

THE EDUCATIONAL PSYCHOLOGICAL EFFECT OF THE COCHLEAR IMPLANT
ON THE HEARING-IMPAIRED CHILD'S FAMILY.

by

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Finally, for the support and encouragement, I wish to thank my husband Louis, to whom I owe so much.

To Him be the Glory

Although hearing impairment is a handicap, I have experienced that hearing impaired children have a special grace like the ostrich in Job 39:13 – 18:

“ The wings of the ostrich flap joyfully, but they cannot compare with the pinions and feathers of the stork... Yet when she spreads her feathers to run, she laughs at horse and rider.”

Title: The educational psychological effect of the cochlear implant on the hearing-impaired child's family.

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Summary

The cochlear implant represents a radical intervention in the hearing-impaired child's life, which has a profound influence on the feelings and emotions of the child's family. In this study it is endeavoured to identify and to describe this influence. A literature study was done. Families of implanted children in Scotland and in South Africa filled in questionnaires and interviews were held. This study illuminates the fact that parents suffer stress and have various concerns before as well as after the implant. Different reasons why parents decide to give their child a cochlear implant are described. The researcher came to the conclusion that the implanted child functions in a more balanced way and that parents are very satisfied after the implantation.

The effect of the implant is described under the following categories: communication, feelings of parents, effect on the deaf child, normality, effect on parents, effect on siblings.

The educational psychological effect of the cochlear implant on the hearing-impaired child's family.

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The educational psychological effect of the cochlear implant on the hearing-impaired child's family.

Chapter 1: Orientation to the study

1.1 Background

Hearing impairment has always been regarded as one of the most far-reaching disabilities for a human being. It has a poignant effect on the impaired child as well as the child's family. Researchers and other interested people have done a lot of research on a wide variety of subjects concerning hearing impairment. Topics like the medical aspects of hearing impairment, the physical aspects of the ear, the emotional, psychological, social and educational effects of hearing impairment have been looked at and are widely discussed and researched. A lot has been done to find out about the factors related to this impairment, like the stress on the child, the mother, the father and the rest of the people in the child's social and family group.

The problem we are looking at has to do with the fact that a child cannot hear. Being deaf is a major handicap. One of the biggest facets of this handicap is the problem of not being able to communicate verbally. If a child cannot communicate, it has a devastating effect on the child's educational, psychological and social development.

There are a few different ways of helping the hearing-impaired child. The most common way is the using of hearing aids. Hearing aids have developed from very big, uncomfortable aids (that were carried in suitcases by the child), to very effective and unobtrusive aids. Children gained a lot by using hearing aids. It even helped a lot of children to learn to speak and communicate verbally. The effectiveness of the hearing aid however, is limited. The profoundly deaf child finds it difficult to learn to speak with the limited information that the hearing aid provides.

The cochlear implant is a fairly new development in the science of aids for the hearing-impaired. It is known for its improved quality of sound. The hearing-impaired child benefits in most cases from having a cochlear implant.

This improved device seems to have a major effect on the hearing-impaired child. The child can hear many more sounds, can learn to communicate verbally and gain a lot of confidence. All these have an influence on the hearing-impaired child's family.

The researcher has been much involved with hearing-impaired children, as a teacher, a parent and a counselling therapist. It was inspiring to see what happens to a child after the implant. It was always reassuring to see how well the parents and the families adapt to their new circumstances, that is the transition from a hearing-impaired child with very limited audio input, to one with a remarkable improvement in audio input by means of the cochlear implant.

It always struck the researcher that the families in general seem happy and satisfied after the implant. Because of all these observations, the researcher was stimulated to determine the emotions, feelings and other related educational psychological factors of the family of the child with a cochlear implant.

1.2 Analysis of the problem

1.2.1 Awareness of the problem

The researcher was part of a support group for families of children with cochlear implants. She was very much involved in the different families' lives, as she was also their parent counselling therapist at the nursery school where these hearing-impaired children were trained.

During a meeting of the support group she listened to different brothers and sisters of children with cochlear implants. It was very clear that the brothers and sisters had their own unique way of coping with this implantee. While a teenage brother of one of the implantees spoke about his deaf sister, he burst into tears because he felt sorry for his sister. He concluded by saying that life was much easier after his sister had the cochlear implant.

Was he really sorry for her? It might be that children struggle with other emotions and feelings like stress, shyness and feelings of being uncomfortable, having a hearing-impaired brother or sister. This situation contributed to the researcher's initial ideas that the cochlear implant not only has a notable effect on the hearing-impaired child's functioning, but also has a definite effect on the family. The relations between the family members and the hearing-impaired child, as well as the relations amongst each other are influenced in some or other way by the cochlear implant.

The effect of the cochlear implant on the hearing-impaired child does not only improve hearing. The fact that the child can hear better has other positive implications. This is why the study is important for the educational psychologist. Hearing impairment in children involves a variety of aspects of the child's life. Some of these aspects are medical, because it has to do with the ear and its functioning. Some of the aspects are social, because it has implications for the way the child functions in social structures. The educational psychological approach embraces the medical and social aspects as well as other aspects of hearing impairment.

The educational psychologist deals with the child as a whole. Hearing impairment affects communication. When communication is impaired, the child has problems with general development. The educational development of the hearing-impaired child is complicated. A problem with communication also has an effect on the child's relations. The relation to the teacher, his friends and himself is influenced in a negative way. If there are problems with the child's general development, communication, relations and educational development, the hearing-impaired child will eventually have problems with self-image, self-concept, and eventually with self-actualisation.

As a result, parents and siblings experience stress with a hearing-impaired child in the family. Parents find it difficult to come to terms with the fact that they have a hearing-impaired child. Parents are overwhelmed by emotional feelings like feelings of guilt, anger, anxiety, denial, sadness and shock. Siblings normally feel that they are

neglected, as the hearing-impaired child gets more attention. Some siblings feel that they are to blame for the hearing impairment. Siblings feel sorry for the hearing-impaired child, but do not always know what to do to help with the situation. Siblings feel anxious, because they see their parents grieve and do not know what to do about it. Siblings do not always understand exactly what the effect of hearing impairment could be.

Becoming aware of the fact that a cochlear implant could have an effect on the child and the family, a lot of questions arise:

- Who in the family is mostly affected by die cochlear implant?
- What are the parents' feelings?
- What feelings does a sibling have concerning this implanted brother or sister?
- What effect does the implant have on the siblings?
- What effect does the implant have on the family's budget?
- How does the implant affect the family's social life?
- How does the implant influence communication between all the children?
- How does the implant influence communication in the whole family?
- How does the implant affect the volume settings of the radio and the television?
- What are the implications for listening to music in the house?
- Does the implantee enjoy music nowadays?
- Does the implant have any effect on security regulations in the family?
- Do the parents see a change in the interaction in the family as a whole?
- Is there a significant difference in the exercising of discipline in the family?
- Do the members of the family understand the implantee better?

Matters concerning the hearing-impaired child are:

- How does the hearing-impaired child feel about being deaf and wearing a cochlear implant?
- Does he/she have more or less self-confidence than before the implant?

- Does the child feel part of the environment?
- Does the child struggle with loneliness, feelings of depression, feelings of incapability?
- Does the child have feelings of anger? If so, against whom?
- Does the child feel that he or she is a burden to the family?
- Does the child need help in practical things like buying, using a telephone and communication?
- Does the implant enable the child to participate in more activities?
- Does the hearing-impaired child feel shy about wearing a cochlear implant?
- How does the child feel about the rest of the family?
- Does the child feel that the family understands his or her situation?
- If attending school, what does the child experience as difficulties?

1.2.2 Literature overview

The following authors have all made important contributions to the study of certain aspects that are included in this dissertation. The researcher regards this as a point of departure, as these are some of the most recent literature available on the different aspects of the topic:

The phenomenon of hearing impairment and the different facets of it, are discussed to a great extent. A number of themes are discussed:

The impact of deafness on the parents is discussed to great lengths by a variety of authors:

- ❖ Moores (1973, 1996), Atkins (1987), McKellin (1995), Murphy (1979), Luterman (1987) and Greenberg (1983) give lengthy discussions on this topic.
- ❖ Coetzer (1990) discusses the theoretical background of deafness, including the following topics: hearing, sound, frequency, hearing impairment, types of hearing loss, degrees of hearing loss, hearing tests, stress, parenting of the hearing-impaired and the parents' reaction to the discovery of the hearing loss. She also

describes the different phases through which a parent goes when becoming aware of the child's problem, parent guidance and the services rendered by the Carel du Toit Centre at the Tygerberg hospital in South Africa.

- ❖ Kashyap (1986) also did a study on the adjustment a family has to make when there is a deaf child in the family. The impact of the deafness on the family is discussed as well as parental expectations and intervention. Differences between fathers' and mothers' feelings are also discussed by Kashyap. Fenster (1988) and Nolan (1988) also discuss similar matters as well as the impact on the family structure and interactions within the family. They describe the effect of deafness on the emotional structure of the family.

- ❖ Vaccari (1997), Wilson (1982), Greenberg, Lengua and Calderon (1997) describe the effect of deafness on the person itself.

Statistics on deafness are given by Schwartz (1996), Vaccari (1997), Turner (1998), McKellin (1995) and Bamford and McSporrán (1993).

- ❖ Schwartz (1996) gives a good and understandable **classification of hearing loss** whereas Moores (1996) discusses the major **etiology of deafness** in a similar clear and understandable way.

Parenting stress:

- ❖ Quittner (1991) focuses on parenting stress. Quittner (1991 (supplement)) discusses the stress and adjustment related to cochlear implants (psychosocial issues). Differences in parenting stress and adjustment among families of children receiving single- versus multi-channel devices are discussed. Stressors related to daily family routines and the difficulties of raising a hearing-impaired child are also measured and discussed.

- ❖ Meadow-Orlans (1995) discusses the **stress** of fathers and mothers of deaf and hard of hearing children.

Siblings:

- ❖ Murphy (1979) discusses the involvement of siblings as part of a family with a handicapped child. The role played by the siblings is been discussed.
- ❖ Israelite (1986) did research on the presence of a hearing-impaired child in the family and concludes that some aspects of the psychological functioning of siblings are influenced.

Assessing of auditory speech perception:

- ❖ Geers (1994) describes special considerations involved in selecting a speech perception test battery for young deaf children.
- ❖ Moog and Geers (1991) describe the monitoring and caring of the cochlear implant device as well as the impact of cochlear implants on spoken language.

Psychological effects of hearing impairment:

- ❖ Meadow and Trybus (1979), Reivich and Rothrock (1972), Hindley, Hill, McGuigan and Kitson (1994) and Hindley (1997) discuss this matter in connection with the effect on the hearing-impaired child.
- ❖ Moore (1982) gives a valuable discussion of the psychology of hearing.
- ❖ Greenberg (1983) explains the effect of having a hearing-impaired child on the family and also highlights the importance of early intervention for families with deaf infants.
- ❖ Turner (1998) describes the effect of sensori-neural hearing loss on the deaf person in great detail.
- ❖ The studies of Fisiloglu (1996), Greenberg, Lengua and Calderon (1997) and Marschark (1993) are worth mentioning.

- ❖ Freeman et al (1975) describe in a comparative study the psychosocial problems of deaf children and families.
- ❖ Working with a hearing-impaired child and his or her family is discussed by Rushmer, (1994), Williams (1982), Williams and Darbyshire (undated), Tye-Murray and Kelsay (1993) and Kashyap (1986). Downs (1986), McCarthy et al (1986) and Sanders (1988) give practical hints about working with these families.
- ❖ Turner et al (1998) discuss the support for families of the deaf, as well as collaboration between education and social services.
- ❖ Fellendorf (1970) describes the frustration of parents before the final diagnosis of hearing impairment was made, as well as the implications of receiving the news of having a hearing-impaired child.

Cochlear implants:

Although this is a fairly new field in hearing impairment, a lot of research concerning related aspects of the topic is been done already. Aspects like the following are discussed:

Description of the device and how it works:

- ❖ Carrol (1995) gives a description according to information provided by the National Institute on Deafness and other Communication Disorders.
- ❖ Schwartz (1999) gives a very clear description on the development of the cochlear implant, how it works, the surgical procedure and who can benefit from an implant.

Deaf Culture:

- ❖ Carrol (1995) only touches the subject.

- ❖ Vernon (1994) discusses the issues involved in the use of the cochlear implant with prelingually deaf children. He raises the matter of research integrity and criteria success involved in research that has been done in connection with cochlear implants. He bases his paper on the critical stage Theory of Language Development and the early implanting of prelingually deaf children (and shows on the flaw in the critical stage hypothesis when applied to young deaf children). He also discusses the cost of the procedure and the follow-up rehabilitation, medical risks and parental dilemmas. He also discusses the views of the deaf community with regard to cochlear implants.
- ❖ Power (1992) describes the fears and objections of the deaf community about the cochlear implant.

Preoperative evaluation:

- ❖ Hellman et al (1991) demonstrate the relationship between evaluated factors and show how the profile is used to address and remedy areas of concern when deciding on a suitable candidate for a cochlear implant. Children's implant profile (ChIP) is discussed according to 11 factors.
- ❖ Pollard (1996) and Gantz et al (1988) discuss the evaluation and assessment of the patient before the cochlear implant.

Parents expectations:

- ❖ Kampfe (1993) discusses in detail the importance of realistic expectations with parents of children going to have a cochlear implant.

Advantages and disadvantages of the cochlear implant:

- ❖ Tyler (1990) discusses the effect of the cochlear implant on the following topics: speech perception when speech reading can be used, environmental sound perception, psychological effects on the hearing-impaired, speech perception when speech reading cannot be done, lifestyle and social effects, speech production. He also discusses the effects of the cochlear implant on tinnitus.

- ❖ Miyamoto (1995), Downs et al (1986) and Hellman (1995) discuss the stressful demands that will be made on to the family after the cochlear implant.
- ❖ Garud and Rappa (1994) discuss a socio-cognitive model of cochlear implants.
- ❖ Maillet et al (undated) describe the effect of the cochlear implant in the quality of life of adults.

Oral Communication:

- ❖ Robbins (1994) discusses six speech training guidelines to enhance oral communication. Specific teaching activities and therapy tools are described.
- ❖ Tye-Murray and Kelsay (1993) describe a home training programme for teaching a child using a cochlear implant, to communicate verbally.
- ❖ Tomblin et al (1999) compare the language achievement in children with cochlear implants and children with hearing aids.

The effect of age at implantation receives a lot of attention by the following writers:

- ❖ Osberger (1993; 1994; 1998), Fryhauf-Bertschy (1997), Tye–Murray and Kelsay (1993), Nicholas (1994), Miyamoto (1995), Quittner (1991) and Vernon (1994) give a positive view on the effect of the cochlear implant. Lane (1993), Rose (1994; 1996) and Vernon (1994) are sceptical about giving the cochlear implant to young pre-lingually deaf children.

Prediction of results of cochlear implants:

- ❖ Fritze and Eisenworth (1989) describe language competence, duration of deafness on the operated side, speech discrimination and threshold of acoustical sensations on promontory electrostimulation – irrespective of prelingual or postlingual deafness.

- ❖ Quittner and Steck (1991) did research on predictors of implant use in children. The relationship between the variables of age of onset of deafness, etiology and communication mode measured prior to implant surgery was correlated with behavioural measure of cochlear implant use in everyday situations.

Speech perception by children with cochlear implants:

- ❖ Robbins et al (1988) describe speech perception abilities of profoundly deaf children who use either a cochlear implant or tactile aid.
- ❖ Eilers et al (1997) did research on 19 profoundly deaf children's speech perception who utilise either cochlear implants or multichannel tactile aids plus hearing aids. A battery of speech perception tests is applied and the results indicate that overall both groups improved significantly over time but no differences were found between users of tactile aids and hearing aids and cochlear implants at any level.
- ❖ The study that has been done by Geers (1994) can not go unnoticed. In this field the names of Fryhauf-Bertschy, Tyler and Gantz (1992), Miyamoto, Osberger, Brimacombe, Mecklenburgh and Arndt (1991), Waltzman (1995), Tye-Murray, Spencer and Woodworth (1995) and Quittner (1991) regularly appear in the literature.
- ❖ Moores (1982) gives a very technical description of speech production.

Speech intelligibility by children with cochlear implants:

- ❖ Osberger (1993; 1994) did research on the speech intelligibility. Tye-Murray, Spencer and Woodworth (1995) give a valuable contribution in a comparison of speech intelligibility before and after the implant.

Electrode discrimination:

- ❖ Busby (1996) compares the electrode discrimination performance of early deafened patients for two stimulation paradigms as well as the performance of

patients with two different data collection methods. This is done in a very technical way.

Personal Adjustment:

- ❖ Lansing (1990) discusses the effect of the implant on the hearing-impaired child, the effect of aural rehabilitation and the effect of implant type.
- ❖ Caleffe-Schenk (1995) describes the therapy, educational and parental issues, related to the cochlear implant.
- ❖ Hindley (1997) gives a very interesting and valuable discussion of the psychiatric aspects of hearing impairment, psychiatric aspects of fluctuating hearing impairment, developmental and psychiatric aspects, permanent hearing impairment, demography of deafness, family response and adaptation to deafness, factors specific to the deaf child, coping processes and resources, deafness and specific disorders and mental health aspects of cochlear implants. The researcher regards this as a very valuable piece of work in the field of study.
- ❖ Downs et al (1986) describe psychological issues surrounding children receiving cochlear implants.
- ❖ Sierra (1996) discusses the psychosocial adjustment following cochlear implants in adults.

Effect of the cochlear implant on the family

- ❖ Quittner (1991) gives a description of this and Cunningham (1990) describes parents' views on the effect of the cochlear implant on their children.
- ❖ Tyler (1990) discusses the effect of the cochlear implant on the perception of sound after the implant. Moog (1991), Robbins (1994), Smith (1998), Nikolopoulos (1999) also did a lot of research on the subject.

1.2.3. Demarcation of research

The topic of hearing impairment and all its implications are discussed in a large number of academic publications. In this study, it was necessary to read extensively in order to understand the context of hearing impairment as the background against which this specific study is undertaken. For the benefit of the reader, references are supplied to authoritative sources relating to the broader context of hearing impairment. Although valuable insights are gained from these sources, the scope of this dissertation compelled the researcher to deal with many aspects of hearing impairment in general terms only. However, the child with a cochlear implant can still be regarded as hearing-impaired, and therefore much research on the hearing-impaired child in general is also relevant to the study of the child with a cochlear implant. In this dissertation, those aspects that the cochlear implantee is sharing with other hearing-impaired children, are studied in detail. Emphasis is also laid on differences between the child with a cochlear implant and other hearing-impaired children.

As this study is focused on the effect of the cochlear implant on the family of the implantee, the object of research is not hearing impairment as such, but its educational psychological effects on the family.

By focusing on the child with a cochlear implant, a number of exciting new issues have to be addressed. The cochlear implant is a radical and revolutionary development. Although it is a relatively new development, an enormous amount of literature is already produced on this topic, especially of a medical or technical nature. It is necessary to take note of these details and there are references in this dissertation to technical publications, but it is not the focus of this study. Here the emphasis is on the effect of the implant on the family. Although there is valuable literature available, this is a field of study that is not yet sufficiently explored. The challenge will be to reconcile academic studies on the feelings and emotions of the family of the deaf child with what is already known of the implications of the cochlear implant. It must be admitted that publications on this specific topic are limited. This study does not pretend to be exhaustive, it is only trying to pave the way for future study.

Although academic literature constitutes the backbone of this study, there is the desire to put the academic insights in a practical perspective. For this purpose, a number of questionnaires were completed by parents of cochlear implantees and a number of interviews were conducted. The questions in the questionnaire focus on the feelings, emotions and experiences of the young child (up to 8years old), the siblings of these children and the parents of these children, shortly after the implant and a year or more after the implant.

The other developmental phases of the child are not part of this study. This can be an interesting field for further research.

The choice of participants will be determined by practical as well as logical considerations. Institutions will supply the information concerning implantees and their families. The availability of families will be a decisive factor. The children who will be involved, will have had their cochlear implant for more than a year. This empirical study does not pretend to be a representative test sample, it serves to complement the literature study by framing the academic insights in a practical perspective.

1.2.4 Statement of the problem

What is the educational psychological effect of the cochlear implant on the hearing-impaired child's family?

This implies the following aspects:

- The implications of deafness as a major handicap, specifically the cochlear implant as intervention.
- The research will include different aspects of parents' feelings and emotions like their fears before the implant, their expectations after giving the child the cochlear implant, and the effect on the communication between the parents and the hearing-impaired child after the implant.

- With regard to the family, communication amongst the children, communication between parents and the other children and communication between parents and the hearing-impaired child, will be studied.
- Parents' reasons for giving their child a cochlear implant will be examined.
- With regard to the hearing-impaired child, a study will be made of the cochlear implant, practical problems regarding deafness before the implant and the child's experiences about coping in a hearing world after the implant. The hearing-impaired child's psychological and intra-psychological functioning will also be discussed.
- Practical guidelines will be given.

1.3. Hypothesis

The cochlear implant has a distinct effect on the feelings and emotions of the hearing-impaired child's family. The emotions and feelings of the parents and siblings of the hearing-impaired child with a cochlear implant can be described and understood.

1.4 Aims of the research

1.4.1 General aim

- A study will be done on the phenomenon of hearing impairment through a literature study.
- Cochlear implants will be examined in a literature study.
- The effect of the cochlear implant on the child, his parents and the siblings will be looked at by means of interviews, a questionnaire and by observing the interrelationship between the hearing-impaired child and the rest of the family.

1.4.2. Specific aim

The effects of the cochlear implant on the emotions and feelings and other inter- and intrapsychological processes of the father, the mother, brothers and sisters of the hearing-impaired child will be studied.

1.5. Research Method

In this study, the descriptive research method is used. The study also reflects aspects of the ideographic and empirical approach. These methods will be described in Chapter 4.

As this is a delicate and sensitive topic, the researcher will make use of randomly selected families who are willing to participate in the study. The persons that will take part in the study will be families whose names are given to the researcher by a cochlear implant unit in Scotland and a school for the hearing-impaired in South Africa. Questionnaires will be given to families of hearing-impaired children that are using cochlear implants for a year or longer, to find out whether there is an effect on the family's psychological and emotional aspects. The results of the questionnaires will be interpreted in combination with the other aspects of the study.

The researcher will have interviews with approximately three families of children with cochlear implants. The aim with these interviews is to get to the deeper feelings and emotions of the family in connection with the hearing-impaired child after the cochlear implant.

Observation will be done to determine the functioning of the hearing-impaired child in the family. The parent's and sibling's functioning in the family will be observed.

A proper literature study will be done to describe the following:

- Hearing impairment
- Cochlear implants
- Feelings and emotions of the hearing-impaired child and his family.

1.6 Clarification of the concepts

Cochlear Implants

It is a type of hearing aid, which is fitted by means of an operation. It is an electronic device that stimulates the auditory nerve using electrical signals and thus provides a sensation of hearing to the user (Information for patients. Cochlear Implants. SCIP for adults and paediatrics; Garud, 1994:348; Schwartz, 1999:4).

Speech production

The type of words as well as the way in which sounds and words are pronounced or produced.

Speech intelligibility

How understandable a person's speech is for other people.

Cued speech

This is a system of hand shapes that represent the sounds of spoken language. It is used as an aid to lip-reading oral language in that it make speech-reading unambiguous (Schwartz, 1999:91).

Binaural amplification

To make use of two hearing aids, one in each ear (Schwartz, 1999:33).

Total communication

It is a way of teaching hearing-impaired children by using a manual sign system simultaneously with residual hearing, speech reading and speech (Schwartz, 1999:91).

Speech reading

This is when speech information is understood by looking at lip movements. The child has to "complete" or fill in the missing information by familiarity with the language, drawing on his knowledge of the situation or previous experience. It does not give the child access to a complete language (Schwartz, 1999:92 and 164).

Signing

It is a visual language used by some hearing-impaired people. American Sign Language has its own syntax (the relationship among phrases, words and clauses forming sentences), grammar (the way words are arranged in sentences) and semantics (having to do with the changes and development in the meanings of words). Sign languages are continually modified, signs being added and deleted.

Open set speech perception

Hearing and recognising the spoken language without using a visual system (Schwartz, 1999:50).

Language

It is described in the broadest sense as the ability to understand and use particularly verbal symbols, in communication and in thinking. To "speak" is only one aspect of language (Cooper et al, 1984:20).

Audiogram

A hearing test's results will be recorded on an audiogram. The audiogram depicts each ear's reception of tones heard through headphones or of tones heard through the bone vibrator. This is a graph of the child's hearing (a picture) (Schwartz, 1999:27).

Post lingual hearing loss

When a hearing loss develops after language and speech development has begun or has been completed (Schwartz, 1999:6).

Pre linguistically deafened

It is when a hearing loss is present prior to speech and language development (Schwartz, 1999:6).

Residual hearing

This is the amount of hearing that a hearing-impaired child still has. It determines which sounds can be heard and how clearly it is heard (Schwartz, 1999:32).

Sensori-neural hearing loss

This hearing loss results from a disease or an abnormality of development that affects the cochlea. In general it cannot be treated by current surgical or medical techniques, because there is permanent damage to the auditory nerve or the inner ear (Schwartz, 1999:5).

1.7. Summary

In the light of the literature study that has already been done, the researcher is convinced that this study is of the utmost interest and importance to cochlear units as well as to educational psychologists. She is aware of the need of information on the various effects that the cochlear implant might have on the hearing-impaired child's family.

When I was small, I can remember that it was difficult for me to understand what was going on around me, that was before I got the cochlear implant. Sometimes I felt out of place in this small world around me. I never felt part of the world until the day came that my parents told me that I was going to get a cochlear implant. I was excited about it, because I knew that this was my chance to become part of the "normal" world. I was only 6 when I got my operation. I knew that this operation was important, but I never really felt scared, but I was nervous about this -- maybe I was scared, but that feeling was gone because my parents were there, the doctor seemed nice to me. I knew that there was a hard time waiting ahead of me after the operation.

