het daar is hoop en daar is hierdie apparaat wat werk en dit is ongelooflik baie geld maar dit gaan jou kind in staat stel om te kan praat, en hier is nog 'n ouer wat dieselfde situasie deur is, wat se kind reeds ingeplant is en wat dalk al begin praat het se nommer gaan praat met daai ouer gaan hoor hoe praat daardie kind gaan werk dit vir jouself uit en sien dat hierdie apparaat werk, want hierdie kind praat tog. Ek dink dit sou makliker gewees het.

**I: So jy voel dat effek daarvan as 'n ouer sou kon kies oor watter inligting en watter ondersteuning het hulle nodig sou die ervaring anders gewees het?**

Ouer A: Verseker, ek dink ja die kind het eers nodig om te begin hoor en te begin praat, maar ek dink hulle fokus te min op wat die ouer van daardie dowe kind nodig het. Want die ouer moet tog ook self deur al daardie goed werk die emosies en die finansies. Dit is 'n ongelooflik skok om te hoor hoeveel kos 'n kogleêre inplanting en jy is so gedruk en gebonde vir tyd en jy moet al hierdie emosies en finansies en inligting moet jy binne 'n ongelooflike kort tydjie verwerk en aanvaar en ja sê. Ek dink dit is te veel goed op een slag.



**I: As ek kan opsom van alles wat ons nou bespreek het, wat dink jy sal ouers se grootste behoefte wees aan inligting en ondersteuning voordat hulle kind 'n kogleëre inplanting kry?**

Ouer A: Weet jy meer inligting rondom die apparaat, en presies hoe dit werk. Ons is inligting deur die terapeute gegee. Partykeer weet jy nie regtig watter vrae jy wil vra nie. Jy het nie geformuleerde vrae vooraf in jou kop nie. Die meeste van die inligting wat ek wou gehad het en wou bekom het, het ek op die internet gaan soek. Ek het daar baie antwoorde gekry. Op Medel se website is daar baie vrae en antwoorde van ouers op van ouers met kinders met kogleëre inplantings met frequently asked questions dan is daar vrae wat die meeste ouers van ingeplante kinders vra en dit is ook maar toe ek dit begin lees het dat ek besef het dit is ook eintlik die vrae wat ek wou vra. Ek het net die geweet presies hoe nie, en hoe om dit te vra en wat sou die antwoord daarop sou wees nie. Hulle moet vir jou meer inligting of jou in staat stel omdat nie alle ouers toegang tot die internet of rekenaar het nie. Dalk kan hulle vir die ouers by die hospitaal sê dit is Medel se website, dit is die meeste vrae wat ouers vra, is dit dalk die vrae wat jy wou vra, dit is die antwoorde, want mens het nie, want jy het nie regtig vooraf vooropgestelde vrae wat jy wil vrae nie, totdat jy so iets gaan lees en besef ek wou dit ook nog eintlik geweet het, ek wou eintlik dit ook gevra het.

**I: So ek nou opsom dit wat jy gesê het, jy het gesê, julle wou weet hoe dit werk, en jou wou statistieke geweet het om te weet watter presentasie praat na 'n jaar, soveel kinders het 'n sukses daarmee, soveel kinders gaan hoofstroom toe en met ondersteuning wou jy wou gehad het dat iemand jou deur die trauma van daardie diagnose wou help en jy sou wou gehad het om die geleentheid te kon hê om met ander ouers te kon gesels en wat hulle ervarings was en om bietjie uit 'n ouer se perspektief die storie te hoor in plaas daarvan om dit net deur 'n professionele perspektief te hoor. Som ek dit reg op?**

Ouer A: Ja

**I: Is daar dalk nog iets wat jy wil byvoeg?**

Ouer A: Nee nie regtig nie.



## Onderhoud 2 met ouer B

### I: Vertel vir my hoe het jy uitgevind (kind se naam) het 'n gehoorverlies?

Ouer B: Op nege maande het ek begin sien sy kan nie hoor nie. Dit het so gebeur Ilouise, toe op 9 maande toe loop die ore, toe vat ek haar kliniek toe, toe gee hulle my die antibiotika toe drink die kind die bottel toe word hy klaar, lek die ore nie meer nie, toe word sy gesond vir 'n lang tyd. Weer toe begin die kind krap, krap by die ore, en toe begin die ore weer lek, dit was die tweede keer. Toe vat ek haar weer kliniek toe, toe kry sy weer die antibiotika, so kliniek, lek, stop, kliniek, lek, stop toe vat ek haar na Dr (dokter se naam) toe, toe verwys hierdie dr. my na Universitas hospitaal toe. Toe sê hulle vir my hulle werk nie met die ore nie, hulle stuur my na die dokter van die ore toe, die specialist by Universitas, tot hierdie tyd (kind se naam) is nog by hierdie mense. Toe was sy 4 jaar, toe ek kan sien sy kan nie hoor nie, ek moet hard praat en ek was op verlov toe gaan sê ek vir die dokter maar die kind sy kan nie hoor nie. Die dokter sê nou hoe dan, kan die kind nie hoor nie? Sy sê nie ja of nee nie sy reageer nie, as ek harder praat of skree dan eers kan ek sien sy skrik. Toe sê die dokter moenie tyd mors nie, bring daai kind dat ons die ore kom toets. Toe doen hulle daai BERA.

### I: Hoe het jy toe gehoor van 'n kogleêre implanting?

Ouer B: Ek het by (spraakterapeut se naam) gehoor. Ek het hom net gesien hy word gedoen daar by die teater. Toe vra ek watter prosedure is hierdie, toe sê hulle dit is kogleêre implanting. Die kinders wat nie kan hoor nie, ons sit hierdie implanting in, nadat die operasie dan kan hulle hoor. O, toe sien ek, toe was ek so bang en vrees as ek dit so kyk. Maar daai dag toe (spraakterapeut se naam) my gesê het van (kind se naam), o ek nie geslaap daardie nag nie, ek het nie geslaap nie, ek was nie lekker nie, toe ek by die huis kom toe sê my ouers hoe nou, hoekom moet sy daardie implanting kry? Volgende dag toe gaan ek by die werk, toe sê daai kollega van my, (kind se naam) kom kry 'n implanting, o toe huil ek, toe was ek nie lekker nie en toe sê die suster vir my man, jy moet sê dankie sê vir (spraakterapeut se naam) en jy moet dankie sê vir die staat vir daai geskenk vir (kind se naam) se implanting. Weet jy hoe duur is daai ding? Toe weet ek nie eers die prys, hoeveel is dit nie. Toe sê sy solank as dit nog Prof Claassen, wat vir jou daai geskenkie gee van die staat af, sê ja dit is reg, want jy is single, jy het nie die man wat vir jou help nie, jy sukkel met (kind se naam), so daai ding is goed vir jou. Daai ding is baie duur, die mense as hulle van daai ding kry, hulle kry altyd van die hulp van ander mense van ander company om daai geld bymekaar te maak dat die kind daai kogleêre implanting kry, so dit is geluk dat (kind se naam) dit gekry het, sê ja dit is reg. Maar toe dink ek net van daai, geboor en daai groot gat in my kind se kop! Maar na dit, alles het goed gegaan. Ek was net bang want ek net gesien hoe word hy ingeplant.

### I: Ja, ek dink jy het 'n unieke ervaring gehad, nie alle ouers sien hoe die operasie plaasvind nie. Sê vir my (ma se naam) daai tyd vandat jy gehoor het dit is 'n opsie tot daardie dag van die operasie, daardie tyd wat jy moes besluit het, wat was vir jou moeilik in daardie tyd, watter uitdagings het jy ervaar tydens die besluitnemings proses voor die operasie?

Ouer B: Ek sal sê Ilouise nie alles was lekker vir my nie. Want ek was net bang vir daai ding, daai implanting. Toe sê (kollega se naam), man dit is die geleentheid wat jy gekry het, jy moet sê dit is reg, want daai ding is baie duur. Die ergste is daai ding is duur, en jou kind sal nooit weer kan hoor in die lewe. Dit is nou die tyd dat jou kind die operasie kan kry dat sy kan hoor. Want dit is die res van haar lewe dan kan sy nie hoor nie. So jy moet besluit en jy weet hoe word hy ingeplant en die ouers daar by die huis weet niks, jy moet vir die ouers gaan sê hoe word hy gemaak, en vir hulle mooi gaan verduidelik hulle gaan ook bang wees, jy is ook bang maar jy weet hoe word hy ingeplant. O maar ek was klaar daai dag. O Ilouise, ek was regtig klaar. Toe sê ek hulle by die huis, toe sê my pa nee, my kind gaan nie operasie toe nie. Toe sê ek vir hom maar pa dit is goed vir (kind se naam) want ons weet net van vandag ons weet nie van môre, wat sal gebeur met (kind se naam). So dit is goed dat ons sê hulle kan die operasie maar doen. Maar my pa het gesê nee, nee, nee. Maar na 'n paar dae het hy gesê dit is reg, as jy so sê en so voel. Ek sê baie kinders kom van die operasie af, hulle kan hoor daar is niks probleme nie. Ander mense hulle is net bang vir die teater, hulle sê as jy daar gaan jy kom nie weer terug nie, dan is jy dood. So hulle het net daai vrees om te sê teater maak altyd die mense dood. Toe sê ek teater is niks nie, dit maak mense gesond.





**I: So jy was baie bang vir hierdie operasie en jy het baie spanning ervaar, dit was vir jou moeilik.**

Ouer B: Dit was moeilik, dit was regtig baie moeilik. Ek het net gehuil by die huis. Dan sê hulle moenie huil nie, jy het die eerste dag gehuil toe jy vir ons kom sê van die operasie. Dit is vandag operasie dag, ek wil nie trane sien by daai gesig nie. Ek het nie gehuil nie, maar ek was nie lekker gewees nie. O ek was nie lekker gewees nie. Toe sê my ma is jy reg toe sê ek ja ek is reg. Toe ons by die huis kom toe vra sy vir my is ek reg, maar sy het dan gesien ek is nie reg nie. Dit was 'n groot dag daai.

**I: Daardie tyd voor die kogleêre inplanting watter behoefte het jy gehad aan inligting, wat wou jy weet van die kogleêre inplanting?**

Ouer B: Ek wou net geweet het sal my kind kan hoor na die operasie. Dit was die belangrikste, en ek het gedink hy word sommer nou vandag gedoen, môre dan kan my kind hoor. Dit was nie so nie, dit moet eers 'n paar dae wees, en dan word hy ingeplant en dan ingestel, dan kan hy hoor, dan word hy gestel bietjie, bietjie tot vandag. En ek het gedink na die operasie, sy kan sommer hoor dadelik.

**I: En wat wou jy nog weet...**

Ouer B: Van die inplanting, ek het gedink miskien as sy nie kan hoor nie gaan hulle weer daai inplanting uithaal? Toe sê ek nee hulle kan maar los, daai kind maar so bly met daai inplanting al kan sy nie hoor nie, ek wil nie hê hulle moet weer daai groot gat gaan maak nie. So nou by daai plek van die operasie sy groei nie weer hare nie, toe sê Dr bring haar ons sal na plastiese teater toe vat, ek weet nie wat maak hulle nie, maar dan groei die hare. Toe sê ek nee, ek vat nie weer my kind teater toe nie. Dit is reg so.

**I: So jy wou geweet het of sy gaan hoor en of hulle dit kan uithaal. Is daar nog iets wat jou ouers wou weet of wat jy wou weet voordat julle besluit het, julle gaan dit die inplanting laat doen?**

Ouer B: Die ouers was eintlik bang, toe sê hulle los maar daardie operasie. Toe sê ek nee, dit is belangrik vir haar want as sy nie kan hoor nie, die belangrikste is dat sy kan hoor na die operasie. So los die dokters dat daai inplanting maar ingeplant word.

**I: Watter behoefte het jy gehad aan ondersteuning? Hoe wou julle gehad het dat mense julle moes help of ondersteun?**

Ouer B: Julle het vir ons ondersteun. My kollegas daar het my ondersteun. (Spraaakterapeut se naam) het vir ons ondersteun.

**I: So julle het gevoel iemand stap saam met julle die pad...**

Ouer B: Dit het so gevoel daai dag van die operasie, toe is al die hospitaal se mense susters en dokters sê O kind se naam. Toe kry sy 'n teddy beer en als toe sien ek al die mense ondersteun ons want hulle weet dit is 'n lelike groot operasie hierdie. Toe sê my ma is dit (spraaakterapeut se naam) toe sê sy dit is die spraaakterapeut. Sy was by die operasie, sy was by na die operasie. Volgende dag, toe sê sy is die mense dan so, toe sê ek hulle is mal oor die kinders, die stout kinders. Maar ons het regtig baie ondersteuning gekry.

**I: As jy nou dink is die belangrikste area van inligting wat ouers benodig, voordat hulle kinders kogleêre inplantings kry? Watter inligting is die belangrikste om vir ouers te gee?**

Ouer B: Dit is om die ouers te sê van die inplanting, hoe word hy gedoen, na die inplanting wat sal gebeur, die kind sal nie dadelik hoor soos wat ek gedink het nie, hy sal 'n paar maande vat voor hy ingeskakel word, hulle moet ook weet hy word nie dadelik ingeskakel nie, dit vat eers daai tyd. Hulle moet mooi ingelig word.

**I: En wat is die belangrikste vorm van ondersteuning om vir ouers te gee? Wat dink jy is die belangrikste om te doen om ouers te ondersteun?**



Ouer B: Hoe moet ek nou sê Ilouise, om nie bang te wees soos ek nie. Ek was bang gewees omdat ek weet hoe word hy gedoen. So hulle hoef te bang nie, hulle moet net sê ja dit is reg, want dit is goed vir onse kind. Want hulle weet nie hoe word dit geopereer nie. Ek dink ek was net bang want ek weet hoe word hy ingesit.

**I: En hoe dink jy moet die spraakterapeute ouers beter ondersteun? Hoe kan die dokter, spraakterapeut en dokter die ouers help om nie meer bang te wees nie?**

Ouer B: Dit is belangrik daai inplanting. Die ouers moet gesê word van daai inplanting. Hoe word hy ingeplant, hoe werk hy? Is daar advantage and disadvantage van die inplanting?

**I: Wat dink jy sal daai bang wegvat? Jy het gesê jy was bang voor die inplanting? En baie ouers is bang. Wat dink jy sal dit verbeter?**

Ouer B: Dit om te praat met die ouers en wys hulle die kind sal veilig wees, die kind sal in die regte hande wees, hulle kyk alles deur die operasie, die kind gaan nie brand nie, hulle moet net weet die kind is veilig, want daai tyd, die kind sien niks nie, ons is sy oë alles sal reg wees. Daar sal nie nat plek wees dat die kind gaan brand nie. En die plakker wat geplak word op die regte plekke geplak wees en dit moet nie nat wees nie en al daai tipe dinge. Ons maak seker die kind is veilig, want as ons dit nie doen nie, gaan ons probleme kry oor daai pasiënt.

**I: So jy wil hê ons moet die ouers kan gerusstel en sê die dokters weet wat hulle doen, hulle maak seker van alles, hulle het dit al baie gedoen en jou kind is in veilige hande. Is dit reg? Dat ons ouers moet gerusstel?**

Ouer B: Ja want party mense as hulle daar kom dan huil hulle, o my kind. Dan sê ek vir hulle moenie huil nie, hulle kind is nou groot of hulle is klein, my kind was 4 keer in die teater, die 5 de keer toe kry sy daai groot operasie. Jy moenie bang wees nie, jy moet net weet die kind is veilig, die kind gaan net so uitgaan uit die teater uit lewendig. Moenie bang wees en daai klomp dinge dink nie. So dan sien ek hulle word beter hulle kalmer en hulle huil nie meer nie. Hulle sê "Regtig was jou kind hier? Sy was 6 jaar toe kry sy daai inplanting, sy is nou 8 jaar, sy maak 9 Desember. My kind is oraaie ek het nie probleme nie, so wees rustig jou kind sal reg wees.

