

1. INTRODUCTION

Rationale

New technological and scientific developments in the field of audiology have ensured that the majority of children with a wide range of hearing impairments have the opportunity to access all the sounds in the speech sound spectrum which increases their chances to develop spoken language (Cole and Flexer, 2007; Geers, 2006; Kurtzer-White, 2001; Sharma, Doman, and Kral, 2005; Watkin et al., 2007). These audiological developments have led to the introduction of cochlear implants which are electronic prosthetic devices that were approved by the Food and Drug Administration in the USA in the 1980's to successfully treat profound sensorineural hearing losses (Balkany et al., 2000). Since then, cochlear implants have evolved both in terms of technological capabilities and also patient candidacy. The increased candidacy base now includes children as young as 12 months, which has an immense impact on the family to make decisions about their child's future very early on.

The majority of the research in the field of cochlear implants has been clinical in nature (Edwards, Khan, Broxholme & Langdon, 2006; Kluwin & Stewart, 2000; Simonsen, Kristoffersen, Hyde & Hjulstad, 2009). Hence the experiences of the impact of cochlear implants on both children and their families have not been adequately captured. In addition, numerous studies have documented the grieving period for hearing parents when the diagnosis of a hearing loss is made (Aganostou, Graham & Croker, 2007; Kluwin & Stewart, 2000; Kurtzer-White and Luttermann, 2003). During this emotional and devastating period, parents are expected to make critical life changing decisions on the part of their young child. Hence, parents are expected to make these huge decisions during a time when they are not fully cognisant of the implications of these decisions as well as other alternatives to such a

situation (Kluwin & Stewart, 2000). Furthermore, studies have revealed that the majority of hearing impaired children are born to hearing parents which confounds the decision making even more as most of these parents are unfamiliar with or have never experienced deafness.

There is a strong need to expand research in this direction where in the midst of limited data we endeavour to enquire about how parents came to the decision about an elective and invasive procedure that has tremendous implications. Insight into parental decisions about whether to implant as well as the factors that influenced the decision is critical to expand our own understanding and is therefore the goal of the current study. The findings of the study in terms of the parents' perspectives when making the decision regarding cochlear implantation, is aimed at contributing to the recommendations for service providers to improve and enhance cochlear implant services for families.

Literature Review

Newborn hearing screening and the early detection/ intervention programs have paved the way forward for improving the quality of life for children with a hearing loss. Yoshinaga-Itano and Apuzzo (1998) indicated that early identification is effective if intervention is provided timeously. Various studies demonstrate that the early management of a hearing loss yields favourable outcomes in terms of educational and social aspects (Eleweke, Gilbert, Bays and Austin, 2008; Lesinski-Schiedat, Illg, Heerman, Bertram & Lenarz, 2004). In addition earlier works suggested that early intervention is critical for the development of language, communication, emotional and cognitive needs of the hearing impaired child (Desjardin, 2005; Watkin et al., 2007). Considering the impact of early intervention, professionals in the field of hearing impairments are faced with the challenge of ensuring that parents of hearing impaired children fully understand the hearing technology, communication options and educational implications very early on (Gravel & O’Gara, 2003; Marshark, Rhoten & Fabich, 2007; Young, 2002).

Cochlear implants have increasingly been utilised in the intervention of profoundly deaf children (Spahn, Burger, Loschmann & Richter, 2004). This type of hearing technology consists of an electronic device that is surgically implanted and enables these children to access sounds (Sachs and Whynes, 2005). In the 1990’s cochlear implants especially in the young population were a controversial issue. Opposition to cochlear implants in the paediatric population was based on the unknown extended psychological effects that it may have on both the hearing impaired child and their family (Balkany et al., 2000). Furthermore, it has been argued that cochlear implants are considered by families that show a resistance to accept their child as deaf. To date, the issue of cochlear implants continues to raise concerns among the Deaf community (Most, Wiesel & Blitzer, 2007). While some people in the Deaf

community oppose cochlear implants as they are of the opinion that it compromises the identity of deaf individuals, audiologists and other health professionals appear to strongly support paediatric cochlear implants with the view to promoting oral communication due to the long term global outcomes that have become available (Archbold, O'Neill, & Lutman, 2006; Swanwick & Tsverik, 2007). The long term global outcomes achieved with cochlear implantation have been associated with both interactive skills between the child and parents as well as the psychological benefit, thus there has been a shift in the degree to which cochlear implants are considered controversial (Hauser, O'Hearn, McKee, Steider & Thew, 2010).

Research has shown that the diagnosis of a hearing loss can have a devastating impact on the emotional state of a family (Bergeron & Ferron, 2005; Marschark & Spencer, 2007; Thompson, 1998). The family becomes laden with a new responsibility of caring for a child with a hearing loss without prior experience and no or very little preparation for the task ahead (Birman, 2009; Luterman, 2003). The new responsibility together with their other commitments within their family structures adds pressure and the ultimate likelihood of stress (Kermit, 2009). In addition a new direction for this family is necessary, one that encompasses the world of deafness. Unexpectedly, parents with hearing impaired children have to now consider a multitude of issues ranging from choosing an appropriate communication mode, weighing up the decision as to whether to select to pursue a cochlear implant or other alternatives such as signing (Punch & Hyde, 2010).

In addition parents need to be informed regarding the impact of their current decision on various issues including future school placement. Firstly, parents are faced with the decision whether cochlear implants are their preferred choice of amplification. This consideration can

be difficult when parents become entangled in the struggle between the Deaf community who are against cochlear implants and the aural activists who promote cochlear implants (Luterman, 2003; Most & Zaidman-Zait, 2007). Secondly, parents have to undergo the lengthy cochlear implant candidacy process which according to Gray, Jones, Shipgood & Court (2003) consists of 7 important stages namely; confirmation of diagnosis, trial of appropriate hearing aids, referral to the implant centre, further audiological assessments, communication and language assessments, MRI and CT scans and finally a team decision. During this process, delays may occur which may add further stress and frustration to the parents involved. Thirdly, parents are then faced with the financial implications of their decision for a cochlear implant. In South Africa, a single cochlear implant costs approximately R300, 000 excluding the associated medical costs that range from surgeon's fees, hospital costs and scans (Southern ENT, 2010). Currently, only a few medical aids are able to cover the full costs of paediatric cochlear implants which mean that parents without medical aids or those with partial cover will need to raise these funds. Later through this process, parents will have to endure the anxiety and fear that is associated with the complicated surgical cochlear implant procedure (Perold, 2001). Finally, parents need to make a decision regarding their child's educational placement and their preferred mode of communication that they have chosen for their child. Additionally, attached to this decision is their commitment and involvement in the very lengthy and sometimes complex rehabilitation process as intelligible speech is usually attained after a considerable time (Jackson, Wegner & Turnbull, 2008).

The consideration of the medical costs, maintenance costs, rehabilitation costs as well as the specialised education costs are critical factors that are intertwined with the decision to implant. A study conducted by O'Neill, O'Donoghue, Archbold and Normand (2009)

considered the cost implications of children with cochlear implants between 1997 and 1998 in the United Kingdom. The estimated cost in 2009 of implanting and maintaining a child was \$78,011. In South Africa, a Trust has been set up by a popular radio station to fund cochlear implants some parents should they not have a health care provider. However, only a limited amount of funding is available for this project. Other parents, who do have health care providers, can attempt to seek funds for the cochlear implant but the amount received can vary. In this instance, an independent financial company has employed a means end test for parents financial needs and would fund the remainder of the cochlear implant cost. However, parents are still responsible for the maintenance of the implant, rehabilitation fees as well as the educational costs which can be overwhelming.

Birman (2009) as well as Johnston et al., (2008) emphasised the importance of providing parents with comprehensive and unbiased information on the potential risks and benefits of cochlear implantation. Since the introduction of cochlear implants, there has been much research concerning their surgical safety (Rembar, Lind, Arnesen & Helvik, 2009; Warren, Fey & Yoder, 2007). Although literature has shown the positive outcomes associated with cochlear implants, there still remains the potential for surgical complications. Johnston et al., (2008) outlined both the minor and major risks related to cochlear implants. Some of the major surgical complications included facial nerve paralysis, bacterial meningitis or flap infections whereas the minor complications included haematoma's. The effect of the anaesthetic is also another concern for this type of surgery especially in the paediatric population. Birman (2009) found that the surgical outcomes for children 12 months and younger are good and safe under conditions of reliable audiological testing, experienced and specialised paediatric anaesthesiology as well as procedures for facial nerve monitoring. In

addition to the possibilities of surgical complications, other adverse effects associated with the implantation process include tinnitus or imbalance.

A child receiving a cochlear implant will require intensive intervention that focuses on helping him/her understand and interpret the auditory sensations provided by the device into meaningful sounds. It must be noted that cochlear implants have proven to raise unrealistic expectations from parents (Most, Zaidman-Zait, 2007). Research has indicated that some congenitally deaf children will begin to produce spoken language as well as receive a good degree of auditory benefit two years following implantation (Wheeler, Archbold, Hardie, Watson, 2009). In comparison to normal hearing children, this ability to hear and communicate effectively occurs over a longer period of time and the parents' understanding of this challenging and intense process is not fully understood.

Although current literature continues to reinforce the significant positive outcomes associated with cochlear implants, there is sparse literature available on the parental readiness for cochlear implantation (Duncan, 2009; Perold, 2001). The concept of readiness has many viewpoints. Dalton and Gottlieb (2003) viewed readiness as a 'ubiquitous term' that encompassed a state of being as well as a process. They defined the process for readiness as identifying the need to change, carefully considering the costs and benefits as well as planning for change should the need arise. Another perspective discussed by the authors was the concept of readiness in the learning context. Within this context, the persons' motivation and ability to accept teaching as well as their ability to acquire new skills and attitudes are considered. Bernerth (2004, p. 40) added that "readiness is more than understanding the change, readiness is more than believing in the change, readiness is a collection of thoughts and intentions toward the specific change effort". Other researchers such as Madsen, Miller

and John (2005) support the latter idea but further opined that readiness is not a fixed factor within individuals and would vary depending on internal or external components. Considering all the above mentioned viewpoints, parents' readiness to decide to implant can be a long and complicated process.

With the drive towards early detection and intervention comes the added professional responsibility of ensuring that parents are well informed and are able to make timely decisions. Ben- Itzhake, Most and Wiesel (2005) discussed the influence of professionals on parents during the decision making process. Professional's expectations of technology and well as their preferred communication modes may bias the parents' decisions. Given the stated influence of professionals in terms of certain decisions, as indicated in other research contexts, it would be important to ascertain whether this applies to the South African population. As with other countries, South Africa varies in terms of its economic and social status and it would be interesting to ascertain whether or not these influences exist as well as the degree of variability. Recent research carried out at the Nottingham Cochlear Implant Programme (Archbold, Nikolopoulos & Lloyd-Richmond, 2009) revealed the lack of flexibility in the professionals' ability to cater for the individual needs of parents with hearing impaired children. Furthermore some parents expressed their difficulty when the child's communication needs changed as well as their listening abilities following implantation. Furthermore, supporting parents in their communication journey is challenging for some professionals due to organisation and bureaucratic restrictions (Wheeler, Archbold, Hardie, Watson, 2009).

Ingber and Dromi (2009) cite the influential theory that was proposed by Maslow in 1964, which considered the connection between needs and personal attributes. When applied

to the early intervention programmes used with the hearing impaired population, this theoretical model stresses the importance of professionals to strongly consider the families' emotional state, social supports and other ecological, personal and social systems (Ingber and Dromi, 2009). Hence, research continues to reiterate that successful early intervention programs not only focus on the child's needs but also on the needs of the family system in which the child is nurtured (Eleweke, Gilbert, Bays and Austin, 2008).

In a study conducted by Eleweke, Gilbert, Bays and Austin (2008), the researchers recognised the difficulties that hearing parents face with no prior experience with deafness as well as the importance of timely and objective information. They further stressed the relationship of this well timed and unbiased information on the parents' ability to then respond appropriately to various issues. Such issues ranged from the emotions associated with a diagnosis of a hearing loss to decisions regarding active involvement in early intervention for their child as well as effective partnership with all the professionals involved.