After the operation, I was confused. "Why couldn't I hear, what was wrong?", I thought when I woke up. The people told me that I have to be patient because they have to give me a "map". We waited a few weeks until the big day came, the day when they were going to install my hearing aid.

It took a long time, I had to "listen" to strange noises and I had to say how it felt and how loud or soft the sounds were. Suddenly they turned my aid on, and I was shocked because I could hear! I could hear my dad, my mom, the nice lady who installed my aid. Their voices all sounded strange -- it was like music to me. I heard sounds that I never thought I would hear.

Later on I had to return every few months to get a new map. From there I started to become part of the world. I learned to talk even more, I learned to listen. We, me and my parents, worked hard to help me to become normal -- it was a long and a hard journey for me but this was a new adventure for me. I started to hear the car engines, the TV, the telephone. I could hear the birds!

When I was 11 years old, I started listening to the music tapes of my brother. I liked it very much although I couldn't understand what they were singing. I just listened to the music but later on I followed the lyrics of the songs -- without the words I cannot hear what they were singing.

Today as I sit here and remember times before the implant, I am grateful that I got the implant because it changed my life and with the implant and my family's support I am what I am now.

(sic) Girl, age 14.

Chapter 2: Literature study - Hearing impairment, cochlear implants and its psychological implications

*“What is it like to be a small child
In a school, in a room void of sound –
With a teacher who talks and talks;
And then when she does come around to you,
She expects you to know what she’s said?
You have to be deaf to understand.*

*What is it like to be curious,
To thirst for knowledge you can call your own,
With an inner desire that’s set on fire –
And you ask a brother, sister, or friend
Who looks in answer and says, “Never Mind”?
You have to be deaf to understand.*

[Excerpts taken from poem by Willard Madsen, professor of journalism, Gallaudet]

2.1 Introduction

This chapter aims to describe the phenomenon of hearing impairment. It is important to have a general knowledge of hearing impairment before the cochlear implant can be studied. This is followed by a discussion of the technical aspects of the cochlear implant.

2.2 Hearing Impairment

Deafness still occurs in significant numbers among children. In the United States about 4000 children are born profoundly deaf each year. That means that approximately one tenth of one percent of newborn babies are profoundly deaf (they can’t even hear the loudest sounds without hearing aids.) The percentage of partially hearing-impaired babies is approximately 10 – 15%. (Schwartz, 1999:1). Sensori-

neural hearing loss in young children affects approximately one in 900 children. (Bamford and McSporrán, 1993:19 – 31).

Over 90% of deaf children have hearing parents (Vaccari, 1997:793; Turner, 1998:33; Mc Kellin, 1995:1473). Deaf children who are most competent in social, cognitive and language development are those who participate actively in linguistic interactions with their parents from an early age (Vaccari, 1997:793).

Determining the causes of deafness in children is a difficult process. The most common presently identified causes of childhood deafness are hereditary causes, maternal rubella, cytomegalovirus, mother-child blood incompatibility, meningitis and complications of prematurity (Moores, 1996:95). Since 1980, rubella and Rh factor have been very infrequent causes of deafness, but they still account for a large portion of prevalent deafness (Moores, 1996:95).

2.2.1. Classification of hearing loss

The three different ways to classify hearing loss are (cf. Schwartz, 1999: 3-8):

- Based on the location of the disease in the ear.
- Based on the onset of the hearing loss in relation to the language and speech development.
- Based on the cause of the problem within the ear (see Table 1).

2.2.1.1 The location of the disease in the ear

Hearing loss can be classified into three basic types according to the location of the disease in the ear (see Table 2).

i Sensori-neural Hearing Loss

This develops from a disease in the cochlea or the auditory nerve and an abnormality of development. The cochlea is the organ that converts sound waves to electrical energy. The auditory nerve transmits the sound in the form of electrical impulses to the auditory centre of the brain. At the moment medical or surgical techniques cannot be used to treat hearing loss of this nature, because there is permanent damage to the inner ear and the auditory nerve (Schwartz, 1999:5). A few causes of sensori-neural

hearing loss are prematurity (although this is becoming rare because of improved facilities for after-care), anoxia (shortage of oxygen), neonatal jaundice and Rhesus incompatibility (Nolan and Tucker, 1981:32). After birth, viral infection and meningitis are possible causes for hearing loss (Nolan and Tucker, 1981:34).

ii. *Conductive Hearing Loss*

When sounds cannot be conducted to the inner ear because of a problem that originates with the outer or middle ear, we call it conductive hearing loss. Conductive hearing loss can occur when there is an abnormality in the development of a part of the external or the middle ear system. Incomplete information results also in conductive hearing losses. Medical and surgical intervention can in general correct the hearing loss and can permanently restore hearing (Schwartz, 1999:5). A conductive hearing loss is, generally speaking, less severe, but can have significant implications for the young child (Webster, 1986:18). The major causes of conductive hearing loss are related to blockages, like fluids or foreign bodies, in the outer or middle ear. This results in a dampening of the sound vibration, which effectively makes the sound too soft to be heard. (Nolan and Tucker, 1981:30).

iii. *Mixed Hearing Losses*

When conductive hearing loss, as well as sensori-neural hearing losses are involved, it is referred to as mixed hearing loss. It is partly treatable by doctors, as the conductive part of it may be treated by medical or surgical means (Schwarz, 1996:6).

2.2.1.2. The onset of the hearing loss in relation to language and speech development

i. *Prelingual hearing loss:*

This is when the hearing loss is present before language and speech have developed.

ii. *Postlingual hearing loss:*

This refers to a hearing loss that develops after the development of speech and language has started or has been completed.

2.2.1.3. The cause of the problem within the ear:

i Genetic hearing loss:

Although more than two hundred kinds of genetic deafness have been identified, the chromosomal location of the genes was known for only a few genetic forms. This means that a specific genetic type of deafness may be identified, often as part of a syndrome, but the chromosome on which the genes resides usually cannot be identified (Moore, 1996:82). Knowledge of chromosomal locations of genes for deafness can be used to determine the likelihood that two people will have a deaf offspring (Moore, 1996:82).

When there is an abnormal gene within one of 46 chromosomes, the hearing loss is a genetic hearing loss (Schwartz, 1999:7). This is more likely to happen with boys than with girls (Mc Conkey and Price, 1986:26). About 70% of children born with a genetic hearing loss have developed this hearing loss because the same abnormal gene is inherited from each of the parents. The abnormal gene does not affect the child's hearing unless it is inherited from both parents. If the child inherits the abnormal gene from one of the parents and a normal gene from the other parent, the normal gene will override the abnormal gene and the child's hearing will not be affected.

Parents with autosomal recessive types of hearing (when there is one abnormal gene in each parent) may both have normal hearing – if they have one normal and one abnormal gene. Their children would have a 25% chance of having a hearing loss. About 30% of children with a genetic hearing loss have this because of a autosomal dominant gene.

Dominant genes normally override normal genes. A child's hearing will be affected if he inherits a normal gene from one parent and an abnormal gene from the other parent. The abnormal gene will have this effect.

Mutation or defects may occur in families, so that the child would be the first to develop a hearing loss in the family (Schwartz, 1999:7-8).

ii Rubella babies

Babies where the mothers had rubella during the early stages of pregnancy are also likely to have hearing losses (McConkey and Price, 1986:26). The virus can kill growing cells, and attacks tissues of the eye, ear and other organs (Moore, 1996:101).

Table 1: Literature synopsis - Classification of hearing loss

- ❖ The location of the disease in the ear
 - ◆ Sensori-neural hearing loss
 - ◆ Conductive hearing loss
 - ◆ Mixed hearing losses

- ❖ The onset of the hearing loss in relation to language and speech development.
 - ◆ Prelingual hearing loss
 - ◆ Postlingual hearing loss

- ❖ The cause of the problem within the ear.
 - ◆ Genetic hearing loss
 - ◆ Deafness as a result of Rubella in babies

2.2.2. The etiology of deafness

Moore (1996:97-104) discusses the major etiology of deafness according to the following:

2.2.2.1 Hereditary childhood deafness

The three major types of congenital hereditary deafness are dominant, recessive and sex linked (Moore, 1996:98).

Moore (1996:98) gives the following description of dominant transmission:

Dominant transmission of hereditary deafness is usually estimated to account for 10% of the cases of early childhood deafness and 20% of the cases of hereditary deafness. In this situation a single gene can produce the deafness. Dominantly inherited hearing loss is affected by the penetrance of the gene. Penetrance is a statistical concept referring to the frequency with which a genetic abnormality is manifested among individuals possessing the genes involved.

With the recognition of the low penetrance of some genes that produce deafness it is understandable that the majority of cases of unexplained severe congenital hearing loss and deafness are actually sporadic hereditary deafness (Davis, 1970:26).

Recessive Congenital deafness is typically transmitted to a child by parents who have no hearing loss, but are carriers of genes for deafness. This type of deafness accounts for as much as 40% of early profound childhood deafness and 80% of genetic deafness (Moore, 1996:99).

Sex-linked Congenital deafness.

Sex-linked congenital deafness appears to be a factor in a relatively small number of cases. This is explained by Moore (1996:100) as follows:

Males and females differ genetically in that females have two chromosomes and males have one X and one Y chromosome. The sex of a child is determined by whether the father contributes an X chromosome or an Y chromosome. XX children will be female, and XY children will be male. If one of these genes is abnormal, its effects will depend on the sex of the child. In the XX pairing, the abnormal gene may be recessive, making a daughter normal, but a carrier. In XY pairing, the abnormal gene will not be inhibited, and thus male offspring will be affected. In cases of sex-linked genes, males are affected, but not females.

When the mother carries an X-linked gene for deafness and the father has normal hearing, transmission can occur (Moore, 1996:100).

2.2.2.2 Maternal rubella

Rubella was identified as the greatest cause of hearing loss in the middle 1960's and has been recognized as the major cause of deafness in school-age children in the 1980's (Moore, 1996: 101).

2.2.2.3 Mother-child blood incompatibility (Rh-factor)

Although other types of blood incompatibility have been associated with deafness, the type most commonly involved is Rh-factor complications. The difficulty arises when a woman who is Rh- (does not have the factor), carries a Rh+ fetus. The mother's system develops antibodies that may pass into the fetal circulatory system and destroy Rh+ cells of the fetus. The result is a breakdown of blood cells (Moore, 1996:102). It is however good to know that we have the means to eliminate Rh-factor complications. The vaccine Rh immune globulin (Rhogam) was developed to prevent Rh- mothers to develop permanent antibodies (Moore, 1996:102).

2.2.2.4 Meningitis

Meningitis is a disease of the central nervous system, which may extend to other organs including the ear (Moore, 1996:102). It remains the most common cause of postnatal deafness in the school-age population (Moore, 1996:102). Although the proportional contribution of meningitis to deafness has decreased, those whom it afflicts now tend to have severe neurological impairments additional to deafness (Moore, 1996:103).

2.2.2.5 Prematurity

Although prematurity is more common among the deaf population than the hearing, the degree to which it is causative is debatable (Moore, 1996:103).

2.2.2.6 Congenital Cytomegalovirus (CMV) Infection

The CMV virus is a herpes virus, which is a major environmental cause of deafness. No vaccine exists (Moore, 1996:103). CMV can be acquired through the placenta of the mother during birth if the virus is being shed in cervical secretions, or after birth through transmission of the virus in breast milk (Moore, 1996:103). In severe cases symptoms may include sensori-neural hearing loss, low birth weight, low blood count, abnormally reduced head size, jaundice, enlarged liver and spleen and mental retardation (Moore, 1996:104).

Table 2: Literature synopsis - Aetiology of deafness

- ❖ Hereditary childhood deafness
 - ◆ Dominant transmission
 - ◆ Recessive Congenital deafness
 - ◆ Sex-linked congenital deafness
- ❖ Maternal rubella
- ❖ Rh-factor
- ❖ Meningitis
- ❖ Prematurity
- ❖ Congenital Cytomegalovirus Infection

2.2.3. *The serious implications of sensori-neural hearing loss*

Turner et al (1998:33) make the following statement:

Without normal hearing, children do not receive a clear pattern of speech on which to model their own spoken language and are hindered in the process of learning to attach meaning to the spoken language of other people.

Through interaction with caregivers, children with normal hearing start to use recognizable words at 10 to 12 months. They begin to put words together and reach the stage of being able to hold a simple conversation at the age of two to three years. At the same time they develop the ability to process more complex utterances. A hearing child has at the age of 5 years full command of the syntax of language and a vocabulary of about 2 000 to 3 000 words. Hearing impairment threatens the normal

processes of early interaction and language development. This in turn has implications for cognitive development and the development of social skills (Turner, 1998:33).

Irrespective of their intelligence, without the ability to express their own feelings and to understand people, hearing-impaired children are likely to be frustrated. This may result in temper tantrums, or they can even become withdrawn. Such abnormal behaviour has an inevitable effect on the whole family (Turner, 1998:33).

2.3 The Cochlear Implant

2.3.1 Introduction

The cochlear implant is one of the most recent developments in treating hearing impairment since the development of hearing aids (Schwartz, 1999:39). Children with profound hearing loss have been helped to hear and develop speech and language after having a cochlear implant. The researcher agrees with O'Connor (1983:1) when he says: *"The spoken word is, and is likely to remain, by far the most frequent medium of communication between man and his neighbour and it is, to this extent at least, the most important such medium."* In a sociological study Giddens (1979:24) duly says: *"Language is intrinsically involved with that which has to be done: the constitution of language as "meaningful" is inseparable from the constitution of forms of social life in continuing practices"*. From linguistic interactions deaf children not only gain facts; they gain behavioural and cognitive strategies, knowledge of self and others, and a sense of being part of the world (Vaccari, 1997:793).

Vaccari (1997:793) proceeds by saying:

Communication is the essential tie that binds children to their parents and to society. Communication also breeds communication, as the language produced for and by young children fosters subsequent language development. Indeed, all available evidence indicates that "normal" development requires the ability of young children to communicate effectively with those around them.

2.3.2 The development and history of the cochlear implant

The cochlear implant is an electronic device used to compensate for poorly functioning and absent hair cells in the inner ear (Schwartz, 1999:39).

The first model was a single channel electrode and was tested in adults in the early 1980's, and received approval by The Food and Drug Administration (FDA) for commercial use in adults only in 1984. At the same time the cochlear implant was used with children on a trial basis. An awareness of environmental sounds, improving of lip-reading skills and help was given to some children to modulate their own voices. The FDA did not approve the single channel cochlear implant for commercial use in children, because of the following reasons:

- The children had limited benefits from the device.
- There was great concern for the long-term effect of continuous electrical stimulation on the developing ear and brain in children (Schwartz, 1999:40).

The rapid technological advances led to the development of the multichannel cochlear implant. The 22 multichannel cochlear implant device was approved for commercial use in children. The original single channel cochlear implant is no longer approved either for adults or children (Schwartz, 1999:40).

2.3.3 The innovation of the cochlear implant

Hearing aids amplifies sounds. Cochlear implants, in contrast with hearing aids, are developed to take over the function of the inner ear that does not work properly. To understand this, a description of the ear and its function is necessary.

2.3.3.1 Background on the physiology of the ear and how we hear

The ear receives invisible multi-frequency sound waves coming through the air. The ear is picking up the sound signals and this information is passed on to the brain where it can be interpreted or given meaning. These waves constitute the different sounds that a person hears. The ear is designed to pick up sounds from this vibrating sound source through the air, by means of variations in air pressure.

The outer ear, the *pinna*, traps and feeds the sounds vibrations along and into the outer canal where they meet the eardrum (*tympanic membrane*). These sound waves cause vibrations of the eardrum and the tiny bones in the middle ear. The middle ear serves as an amplifier and compensates for the loss of intensity of the sound. The sound, which travels from outside the ear through an air medium, is continued through the oval window in the fluid medium of the cochlea or the inner ear. The cochlea is a coiled tube like the shell of a snail (see figure 1). The function of the cochlea is to convert information transmitted through the oval window into electrical impulses. In the centre of the cochlea tube are the hair cells, which are sensitive to the different sound frequencies. The vibrations in the fluid are passed on to the hair cells. These hair cells are positioned throughout the cochlea. There is an interaction between the tectorial membrane and the hair cells. Each hair cell forms a connection with a multitude of nerve fibres, which pass inwards towards the cochlear nerve, which runs in the bony part of the cochlea. The neurons, which innervate these hair cells, pass nerve impulses along the auditory tract to the auditory centre within the brain. Here they are all coordinated and coded into the different sounds we hear (cf. Webster, 1986:15-17; Schwartz, 1999:41; Whetnal, 1970:13).

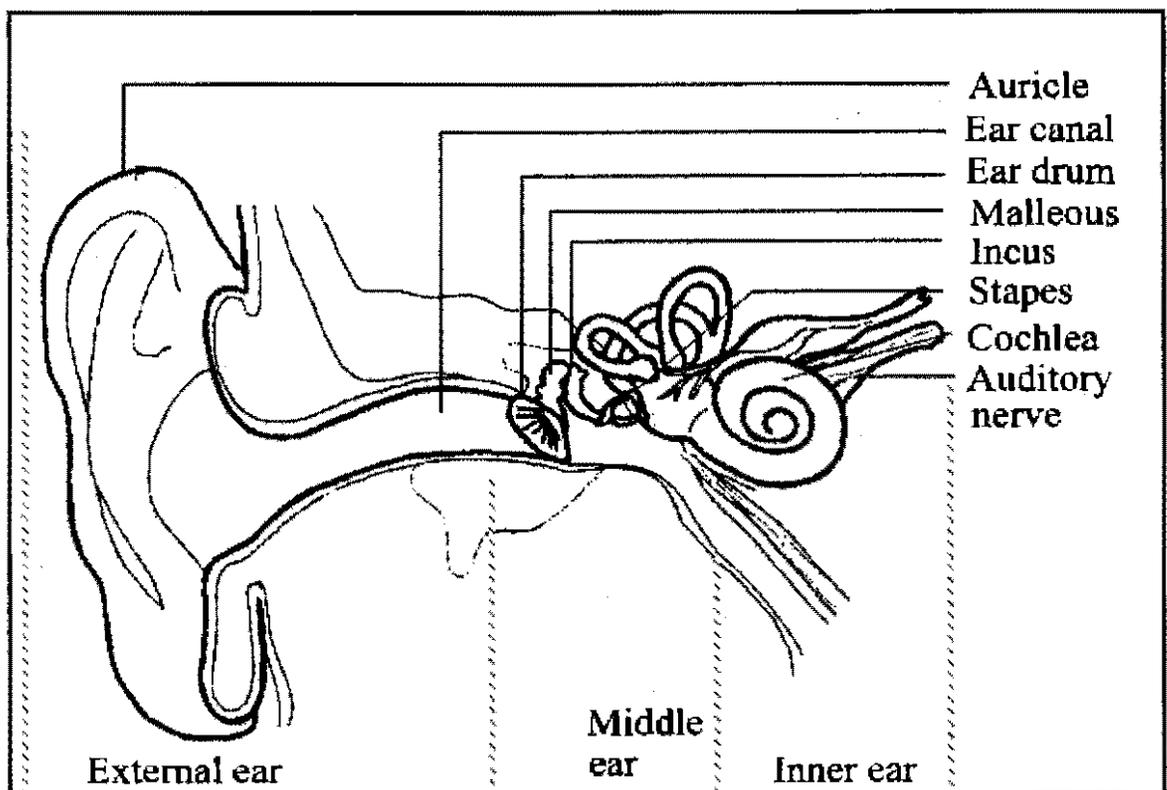


Figure 1: Cross section of the ear (cf. Schwartz, 1999:41)

In most cases children with a profound hearing loss do not have normal functioning hair cells in the inner ear. Schwartz (1999:41) states that *"the most common defect associated with genetic or nongenetic hearing loss in children is the reduction or absence of functioning inner hair cells"*. It is also important to know that often there is nothing wrong with these children's auditory nerves. It has been seen that they can hear if the nerve is directly stimulated, bypassing the non-functioning inner hair cells (Schwartz, 1999:41).

The cochlear implant works on the basis to replace the function of the damaged or absent inner hair cells. The many different frequencies of incoming sounds are being sorted out and coded into electrical signals that resemble the sounds created by a normally functioning inner ear. The auditory nerve picks up the signal and transmits them to the auditory centre in the brain. Here the sounds are coded and coordinated into the sounds that we hear (Schwartz, 1999:41). The cochlear implant can only work when the auditory nerve as well as the auditory centre in the brain is functioning normally (Schwartz, 1999:41).

2.3.3.2 The functioning of the cochlear implant

The cochlear implant consists of two basic components. They are:

- external component consisting of a microphone and a sound processor and the
- the internal component that consists of a receiver / stimulator and electrodes

The external parts

The microphone is similar to the behind the ear hearing aid in appearance as well as functioning. It receives the sound stimuli in the same way as the hearing aid. It is important to note that the sound in the hearing aid is simply amplified, whereas in the cochlear implant, the sound is being sent to the speech processor. The speech processor selects and codes the sounds that are useful for understanding speech. Different frequencies are allocated to different electrodes. These electronic codes are then send back to the external coil up the thin cord. The external coil (transmitter) is held in place directly over the implanted receiver stimulator underneath the scalp by magnets (see Figure 2).

The codes are then sent as radio signals to the receiver stimulator that is situated under the skin behind the ear beneath the skin.

There are two different versions of the cochlear implant of which the “Behind the ear” version is the most recent development (see Figure 3). In the “Behind the ear” version all the electronic hardware (the microphone and the processor) are fitted into a small headpiece looking very much like an ordinary hearing aid. In the previous version of the cochlear implant, the processor is separated from the headpiece.



Figure 2: Previous version of the external parts of the cochlear implant
(Image scanned from actual device)



Figure 3: “Behind the ear” version of the external parts of the cochlear implant (cf. The Nucleus Cochlear Implant System, undated:4)

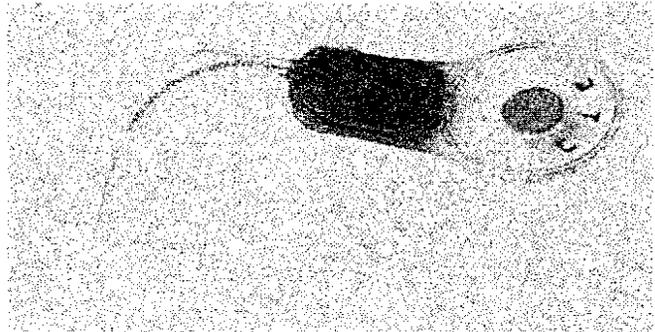
The internal parts

The internal component of the receiver stimulator is about three inches long and implanted in the mastoid bone underneath the scalp (see Figure 4). This receiver stimulator converts the sound codes to electrical signals, which are sent to the electrodes (Schwartz, 1999:43). The electrodes (which are distributed along a wire-like structure) are implanted in the cochlea. The number of electrodes that are implanted depends on the model of the cochlear implant. These arrangements of multiple electrodes give a number of independent channels of stimulation (Schwartz,

1999:44). The cochlea is stimulated at different frequencies. This correlates with the function of the inner hair cells of a normally functioning ear. This stimulation is picked up by the auditory nerve, sent to the brain and is recognised as sound.

Figure 4:

The internal part of the cochlear implant (Scottish Cochlear Implant Programme for adults and paediatrics. Information for Patients, undated:3)



2.3.3.3. The surgical procedure for the cochlear implant.

This operation is a major surgical procedure. It takes about four hours and is performed under general anaesthesia. It is the receiver stimulator that is implanted.

The first part of the operation

An incision is made behind the ear in the skin. The bone of the skull is exposed. The mastoid bone is prepared to form a bed in the skull for the receiver. The receiver is laid in this bed and sealed underneath the skin (Schwartz, 1999:44).

The second part of the operation

The mastoid air cell system behind the middle ear is exposed. Through this mastoid cavity the surgeon exposes the middle ear cavity and the first turn of the cochlea. The electrodes or stimulator is then carefully placed directly in the cochlea (Schwartz, 1999:44).

After the operation

First of all the wound must have enough time to heal. As the external and internal parts are not connected at this stage, the child will not be able to hear. After approximately 6 weeks, the child will return for the tune-in session. The external part is now attached to the internal component by means of the magnet.

The speech processor is programmed for each child's individual hearing needs. The threshold level and the maximum comfort level for each electrode is measured. It is very important that families and the children must have realistic expectations of this session. *It can be very exiting for the child, because this might be the first time to hear any kind of sound. This session can also be very disappointing, because the child as well as the parents may have too high expectations* (Schwartz, 1999:45).

Several other programming sessions will follow on this initial session. This is to ensure that the cochlear implant is perfectly tuned in for the child's individual hearing needs. Once this has been done, the child is trained to listen with the cochlear implant. The new sounds sensations must be related to meaningful speech and other sounds in the real world (Schwartz, 1999:45). Speech perception, speech production and language production will be focussed on. It is important to know that *the cochlear implant is not an instant solution to the hearing-impaired child's problems*. However, with enough guidance from professionals, and individual attention to the child, there is the prospect of hearing of sounds, and learning to speak.

2.3.3.4. Who can benefit from the cochlear implant?

Children achieved better results with the cochlear implant if the time between the implant and the onset of the hearing loss was relatively short. (Schwartz, 1999:46). The younger the child, the better he or she learns to hear. There are individual differences in the amount of benefit that the children receive at different ages (Schwartz, 1999:47). Older children and adults, who have made good use of hearing aids and have spoken language, may be able to benefit more from an implant (Issues and answers:6)

The ideal candidate for an implant would be:

- a child with a profound sensori-neural hearing loss,
- a child who has not achieved appropriate language and speech and
- a child that had a trial period of at least six months of appropriate amplification as well as intensive auditory training (Schwartz, 1999:47).

From a medical point there are also specific criteria that should be met, before having a cochlear implant:

- The child must be at least two years old.
- The child must have a bilateral profound hearing loss.
- The child must be in good health.
- The child as well as the family must be interested to develop oral speech and language (with or without visual input).
- There must be realistic expectations from everybody involved.
- The child must be motivated to use the cochlear implant.
- There should be no active ear disease like infection of the middle ear or the mastoid cavity.
- A CAT scan of the inner ear must be done to rule out any abnormalities of the cochlea (Schwartz, 1999:47).
- The auditory nerve as well as the auditory centre in the brain must function normally (Schwartz, 1999:41).