**I: (Ouer se naam) hoe dink jy kan die kogleêre span, die dokters, terapeute en oudioloë ouers meer effektief of beter bystaan met inligting en ondersteuning in daardie tydperk vandat jy hoor jou kind het 'n kogleêre inplanting nodig tot en met die operasie?**

Ouer B: Ek dink hulle moet met hulle sit en vir hulle wys die prentjies soos by die teater. Hier is die prentjie, dit sal so gebeur en so gebeur en na dit so en so. Laat die ouers net inligting kan kry wat en wat gedoen by my kind. Na die operasie wat moet ek verwag, en wat moet ek nie verwag. Ek dink hulle gesê word van die operasie want ek was nie gesê want ek het geweet wat kom doen hulle.

**I: Hoe sal jy daarvoor voel as ouers, 'n keuse gegee word voor 'n kogleêre inplanting oor die tipe inligting wat hulle wil hê en hoeveel inligting en ondersteuning wat hulle nodig het?**

Ouer B: Ek dink die inligting is reg, hulle kan die inligting kry, maar ander mense sê dit is reg ek hoor wat julle sê maar as my kind nie kan hoor na die operasie nie. Want daar is die advantages en die disadvantages, gaan hulle nie sê nee ek gaan sue julle nie, julle het my gesê my kind gaan hoor, julle het die operasie gedoen en dit het nie gewerk nie, nou wat? En ek het daai baie geld betaal en wat wat. Ons was gelukkig (kind se naam) werk goed, sy kan mooi hoor. Sy kan sê nee daai tyd maak net geraas, bietjie sagter, dit is (kind se naam) daai. So sy kan goed hoor en nou sy lees nie meer die lippe as jy praat. Jy kan praat al kyk jy soontoe sy kan hoor wat sê jy.

**I: Ja dit is baie goed. Dink jy dit sal beter wees as ouers kan kies hulle wil weet van die operasie, en hulle wil dit weet of dat weet. Dink jy dit sal anders wees as ons vir ouers 'n keuse gee en vir ouers vra wat wil jy weet en watter ondersteuning wil jy hê?**

Ouer B: Ek dink dit sal beter wees want anders kan ouers sê ek wil my kind laat hoor maar ek wil nie hê hy moet deur die operasie gaan nie, of hy moet deur die operasie gaan. Jy kan nie sê ek wil my kind laat hoor maar ek is bang vir daai operasie nie. So julle moet hulle regmaak vir die operasie.

**I: Van alles wat ons nou bespreek het, wat dink jy is ouers se grootste behoefte aan inligting en ondersteuning voordat hulle kinders 'n kogleêre inplanting ontvang?**

Ouer B: Jy moet hulle sê wat is die kogleêre inplanting, hoe word hy behandel, want soos nou (kind se naam) se pocket battery het weggeraak. Want toe het ek nie geld om dit weer te koop nie, want alles van die inplanting is duur. So die ouers moet ook weet alles is duur van die inplanting. Hulle moet versigtig wees vir die inplanting van die kinders. Die kind moet ook geleer word, my kind jy moet weet die ding is duur, jy moet hom mooi behandel. Jy mag nie dat ander kinders krap, krap by jou ore nie. Want by Carel du Toit ons het nie probleme gehad nie want al daardie kinders het gehoorapparate en inplanting gedra. Maar by daai normale skool toe kry ek probleme, want daai kinders ken nie gehoorapparate nie, hulle ken nie kogleêre inplantings nie, so hulle het gekrap krap by (kind se naam), uiteindelik toe word die battery weggegooi.

**I: So ouers moet weet watter implikasies het die kogleêre inplanting...**

Ouer B: Ja en die kinders moet ook leer, hoe word hy aangeskakel hoe word hy afgeskakel. Hoe sit sy hom aan al daai goed. Die kind moet weet want (kind se naam) kan hom self afhaal, die battery insit, uithaal. Sy kan dit self doen daarom kan sy vir ander ook wys hoe word hy gemaak. Die niggie het die juffrou ook by die skool gewys hoe word hy gemaak. So hulle het nie probleme met dit nie, hulle moet net mooi gesê word dit is baie duur, niemand krap aan jou ore nie.

**I: Kom ek som nou op wat jy alles gesê het. Jy het gesê jy wou graag geweet het wat is die inplanting, hoe werk hy, dat jy wou weet dat hy nie weer uitgehaal kan word nie, dat die ouers moet geleer word hoe hy lyk en hoe hy aanmekaar sit en hulle moet ook die kinders leer hoe om hom te gebruik en hulle moet weet dat dit baie duur is en dat al die parte duur is.**

Ouer B: En hy moet ook nie water kry nie, dit is die belangrikste een. As die kind gaan bad of gaan stort hulle moet dit afhaal. As dit reën, as sy net sien daar kom wolke, dan wil sy dit afhaal. Dit reën nie, dit is net die wolke maar as dit begin reën dan vat jy hom af.

**I: So die versorging van die apparaat is vir jou belangrik om vir ouers van in te lig. En van ondersteuning voel jy, jy het eintlik genoeg ondersteuning gekry omdat jy al mense goed geken het. Die pad wat jy gestap het was dat jy eers lank terapie gekry het en toe het julle die inplanting gekry so dieselfde mense het saam met jou gestap. Jy voel daardie ondersteuning was vir jou genoeg maar dit is belangrik dat mense jou kan ondersteun en vir jou kan raad gee.**

Ouer B: Dit is.

**I: Is daar nog iets wat jy voel is belangrik wat jy wil byvoeg?**

Ouer B: Dit al Ilouise. Dit is 'n lang prosedure. Ek onthou ek het 2 weke gehad met huiswerk. Dit was nie lekker nie. Toe moes ek die ouers gaan reg kry daar by die huis, maar uiteindelik het alles goed afgehoop, hulle het ook verstaan. Alles het goed geloop.

### Onderhoud 3 met ouer C

**I: Hoe het jy uitgevind jou kind het 'n gehoorverlies?**

Ouer C: Met die standaard gehoortoetse wat hulle met die babas doen voordat hulle uit die hospitaal gaan.

**I: Hoe het jy toe gehoor van 'n kogleêre inplanting?**

Ouer C: Wel toe ons die uitslae kry om te sê sy is doof, sy kan nie spraak hoor nie. Toe vra ek wat is die volgende stap? Toe sê hulle ons kan kogleêre inplantings oorweeg. Toe het ek nie 'n clue wat dit is nie, toe verduidelik hulle vir ons wat dit is en hoe dit werk en toe is ons vir toetse Kaap toe.

**I: So dit was dieselfde personeel wat die gehoortoetse gedoen het wat vir julle die inligting gegee het? Was dit 'n oudioloog?**

Ouer C: Ja dit was 'n oudioloog. Toe is daar verder toetse gedoen om vas te stel waar is die probleem wat kan sy hoor, werk die senuwee, x-strale gedoen, en al daardie goed. En toe het hulle vasgestel sy is 'n goeie kandidaat vir 'n kogleêre inplanting.

**I: Vertel vir my watter uitdagings het jy ervaar in daardie tyd voor die inplanting, tydens die besluitnemingsproses? Wat kan jy onthou van daardie tyd?**

Ouer C: Wel toe hulle vir my sê sy kan kogleêre inplantings kry mits die senuwee na die brein toe werk, was dit my grootste worry op daardie stadium. As die senuwee net werk terwyl hulle die toetse doen. En toe hulle vir ons sê sy kan die inplanting kry, ek weet nie toe het die dinge outomaties gebeur. Toe begin hulle oor geld praat, dit is wat die goed kos en so aan. En ek het onmiddellik geweet, ek weet nie of my medies gaan betaal nie, want hulle is maar baie stubborn. En ja toe het dit nou net van daar af gebeur.

**I: Wat was vir jou moeilik in daardie tyd?**

Ouer C: Dit was moeilik dat my kind nie hoor nie, om te kommunikeer met haar of ek praat met haar en ek weet eintlik mors ek my asem want sy hoor my nie. Ja dit was seker die moeilikste.

**I: As jy nou terugdink aan daardie tyd voor die inplanting, wat wou jy weet, watter inligting wou jy gehad het?**

Ouer C: Wel eerstens, wou ons geweet het waar word die operasie gedoen. Wie doen dit, hoeveel kos dit, hoe lank gaan sy in die teater wees, wat presies gaan hulle doen, hoe gaan haar gehoor wees na die tyd. Ja dit is maar basies die vrae.

**I: En ondersteuning? Watter behoefte het jy aan ondersteuning gehad in daardie tyd?**

Ouer C: Ek wou maar net by die mense wat die inplantings doen en vir jou raad gee, die oudioloë wou ek net heelyd daai bevrediging hoor dat dit gaan oraait wees sy gaan kan hoor, dis net harde werk en spraakterapie. Dit was die tipe ondersteuning wat ons gekry het en dit was voldoende.

**I: En addisionele bronne van ondersteuning? Sou julle hulp van ander bronne ook wou hê?**

Ouer C: Nee, ons het geweet dit is tot ons beskikking en ons het geweet as ons in 'n situasie beland waar sy dalk Carel Du Toit toe moet gaan en ons dalk Kaap toe moet trek, dan is hulle daar vir ons en hulle sal ons help as dit nodig is.

**I: As jy kan sê wat is die belangrikste area van inligting, jy voel ouers moet weet, voor die inplantering van hulle kinders. Watter area van inligting sal jy uitsonder as die belangrikste?**



Ouer C: Jou werk hou nie op na die inplanting nie. Dit is harde werk. En ek is nie 'n ma wat gaan werk het nie, ek was by die huis by my kind en vir my was dit harde werk. Nie dat kinders maklik is om groot te maak nie, jy verwag nie dit nie maar, ek weet nie hoe 'n ouer dit doen wat heeldag moet gaan werk nie. En dit was nie moeilik nie, dit was 'n plesier maar dit was harde, dit was regtig harde werk. Dit is nie jy los nou jou kind en jou kind moet aangaan nie. So die worries hou nie op na die inplanting nie. Dit gaan aan. Ek dink nie dit hou nooit op nie.

**I: Ek dink dit is baie goed wat jy sê dat ouers nie net vaskyk tot en met die operasie nie maar dat hulle weet dit is net die eerste stap daarna lê hierdie hoeveelheid werk voor. En jy moet daarvan ingelig wees voordat daar 'n besluit geneem kan word. En ondersteuning wat dink jy is die belangrikste vorm van ondersteuning wat ouers benodig voordat hulle kinders 'n inplanting kry?**

Ouer C: Ek sou sê hulle moet 'n goeie spraakterapeut hê, wat hulle kan ondersteun nog voordat die kind geïmplanteer word. Ek bedoel (kind se naam) het spraakterapie gekry, van 'n jaar en 3 maande af, waar sy nog nie eers kon hoor nie. Ek dink die ondersteuning van die spraakterapeut is baie belangrik. En ook van jou oudioloog wat jou van die begin af help met die inplanting. Ek bedoel selfs vandag as ek enige probleme het, of enige vrae het dan bel ek eerste die oudioloog waar sy geïmplanteer is. En sy sal jou altyd bystaan en altyd raad gee.

**I: Hoe dink jy kan die kogleêre span ouers meer effektief bystaan in die besluitnemingsproses? Wat dink jy kon meer effektief gewees het wat die kogleêre span vir jou gee voor die inplantering?**

Ouer C: Hulle het my goed ondersteun. Ek het eintlik te veel inligting gehad. Ek dink nie dit is altyd nodig om so baie inligting te hê nie. Want met die tweede inplanting toe weet ek nou alles, nie alles nie maar al die inligting. Die tweede inplanting was vir my baie erger. Dit was baie, baie erger. Daardie 3 ure in die teater was vir my nag want toe weet ek nou presies wat hulle doen, hoe hulle dit doen, hoe hulle die oor oopsny, wat hulle daar binne doen want toe het ek 'n video ook gekyk en ek sal dit nie aanraai nie.

**I: As jy sê jy is effektief bygestaan, wat sal jy aanbeveel moet 'n kogleêre span doen met 'n ouer wat jy ervaar het as positief en effektief?**

Ouer C: Wel toe ons begin het met hierdie hele inplanting storie, het hulle vir my presies gewys hoe lyk dit, die apparaat, ek het op 'n skedel gesien daar boor hulle die gaatjie, daar sit hulle die inplanting in, en hulle het bv. X-strale geneem van haar koppie en dan het hulle vir ons presies vir ons verduidelik dit is waar hulle sny, dit is waar hulle boor, en jy worry tog as jy 'n meisiekind het, hoe lyk die goed op haar kop, en hulle het genoeg foto's gewys van kinders, en in die teater die hele prosedure het hulle bespreek met ons. So ek was redelik goed ingelig van hoe dit werk.

**I: En die emosionele ondersteuning...**

Ouer C: Ek weet nie, ek is nie 'n baie emosionele tipe mens nie, so ek het nie regtig emosionele ondersteuning nodig nie. Ek is nie so tipe mens nie so ek kan die regtig assosieer met dit nie. Maar in die teater toe hulle opereer, toe die inplanting getoets is voor hulle toemaak, het hulle uitgekóm na my toe en gesê alles is oraait, die inplanting werk, hulle gaan nou toemaak. So ek was heeltyd bewus wat gaan in die teater aangaan. Hulle het my op hoogte gehou want hulle weet mos ons ma's staan daar buite en worry. Dit is 'n verligting om te weet dit was 'n sukses. Die binnekant werk.

**I: Hoe sal jy daarvoor voel as ouers voordat hulle kinders geïmplanteer word, 'n keuse het oor watter inligting het hulle nodig en watter ondersteuning het hulle nodig?**

Ouer C: Ek dink hulle kan maar kies, want ek dink dit hang van mens tot mens af watter tipe inligting jy wil hê. Maar nou moet ek ook vir jou sê in so situasie is daar soms net 'n blok oor jou, jy het nie 'n idee wat jy wil weet nie, wat jy moet weet nie, want dit is nuut. Ek bedoel as jy nou iemand van die straat af gaan haal en jy sê jou kind moet 'n kogleêre inplanting kry, almal weet nie wat dit is nie, want ek dink dit is partykeer so groot skok as jy hoor jou kind is doof dat jy het half 'n mental block. Jy weet nie wat is die volgende stap nie, jy wil hê iemand anders moet nou vir jou sê ok dit is nou die volgende stap. En as daai

stap nou gedoen is dan wil jy weet dit is nou gedoen, wat is nou die volgende stap. So ek dink dit sal goed wees as hulle kan kies watter inligting hulle wil hê en hoeveel hulle wil hê.

**I: As jy nou kan opsom alles wat ons nou bespreek het, wat dink jy sal ouers se grootste behoefte wees aan inligting en ondersteuning voor 'n kogleêre inplanting?**

Ouer C: Dit is hoe om met hulle kinders te kommunikeer. Hoe om spraakterapie toe te pas met hulle kinders of hulle nou al kan hoor of nie. Want hulle tel tog 'n ou se lippe op.