In light of the recommendation of evidence based practices we are continually striving to provide services that efficiently and effectively meet the needs of our hearing impaired population. The purpose of this research report is to investigate the parental experiences of decision making when considering cochlear implants. This study will also aim to add to the current body of literature regarding the impact of decision making in cochlear implantation particularly in the South African context.

2. METHODOLOGY

This section will include a description of the aims of the study, the research design as well as the ethical considerations. It will then discuss the characteristics of the participants, details of the questionnaire and interview guide as well as the procedure of eliciting the data.

2.1. AIMS

The overall aim of this study was to determine parental descriptions of their experiences with regard to the decision of cochlear implantation for their young children with a hearing loss.

The sub-aims included:

- a) To determine if the child's audiological and medical history influenced the decisions made.
- b) To determine the advice given to parents on receiving the diagnosis.
- c) To determine if the advice given by the professionals influenced the decisions made.
- d) To determine the factors needed to be considered by the parents for the child when deciding on a cochlear implant.

2.2. ETHICAL CONSIDERATIONS

A. Ethical Clearance

The researcher applied and secured approval from the Human Research Ethics Committee (HREC) at the University of Witwatersrand. The certificate is in appendix 1.

B. Ethical Issues

As the researcher is employed at the Learning facility where the research was conducted, it raised the issue of coercion of participants. In order to address this issue, the researcher ensured that participants invited for this study were not approached by the researcher but rather by a professional not associated with the study or the management of the hearing impaired population. The professional was given a list of the contact numbers as well as the information sheet and telephonically contacted the parents of the hearing impaired children.

Additionally in view of that fact that the interview was to be conducted by the researcher this posed the problem of researcher bias and the elicitation of socially desirable responses from the participants. To attend to these issues, the researcher discussed at the outset with the parents the purpose of this research and emphasized that their participation in this research would not have any influence on their services received at the Learning facility. Voluntary participation was made clear as well as the option to withdraw with no negative consequences. In addition an attempt was made to address the issue of researcher bias, by conducting the interview with another person present, a speech and language therapist (SLT), who was not involved in the management of the hearing impaired population at the Centre. The purpose of including another person was to ensure that the interview would be conducted without researcher bias as the SLT was allowed to interject on the parents behalf should she have felt that the line of questioning was inappropriate or not in accordance to the guideline set out in the interview guide. A confidentiality form was signed by the SLT who was under oath by the Health Professions Council of South Africa (A copy of this form is included in the appendix 2).

C. Confidentiality

To ensure confidentiality the researcher agreed not to report to anyone at the Learning Facility on any part of the study. In addition, parents were advised not to discuss their interviews with one another. Anonymity was maintained by omitting the biographical details obtained in the interview from the research report and no personal information was made available to anyone except the researcher.

D. Sensitive Nature of Research Topic

The researcher was aware of the sensitive nature of the research topic and the possibility that certain feelings/emotions may have surfaced during the interviews. At the beginning of the interview, the parents were provided with the option of voluntary counselling with a qualified psychologist affiliated with the Learning Facility at no cost to them. None of the parents required this service.

E. Consent

Parents were provided with an information sheet detailing the nature of this study (Appendix 3). Voluntary participation in this study was highlighted as well as the option to withdraw at any point during this study. In addition written consent for participation in the study as well as permission to video record the interview was obtained from all participants in the study (Appendix 4 and Appendix 5).

F. Data Storage

As per the requirements of the Health Professions Council of South Africa and those of the HREC, the transcriptions of the interviews, video tapes and brief questionnaire would be kept for a period of five years, in a safe place at the Department of Speech Pathology and Audiology, University of Witwatersrand, for 2 years (if a publication in an academic journal results) or for 6 years (if no publication results). The results obtained from the research may be published and participants were informed of these possibilities within the informed consent form. The overall results of the study were made available to participants, but individual results were not given to individuals, in order to maintain anonymity. Confidentiality of the data was maintained by the researcher, and no identifying characteristics of participants have been included in this research report.

2.3. PARTICIPANTS AND SAMPLING

The data for this study were restricted to a Learning Facility that caters for hearing impaired children, including those fitted with cochlear implants in Gauteng. Parents of children with cochlear implants enrolled at the Learning facility acted as participants. In South Africa, the South African Cochlear Implant Team is responsible for identifying and managing all children with cochlear implants. Under this umbrella, the Johannesburg Cochlear Implant Team (JCIP) is accountable for the management of families within Gauteng. The Learning Facility chosen for this study is closely affiliated with JCIP as it remains the main educational option for children with cochlear implants.

A non-random sample of 10 parents of cochlear implanted children enrolled at the Learning Facility was selected to participate in this study. Purposive sampling aims at producing rich, in-depth information (Liamputtong & Ezzy, 2007). The sample chosen had particular characteristics in common, in that they were parents that had decided on cochlear

implantation for their children, which allowed the researcher to gain further understanding into the topic being explored (McBurney & White, 2003). The sample consisted of parents at different stages in the cochlear implant process. Some of the children were in the process of being assessed for cochlear implant candidacy, others were awaiting cochlear implant surgery and some had undergone cochlear implant surgery in the last 2-3 years. Seven families agreed to participate in the study. Six out of the seven interviews were conducted with both parents present, and the mother of the seventh child was interviewed.

Description of Participants

Table 2.3.1 illustrates the demographic characteristics of the thirteen respondents with regard to their age range, gender, home language and education.

Table 2.3.1: Demographic Statistics of the Parents (N=13)

		n
Age Range	25-30	3
	31-35	4
	36-40	4
	41-45	2
Gender	Male	6
	Female	7
Home Language	English	11
	Other	2
Mother Education	No Matric	0
	Matric	5
	Post-Matric	2
Father Education	No Matric	0
	Matric	1
	Post-Matric	5

Table 2.3.2 illustrates the demographic characteristics of the siblings in terms of the number of siblings, their respective ages and the number of siblings with a hearing impairment. As indicated in Table 2.3.2 most of the hearing impaired children involved in this study had

siblings that ranged between the ages of 1-20 years of age. None of the siblings had a hearing impairment. Table 2.3.3 describes the demographic characteristics of the cochlear implant children in terms of the age range and gender.

Table 2.3.2: Demographic characteristics of the siblings (n=7)

Age Range	n
1-5	2
6-10	1
11-15	2
16-20	2

The age and gender of the child with the hearing impairment are illustrated in Table 2.3.3. Most of the hearing impaired children involved in this study fell in the age group of 3-6 years and that there were minimal difference between the number of males and females.

Table 2.3.3: Demographic characteristics of the child (n=7)

		n
Age Range	3-4	3
	5-6	3
	7-8	1
Gender	Male	3
	Female	4

The audiological and medical history of the children involved in this study is illustrated in Table 2.3.4. Information on the aetiology, age of onset of the hearing impairment, the age of diagnosis, the age at which they were fitted with hearing aids, the severity of their hearing loss, the age at which the children were implanted and the duration of their implant was gathered. In terms of aetiology, most of the respondents reported that they were unaware of the cause of the deafness in their children, whereas two respondents attributed the cause of

deafness to prematurity and one respondent reported the cause of deafness to be genetic. Information gathered on the age of onset of the deafness, most of the respondents reported that this was noticed during the first year of life, whereas two respondents described the age of onset of deafness to occur between 25-36 months. The age of diagnosis varied among the respondents with the majority of them reporting that this occurred within 13-24 months, two within the first 12 months and only one between 25-36 months. In terms of the severity of the hearing loss, the majority of the respondents reported a profound hearing loss, whereas the remainder were considered to be severe. Most of the children (71%, n=7) were fitted with hearing aids within 13-24 months. With regard to receiving a cochlear implant, there was an even spread of children being implanted between the age range of 25-36 months and 37- 48 months. However, two children at the time of the study were waiting to be implanted.

Table 2.3.4: Audiological and Medical History - Demographics of the Children

		n
Aetiology	Genetics	1
	Prematurity	2
	Unknown	4
Age of Onset	1-12 months	5
	13-24 months	0
	25-36 months	2
Age of Diagnosis	1-12 months	2
	13-24 months	4
	25-36 months	1
Age Fitted with Hearing Aids	1-12 months	0
	13-24 months	5
	25-36 months	2
Age Implanted	Awaiting Implant	2
	13-24 months	0
	25-36 months	2
	37-48 months	2
	49-56 months	1
Severity of Hearing Loss	Severe	2
	Profound	5
Duration of Implant	Awaiting Implant	2
	1-12 months	2
	13-24 months	2

2.4. RESEARCH DESIGN

The design selected was a survey using both a questionnaire and a semi-structured interview. The decision to place the study in a qualitative framework was made on the basis of the topic: since the project was aimed at exploring the parent's experiences of cochlear implantation, conducted within the context of the person's life, a qualitative framework could produce results that would openly document what the person felt as reflected in their own words (Minichiello, Aroni, Timewell & Alexander, 1990; Patton, 1990). This allowed the researcher to gain an in-depth understanding of issues being raised, pursue a greater detail of inquiry and openness to the topic being investigated (Marshall & Rossman, 2006). Furthermore, as the research study intended to explore parents' experiences during the decision making process of cochlear implantation, a qualitative method was deemed most favourable as it provides insight into how people make sense of their experience that is not easily provided by other methods (Liamputtong & Ezzy, 2007). Additionally, researchers have identified the need for further qualitative studies that describe the experiences of parents with diverse perspectives, especially parents with hearing impaired children of varied ages that are considering cochlear implantation (Neuss, 2006; Jackson, Traub and Turnbull, 2008).

In qualitative research, the issue of generalisation is often raised due to the selection and size of the sample. The aim of this study is to provide insight and understanding of the experiences of parents when considering a cochlear implant for their child. While the findings of this study may be less generalisable than other global studies results, they will be valuable for shedding light on the decision making process. Hence the results can be regarded as examples of what some parents may experience.

2.5. MATERIALS AND INSTRUMENTS

2.5.1. Questionnaire

A questionnaire was designed to obtain the biographical and hearing history information. The purpose of using a questionnaire was to ensure that the responses of parents were gathered in an objective and standardised manner (Pitney & Parker, 2009). Therefore, the biographical information section aimed at collecting information about the respondents (parents/families) and the child involved. It was essential that the researcher identified the parents and child's demographics as this strongly influenced the outcomes of cochlear implants (Sach & Whynes, 2005). The hearing history section included various areas such as aetiology, age of diagnosis, severity of hearing impairment, presence of additional disabilities, trial period of hearing aid, age of implant and duration of implant. The purpose of this section was to determine the similarities and differences among the various cochlear implant users. According to Marschark (2001), intervention approaches chosen by parents were heavily influenced by the differences in hearing diagnosis. This was of particular importance when determining the parental decision for cochlear implantation. The questionnaire (Appendix 6) was given to all parents to complete 15 minutes prior to the commencement of the interview.

2.5.2. Interview

Development of the Structure of the Interview

A semi structured interview was used to elicit the parents' experiences of cochlear implantation. Semi structured interviews are mainly considered when topics being investigated are of a sensitive nature as well as when the participants being interviewed come from divergent backgrounds (Welman and Kruger, 2001). They offer a versatile way of collecting data as it allows the interviewer to use probes with a view of clearing up vague

responses, seeking clarity and asking for elaboration. It is acknowledged that this research design had limitations such as it required an experienced interviewer which lent itself to researcher bias. However this study attempted to reduce researcher bias by conducting the interview with another person present.

In qualitative research, a semi-structured interview guide is highly recommended as it contains a predetermined list of questions that is posed to all participants while allowing the researcher to probe and add further questions as needed (Pitney & Parker, 2009). Further enquiry through probing is extremely valuable as it permits tangential discussions which elicit critical and noteworthy information (Liamuttong & Ezzy, 2007). Therefore, an interview guide (Appendix 7) was utilised to determine the parents experience and their readiness of cochlear implantation. The recommendations of Schiavetti and Metz (2002) were followed which included a balance between open and closed questions. These types of questions allowed the researcher flexibility and accuracy in terms of understanding and interpretation of themes (Chapin, 2004). Furthermore, the use of open ended questions encouraged the participants to “respond in their own words, in a narrative fashion” (Rembar, Lind, Arnesen & Helvik, 2009, p. 191). As a result, the researcher was able to obtain a detailed description of the participants’ own perspective and experience. Using the aims of this study together with a comprehensive literature review, questions were formulated to answer the research question proposed.