2.4. Conclusion

In this chapter the phenomenon of hearing impairment as well as the technical aspects of the cochlear implant are described. It is clear that hearing impairment has serious and extensive implications. The cochlear implant as a modern aid for hearing impairment seems to have significant benefits for the child and the family.

To the hearing impaired child: (Please help mum!)

Please write a paragraph about your experiences having a cochlear implant and what it means you.

I like my implant because
When I don't like that noise
so I take off.
I like both hearing and quiet.
I like hear teacher at school.
I like hear music.

Chapter 3: Literature study - Implications of deafness and the cochlear implant with regard to the child and the family

3.1 Introduction

In the previous chapter deafness and the technical aspects of cochlear implants are described. This chapter aims to discuss the implications of deafness and of the cochlear implant, with the intent to describe the effects of the cochlear implant on the child and the family.

3.2 Psychiatric aspects of hearing impairments

Hearing impairment can be viewed as a medical condition and classified in a number of ways, but it can equally be considered as a social and cultural condition. It is useful to think of hearing impairment as a multifaceted condition because a variety of factors will determine the effect of hearing impairment on children's development (Hindley, 1997:101). It is important to bear in mind how a child's growing awareness of his or her hearing impairment affects his or her development (Hindley, 1997:101).

There is a disproportionately high number of deaf children with serious mental health problems and adjustment problems (Hindley, Hill, McGuigan and Kitson, (1994:917-934); Meadow and Trybus (1979:91-111)). Some deaf children are at risk with regard to a number of adverse outcomes. These include low academic achievement, delays in some cognitive and social-cognitive processes, as well as higher rates of social maladaptation, psychological distress and psychological disorder (Greenberg, Lengua and Calderon, 1997:302). Some studies have found additional deaf-specific factors that include problems in communication and isolation (Reivich and Rothrock, 1972: 93-104).

Deaf children are often described as "*having behaviour disorders with a relative lack of emotional disorders*" (Hindley, 1997:106). Children with fluctuating hearing impairments are at greater risk of behavioural problems and language and reading delay.

Children with permanent hearing impairment experience the same range of mental health problems as hearing children, but their presentation, treatment and outcome can differ because of differences in communication and language use (Hindley, 1997:101).

The most striking impact of deafness is the deaf child's reliance on visual means of communication and lack of access to auditory communication (Hindley, 1997:104). Marschark speculated that the lack of intrauterine auditory interaction between mothers and their congenitally deaf children might influence attachment formation (Marschark, 1993:39–40). Studies of early infant-mother interaction confirm that there are differences in the way in which deaf and hearing infants interact with their deaf and hearing mothers (Hindley, 1997:104).

Reliance on visual channels of communication presents parents with a fundamentally difficulty in their task of facilitating language development. It is difficult to supply a deaf child with the language that accompanies an activity without disrupting the child's visual attention. This results in a child with divided attention. Wood, Wood, Griffiths and Howarth (1986) first described this problem of "divided attention". If a person's attention is divided, it will surely have an effect on the his or her educational development.

Difficulties in communication affect relationships as deaf children develop. Already at an early stage, there can be deficiencies in the relations between a mother and her child. In a longitudinal study, deaf toddlers were less likely to communicate with their mothers, who were less likely to understand their toddlers' communication. In the same study, deaf toddlers were less likely to spend free play with their mothers. (Lederberg and Mobley, 1990: 1596–1604).

Spencer and Deyo (1993:73) summarise research on differences in the play of deaf children as follows: *Deaf children are more likely to engage in solitary play; show decreased use of object substitution or imaginary objects; and show less play despite having basic play competence.*

Verbal skills are most influential in literacy development (Stackhouse and Wells, 1999:1). Children with a history of speech, language and/or literacy problems are most likely to have problems with reading and spelling development (Stackhouse and Wells, 1999:1). When a child has a hearing problem, it affects not only how the words are heard, but also how they are classified and stored (Stackhouse and Wells, 1999:10)

3.2.1 Personality development, social competence and maladjustment in deaf children

Early studies in Psychology led to an unfortunate characterisation in which deaf children were seen as egocentric, impulsive, and immature in their social orientations (Greenberg, Lengua and Calderon, 1997:307). This is not the case anymore, because these characterisations were likely due to a combination of factors, including generalising from clinical populations, the use of inappropriate assessment measures, and the inability of examiners to use the deaf person's best mode of communication. It is now obvious that deaf persons vary widely in their characteristics, personalities, motives and interests. Many deaf children (and adults) share developmental experiences that are less than optimal. These experiences include early and continued communication deprivation, difficulties in their families of origin, less than adequate educational experiences, and continuing social stigma and prejudice. A significant portion of deaf persons shows developmental misintegrations of language, cognition and affect (Greenberg, Lengua and Calderon, 1997:307).

3.2.2 Social cognition of the deaf child

Although there are wide individual differences among deaf children (and there are many who do not show delays), compared to hearing children they do show significant deficits as a group in such areas as impulse control, empathy development, role taking ability, the ability to interpret facial expressions, social problem solving, social attributions, and moral development (Greenberg, Lengua and Calderon, 1997:307- 08).

3.2.3 The deaf child's personality

A variety of studies have found that compared to hearing adolescents, deaf adolescents have more external locus of control, lower self esteem and greater learned

helplessness. A focus on assets and conditions that promote healthy social and cognitive outcomes is essential for the development of preventative interventions (Greenberg, Lengua and Calderon, 1997: 308).

3.2.4 Psychosocial aspects of language acquisition

As children acquire language, they acquire a system, which bears important relationships to both social and cognitive aspects of their life. Hickmann (Fletcher, 1988:9) contrasted Vygotsky's developmental theory to Piaget's developmental theory and shows the differences in the status of language in the two theories. According to Hickmann (Fletcher, 1988:9), language is attributed to social interaction in Vygotsky's theory. In Piaget's theory, language plays a relatively secondary role in social interaction. This is the result from the different ways in which Vygotsky and Piaget define language and interprets its development. It is important for this study to note: "*although Vygotsky sees language as a tool among other tools that participate in the organization of sensori-motor activity, he also sees language as a very special tool in comparison with others: by mediating the means-ends organization of sensori-motor activity, the uses of language transform this activity ... For Vygotsky, thought is mediated by inner speech; i.e. its development is initially the result of internalizing a new kind of means-ends organization which is imposed by speech and transforms the organization of all activities.*"(Fletcher, 1988:13).

Cognitive development is highly dependent, according to Vygotsky, on language (Fletcher, 1988:13). The social interaction is a kind of interaction, which is a primary factor to the development of cognition (Fletcher, 1988:14). A good summary of Vygotsky's point of view is found in Fletcher (1988:14):

Vygotsky's relatively strong view on the relation between cognitive development and social interaction, particularly early interactions between children and adults or elder peers, can be summarized by his claim that all higher mental functions appears twice in ontogenetic development: they first appear as social or interpsychological functions, during interactions with other social agents, and only later do they become individual or intrapsychological functions, through the internalization of social-interactive processes.

According to Vygotsky's writings, in the processes of social interaction between adults and children, children are allowed to organize complex series of actions in problem solving. The regulative behaviour of adults in these interactions becomes more a part of children's own behaviour (Fletcher, 1988:15). The processes that involve language make the shift from interpsychological to intrapsychological functioning possible (Fletcher, 1988:16). Fletcher (1988:18) summarizes Vygotsky's approach as follows:

Cognitive development is necessarily dependant on the fact that language is multifunctional, i.e. it is a sign system which is simultaneously used for abstract representation (e.g. internal logical reasoning) and for communication in social-interactive contexts. Furthermore, the context-dependent indicatory aspects of communication in social interaction are primary and constitute the foundation for the development of abstract reference-and-predication.

Vygotsky makes language the centre of inter-relationships (Fletcher, 1988:29).

According to Hindley (1997:101) children with permanent hearing loss experience the same range of mental problems as hearing children, but the outcome, treatment and presentation differ, because of the differences in language use and communication. It is not possible to generalize about the psychological consequences of hearing impairment. Hearing impairment offers a number of questions like the nature of language, the role of language in cognitive and social/emotional development, the consequences of living with a hearing-impaired child for the family, and the effect of problems with communication on the family (Hindley, 1997:102).

There is no significant difference in the rate of psychiatric disorder amongst hearing children (15.8%) and deaf children (18.7%) (Sinkkonen, 1994:60,69). Low communication ability in deaf children was associated with high scores on the Rutter B hyperactivity scale (Sinkkonen, 1994:95). It seems likely that if there is effective communication in the family there is a low prevalence of psychiatric disorder at the hearing-impaired children (Hindley, 1997:107).

3.3 Psychological aspects after the cochlear implant

Parents and children are faced with a number of stressors associated with the cochlear implant (see Table 3). It includes an extensive screening battery of auditory, language and psychological tests, hospitalisation and the operation, financial costs of the procedure, and frequent return visits for training and rehabilitation (Quittner, 1991(b): 96).

Communication issues, behavioural problems and differential treatment of the child present the greatest difficulty in examining disability-specific stressors in the mothers. Quittner also says that family stressors such as safety, communication with other family members and discipline are higher than normal. She predicts that stress will decrease as the performance of the children with multichannel implants improves over time (Quittner, 1991(b):102).

In Quittner's study on the effect of the cochlear implant on parents' stress levels, she reports that mothers reported greater demands on their time (Quittner, 1991(b): 102).

The use of cochlear implants has provoked fierce criticism from Deaf communities across the world. Professionals in mental health have been involved in cochlear implant programs in the following ways:

- highlighting the ethical dilemmas that surround the use of cochlear implant devices,
- helping to identify the psychological characteristics of families and deaf children, and to identify the children that will most likely gain from a cochlear implant,
- identifying the psychosocial consequences for the child's family, but not yet for the child (Hindley, 1997:113).

It is unclear whether or not the benefits attributed to cochlear implants are primarily a result of high commitment from the child and the family, or a direct result of the implants themselves (Hindley, 1997:113). It appears that, in general, family stress is no less for parents of children with implants than for families with deaf children (Hindley, 1997:113).

Parental diaries between 1993 and 1994 in New Zealand show that for some children changes in behaviour and communication are most dramatic immediately after the implantation, whereas for other children the changes are slow to occur. In general the children have no significant behaviour problems, but if there were any, it improved after the implant. (Purdy, 1994:335 in Book of abstracts. A Symposium on hearing aids, Cochlear implants and other prosthetic devices. Melbourne).

The researcher's practical experience compels her to agree with Freeman's conclusion that, although being deaf means being different it is clear that deaf children need not present psychiatric problems in the majority of instances (Freeman, 1975:404).

There are three factors that stand out as having critical implications for deaf children's competence in dealing in the world:

1. early language experience
2. diversity of experience
3. social interaction (Marschark, 1993:237).

There are also other psychological aspects that have advantages on the patient. In his research Tyler reveals that the following aspects have positive outcomes after the cochlear implant: Deaf people with a cochlear implant say that they:

- escaped the world of silence,
- have increased confidence,
- have increased happiness,
- are more relaxed, feel less frustrated or frightened,
- experience better acceptance by others/ and don't feel longer isolated,
- have overcome loneliness and depression,
- experience improvement in general psychological health (Tyler, 1990:284), and that
- improved ability to focus attention may reduce the high rates of behavioural difficulties (for example: easily distracted, being impulsive) that is frequently found among hearing-impaired children (Quittner, 1991(b):96).

Tyler states that the candidates with a cochlear implant have improvements in all aspects of life like for example improvements in social interactions with family and individuals (Tyler, 1990:287).

The cochlear implant does not eliminate the disability, it appears to modify the stress in the child's life (Evans, 1989:313). Quittner (1991(b):101) agrees with this when she says that levels of stress remain high after a cochlear implant. The cochlear implant does not cause undue hardship, but presents ongoing challenges for families in areas of communication, discipline and greater time demands (Quittner, 1991(b): 101).

In a preliminary analysis, Knutson (1991:821) reveals data which strongly support the possibility that psychological variables may play a role in the audiological outcome of cochlear implants. The significant correlations between the experimental cognitive measures and audiological outcomes suggest that the ability to extract information from sequentially arrayed signals and to rapidly process that information may be relevant to implant success. The general pattern of the results in Knutson's study suggests that rapidity in accurate responding might be a critically important feature of cognitive measures that successfully predict implant outcome (Knutson, 1991:821).

Table 3: Literature synopsis - Psychological aspects after the cochlear implant

- ❖ Stressors:
 - ◆ Auditory, language and psychological tests
 - ◆ Hospitalisation and the operation
 - ◆ Financial costs of the procedure
 - ◆ Frequent return visits for training and rehabilitation
 - ◆ Communication issues
 - ◆ Behavioural problems
 - ◆ Safety
 - ◆ Discipline
 - ◆ Greater demands on parents' time

- ❖ Positive outcomes after the cochlear implant:
 - ◆ World of silence is defeated
 - ◆ Increased confidence
 - ◆ Increased happiness
 - ◆ More relaxed, less frustrated
 - ◆ Better acceptance by others
 - ◆ Overcome loneliness and depression
 - ◆ Improvement in general psychological health
 - ◆ Improved ability to focus attention
 - ◆ Improvements in social actions

3.4 Role of the psychologist

3.4.1 Working with families of hearing-impaired children

A large problem for families with a hearing-impaired child is their sense of isolation. When parents become aware of their children's hearing impairment, social circles and support systems shift and they do not know to whom to go or who can help (Atkins, 1987:34).

Guidance includes the introduction of supporting devices and methods of communication, helping parents to clarify their perceptions of each. The psychologist should discuss the positive and negative aspects of the different devices with the parents (see Table 4). Families need to receive unbiased information supported by objective facts. They need the opportunity to observe alternative programs, and contact with other parents of hearing-impaired children. (Rushmer, 1994:160). The counselor should not give personal opinions or make decisions for the parents. The guidance process should facilitate the exploration of options and assistance to parents (Kampfe, 1993:302).

Empathic listening that conveys to parents that they are being understood and their concerns validated, is most important when working with parents of hearing-impaired children (Matkin, 1988:209-222). One professional has warned against the dangers of responding too quickly to a parent's cry for help because it might be more beneficial to encourage the parent to find his or her own solution (Packens, Personal Communication 1994 in Meadow-Orlans, 1995(b)).

Only by understanding the complexities of a specific family unit, such as size, health, interaction patterns, and socio-economic factors, can a professional effectively assist a family in developing a habilitation program that best fits its members. This requires sensitivity to cultural values, the difficulties faced by working parents, and the stresses placed by society upon single-parent and non-traditional families (Rushmer, 1994:161-162). Meadow-Orlans (1995:18) also discusses these topics.

All habilitation endeavours with the child must include his or her family, with parents becoming prime therapists and "*main agents of change*" (Williams and Darbyshire undated: 29). Parents should be given sufficient training to enable them to be effective home educators. The parents of hearing-impaired children are asked to walk a tightrope between over-anxiety and complacency (Williams and Darbyshire undated: 30).

The stability and growth of the family hangs on a delicate balance of interaction and emotional flow. Hearing impairment may make or break the relations in a family,

having far reaching effects on the functioning of the family as a group or as individuals (Kashyap, 1986:36).

Before a family can be helped, positive and healthy communication between parents is essential. The stress related to hearing impairment could be treated effectively by involving parents in well-designed training programs as indicated by Tye-Murray and Kelsay (1993:21-31).

Professionals need to understand the nature of their relationships with families. Behaviours that promote feelings of competence must be promoted and powerlessness in families must be decreased. (Schlesinger in Meadow-Orlans, 1995:316). It is very important to establish trust and communication to work effectively with any parent in this situation (Rushmer, 1994:161). By working with the family as a system, the therapist tries to create a healthy, functioning environment in which each component has a space to grow (Luterman, 1987:2). Group counseling does not apply to all parents of hearing-impaired children (Backenroth, 1984: 269-272).

When a psychologist is working with parents of a hearing-impaired child, it is important that the psychologist should offer support and have empathy with the people involved. It implies that he or she should share their feelings and experiences, their joy and their pain (Backenroth, 1984:269).

The relationship between the psychologist and the family

The quality of the relationship between the family and the professional is of the utmost importance. The most effective relationship is collaboration between "experts", the parents and the child. It is most effective when parents and professionals consider themselves as equal partners, working together to solve problems. Parents appreciate informality, emotional sensitivity and respect in the relationship with a professional (Rushmer, 1994:162).

Counseling skills

The feelings that parents of a hearing-impaired child have to deal with, are typical human emotions. Psychologists have to accept those feelings as a normal reaction and appreciate it as meaningful to the parent (Rushmer, 1994:162). What parents

experience, is a very personal and internal process, the process needs an accepting listener (Rushmer, 1994:162-163). Psychologists need skills in the use of active listening techniques, understanding of the grieving process, understanding one's own feelings and the situations that evoke them, the ability to communicate with empathy, respect and warmth (Rushmer, 1994:163).

Parent groups

Ideally every parent should have access to a group where they could share their feelings and experiences, make contact with other parents, and experience understanding and acceptance under the guidance of a professional counselor. The support parents gain from one another in a group is very valuable and long-lasting (Rushmer, 1994:163). A support group needs to be a fundamental part of any habilitation program for families. The group becomes a powerful vehicle for imparting information and helping one another. In a group, families can recognize the universality of their feelings (Luterman, 1987:113).

Contact with other hearing-impaired children and adults

Parents need information on how their hearing-impaired child's life will be affected by the impairment. To be able to envisage the possibilities for their child, they should be brought into contact with other hearing-impaired people. Parents should have the opportunity to meet individuals with different degrees of hearing impairment using a variety of communications modes – speech as well as signing (Rushmer, 1994:163).

Supporting all family members

People are inclined to focus on the mother in habilitation interaction. The mother is unfairly burdened if she is expected to "teach" the rest of the family. Every member of the family needs to acquire information, share feelings, and come to their understanding of the hearing impairment. Special care must be taken to involve siblings and to attend to their needs. Grandparents should also not be forgotten. They also need information and support (Rushmer, 1994:164). Fathers and mothers participate in the learning process in different ways and need individualized approaches from professionals.

Parents expressed a desire for better counseling at the time of the diagnosis, and subsequently in relation to educational and behaviour difficulties (Williams, 1982:24). Parents need assistance in how to discipline their child (Williams, 1982:28).

3.4.2 Working with families after a cochlear implant

Fritze (1989:297) mentions the importance of counselling of candidates for cochlear implantation (see Table 4). Patients must be prepared as well as possible to know what they can expect of the implantation. When patients are well informed preoperatively, they are likely to be more satisfied with the postoperative results (Fritz, 1989:297).

Counsellors must be aware of the parents' progress in the mourning process and the way in which they accept their child's deafness. This will enable the counsellor to help them to view the implant more realistically (Kampfe, 1993:300). The psychologist can also help in clarifying scientific terminology for the parents. (Kampfe, 1993:300).

Counselling can help parents to come to terms with their feelings about their child's deafness as well as the reasons for wanting the implant (Kampfe, 1993:302). The psychologist can assist the family to create an environment for family members to discover a new version of normality, to create new dreams that are appropriate and realistic and to help each person to feel good about himself or herself in relation to the family.

Psychologists should identify potential stressors for parents considering an implant device and assist them in developing strategies for coping with difficulties as they arise. Careful follow-up of these families, at least during the first year or two after the procedure, may also be warranted, with referral to appropriate professionals in cases where they are needed (Quittner, 1991(b):103).

According to Sierra (1996:79) auditory improvements and improvements in social relationships are the most significant improvements after having a cochlear implant. A low prevalence of psychiatric morbidity was found after the implementation of the cochlear implant.

Hearing problems are expected to increase negative aspects of both psychological and social functioning. As a consequence, personality, behavioural and cognitive disorders appear, such as difficulty in attention and abstract thinking. Emotional deprivation as a psychological disturbance is a result of the inability of hearing the human voice and environmental sounds (Sierra, 1996:77).

Sierra's study on the evaluation of psychosocial adjustment following cochlear implants reveals the following:

- a low prevalence of psychiatric morbidity
- all patients were within normality on psychometric tests (WAIS and Hamilton Anxiety and Depression Scales)
- post cochlear implant adjustment is most successful in auditory and social relation areas (Sierra, 1996:79).

According to Sierra (1996:800) cochlear implants enhances self-confidence, decreases dependence, reduces frequency and intensity of emotional distress, promotes communication, and significantly diminishes fear of social relations.

It is interesting to note that according to Sierra (1996:80) the family of the patient often needs psychiatric care due to the excessive anxiety levels caused by the cochlear implant. However, cochlear implants are intended to help patients minimise harmful psychological effects and to promote communication and social integration (Sierra, 1996:81).

3.4.3 Role of psychologist in assessment and intervention

The educational psychologist as part of the pediatric cochlear implant team is involved from the earliest stages of the implant evaluation. Parents are interviewed and the child's school is visited. After the implant the psychologist visits the school, explains the components of the device and discusses relevant matters. Listening activities are demonstrated to the teacher and the child's progress is monitored (Nevins et al, 1991:197).

The educational psychologist can assist the parents as well as other professionals in many different ways, like counselling or supporting the patient or the family, helping to make decisions concerning school placements, serving as a contact person between the cochlear team and the parents or the other professionals and supporting the teachers who work with the implanted child.

The psychologist would provide ongoing evaluations and therapy as needed. The educational psychologist should be involved in making recommendations for further assessment and treatment (Downs et al, 1986: 384).

Counselling consists of two basic areas:

- informational counselling which serves to provide the family as well as the client with an understanding of the hearing loss, its consequences and the role of the amplification, and
- personal adjustment or affective counselling. This includes the identification and discussion of feelings and attitudes toward hearing loss. (Lansing, 1990:64; McCarthy et al 1986:49-52; Sanders, 1988:345-396; Northcott in Williams, 1982:24)

The rehabilitative effort may be influenced by unwillingness to admit difficulties in adjusting to hearing loss. Denial problems like these should be addressed through counselling (Lansing, 1990:74).

The psychologist must initiate a partnership with the individual and his or her significant others, where it is understood that there is more to learn, consider and evaluate before the final decision about candidacy can be made. (Pollard, 1996:22). *In practice, psychological assessments often move back and forth between objectives related to data collection and objectives related to education or counselling* (Pollard, 1996:22).

Table 4: Literature synopsis -The role of the psychologist

Working with families of hearing-impaired children	Working with families after the cochlear implant
<ul style="list-style-type: none"> ❖ Help families with their sense of isolation. ❖ Give information about assistive devices and methods of communication. ❖ Listen with empathy. ❖ Help parents to come to terms with their feelings. ❖ Keep parents' progress in the mourning process in mind. ❖ Understand the complexity of the specific family unit. ❖ Include the family in habilitation. ❖ Interaction and emotional flow must be balanced. ❖ Facilitate healthy and positive communication between parents. ❖ Identify potential stressors for parents. ❖ The relationship between the family and psychologist is important. ❖ Use usual counselling skills. ❖ Start with parent groups for parents. ❖ Facilitate contact with other hearing-impaired children and their families. ❖ Support all other family members. 	<ul style="list-style-type: none"> ❖ All the issues that are part of working with a hearing-impaired child's family are also relevant when working with families after the cochlear implant. ❖ Do counselling of candidates for the cochlear implant. ❖ Involved in assessment and intervention. ❖ Clarify scientific terminology for families.

3.5 Effect or impact of deafness on a family

The presence of a hearing-impaired child in a family precipitates a crises in the family and may serve as a source of severe psychological disruption to the family and to parental adjustment (Kashyap, 1986:31). This grief should not be viewed as a single reaction to the crises, but a complex human progression involving many emotions and attempts to adjust to the crisis (Wilson, 1998:20) (see Table 5).

There is a duality concerning the mutual influence in a family. On the one side, the family plays an important part in determining human behaviour, building personality, influencing the course of moral, mental and social evolution (Buscaglia, 1975:69). On the other side, the presence of a person with a disability imposes certain demands on family and friends. Hearing impairment may easily go unnoticed except in direct communication, but the impact on the family is equally profound (McKellin, 1995:1469).

A family is a social system. It is an organisation of individuals who are in a dynamic interchange with one another and who jointly and severally stand in interchange with the environment (Kashyap, 1986:31). Each family member has expectations for the whole family as well as for himself or herself (Atkins, 1987:33).

The impact of having a hearing-impaired child is shared by the entire family (McKellin, 1995:1469). Family members take part in communication programs, move house to gain access to services and band together with other families for support, share the child's liminal status as they move within the hearing society and join the networks of those with hearing losses (McKellin, 1995:1470). To have a deaf child means that the family will have to change, that everyone will have to respond differently and that there will be new demands on the family structure. It is difficult for such a family to maintain balance as stress is generated by having a child who is deaf (Luterman, 1987:6).

Rural parents are left with few options after hearing that they have a hearing-impaired child. Either they have to move to a place where facilities are available or they have to create their own programme. Relocating may involve changing jobs. Placing a

child in a residential school changes family dynamics and it leads parents to equate deafness with separation of the child from the family (McKellin, 1995:1478).

At the discovery of a hearing loss, parents often feel bombarded with new and various concepts concerning their child's condition. They are either confronted with a restricted set of opinions, or overwhelmed by a bewildering list of educational options – of which some are unavailable. They find themselves confronted with a lot of new medical and audiological terminology describing hearing loss. Parents often feel confused by the variety of competing forms of communication with the hearing-impaired child (McKellin, 1995:1473; Fenster, 1988:230).

The arrival of a new baby is usually a joyous occasion for a family. When there is a deaf new baby in the family, additional stressors impinge upon the family system (Fenster, 1988:226). To go into more depth about stress in the family, especially the mother, Quittner's article (1991) on "Coping with a hearing-impaired child", is recommended. In reality parents have recurring specific critical periods in their hearing-impaired child's development (Wilson, 1982:20).

Families appear to go through four periods of extreme stress during their deaf child's development, namely:

- the process of identification of hearing loss
- entrance into the school situation
- beginning adolescence
- early adulthood .

For a detailed discussion of this Moores (1973:115) and Moores (1996:138-147) can be consulted.