**I: So as ek nou alles kan opsom wat jy gesê het dan sal dit wees dat jou grootste behoefte aan inligting was wat kan jy verwag verder en hoeveel werk is nodig na die kogleêre inplanting. Dit voel jy is belangrik vir ouers om te weet. Wat ondersteuning betref glo jy die rol van 'n spraakterapeut voor en na die tyd is baie belangrik om ouers te ondersteun met raad en leiding oor wat is die proses en wat moet jy doen. En dat jy hulle kan vrae vra. Het ek dit reg opgesom?**

Ouer C: Ja.

**I: Is daar nog iets wat jy wil byvoeg?**

Ouer C: Ja ek sou sê dat as ouers die keuse het kogleêr of nie, sal ek sê gaan vir die kogleêr. As iemand vir my vra een of twee inplantings sal ek sê twee inplantings. Maar dit hang van mens tot mens af.

**I: Baie dankie.**

#### **Onderhoud 4 met ouer D.**

##### **I: Hoe het julle uitgevind van (kind se naam) se gehoorverlies?**

Ouer D: Weet jy Ilouise, ons was by die see en daar het jy oorontsteking gehad. Toe ons terugkom het ons met hom begin speel, met hom gesit en speel op die grond en dan het ons geklap op die tafel en dan het ons gekyk of hy omgekyk het. Toe het ons gesien nee hy reageer nie en harde goed geklap en toetse begin doen met hom en dit was net na 6 of 9 maande. Dit was die ouderdom wat ons agtergekom het daar is iets nie lekker nie. Dit is toe dat ons goedjies begin doen het. My man het 'n vriend (Dr. se naam) gekontak en toe sê hy ons hoef nie nou bekommerd te wees nie, dit is dalk net vog op die oor ons moet grommets en goed doen. Toe het hy in Welkom grommets gekry. En daarna het ons gesien dit het nie regtig 'n effek nie en toe het hy terugverwys en (Dr. se naam) het ons toe verwys na (Dr. se naam) wat ons verwys het na Dr. Butler.

##### **I: Waar het julle toe gehoor van 'n kogleêre inplanting?**

Ouer D: By Dr se naam (Oor- Neus en Keel spesialis)

##### **I: Vertel vir my wat kan jy onthou van daardie tyd vandat hy gediagnoseer is tot en met die inplanting. Wat was vir jou uitdagings in daardie besluitnemings proses?**

Ouer D: Baie deurmekaar tyd. Emosioneel baie stremming op 'n mens. Jy voel regtig jy stoei hoekom my kind? Is dit my kind? Daardie tipe goed wat in jou kop aangaan. Huil fases wat jy deurgaan. Sulke tipe goed. Dan begin jy worstel, as jy dit begin aanvaar. Gaan dit werk met my kind? Daardie tipe vrae. Dit maal in jou, die onsekerheid wat opbring en voorkom, daardie tipe goed. Dit is maar 'n emosionele gespanne tyd. Want jy weet dan begin almal met jou praat en sê doen dit eers doen dat eers. Is jy seker van dit? Doen jy die regte ding? So dit is 'n deurmekaar emosionele tyd.

##### **I: Wat wou julle weet voor die inplanting? Watter behoefte het julle aan inligting gehad voor die kogleêre inplanting?**

Ouer D: Inligting is 'n groot behoefte. Behalwe vir die finansiële deel daaraan verbonde, is dit werklik die uitkoms? Gaan daar nie, nie nog vir jou kind 'n ander paadjie oopgaan nie? Daardie inligting kom in, maar dit is so 'n magdom wat nou jou toe kom. Ons het nie eers geweet wat (kind se naam) se oorsaak was van die gehoorverlies nie. So ons het nie ingegaan en gesê hy het byvoorbeeld 'n hoë koers gehad nie, kyk dit is die rigting waarin ons moet beweeg nie. So ons het hierdie magdom, dit is 'n kogleêre inplanting en ons moet daarvolgens ingaan. So ons het baie behoefte gehad om te weet dit is dit en dit is die rigting waarin ons moet gaan en dit is (kind se naam) se rigting.

##### **I: Wat wou julle alles weet oor 'n kogleêre inplanting?**

Ouer D: Ek het bietjie met my man gepraat en soos hy sê hy sal graag wil hê daar moet 'n model gebou word van 'n oortjie. En dan moet daar vir ons gewys word, hier gaan nou 'n snit gemaak word. Want jy weet dit nie. Dat hulle vir jou wys hier gaan ons die snit maak, hierdie tipe apparaatjie sit nou binne die kop en van hier af gaan daar dan 'n draaitjie na die plekkie toe en van daar af. So die binnekant sal dalk ook vir ons meer duidelikheid gee van hoe werk die kogleêr. Ons het nogal gewonder oor dit. Die viseule voorstelling van 'n kogleêr.

##### **I: Enige iets anders wat julle wou weet?**

Ouer D: Ons wou ook weet van die tipes kogleêre inplantings. Ons het nou die Nucleus en daar was nog 'n ander enetjie. So jy ken dit nie, jy weet nie van die verskillendes nie. Jy weet nie watter een is die beste nie. As jy vra vrae wil niemand vir jou sê maar daardie een nie, want almal is bang jy kom die ander een te na. So jy kry nie werklik die eerlike antwoord om te weet dit is die beste, kies dit nie. So om duidelikheid te kry om te weet wat is die belangrikste verskille tussen die apparate.

##### **I: Dit maak sin. En ondersteuning? Watter behoefte het julle gehad aan ondersteuning?**

Ouer D: Weet jy ons wou ook graag mense ontmoet het wat daardeur gegaan het. Na 'n ruk was ons by mense in Pretoria wie se seuntjie ook 'n kogleër het. Maar dit was soos in vinnig met wie ons gepraat het. Maar ons sou graag mense wou ontmoet het wat die pad gestap het en alles deurgegaan het.

**I: Dit is 'n baie belangrike behoefte by ouers.**

Ouer D: Dit is baie belangrik want mense verstaan nie as hulle daardie omstandige ken nie. Hulle verstaan nie werklik die omstandighede rakende dit nie. So dit sal nogal lekker wees al gaan mens deur 'n groep sessie of iets.

**I: So as jy nou die heel belangrikste area van inligting kan uitsonder wat sal dit wees? As jy met ander woorde vir my kan sê, Ilouise ek dink dit is die heel belangrikste om ouers dit te laat weet....wat sal dit wees?**

Ouer D: Die uitwerking van die kogleëre inplanting. Hoe dit jou kind gaan beïnvloed na die operasie. Jy weet dit gaan verander, dit is 'n lang proses. Voor die tyd het ek nogal gecope met als, maar na die tyd dink jy nou is my kind geïmplanteer na 'n jaar wil hy darm praat. Daardie dinge weet jy ook nie. So ek sal sê hoe die kogleëre inplanting mense beïnvloed. Of jou kind beïnvloed of die proses?

**Jy voel dus 'n mens moet ouers voorberei vir na die aanskakeling, wat kan jy verwag en wat is belangrik rondom sy ontwikkeling na die aanskakeling...**

Ouer D: En oor inligting. Jy weet ek rig net al die inligting wat ek kry by my spraakterapeut. Jy weet, ek wil graag 'n handleiding hê wat vir my sê werk hieraan 'n maand. Hier is 'n boek wat vir jou sê doen hierdie oefeninge met hom. Doen dit met hom, so daardie prosesse want julle is vertrouwd met dit en weet ek moet nou op Ling klanke konsentreer doen dit met hom. So verskillende oefeninge wat jy met jou kind kan doen.

**I: En ondersteuning? Wat dink jy is die heel belangrikste vorm van ondersteuning wat jy vir ouers moet gee?**

Ouer D: Kommunikasie. My man het ook gesê 'n oop lyn van kommunikasie en ook die gerussteling dat dit kan werk. Dit maar net dat oop eerlike vrese gedeel kan word. Dit is maar die oop lyn van kommunikasie wat daar altyd moet wees, selfs al is die net een persoon. Wat ons ook ondervind daar is spraakterapeute, dokters en ek het nog my buite spraakterapeut en die Carel de Toit, so dit is vier groepe waarmee ek moet kommunikeer en elkeen sê iets anders en dit het vir my baie verwarring veroorsaak. So ek dink daar moet een persoon wees waarmee jy moet werk en nie twee of drie verskillendes nie. In my geval het (oudioloog se naam) en (spraakterapeut se naam), dat sy nie voel sy meng in haar veld as sy aanbevelings maak nie of as ek iets vra nie. Want baie keer sê sy sy kan dit nie doen nie, want sy is nie my spraakterapeut nie. As ek iets gevra het dan het hulle gesê vra eerder jou spraakterapeut. Want dit is ook maar 'n proses want sy het nog nie met kogleëre inplantings gewerk nie so sy moes ook baie uitvind. Dit is weer die kommunikasie met die ondersteunings velde wat ook daar moet wees.

**I: Dit is 'n baie belangrike punt wat jy maak. Hoe dink jy kan 'n kogleëre span ouers meer effektief bystaan met inligting en ondersteuning in daardie besluitnemingsproses?**

Ouer D: Om vir ons presies te wys wat gaan gebeur, wat alles benodig word. Die finansiële inpak duidelik stel. En vir ons by die mediese fondse...jy weet ons kan nie die tweede een bekostig nie. Jy weet daardie finansiële prosesse....dat hulle net vir ons duidelikheid gee want jy gaan maar toe oë in en hoop jy kry die fondse. So die kommunikasie na die fondse toe. Daar is vir my ook 'n gaping. Die ondersteuning hoekom betaal 'n fonds nie. Ek weet nie of dit vir jou duidelik is nie...

**I: So dit is dalk ook hoe om te motiveer of die proses oor hoe om fondse beskikbaar te kry.**

Ouer D: Ja.





**I: (Ouer se naam) hoe sal jy daarvoor voel as ouers 'n keuse gegee word voordat hulle kind 'n kogleêre inplanting kry oor die tipe en die hoeveelheid inligting en ondersteuning wat hulle benodig?**

Ouer D: Mens weet nie watter vrae om te vra nie. So as daar vir jou 'n lys is wat vir jou sê alles wat daar is en jy daardeur kan gaan en jy kan sê jy weet nie van dit nie. Jy weet nie altyd watter vrae om te vra en wat het jy nodig nie, watter ondersteuningsnetwerke daar vir jou is nie. Want vir 'n ouer wat nie weet wat beskikbaar is nie weet hy nie wat daar is nie. So alles moet daar op 'n lys beskikbaar wees en sê hierso jy kan my vrae oor die beskikbaarheid van apparate, hier kan jy vir my vra watter spraakterapie word aanbeveel, watter boeke is daar Carel du Toit sentrum, daar is die Eduplex sentrum is beskikbaar, waarna toe kan ek gaan. Waar gaan ek my oudiogramme doen? So jy weet nie, jy kom nou maar so met die pad wat jy stap agter, ok nou moet ek dit doen. So dit is nie dat daar beskikbare inligting is vir 'n ouer om te sê ek wil dit weet nie. So die proses met jou kind stap kom die vrae maar op jy weet nie van al die vrae wat jy eers moet vrae nie. So daar is 'n behoefte aan inligting oor alles wat 'n ouer wil weet en moet weet.

**I: So jy dink dit sal positief wees as ouers 'n lys het en hulle kan areas kies wat hulle nou voel ek wil dit nou weet. Soms lees ouers op die internet op en dalk is daar areas wat nie gedek word wat die ouer wil weet bv. oor skoolplasing of ondersteuningsdienste...**

Ouer D: Ja of voor die kogleêre inplanting lê klem op dit. Na die inplanting lê klem op dat. Is daar 'n raamwerk waarvolgens ouers inligting kan inwin. Of sê gaan na die internet toe en gaan kyk by hierdie website en kry daar hierdie inligting.

**Goed. Laat ons opsom. As jy nou van alles wat ons bespreek het, wat dink jy is ouers se grootste behoefte rakende inligting en ondersteuning voor die kogleêre inplanting?**

Ouer D: Ilouise ek het ook nie toegang tot die internet nie. Dit is dalk ook hoekom dit vir my moeilik was. Ek sal sê as daar 'n raamwerk is vir 'n ouer waarnatoe hy kan gaan al win iemand anders dit vir jou in, 'n boek wat vir jou sê dit is die stappe wat 'n ouer moet volg dan sal dit nogal lekker wees. Ek dink die groot ding voor (kind se naam) was die onsekerheid wat ons gehad het oor wat wag vir ons, wat is daar vir ons dat mense eerlik sê ek kies daardie een en dit en dit is die rede. Dat daar duidelike riglyne daar is vir 'n ouer al is daar keuses wat hy self moet maak.

**I: Sodat die ouer 'n meer ingeligte besluite kan maak...**

Ouer D: Ja

**I: Ek gaan nou opsom. Jy sê dat vir jou was dit baie belangrik dat ouers goeie inligting moet kry voor die inplanting, dit sou gehelp het as daar 'n visieule voorstelling kon wees van die inplantingsproses, waar word dit ingeplant, hoe word dit ingeplant. Jy wou graag kontak met ander ouers gehad het. En jy voel dit sal dit sal baie help as daar 'n lys is wat al die areas van inligting en ondersteuning kan gee sodat jy om te weet waar is 'n area waarvan jy nog wil weet aangesien nie alle ouers toegang het tot die internet nie. Die ander aspek wat vir jou belangrik is, is die kommunikasie wat die inplantingspan moet hê. En die finansiële implikasies....**

Ouer D: Ja, hoekom is daar so groot gaping tussen wat mediese fondse betaal en wat 'n kogleêre inplanting se koste. Hoekom is daar so groot gaping?

**I: (Ouer se naam) is daar nog iets wat jy wil byvoeg?**

Ouer D: Wat ek ook graag wil verstaan maar dit is nou meer na die kogleêre inplanting is die mappings. Dit is baie onduidelik. Ek weet nou van die dinamiese gebied en daardie goed maar die mappings die verstellings rondom dit, dit is nog iets wat ons nie lekker verstaan wat gebeur met die mappings nie.

**I: Mens kan dalk voor die inplanting ouer ook daarvoor inlig en op die rekenaar wys hoe dit lyk.**



Ouer D: Ja en dat hulle weet dit is nie 'n gewone....soos oudiogramme nie. Jy weet dit is nog vreemde verskynsels vir ons.

**I: Ja dit is baie belangrik. Nog iets...**

Ouer D: Ilouise ek dink dit is dit. Dalk bel ek jou nog met iets. Ek dink dit som goed op wat ek vir jou wou sê.

**I: Doodreg. Baie dankie.**

## **Onderhoud 5 met ouer E.**

### **I: (Ouer se naam) vertel vir my hoe het julle uitgevind (kind se naam) het ‘n gehoorverlies?**

Ouer E: Sy was by my ma gewees en toe sit sy so voor die kar, net so entjie weg van die kar af. En haar pa druk die hooter van die kar en sy kyk net voor haar en sy kyk nie agter toe nie toe kom ons agter. Maar net so rukkies voor dit, toe sê my man vir my maar die kind kan nie hoor nie. En toe druk hy die hooter daardie dag toe sien ons maar sy kan regtig nie hoor nie, want jy weet ‘n hooter is hard en sy skrik nie eers nie. Sy was omtrent ‘n jaar oud.

### **I: Hoe het julle toe gehoor van ‘n kogleêre inplanting?**

Ouer E: Kyk ons mos eers by (oudioloog se naam) vir die gehoorapparate. En toe het ons by Prof. Claassen geloop en hulle het ons vertel van ‘n kogleêre inplanting en vir ons gevra of stel ons nie belang nie.