The interview guide consisted of open and closed ended questions to determine parents’ experiences with the cochlear implantation process. Questions focussed on:

- a) reasons for considering a cochlear implant,
- b) factors that needed to be considered when deciding to choose a cochlear implant,

- c) difficult and most challenging experiences during the cochlear implant process,
- d) the most encouraging and rewarding experiences during the cochlear implant process,
- e) advice and support given by the local professionals, cochlear implant team and family members,
- f) the options available to the parents at the time,
- g) the perceived benefits and risks associated with their decision,
- h) and parents' knowledge and expectations during as well as after the cochlear implant process.

A copy of the interview guide that was used with the parents is provided in Appendix 7.

Procedure

The interviews were conducted by the researcher in a private office at the Learning Centre. In addition a speech and language therapist was present for each interview. Each interview lasted between 60-90 minutes and was videoed. The room consisted of three chairs, arranged in a semi circle which facilitated an open flow to the interview. A Sony 160GB hard drive black DVD recorder was used and the camera was permanently mounted on the wall facing the parents.

2.6. DATA ANALYSIS

The information obtained during the interviews was transcribed. This method fulfilled two objectives as it allowed the researcher to devote her complete attention to the responses from the participant as well as record any non verbal behaviours observed during the interview. Thematic content analysis was used. The transcribed data were analysed using a descriptive method of analysis (Malterud, 2003). Data were read and analysed thoroughly to determine and identify phenomena. These phenomena were then categorised according to themes that

recurred within the data. According to Ely (1991) themes are thought to be statements of meaning that occur and flow through the relevant data.

Determining Categories

The transcribed conversations were broken down by reducing the raw data into meaning units. Meaning units were formed by coding thoughts and comments within each of the respective transcribed conversations. Units that shared similar concepts and ideas were then grouped into categories within each transcribed conversation. Based on the recommendations of Graneheim and Lundman (2004), all data needed to be included so that categories formulated can be both exhaustive and mutually exclusive. Once these categories within each transcript were determined, they were then compared to categories of other participants. This constant comparative method was used to determine if the categories were similar or different.

Identifying themes

The categories obtained from the inductive analysis between and within each participant transcribed conversation was used to identify themes. By comparing and contrasting the emerging categories, the researcher was able to interpret the themes that had arisen. In order to validate the categories and themes, a content analysis was conducted by two speech and language therapists. The first speech and language therapist confirmed the reliability of the raw data by checking the transcripts against the videotaped interviews. The second speech and language therapist who was not involved in the data collection read the transcripts to validate the identified categories and themes that emerged from the data. It is essential in qualitative research studies to ensure member checking in order to refine and verify the themes identified (Green and Thorogood, 2009).

Ensuring rigor and trustworthiness

In order to ensure rigor and trustworthiness the researcher employed various methods such as member checking and a pilot study. According to Graneheim and Lundman (2004), trustworthiness can be described in terms of credibility, dependability and transferability. Although the research was conducted at a single learning facility, credibility was addressed by including parents at the different stages of cochlear implantation to ensure various perspectives. This is critical as choosing participants with varied perspectives enhances the richness of the data as it allows the research question to be answered from different aspects (Pitney & Parker, 2009). To further ensure credibility, a speech and language therapist read the transcripts to confirm the categories and themes. Dependability was addressed by ensuring that the data collection occurred with a short space of time, which was a week, to reduce the threat of discrepancy during data collection. In addition, dependability was also ensured by using an interview guide during the semi-structured interviews to ensure that all participants were asked similar questions. To assist transferability, the researcher ensured that a detailed description of the context, selection and characteristics of the participants, data collection as well as data analysis were provided. In addition, based on the recommendation of Graneheim and Lundman (2004), quotations in support of the findings were provided, to also facilitate transferability.

Pilot Study

A pilot study was carried out to determine the applicability of the research project. Prior to the commencement of the research project, any discrepancies in the procedure as well as the interview guide were addressed. The pilot study was conducted on one set of parents and the aims of the study were to determine any concerns such as:

- a) Contents of the interview guide,
- b) Length of the interview,
- c) Positioning of the participants and the video equipment,
- d) Presence of an additional person in the interview,
- e) Bias,
- f) Elicitation of appropriate and effective responses from participants.

The pilot study was carried out at the Learning Centre and a few changes were considered. One of the considerations that arose from the pilot study was the ambiguity/lack of clarity with certain questions in the biographical section of the questionnaire. The second consideration was the flow of the interview questions in the semi-structured interview guide which is important in order to ensure appropriate and effective responses. These questions were rearranged to ensure that the above requirement was met.

3. RESULTS

Given that all the parents were asked to respond to the same list of questions from the questionnaire and interview guide, the responses from the semi-structured interviews were collated and are represented in Table 3.1 and Table 3.2.

3.1.AUDIOLOGICAL AND MEDICAL HISTORY INFLUENCES

The first major finding to be identified was that there were three themes that the participants identified as influencing their decisions. These themes are shown in table 3.1.

Table 3.1: Audiological & medical history influence on the decision for implants

Inadequate amplification and deteriorating hearing loss

Language and speech outcomes

Ear infections and other additional complications

These themes are discussed below.

3.1.1. Inadequate amplification and deteriorating hearing loss

The majority of the parents that opted for cochlear implants attributed their decision to the inadequate amplification that was provided by hearing aid technology. All the parents interviewed commented that the hearing aid trial did not demonstrate sufficient difference in their child's overall hearing abilities as evidenced in the following statements:

"Hearing aids were not working";

"He was not progressing well on his hearing aids, although he had good hearing aids";

"It initially started as obviously with the hearing aids and as it progressed it was clear that he wasn't getting much";

"We did the hearing aids and because he was not getting any response from that we decided on cochlear implants".

Only one parent described his introduction to cochlear implants due to his child's deteriorating hearing loss. This parent stated:

"her hearing was deteriorating very quickly in that ear and we were told that it was going to turn into nothing; her hearing loss started off in the high pitched sounds and she's losing her hearing and it's getting worse and worse and worse; it was a very difficult thing for me to understand but I think when she showed us how bad it was deteriorating on the graphs then that made sense to me"

3.1.2. Language and speech outcomes

When asked about their reasons for choosing a cochlear implant for their child, all parents decided on an oral method of communication and were enrolled in an aural rehabilitation program. The majority of the parents commented on the fact that being able to use language to communicate would be important both educationally and socially for their child. In addition, most parents reported that cochlear implants would provide better speech and language outcomes which would help their child to become "normal". Furthermore, the perceived speech and language benefit attributed to cochlear implants was seen to contribute to greater opportunities in life. These themes were articulated in the following statements:

"For her to be able to brought up in a comfort environment where she can communicate not only with us, with her friends at school";

"To try and reduce the stress and frustration that she is going through by not being able to use words";

"she will be seen as a normal child, that she can communicate whenever she wants, how the way she wants it";

"it will allow her to be a child, a normal child where it's possible";

“to give him a chance in life; it’s an opportunity for her, cos she needs to advance in life, especially educationally”;

“it will benefit her in every way and from what I understand my child”;

“she can be able to do things like a normal child”.

3.1.3. Ear infections and additional complications

The decision elect to select a cochlear implant can be dependent on additional complications such as co-morbid difficulties of apraxia or sensory integration difficulties that may be associated with a hearing loss (Gravel & O’Gara, 2003). None of the parents reported such complications. However, one parent commented on recurrent ear infections which hampered the decision making process as well as the impact of the ear infections on the child’s overall health.

“Lots of ear infections and antibiotics; which damaged her teeth and she had to have them all removed. It was more than one time that she had a very bad infection”.

3.2. LACK OF KNOWLEDGE AND RELIANCE ON PROFESSIONAL ADVICE

All of the parents reported that the professionals discussing the option of a cochlear implant were doctors, audiologists and speech therapists. When asked about how cochlear implants were introduced to them, varied answers were provided. Some parents considered a cochlear implant on the basis of recommendations made by the different professionals whilst others relied heavily on the professionals to make their decision as they did not know much about cochlear implants. What was clear was that the professionals played a significant role in the decision making process. The varieties of responses are evident from the quotations displayed below:

“We obviously didn’t know much about cochlear at that time”;

“the people involved in terms of speech therapy and Dr X advised that’s the best way to go, so we were ok let’s do it then”;

“I think once Dr X said she was a good candidate we just sought of put the hearing aids aside and carried forward in terms of the cochlear”;

“I wouldn’t say it was something we were pushed into but because of people advising and we not knowing anything about it seemed like the right thing to do”;

“I think this was basically a recommendation from the doctors”;

“I mean it was all, it was all lead by the doctors, from a professional perspective, it was what they recommended as the next best thing”;

“this was the recommendation from them and we basically left it in their hands”;

“well it was suggested to us by an audiologist”;

“if somebody suggested that we okay – okay cool cos we trust their opinion”;

“we’d go because you guys are the professionals and that’s why we ask you certain things because you’re there on a constant basis and you know what’s happening and you look at it from a physical and mental point of view and regards to involving yourself as a normal person and obviously as a professional as well”.

An overview of the factors that were considered by the parents regarding cochlear implants is provided in Table 3.2. Each factor will be discussed in greater detail and parents’ comments supporting them are included.

3.3.GENERAL FACTORS CONSIDERED

The thematic analysis showed twelve general factors that parents' identified as contributing to their decision. These are listed in table 3.2 and discussed thereafter.

Table 3.2: Factors considered with regard to cochlear implantation

Financial Responsibility
Medical Aid Assistance
Success Rate and expectation of outcomes
Operation and the safety aspect
Family Relationships, Family Support & Stability of Partner relationships
Psychological Readiness
Time Management
Aesthetics of the Cochlear Implant
Time Constraints/Urgency
Empathy on part of the child
Previous Experiences of other parents and seeing a cochlear implanted child
Professional Advice

3.3.1. Financial Responsibility

When asked about what factors were considered when deciding on a cochlear implant, most of the parents reported the vast financial implications of such a decision which ranged from the costs of the device, surgery, maintenance of the device, therapy requirements and future schooling needs.

<i>“We had to obviously consider the costs, that was very important”;</i> <i>“It’s a very expensive process, more to actually purchase the cochlear itself”;</i>
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“You could actually have an op and you find that you can’t actually have the device – you need to pay it in full before you get it installed or released so that could be a disaster if you don’t have the money”;

“Financially there were a few factors contributing to it. So it was basically the maintaining of everything, the schooling, and then any other additional stuff as well that may come later for instance, therapy bill”;

“Schooling was another cost, obviously therapy, whatever additional costs after that like maintenance of the cochlear itself”;

“as I know you can’t just put the device and send the child home, he needs to come here and go through therapies you know”.

Some parents were unprepared for the financial implications of the cochlear implant whilst others were unaware of the costs involved from the beginning.

“They didn’t tell us how much they would cost, they just said that it is costly, they never put a price tag on it”;

“you don’t think of all the costs involved, when they asked us about or told us about the deafness, we didn’t realise at the time that although we were on the highest plan it didn’t cater for any of the cochlear/hearing aids, nothing”;

“You don’t realise all the additional costs that come with it, your speech therapy, school therapy, all these things are additional costs that we never knew about and only as we are going along we like are aware of it”;

“So its ongoing costs because obviously now we have realised that it’s not just the cost of the device now, you’ve got to upgrade as you go along, plus with the upgrade you get the additional accessories, so all of its ongoing expense”;

“I mean it doesn’t end there, there are costs for the doctors which to be honest with you I only realised afterwards that it was not in there”;

“I think that for any family going into this I would really advise them to, maybe be explained to them a bit more, it’s not just that quotation – there’s more. I mean there are things that you don’t know”.