According to Luterman (1987:8-9), the healthy family exhibits the following characteristics:

- Communication among all members is clear and direct.
- Roles in responsibilities are clearly delineated. The family allows for flexibility in the allocation of roles.

- The family members accept limits for the resolution of conflict.
- Intimacy is a valuable characteristic of a family.
- A healthy balance between the maintenance and change of stability.

Communication limitations arising from deafness have an early and profound impact on the family and on parent-child communication (Moore, 1996:141; Fenster, 1988:230; Greenberg, 1983:407). As a result of limited communication, relations between the members of the family are affected (Kashyap, 1986:34). Poor communication and poor relations result in uncertainties for parents about whether they are being overprotective or underprotective (Moore, 1996:141). Deafness results in delayed communication, which adversely affects cognitive and social development. Without a way of communication, closeness and an emotional bond between the deaf child and the parents is inhibited (Fenster, 1988:226). It is important to take care that the deaf child as well as the family members do not become isolated and disengaged from one another (Fenster, 1988: 225).

The desired outcome of the habilitation of the deaf child is the development of meaningful communication between the child and the family (Greenberg, 1983:407). There are a number of negative social outcomes like fragmented and disturbed communication, the deaf child's isolation from the family, high parent stress, and higher rates of psychiatric disturbances (Greenberg, 1982:407). Fathers may become alienated and siblings may be forced into compensatory roles (Fenster, 1988:229; Mendelsohn, 1983:40).

Siblings serve also important family functions (Murphy, 1979:353). Murphy describes how an older sister would spend more time with the hearing-impaired child when the father was very depressed about the child's hearing impairment and avoided the child. The hearing-impaired child also plays an important role in the family. To demonstrate this Murphy (1979:353) reports that on an occasion the daughter, meeting resistance from the father to her going to a dance, was granted permission to go when her deaf brother interceded for her. It is interesting that Murphy also notes that the sibling closest in age to the handicapped child often has relatively more

difficulty in overall adjustment in having a hearing-impaired brother or sister (Murphy, 1979:357).

It is an accepted fact that parents have a paramount influence on the child. However, it is often overlooked that the child's behaviour equally influences the parents' behaviour. There is a bi-directional flow of effect. If the parents experience success in terms of their expectations for the child, it leads to changes in the parents' behaviour. Parents tend to restrict successful children to a lesser extent, while less successful children are more restricted (Luterman, 1987: 5).

Family members experience emotional confusion, which is strengthened by difficulty in precise diagnosis and knowledge of hearing impairment in young children (Fenster, 1988:225). Parents need to assume new roles like being an educator, a lobbyist, an advocate, a speech / language therapist, and a chauffeur. Parents are confronted to make early decisions for and about the hearing-impaired child (Atkins, 1987:33; Mendelsohn, 1983:40; McKellin, 1995:1474).

The most obvious effect of having a hearing-impaired child in the family is the amount of parental activity that revolves around the child and his or her programs, whether signing or oral. The stress of learning a training method is compounded by the demands it places on the parent's time, and on their relations to siblings and other family members (McKellin, 1995:1477).

Another complicating factor in a family with a hearing-impaired child is the fact that grandparents may be overprotective of the deaf child, and as a result sabotage the parent's efforts of trying to foster his or her independence (Fenster, 1988:229). Grandparents may totally deny the child's deafness (Fenster, 1988:229).

As far as the overall impact of the deaf child's presence is concerned, Kashyap (1986:34) found that only two of 100 mothers consider it as positive. These mothers feel that the family had come closer to each other because of their common concern over the deaf child. These mothers report that their husbands are very supportive and help in the care of the child. Sixteen of the 100 mothers report that the presence of the deaf child has a negative impact (Kashyap, 1986:34). The majority of the parents feel

that there is no impact or that the impact is neutral. This could lead to later problems in the family system, because the researcher expects that this might not be the real feelings of parents. Parents may not have elaborated on their own emotions and on the fact that the interactions between them and the deaf child would later on become more complex.

Table 5: Literature synopsis - The effect or impact of deafness on a family

- ❖ Families experience it as a crisis.
- ❖ Deafness has a dual influence on the family
 - ◆ the family determines human behaviour and social evolution, builds personality, influences morally and mentally.
 - ◆ hearing impairment imposes demands on the family and friends.
- ❖ The family as a social system is influenced, for example: the communication cannot continue in a normal way.
- ❖ The entire family shares the impact of hearing impairment.
- ❖ Families have to make the following adjustments:
 - ◆ Parents in rural areas need to move to get closer to centres where their child can be helped. This is upsetting, can cause insecurity with regard to a job and an income.
 - ◆ Parents are bombarded with new concepts.
 - ◆ Stress continues according to the different phases of the child's development.
 - ◆ Communication limitations.
 - ◆ Siblings: more is expected from them with regard to their responsibility, understanding of difficult situations; have to cope with less parental attention.
 - ◆ Parents struggle to cope with their own emotions.

3.5.1 The effect of deafness on the individual aspects of the family's daily living

(see Table 6)

3.5.1.1 Parent's physical and mental health

Mothers as well as fathers feel an adverse effect on their health. Some fathers suffer from insomnia, worry constantly about their child and even develop heart trouble (Kashyap, 1986:35). Parenting a deaf child could be considered a potentially chronic

stressor to parents (Calderon and Greenberg, 1993:27-48; Quittner, Gluekauf and Jackson, 1990:1266-1278). Most parents experience feelings of confusion, denial, anger, disbelief, guilt, hope, frustration, depression, mourning, isolation, sadness, anxiety and understanding. Feelings are neither progressive nor orderly - they appear and reappear (Atkins, 1987:36). It is also important to be aware of the fact that when anger is turned inward, it results in depression (Fenster, 1988:227).

3.5.1.2 The effect of deafness on household responsibilities

Mothers say that there is an increase in household responsibilities. Parents are expected to do so much more like giving intensive language training, making eye contact when communicating and playing listening games. A few parents complained of deterioration in their social life and leisure time activities. There are even mothers who give up their careers, which would have an effect on the family's financial situation (Kashyap, 1986:35).

3.5.1.3 The effect of deafness on the marital relation

Having a hearing-impaired child affects the relationship between the two parents to a great extent. Parents have to restructure their relationship in terms of time spend together and their time with their children. Extra time is taken to communicate with the child and this is limiting the couple's availability to each other (Fenster, 1988:228-229).

Most of the burden falls on the mother, thus driving a wedge in between the parents. The marriage can be affected positively as well as negatively. The presence of the deaf child can bring parents closer to each other, but it can also precipitate conflict. Each partner may blame the other for the child's deafness. This may lead to conflict, either rejecting the partner or the deaf child.

Disagreements on how to discipline the child, which mode of communication is best, and how to deal with outsiders can occur. The added stress affects the marriage and relationship with extended family and friends (Greenberg, 1997:309).

Parents become closer to each other, because they talk to each other much more after the birth of the child, not only about the child, but about other things as well. These

parents gain strength from one another and support from each other (Kashyap, 1986:35).

There are also parents whose marital relationship has deteriorated, but no differences in divorce rates between families with deaf children and those with no deaf children are reported (Moore, 1996:141; Kashyap, 1986:35).

Increased medical expenses may lead to changes in roles. In a two-parent family, the mother who may not have worked can find that she needs to start working; or the father may assume that he needs to take an extra job to meet expenses. If the wife begins to work the father can take on the household chores, which can lead to further altering of family structures (Fenster, 1988:229).

A complex situation may arise from bringing up a hearing-impaired child and can be related to personal unhappiness and anxiety about the effect on the rest of the nuclear family (Brand and Coetzer, 1994:1367).

3.5.1.4 Parent's interactions with other children

Parents are sometimes so involved with the deaf child's needs and problems, that they may overlook the other children's needs. Mothers complain about the fact that there is a decrease in their interactions with their other children (Kashyap, 1986:35).

Family processes or interactions are slowed down considerably. Time is taken to communicate with the deaf child, *limiting the parent's availability to the other children* (Fenster, 1988:228).

According to Kashyap (1986:35) some parents withdraw from their hearing-impaired child when the child needs the contact desperately. This can be devastating to the child's development.

3.5.1.5 The effect of hearing impairment on the siblings

Siblings can sometimes feel pressured by the parents to balance the scales against their handicapped sibling's shortcomings, which creates anxiety and resentment

among the siblings (Murphy, 1979:358; Israelite, 1986:47; Atkins, 1987:36; Mendelsohn, 1983: 40).

Children learn a lot from each other. They can learn how to resolve conflicts and support one another. They learn how to negotiate among other equals or near equals, how to make friends, how to save face while losing and how to achieve recognition for their skills. Amongst the other children in the family, children learn to negotiate, compete and co-operate (Luterman, 1987:73). Siblings have an effect on each other's personality and development as well. They learn from each other and can even serve as a buffer between each other and the parents or the outside world (Murphy, 1979:352-353). These dynamics are also present in a family with a hearing-impaired child.

The oldest and healthiest sibling often serves as interpreter of external reality to the other siblings, however, any of the other children may function as intermediary. In addition, parents may rely on a sibling to explain or translate what a deaf child is saying (Murphy, 1979:358).

The relationships in the family are affected. Less attention is given to the other children, because extra care, attention and time are given to the deaf child. Parents may knowingly or unknowingly become less involved in the lives of their other children (Atkins, 1987:33; Fenster, 1988:229). This may lead to jealousy. Parents can also put more pressure on their normally hearing child to be more successful in order to compensate for the deaf child. The other siblings may be encouraged to become more independent. Jealousies become more intense and the other children may resent the deaf child. Sibling rivalry between the deaf child and the other children are reported in 56 out of the 100 cases (Kashyap, 1986:35). A major sibling complaint relates to discipline. Most siblings feel that discipline is not fairly administered (Atkins, 1987:35).

However, siblings of hearing-impaired children demonstrate a generally positive feeling about themselves, their family circumstances apparently influenced more subtle aspects of their psychological functioning (Israelite, 1986:53).

The researcher agrees with Murphy saying that siblings are not problem prone. The majority of siblings appear to function quite normally (Murphy, 1979:358). Many siblings report that a handicapped brother or sister has a positive influence on their adjustment and coping behaviours (Cleveland and Miller in Israelite, 1986:47). Siblings' feelings about their personal worth or their worth as family members are not influenced (Israelite, 1986:53).

Wilson adds another dimension. She says that siblings are known to add tension to the family circle as they seek to have their needs met (Wilson, 1982:22). It is difficult to pinpoint one variable that affects the siblings in the family. Age differences among siblings, socio-economic status of the family, age differences between siblings, family size and sex of siblings influence the siblings' experiences of having a hearing-impaired child in the family (Luterman, 1987: 77; Israelite, 1986:48-52). Siblings have concerns, which include things like: How do I deal with my friends? Will my chances of marriage be lessened? What effect will this have on my relationship with the opposite sex now or later? According to Wilson (1982:22) and Luterman (1987:79) the parents can determine to a great extent whether the siblings benefit or are disadvantaged by the presence of the deaf child. It depends on the parents' management of their own feelings, and their child-management skills.

According to Murphy and Israelite, siblings not only hold important places in the life of the family and the handicapped child, they deserve attention in their own right as they evolve to become fully mature individuals (Murphy, 1979:360; Israelite, 1986:53).

In a general discussion on siblings of handicapped children, Parfit (1975:19-21) discusses some ways of meeting siblings' needs. This will be included in the guidelines to parents that will be discussed in Chapter 6.

3.5.2 The effect of deafness on the deaf person

To be deaf is more than a medical problem. It is also a cultural phenomenon in which emotional, linguistic, intellectual and social problems are bound together (Wilson, 1982:23). If a person cannot hear, there is a very wide variety of problems with which the person is confronted.

For most deaf children explanations concerning the reasons for actions, expectations and emotional situations experienced by parents and the child will be less frequent and less competent due to the communication barrier (Vaccari, 1997:795). Deaf persons are likely to experience more small daily hassles relative to hearing individuals, like problems with language and communication, the experience of stigma or prejudice from the hearing culture and isolation (Greenberg, Lengua and Calderon, 1997:310).

Deaf children cannot learn through imitation of sounds. Everything must be explained clearly and identified specifically (Fenster, 1988:227).

Often those with profound hearing loss report feelings of isolation and of being a burden to family members. Signs of paranoia, depression, withdrawal, irritability and nervousness are reported (Maillet undated: 31).

Using parental and teacher reports as a rough indicator, 27 % of mothers, 40 % of fathers and 32 % of teachers feel that the child is unaware of being deaf. About the same percentage of mothers and fathers as just mentioned believe that the child is aware but untroubled by it (Freeman et al, 1975:399).

Early onset profound deafness has shown to have devastating consequences for the development of language. Delays in the following areas have been documented: receptive skills, expressive skills, vocabulary, grammatical and pragmatic abilities (Hasenstab in Vth International Cochlear Implant Conference Programme and Abstracts, 1997: 92; Vaccari, 1997:799).

According to Fenster (1988: 226-227) the developmental aspects of the deaf child include, amongst others, the following:

- A deaf child cannot hear his or her mother's voice. *"In essence, the deaf child cannot hear his or her mother's love"* (Fenster, 1988:226).

- A deaf child responds in a different way. The child cannot respond to his / her name, or identify objects in the environment. The hearing child does the following:
 - ceases activity when called at 8 months
 - reacts to “NO” at 9 months
 - responds to questions at 11 months of age.
 - babbles during the first year
 - follows two directives at 21 months
 - knows the names of food eaten or clothes worn at 5 years.

The inability of the deaf child to respond according to this leads to the following questions and problems.

- How does the hearing-impaired child develop a sense of self, a sense of belonging, a sense of family and a sense of the outside world?
- The child must concentrate on subtleties from the environment that most of us take for granted.
- The child does not hear his parents’ discussions on finances, the in-laws, and so on.
- Deaf children see the parent’s angry faces, but does not understand what the matter is.
- Eye contact is very important for the hearing-impaired child.

When the light goes out or when the child closes his eyes, the world has “*vanished*” (Fenster, 1988: 226).

The effect of deafness on the deaf child is overwhelming. It has definite implications for his / her educational psychological development.

3.5.3 Parental expectations and feelings

Parents’ feelings about the news of having a hearing-impaired child is well described in a father of a 15 year’s own words: “*At first you hurt like hell and then it becomes a dull ache that does not go away* (Luterman, 1987:41)”.

The parent's own sense of invulnerability is threatened. *"After the initial shock and active period of mourning, parents may resort to individually suited mechanisms of defence to bring to an end the period of mourning and to defend against anxiety which appears as a reaction to the threat of ego integrity. Yet, while the personality of the individual may thus be restored, this integration is achieved at the expense of others in the family (Kashyap, 1986:32)"*.

No parent is ever prepared to be a parent of a hearing-impaired child. Feelings of anger, fear, frustration and impotency abound, because parents are unable to communicate with their child (Fenster, 1988:227). Deafness challenges the parents' capacity to cope with the responsibility of bearing and rearing the child (Wilson, 1982:22). To begin with, it calls for considerable adjustment of parental expectations (Kashyap, 1986:31). The parental process of acceptance of their child's hearing impairment is the grief reaction, as described by Kubler-Ross.

This model includes:

- denial
- anger
- bargaining
- depression
- acceptance (Luterman, 1987:41)

Parents have feelings like shock, anxiety, anger, depression, guilt, resentment, vulnerability, overprotection, confusion, panic and denial (Luterman, 1987:41-47; Goldberg, 1979:299-305).

The grief in question should not be viewed as a single reaction to crises, but a complex human progression involving many emotions and attempts to adjust to the crises (Wilson, 1982:20).

Parents have a very normal expectation that they will have a physically and mentally healthy child. When parents realise that they have a hearing-impaired child, they

have to adapt their expectations of the child and this results in a crisis in the family (Kashyap, 1986:32). In many cases the unfulfilled expectations lead to anger directed to the hearing-impaired child. This is followed by rejection of the child and finally ending in despair. Anger occurs when parent's expectations of a perfect child are violated. It may be directed to the deaf child, displaced onto the professional, or ultimately turned inward, resulting in depression (Fenster, 1988:227). It is therefore very important that parents would resolve the conflict created by the discrepancy between what they anticipated and what is reality. Parents have to deal with the consequences of deafness in a constructive manner (Kashyap, 1986:32).

Parents are concerned about their child's future, have a predominant feeling of guilt, and have feelings of denial, which can continue throughout the child's life (Fenster, 1988:228).

Parents may have the expectation that a professional will take care of the child, cure the deafness or repair the damaged ear. Parents can expect that professionals will take the responsibility for educating their child. It is emotionally devastating for the parents to come to terms with the fact that nothing medically can be done to correct the hearing problem (Kashyap, 1986:32).

3.5.3.1 Parents' expectations of hearing aids

Parents often expect, despite the warnings of the professionals, that a child would start hearing properly the moment he starts wearing a hearing aid. The child has to "learn" to listen with the hearing aids. If parents do not have realistic expectations of the hearing aid, their feelings can lead to the disappointment-anger syndrome. This often leads to a situation where the child does not wear the hearing aids. Mother's would say that the child does not like wearing the aids, or that mother's don't think that hearing aids are useful to the child (Kashyap, 1986:33).

3.5.3.2 Parents' expectations of the socio-economic future of the child

According to research on this topic, Kashyap (1986:33) states that considerable adjustments are to be made by the parents, particularly with regard to the aspirations about the child's future. In a sample of 100 children that were studied, mothers of 39 and fathers of 59 children had more or less positive expectations from their child.

They felt that their child would be able to study, earn a living, marry and adjust to the hearing society. These parents have to a great extent reached some level of acceptance of their child's deafness and are thinking constructively (Kashyap, 1986:33).

3.5.3.3 Parents with unrealistic expectations

Parents, who have not yet come to terms with the disability, are ignoring or denying the presence of the problem. These parents would still think that the child could be completely cured after some years. This is unrealistic. As long as this denial is maintained, it would not be possible to take realistic steps to help the child (Kashyap, 1986:33).

3.5.3.4 Parents with low expectations

In Kashyap's study (1986:33), mothers of 10 and fathers of 8 children had low expectations from their child. They had the fear that the child would always be dependent on them, that it would be very difficult even impossible to get them married, that they won't be able to look after the parents when they are old. These parents were very overprotective, have low expectations of what the child can do and would meet the child's every need. They would demand very little or no effort from the deaf child. This results in an excessive reliance of the child on the parents and a lack of confidence in his own abilities. This can become as great a handicap to the child as the deafness itself.

3.5.3.5 Parents with no expectations

Mothers of 18 and fathers of 30 children in Kashyap's study stated that they had no expectations for their child (Kashyap, 1986:33). A child strives for greater achievement to gain approval from his or her parents and appreciation for his or her own self-esteem. If no expectations are forthcoming, the child will cease to strive for achievement (Kashyap, 1986:34).

There were also parents in this study who were too afraid to verbalise their expectations, if any (Kashyap, 1986:34). This can be an interesting study in future research.

3.5.3.6 Parents with positive expectation

In the above-mentioned study both parents in 27 families had positive expectations of the deaf child.

3.6 Differences between expectations and experiences of fathers and mothers

Fathers say the following:

- They hardly communicate with their deaf child (Kashyap, 1986:32).
- They withdraw emotionally from their deaf child (Kashyap, 1986: 32).
- Fathers experience more difficulty in communicating with the deaf child compared to their wives (Meadow-Orlans, 1995:352).
- According to Upshur (1991) fathers and mothers differ in evaluating early intervention services (Meadow-Orlans, 1995:353).
- Fathers' personal adjustment is related to general life stress, paternal locus of control and intimate social support (marital satisfaction) (Greenberg, 1997:316).
- Fathers are likely to seek information rather than emotional support (Meadow-Orlans, 1995b: 319).
- Fathers may need more support for and information about future opportunities and possibilities for their deaf child, while mothers are more orientated to current intervention (Meadow-Orlans, 1995:354).
- For discussion of the father's role and the effects of involvement in the father's programme, the reader can consult Crowley, Keane and Needham, 1982:38–40 and Vadasy et al, 1986:16–31.

Mothers differ from fathers in the following ways:

- During her interviews with parents of hearing-impaired children Kashyap (1986:32) found children who do not have hearing aids at all. Their mothers were unable to give a reason why this is so. This is in line with the disappointment-anger syndrome that is mentioned in paragraph 4.3.1 in this dissertation.
- Some mothers are very emotional and are not always capable of talking about the deafness (Kashyap, 1986:32).
- Mothers need support of their spouses (Meadow-Orlans, 1995:352). Mothers place a high value on emotional support (Meadow-Orlans, 1995b:319). Mothers

do not perceive their emotional support to be consistent (Quittner, 1991:218; Greenberg, 1997:316).

- Mothers reported higher levels of general parenting stress compared to fathers (Meadow-Orlans, 1995:353; Quittner, 1991: 217; Brand and Coetzer, 1994:1367). Mothers did however experience more stress relating to their perception of difficulties for themselves, other family members and the family as a whole (Brand and Coetzer, 1994:1367). This correlates with Quittner's research on psychological adjustment of mothers (Quittner, 1991:217).
- Mothers expressed higher levels of anxiety and depression compared to their husbands (Meadow-Orlans, 1995:352 and Quittner, 1991: 217-218). Mothers have more feelings of restriction of role and more concerns about their relationship with their husbands (Meadow-Orlans, 1995:354).

3.7 The diagnosis of deafness: The family's needs and responses

To know that you have a hearing-impaired child tends to precipitate a crises for parents. Parents' reactions to the diagnosis of the hearing loss are severe (Williams and Darbyshire undated:25). The parents' lack of understanding of hearing loss and its implications inevitably contribute to the severity and persistence of their reaction. Most parents do not understand what hearing loss would mean to their child and do not have a realistic appreciation of how hearing loss would affect their own lives. Parents sometimes feel embarrassed about their child's problem. This inhibits them to ask questions (Williams and Darbyshire undated:28). The results of Freeman et al (1975:395) seem to indicate a disruption of a lesser degree. According to him, only in 10% of the cases the initial impact of having a hearing-impaired child was severe enough on the parents to impair their functioning substantially. In 36% of the cases the impact was moderate, and in 50% it was mild or neutral.

Ferguson and Watt (1980:60) reveal more optimistic results with regard to families. In their study, 30 mothers of severely handicapped children scored no higher on an anxiety scale than the working class mothers of non-handicapped children. This can be contributed to improved parent-professional relationships. It is probably also the result of earlier detection and more successful management (Williams and Darbyshire undated: 25).

Williams and Darbyshire say that the psychological effect of sympathetic and effective management at the time of diagnosis and immediately after, was crucial to parents' realistic acceptance of permanent hearing losses and their subsequent involvement in constructive training procedures with their children (Williams and Darbyshire undated: 25).

Professionals recognise the need for early parent guidance. This comprehensive parent programme should include the following:

- (a) counseling to deal with negative feelings and to provide psychological and emotional support,
- (b) giving of factual information regarding the hearing loss,
- (c) instruction to increase parental competence in the auditory and linguistic training of their child (Northcott, 1975:159–186).

Parents reported that the responses of medical personnel contributed in the majority of cases to the postponing of the diagnosis of hearing impairment. Some family doctors (40%) agreed that something was wrong and suggested that the parents should "wait and see". A number of doctors (28%) agreed that something was wrong and suggested an explanation other than hearing loss, but did refer the child to a specialist. The remaining doctors (32%) agreed with the family with regard to the possibility of hearing impairment and referred them to a specialist (Williams and Darbyshire undated:25). It is shocking to know that even today this is still a problem. In interviews and social conversations, the researcher realised that doctors nowadays are not as accurate in their diagnosis of hearing impairment as it should be. For a fuller description of these unpleasant experiences of parents while seeking diagnosis, the reader can consult Fellendorf and Harrow (1970).

Parents frequently admit difficulties with discipline (Williams and Darbyshire undated:28). Most parents in William's and Darbyshire's research expressed a need for factual information about hearing loss, its implications and their child's future prospects. They also need assistance with child management problems and counselling at the time of diagnosis on an ongoing basis (Williams and Darbyshire undated:29).

Table 6: Literature synopsis - The effect of deafness on the individual aspects of the family's daily living

- ❖ **Parents' physical and mental health:** feelings like denial, anger, disbelief, hope, frustration, mourning, isolation, sadness, anxiety, depression.
- ❖ **Household responsibilities** increase, deterioration in social life, less leisure time.
- ❖ **Marital relationship:**
 - ◆ Less time for each other
 - ◆ Positive – can bring parents closer to each other
 - talk and discuss more things
 - parents gain strength from each other
 - ◆ Negative – can precipitate conflict
 - disagreements on discipline, which way of communication.
 - ◆ Increased medical expenses
- ❖ **Interactions with other children:** decrease, because of less time
- ❖ **Effect on siblings:**
 - ◆ Can feel to balance the hearing-impaired child's shortcomings
 - ◆ Anxiety and resentment
 - ◆ Learn how to support other children
 - ◆ Oldest sibling often serves as interpreter
 - ◆ Relations are affected: jealousy, sibling rivalry can occur, siblings feel that discipline is not fair in the family
- ❖ **Effect on deaf person:**
 - ◆ Not only medical problem, also cultural: emotional, linguistic, intellectual, social
 - ◆ Problems with language and communication
 - ◆ Feelings of isolation and burden to family
- ❖ **Parental expectations and feelings:**
 - ◆ New challenge to cope with a deaf child
 - ◆ Process to accept the child's hearing impairment.
 - ◆ Feelings like shock, anxiety, anger, depression, guilt, resentment, vulnerability, overprotection, confusion, panic, denial.
 - ◆ Fear for child's future.

- ◆ Expectations of hearing aids: often disappointed, because child does not start hearing immediately
- ◆ Expectations of socio-economic future of the child: some have normal expectations, some have no expectations
- ◆ Unrealistic expectations: still think that child would hear one day
- ◆ Low expectations: child would always be dependent on parents, impossible to get married; demand no effort of child
- ◆ No expectations: lead to a child who does not strive for achievement
- ◆ Positive expectation: most of parents do have.

3.8 The cochlear implant and the family

(see Table 9)

3.8.1 Effect of the cochlear implant on the deaf child

The area where use of a cochlear implant seems to be most beneficial is in speech perception. Individuals experience improvements in psychological aspects.