### **I: Vertel vir my vandat julle uitgevind het van ‘n kogleêre inplanting totdat sy geïmplanteer is, wat was vir julle uitdagings in daardie tyd?**

Ouer E: Daardie tyd is dit maar oor die finansies. Want die finansies is altyd die belangrikste. Ons mos maar kyk waar ons die geld in die hande gaan kry om dit te finansier, die gedeelte wat die mediese fonds nie gaan betaal nie. Ek het gebel en ek het uitgevind by hulle, hoeveel gaan hulle vir my gee vir die kogleêre inplanting want ons mos nou so R20 000 in die hande kry vir die inplanting. So dit was nogal bietjie ‘n uitdaging!

### **I: Nog iets wat jy kan onthou van daardie tyd....**

Ouer E: Kyk ‘n mens is altyd maar bietjie skepties aan die begin as jy hoor van hierdie inplantings en goed en jy wonder net hoe gaan dit vir jou werk en ons het maar net besluit ons doen dit vir haar, sodat sy ‘n beter gehoor kan hê.

### **I: (Ouer se naam), daardie tyd voor die inplanting wat wou jy alles weet? Wat was vir jou belangrik om te weet?**

Ouer E: Ek wou weet gaan dit werk? ‘n Mens moet altyd wonder. Is dit iets wat gaan werk? En in die lang termyn hoe gaan dit vir haar werk? Want voor die inplanting kon sy mos nie goed hoor nie en sy het die een gehoorapparaat in die linkeroor gehad maar dit het nog steeds nie gehelp nie en sy het nog steeds nie goed gehoor daarmee nie. So ons het maar besluit ons gaan voort met die inplantering sodat sy ‘n beter lewe kan hê.

### **I: So julle wou weet of dit regtig gaan werk. Nog iets oor watter inligting julle wou gehad het voor die tyd...**

Ouer E: Ek moet nou hard dink. Ek kan nie praat oor die finansies nie, want die medies het my baie gehelp. Ons wou geweet het of die kinders wat daar is, hoe vorder hulle op die kogleêre inplantings. Want kyk mens moet altyd weet. Al het ons nou nie iemand gesien wat dit gedra het nie, wou ons altyd weet hoe vorder die kinders wat dit het. Want kyk dit is ‘n nuwe ding, dit was vir ons iets nuuts om te weet van kogleêre inplanting af. So ons wou net weet hoe vorder ‘n kind wat ‘n kogleêre inplanting het.

### **I: Dit maak sin. (Ouer se naam) wat van ondersteuning? Watter ondersteuning wou julle gehad het?**

Ouer E: Ai ek kan nie onthou wat het daardie tyd gebeur nie. Alles het vir my so vinnig gegaan. (Lag). Dit het alles so vinnig gegaan. ‘n Mens moet darem weet daar is mense wat omgee. As jy nie iemand het wat omgee nie, wat vir jou kan bystaan in so proses nie, dan gaan dit ook nie ‘n maklike proses wees nie. Ons het nogal goeie ondersteuning gekry.



**I: Watter tipe ondersteuning het jy gekry wat jy gevoel het, is goed? Wat het jy gesien as ondersteuning?**

Ouer E: Kyk soos by die kleuterskool, mense het jou aangemoedig, haar kleuterskool, nee julle moet maar gaan daarvoor. Want sy was daardie tyd nog nie daar nie, ek het net gegaan vir ouerleiding. En toe ek vir hulle vertel van die kogleêre inplanting en alles toe sê hulle vir my nee julle moet gaan want dit is 'n goeie ding. En dit is vir my goeie inligting as daar iemand is wat vir jou goeie inligting kan gee en vir jou kan sê gaan daarvoor jy sal nie spyt wees nie.

**I: So die kleuterskool het julle ondersteun en die ander personelede van die kogleêre span...**

Ouer E: Ja hulle het my ook ondersteun en vir my goeie inligting gegee. Ek onthou ek het nog 'n boekie gekry wat wys hoe lyk dit en om inligting te lees waaroor gaan dit alles.

**I: (Ouer se naam) as jy nou kan sê wat is die belangrikste inligting om vir ouers te gee voordat hulle kinders geïmplanteer word?**

Ouer E: Ouers moet net weet, verstaan jy dit wat jy doen, doen jy vir die toekoms van jou kind. Want ons is mos nie altyd by onse kinders nie, jy kan nie jou kind net so los nie. Sy moet nog groot raak en sy gaan nog eendag trou en so dit wat jy nou doen, is vir jou kind se toekoms. Dit is nie vir, ek moet nou geld uithaal, verstaan jy? Jy kry mense wat sê ek het net nie die geld daarvoor nie. Waar moet ek nou geld kry? Want dit is baie geld om nou uit te haal, maar daardie geld wat jy gaan uithaal is vir die toekoms van jou kind. So dink daarvoor, praat daarvoor met jou familie of jou kollegas, mense wat jy mee saamwerk. Doen dit, dit is vir jou kind.

**I: En ondersteuning? Wat dink jy is die belangrikste vorm van ondersteuning wat ouers nodig het voordat hulle kinders 'n kogleêre inplanting kry?**

Ouer E: Kyk die span wat met jou kind werk, soos die dokters, die spraakterapeute as hulle jou kan goed ondersteun soos wat hulle gedoen het, gee vir ons inligting en praat daarvoor of sê vir jou ek weet van kinders wat dit gehad het en hoe vorder hulle daarop. Dit is goeie ondersteuning. Dit laat 'n mens nogal dink. 'n Mens dink baie voordat jy 'n kogleêre inplanting kry. Kyk, hulle het mos vir my mooi verduidelik hoe gaan hulle dit doen. Ons sny hier oop en sit hom daar in. Want dan weet jy ten minste wat gaan gebeur. 'n Mens is voorbereid daarop.

**I: En jy voel daardie goed help jou om dit goed te hanteer...**

Ouer E: Ja om dit goed te hanteer en dit maak dit dan makliker vir jou. Dit is beter is as die kind klein is, ek weet nou nie as die kind groot is nie. Maar dit is beter as hulle klein is hulle aanvaar dit dan makliker.

**I: (Ouer se naam) wat sal jy sê vir die kogleêre span, hoe kan hulle nog meer effektief bystaan met ondersteuning en inligting?**

Ouer E: Party van die ouers wat miskien bietjie negatief kan wees, dit is nie almal wat positief gaan wees nie. Jy kry mense wat nogal negatief kan wees. Soos ouers wat dit moeilik het met finansies so probeer maar om te help waar julle kan, verstaan jy? Want ek onthou ek was daar by Prof. Claassen se spreekkamer toe is daar ouers wie se mediese fonds nie so baie uitgehaal het soos myne nie. Hulle wou amper nie eers die helfte uitgehaal het nie. Toe dink ek nogal dit is sleg. Jy dink as ek maar die geld gehad het, het ek maar solank gehelp bydrae maar jy het nie daardie finansies self nie. Maar jy dink as jy die finansies gehad het dan het jy daardie een gehelp bystaan. Miskien kan hulle, hoe sê mens, dalk hulpfondse kry om daardie ouers by te staan wat nou nie het nie.

**I: Hoe sal jy daarvoor voel as ouers kan kies watter inligting en ondersteuning hulle wil hê? En hoeveel inligting wil hulle hê? En watter tipe inligting wil hulle hê?**

Ouer E: Ja, ek weet nie. Ek het nie eers nodig gehad om te kies nie, want die inligting is vir my gegee. En dit was vir my voldoende gewees. Vir my was dit voldoende, die inligting wat ek gehad het en die ondersteuning wat ek gekry het, was vir my voldoende.

**I: So jy wou nie meer geweet het van iets? Noudat sy klaar geinplanteer is, het jy nog nooit gedink shoe ek wens ek het dit voor die tyd geweet?**

Ouer E: Kyk ek het, dit was in daardie tyd toe lees ek 'n tydskrif van 'n meisie. Sy was seker so 18 of so wat 'n inplanting gehad het, maar sy was 'n ballerina. So sy het vir die eerste keer het dat sy 'n inplanting gehad het en sy het nou vertel wat gebeur. En sy het nou gesê dit was vir haar so goed toe sy haar ma gehoor lag het. En dit is wat sy nooit geweet het nie, sy het nooit geweet hoe lag haar ma nie, hoe klink dit as haar ma lag nie. En dit was vir haar goed om dit te weet. Toe dink ek maar as iemand wat so groot is al, want sy was nou al 'n tiener, as iemand wat so groot is al dit kan ervaar dan kan my kind ook iets goed kry daardeur. Dit was nou voordat sy geinplanteer is, toe lees ek daardie stuk van die meisie. En dit het my baie gehelp. Dit is vir my goed, ek lees tydskrifte en soms kom jy op goed af wat jou help.

**I: Ja, jy weet sê nou maar jy kon gesê het, het julle nie dalk vir my 'n artikels oor mense wat dit al self ervaar het...**

Ouer E: Ek het nou nie daardie tyd daaraan gedink nie. Ek het dit nou maar voor daardie tyd raak geles. En dit het my gehelp.

**I: Miskien kan mens dit ook vir ouers gee...**

Ouer E: Ja 'n mens kan dit ook vir ouers gee om te lees. Dat hulle dit darem weet watter ervaring is dit vir iemand wat nie kon gehoor het as hy 'n inplanting kry. Want kyk sy was nou al 'n groot meisie.

**I: Goed dit is baie interessant. (Ouer se naam) as jy nou kan opsom, wat jy gesê het, op die einde van die dag, wat dink jy is die belangrikste inligting en ondersteuning om vir ouers te gee?**

Ouer E: Die inligting van daardie kogleêr, daardie boekie. Want dan weet hulle ten minste hoe lyk dit, waar sit hulle dit in. Sodat jy nie net 'n vae idee het van hoe dit lyk nie. Dat jy 'n inligting stuk het dat dit ten minste vir jou goed kan wees en vir jou vir jou hulp is om jou by te staan. Dat jy weet hoe lyk dit en waar gaan dit in.

**I: As ek kan opsom wat jy alles gesê het. Die finansies wat vir julle 'n groot ding. En julle wou weet wat kos dit, die inligting wat julle wou gehad het, was hoe werk dit waar word hy ingesit, daardie tipe inligting. En ook inligting oor die finansiële implikasies, mediese fondse ens. Julle voel julle het genoeg ondersteuning gekry dat mense na julle geluister het, verduidelik het en gesê het dit was die regte ding om te doen vir julle kind. Jy voel dit sal goed wees as ouers mooi gewys word waar word dit ingesit en as ouers finansiële ondersteuning ook kan kry as dit 'n probleem is. En dalk artikels van mense wat self 'n kogleêre inplanting gekry het, voel jy is dalk goeie inligting vir ouers om te lees. Het ek alles reg opgesom?**

Ouer E: Ja.

**I: Is daar nog iets wat jy wil byvoeg?**

Ouer E: Ek kan nie nou aan iets dink nie.

**I: Baie dankie. Dit is heeltemal reg.**



## **Onderhoud 6 met ouer F.**

### **I: Sê vir my hoe het julle uitgevind dat (kind se naam) 'n gehoorverlies het?**

Ouer F: Ons het maar net gesien hy reageer nie. As ons praat of iets val het hy nie omgekyk of gereageer nie.

### **I: Hoe het julle toe gehoor van 'n kogleêre inplanting?**

Ouer F: Ons het hom getoets by (oudioloog se naam) en hy het ons vertel.

### **I: En toe is julle verwys...**

Ouer F: Ja eers na Prof. Claassen toe, toe na (spraakterapeut se naam).

### **I: (Ouer se naam) as jy nou kan onthou vandat jy uitgevind het van 'n kogleêre inplanting totdat hy geïmplanteer is, in daardie besluitnemings proses wat was vir jou moeilik of uitdagings?**

Ouer F: Definitief die finansies. Jy weet nou jou kind is gehoorgestremd waar gaan jy nou die geld kry? Dit is maar net 'n groot aanpassing en 'n skok om te verwerk. Dit was maar definitief waar gaan jy nou die geld kry daarvoor. Want almal het dadelik vir jou gesê dit is baie geld. En dan hoop jy maar en dan sê hulle vir jou dit is ook maar 'n risiko deur al hierdie toetse en goed waardeur jy moet gaan. Jy weet nie gaan hy reg wees nie. Jy weet daardie MR toetse en goed. Dit was nogal nie lekker nie. So dit was nogal baie stres gewees. Want jy hoor nou van hierdie wonderlike ding, maar nou wonder jy gaan my kind nou reg wees vir hierdie ding? Gaan hy dit kan kry?

### **I: As jy nou terug dink aan daardie tyd wat jy en jou man weet? Watter inligting het julle nodig gehad?**

Ouer F: Ons wou geweet het hoe werk die ding. Hoe werk dit? Ons het nog glad nie, ons het nog nooit daarvan gehoor eers nie. Ons het nie eers geweet jy kan 'n gehoorgestremde kind help met dit nie. So hoe werk dit? Ons was nogal bekommerd oor ok dit werk nou maar wat van sy toekoms? Gaan hy 'n normale lewe kan hê? Gaan hy moet handgebare gebruik? So ons het eintlik meer gewonder: Gaan dit vir hom werk? Hoe gaan sy toekoms lyk? Dit was nogal die grootste vir ons.

### **I: Goed. En ondersteuning? Watter behoefte het julle gehad aan ondersteuning?**

Ouer F: Ons het eintlik goeie ondersteuning gekry van almal af. Ja, eintlik kan ek nie sê nie, want almal het van die begin af. Almal was baie sensitief en het gehelp. Familie het ons nogal baie gehelp. Familie ondersteuning was nogal vir ons baie belangrik. Gelukkig almal is baie close en so dit het baie gehelp. Al wat eintlik vir ons nie lekker was nie, ek het eers na die tyd uitgevind daar is verskillende tipes inplantings. En die Medel is dadelik vir ons.... jy weet ons gaan nou met Medel werk en jy gaan hierdie apparaat kry en ek het nie geweet voordat ek op die internet gegaan het daar is 'n verskeidenheid nie. Ek weet nou nog nie eintlik wat is die ander nie.

### **I: Ja so jy wou ten minste geweet het van daardie opsies. En (ouer se naam) as jy nou kan sê wat dink jy is die heel belangrikste inligting om vir ouers te gee voordat hulle kind 'n kogleêre inplanting kry. Wat sal jy sê?**

Ouer F: Definitief vir hulle vertel van na die tyd die finansiële koste daaraan verbonde. Die batterytjies wat gekoop moet word, die draadjies en goed wat in stand gehou moet word. Want dit is nogal redelik baie. En dan die, seker nie almal het dit nodig nie maar dan die mediese onkoste, arbeidsterapie, spraakterapie en as daar iets ander bykom. Want al daardie goed dit is ook nogal belangrik. As hulle net daarvoor ook meer kan uitbrei want ons het nou maar dit so stap vir stap gevat. Jy hoor mos die ding is 'n vreeslike duur ding en jy weet die operasie kos baie en op daardie stadium is jy eintlik meer net



gefokus op ek wil my kind laat hoor. So hulle kon dit dalk gesê het maar dit het verby gegaan. Maar na die tyd het ons nie eintlik weer daarvoor gepraat nie. Dit het maar so opgekom. Nou het my apparaat gebreek, wat nou? Nou moet jy 'n kabeltjie kry van R500 of wat ook al en jy weet ons het nou nie, ons was nie voorbereid gewees daarop nie.