3.3.2. Medical Aid Assistance

Most of the parents received help from their respective medical aid companies. However, various medical aids meant that each one contributed a differing amount which varied the financial demands placed on each family. One parent had to change their medical aid for the cochlear implant to be financially feasible. However, the overall feelings expressed by the parents were one of relief and gratitude towards medical aid assistance.

“My medical aid covered a huge huge portion of it”;

“I think without that medical aid we would have been in a very different situation”;

“you have to go through things like applying for ex gratia payment from the medical aid and I must say my medical aid was quite generous”;

“When we went back and did our homework, to see if the medical aid could assist, it couldn’t so we then had to find a medical aid that could”.

3.3.3. Success Rate and Expectations

Most of the parents were concerned about the success of the operation. The success rate appeared to be a critical factor that needed to be considered when deciding on cochlear implantation, as evidenced by one parent who used the term “scared me to death” in relation to the success issue. Furthermore, the majority of the parents reported that they were informed by the professionals of the risks of the operation in terms of the success rate and

complications. Despite the possibility of an unsuccessful cochlear implantation together with the fact that residual hearing is not guaranteed to be preserved, parents still attempted to proceed with their decision. However, as evidenced by the following statements, the success rate of this operation weighed heavily on their minds.

“Well the biggest and the scariest part is that there is a miss there is a percentage that don’t work”;

“At the same time you get told that it might not be 100% successful, so you sought of sitting with a 50/50”;

“I think the scariest part of that was that if we go ahead and do the surgery and it doesn’t work, now she’s lost all her natural hearing in that ear”;

“Miss rate - I was very worried about that. When it comes to ..., whose my daughter she’s my whole world even 1% miss rate is too much you know and that scared me to death but I mean if you had to put it on scales 1% or whatever it is versus not hearing at all you know it’s gonna end up there anyway”;

“I had to get my head around it and we had to get our heads around it and make a decision about what was best what in her best interest”.

3.3.4. Operation and safety aspects

Most of the parents interviewed expressed concerns with regards to the length of the operation and the safety of such a procedure. In spite of being informed about the operation, risks involved and of realistic expectations, most of the parents still expressed uncertainty about what to expect, fearfulness of complications and apprehension about the sedation.

“For me, it is also just a safety part of it, I know we have been assured several times that its safe and the risks are minimal but time and again, I am like I hope that she doesn’t come out worse than she is you know and several things going wrong”;

“it’s not really scepticism as its some kind of fear you know of the unknown”;

“This op were are told is 8 hours so you ask yourself you know what will I will be doing for 8 hours, trying not to think negative you know, to have negative thoughts to consume you”;

“we know there will be few cases where it will go wrong, but so far I think their record is positive so it helps us to reduce some anxiety”;

“It was a bit scary, as you know operation can go very well or something could go wrong, they do say there is a risk where the child could have facial nerve”;

“we had to really consider the fact that he would have had to be taken to hospital and sedated and it’s not one op that you could take lightly”;

“because you think about this thing you know, people explained to us regarding the op the whole thing so now I guess there’s this part that doesn’t go away, my baby going through the knife and going through this it’s really something, its life, its huge.”

3.3.5. Family relationships, family support and stability of partner relationships

A few parents mentioned the importance of family support during the decision making process. The amount and type of support was variable with each family. Some parents reported that they were in full control of the decision making process and family members supported them through this process by understanding and remaining positive.

“ with family members, we are the leaders”;

“Our families, we explain to them, they see its better and then its fine because our concern is well their concern so our families they are wise, they are very positive, they understand what we need to do this was going to be different for them because they hadn’t basically gone through it and it was something completely new for them.”

However, some parents reported considerable involvement from both sides of the families and expressed the impact of such a decision on families with little or no experience with cochlear implantation.

“it was my mum, then it was your mum and them and it was like a whole big thing and then there was to come to a decision of what’s gonna happen which was the implants”;
“we have never had anything like that in our family, so you know the reception and how they were going to view this was a factor and I think my wife spent a lot of time explaining to them what this whole thing was about.”

Three families commented on the importance of stability within their relationships with each other. Recognition of a united front for both the children and families was deemed important.

“If the two of us are gonna have that type of unstable relationship it will obviously filter down through to the girls or into the families”;
“It’s a nice thing that we are always together when we’re going for our child”;
“I think that kind of support starts with us because if somebody is going to see a division in us, even if it was you, maybe you get impressed we come together all the time. I guess it’s very important to have a united front put by the parent, it benefits the kids”;
“if we can keep that connection then together and strong then it obviously wouldn’t cause a rift between any of the families”.

3.3.6. Psychological readiness

Most of the parents interviewed adopted a fix-it-quickly attitude and expressed little regard for their own preparation or readiness for such a decision. The urgency of the decision for

cochlear implantation appeared to leave little time for parents to explore their feelings and attitudes.

“Yes I think maybe when we first found out that there could be a problem we were forced to have it sorted out then”;

“I just have to carry on going because I feel I should not be weak in that sense I need to be strong so that if she has a breakdown about something I need to there emotionally that how I feel you can’t always just sit there the whole time and wonder”;

“I don’t think I ever actually really sat down and thought about it. Because I don’t know if I had time which sounds really selfish”.

However one set of parents did describe the importance of readiness for themselves. These parents acknowledged the significance of being psychologically ready for the child and themselves especially when faced with an unfamiliar experience.

“Psychological readiness and psychologically to be there for her”;

“Knowing that after the operation we might have to make other adjustments so psychologically we are there and we would move things around to ensure that we accommodate the process and anything that may demand our time”

“To show her that we care, love her well, support her and I think to psychologically to prepare ourselves”;

“It’s not something that we’ve gone through before, we don’t know what to expect, we might be surprised even after we’ve gone through counselling you are giving us a lot of information but you know each situation might be different, we might experience what other parents have not experienced”.

3.3.7. Time Management

Some parents were cognisant of the time implications regarding their decision for cochlear implantation. The time management revolved around appointments with the audiologists, speech therapists and also dedicating quality time for their child.

“We have to attend to understand a lot of things, therapy for her, counselling to get her adjusted, I understand every week after switching on”;

“Dedicating more time and emotionally being there for your child cos kids can actually sense through if you really there for them or just being there”;

“I am saying with this going forward, we are gonna make more time”;

“But then again with the time management factor, just reverts us to learning to move things around so that we make time for her”.

3.3.8. Aesthetics of the cochlear implant

Most of the parents commented on the aesthetics of the cochlear implant and the effect that it would have on the hearing impaired child. Interestingly, some of the parents' initial thoughts of the aesthetics of the device did not match their expectations. They expressed the desire for cochlear implants to be less conspicuous in order for the child to be readily accepted by their peers and other members of society. Although the look of the device was an important factor in the decision making process, most parents still proceeded with the cochlear implants due to the benefits associated with the device.

“That was the main thing - the look”;

“one thing that I certainly had to think about was how this thing was going to look like on him”;

“In fact I thought it's so tiny they would do the op and it would be under you won't see much”;

“although they only showed me it from the box I never saw it on the child’s ear”;

“I must admit that initially what I had in mind and what eventually I saw was completely different”;

“As far as the look is concerned, I had the impression this thing would be almost, non-conspicuous you know”;

“After the op I realised it was big, I just had this impression that you wouldn’t be able to see it”;

“So when we come out and realised it was quite a big device, you can see it quite easily”;

“I just hope that in the future technology will bring out something that is... very tiny”;

“So if you could avoid kids seeing it cos you know they always are wondering what is this? Always attracting attention to the child”;

“It brings in a lot of questions but the main thing for me was I was looking at the benefit and not really the device you know? ...the main thing was the outcome of the whole thing.”

3.3.9. Time constraints and urgency

Some of the parents expressed concerns with the length of the hearing aid trial especially when they perceived no benefit from them. One of the parents reported that the process preceding the cochlear implants had been long and would have preferred if they did not have the hearing aid trial or the medical aid delay.

“I mean ... is the type of person that things need to be done now”;

“The process from 19 months to the 3 yrs, I think was the longest process ever for us”;

“Because if anything if that 6 week trial of HA’s didn’t work which it didn’t he would have rather had the cochlear there and then”;

“So if were given the opportunity to do things differently I think we would have done the cochlear at 19 months”;

“Also with changing medical aids they gave us a 3 months gap which also entailed a waiting period”.

3.3.10. Empathy on part of the child

When parents were asked about what factors were considered when they were deciding on cochlear implantation, the majority of the parents reported that it was crucial to consider the child’s perspective. Weighing heavily on the minds of all of the parents were their child’s views and acceptance of their decision.

“You have to make a decision on her behalf, it’s not an easy thing to do; I had to think about just more than anything what was the best for her you know because it is a situation where I have to put myself in her shoes”;

“She cannot tell/ask me why am I going through these things”;

“I don’t know what she is going through and I think that’s what makes it more difficult than anything else”;

“It is very difficult to explain what it is and what’s going to happen and what to do and find out what she wants and that’s also very difficult – making the right choice as far as she is concerned, what she would want to do”.

3.3.11. Previous experiences of other parents and seeing a cochlear implanted child

A few of the parents emphasized the impact of speaking to other parents and meeting cochlear implanted children during the decision making process. Other parents did not have similar experiences but did share similar views on the importance of engaging with parents that have gone through the process.

“What happened was that I met a little girl, she was one of the first cochlear implantations and my experience with that little girl was what made me change my mind there and then”;

“it was the best thing ever you know; that little girl was amazing, she changed my life”;

“When I was crying after 3 weeks of crying, crying all the time, nobody could talk to me I stopped that night because I knew there was a good thing to come from that I mean I look at this –she does everything gymnastics, dancing, music, singing she does everything”;

“I remember there was this other day when they took us out to all the other classes to see the school and they showed me this girl, she had 2 implants and she was doing very well which helped me”.

3.3.12. Professional Advice

Another factor that contributed to the parent’s decision making process was the advice given to them from the different professionals involved. Most of the parents were satisfied with the advice given and a few parents admitted that they did not have the experience or knowledge of cochlear implants and relied heavily on the professionals to provide the information. Only one parent remarked that she was given incorrect advice on amplification options and thus causing a longer delay in receiving a cochlear implant. Upon further enquiry on the reliance of professional advice, some parents questioned their lack of investigation for additional information through research and especially the internet.

“you know for me I was just like okay cool if that’s what they say”;

“We were pretty happy go lucky if somebody suggested that we okay – cos we trust their opinion”;

“You think - why didn’t you go onto the internet and actually research it”.

4. DISCUSSION

This research study was conducted to determine parental descriptions of their experience with regard to the decision of cochlear implantation for their young children with a hearing loss. In addition, this research study also examined the influence of the child's hearing history on the decisions made, the advice given to parents on receiving the diagnosis and whether the advice given by the professionals influenced the decisions made. Furthermore, the study aimed at determining what factors needed to be considered by the parents for the child when deciding on a cochlear implant. This section will discuss and explain the findings obtained as well as consign them in future research and practice. The findings showed that the participants in this study made the decision to implant their children mainly on the basis of two variables: the urgency in getting their children amplified, and the availability of finances to fund the cochlear implant. The study showed that parents were heavily influenced by the advice given by professionals as well as the context in which the advice was given. This discussion addresses the main findings and relates them to previous findings as well as specific issues highlighted by cochlear implantation in South Africa.

Amplification: a sense of urgency

The majority of the parents reported that their primary reason for deciding on a cochlear implant was the lack of amplification that was provided by hearing aids. The parents in this study described the delay in getting amplification for their children because of delay in the identification of the hearing loss, the length of time that the hearing testing took, as well as the length of time that it took to provide amplification for the children. In addition, they emphasised the time that was taken to test out the efficacy of amplification with hearing aids. They also pointed out that despite the fact that the hearing aids were of little benefit to the

children they were encouraged to continue to wear them which parents found to be a factor that contributed to the delay in accessing appropriate amplification.