They feel safer and more at ease in their environment. This may be a result of being able to perceive sounds better and thus making the environment more predictable. Individuals feel more at ease in social situations after receiving the cochlear implant, which could be due to improved communication (Tyler, 1990:287).

Lansing (1990:65) says that a *“fairly immediate change in hearing-related feelings may be associated with provision of a cochlear implant”*. The acquisition and first month of use of an implant itself may have a greater impact on perceived communication performance than the additional experience with the implant device and formal training. It may produce a fairly immediate reduction of negative attitudes and feelings towards hearing loss and ease of communication (Lansing, 1990:74).

Improvements in all aspects of lifestyle, including social interactions with families and individuals were reported in Tyler’s study. Tyler reports also restoration of confidence, improvement in speech reading and the hearing of warning sounds (Tyler, 1990:288).

Individuals who received an implant report fewer feelings of isolation and a decreased perception of being a burden to family members (Maillet, undated:31; Tyler, 1990:284).

It is worth mentioning that a boy, Stone, reported on a conference on the cochlear implant, that the implant enables him to carry on with conversations with his family. He lost his hearing as well as his vision. He said that the implant put him in touch with his family (Carroll, 1995:18).

3.8.1.1 Implications of age at implantation

The quality of the parent-child relationship is adversely affected particularly when the child is prelingually deaf with a severe to profound hearing loss. This degree of loss precludes the ability to understand speech, even with hearing aid use. Most often profound hearing loss is present at birth or occurs within the first 3 years of life, a critical time for the development of speech and language. The delayed communication affects cognitive as well as social development (Fenster, 1988:226).

Advocates of cochlear implantation claim that the cochlear implant has a dramatic impact on the acquisition and use of spoken language by deaf children, with positive ripple effects socially and psychologically (Osberger, 1993: 19-23).

Opponents of the cochlear implant suggest that implanting prelingually deafened children deprives that child of his or her Deaf Culture and yet does not provide enough hearing to enable the child to become part of the hearing world. (Lane, 1993: 19-23).

Fryhauf-Bertschy (1997:184) says the result of studies published to date indicate congenitally deaf and other prelingually deafened children may not show measurable changes in speech perception performance until the cochlear implant has been used for two or more years. Rose (1996: 259) says that children who cannot depend on speech either expressively or receptively for basic oral communication may have measurable improvement in their ability to identify or produce certain phonemes, but these benefits are comparable to what is obtained with hearing or tactile aids. Rose (1996:258) also says that *"we have yet to see a prelingually deaf child who acquired*

even modest results with the implant who did not undergo intensive habilitation over a period of years...even after habilitation the results with these children appear to be, at best, equivocal”.

It is the researcher's belief that the slightest improvement in a hearing-impaired child's listening skills, speech and functioning, gives the hearing-impaired child a better quality of life. Children receive enhanced benefits from the use of cochlear implants when parents play a major role in the rehabilitation process (Tye-Murray and Kelsay, 1993:21). The following research results are offered to show that the cochlear implant given to prelingually deafened children is worthwhile.

Children who receive an implant before the age of five years may show greater benefit in terms of speech production measures than children who receive cochlear implants after five years (Tye-Murray, Spencer and Woodworth, 1995:336). Children who received a cochlear implant under the age of four years appear to increase their overall ability to communicate. They appear to use intelligible speech at a faster rate, on average, than similar children using hearing aids or tactile aids (Nicholas, 1994:197; Tye-Murray, Spencer and Woodworth, 1995:336).

It is, however, possible that older children will also continue to improve their intelligibility with continued cochlear implant experience. Progress may be at a slower rate, or require more time (Tye-Murray, Spencer and Woodworth, 1995:336).

Osberger's (1998:157) research on the effect of the child's age at implantation reveals that older, prelingually deafened children who use oral communication have the potential to derive significant benefit from cochlear implant technology. Implant benefit is more limited in children with long duration of deafness who use total communication.

The age of onset of deafness and the duration of deafness strongly influence the benefits that patients receive from cochlear implants. Recently deafened children who had achieved normal speech and language concepts show most rapid improvement in performance (Miyamoto, 1995:293; Osberger, 1993:188). Quittner's research confirms this (1991:92). Quittner also states that children using oral communication

were significantly better users of sound in everyday situations with cochlear implants, than children using total communication. Quittner suspects that this is because of their greater exposure to spoken language, an educational emphasis on interpreting auditory information and more intensive auditory training (Quittner, 1991:92-93).

Staller (1991:132) supplies the following data with regard to postoperative performance taking the age of onset into account (see Figure 4). The Y-axis represents the percentage of correct answers in the word subtest of the MTS. The X-axis represents the stage of onset of deafness. Grey bars represent preoperative performance and black bars postoperative performance.

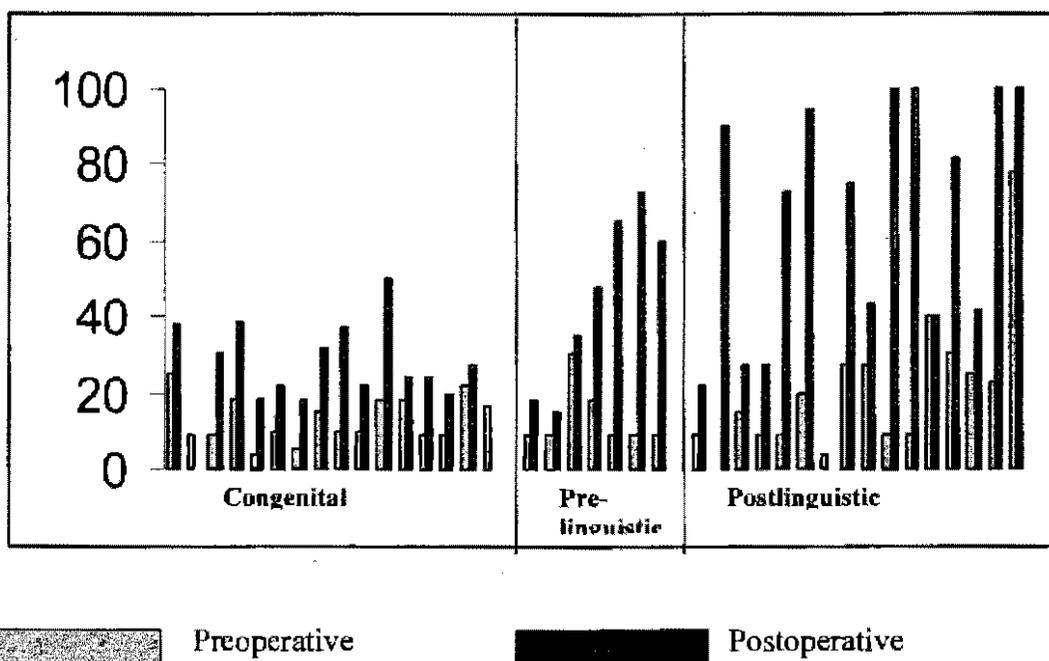


Figure 5: Postoperative performance in cochlear implantees taking the age of onset of deafness into account (Staller, 1991:132).

It is, however, important to note that success of the cochlear implant has not been documented with prelingually deafened adults, and that despite the lack of supporting evidence with congenitally deaf adults, the procedure was nevertheless approved for use with prelingually deafened children (Vernon, 1994:486). Geers (1992:129-140) indicates limited auditory gains for implanting prelingually deaf children. Vernon says that to be considered successful, the cochlear implants should result in three major improvements, namely it should enable a child to hear speech well enough to understand conversation in a quiet one-to-one setting; intelligible speech should be

acquired and competence in English is expected. He also says that parents would be disappointed if they believe that cochlear implants with profoundly deaf children will bring clear speech within the normal range. The researcher agrees with Vernon that the best case scenario on implants is one of an amazing medical advance that offers the ultimate potential of enabling deaf people to hear speech well enough to converse and to gain the capacity to speak intelligibly (Vernon, 1994:486-490).

At the time when Vernon's article was written, there was not much positive evidence that the cochlear implant was effective with prelingually deaf persons. Today, however, much research on this topic has been done, with a lot of results to prove that the effect of the cochlear implant on prelingually deaf children is quite positive (Eilers, 1997:53; Osberger, 1994:171-173).

In a study to analyse the longitudinal speech perception performance of prelingually deafened children who have used their implants for 3 to 5 years, Fryauf-Bertschy (1997:195- 196) reveals the following:

- Regardless of age at implant and amount of daily device use, cochlear implant use affords improved pattern perception.
- Children who are consistent users of their cochlear implant devices show improvement over time in their abilities to recognise words from a closed set. This suggests that prelingually deafened children can develop improved understanding of speech with consistent cochlear implant use.
- Open-set word understanding is a measure frequently used to assess the benefit of cochlear implantation in adult cochlear implant users, but it must be interpreted somewhat differently in children. Unlike postlingually deafened adults, prelingually deafened children do not have the auditory memory of spoken language to help them interpret the electrical signal of the cochlear implant. Open-set word testing can help us understand what elements of speech can be processed and delivered electrically to a congenitally deaf ear. We must realise, however, that interpretation of speech depends upon the child's linguistic skills, his or her willingness to guess, and his or her ability to fill in missing bits of auditory information. Almost all children, regardless of when they received the

cochlear implant, can repeat some phonemes from a list of presented words. Paired with lip-reading, this can be a significant contribution to communication.

- The differences in performance between the full-time users and the minimal users were significant.
- Less than full-time use of cochlear implants by children occurred primarily in children implanted after the age of 5 years. This supports the notion that longer duration of deafness in a prelingually deafened child may result in less functional benefit and more difficulty adjusting to a cochlear implant.
- Children who do not achieve high test scores may still benefit from cochlear implants by demonstrating pragmatic use of audition, awareness of communication by others, and awareness of environmental sounds.
- Each child's functional use of a cochlear implant depends upon his or her social and educational environment, as well as the consistent use of the device.

Having had experience in working with children with cochlear implants, whether postlinguistic or prelinguistically implanted, the researcher agrees with the findings of Fryauf-Bertschy.

Most children with prelingual deafness should be fully capable of acquiring any lexical and grammatical aspects of a language regardless of its modality, as long as the sensory system provides appropriate input and there are mature language users providing adequate communication experiences (Nelson, Loncke and Camatra, 1993:123-51).

The following statement is noteworthy: *"Although older children derive considerable benefit from a cochlear implant, our latest data suggest that the younger the child, the better the long term ability to understand conversation without lip reading and speech intelligibility. Moreover, recent surgical audit shows that children who have surgery under three years of age are no more likely to have a surgical complication than children aged five years and older (Cochlear Implants in Children: Outcomes Update: August, 1998)."*

3.8.1.2 Language development after the implant

Language competence is the most significant variable for prognosis. It elucidates perilingual deafness and includes the extent of prior supportive programs (Fritze, 1989:296).

Robbins' (Vth International Cochlear Implant Conference Programme and Abstracts, 1997:92) recent investigations state that children with implants exhibit similar language improvement as did the normal hearing peers. The overall language ability of children with cochlear implants remain delayed, given that they started out much farther behind their peers with rehabilitation.

It is interesting to note the following difference among researchers: Schopmeyer (Vth International Cochlear Implant Conference Programme and Abstracts, 1997:95) says that deaf children acquire language at a slower rate than their hearing peers and that the influence of the cochlear implant on the rate of language development is not fully described. It appears that cochlear implants positively influence the rate of language development in young deaf children.

3.8.1.3 Sound perception after implant

I'm learning to listen

I'm willing to try

Nothing's impossible

Reach for the sky

I may not be perfect

Though I'd like to be

I'm learning to listen

Just being me.

(Estabrooks 1994)

Learning to listen involves four levels:

- ◆ detecting sounds,
- ◆ discriminating between them,
- ◆ identifying familiar auditory patterns and
- ◆ comprehending their meaning (Ling, 1986:24).

Comprehension of the meaning of sound is most important and to have this, auditory detection is needed. Improved detection of sound alone is not enough, as Ling duly says: *“Selecting new devices with care, providing auditory experiences in contexts of real life situations, relating auditory skills to each child’s cognitive, speech, and spoken language development, communicating through audition from early infancy, learning through listening... appear to be the most essential features of present and future work”* (Ling, 1986:25).

The most basic measure of performance with a cochlear implant is the ability to detect sound. All children show a marked improvement in thresholds for sound field warble tone stimuli when using implants, compared with hearing aids. The children can hear conversational speech, which was not possible before the implant (Nottingham information booklet:6). For a more technical discussion on this topic please read Busby and Clark (1996).

The implant provides more information to the auditory system of some persons with profound hearing loss than does a hearing aid. This results in that hearing is a much more viable channel for developing and monitoring speech in persons with profound hearing loss (Robbins, 1994:76). Children using the cochlear implant demonstrate improvement of their speech and speech perception abilities (Moog, 1991:70; Tyler, 1990:287).

Sound plays a role in organising visual attention. Profoundly deaf children, who had access to auditory information through cochlear implants, performed more like hearing children on visual selective attention tasks. For detailed information on the topic the reader is referred to Smith et al (1998:840-850).

Nikolopoulos produced the following table at the Nottingham paediatric Cochlear implant Advanced Course (Timetable and course notes),1999.

Table 7: Review of outcomes following cochlear implantations

CATEGORY OF PERFORMANCE	P R E	1 YEAR	2 YEARS	3 YEARS	5 YEARS
Use of telephone with known speaker	0%	0%	7%	12%	35%
Understand conversation without lip-reading	0%	3%	23%	46%	75%
Understand common phrases without lip-reading	0%	26%	75%	90%	90%
Discrimination of speech sounds	0%	94%	100%	100%	100%
Identification of environmental sounds	4%	99%	100%	100%	100%
Response to speech sounds	6%	100%	100%	100%	100%
Awareness of environmental sounds	16%	100%	100%	100%	100%
No awareness of environmental sounds	84%	0%	0%	0%	0%

Nikolopoulos suggests that prelingually deaf children should be implanted as early as possible and that the rehabilitation should include a strong oral / aural component (Course Notes of the Paediatric Cochlear Implant Advanced Course, 1999).

3.8.1.4 Speech intelligibility after implant

Parents indicated in a questionnaire that they recognise their children's speech better than strangers or other family members do (Tye-Murray, 1995:333).

After using the cochlear implant for 5 years, an experienced listener finds the speech of 28 out of 32 children (87%) intelligible (Nottingham information booklet:7). The following data is supplied by Nottingham.

Table 8: The improvements in speech intelligibility over the years after implantation

Speech Intelligibility Rating	Before implant	Time after implant (months)					
		6	12	24	36	48	60
Intelligible to all	3	2	5	3	4	4	8
Intelligible to listener with little experience	3	4	0	2	7	9	6
Intelligible to experienced listener	8	4	17	33	37	25	14
Unintelligible	22	34	61	44	21	5	2
Sign language	89	89	48	14	6	2	2
Preverbal	66	32	12	2	-	-	-
Total numbers of children	191	165	143	98	75	45	32

This is in general agreement with Tobey et al (1991:165-173) who reported a pre-implant intelligibility score of 18% and post-implant score of 34% in 27 paediatric users of the cochlear implant.

The effects of age at implantation on speech intelligibility is as follows:

After five years of implant

- 75% of children implanted under the age of three years are rated as being intelligible to a listener with little experience.
- This can be compared to 40% of children implanted between the ages of three and five years, and 20% of children implanted at five years and older (Cochlear Implants in Children: 1998). Osberger's (1994:171) findings correlate with this.

Another factor that might affect speech intelligibility is the age of the talker when deafness occurs. In their study Osberger, Maso and Sam (1993:188) describe that most of the children classified as having early onset of deafness, acquired their hearing losses before age two, whereas the majority of children classified as having late onset of deafness acquired their hearing losses between ages five and seven. Research suggests that children who acquire deafness during the first two or three

years of life demonstrate rapid speech deterioration and fail to retain all of the speech sounds that presumably had been developed prior to the onset of the deafness.

Even with intensive training these children do not regain previously developed speech skills after the onset of their deafness. Data reported by Osberger, Maso and Sam (1993:189) showed a systematic increase in the size and diversity of children's phonetic inventories as the age at onset of deafness increased from birth to age three. Differences in speech production as a function of age at onset of deafness remained even after the children received a cochlear implant (Osberger, Maso and Sam, 1993:188-189).

Children who were implanted before they were teenagers show higher speech intelligibility and good speech perception skills. The speech of these children was about 15% more intelligible, on the average, than the speech of subjects that were implanted after age 10 (Osberger, Maso and Sam, 1993:200).

3.8.1.5 Functional benefit after the implant

Substantial benefit from the cochlear implant is gained over time. After three years, 91% can understand common phrases without lip-reading (Nottingham information booklet: 7)

In general it is predicted that all children will develop the ability to monitor their acoustic environment and detect speech sounds soon after implantation. The majority of children will in the longer term attain spoken language, using hearing and speaking for everyday communication. Many will be able to make practical use of the telephone. These benefits are only achieved after some years after the implantation, with sufficient and appropriate support (Nottingham information booklet:7).

The dramatic increase in communicative behaviour is accompanied by an overall profile of communicative functions which more closely resembles that of younger, normally- hearing children than it resembles other hearing-impaired age-mates, according to research done by Nicholas (1994:197).

3.8.1.6 Speech production after the implant

A factor that might affect speech production skills with an implant is the method of communication used by children in their educational setting and their interpersonal interactions. Children with a cochlear implant who use oral communication demonstrate higher levels of performance on speech perception measures than implanted children who use total communication (Staller et al, 1991:126-136; Somers, 1991:174-178).

Children who have been evaluated after using the cochlear implant for at least 24 months performed well above average. This may be an indication that the cochlear implant is especially beneficial for the development of supra-segmental aspects of speech. This means syllable stress and intonation can be better after a cochlear implant (Tye-Murray, Spencer, and Woodworth, 1995:336).

Children with a cochlear implant are able to discriminate spectral differences in speech sound. It is important to note that even when the ability to understand speech through listening alone improves only slightly, the improvements may be significant in facilitating the understanding and production of speech when listening is combined with lip-reading (Moog and Geers, 1991:71). Children with cochlear implants exhibit a greater rate of progress in acquiring speech perception skills (Moog and Geers, 1991:74). According to Tomblin, prelingually deaf children are better able to acquire English when provided with cochlear implants than when provided with hearing aids (Tomblin, 1999:507).

Vowel production ability as well as consonant production in the final and initial position in syllables improves significantly after a cochlear implant (Moog and Geers, 1991:75).

In an interesting study about children's speech production with their devices turned on and off, Tye-Murray (1996: 608-609) came to the following conclusions.

- Children with prelinguistic deafness who have prolonged cochlear implant experience do not change their speech output when speaking with their cochlear implants turned off.

- Children with prelinguistic deafness who have better intelligibility are more likely to alter their speech production in a device-off speaking condition than children who have poor intelligibility. One possible interpretation of this finding is that children who have been profoundly deaf and who have acquired better speech skills as a result of using cochlear implants do not depend upon on-line auditory feedback for regulating ongoing speech production. Another interpretation is that these children use on-line feedback, but are able to speak in its absence, either because articulatory behaviours are reasonably well established or because they can rely on other channels of afferent information (Tye-Murray, 1996:609).
- The fact that some children nasalize their vowels suggests that they may be attempting to maximise proprioceptive (to feel the sound) information, even though they receive some auditory feedback via their cochlear implant. Nazalization of vowels is associated with lowering the velum, which causes airflow through the nose. This might provide children with information about voicing as well as provide them with an increased proprioceptive awareness of their speaking behaviour.
- For an advanced and more technical discussion of speech recognition performance of children with cochlear implants, the reader is referred to Osberger et al (1998:152–157.).

3.8.1.7 Speech perception after the implant

Moore (1982) and Robbins (1988) can be consulted for a technical description of speech production, speech perception skills and tests.

It is generally accepted that there are differences in speech perception abilities among profoundly hearing-impaired listeners (Robbins, 1988:11). Geers (1994:95) did an extensive research on the speech perception of hearing-impaired children. She anticipated that the cochlear implant would contribute to the significant auditory benefits for the perception of speech. Numerous research groups have examined speech perception performance in children with prelingual profound hearing loss who have cochlear implants (Carney et al, 1991: 93–113; Cowan et al, 1994:318–321; Fryauf- Bertschy, Tyler, Kelsay, and Gantz, 1992:913–920; Fryauf-Bertschy, Tyler, Kelsay, Gantz and Woodworth, 1997:183–199; Gantz, Tyler, Woodworth, Tye-

Murray and Fryauf-Bertschy, 1994:1-7; Geers and Brenner, 1994:97-108; Kirk et al, 1995:370-380; Miyamoto, Osberger, Robbins, Myres, Kessler et al, 1991:42-46; Miyamoto, Osberger, Todd, Robbins, Kasarek et al, 1994:498-502; Miyamoto, Kirk, Todd, Robbins, and Osberger, 1995:334-337; Miyamoto, Kirk, Robbins, Todd and Riley, 1996:240-243; Osberger, Miyamoto, et al, 1991: 66-80; Osberger, Robbins, et al, 1991:105-115; Somers, 1991:174-178; Staller, Beite, Brimacombe, Mecklenburg, and Arndt, 1991:126 -136; Staller, Dowell, Beiter, and Brimacombe, 1991:34-47; Waltzman et al, 1994: 9-13; Waltzman et al, 1995: 341-342).

In Meyer's research the results suggest that on average, children with hearing losses in the 101-110dB range would receive greater speech perception benefits from a cochlear implant than they do from their hearing aids, irrespective of their current communication programme. Although speech perception skills of children using hearing aids increase over time, it is not on par with the average gains achieved by children who receive a cochlear implant (Meyer et al, 1998:855).

Moog and Geers (1991:75) revealed that implant subjects show greatly improved vowel production ability, averaging three times more improvement than the matched subjects with tactile and hearing aids. Similar levels of improvement were observed for consonant production in the final and initial position in syllables.

Children with higher levels of preoperative residual hearing are more likely to achieve speech perception benefits than children with total or profound hearing impairment. Children with the least preoperative residual hearing show more limited benefit to speech perception (Cowan in Vth International Cochlear Implant Conference. Programme and abstracts, 1997:78).

According to research done by Tyler (1990), speech reading enabled speech perception in 69,8% of the subjects. Without speech reading, only 41,5% of the subjects were able to have adequate speech perception (p. 284).

In the relationship between speech perception and production there are significant correlations. Speech production skills correlate with speech recognition skills. It

means that children with better speech production skills are more likely to have better speech recognition skills (Tye-Murray, Spencer and Woodworth, 1995:336).

In research done by Vermeulen et al (1997:57) the following results are noteworthy: Children who became deaf early in life progress at a slower rate than children who became deaf later in time. Children in total communication settings progress slower than those who use the oral / aural method (listening and speaking).

Duration of deafness (the length of time that has elapsed between the onset of deafness and receipt of an implant) is an important variable in speech perception performance with implants (Staller et al, 1991:126-136).

The importance of listening cannot be stressed enough. By listening, children learn things like the following:

- to regulate their speech breathing,
- to produce specific speech events - for instance, they learn to distinguish /p/ with a rapid velocity opening,
- gesture and /w/ with slow velocity,
- through listening they learn linguistic rules,
- by listening, children are informed about the consequences of their articulatory gestures, and how these consequences compare to sounds produced by other talkers (Tye-Murray, Spencer and Woodworth, 1995:336).

Speech discrimination ability points to a favourable prognosis in Fritz's research (1989:296).

Maillet (undated:35) investigated the changes in patient's perception of quality of life as the result of a cochlear implant. The results indicate that a cochlear implant makes a very perceptible improvement in a patient's quality of life. It showed statistically significant changes in life quality from preimplantation to 24 months postimplantation. The patients were aware of significant improvement in their ability to communicate after the implant. Although most patients perceived significant improvement in their quality of life after the implant, the degree of perceived

improvement was a function of the number of years that they had been deaf (Maillet undated:35). This finding is consistent with the relationship between years of profound deafness and measured speech perception abilities in implanted patients reported by Tyler (1990: 282-289).

3.9 Parents' expectations of the cochlear implant

Unrealistic expectations can lead to disappointment and even anger when they are not met (Luterman in Kampfe, 1993:298; Luterman, 1979; Mitchell, 1981:330-345). The intensity of unrealistic expectations about cochlear implants might influence parents' ability to internalise information that does not support their expectations. Parents' expectations should be broadened by meeting other parents of children with an implant, showing them videotapes, providing objective information and observing speech therapists while working with children with cochlear implants.

If parents have realistic expectations of the cochlear implant, the probability of feelings of success after the implant will increase. These positive feelings will provide positive reinforcement to maintain the schedule of aural rehabilitation for optimal progress. (Kampfe, 1993:298-300).

3.10 Parents' view on the effect of the cochlear implant on their children

Parents indicate their overall satisfaction with the cochlear implant. According to Cunningham's research on evaluation of the 3M/House Cochlear Implant, 57% of parents said that implant performance was better than the cochlear implant team's description. 34% said it was the same and 9% said it was worse (Cunningham, 1990:376).

Parents feel that:

- the implant has a greater effect on awareness of sound than on discrimination of sound.
- the implant's effect on speech production was greater than its effect on speech perception.
- the effect of the implant on environmental sound perception was superior to its effect on speech (Cunningham, 1990:379).

In Cunningham's research (1990:380), parents reported several problems with the implant as well. The two most frequently reported problems were

- the inconvenience of the cords and
- the size of the implant.

Although this is valuable information, the researcher expects that these findings would differ in the near future. The latest development with the ear level implant device ("Behind the ear"-version), excludes to a great extent these problems. The latest cochlear implant is much smaller and much shorter cables are used. This can be an aspect to examine in the future.

Parents were significantly more positive about the implant than they felt their children were. However parents reported that their children liked the implant (Cunningham, 1990:380).

3.11 Effect of the cochlear implant on the family

As discussed previously, deafness has a far-reaching effect on the hearing-impaired child and his or her family.

A child with a cochlear implant is still a hearing-impaired child. Therefore everything discussed in paragraphs 4.1-4.5. is relevant to this discussion.