**I: Ja. En ondersteuning? Wat dink jy is die belangrikste ondersteuning om vir ouers te gee voordat hulle kind geïmplanteer word?**

Ouer F: Om definitief bystaan. Vir ons, wat vir ons nogal lekker was, was dit hulle vir ons stap vir stap verduidelik het, die prosedure en wat gaan gebeur. Ons was nogal gelukkig met dit. Ons het vir (ander kind met kogleëre inplanting se naam) gesien, met sy aanskakeling. Ons het gevoel ons kind is darm nie die enigste een in Bloemfontein wat hier is nie. Dit was lekker om te sien sy vorder. Jy weet sy kan al mooi praat. Jy weet sy is eintlik doof maar hier praat sy. Dit was nogal motiveerend gewees.

**I: Dit is belangrik. (Ouer se naam) as jy nou kan raad gee vir die kogleëre span. Hoe dink jy kan die kogleëre span ouers meer effektief bystaan met inligting en ondersteuning?**

Ouer F: Ek dink as hulle dalk 'n groep kan maak of stig. 'n Ondersteuningsgroep vir die ouers. Jy weet dat hulle bymekaar kan kom en dat hulle vir mekaar kan vertel my kind het dit so ervaar of ons het dit so ervaar. En die een sê ons het weer so ervaar. Dan is jy bietjie meer voorbereid op die ding. Wat vir jou wag en hoe dit gaan wees na die tyd.

**I: Goed. Hoe sal jy daarvoor voel as ouer 'n keuse kan kry oor die hoeveelheid inligting en tipe inligting en ondersteuning wat hulle kan kry voor 'n kogleëre inplanting?**

Ouer F: Sê gou weer....

**I: Wat dink jy sal die effek wees of hoe sal jy daarvoor voel as ouers kan kies oor watter inligting en watter ondersteuning hulle kan kry voor die inplanting?**

Ouer F: Dit is nogal lekker as jy weet of die ding vir jou kind gaan werk. Maar jy kan dit nie voor die tyd sê nie. Maar as jy dalk bietjie inligting daarvoor kan kry. En dan definitief dan finansiële inligting kan kry. Te sê ok, om die geld bymekaar te maak, julle kan sê nou maar 'n insamelingsdag hou of daarmee help. Jy weet waar kom die geld vandaan? As jy nie 'n tweede verband op jou huis kan kry nie of iemand nie die geld kan skenk nie waar hoe anders gaan jy dan heen?

**I: So bietjie inligting oor hulpbronne en fonds insamelings....**

Ouer F: Ja sulke tipe goed as die ouers nie kan nie. Want waarnatoe gaan hulle dan? Help planne maak want jy sit nou met hierdie groot ding, my kind gaan kan hoor maar ek het nou R200 000 nodig daarvoor. Mediese fondse betaal onsettend min, hulle het vir ons R100 000 gegee en die res moes ons nou self bymekaar maak.

**I: Ja en dit is nogal 'n aansienlike bedrag. Van alles wat ons nou bespreek het, as jy kan sê wat dink jy op die ou einde is ouers se grootste behoefte aan inligting en ondersteuning voor 'n inplanting?**

Ouer F: Definitief van hoe dit werk en hulle het vir jou verduidelik en jy kry die ou boekies maar dit verduidelik nie so goed nie. Wat ek maar gedoen het as ek gewonder oor goed het ek maar op die internet gegaan en bietjie gaan soek daar. Daar het ek nogal baie oulike goed gekry. Testimonials en sulke goed.

**I: So jy dink dit sal dalk help as mens internet websites vir ouer kan gee...**

Ouer F: Ja kan bygee. Ja dit sal. Dit is maar wat ek gaan doen het. Ek het maar gaan Google en ingesit: kogleêr. En dit is maar waar ek die meeste inligting gekry het. Wat is dit? Hulle verduidelik vir jou en sê, maar dit is groot woorde en dit kom in en gaan uit want jy luister nie, want jy ly nog aan skok. Dit is nogal lekker op jou eie as jy by die huis kom dan het jy bietjie die agtergrond en dan lees ek en jy het nou maar die boekies gelees maar dit is ook maar, daar is 'n video, die video het nogal gehelp. Ek kan dit sê. Daardie een van Medel self. Maar definitief die internet websites adresse en so.

**I: So (ouer se naam) as ek nou kan opsom. Julle grootste behoefte was dat julle wou weet oor die finansiële implikasies. Die operasie self en die apparaat maar ook die finansiële implikasies na die tyd vir onderhoud en instandhouding en julle wou geweet het hoe dit werk. Julle wou verdure bronne van inligting gehad het soos websites wat mens na kan gaan kyk. En wat ondersteuning betref, dink jy dit sal goed wees as ouers as 'n groep kan sien wat almal se ervarings is. Dink jy ek het alles reg opgesom?**

Ouer F: Ja.

**I: Is daar nog iets wat jy wil byvoeg?**

Ouer F: Nee, ek dink dit is reg.

**I: Dit is dan goed so. Baie dankie.**



## Onderhoud 6 met ouer G

### **I: (Ouer se naam) vertel vir my hoe het julle uitgevind sy het 'n gehoorverlies?**

Ouer G: My ouers het by my gewoon en ouma het agter gekom, want sy het na haar gekyk en sy agtergekom (kind se naam) slaap deur geraas. Honde wat blaf, ons hondjies hierso en toe sien sy daar is iets fout. My man het ook agtergekom daar is fout. Nie noodwendig haar naam geroep nie maar gesien sy draai nie haar kop 'n klank of 'n geluid toe nie.

### **I: En hoe het julle toe gehoor van 'n kogleêre inplanting as 'n opsie?**

Ouer G: Na ek gehoor het my kind is doof, moes ek uitvind wat is 'n opsie, wat nou? Om haar lewenskwaliteit te gee. Moet daar iets wees? Hierdie opsie kom toe maar dat 'n kogleêre inplanting is een van die beste tegnologie wat gevorder het kom ons kyk of is sy 'n kandidaat.

### **I: Het julle by die oudioloog gehoor wat julle toe verwys het?**

Ouer G: Ja, kyk wat gebeur het. Ek was van die begin wat die goed begin het met (kind se naam) by Universitas Hospitaal ingeskakel. So toe ons by (oudioloog se naam) hoor sy is doof, want hy het toetse op haar gedoen. Ons is toe na (ONK se naam) toe vir pypies in die ore en ons het gehoor ons gaan 'n kind terugkry wat gaan hoor en daar het niks gebeur nie. Daar het geen gom uit haar ore geloop nie. Ek is weer terug by (oudioloog se naam) vir 'n check-up en toe sê hy vir my hier is groot fout. Want volgens die toets wat hy op haar doen kom daar nie klankgolwe terug nie. En hy verwys my toe na Universitas Hospitaal toe vir 'n BERA toets, dit is daardie toets in die vertrekke wat hulle haar laat slaap en dan daardie goetertjies opsit. Daar het my tyd met (kind se naam) begin. In die kamertjie en dit was in 2004. Dit was die BERA toets om te bepaal hoeveel is sy doof.

### **I: Vertel vir my, vandat jy gehoor het dit is 'n opsie totdat sy geinplanteer is, daardie tyd, wat het jy beskou as uitdagings in daardie tyd?**

Ouer G: Vandat ek gehoor het dit is 'n opsie was ek baie opgewonde. Ek het net besef ek kan my kind kwaliteit, lewenskwaliteit teruggee. Sy kan hoor 'n voëltjie fluit, sy kan ons stemme hoor, sy kan begin praat. Want ek het besef sy kan nie andersins aangaan nie. Dan stel hulle ook eintlik weer gehoorstukke voor, voor die inplanting. Dit was ook 'n proses met my, dit het nie die ding gedoen nie. Ons het nie die effek gekry nie. Toe moes sy gaan toets word vir die inplanting, want jy moet 'n senuwee hê om die inplanting suksesvol te kan maak, om 'n kandidaat te kan wees. En ons het deur daardie drom gegaan en al die toetse gedoen en Prof. het gesê sy is verseker 'n kandidaat. Haar senuwee is daar ons kan die dinge doen.

### **I: Wat was vir jou in daardie besluitnemingsproses vir jou moeilik?**

Ouer G: Nou moet ons gaan kyk vir befondsing om hierdie ding nou moontlik te maak wat nou moet gebeur. Mediese fondse dek nie noodwendig al hierdie goed nie. Discovery weet ek gee R80 000 maar ons is nie by Discovery daardie tyd nie. Ons is by MediPos toe ek nog by die Poskantoor gewerk het en Old Mutual gewees die Mediese fonds. Ek het hulle gekontak en ek moes vir hulle 'n motivering deurstuur van al die dokters sodat hulle kan sien sy is 'n kandidaat en dit is nie 'n lewensgevaarlike siekte nie maar ek voel hulle moet dit oorweeg om haar te help. En na knie deur gebid en absoluut hoe ek die Here vertrou het hulle my eendag gebel, 'n paar maande na hierdie situasie en vir my gesê hulle



gaan betaal. So dit was vir ons 'n baie goeie tyd in ons lewe om te besef ok, hier het ons dit nou, ons moes 'n bedrag inbetaal. Miskien R10000. Die res het hulle alles gedra. En voordat hulle 'n inplanting doen, moet hulle alreeds daardie go ahead kry van jou mediese fonds. Mens moet mooi kyk met die finansies. Want mens is bekommerd heeltyd as 'n ouer en voordat hulle die switch on kan doen na die inplanting moet dit heeltemal betaal wees. Want daardie inplanting kom van Duitsland of waar ook al hulle dit vanaf kry. Wat vir my baie sleg was, in ons situasie met (kind se naam)...hulle het toe weer 'n toets gedoen op haar net om te kyk voor die inplanting geskeduleer is, om te kyk na die overall ....om te kyk watter kant mos nou die ding doen want hulle probeer altyd mos regs sodat dit linksom jou brein se funksie werk andersom met jou spraak en jou taal. Toe het hulle die regterkant besluit op haar ook. Toe sê hulle daar is abnormaliteite binne haar ore en ek en my man skrik toe en vra wat is dit nou? Sê toe nee dit kan dalk van die uitgehaal met 'n instrument, daar is fout daar. Almal het daardie opening in jou binne oor maar hare is net groter as normaalweg. En toe sê dr. en prof. Sjoë die bal is nou in ons hande. As hulle sou deur boor en die coil deursteek kan daar vog opgaan en sy kan baie nuwe-effekte daarna hê bv. sy kan verlam wees as daardie goed nie reg loop nie. Maar as dit van hulle afhang is dit die beste om 'n kind 'n kans te gee. So ons moet maar gaan besluit wat ons wil doen, wil ons aangaan of nie? Jitte en ek en my man was vir 'n hele ruk stil gewees rondom dit want wat as iets fout loop? Wat dan hou? Dan vat ons haar doof en klaar. My man was nogal baie teengekant teen hierdie inplanting, hy wou nie hy het my gelos dat ek aangaan. Nou nog doen ek maar my eie dinge, nou nog persoon wat, ek het natuurlik baie ondersteuning van hom en hy is baie lief vir my dogtertjie. Al wat hy vandag sê is as sy doof is dan is sy doof. Want as jy die inplanting kry en jy haal hom af met badtyd en swem tyd, daardie kind is doof. So jy moet as ouer ook nog 'n alternatief kry om met jou kind te kommunikeer as daardie ding sou af wees. Maar in elk geval om terug te kom. Ons het besluit ons het 'n groen lig gekry vir die inplanting. Die fonds gaan betaal ons gaan dit doen. As die Here ons tot hier gebring het, sal hy ons nie in die steek laat nie. En ja met die operasie het Prof. gesê die vog het opgestyg en net soos wat dit gekom het, het dit gegaan. En ja sy is toe nou ingeplant en dit is aangeskakel. Ons ondervinding met die inplanting was natuurlik, dit was nie goed nie. Hulle na die inplanting weer x-strale geneem rondom (kind se naam) om presies te weet wat waar draai die elektrode in die koglea, wat mos soos 'n slakkie lyk, toe sien hulle oops, daardie opening, het daardie elektrodes buite gaan draai. Sy het dus nie die volle effektiwiteit om met 12 elektrodes gestimuleer geseën te wees het nie, nou is daar 7 op die oomblik wat aangeskakel is. Nou ja dit is nie bilateraal nie, dit is net die eenkant. Ons voel nie nou op die oomblik om die ander kant te doen nie. Omdat ons nie gekry het wat ons nie moes kry in ons situasie nie. En vir ons is gesê met hierdie 7 kan 'n mens ook werk. Ek wil net sê iets is daar definitief. Daar is geluide. As jy haar naam sê hoor sy miskien net die klinkers. So dit is moeilik vir taal daarom kon ons nog nooit vasstel wat beteken dit vir haar werklik hierdie inplanting nie.

**I: (Ouer se naam), sê vir my voor die inplanting, watter inligting wou jy en (man se naam) gehad het? Wat wou julle weet?**

Ouer G: Dit wat met ons meegedeel is, was vir my genoeg. Ek het besef wat dit behels en waarom dit gaan. Bv. jy moet dit afhaal wanneer jy dit moet afhaal. Medel het vir ons 'n boekie gegee met al die inligting rondom die inplanting. En die spraakterapeut het ons ook ingelig rondom hierdie inplanting. Maar daar is vir ons gesê dit word gedoen deur die dokter ingeplant maar daarna is dit die spraakterapeut se verantwoordelikheid om verdure levels te neem. So die dokter het nou gedoen wat hy kon en alles en nou is dit die spraakterapeut se verantwoordelikheid. So ek kon nooit teruggaan na die dokter toe en sê maar, dit of dit of so of wat nie. So hulle doen hierdie ding en gooi dit terug na die terapeute toe. Vir my voel dit hulle verwag miracles van hierdie terapeute. Nou kry hierdie outjies nie die effektiwiteit van dit wat mos gebeur het nie, vir hulle is dit nie effektief nie, na hulle moet ook gekyk word want wat gaan nou hier aan. Dit word nooit oor gepraat nie. Dit is waarmee ek swaarkry.

In my hart het uitgegaan na hierdie kant toe na die rehab na hierdie ding. Dit kom nie net neer op 'n terapeut nie. Dan moet dit weer ingeroep word saam met dokter, dan moet mens praat dan moet dit vir mens pertinent gesê word nou kan hulle ook nie doen wat hulle doen was dit nie effektief was nie. So hulle doen ook nou wat hulle kan, so dit was vir my sleg.

**I: So jy voel jy het goeie inligting gekry....**

Ouer G: Ek dink tog so. Wat ek gedoen het natuurlik, ek het op die internet gegaan. En ek het baie getuïenisse van ouers gaan trek. En ek het alles opgeswot wat ek kon leer oor kogleëre inplanting so ek het myself dit gaan doen. Ek het net 'n bietjie gekry, die ou boekie, klein ou boekie met paar prentjies. Maar ek toe self gaan navorsing doen. Ek dink ek kon in 'n stadium self die inplanting doen soos wat ek die goed opgeswot het. So ek het getuïenisse gaan luister, ek onthou die ou dogtertjie wat haar ma gesê het: " My child had a chance now to listen." So dit op die internet was absoluut net goeie dinge. Die gevalle wat nie gewerk het nie, was nie daar nie. Maar ek wou dit nie luister nie. So ek dink 'n ou moet eers by daardie situasie kom. Dan begin 'n ou kyk maar 'n ou wil net hierdie positiewe kant van hierdie inplanting kry.