The late identification of hearing loss is a well documented phenomenon (Eleweke, Gilbert, Bays & Austin, 2008; Gray, Jones, Shipgood & Court, 2003). The premise behind early detection and intervention is timely diagnosis of a hearing loss and prompt intervention to provide the child with opportunities to develop language. Lack of awareness of a hearing loss by primary care workers and parents can cause delays in the process. Early identification and intervention have been proven to be key factors in the effective acquisition of spoken language and the potential for developing age appropriate communication skills (Pittman, Lewis, Hoover and Stelmachowitz, 2005; Ramkalawan and Davis, 1992; Young, 2002; Yoshinago-Itano & Apuzzo, 1998). Similarly, with hearing impaired children acquiring sign language, early intervention plays a crucial role in the effective development of linguistic, social as well as academic skills (Magnuson, 2000; Swanwick & Tsverik, 2007).

Van de Spuy & Pottas (2008) showed that the average age that a hearing loss was identified was around 23 months in South Africa. This is very late in comparison to the guidelines set out in the early hearing detection and intervention programs (EDHI) by the Health Professions Council of South Africa (2007), which stresses that the diagnosis of a hearing loss should occur before four months of age. In addition the study (Van de Spuy & Pottas, 2008) also revealed that the average age for participation in an early intervention program was around 31 months of age, which was also considered late when compared to the recommendations set out by the EHDI programs in South Africa Position Statement (Health Professions Council of South Africa, 2007). A number of recommendations have been put forward internationally and locally to lower the age of identification. For example,

compulsory neonatal screening as well as regular education of parents and primary care workers on the key indicators and manifestations of a hearing loss would help to ensure early diagnosis (Van de Spuy & Pottas, 2008).

Not only were the children of the participants in this study diagnosed after 4 months of age, but the lengthy audiological procedures added to the delays in acquiring amplification for the children. It is important to note that the decision to implant is based primarily on the results of objective, consistent and comprehensive audiological diagnostic procedures. However, in the paediatric population, the diagnostic audiological procedures are lengthy and difficult to interpret further complicating the fitting of appropriate hearing aids (Gray, Jones, Shipgood and Court, 2003). Despite the lengthy and complicated process of hearing aid fittings, the audiological assessment of the child's auditory development is a critical component in determining cochlear implant candidacy as it measures the extent to which residual hearing is functional. The findings of this study suggest that the counselling process should include a preliminary warning to the parents about the time that accurate audiological testing takes.

Allied to the delays caused by lengthy testing, the parental reports revealed that there appeared to have been no uniformity in the length of hearing aid trials which aimed at determining whether the chosen hearing aids were benefitting the children. This is a pattern that is evident in international practice (Eisenburg and Johnson, 2008). Having clearer recommendations regarding the trial period of hearing aids for the paediatric population would be a useful guideline for professionals and in turn help prevent delays. In a UK study that focussed on paediatric cochlear implantation, a recommendation of a 3-month hearing aid trial was made based on a retrospective audit that examined the clinical practice within this programme (Gray, Jones Shipgood and Court, 2003). There is no literature to the

researcher's knowledge to date that has determined the optimal length of hearing aid trials, and the variables associated with such trials. The results of this study point to the importance of establishing some degree of uniformity that can inform parents about the impending delay with some detail. The study also highlights the importance of pointing out to parents in advance that the delay should not necessarily influence the decision about the choice of cochlear implantation. Similarly, in South Africa, studies should be carried out to determine the appropriate length of time for a hearing aid trial whilst taking into consideration the current issues of later diagnosis as well as differing health care provision in terms of both local and private settings.

Although many parents reported that the hearing aids did not provide much benefit for their children, research has strongly shown that consistent use of the hearing aids even with no real benefit to the child will still play an important part in the cochlear implantation process (Balkany et al., 2000). The reasons behind the consistent use of hearing aids is twofold; it allows the family and child to become comfortable with wearing an audiological prosthesis; and it encourages the child to become familiar with wearing an audiological prosthesis for further later audiological testing (Gray, Jones Shipgood and Court, 2003). The findings thus alert the audiologist and others in the counselling process to make explicit to parents the justification behind encouraging hearing aid use despite little amplification. Further, the findings encourage audiologists to question their rationale behind encouraging hearing aid use given the influence that this delay has on the parents' decisions to implant their children.

Other factors contributed to the delayed fitting of appropriate amplification. Research has demonstrated that more than 40% of hearing impaired children have additional complications (Gravel and O'Gara, 2003), but this was not the case in the present study. It may be argued

that parents may have considered only additional medical complications and did take into account additional communication complications such as apraxia. However one of the audiologically-related complications that were reported was the presence of middle ear infections which confounded the process and played a role in the overall health of their children. Reports from the parents indicated frustration towards both the delay that resulted from the recurrent ear infections but also the overall impact they had on the health of their hearing impaired child who had already undergone many tests and was still waiting further testing. Information about the levels of the parents frustration associated with the delay process will help professionals streamline their process if possible or try to help parents understand the relevance of ensuring appropriate and correct testing results.

Finances: the overriding deciding variable

Cochlear implantation is very expensive and can only be done if finances are available. In this study, all participants were advised of the cochlear implant and had made the decision to implant because they were assisted with procuring finances. Hence, the key factor that parents considered in the decision making process was the financial aspect of the cochlear implant procedure. Many of the parents were unaware of the financial obligations of such a procedure as well as the financial implications of rehabilitation and schooling. Initial costing of the cochlear implant device was made available to most parents but they did not anticipate the continued costs from ongoing maintenance of the device as well as the costs associated with the intensive therapy and educational fees of a specialised school environment. Feelings of being overwhelmed, unprepared and surprise were clearly evident in parental reports.

The financial considerations in relation to cochlear implantation have been discussed in a number of publications (Duncan, 2009; Fink et al., 2007; Preisler, Tvingstedt & Ahlstrom,

2005) and clinicians are well informed about the need to counsel parents in this regard. However, the particular financial arrangements regarding cochlear implantation in South Africa needs to be considered and further research is needed to determine and document the costs of cochlear implantation in South Africa. Recommendations arising from such research would better inform clinicians in South Africa to discuss in detail the financial impact of such a decision as well as consideration of other services that will be needed for rehabilitation and schooling to better prepare the parents. The research needs to consider estimates for the costs for the device, surgery including anaesthetic, rehabilitation services which encompass regular audiological sessions and intensive speech and language therapy services as well as the possible educational schools available and their tuition costs. Provision of all the necessary information would help financially prepare the parents as well as contribute to an informed decision.

Within the discussions on the financial considerations with regard to implantation, all of the parents commented on the huge part that medical aid played in the decision making process. The financial help that medical aid was able to provide these families enabled them to begin to consider cochlear implantation and relieved the huge financial costs associated with the device. Although parental reports varied in the amount that each medical aid contributed, there was an overall feeling of gratitude and relief.

Considering the socioeconomic status of the majority of the South African population, it is doubtful whether the option of medical aid is financially feasible for most families. The dilemma arising from the reality of the financial difficulties facing most South African families would be the provision of similar equitable services to disadvantaged populations. Currently in South Africa, a major financial company that has a 10 year commitment to the

funding of the cochlear implant programme that was used by the participants in this study, together with a popular radio station are able to provide financial help to those families without medical aid as well as to those whose medical aids are unable to fully cover the device costs. The mission set out by the radio station endeavours to help those families without any medical aid. Their financial support caters for the device, surgery, audiological sessions as well as speech and language therapy input. However, in reality not every family applying would receive funding. For those families fortunate to have some sort of medical aid cover, the alternative aid which is the financial company has offered financial support after meeting certain criteria. Each family is requested to fill in a loan application form as well as provide their salary slips together with a detailed description of their monthly expenses in order to complete the standardised means end evaluation of their financial situation. Based on these calculations, financial help is made available but only for the initial costs of the device and surgery associated with the procedure. However, no provision is made for the audiological services, intensive therapy, maintenance and educational costs associated with the cochlear implant process.

Choosing the oral alternative

The majority of the parents reported that their motive for choosing a cochlear implant was the belief in improved learning and development of their child's oral communication skills associated with the implant. One of the parents anticipated psychosocial changes with regard to his or her child's behaviour and social interaction. Comparable studies regarding parental expectations of cochlear implants also revealed this expectation as parents relied on cochlear implants to provide a means for their child to hear and talk (Wheeler, Archbold, Hardie and Watson, 2009; Wie, Falkenburg, Tvette & Tomblin, 2007). This finding was further substantiated in the parental reports about their frustration with their children's limited

communication skills prior to the implant. Linked to this frustration was their concern about the children not being able to communicate with hearing people and they anticipated a positive change after cochlear implantation which would integrate their children into mainstream society.

It is evident that speech and language outcomes associated with cochlear implantation played a major role in the decision making process and therefore needs to be carefully and accurately presented to the parents. The importance of this aspect of counselling has been pointed out in previous literature (Archbold, O'Neill, Lutman & Gregory, 2008). As in the present study, previous studies have shown that realistic expectations of the outcomes of cochlear implantation should be an objective for all professionals involved in the process (Jackson, Traub & Turnbull, 2008; Rembar, Lind, Arnesen & Helvik, 2009). This means that although the outcomes of cochlear implantation can be beneficial to some children, there is a degree of variability within each child that needs to be accounted for as well as consideration of other key factors that influence outcomes.

A high success rate for cochlear implantation is dependent on a few factors namely; stringent selection criteria, an experienced surgical team and rigorous follow up (Black et al., 2007). Numerous studies have been conducted in the UK and Canada to determine the success rate of cochlear implantation in the paediatric population (Johnston et al., 2009; Migirov, Muchnik, Kaplan-Neeman & Kronenberg, 2006). However there is considerable variability that exists within these studies such as the sample characteristics and size as well as differences in the classification of certain complications which may contribute to the overall success rate. To date, no studies have been conducted in South Africa to determine the success rate of paediatric cochlear implantation.

Despite the lack of empirical evidence majority of the parents were informed of a high success rate and this played an instrumental part in their decision to proceed with cochlear implants. In light of limited data available in South Africa and the variability that exists in other countries regarding the overall success rate, a cautious approach in terms of the provision of statistics should be used by all professionals involved.

There is no doubt from the results of this study that the primary guiding factor in the decision making process was the desired oral communication outcomes. However, one of the major factors affecting the decision for cochlear implantation was the appearance of the device. Many of the parents expressed concern regarding wearing such a conspicuous device and the impact thereof on their child's ability to integrate with the hearing society. Parents expressed concerns for their child's socialisation opportunities and whether unwanted attention would be placed on their child for looking different. Interestingly, although parents were concerned about the appearance of the device they still pursued cochlear implantation. This study highlighted the consideration of the aesthetics of the device but more importantly that this did not ultimately change their decision for cochlear implantation.

As deciding factors, language outcomes and the aesthetic appearance were validated for the participants by meeting with children who had been implanted and their families. Seeing the child integrate into mainstream society alleviated some of the parents' fears and provided hope for their child's future. The participants had reported on the benefits of consulting with other parents that had undergone a similar process as being invaluable and served as useful means to discuss their fears, concerns and expectations. Although the benefit of meeting

these parents was emphasised in the transcripts, majority of the parents did not experience this. Reasons for this were not further investigated.

The need for involvement of other families and cochlear implanted children presents a challenge for the cochlear implant team. Each family's situation may be different in terms of their socioeconomic status, emotional wellbeing, social interaction and expectations and it may be difficult to find similar families. However, it may be argued that although each family's situation may be different the emotions experienced of fear, uncertainty and isolation is common (Sach and Whynes, 2005). Based on the insights of the parents, it would be useful for cochlear implant teams to compile a list of voluntary parents who have undergone cochlear implantation that would help support other families undergoing the decision making process. Careful consideration must take place to ensure that parents are paired with other parents that have the ability to provide support without forcing their ideas and beliefs (Duncan, 2009; Preisler, Tvingstedt & Ahlstrom, 2005).

As well as the benefits, meeting other cochlear implanted children can also be a challenge. Although professionals would like to show parents the successful cochlear implanted candidates with good speech and language skills, it is important for parents to also meet other children with less than optimal speech and language skills. Throughout this process, parents should be constantly reminded of the variability that exists among each child as well as the additional factors such as the age of diagnosis and intervention, cognition, child's learning style and parental input that may influence the outcomes associated with cochlear implantation (Fink et al., 2007; Niparko, 2009). Research has acknowledged the feelings of regret that parents often experience when their child's actual speech and language skills do not meet their initial expectations (Zaidman-Zait, 2007). To alleviate the feelings of regret,

professionals must be able to provide a balanced outlook of the outcomes of different cochlear implanted children.