Kashyap (1986), Fenster (1988), Moores (1973), Greenberg (1983) and others have discussed the effect of deafness on the family (compare paragraph 3.5.1). However, if the negative and the positive implications of the cochlear implant are taken into consideration, it is expected that there might be a few differences between the effect of deafness as such on the family and the effect of deafness aided by the cochlear implant on the family.

The age on which the child receives his or her implant, is a sensitive issue. There are different opinions among researchers. Rose (1996) and Lane (1993) are not in favour of implanting children at an early age, while Osberger points out the benefits of early

implantation (1998). However, the age of implantation has an effect on the relations in the family, as an early implantation leads to improvement in communication between parents and the hearing-impaired child and siblings and the child.

To add to these benefits, Miyamoto (1995) and Osberger (1989) say that a shorter duration of the deafness leads to better performance of the hearing-impaired child with a cochlear implant. If the hearing-impaired child can improve his or her speech, relations and general functioning, this surely decreases the stress with which parents struggle. Parents would be more relaxed and have higher expectations for the hearing-impaired child. This would enable parents to give more attention to the other siblings as well.

The fact that the implanted hearing-impaired child can understand better (cf. Fryhauf-Bertschy, 1997) relieves the parents and siblings of considerable stress.

Even if there is not a marked improvement in communication skills, a hearing-impaired person still benefits from the cochlear implant by being more aware of communication and of environmental sounds (Fryhauf-Bertschy, 1997). Parents' worries about the safety of hearing-impaired children are reduced by the fact that the children can at least hear warning sound like oncoming vehicles.

Although the research results with regard to the rate at which children acquire language after the implant are not consistent (cf. paragraph 4.6.1.2), it can be accepted that language development is enhanced by the cochlear implant. When a child's language develops (even if it is very slowly), it will inevitably have an influence on the family as mentioned above.

The level of sophistication of the child's listening skills determines the child's sound perception skills as well as speech abilities (Tyler, 1990). Parents will feel relaxed and satisfied after the cochlear implant, because their child would hear better and their speech would improve. Parents and siblings do not have to make eye-contact each time when they speak to the hearing-impaired child, they can rely on the child's listening abilities.

The fact that the hearing-impaired child's speech would be clearer, will improve communication in the family. Parents and siblings will experience less frustration because of improved mutual understanding and the child's better comprehension of language. Improved speech intelligibility will also improve the family's social life, because other people will also be able to communicate with the hearing-impaired child.

As described in paragraph 3.8.1, the implanted child benefits in the areas of functioning as well as in speech perception. The child with a cochlear implant develops new skills like the ability to use the telephone, listening to the radio, better speech recognition and in general coping better in groups. As life is so much easier for the hearing-impaired child, it will have a positive effect on parents and siblings. It seems as if life in the family is approaching normality.

The psychological benefits of a cochlear implant will also decrease parents' and siblings' worries. The increase in confidence and a feeling of well-being will have a positive effect on the parents and siblings. When the implanted child escapes the world of silence, it means that parents and siblings will have better emotional contact with the hearing-impaired child. This normalises communication and relations in the family to a great extent. The improved socialising skills of the hearing-impaired child after the implant will inevitably improve the whole family's social life (Tyler, 1990).

In an interesting study about the differences between single channel and multichannel cochlear devices, Quittner says the following. There is a difference in parenting stress and adjustment among families of children receiving single- versus multichannel devices. Quittner (1991b:102) obtained evidence of higher levels of parenting stress in the multichannel group as opposed to the single channel group. This observation is difficult to explain, as the multichannel device is a great improvement on the previous and now outdated single channel device. It has to be kept in mind that these observations were made ten years ago. The familiarity with the old and the unfamiliarity with the new may be a determining factor with regard to parental stress.

The researcher is convinced that the cochlear implant has a very positive effect in general on the hearing-impaired child. All the positive developments associated with

the implant result in a decrease in parents' stress levels, provide more time to parents and the other siblings. Parents have better expectations of the hearing-impaired child's future. Communication and relations in the family inevitably improve. Parents and siblings will experience normalisation with regard to many of the adaptations they had to make due to the hearing impairment of the child.

3.12 Arguments for and against the cochlear implant

Tyler (1990) gives a detailed description of advantages and disadvantages of the cochlear implant.

The expected benefits of the cochlear implant for the acquisition of spoken language and the incorporation of the impaired person in the hearing community, have been questioned recently. Tyler (1993), Crouch (1997) and Lane (1992) have voiced strong opposition against the use of cochlear implants in congenitally deaf children. Lane (1992:224-225) stated that *"it is highly unlikely that an impoverished auditory signal such as the implant provides will yield the same benefits for later language acquisition that normal hearing does; indeed, the coding carried out by the speech processor of the implant may work against the usefulness of the auditory input for language development, since the human nervous system did not evolve to acquire language from cochlear prosthesis."*

Crouch (1997:14-21) noted that it remains to be shown that children receiving cochlear implants obtain sufficient benefit from these devices to permit them to be fully participating members of the hearing community.

Similar scepticism is expressed concerning the effectiveness of speech production and speech perception by using cochlear implants (Tyler, Davis and Lansing, 1987:41-49).

Power and Hyde describe the reservations of the Deaf Community concerning the cochlear implant as follows: *"The major concern that the Deaf Community has about implants is social. The Australian Association of the Deaf feels that many deaf people and their families have been disturbed by misleading publicity through the mass media or other more professional sources. This publicity implies that deaf people are*

ill or incomplete individuals, are lonely and unhappy, cannot communicate effectively with others and are seeking for a cure for the condition. Such publicity demeans deaf people, belittles their culture and unique language and does not acknowledge the diversity of lives deaf people lead and their many achievements" (1992:421). "They ask that the social, educational, vocational and personal implication of the status be understood by the hearing community, especially by those advising parents of young deaf children. Greater sensitivity to these matter by those involved in cochlear implant programs would improve communication between them and deaf people" (1992: 422).

Several research programs have demonstrated that children with cochlear implants show improvements in speech production skills as well as in speech perception (cf. Fryauf-Bertschy, Tyler, Kelsay and Gantz, 1992:913-920; Osberger et al, 1991:151-163, Tobey, Geers and Brenner, 1994:109-129, Tye-Murray and Kirk, 1993: 488-502). The following statements can be accepted without reservation: *"Improvements in the speech perception and speech production of children are often reported as primary benefits" (National Institutes of Health, 1995: 9). "The positive result from studies of speech perception and production strongly suggests that cochlear implants provide sensory experience of spoken language and thus should provide gains in the acquisition of higher levels of language involving the lexicon, grammar and discourse" (Tomblin et al, 1999:498).*

Geers and Moog (1994:131-148) compared the language development over three years of a group of 13 children who received cochlear implants, with similar groups of children fitted with hearing aids or tactile aids. All three groups were provided with intensive oral speech and language training. Children with cochlear implants equalled or exceeded the language growth of other groups on receptive and expressive measures of spoken English.

In research done by Miyamoto et al (1997:154-157) they found that even 12 months' experience with a cochlear implant was sufficient to produce significant gains in expressive language over predictions based on non-implanted children.

In Tomblin's study to examine the influence of the cochlear implant on the English language achievements levels of children who were implanted between two years and nine months and 13 years of age, it is found that there are statistically significant differences in English language achievement levels, favouring children with cochlear implants (Tomblin et al, 1999:506).

It is interesting to note that in the same study the following was found: There is no relationship between chronological age and language achievement among children with cochlear implants, as expected by children who are still developing language (Tomblin et al, 1999:506).

Deaf children with cochlear implant experience have higher English grammatical achievement than those without cochlear implant experience. In addition, children with more cochlear implant experience do better than those with less experience (Tomblin et al, 1999:507). Children who receive implants can be evaluated with respect to their language development **early** in their implant experience. The children who are failing to benefit from the implant experience can also be identified early and additional efforts directed toward language development may be implemented (Tomblin, 1999:507). Tomblin et al (1999:508) concludes by saying that cochlear implants are providing the gains in linguistic development promised by previously demonstrated improvements in audibility, speech perception and speech production.

Cochlear implantation and subsequent improvements in speech skills appear not to eliminate children's use of sign to communicate (Tye-Murray, Spencer and Woodworth, 1995:337).

The results of Osberger, Fisher, Zimmerman-Philips et al (1998:157) suggest faster rates of learning and higher levels of speech recognition in children who use current implant technology than were achieved with the previous generation of implants.

Considering the arguments in favour of and against the cochlear implant, the researcher has to conclude that the benefits outweigh the disadvantages. The benefits are even more conspicuous when the effect of the cochlear implant on the family of

the implanted child is taken into account. This observation is supported by the results of the case studies and questionnaires that are included in this dissertation.

3.13 Support provided to the families of deaf children

To help the hearing-impaired child, the quantity as well as the quality of services provided is important. The role of the parent in the development of the child cannot be ignored. All habilitation endeavours with the deaf child should include the family. Parents should be given sufficient training to be able to help their deaf child. Professionals should help parents to maintain the fine balance between over-anxiety and complacency, so that the hearing-impaired child can become an active and non-disadvantaged participant in the community (Williams undated:28).

There is a strong need for increased quality and availability of parent counselling services following diagnosis of hearing impairment in the child (Fellendorf, 1970:51).

3.13.1. Problems that parents experience with professional support

According to a study done at The Counselling and Home Training Programme in the lower Mainland of British Columbia, parents express the following feelings:

- There is a need for greater emphasis on speech and auditory training. They felt that not enough emphasis is placed on the use of voice (Greenberg, 1983:413).
- There was little provision of support for the family.
- Intervention is focused on the mothers.
- There is a need for parent counselling.
- There is a need for assisting fathers (Greenberg, 1983:415).

The psychological effect of sympathetic and effective management at the time of diagnosis, and immediately thereafter, is crucial to parents' realistic acceptance of hearing loss. This has an influence on the parents' involvement in constructive training procedures with their children (Williams, undated: 25).

Today there are facilities that meet the requirements expressed above. The researcher is aware of a number of facilities for hearing-impaired children and their families,

where more professional help is offered regarding parent counselling, auditory training, assistance of both the parents and the siblings and general intervention.

3.14 The cochlear implant programme

It is of vital importance that a cochlear implant programme involves the child's parents. Therapeutic, educational and parental issues must be addressed during and after the implantation (Caleffe-Schenk, 1995:13).

It is important that the educators in the team should visit the school to observe the child in the classroom. It is important to include speech-language pathologists and audiologists in the team. It is their responsibility to work in conjunction with school personnel in establishing goals and assisting them in doing the therapy programme, and to provide therapy at the implant centre (Caleffe-Schenk, 1995:13)

The following is a compact description of the Cochlear Implant Programme at Crosshouse Hospital as an example of the type of support that is available for cochlear implant patients and their families:

3.14.1 Introduction

It was the first dual adult / paediatric programme to be established in the United Kingdom. The programme provides a national Cochlear Implant service for the whole of Scotland. It provides a range of specialist skills for the assessment, implantation and rehabilitation for people with a profound sensori-neural deafness who cannot benefit from the strongest conventional hearing aids. It is the only centre in Scotland undertaking paediatric implantation (Scottish Cochlear Implant Programme. Information for patients, undated:2). The first child received a cochlear implant in 1987 in the UK (Quality Standard in Pediatric Audiology, 1999:4).

To define good practice and quality service for deaf children who are considered for or who receive a cochlear implant, there is a joint review by the National Deaf Children's Society and the British Cochlear Implant Group (Quality Standard in Paediatric Audiology, 1999:5).

3.14.2 The programme's "Mission Statement" for paediatrics

- To promote spoken Language through Cochlear Implantation.
- To advise on the effective management of the implanted child in three key areas:
educational placement
mode of communication
auditory training.
- To recommend an oral / aural approach within the home and school environment.
- To take responsibility for the liaison between the implant team and the child's local professionals, to give advice, share information and monitor progress of the child (Information for Patients, undated:1).

3.14.3 Local Services and support

Local health and local education services are involved in the management of the cochlear implant of a child (Quality Standard in Paediatric Audiology, 1999:6).

It is the role of the support groups and voluntary organisations to provide parents considering a cochlear implant with information on all aspects of deafness, as well as on cochlear implants, in order that the child (wherever possible) and their families can make informed choices (Quality Standard in Paediatric Audiology, 1999:5).

3.14.4. Key personnel and facilities

The clinical facilities:

The clinical facilities are located within the Crosshouse Hospital's paediatric surgical (for children) and Ear Nose and Throat Department (for adults). Facilities are available for the following functions:

- pure tone audiometry
- visual reinforcement audiometry
- auditory brainstem evoked response measurement
- objective measurement facilities, for example electrical auditory brainstem response, neural response telemetry.
- soundfield hearing aid testing
- probetube microphone measurements

- tympanometry and otoacoustic emissions. (Quality Standard in Paediatric Audiology, 1999:6)

Paediatric Surgery:

The hospital care is undertaken in an appropriate paediatric setting

The paediatric cochlear implant team

The team consists of:

3 surgeons

one clinical scientist acting as co-ordinator, and

three other clinical scientists

teacher of the deaf

speech and language therapist

audiologist

secretary

A.T.O. (Information for Patients: 16)

3.14.5 Referral Procedure

Prospective patients should be referred to the Consultant Otolaryngologist via a General Practitioner or Ear Nose and Throat Specialist. An appointment will then be issued to attend for an initial consultation at the cochlear implant clinic (Information for Patients, undated:8).

The purpose of the initial consultation is to exchange information and to ascertain that a cochlear implant is the appropriate option. No formal assessment is carried out at this visit. It involves outpatient attendance at Crosshouse Hospital where the family will have the opportunity to discuss the cochlear implant with members of the team.

Family accommodation is provided within the hospital grounds, free of charge, for families travelling a distance (Information for Patients: 8).

3.14.6 Assessment

3.14.6.1 Pre-assessment

The cochlear implant team will request the following information from the child's local health and education services:

- medical history
- history of hearing loss including aetiology
- use of hearing aids
- communication methods
- speech and language development
- educational support
- support for parents and carers (Quality Standard in Paediatric Audiology, 1999:9)

3.14.6.2 Audiological assessment

Clinical Scientists, Audiologists, Teachers of the deaf and Speech and Language Therapists carry out assessments. These include assessment of:

- language and communication skills
- hearing evaluation
- audiometric assessments
- medical imaging (CT or MRI scan)
- assessments are also carried out in conjunction with "local professionals" in the child's school or home (Information for Patients: 8).

3.14.7. Implant and rehabilitation

- **Pre and post surgery**

The operation is carried out at Crosshouse Hospital by one of the surgeons on the team. It involves a 3-4 days stay in the hospital (Information for Patients: 8).

The family will be given clear guidance about care of the wound and a safety leaflet as produced by the BCIG Safety Working Group will be given to the child's family prior to initial programming (Quality Standard in Paediatric Audiology, 1999:14).

- **Attending the Cochlear Implant Clinic**

The implantee returns approximately one month after the operation to the Cochlear Implant Clinic at Crosshouse Hospital. The external equipment will be issued to the patient. The speech processor will be programmed at this first visit. It is called the 'switch-on'. Further adjustments and follow-ups will be necessary and therefore several more visits to Crosshouse Hospital are expected over the next few weeks. Thereafter regular check-ups will be required every 6 months (Information for Patients, undated:9).

- **Progress Assessment**

The progress of the children is monitored regularly by the Teacher of the Deaf and Speech and Language Therapist. These professionals liaise with the local professionals supporting the child on a day to day basis. (Information for Patients: 9).

- **Support group**

A user support group known as the F.O.C.U.S. (Friends Of Cochlear Users In Scotland) has been formed at the clinic. The aims of the group are:

- to provide accurate information to potential implantees, families and friends
- to exchange experience and offer support and
- to support the Cochlear Implant Programme in Scotland.

Social events are organised as well as a Christmas party. This is been done for the children and their parents to become better acquainted (Information for Patients:16).

The Cochlear Clinic at Crosshouse Hospital has the following information booklets available for the patients and the families:

“I’m going for a Cochlear Implant Assessment”

“The Scottish Cochlear Implant Programme for Adults and Paediatrics”

“Switch-on. What happens?”

“Paediatric Cochlear Implantation. Post Operative Advice.”

“Cochlear Implant preliminary Questionnaire”

“Paediatric Audiology Assessment Aims”

“... gets a Cochlear Implant at Crosshouse Hospital”

“Deaf children and cochlear implants”

Table 9: Literature synopsis - The cochlear implant and the family

❖ **Effect of cochlear implant on the deaf child:**

- ◆ Before age five: better speech production
- ◆ Recently deafened children show rapid improvement
- ◆ The younger the child is when receiving the cochlear implant, the better the long term ability to understand conversation
- ◆ Language development: similar to normal hearing peers
- ◆ Sound perception: improved hearing assists in developing and monitoring speech.
- ◆ Speech intelligibility improves in general
- ◆ Functional benefit: increased communicative behaviour, ability to use the telephone
- ◆ Speech production: improvement in supra-segmental aspects, intonation, discrimination, vowel production, consonant production (initial and final position)
- ◆ Speech perception: greater speech perception benefits from cochlear implants than from hearing aids.

❖ **Effect of cochlear implant on the family:**

- ◆ Age of implantation
 - earlier improvement in communication
 - shorter duration in deafness leads to better performance
- ◆ Better understanding relieves stress
- ◆ Improved awareness of communication and environmental sound for family members
- ◆ Clearer speech improves communication in family
- ◆ Psychological benefit:
 - better relations in the family
 - better emotional contact between parents and deaf child.
 - normalised communication
 - improved socialising skills.

3.15 Concluding remarks

The role of the psychologist in both hearing impairment and cochlear implants is shortly described. It is clear that deafness has a devastating effect on the child and the family.

In the light of the effects of deafness on the child and the family and also the effects of the cochlear implant on the child and the family, it was necessary to look at the facilities that are available to assist the implanted child and the family. It is evident that these facilities fulfil a very important function. The facilities at the Crosshouse Hospital meet to a great extent the needs of the child and the family.

The facilities address the needs of the parents and siblings as well as the therapeutic and educational needs of the child. This programme advises parents on issues like the educational placement, the mode of communication and auditory training. In this way parents are supported in areas where it is needed. The fact that parents do not have to make decisions in isolation, takes a lot of stress away from parents. The professionalism of the programme with regard to the liaison between school and the implant team helps to relieve the stress of the parents - they can rely on a professional opinion.

Parents find it difficult to make decisions about having a cochlear implant. The support groups and the voluntary organisations provide parents with information on this issue, which is valuable to parents.

The paediatric cochlear implant team is an inter-disciplinary team that is able to supply the child as well as the siblings and the parents with essential support.

With regard to the assessment procedure, the parent is assured of a thorough and well-organised procedure. It is reassuring for parents to know that all relevant aspects are attended to before and after the operation.

Parents feel at ease to know that their child is treated at an institution that is equipped with modern and efficient appliances and facilities.

Assistance with practical issues like accommodation, the issuing of batteries and the mapping of the cochlear device when there is a problem, is very valuable to the whole family and will help to decrease the family's stress. The fact that parents do not have to worry about these matters, allows parents to concentrate on issues like the rehabilitation of the hearing-impaired child and to give attention to the siblings.

Listen

*When I ask you to listen to me
and you start giving advice
you have not done what I asked.*

*When I ask you to listen to me
and you begin to tell me why I shouldn't
feel that way; you are trampling on my feelings.*

*When I ask you to listen to me
and you feel you have to do something to solve my problem
you have failed me, strange as that may seem.*

*Listen! All I asked was that you listen.
not talk or do – just hear me.
Advice is cheap: 10 cents will get you both
Dear Abbey and Billy Graham in the same newspaper.*

*And I can do for myself; I'm not helpless.
Maybe discouraged and faltering, but not helpless.*

*When you do something for me that I can and
need to do for myself, you contribute to my fear and weakness.*

*But, when you accept as a simple fact that I do
feel what I feel, no matter how
irrational, then I can get about the
business of understanding what's
behind this irrational feeling.
And when that's clear, the answers are
obvious and don't need advice.*

*Irrational feelings make sense when we
understand what's behind them.*

*Perhaps that's why prayer works, sometimes, for
some people, because God is mute, and He
doesn't give advice or try to fix things.
"They" just listen and let you work it out
for yourself.*

*So, please listen and just hear me. And if
you want to talk, wait a minute for your turn; and, I'll listen to you.*

Anonymous.

Chapter 4: Research Method

4.1 Introduction

This study is focussing on the following question: What is the educational psychological effect of the cochlear implant on the hearing-impaired child's family? The literature study is the first part of the endeavour to find an answer to this question. The empirical study aims to examine the following hypotheses: The cochlear implant has a distinct effect on the feelings and emotions of the hearing-impaired child's family. The emotions and feelings of the parents and siblings of the hearing-impaired child with a cochlear implant can be described and understood.

4.2 The selection of a research method

Every research problem is done against the background of antecedent knowledge. This implies that a study of the literature must be done. The topic that is selected to be studied, gives a guide to selecting relevant literature and research material. A literature study seeks to go beyond fact finding, but to get to the discovery of applicable generalisations or principles (Van den Aardweg and van den Aardweg, 1988:206). In this study the results of the literature will constitute the background of and frame of reference for the empirical research. In the literature study the implications of deafness and the cochlear implant are described (as discussed in chapters 2 and 3). It is clear that these implications have a profound effect on the hearing-impaired person as well as the family. In the empirical research, the educational psychological aspects of this effect will be studied with special focus on the parents and siblings. The results of the literature study will be complemented by the empirical results. The researcher hopes to contribute to knowledge, through own conclusions, discoveries and statements.

There are three broad types of research methods, namely:

Relational research: This is when two or more variables or conditions are measured and related to one another (Rosnow and Rosenthal, 1996:15).

Experimental research involves an experimental and a control group which is usually assembled by random selection or pairing. The researcher manipulates at least one independent variable and determines the dependent variable for each group (Van den Aardweg and van den Aardweg, 1993:207).

Descriptive research: Its goal is to describe what is happening behaviourally (Rosnow and Rosenthal, 1996:15). This method describes existing achievements, attitudes, behaviours or other characteristics of a group of subjects (McMillan and Schumacher, 1993:226).

In this dissertation the descriptive research method is used, because it is the most appropriate method to describe the feelings and emotions of people as it is and does not involve manipulation of independent variables (McMillan and Schumacher, 1993:226).

This method attempts to describe, rather than to establish causes and effects as in the experimental method. In describing the feelings and emotions of parents after the cochlear implant, one seeks to describe the situation as it is. There is no intervention in the part of the researcher and therefore no control. Descriptive research includes the gathering of data through interviews, observation, questionnaires and biographies. To complement the literature study, questionnaires and interviews are also utilised. Observation, interviews and the use of questionnaires are regarded as qualitative rather than quantitative research methods. An empirical study is done in order to put the results of the literature study in an empirical relief, for example to see whether they are reconcilable with evidence from a few interviews and questionnaires. The results of the interviews and questionnaires do not pretend to be representative, therefore, in the empirical study, the deductive method cannot be used to reach general conclusions.

The process involving interviews and questionnaires is regarded as empirical research, as it is guided by practical experience and not by research. To the researcher empirical means being guided by the evidence obtained from systematic research methods, rather than by opinions or authorities (McMillan and Schumacher, 1993:11). The shortcomings and limitations to this research method (like the fact that

the researcher can interpret certain aspects of the results in different ways), will be kept in mind through the study.

Descriptive research can be idiographic (concern individuals) and / or nomothetic (concern groups). In this study the interviews and questionnaires that are used, reflect aspects of the idiographic approach. The focus is on parents and siblings of the hearing-impaired child with a cochlear implant. Although the collective noun is used, the researcher is studying the different individuals. The idiographic approach is used in an attempt to understand and describe the individual's feelings, without attempting to generalise such findings (Van den Aardweg and van den Aardweg, 1993:114). There may be, as can be expected, a lot of tangents, but this will not be seen as generalisations of the results been found (Van den Aardweg and van den Aardweg, 1988:114).

The descriptive research method has a few disadvantages, of which the researcher is aware of. The method is rarely regarded as sufficient, because sooner or later someone will want to know **why** something happens or **how what** happens is related to other events. This is the reason why the researcher regards this study as exploratory, yet it is a very important primary step of any further study in the field of the psychological aspects of the effect of cochlear implants (cf. Rosnow and Rosenthal, 1996:15).

4.3 The questionnaire as an instrument in the research process

The questionnaire is a prepared question form, with the main aim to get information that is submitted to respondents. It can take two forms:

The structured (closed) questionnaire: It contains questions with alternative answers that the respondent selects. In this case, scoring is easy and straightforward, but the respondents do not have any option to give their own answers, they have to choose one of the preselected answers.

The unstructured (open) questionnaire: It contains questions without alternative answers. The respondents are free to give their own opinions and attitudes. This is the reason why the unstructured (open) questionnaire is used in this research. The

researcher expects some general feelings and emotions to be described by the respondents, but she wants the respondents to have the freedom of explaining their feelings in their own words.

The construction of the questionnaire:

For this study the unstructured questionnaire will be used.

For this study, the researcher constructed the questionnaire to measure up to the following standard (cf. Chapter 5). The questionnaire will be open or unstructured. There will be no alternative answers, so that the respondents feel free to give their own answers and opinions.

- The questionnaire includes a personal letter explaining the purpose and value of the study and also why the respondent is included in this study.
- The questions are well organised and thoughtfully compiled. Questions are asked to reveal the feelings of parents and siblings. The questions are chosen to reflect aspects that are highlighted in the results of the literature study as well as aspects that presented itself as prominent in the experience of the researcher.
- The questions are easy to be understood and clearly formulated. The researcher made a special attempt to make sure that the respondents would understand the language as well as the question.
- Questions are carefully constructed in order not to be biased. Any prejudice of the researcher is ruled out, in order not to influence the respondents' answers.
- Questions, which may cause embarrassment, hostility and suspicion, are avoided in this questionnaire.
- The questions are arranged in psychological order. The first part is the general information about the respondents, which is followed by more specific questions about the specific feeling in different situations (cf. Van den Aardweg and van den Aardweg, 1988:108).