**I: En ondersteuning (ouer se naam)? Sê vir my watter behoefte het jy gehad aan ondersteuning voor die inplanting?**

Ouer G: Miskien om met ouers te praat wat fisies wat hierdie ding al deurgegaan het. Om te sê dit gaan goed met my kleintjie. Of dit is nie eintlik hoe ek dit wil hê nie maar dan weet 'n mens ten minste wat om te verwag. So daar is 'n moontlikheid dat dinge nie gaan volgens plan nie of dit kan briljant gaan. Dit is sleg om na die tyd ouers raak te loop hier en daar by 'n winkel of plek wat sê my kind, dit gaan so goed met my kind en jy het die teenoorgestelde. Dit was vir my baie swaar. Ek moes ook deur dit werk. Om nou te sê: Wat nou? Ek het gedoen dit wat ek gedink het menslik moontlik was as 'n ouer om te doen en nou? So dan het 'n mens ook ondersteuning nodig. Ook van daardie persoon vir wie se kind dit gewerk het. Om te sê maar daar bly hoop want daar is altyd hoop. En vandag nog, hier waar ek sit, is daar nog steeds hoop vir (kind se naam). Hulle het vir my gesê ons moet eers net vir (kind se naam) kry sodat sy in 'n skool opset kom en kan leer, dan gaan ons hom weer opsit. Ons gaan hom vat want ons wil hom hê en die ander oortjie gaan ons kyk na 'n gehoorstukkie weer. So mamma jy moet hom saambring, want op die oomblik is hy hier in die kas. Ek het hom nie saamgevat nie. Want dit nie belangrik op hierdie oomblik vir ons belangrik in (kind se naam) se lewe nie, sy het eers ander goed, haar gedrag, om aan te werk. Totdat dit in plek kom, dan gaan sit ons hom weer in. Want dit is die voordeel van die inplanting, jy het hom altyd. Al moet hy permanent op en stimuleer, sy wil nie op die oomblik dra nie. Dit is maar ons situasie. Maar daar is altyd hoop, al is daar net 7 elektrodes aan.

**I: Wat dink jy is die belangrikste inligting om vir ouers te gee voordat hulle kinders geïnplanteer word? Wat moet hulle weet?**

Ouer G: Dat dit ook nie kan werk nie. Want ek het regtig hierdie hoop gehad. Ek het dit regtig met my hele hart gehad en in my geval, toe was dit nie hoe dit moes wees nie. En dit was vir my bitter swaar. En ek het ook hierdie gedagte gehad gaan julle aangaan met hierdie ding of gaan julle nie. Dit is nie vir my gesê dit kan werk of dit kan nie werk nie. Dit was net gaan ons die kans vat of gaan ons nie die kans vat nie. Maar ek het geglo, vat ek die kans dan is daar nog steeds 'n moontlikheid dat dit kan goed gaan. Mens moet dit maar op die tafel sit en as jou kind nou nie 'n abnormaliteit in die oortjies het nie dan, die dingetjie draai mooi en die goed is daar gaan dit tog ook nog tyd in beslag neem vir spraak terapie. Want daardie kind is reeds agter, so ek dink ons as ouers gaan in hierdie ding in onwetend, met baie hoop, baie. En dan sit jy later vir 2 of 3 jaar by spraakterapie en dan gebeur daar niks. En dit is vir my

hartseer. So ons moet besef, ons weet alle kinders is nie dieselfde nie. Hulle verskil individueel. Maar dat dit tog aan ons meegedeel word dat is hierdie negatiewe sy van hierdie hele proses ook. En ek weet ons wil graag en ek wou self die positief gesien het met my hele hart. En die dinge het ander uitgedraai vir my.

**I: En ondersteuning? Wat dink jy is die belangrikste vorm van ondersteuning om vir ouers te gee wat deur daardie besluitnemingsproses gaan?**

Ouer G: Weet jy daar moet verseker soos wat Medel vir ons gesê het hulle het 'n 24/7 ondersteuning wat die inplanting instrument aanbetref. Hulle beleid is nie langer as 24 uur sonder gehoor nie. Met ander woorde, sou jou coil stukkend gaan, sou iets gebeur vervang hulle dit binne 24 uur. Hulle stuur dit met courier dienste. Dit is hulle beleid rondom die instrument. Maar wat is hulle beleid rondom ons as ouers? Daar was nooit so iets nie, daar is nie so iets nie. En ek voel net soos wat hulle met 'n instrument kan sê daar is 24/7, moet daar 24/7 'n call centre, 'n call line wees. Ouers wat hierdie goed deurgegaan het daar moet hierdie ondersteuning, verseker moet dit daar wees. Ek moes een aand byvoorbeeld, my liggie het bly flikker van (kind se naam). In die begin is dit 'n vreeslike ding vir 'n ouer, jy is behep met hierdie inplanting en as iets net nie reg is nie dan is dit 'n vreeslike ding. Ek kon nie die spraakterapeut in die hande kry nie, hulle gee nie, kontak selfoonnummers en goed nie. Nie dat hulle sou omgee het as jy hulle gevra het nie maar jy is maar eintlik op jou eie geholpe. Al nommer wat jy gekry het van Medel is 'n Duitsland nommer. Ek bedoel regtig. Anyway dan bel jy die vrou wat nou vir Medel 'n rep was. Soms antwoord sy haar foon soms antwoord sy nie haar foon. Toe moes ek een van die mammas bel, wie se kind nou 'n paar maande voor myne ingeplant was. En ek het vir haar gevra op wat is jou dingetjie gestel? Want myne is op so. En toe kyk sy en sy verstaan my nie eintlik oor die foon nie en ek verstaan nou nie eintlik nie en luister dit is eintlik chaos. Chaos verby. Terrible. So ek het lanklaas gepraat van hierdie goed waarvan ek nou praat. Maar soos ek praat kom hierdie goed net terug en terug. En van hierdie goed is nie lekker memoirs nie van hierdie pad wat ek gestap het nie. So dit voel maar net asof jy ook maar net 'n proefkonyn was. Dit is gedoen en daar gaan jy ook maar weer. So dit is sleg. Dit was nie vir my 'n goeie tyd in my lewe rondom die inplanting nie.

**I: Dit is belangrik wat jy sê. As jy nou vir 'n kogleêre span kan raad gee. Hoe sou jy sê kan hulle ouers meer effektief bystaan met inligting en ondersteuning voor 'n inplanting?**

Ouer G: Weet jy, jy moet verseker as jy internet het en epos kan ontvang moet jy gedurig soos news headlines kry oor nuutste tegnologie. Verseker 'n call centre waar jy voor die tyd goed kan uitklare. Daar moet definitief 'n band wees tussen hierdie span. Ek meen ons belê baie in 'n inplanting. Dit is nie 1 of 2 rand nie, dit is duisende rande en dan verwag ons die na. Die na verkope diens. So kry jy dit by plekke, as jy 'n motor koop soek jy dit of wat ook al. Net so met hierdie ding. Dit was nie die geval nie. By hierdie maatskappy nie.

**I: So jy bedoel 'n mens moet nie net voor die tyd ouers inligting gee nie maar ook sê watter hulp is daar na die tyd.**

Ouer G: Die ouers van Duitsland van hierdie apparaat was in my sitkamer om vir my te kom sê dit werk nou nie eintlik soos dit moes nie. Maar hulle kon nie voor die tyd by my wees om vir my te sê dit is hoe dit gaan werk nie. So ek voel hoekom nou altyd eers na die tyd moet jy nou ....ek voel daar moet voorbereiding wees voordat sulke groot stappe in 'n kind se lewe of die ouers se lewe gebeur, moet daar voorbereiding wees on der andere van die kogleêre span af, met ander woorde of jy word gereeld gekontak en gesê Mev. jy is op die lys as 'n kandidaat vir 'n inplanting, is daar nog enige iets wat ons vir jou kan doen? Of is daar nog enige iets wat jy wil weet rondom dit wat nou met jou dogtertjie gaan gebeur? Rondom die operasie? Rondom die klank wat aangeskakel gaan word? Daardie goed moes ek maar op my eie uitvind. Wat gebeur



nou? Weet jy jy as ouer is eintlik heeltemal op jousef aangedrewe. Die terapeut wat my op daardie oomblik gehelp het, was goed ingelig in 'n mate, want sy het gereeld kontak met hulle. Maar die een keer 'n week wat ek haar gesien het, was dit terapie. So ek kon nie regtig klomp goed vra terwyl ons daar is vir terapie nie. As ek kan dink het ek dalk een of twee keer 'n afspraak gehad met haar oor die inplanting. Dan moet julle weet dit was in 2005 gewees ons is nou in 2009, so dit is vier jaar gelede so ek kan nie in spesifieke detail onthou nie, maar ek weet spesifiek sy het dit met my bietjie deurgegaan. Miskien vir 'n uur een middag en gesê dit is hoe dit gaan werk. Die klank gaan aanskakel na 'n maand dit gebeur dan so. So vir my was dit seker genoeg op daardie stadium ek het maar gedink dit is wat jy kry. Na die kogleëre inplanting na die plek hulle fondse gekry het...wat vir my baie sleg was dat daar is no switch on before the money is paid. Dit is vir my hartseer ook want ek bedoel hierdie inplanting, jy het dalk 'n groen lig gekry by jou mediese fonds en jy sal terugbetaal maar hulle sal nie aanskakel voor hierdie ding nie gebeur het nie. Jitte, dit was nie vir my 'n great manier om dit te stel nie. Dit was nogal vir my sleg. So hulle het daai maand na die operasie, het hulle my baie gedruk en bly sê ons hoor niks van jou fonds nie. Wel dan moet hulle ook eers wag voor dat hulle die geld kry en dan sê dit is betaal nou gebeur dit ten volle. Want weet jy hoeveel spanning het jy in daai tyd van jou lewe, jy kry die implantaat maar dit is nog nie uitgesorteer met jou mediese fonds nie, en hoe dit gaan wees nie en dan moet jy nog wonder gaan ek nou aangeskakel word of nie? So ek sê hulle moet alles hê, al die geld al vat dit dan nog 'n maand of twee langer vir die inplantingsproses. Dat al daai goed in plek is voor hierdie goed gebeur, want dit is traumaties genoeg. Ons ouers het nie nog krag vir hierdie goed nie wat nou gebeur nie.

**I: (Ouer se naam) hoe sal jy daarvoor voel as ouers eerder 'n keuse gegee word oor watter tipe en hoeveelheid inligting en ondersteuning hulle wil hê voor die inplanting?**

Ouer G: Dit is wonderlik, dan kan jy mos besluit party het nie 'n rekenaar nie, party het. So as jy een het, besluit op eposse gereeld of kontakte, sms'e. Ons het regtig tegnologie. So jy as ouer kan besluit wat jy wil hê. Wil jy 'n ondersteuningsgroep hê? Soek jy 'n call centre? Daar moet darm net vrye toegang wees as iets sou gebeur? Net 'n voorbeeld as jou inplanting klaar gedoen is en jy is by die huis, 'n Saterdagmiddag, met kuiermense en daar word gebrui en iets gebeur nou met hierdie inplanting. Dit is ver tot Maandag. Die ligging bly nou flits dit is nie batterye nie, dit lyk nie soos die coil nie. Wat gaan nou hier aan? Wat nou? Ek meen jou rep van die plek, daar is net een rep daar is nie 'n paar nie. Dit is net hierdie een spesifieke vrou wat in ons situasie by hierdie plek met dit gewerk het. Daar was geen ander antwoord nie, sy moes sit sonder klank tot die Maandag. Hoe werk hierdie goed dan nou? Dan is jy somer kwaad. Dan sê jy somer hulle het klaar die R300000 wat worry hulle nou oor jou? Jy moet maar net sien en kom klaar en cope. Ek gee regtig nie om nie, jy kan maar tik, my kommentaar is nogal negatief en dit is vir my baie sleg en ek wil nie mense se name noem en plekke en die plek wat dit gedoen het nie. Ek voel maar net dalk het ek voor gegaan om dit deur te gee om meer 'n spektrum te kry rondom hierdie ding, en om dit beter te maak en vir ander ouers. Om net te hoor jou kind is doof is baie, baie erg. En dan is dit 'n pad om te loop en dan is die goed dan ook, die inplanting...die inligting rondom dit. Ek moes self die goed gaan trek het van die internet af om te gaan op swot wat gaan nou hier aan. Hoe werk hierdie dinge? So dit is nogal goed as ons as ouers kan kies wat ons dan wil hê, dat daar vir ons verskeie keuses is rondom inligting vooraf en na die tyd wat die inplanting aanbetref.

**I: Goed. Sê vir my (ouer se naam), van alles wat jy nou gesê het, wat dink jy op die ou einde, is die belangrikste inligting en ondersteuning om vir ouers te gee?**

Ouer G: Definitief spraakterapie. Dit is 'n groot is 'n ding wat nou inkom met hierdie inplanting. Ek bedoel jy moet 'n professionele persoon hê wat jou kind regtig kan bystaan van die begin tot die einde. En nie net een maal 'n week vir 'n halfuur nie en huiswerk kry nie. Ons werk heeldag, ons kom regtig nie by hierdie goedjies uit nie. Wat dit aanbetref moet mens regtig kyk of jy gegear is as 'n inplantingspan om na jou spraakterapie span te beweeg en te kyk ons het op die oomblik het ons 5 kandidate vir inplanting vir hierdie maand, hoe lyk die terapie? Ek bedoel hierdie goed moet balanseer, hierdie skaal. Jy kan nie hierdie 10 inplantings hê by hierdie spesifieke hospitaal en jy het twee terapeute nie. Hoe werk hierdie goed? Dit is vir my baie belangrik so daarna moet die heelyd gekyk word. Hoe loop hierdie goed. So daarna moet die heelyd gekyk word. So as 'n inplanting span hulle identifiseer hierdie hospitaal vir die inplanting en waar dit gebeur, moet hulle gaan kyk waar, dan beteken dit die inplantingspan moet terapeute aanstel. As die instansie nie na hulle kan kyk nie. Want ons kan nie net met 'n halfuur 'n week...want ons verwag baie



meer van 'n kogleër as met 'n gehoorstukkjie. Ons verwag baie meer, as kinders wat dit moet kry en as ouers. Dit is verseker so. Hierdie is 'n heeltemal 'n ander wyer veld waarin ons beweeg met inplantings en dit is baie meer gevorderd ek het al baie meer positief gehoor van inplantings. So ons verwag 'n wye spektrum waar hulle ons kan help met hierdie pad wat ons nou beweeg. Want dit was 'n keuse wat ons moes maak rondom ons kind en dit was 'n groot besluit. Dit was nie net 'n gehoorstukkjie nie, dit was veel meer. En ons verwag ook veel meer van ons inplantingspan.

**I: So as ek kan opsom alles wat jy gesê het wat vir jou belangrik is, jy sê dat die inligting wat jy voor die tyd gehad het, was vir jou voldoende in die sin dat jy het die boekie gekry, jy het geweet waarom dit gaan. Jy sal graag wou ander ouers ontmoet het wat daardeur gegaan het. Jy dink dit is belangrik om vir ouers nie net die rooskleurige prentjie die skep nie, maar ook vir hulle in te lig dat daar 'n kans is dat dit nie gaan werk nie en wat dan? En jy voel ook miskien sou dit goed gewees het as ouers kon kies oor watter inligting kon kry en dat jy dalk web adresse kon kry as jy verder wou lees. Dat iemand dit dalk vir jou kon gee. Met ondersteuning dink jy dit is baie belangrik dat ouers ook weet na die tyd weet wie om te bel as dit breek. Wie bel ek, waar bel ek, kan ek enige tyd bel? Wat is die nommers vir die hulp na die tyd? Sodat ouers dat ouers dit reeds weet voor die inplanting. En ek dink iets anders wat jy gesê het wat belangrik is, is hoe belangrik kommunikasie is. Tussen die spanlede met mekaar, dokters en terapeute dat hulle met mekaar kommunikeer oor pasiënte en kommunikasie met die ouer. Sodat daar gereeld interaksie en kommunikasie met die ouer is. Het ek dit reg opgesom?**

Ouer G: Ja het dit verseker reg opgesom. Ek sit nou skielik en dink terwyl jy praat, dink ek aan 'n ouer standby groep. Dat mens ouers kan identifiseer, sê nou maar 5 mammas. Sê nou maar die een week is die een mamma en 'n ander week is 'n ander mamma beskikbaar met 'n standby nommer vir as ons nie kan ...en dit kan alleenlik gebeur as jy in 'n ondersteuningsgroep is. So ons moet nou eers begin beweeg na hierdie tipe groep toe. En daaruit identifiseer ons standby ouers. So vanaand kan hulle vir (ouer se naam) bel en dat hulle my kan bel en sê jy is nou op diens die week en ek het 'n probleem kan jy my nie kom help met my seuntjie se inplanting nie. So ek kan na jou toe ry. So ek is oop vir enige klagtes of probleme om te help in die aande. Ek kan nie verwag van spraakterapie om 24/7 te werk nie by my afdeling nie. So wat nou? Nou moet ons ander goed nie, ek kan nie Duitsland toe bel nie.