Other concerns

From the parental transcripts, it was clear that despite the associated risks of the surgical procedure, the majority of the parents still pursued cochlear implants which may be interpreted in two ways; either they perceived the benefits of the cochlear implant to outweigh the risks involved or they believed that there was no other communication option available to them. Many of the parents enquired about the success rate and complications that may arise during this elective procedure and were satisfied with the information that was provided by the cochlear implant team. During the interview, parents expressed feelings of fear, uncertainty and anxiety when they recalled the length of the operation, the effect of anaesthetic on their young child, the actual surgical procedure as well as the child's medical well being after the operation. Other parents that were at the initial stages of cochlear implantation consideration also expressed concerns with the duration of the operation and the medical risks associated with the procedure.

Bearing in mind that cochlear implantation involves embedding a prosthetic device surgically all the way through the mastoid and middle ear into the inner ear and close to the auditory nerve, it is reasonable for parents to express concerns about the risks and success rate of this procedure. Paediatric cochlear implant surgery poses various challenges due to the high occurrence of abnormal structures, the close proximity of the facial nerve as well as miniature dimensions associated with young children (Balkany et al., 2000). Furthermore, complications of infections and device failure may be encountered after the operation. Therefore it is important for the cochlear implant teams to recognise the value of providing

accurate, detailed and bias free information to parents. Earlier cochlear implant studies have also acknowledged the significance of equipping and preparing parents about the risks associated with the operation both prior to and after the surgery (Balkany et al., 2000; Migirov, Muchnik, Kaplan-Neeman and Kronenberg, 2006).

The influence of family

Parental reports expressed the importance of family support throughout the decision making process. Although most parents acknowledged that their families did not have experience with cochlear implants, they still felt emotionally supported during their decision. Furthermore, parents placed emphasis on the importance of a united unit of mother and father for the sake of their families and their child. Feelings of grief, denial and helplessness were evident from the statements regarding their experience with their child's hearing loss which can negatively impact their relationships with other family members and their spouse. Three families did comment on the inappropriate and significant influence that some immediate family members had with regards to the cochlear implant as views of being 'pushed aside', 'questioned' and being made to feel helpless by family members, were expressed.

The importance of family relationships and stability is well established with regard to disability. Having a child with a hearing impairment can place great demands on the family structure in terms of time available, difficulties in communication as well as behavioural management (Anagnostou, Graham, Croker, 2007). Although each family is different and may cope in their own way, the presence of a hearing impaired child has been recognised to affect the stability of the family (O'Neill, Lutman, Archbold, Gregory & Nikopoulos, 2004). Spousal relationships are also affected as according to Luterman (1999), having a hearing impaired child may create stress within the marriage.

It was interesting to note that most families placed such a great deal of value on extended family and spousal support when deciding on a cochlear implant. As the process of cochlear implantation is complex and time-consuming since it involves consistent intensive rehabilitation, the significance of emotional support is highlighted. One of the recommendations arising from these findings would be to ensure that cochlear implant teams are equipped with the necessary structures and strategies that are necessary to deal with the impact that this may have on the family. This is an area of expertise that would require trained professionals to provide skilled intervention as a lack of emphasis on parents' ability to cope can affect the eventual outcomes.

The process of cochlear implantation did evoke feelings of being alone and uncertainty of the process which was evident from the parental narratives. The majority of the parents talked about putting themselves in their child's shoes and how the decision of cochlear implantation may alter their future. The phenomenon of trying to understand the difficulties that one may encounter throughout life is not uncommon in the literature regarding disabilities (Luterman, 2003). This study reiterated the importance that parents placed on their accountability for their child's future.

Professional power

Information is gleaned in various ways and from various sources. Confirming previous research, this study showed that the significant nature of these decisions regarding implantation require that the parental need for information on all the various options available is met (Jackson, Traub & Turnbull, 2008; Most & Zaidman-Zait, 2007; Zaidman-Zait, 2007). As evidenced in the statements from the parents about the stress, feelings of disempowerment

and confusion that are felt during this decision making process, it is imperative that professionals tread carefully in terms of the information given to ensure that all options are provided while maintaining an unbiased outlook.

Parents often defer the decision making to professionals instead of taking control (Archbold, Lutman, Gregory, O'Neill & Nikolopoulos, 2002). Further to this, Li, Bain & Steinberg (2004) recognised that the decision to consider a cochlear implant is strongly influenced not only by the eligibility criteria but also through professional recommendations. However, it has been acknowledged that professionals can help the parents to respond to the decision making process challenge by educating them on the different options available as well as by providing unprejudiced support and advice. In reality, the implementation of information-giving-without-bias can be difficult as professional support and advice can be fraught with many controversies (Duncan, 2009).

To fully appreciate how possible controversies could affect the decision making process, it would be important to embed the parental narratives in the context of the philosophy and practice of the facility involved in this study. The facility caters for both preschool hearing and language impaired children with an emphasis on oral communication. A variety of services are provided by the facility which includes diagnostic assessments, habilitation in oralism and education of preschool children with amplification devices. There are 4 approaches being considered by aural habilitation therapists in the management of children with a hearing loss (Lim & Simser, 2005), namely; visual methods which involve signing; total communication that combines lip reading, speech, natural gesture and some signs; Auditory Oral which uses lip reading and natural gesture and children are often placed in a school setting that emphasises auditory teaching and lastly, the auditory verbal approach

which strongly emphasises the importance of listening as the primary modality in the acquisition of spoken language (Lim & Simser, 2005; Wu and Brown, 2004). In order to benefit from the latter three of the approaches, a hearing impaired child would need to be given amplification. The historical philosophy of the facility has been to adopt the auditory oral and auditory verbal approach which helps understand the context in which parents made their decisions about cochlear implants.

Hence it must be argued then that despite the expected ethical and legal practice of professionals involved in the management of the hearing impaired population, the influence of an oral environment played a crucial contextual role in which the decision for a cochlear implant was made. Therefore, the choices facing these parents were to be either part of the Deaf world which meant that they would be referred elsewhere and would leave what was up to that point a source of support and information or become part of the hearing world which would involve hearings aids/cochlear implantation and more importantly remain part of a familiar oral environment. Acknowledging the oral environment in which cochlear implant decisions are made brings to the forefront the professional behaviour and attitudes of those involved in helping parents make life changing decisions for their hearing impaired child. Since the decision for cochlear implantation was made in a facility that promotes oralism one would hope that professionals were unbiased and had a healthy respect for Deafness as well provided the option for entering the Deaf world. However, cochlear implantation literature has frequently described the controversies and difficulties in remaining unbiased (Duncan, 2009; Johnston et al., 2009; Li, Bain & Steinberg, 2004). Possible controversies highlighted included the professionals own beliefs and expectations, the company's philosophy and outlook as well the fact that parents that may have differing views (Duncan, 2009). Therefore the implications of any attempt of professionals to force hearing parents into their preferred

communication mode are fraught with both legal and clinical consequences. It is crucial that professionals step up to the challenge of providing information-without-bias so as to ensure best practice.

Bearing in mind that the parents of hearing impaired children that visited the facility either wanted oralism for their child or did not know what to do with their hearing impaired child, it provides a significant insight on the background of parents' knowledge of hearing impairment. Most of these parents were ignorant of the Deaf culture and the lack of detailed understanding as well as experience of the varying options available to them should be made explicit. Literature has discussed in detail the concept of ethnocentrism which refers to "the tendency to evaluate other cultures in terms of one's own" (Niparko, 2009, p. 222). Hence the ethnocentrism outlook concludes that any culture that is unfamiliar is hence inferior. One may argue that as these parents were immersed in a hearing and oral environment, it would be crucial for them to also experience the Deaf world in order for them to make a balanced, informed decision and prevent an ethnocentrism viewpoint. There was no evidence that the participants in this study had been guided by the advising therapists of all the various options, and had also not been helped to visit Deaf culture and experience its advantages.

Psychological readiness

The construct of readiness in decision-making has been described in the literature in a variety of fields. Some parents commented on the necessity of being in a state of psychological readiness in order to be able to make the various decisions in the cochlear implantation process. Numerous studies have found that the introduction of a hearing impaired child brings about significant changes in the parents own life (Anagnostou, Graham and Croker, 2007;

Burger et al., 2005). In addition, they have shown that parents have to often adapt to having a hearing impaired child which may take time (Rembar, Lind, Arneson & Helvik, 2009).

A possible suggestion arising from the needs of parents deciding on cochlear implantation would be to use a standardised assessment tool such as the Ottawa Decision Support Framework cited in Johnston et al., (2008) which considers 3 fundamental psychological dimensions of decisional need, decisional quality and decisional support that is critical in the cochlear implantation process. The Ottawa Decision Support Framework would hence be able to evaluate the psychological needs of each family which in turn will help the cochlear implant team to help them as they move through the decision making process. Cochlear implant teams often employ the skills of a psychologist which may result in increased insight into the family's psychological needs. Hence it would be beneficial to have a trained professional as part of the cochlear implant team that would be equipped with the knowledge and skills necessary to guide these parents and further explore the feelings experienced throughout the process of cochlear implantation.

Another consideration that is closely related to psychological readiness is time management. Appointments for hearing, speech and language, medical assessments need to take place in rapid succession to prevent further delay and this may place heavy demands on the family in terms of time commitment. Furthermore, these assessments are usually carried out by different professionals, location and times which families will need to fit into their daily routine as well as work. As reflected in the parental narratives, some parents were attempting to prepare for the time demands that we going to be placed on them while others were not fully cognisant of the time commitments that cochlear implantation entailed.

As depicted in Figure 1, the two overriding factors in this study were the sense of urgency and concerns about the child's future that played a significant role in the decision making process.

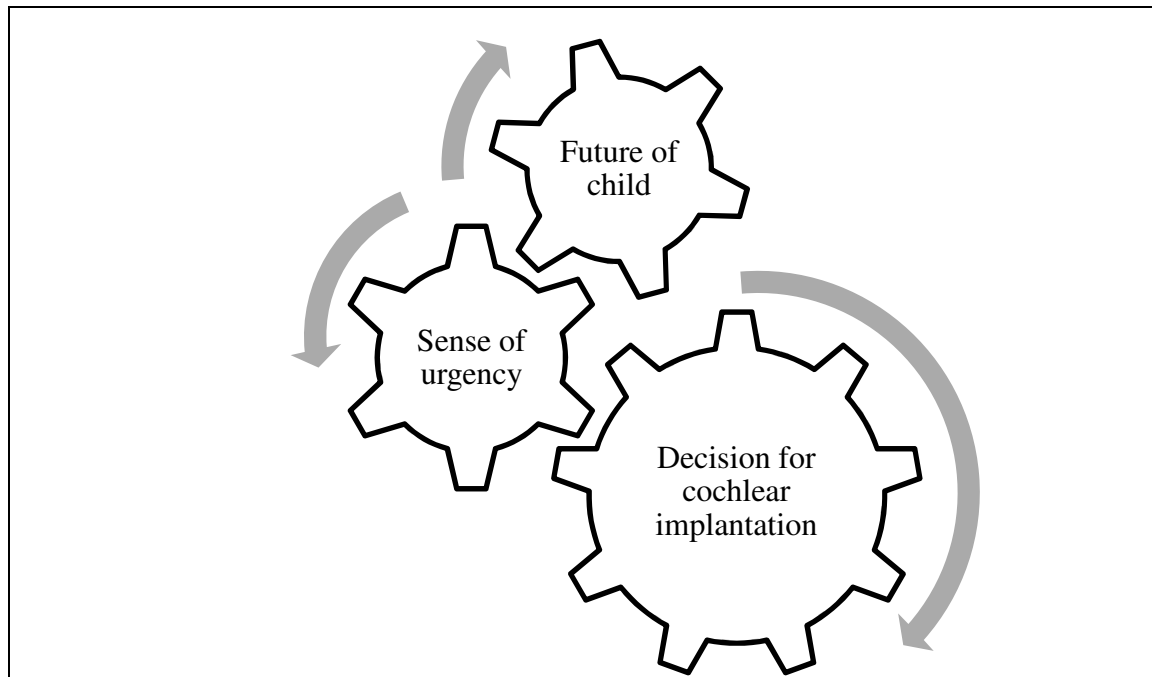


Figure 1: Overriding factors in the decision making process

The sense of urgency felt by the parents related to the tremendous delay involved in the time taken to verify and make the diagnosis, then ensuring appropriate amplification, the long trial period of hearing aids when there appeared to be no/little audiological benefit as well as the additional complications of middle ear infections. To add to this, the need for early identification and intervention that all professionals continue to strive towards as well as the implications on the overall progress of the child's speech and language contribute to this ever growing sense of urgency.