The researcher uses the questionnaire as it has several advantages, which include the following (Van den Aardweg and van den Aardweg, 1988:198):

- The method is economical, both financially and time-wise.
- The method is effective and practical. As the researcher uses respondents in two different countries, this was the most practical way of getting the information.
- A large sample can be reached. Although it was not the aim in this study to reach a large sample of people, it enabled the researcher to involve people who would not have been reached in another way.
- It is easy to give standard instructions to the respondents. This is very convenient, because exactly the same instructions and questionnaires are used for the respondents in both countries.
- The questionnaires are usually completed anonymously. In this study this will not be the case, which might be a disadvantage.
- The respondents will not be influenced by the interviewer in this study.
- The method is exploratory, which means the researcher can find out whether the respondent has anything to say (cf. Rosnow and Rosenthal, 1996:94).

Van den Aardweg and van den Aardweg (1999:198) describe a few disadvantages of the questionnaire according to the following:

The possibility of misinterpretation of questions. Although the researcher tried to make questions very clear, there may be questions that can be misinterpreted by the respondents.

The return may be low and this may bias the results. As the researcher does not want to come to general conclusions in this study, a low return of the questionnaires need not be a sign of bias.

Only those interested in the subject will respond. This may be true in this research's case, because the topic is more of interest to professionals than to parents. Professionals are interested in identifying and interpreting the feelings and emotions of the people they work with. The family of the implanted child does not focus on their own feelings in an academic way - they only try to cope with it.

It takes up much of the respondents' time. This can be one of the most important disadvantages of the questionnaire in this study, because it is a long questionnaire and very time-consuming to answer. It is not easy to give an answer. The respondents have to reflect before they formulate their answers.

Rosnow and Rosenthal (1996:95) add that it can invite rambling and off the mark responses, which may never touch the topic the researcher is interested in.

4.4 Interviews as an instrument in the research process

Van den Aardweg and van den Aardweg(1988:121) describe the following different types of interviews, namely

the structured interview, where questions and answers permitted are predetermined and rigidly followed, and

the unstructured interview. This is more informal and flexible and subjects are given freedom.

There are also the *analytic*, the *in-depth*, the *individual* and the *group interview*. These are not applicable in this study.

The unstructured interview is not supposed to be an exchange of small talk, but should be a goal-directed attempt by the interviewer to obtain valid and reliable information from the respondents.

For this study, the researcher uses the unstructured interview with the aim to get answers on specific questions. The interview is conducted along the lines of the questionnaire that is also used as a research instrument. The researcher allows the respondents to discuss their feelings and emotions freely in order not to inhibit them in answering and hopefully to give information that was not predicted by the researcher.

The advantages of the interview mentioned by Van den Aardweg and van den Aardweg (1988:121) are recognised in this study. These are their views:

- The interview is flexible and applicable to many situations. As in this situation the researcher wants to give space for the emotive aspects of the respondents.
- The interview is useful with the very young and illiterates. This is important for this study, because interviews with children will be done.
- The interviewee can elaborate, explain and retract. This is also valuable for this study, as people do not usually find it easy to discuss their own emotions and feelings.
- The interviewer can make observations about what and how something is said. This will be valuable, because the researcher is also interested in the relationship between family members, which can be observed during the interview.
- Inconsistent and vague data can be clarified.
- Perceptions, personal information, attitudes and beliefs can be obtained through the interview, and
- Once rapport has been established, the respondent is likely to be frank and open about the specific matters.

Van den Aardweg and van den Aardweg (1988:121) and McMillan and Schumacher (1993:250) mention the following disadvantages of interviews:

- In unstructured situations respondents respond in the way they see fit.
- Interviewers may be untrained and biased and
- Opinions rather than facts may be obtained.

Although the research method that is selected for this study has limitations and weaknesses, it is regarded as appropriate with regard to the scope and purpose of this study.

4.5 The questionnaire

Psychological evaluation questionnaire for parents and siblings of children with cochlear implants.

PERSONAL INFORMATION:

1. CHILD WITH THE COCHLEAR IMPLANT:

NAME:
SURNAME:
AGE:
AGE AT IMPLANT:
HOW LONG DOES HE OR SHE HAVE THE IMPLANT?
IN WHAT TYPE OF SCHOOL IS YOUR CHILD? (School for the hearing-impaired, school for children with learning disabilities, normal school, etc)....
.....

2. PARENTS:

MOTHER'S NAME AND SURNAME:
FATHER'S NAME AND SURNAME:
MOTHER'S AGE:
FATHER'S AGE:
OCCUPATIONS: MOTHER:
FATHER:

3. SIBLINGS:

1.NAME AND
SURNAME.....AGE.....SEX.....
2.NAME AND
SURNAME.....AGE.....SEX.....
3.NAME AND
SURNAME.....AGE.....SEX.....
4.NAME AND
SURNAME.....AGE.....SEX.....

THE FOLLOWING ARE QUESTIONS TO BE ANSWERED BY **THE MOTHER**:
PLEASE BE AS HONEST AS POSSIBLE AND ANSWER AS COMPLETE AS
POSSIBLE.

1. Did you have any **worries** about the Cochlear implant before the operation was done? Please explain.

.....
.....
.....

2 Tell me some of your experiences with your child. What changes have you experienced with your child after the cochlear implant?

.....
.....
.....

3. How do you feel about your child's hearing impairment after the cochlear implant?

.....
.....

4. Do the other children experience stress in having a hearing-impaired child as part of the family? Please explain.

.....
.....

5 .How did the deafness as well as the cochlear implant influence your marriage/relationship with your partner?

.....
.....

6. What was the effect of the deafness on the family? Was it unifying or dividing? Please explain.

.....
.....

7. What sacrifice, if any, did you as parents have to make with regard to the deafness and the cochlear implant?

.....
.....

8.1 What practical problems did you have with this deaf child in your family?

.....
.....

8.2 Have any of these problems changed after the implant? Please explain.

.....
.....

9.1 How do you discipline the deaf child?

.....
.....

9.2 Is there any difference in disciplining before and after the cochlear implant? If there is a difference, please explain.

.....
.....

10.1 Did the cochlear implant make any difference in the communication between you and your child?

.....
.....

10.2 If YES, please explain.

.....
.....

11. Please explain if and how your child's deafness complicated your child rearing.

.....
.....

12 What is the nature of your involvement in the training of your deaf child?

.....
.....

13. Did the deafness have any negative effect on the relationship between you and your child? Please explain.

.....
.....

14. How is the functioning of the family affected by having a deaf child? Please be specific.

.....
.....

15 Please name the most important problems you have to deal with in connection with your deaf child

- before the cochlear implant.

.....
.....

- after the implant.

.....
.....

16 What is the effect, of having a deaf child, on the other children?

.....
.....

17. Please reflect on the following in your involvement with your deaf child. Indicate whether the Cochlear implant has had any effect on these aspects.

17.1. Feelings of guilt

.....
.....

17.2. Denial in any way

.....
.....

17.3. Disruption

.....
.....

17.4. Intensified parenting

.....
.....

17.5. My beliefs, dreams and expectations for my deaf child.

.....
.....

17.6. My anger, frustration, fears.

.....
.....

17.7. Free time

.....
.....

18. Reflect on the following issues about your deaf child. Please indicate, if any, the differences between the situation **before and after** the cochlear implant.

18.1. My child's sense of self

.....
.....

18.2. My child's sense of success

.....
.....

18.3. My child's sense of independence

.....
.....

18.4. My child's sense of differentiation

.....
.....

18.5. My child's sense of functioning in a hearing world.

.....
.....

19. Did the deafness and the cochlear implant have any financial implications for you? Please explain.

.....
.....

20. Describe the relationship between:

- mother and child.....
.....
- father and child.....
.....
- brother and child.....
.....
- sister and child.....
.....
- grandparents and child.....
.....

21. Do you feel that there are any positive aspects relating to your child's hearing impairment? Please explain.

.....
.....

22. What was the reason for giving your child a cochlear implant?

.....
.....

23. In retrospect, how do you feel about your child having a cochlear implant?

.....
.....
.....

24. Please write a summary on your feelings having a hearing-impaired child with a cochlear implant.

.....
.....
.....

THE FOLLOWING ARE QUESTIONS TO BE ANSWERED BY **THE FATHER**:
PLEASE BE AS HONEST AS POSSIBLE AND ANSWER AS COMPLETE AS POSSIBLE.

1. Did you have any **worries** about the Cochlear implant before the operation was done? Please explain.

.....
.....

2 Tell me some of your experiences with your child. What changes have you experienced with your child after the cochlear implant?

.....
.....

3. How do you feel about your child's hearing impairment after the cochlear implant?

.....
.....

4 .How did the deafness as well as the cochlear implant influence your marriage/relationship with your partner?

.....
.....

5. What was the effect of the deafness on the family? Was it unifying or dividing? Please explain.

.....
.....

6. What sacrifice, if any, did you as parents have to make with regards to the deafness and the cochlear implant?

.....
.....

7.1 How do you discipline the deaf child?

.....
.....

7.2 Is there any difference in disciplining before and after the cochlear implant? If there is a difference, please explain.

.....
.....

8.1 Did the cochlear implant make any difference in the communication between you and your child?

.....
.....

8.2 If YES, please explain.

.....
.....

9 What is the nature of your involvement in the training of your deaf child?

.....
.....

10. Did the deafness have any negative effect on the relationship between you and your child? Please explain.

.....
.....

11 What is the effect, of having a deaf child, on the other children?

.....
.....

12. Please reflect on the following in your involvement with your deaf child. Indicate whether the Cochlear implant has had any effect on these aspects.

12.1. Feelings of guilt

.....
.....

12.2. Denial in any way

.....
.....

12.3. Disruption

.....
.....

12.4. Intensified parenting

.....
.....

12.5. My beliefs, dreams and expectations for my deaf child.

.....
.....

12.6. My anger, frustration, fears.

.....
.....

12.7. Free time

.....
.....

13. Describe the relationship between:

- mother and child.....
- father and child.....

14. Do you feel that there are any positive aspects relating to your child's hearing impairment? Please explain.

.....
.....

15. In retrospect, how do you feel about your child having a cochlear implant?

.....
.....

16. Please write a summary **on your feelings** having a hearing-impaired child with a cochlear implant.

.....
.....
.....
.....

THANK YOU VERY MUCH! Maybe this can contribute to helping other parents in the same situation.

The following must be answered by the **siblings**. (If the siblings are too young, I would appreciate it if the mother/father can help to answer the questions after **discussing** it with the children)

1. How do you and your hearing-impaired brother or sister communicate?.....

.....
2. How do you two play together?

.....
3. What do you understand about your hearing-impaired brother or sisters cochlear implant?.....

.....
4. Is there anything that worries you about having this hearing-impaired brother or sister? Please explain.....

.....
5. Can you tell me about your brother or sister before the implant and after the implant?.....

.....
6. Is there anything that you are wondering about (e.g. yourself, the hearing-impaired child, etc).....

.....
7. How do you feel about your brother or sister having a cochlear implant?

.....
8. (To teenagers): Having a hearing-impaired brother or sister, how do you feel about:.....

.....
• your friends

.....
• yourself.....

.....
• the hearing-impaired child.

To the hearing-impaired child: (Please help mum!)

Please write a paragraph about your experiences having a cochlear implant and what it means you.

.....
.....
.....
.....

4.6 The rationale of the questions

The questions were not grouped in a specific order, nor according to a specific category. To explain the rationale of the different questions, it will be categorised.

The same questions will be asked for the fathers and the mothers. This will enable the researcher to identify different views by mothers and fathers on some of the questions.

Category 1: Questions about the time before the implant.

These questions are asked to draw a comparison between the time before the implant and the time after the implant with regard to the specific aspects that were discussed. It also gives the respondents the opportunity to respond in their own unique way that may provide extra information.

The questions were:

- Did you have any worries about the cochlear implant before the operation was done? Please explain.
- Do the other children experience stress in having a hearing-impaired child as part of the family? Please explain.
- How did the deafness as well as the cochlear implant influence your marriage / relationship with your partner?
- What was the effect of the deafness on the family? Was it unifying or dividing? Please explain.
- What sacrifice, if any, did you as parents have to make with regard to the deafness and the cochlear implant.
- What practical problems did you have with this deaf child in the family?
- How do you discipline the deaf child?
- Please explain if and how your child's deafness complicated your child rearing.
- Did the deafness have any negative effect on the relationship between you and your child? Please explain.
- How is the functioning of the family affected by having a deaf child? Please be specific.
- Please name the most important problems you have to deal with in connection with your deaf child before the cochlear implant.

- What is the effect of having a deaf child on the other siblings?
- Please reflect on the following in your involvement with your deaf child:
 - Feelings of guilt
 - Denial in any way
 - Disruption
 - Intensified parenting
 - My beliefs, dreams and expectations for my deaf child
 - My anger, frustration, fears
 - Free time
- Reflect on the following issues about your deaf child. Please indicate, if any, the differences between the situation before and after the cochlear implant.
 - My child's sense of self
 - My child's sense of success
 - My child's sense of independence
 - My child's sense of differentiation
 - My child's sense of functioning in a hearing world
- Do you feel that there is any positive aspects relating to your child's hearing impairment? Please explain.

Category 2: Questions relating to different practical and psychological aspects after the cochlear implant.

Questions:

- Tell me some of your experiences with your child. What changes have you experienced with your child after the cochlear implant?
- How do you feel about your child's hearing impairment after the cochlear implant?
- What practical problems did you have with this deaf child? Have any of these problems changed after the implant?
- Is there any difference in disciplining before and after the cochlear implant? If there is a difference, please explain.
- Did the cochlear implant make any difference in the communication between you and your child? If it did, please explain.
- What is the nature of the involvement in the training of your deaf child.

- Please name the most important problems you have to deal with in connection with you deaf child after the implant.
- Did the deafness and the cochlear implant have any financial implications for you? Please explain.

Category 3: Relations.

Questions regarding the different relations in the family are asked. The reason for this is to get information about different aspects of relations and family life.

- Describe the relationship between:
 - mother and child
 - father and child
 - brother and child
 - sister and child
 - grandparents and child

Category 4: Reasons for giving a cochlear implant.

The reason for this question is to illuminate some psychological aspects like the parents' motives, their fears and their dreams for the child. This will also help to determine the level of acceptance of their child's hearing impairment, as well as their progress on the grieving process with regard to their hearing-impaired child.

Question:

What was the reason for giving your child a cochlear implant?

Category 5: A retrospect.

The rationale of this question is to determine how the parents feel about their decision to give their child a cochlear implant. Possible feelings of guilt and regret, possible feelings of satisfaction may be mentioned.

Question:

In retrospect, how do you feel about your child having a cochlear implant?

Category 6: Feelings.

The researcher wants to give the respondents the opportunity to reflect on their own feelings. The aim with this question is to get some psychological information about their feelings. This question can also determine some differences in parents' feelings before and after the implant. It may also have therapeutic value to the parents to verbalise their feelings.

Question:

Please write a summary on your feelings about having a hearing-impaired child with a cochlear implant.

Category 7: Questions to siblings.

These questions are asked in order to identify psychological aspects like fear, worries, frustration, shame and other emotions and to determine the quality of communication in the family.

The Questions

- How do you and your hearing-impaired brother or sister communicate?
- How do you two play together?
- What do you understand about your hearing-impaired brother or sisters cochlear implant?
- Is there anything that worries you about having this hearing-impaired brother or sister? Please explain.
- Can you tell me about your brother or sister before the implant and after the implant?
- Is there anything that you are wondering about (e.g. yourself, the hearing-impaired child, etc)
- How do you feel about your brother or sister having a cochlear implant?
- (To teenagers): Having a hearing-impaired brother or sister, how do you feel about:
 - your friends
 - yourself
 - the hearing-impaired child

Category 8: Question to the hearing-impaired child.

Although the focus of the study is not on the hearing-impaired child, the researcher expects (and knows) that implications of the cochlear implant on the deaf child have a direct effect on the rest of the family. The rationale of this question is to identify the psychological effect of the cochlear implant on the hearing-impaired child, which would influence the rest of the family.

Question:

Please write a paragraph about your experiences having a cochlear implant and what it means to you.

4.7 The selection of respondents

The questionnaires were sent to parents that were randomly chosen. The only common denominator is the fact that all the children had their implants for more than a year. The questionnaires are not statistically based. The aim with this exercise was to integrate the information obtained from the subjects with the literature study. The intention is not to generalise the results, but to expand the understanding of the existing knowledge about the effect of the cochlear implant on the family (cf. MacMillan and Schumacher 1993:238-350).

4.8 The way in which the results will be interpreted

The results will be analysed and interpreted within the context of the specific respondent's situation (interviews and questionnaires). A comparison will be made between the responses of the various respondents in order to identify common aspects as well as differences. The responses will be interpreted in the light of the results of the literature study. The interpretation will be done from an educational psychological perspective.

Chapter 5: Empirical study and research results

5.1 Introduction

The following discussion is based on academic data, questionnaires and unstructured interviews with families of a cochlear implant user.

Of a total of 20 questionnaires that were sent out, only 8 were returned. All the questionnaires were not answered in full. In these 8 questionnaires, 5 fathers did not fill in their part. One of these 5 is divorced and the child is staying with the mother. There is no contact with the father. Four of the questionnaires were completed in South Africa, and four in Scotland.

5.2 Background of the different cases according to the questionnaires

Questionnaire case 1

Girl A has her implant for 3 years. She is now 6 years old. The mother is 34 years old and the father is 38 years old. The mother is the main source of income, as the father is a full time student. The father did not fill in his part. Girl A has one sister who is 8 years old. Girl A uses only spoken language to communicate.

It took a very long time, more than 1 year to see significant development and changes in Girl A's language development. After nearly 2 and a half years of rehabilitation and intensive training, her language developed remarkably.

Questionnaire case 2

Girl B is 3 years and 10 months old and has the implant for 2 years and 2 months. The father is 33 years old and the mother is 33 years old. Girl B has one older sister of 7 years and one brother of 18 months. Girl B showed rapid improvement with her listening skills as well as her communication soon after the implantation. She only uses spoken language to communicate. This father did not fill in his part.

Questionnaire case 3

Girl C is 14 years old and has the implant for 8 years. The father is 46 years old and the mother is 41 years old. Girl C had good language before the implant. The parents wanted to get the implant for their child to enable her to develop more understandable language. She only uses spoken language. Both these parents filled in the questionnaire.

Questionnaire case 4

Boy D is 8 years old and has his implant 4 years. The father is 49 years old and the mother is 37 years old. Boy D has a sister who is 5 years old. His speech is developing slowly, but his listening skills have improved rapidly after the implant. He uses spoken language and some gestures to communicate. Both parents filled in the questionnaire.

Questionnaire case 5

Boy E is 5 years old and has his implant for just over a year. His mother is 32 years old and his father is 32 years old. The parents are divorced and there is no contact with the father. Boy E uses spoken language to communicate.

Questionnaire case 6

Girl F is 8 years old and has the implant for 5 and a half years. The mother is 44 years and the father is 43 years. Girl F has a brother of 10 years old. Sign language as well as spoken language is used to communicate.

Questionnaire case 7

Girl G and Girl H are from the same family. The father is 42 years old and the mother is 38 years old. Both of the children made significant progress in communication as well as socially. There are no other children in the family.

Questionnaire case 8

Boy I is 8 years old and has his implant for 5 years and 5 months. The mother is 38 and the father is 40 years old. There are two brothers aged 13 and 11 years. Boy I attends a normal school.

5.3 The rationale of the interviews

5.3.1 Approach

The interviews were unstructured and were based on the questionnaire. Three interviews were held with parents in Scotland. The three interviews, which were held, are discussed as case studies. The aim with the interviews was to study the thoughts, feelings, beliefs, ideals and actions of the families in their natural situation. All three the interviews were held in each family's sitting room, in a relaxed atmosphere.

The researcher intends to focus on the feelings and experiences of the family of the implanted child after the cochlear implant.

The effect on the parents and the siblings will be described. The relations in the family are observed and described and the general atmosphere in the family is observed and discussed.

This study uses a small sample of information-rich cases. It is meant to be purposeful-sampling (cf. McMillan and Schumacher, 1993:378-402). In this context, purposeful-sampling refers to the fact that the cases used for this sampling are chosen because they are likely to be knowledgeable and informative about the effect of the cochlear implant on the siblings and the parents.

Data collection and analysis strategies for this study includes the following phases:

1. Planning (Phase 1)

For this study, the researcher has analysed the problem statement and the anticipated research questions. Preparation for the interview included studying the questionnaire which was also used for the study, in order to focus in the interview on the relative issues concerning parents' and siblings' feelings and experiences. During this phase the researcher gained permission from the different families to have an interview on the mentioned topic.

2. Beginning of data collection (Phase 2)

The parents were contacted by telephone. A suitable date and time for the interview was agreed upon. These were the first steps to establish rapport, trust and reciprocal relations with the parents. By arranging these, the researcher became orientated to the field of each family's functioning and their activities.

Simultaneously the researcher (interviewer) "polished" the interviewing and the tape recording process. The phrasing of questions / statements for the interviews was planned.

3. Basic data collection (Phase 3)

This is the actual interview. In the basic data collection phase the researcher tried to "hear", "see" and "read" what is going on. She tried to hear, see and read the family's experiences, feelings and relations with regard to the effect of the cochlear implant on them. During this phase the researcher mentally processed the facts and ideas while collecting the information.

The researcher listened at home to the tape recordings that were made of the interviews. The information was summarised in order to continue with the compilation of the report.

4. Closing data collection (Phase 4)

As the interviews were rich of information, the researcher sensed that further data collection would not yield any more relevant data to the research problem.

5. Completion (Phase 5)

During this phase the researcher constructed a meaningful way to present the data. The data will be presented as follows:

A summarised version of each interview will be given. Here the researcher will give a description of the identifying particulars of the family, the feelings / emotions that were observed and the interrelationships in the family.

A summary of the effects of the cochlear implant on the family will be given. Consideration will be given to the specific stage in which a family is with regard to

adaptation to the effects of the cochlear implant. A full reference will be given to the literature study that was done for this study.

The researcher will endeavour to maintain objectivity. The language being used by the participants will be interpreted in the context of the researcher's knowledge and understanding of the phenomenon being studied.

5.3.2 Results of actual interviews

Case study Interview 1

Background

The implanted boy is 8 years old. Both the parents attended the interview. It was clear that the parents found it difficult to speak openly about their feelings concerning the cochlear implant. The mother seldom revealed her specific feelings and repeatedly said that there is no time for feelings - life has to go on. This child uses both gestures and spoken language to communicate. The sister is 5 years old. The boy doesn't have good language, and is developing at a slow rate. His pronunciation is not very clear, but he is very willing to communicate verbally. During this interview the sister was at school – the mother wanted to keep her at home for the interview, but forgot.

The interview – observations and interpretation

The mother answered most of the questions asked by the interviewer. The father only responded to questions that were directed specifically to him. In general feelings like satisfaction, relief and happiness were mentioned. The fact that the child can respond to daily sounds like the telephone, the doorbell and voice makes life more relaxed for the parents. When asked to compare the time before and after the implant, the parents replied that the child does not have temper tantrums and does not scream out of frustration anymore.

The fact that he can hear at least some sounds contributes to the fact that the child feels part of his world and makes more sense of his surroundings. Communication improved and all these aspects help the parents to feel “chuffed”, as the dad said.

The interviewer made quite a few attempts to give the parents opportunity to describe their feeling with regard to the effect of the cochlear implant. The mother did not discuss emotions of grief. She only referred to the child's handicap as part of life and that there is no time to feel sorry for yourself. The mother gave the impression that she knows life and that she had previous experience of the difficult side of life. She might be a bit embittered by previous events in her life. It can also be that she is a private type of person and just does not want to discuss her feelings of sorrow. About halfway through the interview, the mother had tears in her eyes. However, she quickly restrained her emotions.

The researcher is unsure whether the parents really understand the full implications of deafness. They may not have very high expectations of their children. Perhaps the parents do not have the verbal ability to verbalise their deeper feelings. The fact that they cannot readily discuss their sorrow may indicate that they struggle to come to terms with their own feelings, or that they want to give the impression that they are strong. The relationship between parents' reactions and their academic and social background may be an interesting field of study.

The parents did not express any expectations for the child. They were happy because he can cope better, can hear better and communicate easier than before the implant. They focus on the basic life skills and not on the child's potential for future development.

Only the relations between the two parents and between parent and the hearing-impaired child could be observed. The younger sister was not present.

The parent's did not reveal their feelings towards each other. They directed their feelings towards the hearing-impaired child. They were eager to tell how much they love him and what a pleasant child he is.

The mother said that the father has a special relation with the son. The son loves his father, sits at times on his lap, and definitely associates with the father – which is normal for this age. The communication and relation between the child and the

mother seemed to be relaxed. The mother understands her child. The family has adapted in a practical sense to cope with this child.

The parents did not show signs of stress. Although they felt a little uncomfortable at the beginning of the interview, they both relaxed quickly and gave the impression that they are very proud of the son. The father showed me videos of the “switch-on” session of the child. This indicates that the father did experience moments of excitement in the process of the implant.

The boy was aware of the fact that he is the centre of attention – he behaved very well and easily made contact with the interviewer. He does not have much language, therefore a verbal communication between the interviewer and the child was difficult. He showed the interviewer some of his schoolbooks. He feels good about himself and is proud of his schoolwork.

The researcher is aware that this boy’s schoolwork is not up to standard for his age. He is behind his group. He receives a lot of extra rehabilitation at school. This situation can lead to a number of educational psychological problems in future. He might feel that too much is expected of him, or he might feel inferior to his classmates. As he gets older, he might lose his self-confidence and develop a low self-esteem.

General remarks

This family functions as a “normal family”, although the parents are not married. The father is the biological father of the child. This situation may lead to feelings of insecurity for the mother. She may be worried about her and the children’s future. This could be the reason why the parents did not express very high expectations for the child. The fact that there are no high expectations, may lead to educational psychological related problems in future.