**I: Die belangrikste ding wat jy wil sê is jy moenie voel jy is alleen nie. Daar moet hulp beskikbaar wees...**

Ouer G: Ten alle tye as iets sou gebeur...

**I: So of dit deur 'n ouer is of 'n spraakterapeut of 'n dokter, jy sal iemand in die hande kry.**

Ouer G: Ja ek het een naweek was ek baie onsteld, 'n Vrydag middag toe dit nie werk soos dit moes nie. Ek kon niemand op daardie stadium in die hande kry nie en die hele naweek was vir my baie sleg en ek onthou ek het vir my man gesê, en ek het baie gehuil. Want ek kon regtig nêrens regkom nie. En onthou hoe ek vandag die inplanting sien, 4 jaar later en hoe dit toe was, onthou die eerste paar jaar met hierdie inplanting was vir my ultimate. (Kind se naam) het dit permanent gedra. Dit was maar hierdie laaste jaar wat ek as persoon en my man besluit nee dit wag eers. So dit het niks te doen met die inplantingspan nie, dit het niks te doen met die dokter wat dit gedoen het nie of die terapeute wat gehelp het nie. Hierdie was 'n keuse tussen my en my man rondom (kind se naam) se vordering. Dit het niks te doen met die het gewerk of dit het nie. Ek glo met my hele hart niks negatief nie, daar is elektrodes aangeskakel in (kind se naam) se koglea vir vorentoe. Daarmee sal ek hanteer vorentoe. Maar ek wil net sê in my geval op die oomblik vir (kind se naam) as sy vakansies huis toe kom na ons span toe kan neem en sê map weer. Want dit gaan gebeur ek gaan hulle weer nodig hê. Want ek gaan dit gebruik. So al het ek die baie negatiewe sy ervaar van hierdie inplanting, moet ek nog steeds weet ek het hulle nog steeds agter my. Al het hierdie ding gebeur in my lewe, ek het hulle nie afgeskryf nie en ek hoop ook nie hulle het my afgeskryf nie. So ek wil nogsteeds daardie positiewe hê, dat hulle my nog steeds help met haar map. Al dra sy hom net dan en wan ons wil net kyk is alles reg. Want vorentoe as sy ouer word gaan sy dit wil hê. Glo ek. Dit is dit.



**I: Ek dink jy het 'n baie unieke ervaring gehad. Dit illustreer juis die punt dat ouers uniek is en die paadjies wat hulle stap is uniek. En daarom waardeer ek jou insette want dit gee weer 'n ander perspektief op die saak. Is daar nog iets wat jy wil byvoeg?**

Ouer G: Nee dit is...om te hoor kogleêr jy lees dit in boeke, as jy nou 'n dowe kind het. Narstigtelik soek jy na iets om jou kind te help. So vir my bly dit 'n great ding om dit te doen wat ons vir haar gedoen het. Alles werk ten goede mee, dalk nie toe nie maar dalk nog vorentoe is daar baie hoop. So ons moet ook weet, dit is belangrik om hierdie ander prentjie te skilder van al het ek hierdie ander paadjie geloop as individu met my dogtertjie, het ek weer hoop rondom die inplanting vir wat die werd is. Die positief is die senuwee is daar en hy word gestimuleer. Al het ons nou die keuse gehad om dit nie aan te sit nie. My man sê natuurlik heelyd sy is doof en ons aanvaar haar so en ons het probeer help maar op hierdie oomblik los dit maar eers. Maar ek as mamma, die pad wat ek gestap het, spreek ek lewe oor hierdie situasie en nie negatief of dood nie. So dit is vir my belangrik dat mens weer uit hierdie ding kan kom en sê dit was nie verniet nie man. Die terapie sessies verruil ek ook vir niks want dit was goeie tye saam. So ek het deur hierdie rehab gegaan en ek het ekstra goed vir (kind se naam) gedoen. Ek het gedoen wat ek kon ten spyte van my pad en ek het dit nie afgemaak en gesê dit was 'n negatiewe pad nie. Want altyd kom jy by 'n regte pad of punt uit. En dit is dit.

**I: Baie dankie. Jy het regtig 'n mooi boodskap.**

## **Interview 8 with parent H**

### **I: (Parent name) how did you find out about the hearing loss of the children?**

Parent H: I find out because my brother got a small baby, one month difference of (older child's name). And then (older child's name) and brothers child are together. I see sounds from brothers child and (older child's name) no sounds. And then the lady go, I try to speak to (older child's name) for to make sounds. And (older child's name) no sounds, nothing. And I find out there.

### **I: And with (younger child's name)?**

Parent H: With (younger child's name) the doctors, ask for (younger child's name) to make a test. And the (younger child's name) go make a test and then find out the problem.

### **I: Were you pregnant with (younger child's name) when you found out about (older child's name)?**

Parent H: No not yet, I find out first. The time (younger child's name) born, (older child's name) already the cochlear.

### **I: How did you know about the cochlear? Were did you find out about it?**

Parent H: (Audiologist name) send me to the Professor and to the school to, Carel du Toit. And then Carel Du Toit always help me for the information of the cochlear.

### **I: Tell me in that time that you heard cochlear implant must be done, till the operation what was difficult for you in that time?**

Parent H: To receive (older child's name) is deaf. This one is very difficult. And then, me and my husband don't want to go the first time and then you see (older child's name) no sounds. And then you can see (older child's name) need the cochlear. And then me and my husband find out what we need to do. And then do it.

### **I: Before the operation, what did you want to know about the cochlear implant?**

Parent H: Before? Before always me and my husband want to see somebody with the children like that. I never seen. Me and my husband know nobody see like that. An then my husband and me choose to do. Always I wanted to somebody together with the cochlear. Before I never see.

### **I: And anything else you wanted to know about the cochlear?**

Parent H: Sometimes you think, this go help, sometimes you not so...

### **I: So you wanted to know that this cochlear implant will really help (older child's name) to hear?**

Parent H: Ja, you want to know, you think always not sure. You go do this, is it going to work?

### **I: So you wanted to know if it will work. What were you and your husbands needs for support or help before the inplant?**

Parent H: The support from family or...?

### **I: From family, from the cochlear team, from school...what help did you want?**

Parent H: You know, always you want somebody to come and tell you what to think, for go for the operation or not. And the people always say go for the cochlear.



**I: So you wanted other people also to give you advice and tell you that you are doing the right thing.**

Parent H: Yes, yes.

**I: So you wanted to know that. And (parents name) what is the most important thing to tell parents before the implant?**

Parent H: The important thing?

**I: Yes, what parents should know before they receive the cochlear implant. They should know a few things. What do you think is the most important thing to tell parents?**

Parent H: I think it is if the parents find out the problem, to go to the parent or something like that. The problem is the kids, you know you must go to the operation. Because you wait and the parents or doctors or something like that. You go say maybe it is nothing, you see and really its need the cochlea

**I: Ok, so the team must tell parents that you cant wait, its important that if you know the child is deaf you should do it...**

Parent H: Yes, you cant wait.

**I: And support (parents name) what do you think is to most important support or help to give parents before their child gets a cochlear implant?**

Parent H: Before? I think they must decide quickly to make operation. Not take long, you see? Because more long, more difficult.

**I: Why do you say that?**

Parent H: Because, I can see (older child's name), got first one and (older child's name) is smaller than (younger child's name). And (older child's name) catch the things better than (younger child's name). I see this in (older child's name). And (younger child's name) older. By the time (younger child's name) but the cochlear, (older child's name) is young and (younger child's name) is older. And I see it is better for (older child's name). And maybe (younger child's name) is not the same as (older child's name). I can see this one (older child's name) younger and its better.

**I: So the help that the implant team must give parents is to stress that it is hard now, it is difficult for a baby to get a operation. But it is better when they are young.**

Parent H: Better. Much better. And when they find out the problem they must do it. Because it is better than wait, much better.

**I: And (parents name) if you can give advice to the cochlear implant team, how will you say can they help parents better before implantation? What information or help must they provide to parents before the inplant? How can they do it better?**

Parent H: I don't know. I think they should choose and help the baby quickly.

**I: That is a good answer. So they must not waste time?**

Parent H: Yes, not waste time. Find out the problem and help the kids.

**I: How would you feel about it if parents can choose what they need to know and what help they can receive before the inplant?**

Parent H: Before?

**I: Yes, if they can choose this, this is important for me, this I do not need to know now, but this is important. If parents can choose what they want?**

Parent H: About the cochlear?

**I: About the cochlear, about what help they want.**

Parent H: Before? I am not sure.

**I: Before the implant. So if, say for example when you first come with your child, when you find out your child is deaf, you come to the cochlear implant team, you hear a cochlear implant is a good option. And then parents can choose, they get a list and on that list there is different this, there is school, finance, say for example rehab like speech therapy, there is about mapping ....**

Parent H: So this is before cochlear...

**I: Yes before cochlear and there is about batteries. And now parents can say School is not important for me because my child is still young, but I want to know about finance and I want to know about the mapping. So parents can choose these two things I want to know.**

Parent H: Before?

**I: Before.**

Parent H: No, I don't think. You know the things come to you like (older child's name) come. Like (older child's name) got the cochlear, (older child's name) listen already. You want to do something more and more and more. But before I don't know.

**I: So you did not want to know much before hand, you just wanted to know if it will help. And then afterwards you heard about all these things.**

Parent H: Yes. The time your child, your baby got the cochlea then you want to know more things. Where you must go to speech, or something like that.

**I: So before did not want to know that you only wanted to know if it will help.**

Parent H: Yes. The doctors always say it help.

**I: From everything that was said now, what would you say is the most important thing for parents to know and the most important help they should receive before the implant?**

Parent H: I think it is the cochlear implant, you go to the doctors and the doctors say that thing is a cochlear implant, you must do the cochlear because (older child's name) go hear, and go speak, and that.

**I: Ok, so I am going to summarise everything that you said. You said that in the beginning the most difficult part for you was to accept that your child is deaf. That was very difficult. And you wanted to know about other children that received a cochlear implant.**

Parent H: Yes I always wanted to see somebody like that because before I never see and then I (older child's name) need to do it then my idea is to see somebody together with cochlear.

**I: So you wanted to see that and for support you wanted people to tell you are doing the right thing, you doing a good thing.**

Parent H: You know you always want to hear this and it give you power to go.

**I: That is what you think is most important and you also feel that it is important to implant as young as possible.**

Parent H: That is also big thing.

**I: The doctors must be quick to implant, there must not be a long time before they implant. And you feel that before the implant you did not want to know many things...**

Parent H: Yes, not to many things.

**I: You only wanted to hear it is good thing, the child needs it, you must do. And afterwards you learned more about the mapping and the maintenance.**

Parent H: Yes that thing happened to me and my husband, before there is so much things, after the cochlear you want to know. Before the cochlear there are not many things I want to know.

**I: Did I say the right things that you said?**

Parent H: Yes.

**I: (Mothers name) is there anything else you want to say?**

Parent H: The thing is for me difficult. Sometime the machine break very easy. The wires and then the children did not want to look after the machine. It is very, very, very, difficult the first year. This one is very difficult.

**I: Do you think we should tell parents that it is going to be difficult? Before the implant.**

Parent H: Before, yes. The first two years is very difficult to look after the children, to look after the machine everything.

**I: So we should tell parents that it breaks and cost much money and it is going to be difficult but we are going to be there with you.**

Parent H: Yes, like now (older child's name) looks nicer for the machine. Change the batteries at school, and the wire do not break so much. And the magnet not fall so much. Everything is much better now. And (older child's name) is 7 years old now. The first two, three years is difficult. And (younger child's name) is so difficult. (Younger child's name) is more difficult than (older child's name). (Younger child's name) do not like machine in the ear. Through it away and then the magnet go to door and something like that and then I get walk around where is the magnet? Magnet? Magnet? It is difficult.

**I: It is good that you are saying that so that we can prepare parents.**

Parent H: The machine is good, not so safe. You see you got your ears, you don't worry. This machine you put in the ear and you need to worry about. Because the children are small and you have got to look after the machine.

**I: Anything else?**

Parent H: That's all.

**I: Ok, thank you.**

## Onderhoud 9 met ouer I

### I: (Ouer se naam) hoe het julle uitgevind julle kinders het 'n gehoorverlies?

Ouer I: (Oudste kind se naam) het op 2 van die bakkie afgeval en toe het hy harsingskudding opgedoen. Hy was opgeneem in die hospitaal en iemand het daar vir ons gesê ons moet 'n gehoortoets doen van harsingskudding kan gehoorverlies veroorsaak. Toe het ons 'n gehoortoets op hom laat doen en toe het ons uitgevind dat hy wel 'n gehoorverlies het en toe is (jongste kind) net gebore. Toe het Dr voorgestel, weens hy dit het ook maar vir (jongste kind se naam) laat toets, so dit is weens die feit dat (oudste kind se naam) 'n gehoorverlies het dat ons besluit het om hom ook te toets. Toe het 'n breinstam toets bevestig dat hy 'n gehoorverlies het.

### I: Hoe het julle toe uitgevind van kogleêre inplanting as 'n opsie?

Ouer I: Ons het heeltyd geweet met die drempels wat hy het, is 'n kogleêr 'n opsie, maar toe het ons gesê omdat (oudste kind se naam) goed reageer met die Naida 5 gehoorapparaat en sy gehoor drempels amper dieselfde lyk as (jongste kind se naam) gaan ons dit eers probeer. En toe ons sien hy kry nie versterking met die gehoorapparaat nie, het ons die kogleêr oorweeg, maar ons het heeltyd geweet dit is 'n opsie, of die kogleêre inplanting of die gehoorapparaat want vandat (oudste kind se naam) 'n gehoorverlies opgedoen het, het ek ongelooflik baie op gelees oor gehoorverlies en wat is die opsies en wat is die drempels en is die decibels en wat is die frekwensies en so ek het baie self daarvoor op gelees. En toe het ons reeds met (oudste kind se naam) Eduplex in Pretoria besoek, so daar het ons ook baie, ek het 'n onderwysers en ouer opleiding deur hulle gedoen wat ek baie van die inligting rondom die kogleêr ontvang het.

### I: Toe julle nou uitvind dit is 'n opsie vir julle seuntjie totdat hy geïnplanteer is. Wat was vir julle moeilik of uitdagings in daardie besluitnemings tydperk?