While parents are dealing with the diagnosis, the impact of the hearing loss on their family's lives as well as being subjected to different professionals during this process and this constant sense of urgency, they also needed to consider their hearing impaired child's best interests. With reference to Figure 1 it is clear that the parents' concerns for their child's future heavily influence the decision for cochlear implantation. Hearing parents' desires for their child to hear, talk and communicate as soon as possible was clearly another dominant factor in this study. The interaction of the parents' sense of urgency and the concerns over their child's future is represented in Figure 2.

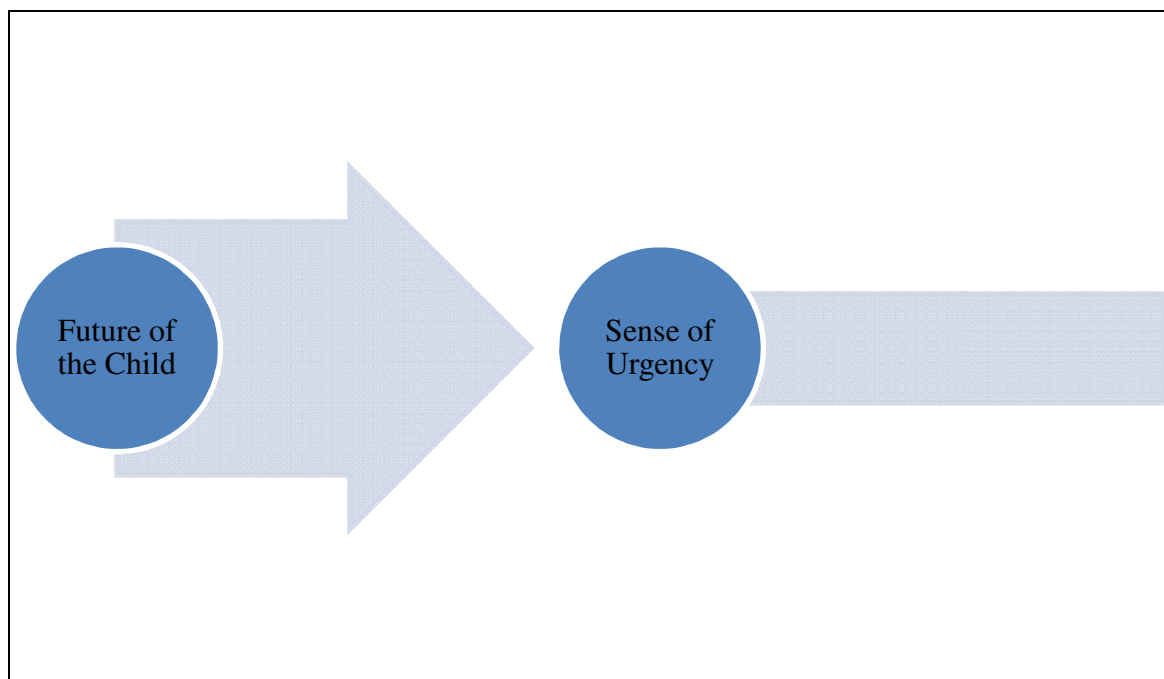


Figure 2: Interaction of the two factors in the decision making process

Parents' were primarily concerned with their child's future, in that they were alarmed about if and when their child would be able to hear, to make sounds and to communicate with them and the rest of their family. The concerns with their child's future further fuelled their sense of urgency in ensuring that delays could be prevented.

The other contributing variables that needed to be considered are depicted in Figure 3. Once these parents were offered the option of cochlear implantation, there were a number of factors that then needed to be considered.

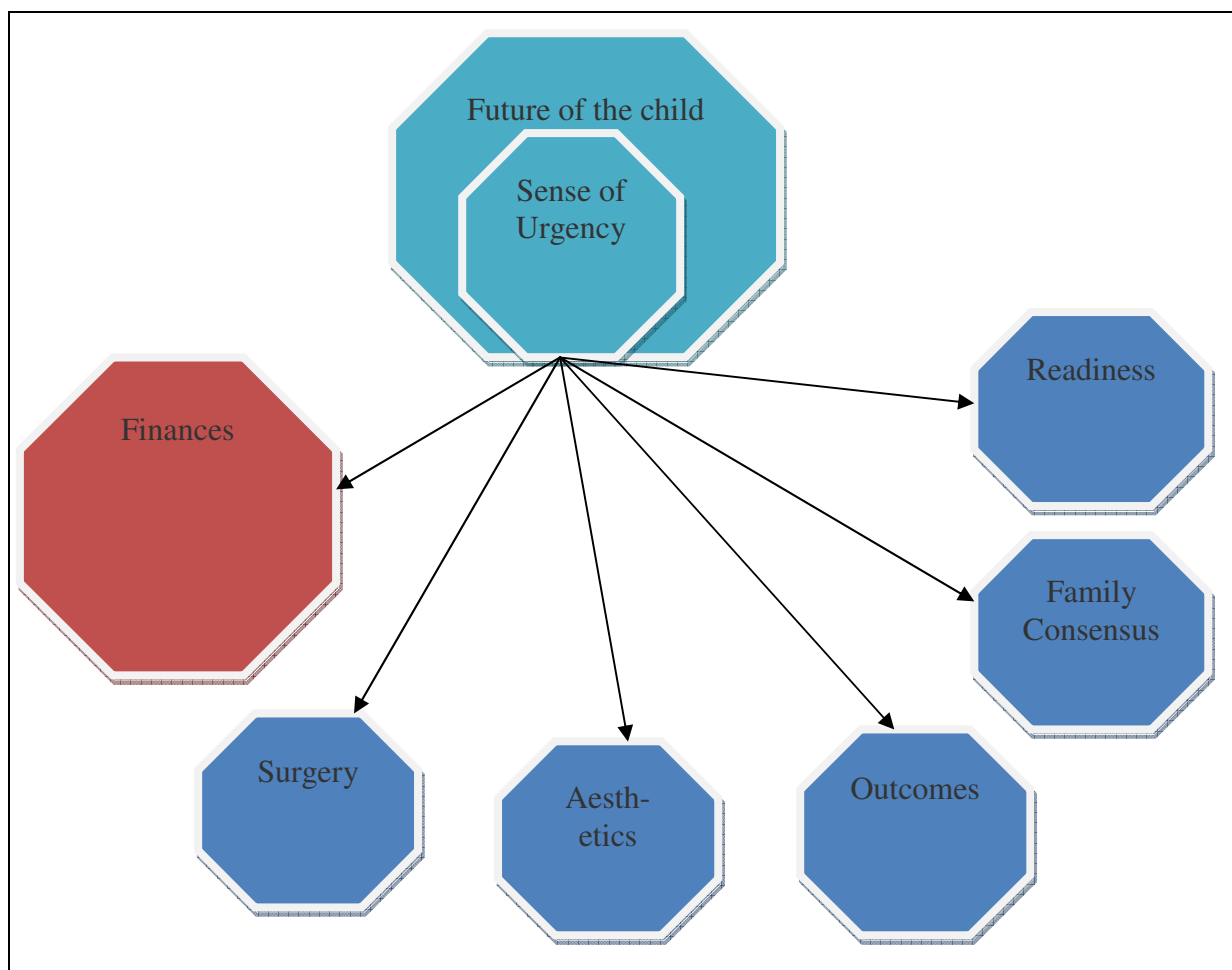


Figure 3: Influencing variables

As can be seen from Figure 3, the sense of urgency and the future of the child in terms of their ability to hear, talk and be educated govern the parents' decision making process. From this structure other factors scaffold in the overall consideration of the cochlear implantation process. The biggest variable when deciding on the cochlear implant was the availability of

finances. Affordability and maintenance of the cochlear implant device which included rehabilitation and educational costs played a significant role in the decision making process. Availability of these costs to the parents as well as informing them of all the possible incurred expenses is highlighted in this study. Without this vital piece of information, parents are inhibited from making an informed decision as financial strain may have severe implications for the family in the long term.

The following three variables namely surgery, aesthetics and outcomes are also considered within the governing structure of a sense of urgency and the future of the child, although not to the same degree of importance. Despite the perceived risks that are associated with the cochlear implantation process and the cosmetic implications of the device, the cochlear implant was still acceptable in relation to the huge significance placed on the child's future and on oral communication. Furthermore, as indicated in Figure 3, family consensus and parental readiness were also considered under the bigger umbrella of the future of the child and the sense of urgency but it becomes clear that these variables mainly contributed in the preparation of the parents in the cochlear implant process.

Like similar cochlear implant studies, the findings of this study demonstrated the parents' motivation to continue with the cochlear implant (Incesulu, Vural & Erkam, 2003; Johnston et al., 2008). However this study further showed that surgery, aesthetics, outcomes, family consensus and parental readiness needed to be considered in preparation for the cochlear implantation process. Addressing these concerns with the parents involved in the cochlear implant process would aim to reduce the level of stress incurred and should be a clinical priority for all professionals involved.

A model of power

Figure 4 represents the three themes that emerged as the leading factors in the decision making process.

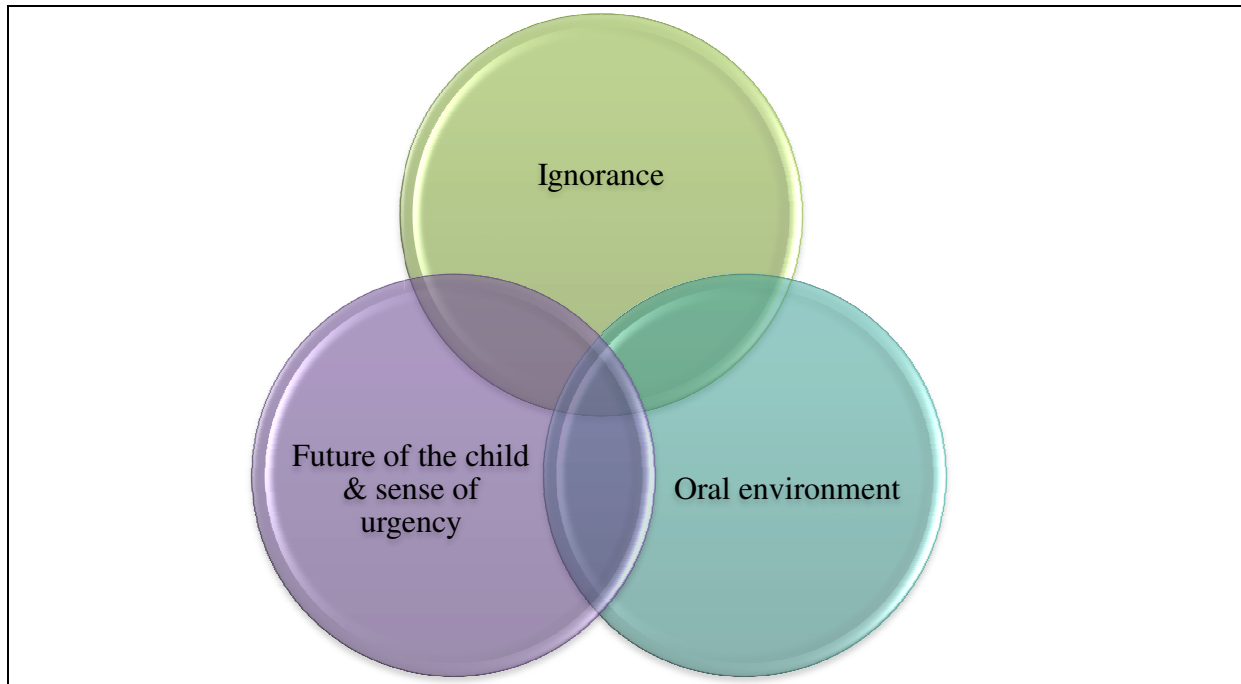


Figure 4: Power of the professionals in the decision making process

In this Figure, three factors are shown to have underpinned the decision making process demonstrating the power that professionals have under these conditions. The immersion of parents in an oral environment, coupled with the fact that most parents were ignorant of the Deaf culture and lived with constant worry for the future of the child as well as the ever growing sense of urgency of parents, places the decision making abilities in an unfavourable context.

The impact of the environment in which parents make the cochlear implant decision should not be taken lightly. At a time when parents are struggling to deal with the diagnosis of a

hearing impairment, the time spent in an oral environment can be influential especially when surrounded by a child friendly atmosphere, happy families and strong supportive framework for developing speech and language. To add to this, regular follow up visits for counselling and diagnostic audiology occurring at the same place fosters a sense of familiarity which can also influence the decision making process.

The lack of knowledge about deafness has widespread implications on the decision making process. Conflict arises when parents are faced with a hearing impaired child, as being part of the Deaf world encompasses a completely different language system which is ultimately not common with the hearing society. Hence Deafness bestows a life experience that is fundamentally different due to the contrasting modes of communication. Having no experience with the deafness, parents are placed in a vulnerable position whereas decisions of the child's future need to be made. Taking cognisance of this fact, parents should be strongly encouraged to make contact with Deaf individuals and opportunities should be created where parents can be exposed to the Deaf culture.

Understanding of the parents' ignorance of the different options available to them as well as the impact of the context in which the decisions are made, sheds light on the power that professionals possess and contribute to the decision making process. When counselling, diagnostic audiology and habilitation is taking place in an oral environment, the professionals involved yield tremendous power over the decision making process. To overcome the lack of knowledge, professionals should at the outset provide parents with all the relevant information while encouraging parents to ask questions. Building on this, professionals should carefully and considerately determine the cultural beliefs and attitudes of the parents

as well as their aspirations of their child's future while ensuring that both the hearing and Deaf world is equally represented.

The findings of this study together with a view of the broader background, contribute to an overall appreciation of the power that professionals possess. Acknowledgment of this tremendous professional influence has clinical implications for the decision making process and should be given considerable attention.

Limitations

There were some limitations of this study that needed to be addressed as it may have affected the interpretation of the findings. Firstly, the limited sample size does not allow the generalisation of these findings. Although the study focussed on a few parents' experiences, the qualitative nature of the findings of this study is aimed at extending and confirming the existing body of literature on parental views and experiences with cochlear implantation. Furthermore, the inclusion of parents during the various phases of cochlear implantation was deemed representative of the different stages of the decision making process.

Secondly the inclusion of another person in the interview may have affected the dynamics. However, the presence of another person was important to reduce researcher bias.

Another consideration is the fact that the study recruited parents from one Learning facility. It may be argued that the experiences of parents during cochlear implantation process are different in other facilities. Inclusion of other facilities providing a similar service in South Africa would have strengthened the study's findings.

Future research implications

A replication of this study involving other learning facilities should be undertaken. In this way, the findings will allow comparison of parental experiences during the cochlear implantation process in the different environments. Information gleaned from this research would be valuable to professionals as it would highlight the similarities and differences within each setting which will contribute to service delivery.

Further research should also be conducted to determine the factors that contribute to the delay in the amplification and hearing aid process, particularly in the South African context. Investigation of the possible causes for the delays in amplification would shed valuable insight for both the professionals and parents involved. The intention of the research should be to provide a documented outline of the actual process so that parents could anticipate each step.

This study also highlighted the broader family context and further research into how to involve the extended family is indicated. Since family support and approval appeared frequently in the parental narratives, it would be essential to include the extended family in the cochlear implant process.

In addition, future research needs to focus on the financial implications of cochlear implantation. The key consideration for parents in this study was the finances associated with the cochlear implant. A more in-depth look at the cost and affordability of cochlear implants among South African families should be investigated.

Another research directive should aim to investigate the power of professionals involved in cochlear implantation in greater detail. Professionals' views, beliefs and attitudes on cochlear implantation and deafness at various institutions must be examined further. The findings of this study will have significant implications on clinical practice in the field of cochlear implantation.

6. CONCLUSION AND IMPLICATIONS

This study aimed at determining the factors that influenced the decision making process at various stages of the cochlear implantation process. The in-depth analysis of parental narratives and the discussion of the various contributing factors affecting the decision making process, allows us to fully appreciate the greater and ultimately more influential forces that govern the parents decision.

Furthermore, there are some important clinical implications that have arisen from this study. The key finding informing clinical practice is huge responsibility and role of professionals. Providing all relevant information to make an informed decision while maintaining a bias-free environment is strongly encouraged. However, the term “relevant information” can be used loosely and hence certain recommendations that have been highlighted in this study should be carefully considered. The initial recommendation would be the request for all financial costs is available to parents in addition to the different communication options whilst allowing them opportunities to be part of both the Deaf and hearing world. Furthermore, considerations of the impact that any delay during this process has on the family is critical as emphasised in this study and parents should be pre-warned of the delay involved in the amplification process.

In terms of the theoretical implications, this study, not unlike other cochlear implant studies or the history of cochlear implantation demonstrated the chasm of the hearing and the Deaf world (Hauser, O’Hearn, Mckee, Steider and Thew, 2010; Kermit, 2009). The practice of cochlear implantation has long been surrounded by the ethical and contentious debate of the actual process, the psychosocial aspect of the child, the perceived cultural identity of the child and the match of this identity with the rest of the hearing society (Niparko, 2009). The

inclusion of professionals in this great divide is also not a new phenomenon (Spencer, 2009). However, the power that these professionals yield in the decision making process at such a critical time was a crucial finding and is extremely important in the contribution of ethical practices of professionals. The vulnerability of the parents and the perceived expertise of the professionals create an unbalanced as well as inferior relationship which is ultimately adds a further dimension of influential power to the cochlear implantation process.

Examining the two most prevalent factors as well as other contributing variables against the broader background of ignorance and an oral environment, provides the comprehensive picture of the conditions in which parents actually come to make the decision. It is clearly apparent that although certain variables which varied in terms of importance, such as finances, surgery, aesthetics, outcomes, family consensus and parental readiness were considered, the overall motivation for their decision lay on two important factors which were the future of the child and the sense of urgency. However, the findings of the study revealed that the decision to implant was not as simplistic as the reliance on two factors but rather the interaction of the other two dominating forces being the ignorance of the parents and the influence of the decision being made within an oral environment.

The most salient question that has emerged from this study is whether professionals have fully recognised their tremendous influential power over critical decisions that involve vulnerable, uninformed and anxious parents. Linked to this question is the further enquiry of professional insight and reflection of ethically sound practice through the provision of unbiased information and support.

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APPENDIX 1

APPENDIX 2

Please complete the form below: Confidentiality Agreement

Dear Shireen Govender,

I am aware of the purpose of this study. My role as an independent person in the interview has been explained as well as my role in interjecting during the interview should I feel that the questions being asked are inappropriate or not within the interview guide provided in Appendix 5. I understand that confidentiality needs to be maintained and will not disclose any information gained during the interviews.

Kind regards,

Speech and Language Therapist

Date

APPENDIX 3

Dear Parents

Request for your participation in a research project that aims to determine the factors considered when making a decision regarding a cochlear implant

I am a Masters Student in Speech Pathology and Audiology at the University of Witwatersrand. As part of the fulfilment of my degree, I am required to complete a research project related to the field. The title of my proposed study is: Making the Decision regarding cochlear implants. As part of this study, an interview will be conducted in order to elicit parent's views on their decision regarding cochlear implants. I would like to invite you to participate in the study by taking part in the interview, which should last between 60-90 minutes.

Participation in this study is completely voluntary and you may withdraw at any stage without notification, and without negative consequences. Confidentiality will be maintained as research data will be reported on anonymously in my research report. As this topic may be sensitive in nature, parents will be provided with the option of voluntary counselling with a qualified psychologist affiliated with the Learning Facility at no cost to them. The results of the findings from the study will also be available on request. In addition the publication of the results of this study will be available on the website.

For any questions, concerns or further information, please feel free to contact me on 0834549484. On any queries or complaints regarding the research study, please do not hesitate to contact the University of Witwatersrand, Human Research Ethics Committee (HREC) at (011) 717 2229. Your cooperation in this regard will highly be appreciated

Yours sincerely

Shireen Govender
(Researcher)

Karen Levin
(Research Supervisor)

Making the Decision regarding Cochlear Implants

Letter of Consent: Participation in the Study

I hereby declare myself willing to participate in the proposed study as set out in the letter. I have read the information sheet and understand that my information will be kept confidential. I am also aware that my participation is totally voluntary and that I may withdraw at any time.

Name: _____

Signature: _____

Date: _____

Please complete the form below: Consent for Videoing

Dear Shireen Govender,

I am aware that for the purpose of this study, the interview will be videoed. I agree to allow the interview to be videotaped and understand that this videotape will be used for analysing the responses to the questions asked in the interview. I understand that this videotape will be stored in a locked cupboard at the Learning Institute. I understand that this video will not be stored, transmitted or in anyway be made available on the internet. I agree to allow this videotape to be used in the research project only under the direct supervision of Shireen Govender at the University of Witwatersrand and that my information will be kept strictly confidential at all times.

Kind regards,

Name

Date

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

Questionnaire:**A. Background Information:***Parents Characteristics:*

Mother's Age: _____

Fathers Age: _____

Mother's Country of Origin: _____

Father's Country of Origin: _____

Mother's Occupation: _____

Father's Occupation: _____

Mother's Years of education: _____

Father's Years of education: _____

Family Characteristics:

Number of siblings: _____

Number of deaf siblings: _____

Age of Siblings: _____

*Child's Characteristics:*Gender : M ☐ F ☐

Age: _____

Hearing History:

Aetiology/Cause of Deafness: _____

Age of onset of Profound Deafness (Birth/after) : _____

Age at Diagnosis: _____

Age fitted with Hearing Aids: _____

Age implanted/fitted: _____

Age at Entering Preschool Intervention: _____

Severity of Hearing Impairment: _____

Presence of additional disabilities: _____

Family history of deafness: _____

Mode of Communication Prior to Implant (gestures/signing/babble/jargon/words): _____

Mode of Communication Used After Implant: _____

Duration of Implant: _____

Implant Type/Make/Model: _____

Any issues since implantation: _____

Interview Guide:

1. Can you tell me why did you consider a cochlear implant for your child/Reasons behind the decision?
2. Can you describe what you as a family experienced throughout the process of cochlear implantation?
3. Can you briefly outline some of the factors that you needed to consider when making the decision to implant? Each factor needs to be discussed in detail. Tell me more about _____?
4. What was the most difficult or challenging experience **for you and your family** through this process?
5. What has been your most encouraging or greatest moment through this process?
6. Has the implant had a negative or positive effect on **the child** and **the family**? Please describe further?
7. Please tell me about the advice/support that you received from your local professionals?
8. Please tell me about the advice/support that you received from your cochlear implant team?
9. Do you have any support structures? If Yes, please elaborate?
10. How would you describe your child to someone that you didn't know?
11. How did he/she communicate prior to the implant?
12. How did he/she communicate after the implant?
13. Have there been any changes to your child's communication mode?

14. What are your views on your child's communication after receiving a cochlear implant?
15. Knowing now what you know about **the process**, the **different communication options** and **educational implications**, would you have done things differently?
16. What advice would you give other parents considering a cochlear implant for their child?
17. What, if anything, would you have liked to happen differently?