Ouer I: Ek dink net om op die punt te kom dat jy moet oorgaan om dit te doen. Want ons het nog heeltyd geglo daar gaan 'n wonderwerk gebeur en die Here gaan ons kind genees. So net om op daardie punt te kom van ons is sterk in ons geloof en die Here gaan hom genees maar genesing kom dalk deur die kogleêr? Dit was vir ons die moeilikste. Dit was altyd vir ons, ons wil die beste vir ons kind hê. So ons het gesê as dit die beste opsie is, 'n kogleêr dan is dit so, as dit deur middel van genesing deur die Here is dan is dit die opsie. Ons het gevoel ons wil hom spaar om die res van sy lewe 'n ding te dra. So ons het maar eintlik bly glo en hoop dat die Here hom gaan genees en dit het nie gebeur nie.

### I: En as jy nou terugdink aan daardie tyd voor die inplanting, watter behoefte het jy en jou man gehad aan inligting? Wat wou julle weet?

Ouer I: Ja eerstens wou ons weet wat dit gaan kos en wat is ons mediese fonds bereid om daarvoor te betaal. En dit was vir ons sleg, om te dink ons moes al hierdie kostes aangaan en ons het nie eintlik 'n keuse nie, want dit gaan vir ons oor wat die beste is vir ons kind en die mediese fondse wil ons nie steun nie. Ons behoefte was rondom die finansies maar dan ook in terme van decibels, omdat ons geweet het van decibels, wat gaan sy decibels gehoorverlies uitkoms wees wanneer hy die kogleêre inplanting het? En tot vandag toe het niemand dit vir ons gesê nie, ek moes dit gaan op swot en oplees daarvoor. So ek voel dit is 'n leemte, wat is sy uitkoms en hoe vinnig 'n mens wat wanneer kan verwag wanneer hy die kogleêre inplanting gaan kry. Niemand het dit nog ooit aan ons uit gestip van jy moenie binne 'n jaar verwag hy gaan woordjies hoor nie en so aan. Dit is nog nie aan ons baie duidelik nie, almal sê die proses is maar stadig, maar niemand het vir ons meer riglyne daarom vir ons gegee nie. En wat is die stappe van as ingeplanteer word, werk eers aan dit of werk eers dit. So dit was ook vir ons 'n leemte gewees.

### I: So jy wou dit voor die tyd weet...

Ouer I: Ek wou dit voor die tyd geweet het, ek hou daarvan om goed te beplan vooruit en voordat jy in 'n ding instorm dat jy weet waarvoor jy jou inlaat. So vir party mense sal die seker te veel information overloading wees maar ek wil weet wat wag.

**I: En ondersteuning? Watter behoefte het jy gehad aan ondersteuning?**

Ouer I: Dr Butler het ons baie mooi ingelig en baie mooi ondersteun, maar ek dink van 'n oudiologiese kant sou mens meer wou gehad het in terme van die uitkomst soos wat ek nou vir jou gesê het en ook wat gebeur voor die operasie en wat gebeur na die operasie. Hoekom is dit juis 'n lang tydperk voordat hy aangeskakel word en dan die dag met aanskakeling ons sou graag bietjie wou weet het wat gebeur die dag as hy aangeskakel word en so.

**I: (Ouer se naam) as jy vir my kan sê wat dink jy is die heel belangrikste inligting om vir ouers te gee voor die tyd, as jy een area kan uitsonder wat sal dit wees? Wat moet ouers weet?**

Ouer I: Ek dink die werking van die kogleêr, want dit is vir almal vreemd. Wat presies gebeur, die klank word elektronies gemaak in die oortjie. En miskien ook as 'n mens 'n kogleêre inplanting doen, hoe werk 'n kogleêre inplanting saam met 'n gehoorapparaat? Want baie keer as daar 'n bilaterale gehoorverlies is dan weet 'n mens nie wat is die behoefte rondom dit nie. En hoe werk dit saam, word die een uitkakel of nie. En dan ja die werking van die kogleêr en dan ook wat is die reaksies wat jy kan verwag as dit aangeskakel word.

**I: En ondersteuning? Wat dink jy is die heel belangrikste vorm van ondersteuning om vir ouers te gee?**

Ouer I: Ek dink die heel belangrikste is om empatie te hê met die ouers. En om dit van die oudioloog se kant af te sien as nie net 'n beroep nie, maar as...die oudioloog moet hulle eintlik instel in die posisie van die ouers, want vir die oudioloog is dit 'n werk en vir ouers is dit 'n kind. So vir ons gaan dit oor ons kind se ontwikkeling en vir die oudioloog gaan dit oor dit is nog 'n kind wat gemak moet word of aangeskakel moet word. So ek dink 'n bietjie meer empatie en 'n bietjie meer riglyne van dit is wat nou gaan gebeur, dit is die volgende stap. So om ouers stap vir stap...al is dit om 'n leestukkie te gee van dit is wat gebeur en dit wat volgende kom.

**I: Sodat ouers voorbereid is op die stappe en dat hulle voorbereid is daarop...**

Ouer I: Ja wat my baie gehelp het, is toe ek 'n boek gelees het, a parents guide to cochlear implants. As ek nie dit gelees het nie, sou ek baie meer vrae gehad het. Baie keer kry ek die idee die oudioloë wil nie vir die ouers inligting gee nie. En ek voel as jy ingelig is, 'n ouer is ook gebore met 'n brein, dan kan jy meer oor daardie goed weet en dan kan jy jou kind ook beter help so jy moet meer ingelig wees daarvoor.

**I: Want op die ou einde moet jy 'n ingeligte besluit neem namens jou kind. So dit is belangrik dat ouers so veel weet soos wat hulle wil weet om daardie ingeligte besluit te maak. En as jy kan raad gee vir 'n kogleêre span wat sal jy sê hoe kan hulle ouers meer effektief bystaan met inligting en ondersteuning voor 'n kogleêre inplanting?**

Ouer I: Ek dink hulle moet hulle meer leesstof gee in terme van wat sluit die pre-inplantings fase in en wat is die inplanterings fase en wat is die post-inplanterings fase sodat ouers 'n mooi prentjie het van wat gaan gebeur voor die tyd. So dit is wat gaan gebeur, dit is hoekom dit nodig is om al hierdie toetse te doen en hierdie rehabilitasie deur te gaan, dit is wat in teater gebeur en dit is die helingsproses voor die aanskakeling en sê nou maar die eerste 2 mappings na die aanskakeling, wat is die uitkomst wat verwag word tydens die mappings want dit is nogal vir ons 'n leemte want ons kom, ons weet nie wat is die uitkomst wat bereik moet wees elke keer nie. Meeste van ons is leeke op hierdie gebied ons weet nie hiervan nie.

**I: En hoe sal jy daarvoor voel as ouers 'n keuse gegee word oor tipe inligting en ondersteuning en die hoeveelheid wat hulle soek. Soos jy gesê het ouers verskil, party ouers soek baie inligting en party soek min. So hoe sal jy daarvoor voel as ouer daardie keuse kan hê?**

Ouer I: Ek dink dit is belangrik om die inligting beskikbaar te hê maar dat ouers wel die keuse het So daar is ouer wat jy sê nie al die inligting wil hê nie en sê goed, gaan net voort. Maar dan is daar ouers wat inligting soek en dan is daar nie inligting beskikbaar nie.

**I: Van alles wat ons nou bespreek het, wat dink jy op die ou end is ouers se grootste behoefte aan inligting en ondersteuning voor 'n kogleêre inplanting?**

Ouer I: Ek dink vir die mans is dit die finansies en vir ons as ma's is hoe vinnig is die herstelproses daarna. En wat is die teater implikasies en die narkose implikasies en dan ook dan die implikasies na die tyd, watter kopwond is dit, hoe moet die versorging daarvan wees. Maar eintlik het Dr Butler dit baie mooi vir ons verduidelik.

**I: Dit is goed wat jy gesê het. Ek gaan nou opsom wat jy gesê het. Met uitdagings wat julle ervaar het voor die tyd, was om te aanvaar dat dit die opsie is.**

Ouer I: Om te berus eintlik.

**I: Om te berus daarby en te besef dit is 'n wonderlike apparaat en dit was steeds vir julle moeilik om te besluit ons doen dit, dit was vir julle 'n groot uitdaging gewees. En oor inligting wou julle graag geweet het oor uitkomst met kinders en wat om te verwag, so jy wou baie goed voorbereid gewees het op die proses. Jy wou inligting gehad het oor pre-inplantasie is dit die stappe wat gevolg word, en post-implantasie is dit die stappe en ook wat, wanneer kan ek verwag? En met ondersteuning voel jy dit is belangrik dat terapeute empatie met ouers moet hê om te verstaan dit is nie altyd 'n voorhandliggende besluit nie, en dit is 'n moeilike besluit vir ouers om te maak...**

Ouer I: En veral omdat ons op die platteland bly en al hierdie bronne nie tot ons beskikking is nie. En die terapeute nie tot ons beskikking is nie.

**I: So jy het daarvan gehou as terapeute vir jou inligting kon gee wat volledig is en jy kon dit op jou eie tyd deurlees en kan kyk of jy onseker is. Daardie kommunikasie en inligting wat vir jou belangrik dat iemand dit nie in een sessie vir jou gee nie maar dat jy op jou eie ook kan gaan lees. En dan voel jy dit sal goed wees as ouers kan kies, want jy sê ook dat ouers verskil en jy is 'n ouer wat hou van inligting en hou van voorbereiding. En jy voel jy wil 'n ingeligte besluit maak oor jou kind. So jy sal daarvan hou as jy kan kies oor watter hulpbronne beskikbaar is. En finansies was vir julle baie belangrik en ook die shurigiëse proses. Het ek alles reg opgesom?**

Ouer I: Ja.

**I: Is daar iets wat jy wil byvoeg?**

Ouer I: Nee.

**I: Dit is reg so. Baie dankie.**

## Onderhoud 10 met ouer J

**I: Vertel vir my hoe het julle uitgevind dat (kind se naam) 'n gehoorverlies het.**

Ouer J: Weet jy eendag het ons die kar gehoot, hy was so entjie voor ons , nie vêr voor ons nie, en toe kyk hy nie vir ons nie. Maar voor dit het hy altyd deurgeslaap, deur geraas het hy altyd deurgeslaap, hy was die soetste babatjie. Jy kon met hom toor. En toe eendag toe ons hoot toe besef ons, daar is iets fout. Want die hooter was hard en ons hoot, een, een twee drie en hy stap nogsteeds aan. Ek meen 'n kind sal mos omkyk, of skrik of iets. Dit is hoe ons agtergekom het Boeta het 'n gehoorverlies.

**I: Hoe het julle toe gehoor van 'n kogleêre inplanting?**

Ouer J: Ek was oorsee daardie tyd so (oudioloog se naam) het vir my ma alles vertel. Sy het my ma vertel van die oorplanting en wat dit behels en wat moet jy weet.

**I: Wat was vir julle moeilik in daardie tyd? Wat was vir julle uitdagings?**

Ouer J: Die moeilikste vir my was om deur die operasie te gaan. Ek wou net sien hy is deur en dit was 'n sukses.

**I: In daardie tyd toe jy uitvind jou seuntjie kan nie hoor nie en julle uitvind daar is iets soos 'n kogleêre inplanting, wat wou jy en jou ma weet?**

Ouer J: Obviously finansiël, of jy dit kan bekostig, die batterye ens. En soos byvoorbeeld wat die operasie behels. En hoe lank na hy geopereer is gaan hy kan hoor, dit gaan nie onmiddellik gebeur nie, jy moet daaraan werk.

**I: En ondersteuning? Watter behoefte het julle gehad aan ondersteuning van die span, vriende, familie, Carel du Toit, enige iemand?**

Ouer J: Inligting, so veel as moontlik inligting wou jy gehad het. Of dit nou negatief of positief was, 'n mens wou net weet wat jy kon verwag.

**I: Goed so julle wou baie mooi geweet het oor uitkomst, wat kan mens verwag en wat is realities.**

Ouer J: Ja.

**I: As 'n ander ouer nou deur daardie proses moet gaan, wat dink jy is die belangrikste inligting om vir hulle te gee voordat hulle kind 'n inplanting ontvang?**

Ouer J: Ek dink Ilouise, jy moet voor die tyd spraak bywoon en altyd met jou kind probeer oefen en dan gebeur die operasie en dan na die operasie dieselfde maar dan nou baie, baie gereeld as voorheen.

**I: So jy dink dit is baie belangrik om ouers voor te berei op die rehabilitasie wat na die tyd volg.**

Ouer J: Ja definitief.

**I: Sodat hulle weet dit is eintlik waar die harde werk lê...**

Ouer J: Ja dit is waar die harde werk lê.

**I: En ondersteuning? Wat is die belangrikste vorm van ondersteuning om vir ouers te gee?**

Ouer J: Ek dink emosioneel en finansiëel. Want mens wil daardie ondersteuning hê. Jy wil die hê. Want so daar iets gebeur kan jy op wie staatmaak. Nie in vandag se ekonoom nie. Jy het nie daardie waarborg nie. Mens moet net weet jou income moet secure wees.

**I: Ja, want dit stel groot finansiële eise, want dit is nie net die operasie nie, dit is ook die onderhoud en instandhouding...**

Ouer J: Ja dit is reg.

**I: Hoe dink jy kan die kogleêre span ouers meer effektief bystaan met inligting en ondersteuning voor die tyd?**

Ouer J: Ek dink dat hulle moet aanhou om jou te motiveer met jou kind. Want as jou kind 'n kogleêre inplanting het en jy dink dinge moet oornag gebeur, dit vat aan 'n ou.

**I: En hoe sal jy daarvoor voel as ouers 'n keuse gegee word oor die tipe inligting en ondersteuning wat hulle wil hê voor die inplanting? Wat dink jy sal die effek wees as ouers kan kies wat hulle benodig en dit dan kommunikeer aan die span en hulle spreek dan daarie behoeftes aan, watter uitwerking sal dit hê?**

Ouer J: 'n Positiewe uitwerking, op die kind en die ouers self. Want as ek nou so praat dan dink ek ook aan enkelouers wie se kinders ook nou 'n gehoorverlies het.

**I: As ons nou alles kan opsom wat jy nou gesê het, wat dink jy aan die einde van die dag is die belangrikste vorm rakende inligting en ondersteuning aan ouers voor die inplantering van hulle kind?**

Ouer J: Ek dink jy moet soveel as moontlik inligting kan kry, rondom die inplanting, rondom jou kind, die spraakterapeut waar jy gaan bywoon, waar na toe jou kind gaan gaan, as hy nou skool gereed is en hy kan nie skool toe gaan nie. Ek dink 'n ou moet dit weet.

**I: Goed as ek nou alles kan opsom wat jy gesê het sal dit wees dat 'n baie groot behoefte van julle was inligting. Julle wou weet hoe werk die inplanting, wat is nodig. Julle wou weet wat is die finansiële implikasies, wat gaan dit kos elke maand en jy voel dit is baie belangrik om vir ouers in te lig oor die rehabilitasie na die tyd en hoeveel harde werk dit gaan kos. Jy voel ook dit is belangrik dat die span ouers moet ondersteun en motiveer en beskikbaar wees as dit finansiëel en emosioneel swaar is, veral as die uitkomst nie is soos wat jy verwag het nie, moet hulle nogsteeds jou ondersteun en motiveer om vorentoe te beweeg met jou kind. Het ek dit reg opgesom?**

Ouer J: Ja.

**I: Is daar nog iets wat jy wil byvoeg?**

OuerJ: Nee, daar is nie iets waaraan ek nou kan dink nie.

**I: Goed baie dankie vir jou deelname.**