Case study Interview 2

Background

This interview was conducted with the father and the children only. He does the housework and the mother is busy with postgraduate studies. This father felt very strongly opposed to the Deaf Culture. The children (both implantees) are 5 years 6 months and 10 years respectively and have good language and communicate easily and reasonably understandable. They both use spoken language only and no sign language. These parents also filled in a questionnaire. The interview gave the father the opportunity to discuss matters more openly and to give even more information than was given in the questionnaire.

The interview – observations and interpretation

When the father was asked how he felt when he first heard that his first daughter was deaf, he said that he was shocked. It is interesting to notice that he immediately focussed on the attitudes of professionals. He was upset about the professionals' way of giving them the news and even said he has "bad feelings" with regard to professionals. This father also has problems with the headmaster of the children's school. He blamed her of having no insight in the problem of hearing impairment. This really may be a very unsatisfactory situation where this family has to do with "professionals" who do not have the appropriate attitude. On the other hand, it can also be that this father is still struggling with a lot of anger and frustration. This father may not have accepted his children's deafness yet and wants to blame someone. It is a very common trend to blame the professionals who want to help you! It would be advisable for this parent to discuss his feelings in order to come to terms with his frustration.

He also complained about the rehabilitation and support that is provided by the school. An educational psychologist can really assist this family in dealing with these feelings – there are various negative feelings like anger, frustration, uncertainty and fear about the children's development. He actually admitted that he is struggling with anger and frustration.

The father said that everything in the house is so much easier since the implant. They can conduct a normal life and treat the children as normal hearing children.

A very important factor in normalising the situation in the family is the fact that the parents can now communicate in a normal way. This must surely contribute to better relations in the marriage and the family.

This father was, however, very excited and positive about the cochlear implant. When asked to name the major changes after the cochlear implant, he mentioned the following: The children can communicate easily. There are a lot of talking, laughing and sharing of jokes. The children can say: "Dad, I love you. Mom, I love you". He mentioned the improved confidence of the children: They take drama classes, horse riding and understand everything much better.

The father fulfils the role of "house husband". He manages the home. Although he is a tensed man, he is very involved in his two daughters' lives. The relationship between him and both the children seemed to be very normal and relaxed. There is a good mutual understanding. The daughters also have a special mutual relationship. They acted in a very normal way towards each other. The youngest daughter was not as at ease with the researcher as the older one. This is understandable. The family appeared to be a normal happy family.

There are no hearing siblings in the family. This was a good opportunity to hear from the implanted children how they experience the other implanted child. The younger of the two said that she gets frustrated when the other sister's cochlear implant does not work, because then she is deaf. Both of them said that they are very glad that they have the implants, because they can appreciate music, hear people talk and hear any sound.

It is inspiring to hear the eldest daughter saying these words: "I know I am deaf, but I am glad I got an implant". This child has reached a stage where she is willing and able to face the reality of her deafness. She has come to terms with her disability. This is a good preparation for her, for the future. The difficulties that she will have to face in life will be a little easier, because she has come to terms with her deafness.

General remarks

The children seemed to behave in a normal way. They had a hearing friend with them and no difference in their functioning was noticeable.

The father gave the impression that he is struggling with tension and frustration. This could be seen in the way he spoke. He never sat still, but was always busy organising the children, preparing tea, etcetera. It would be advisable to persuade the father to receive help in coping. On the other hand, the father may be a restless type of person. The mother's absence from the interview - blaming her work at the library,- suggests an unwillingness to be confronted with the situation. It might have been easier for her not to be confronted with this situation. She may also be struggling with emotions, frustrations or anger. In a case like this, the educational psychologist could do family therapy and debriefing (if necessary) with both the parents.

In the light of the father's stress, the educational psychologist would have to examine the stress levels of the children as well. They may give the impression that all is well, but there may be underlying frustration, fears and tension as well. This can have an effect on their social life, emotional development and educational development and can result in increased stress on the family.

Case study Interview 3

Background

Both the parents took part in the interview. These parents did not hide their feelings and spoke openly about it. The parents felt more open about Deaf Culture and try to give their child the best of both worlds, spoken language and sign language.

The girl, aged 10 years, is a good talker. She is bright and her language is good. She seems to have much confidence, leads a full and balanced life. She has one teenage sister (13 years) and another sister who is 7 years old.

Interview – observations and interpretation

Although the primary aim of the interview was the discussion of the effect of the cochlear implant, it was clear that these parents have a lot of unresolved feelings concerning the deafness of the child, the handling of the diagnosis and the way in which professionals acted.

When asked to elaborate on this, the parents said that they had feelings like shock, they were upset, they were unable to speak to each other and they struggled with a lot of private thoughts and worries about the child's future. If parents are not enabled to cope with these feelings, it may have a negative affect on the inter relations in the family.

According to the mother, her own distress had an effect on the older sister at that time. She did not understand and kept on asking why her mother was crying so much.

Both the parents described how the situation affected their marriage. They said that when one was emotionally on a low level the spouse was able to give support. This seems to be a strong marriage. There is mutual understanding and support.

When talking about the role of the professional, the father said: "Professionals do not know from their hearts, they know in their heads." He said: "You need both." According to him, you need the scientific insight of professionals, but it is not enough, you need to have contact with people who can have empathy with you. In this regard, other parents of hearing-impaired children can play an important role. The parents described how they have benefited from contact with other parents. They have attended a weekend with the National Deaf Society. They enjoyed the interaction with other hearing-impaired children and their parents.

They said that the most difficult decision they had to make before the implant, was whether the child should use signing or not. This decision has far-reaching implications for the general development of the child. The educational psychologist should be equipped to guide parents by giving parents unbiased information, and to establish contact with other implanted children and parents.

The mother mentioned that the time before the operation was stressful for the siblings. It was traumatic for the siblings to be away from the mother during the time she stayed in hospital during the operation. This mother did her best to prepare the siblings. When she went to hospital, she left a present at home. Although this may be a stressful time, it does not have to have a negative effect on the children. In other families it also happens that a mother has to leave the siblings at home when she accompanies a child who is hospitalised.

Before the cochlear implant, they had worries about education, communication, whether their child would get married, et cetera. When the parents were asked about their fears and expectations about the future after the cochlear implant they said that their fears and expectations are the same for all the children after the cochlear implant. They all (the hearing-impaired child included) can achieve as much as they like to.

When the parents were asked whether their parenting has been affected, they were honest by admitting that the hearing-impaired child gets her way easier than the other children. This discrepancy can have an effect on the hearing-impaired child. In future, the child might not be able to conform to rules, or might not be able to accept no as an answer. The other siblings may feel it is unfair, they might feel that she is more privileged – this can cause jealousy and frustration. It is recommended that the whole family should receive family therapy.

With regard to free time, the mother said that she still finds it difficult to relax and to be just a mother. She feels that each situation should be a constructive language experience for the hearing-impaired child. This can become a problem in future. Every child needs to have a mother as well, not only a teacher or therapist, although it is very important to help the child in his or her educational and language development.

These parents (especially the mother) were very thankful for the help which they received from the child's nursery school. The school helped the parents with practical ideas on how to work with their child in order to develop language as well as the total child.

When asked to describe their feelings about having a child with a cochlear implant, the father made a strong point by saying they would make the same choice again with regard to the cochlear implant. He said that they do not have any feelings of guilt, anger or frustration. He mentioned that they might feel guilty in future, if they would see that the cochlear implant was not the right decision. He hopes that this would not happen.

The teenage daughter said that she thinks it was a good idea to give her sister the cochlear implant, because now they can communicate verbally. This is easier for the children, because the hearing children do not know sign language. The fact that the children can communicate in a normal way will improve communication, decrease mutual frustration and will normalise life for all the children.

When the teenage girl was asked to discuss her feelings about the cochlear implant, she said: "I don't feel sorry for her, she has achieved so much, she's always in the newspaper...". There is a possibility that this sister is a bit jealous.

The parents did not mention any extraordinary sibling rivalry that could have been a result of jealousy. The sister may have negative feelings that she does not reveal. The researcher should be on the lookout for any signs indicating unresolved emotions concerning the hearing-impaired child.

The younger sister said that she is glad about the cochlear implant, because it helps the hearing-impaired sister to hear. She also said that she is sorry for the implanted child, although she knows that the doctor helped her by giving her a cochlear implant. She said that the implant help her (the younger sister) as well, because communication is easier - she does not have to tap her on her shoulder every time she wants to speak to her. She said that she is worried about the implanted child's future.

According to the parents, the following improvements with regard to the deaf child can be observed after the implant:

- She is more settled.
- She has gained confidence.
- Her language has improved.
- Her speech is more understandable.
- Her life is easier.
- Communication is easier for her.
- The fact that she is in a mainstream school makes life easier.

The parents experience the effect of the cochlear implant on their child as very positive. These positive feelings will surely have a beneficial effect on the parents and their relationship with their children.

5.4 A discussion of the results of the research

5.4.1 Fears of parents before implant.

The cochlear implant is a major operation. It is permanent and the ear in which it is implanted cannot be used in a normal way again after the implant.

The fear parents have before the cochlear implant can be divided into 2 groups, namely the fears for the risks of the operation and secondly fears concerning the device itself.

Parents in the majority of questionnaires and in all the interviews had definite fears concerning the major operation. They also mentioned their fears concerning the anaesthetic (Questionnaire 1,2,3,4,5,6,7; Interview 1,2,3.).

As all major operations involve certain risks, it is understandable that parents fear the long anaesthetic and the operation itself. It is a great concern to parents that the surgeon is drilling a hole only 3mm from the facial nerve. If this nerve is damaged, it can lead to facial paralysis. A disturbance of the child's balance can also be caused by the operation. Previous experience proves that this is usually not a permanent

problem. Schwartz (1996:39-40) discusses some risks of the operation and also mentions the implications of the long operation and the anaesthetic.

Another fear parents have is whether the device is going to function properly. They are also worried about the appropriateness of the cochlear implant for their child (Questionnaire 1,2,3,4,5,6,7; Interviews 1,2,3). The parents are aware of the fact that the device is safe. Fortunately, this fact is scientifically attested. It has been tested for several years before permission was granted to use the cochlear implant on children (cf. paragraph 3.2.3). Shea et al (1994:69) and Carroll (1995:18) give a clear statement that the cochlear implant is safe and an effective treatment for profound hearing loss in the pediatric population. Carroll (1995:18) even mentions that the replacement of defective implants has proven to be safe as well. If parents could be given statistical data to prove this, their fears could be arrested.

Parents also mentioned a few other fears that are not mentioned in literature. Some parents (Questionnaire 8) were afraid that the child would not qualify as a candidate for the cochlear implant due to the strict pre-implant evaluation. This concern of parents can be neutralised if enough information about the screening process is given to parents. Unnecessary stress should be avoided as it can have a adverse effect on the whole family.

The psychologist should identify the reasons why parents decide on a cochlear implant. If parents want to do the cochlear implant for the right reasons, their expectations would be more realistic and unnecessary stress and disappointment can be prevented. This topic is discussed in detail in paragraph 5.4.2.

An interesting response, is the fact that some parents are concerned about the permanency of the implant (Questionnaire 2). A cochlear implant is a very radical intervention that cannot be reversed. The decision of the parents will have a permanent effect on the child. The literature does not mention this concern.

To adapt to deafness and hearing aids is a major problem for parents. According to the general procedure a child has to wear hearing aids before considered for a cochlear implant (cf. paragraph 3.2.3.4). This implies that most parents of implanted

children have already come to terms with the fact that the child is wearing an aid of some kind. The acceptance of the cochlear implant follows a similar pattern than the acceptance of the fact that the child has to wear a hearing aid. The parent experience similar fears and concerns. The parents' acceptance of the cochlear implant is very important, because the way in which parents react and feel about the device will influence the child's appreciation of the device. Parents should be guided to be positive and to help their child to understand how much the child would benefit from wearing the cochlear implant. From experience the researcher knows that this is a fairly natural process. As the child proceeds to use his or her aid better, as he / she hears better and learns to listen better, the child automatically becomes more attached to the device.

It is interesting to note that the parents who were questioned did not mention concerns about the effect that the cochlear implant may have on human behaviour, or the psychological effect of the implant on the child. Crary et al (1982: 55), Tyler (1990:284) and Quittner (1991(b):96) report that the cochlear implant can contribute to a better quality of life (cf. paragraph 3.6.1). They tested cognitive functioning and found that the cochlear implant does not impair cognitive or neuro-psychological functions in the implant user (Crary et al, 1982:55; cf. Purdy, 1994: 335).

Parents struggle with valid fears before the child's operation. Professionals should give adequate information to the parents. Well-informed parents will have less fears and stress. This is an important aspect, as parents' stress is normally transferred to the children. Excess stress before the implant can result in the children having an unnatural fear of the operation and experience unnecessary stress. If these aspects are handled in the correct way, stress can be minimised.

5.4.2. Reasons for giving a child a cochlear implant

As previously mentioned, it is a major decision for parents to make whether or not to give their child an implant. Although there are a few risks concerning the operation and the device, many parents decide in favour of the implant. Although they are aware of the risks and implications of this decision, they still have enough reason to decide on the cochlear implant.

The reasons that are given in favour of the implant can be divided into 3 categories:

- Improvement of quality of life
- Improvement in speech
- Psychological improvement

“...call it instinct, gut feeling, I don't know, we just knew that we want it for our child” (Interview 2).

The parents' expectation that the cochlear implant will help them to achieve these goals, implies that they must have access to results or perceptions concerning the success of this intervention. Research proves that their expectations are warranted. Their ideals can be achieved to a certain extent. In the following paragraphs research results that are relevant to these aspects are discussed. If these results are communicated with the parents in a suitable way, it will enable them to make the decision on scientific grounds rather than “instinct” or “gut feeling”.

5.4.2.1 Improvement of quality of life

Parents decided on the cochlear implant because they regarded it as a unique opportunity to improve the child's quality of life (Interview3). The majority of parents felt that they wanted to give their child a better chance in life by improving their ability to hear (Interview 1,2,3; Questionnaire 1,2,3,4,5,6,7). The majority was duly concerned about the risks of the operation (Questionnaire 1,2,3,4,5,6,7; Interview 1,2), yet one parent put it into perspective by saying that the risks were outweighed by the benefits for their child (Interview 3). In Questionnaire 6 the parents said they felt the child did not have anything to lose, and could only benefit from the implant. Other parents said they wanted their child to be able to function in the same way as the rest of the family (Questionnaire 5,8).

According to Tyler (1990:287) most of the above mentioned expectations are fulfilled in the hearing-impaired child's life after having a cochlear implant (cf. paragraph 3.4.).

5.4.2.2 Improvement in speech

Parents also mentioned their desire for their child to be able to speak (Questionnaire 1,2). It is also important to parents that the child's pronunciation should improve (Questionnaire 3).

According to the research done by Osberger et al, children who were implanted before they were teenagers demonstrated good speech perception skills (1993:200). Robbins et al (1988:11-28) also did extensive research on this topic. In these studies, the majority of subjects with relatively late onset of deafness demonstrated rapid and marked improvements in their speech intelligibility after the cochlear implant. There were indeed different degrees of intelligibility among children – it appeared to be related to their speech perception performance with the cochlear implant (Osberger et al, 1993:201). The device must be used consistently in order to improve speech perception abilities in deaf children (Fryauf-Bertschy et al, 1997:196).

Gantz et al (1994:1-7) and Meyer et al (1998:846-858) have given enough evidence in their research to confirm that the cochlear implant assists the child to increase speech perception, speech production and speech intelligibility of cochlear implant users. It contributes to better communication. Improved communication will inevitably decrease the child's, parents' and siblings' frustration. Improved communication will enable the hearing-impaired child and the family to have better emotional contact, which will lead to a decrease in the parents' feelings of guilt, anger and uncertainty. If the child is able to communicate, the child's confidence and self-image will improve and the child will regard himself or herself as a competent member of society.

5.4.2.3 Psychological improvement

Parents mentioned a few psychological aspects that they hoped would improve after the implant. They expected the following improvements:

- a less frustrated child (Questionnaire 3; Interview 1,2,3)
- a child who will be accepted by society (Questionnaire 3,7; Interview 1,2,3.)
- a child with more self confidence, who can be more independent (Questionnaire 1,2,3; Interview 1).

Although the cochlear implant can have extensive psychological implications (cf. paragraph 3.4), the parents mentioned only these expectations. These are probably the immediate problems they had to deal with.

Aspects like increased confidence, happiness, psychological health, less frustration, better acceptance by other people, overcoming of loneliness and depression will result in a better balanced child and more relaxed and satisfied parents. The child's positive intra-psychic processes will lead to positive processes in the rest of the family

5.4.3 Practical problems before the implant

The presence of a deaf child in the family implies that the family has to cope with special circumstances. In the questionnaires and interviews some of the most common problems were mentioned.

The fact that the child had almost no hearing before the implant implied that it was very difficult to warn the child not to do dangerous things like touching a hot object or an object that is unstable. In this regard the lack of proper verbal communication could be disastrous. Road safety was a cause for concern, as the child could not hear oncoming vehicles (Interview 2,3; Questionnaire 1,2,3,5,6,7). In Interview 1 and Questionnaire 4 and 8 nothing is mentioned about safety matters. In these cases the parents might have had an adequate way of communicating with the child – either verbally or by means of gestures.

Another practical problem the families had to deal with before the implant is the fact that it was always necessary to turn you face towards the child to enable the child to read your lips (Interview 1,2,3; Questionnaire 1,3,4,6,7).

The parent in questionnaire 5 said that before the implant she found it difficult to understand her child's needs.

Fenster (1988:225-234); Wilson (1982:20-24); and Quittner et al (1991:95-104) describe some of the problems a family has to deal with and some of the changes a family has to make to accommodate a deaf child in the family.

These practical problems can lead to frustration, exhaustion and stress and the relationship between them and the hearing-impaired child can be affected. Communication is sometimes avoided because it is such an effort. This could lead to loneliness and isolation. The hearing-impaired child can experience rejection by the family and this will have a devastating effect on the child's psychological, emotional and general development.

According to some parents, their hearing-impaired children were very frustrated, they had terrible tantrums and screamed a lot. This frustration of the child affected the rest of the family (Interview 1,2,3; Questionnaire 1,3,4,5,6). Parents also reported that they needed much patience because their child found it difficult to express herself (Questionnaire 2) and that parents find it difficult to understand the child's needs and his or her frustrations (Questionnaire 7).

The parents in questionnaire 2 said that the most important problem they had to deal with before the implant was to accept the fact that their child is deaf and may never be able to speak. They also resented the thought that the child as well as they may have to learn sign language.

One mother said that the most important problem she had to deal with, even after the cochlear implant, was people's negativity and ignorance towards a deaf child (Questionnaire 7). This is a great concern for parents as well as for professionals. These negative attitudes towards the hearing-impaired child can have a profound effect on the child's development as well as on the family. It is therefore very important that parents as well as professionals should work together in order to inform the society about hearing impairment and influence it in a positive way.

Parents found it difficult to make important choices and decisions at a very early stage in the child's life (Questionnaire 3,6; Interview 3). This was not mentioned in the other questionnaires and interviews.

It is highlighted that parents often feel frustrated and confused by the many options and strong views held by professionals, other parents and adults who are deaf (cf. Meadows-Orlans et al, 1995:317; Atkins, 1987:33; Rushmere, 1994:160).

The parents in Questionnaire 8 changed their home language from Afrikaans to English. According to them it was very difficult. In the literature the researcher did not find any information about changing from one language to another. There are many factors involved in such a big decision, like the child's cognitive ability, the willingness of the family to make a complete change and the level of language acquisition of the initial language.

In the scientific literature no information is found on bilingualism (the ability to communicate verbally in two different languages). The researcher is convinced that bilingualism is possible under the following conditions:

- a willingness to learn an additional language
- cognitive ability to learn the additional language
- enough opportunity to be able to listen, to read and to speak the new language

5.4.4 Practical problems after the implant

The parents have mentioned the following practical problems that they have encountered after the implant:

In general, rehabilitation seems to start quite long after the implant (Questionnaire 4, Interview 1,3). This is a problem, because parents feel that valuable time is wasted. This can be true in some cases. Yet, the researcher is acquainted with the two cochlear units in South Africa and one in Scotland and in these units, rehabilitation starts as soon as possible.

Some parents with children in primary school are worried about the fact that teachers are ignorant of the needs of their children (Interview2). It may be that teachers are not trained specifically to work with these children. Some parents complained about head teachers' lack of understanding of the situation! (Interview 2)

With regard to the primary en secondary schools, a lot of training and support of teachers is necessary in order to help the implanted child to reach his or her full potential. Some cochlear implant units are already involved in programmes to train and support teachers (cf. paragraph 4.12).

5.4.5 Parents' expectations of the cochlear implant

It is important to have realistic expectations of the cochlear implant. If the cochlear implant does not fulfil the expectations, parents can struggle with feelings of guilt.

Expectations are embedded within a system of supporting beliefs. Expectations that have the potential to satisfy needs are strengthened by that need. Parents who have the expectation that their child should communicate verbally may be more likely to maintain stronger expectations of the implant than a parent who does not have this ideal (Kampfe, 1993:300).

Parents have expressed the following expectations with regard to the cochlear implant:

1. It will be better than a hearing aid (Interview 1,2,3). Miyamoto (1993:437) drew comparisons between hearing aid users and cochlear implant users. The level of performance after the cochlear implant represents a marked improvement over children with conventional hearing aids. Although the cochlear implant proves to give better hearing, parents may be disappointed when they find that the implant does not produce normal hearing for their children. Parents need to know how important it is to be involved and to support their child in their aural rehabilitation, because language skills do not develop without a lot of input from parents.
2. It would give the child a better chance in this hearing world (Interview 1,2,3). As hearing people's abilities and standards determine the pattern of life in a community, this is a very relevant expectation.
3. It would give the child the opportunity to be able to listen and to understand their friends (Interview 1,2,3). Normal communication and improved independence increase a child's self-esteem. The child will feel more self-assured, which will decrease stress on the rest of the family. The parents in Interview 1 appreciated the fact that their child is now able to stay overnight with friends.
4. Parents expected the child to develop better language skills at an earlier stage, but they were aware of the fact that it will require a lot of effort (Interview 2; Questionnaire 1,2,3,4). Although a lot of research has been done on the

language development of the child (cf. Staller et al, 1991:34-47; Miyamoto, 1993:437; Osberger et al, 1994:498-502), there is not much focus on the role of the parent to achieve good results. The total commitment of the parents to the child's language development must be underlined. It is only through hundred percent dedication and hard work by the parents and the child that the child's language skills can develop to an equal or even better level than the normal hearing child. The educational psychologist has a significant role to play. She or he should inform parents and motivate them to carry on even when they lose heart during this long and tiring language training process. The psychologist will also have to monitor the process in order to assure that the development of the child is balanced. In this regard, the insight of a specific parent is noteworthy when he said that they try to focus on the child as a total person and not on the disability (Interview 2).

It is important to note that an earlier intervention does not necessarily imply better language development. There are more determining factors that should be born in mind. The researcher is aware of a few cases where there are two cochlear implantees in one family. One should expect that the children who have been implanted earlier would have developed better language skills at an earlier stage. In two cases known to the researcher, this is not the case. In the first case the second child is implanted at an earlier stage. Although the mother worked very hard with both the children and had more experience when she worked with the second child, this child's language development was not as impressive as the first child's.

In the second case the situation was the same except that the father was to a great extent responsible for the rehabilitation of the two children. The first child, who has not been implanted as early as the second child, does not have the same language abilities as the other child. In this case the father is convinced that if the first child was implanted earlier, she could have developed in the same way as her younger sister (Interview 2). It is important to note the research of Waltzman et al where they found that early implantation is beneficial to development of speech perception in the congenitally and prelingually deafened child (Waltzman et al, 1994:12).

It can be assumed that early implantation is beneficial for the development of language skills, but it is not the only determining factor. Differences in personality and ability can also affect the rate at which the language of children develops.

The way the parents are dealing with the grieving process and the way they are coping with their child's deafness, may influence parents' reasons for wanting the cochlear implant and will influence their expectations of the device (Kampfe, 1993:299). Parents who are in the early stages of recognition may desire the implant as a way of denying deafness in their lives. Parents who are in a state of denial may not recognise or be open to the powerful and positive aspects of deaf culture. They may be seeking a miracle cure, hoping that the implant will remove the deafness from their lives. Parents, who are engaged in constructive action, may recognise that the implant will not eliminate deafness but that it can provide additional auditory input (Kampfe, 1993:299). From the responses of the parents in this study, it is evident that these parents are at an advanced stage of the grieving process. Their expectations are realistic.

5.4.6 The effect of the cochlear implant on the hearing-impaired child and the family.

The cochlear implant has a direct impact on the deaf child's life. It does not only help the child to hear and speak better, but it also helps the child in almost every other aspect of life. As the child lives in a close relationship with the family, developments in the child's life will also have an effect on the parents.

The results in this study are categorised as follows.

- (a) Communication.
- (b) Feelings of parents.
- (c) Effect on the deaf child.
- (d) Normality.
- (e) Effect on parents.
- (f) Effect on siblings.

a. Communication

Communications is much easier in the family (Questionnaire 1,3,8, Interview 3). The one father said that they can laugh about things together. This was not always possible in the past because the hearing-impaired child would have missed the joke or would not have been able to understand it (Interview 2). This correlates with what is said by Lansing (1990:63-77) and Nicolas (1994:197). Poor communication inhibits the typical family discussion with everyone participating verbally (cf. Mendelsohn et al, 1983:41).

One parent said that the cochlear implant transformed an uncertain and frustrating future for the child and the family into a happy and fairly secure future (Questionnaire 8).

After the child was implanted and experienced development in language and speech, one father said: "My child can now come to me and say: I love you dad!" In addition to the fact that the child can express herself verbally, this also means a lot to the parent as well as to the relationship between parents and their hearing-impaired child.

According to Questionnaire 1, communication between the children is easier. Communication in the family has, according to Questionnaire 2, improved considerably after the implant. They say that they can talk, laugh, listen to music, watch television and read books together. The mother said that they can even pray together (Questionnaire 2).

According to a parent, verbal communication would not have been possible without the cochlear implant (Questionnaire 8). This may be a radical statement, but it is attested that the cochlear implant makes a dramatic contribution to the development of communicating skills (cf. Lansing (1990:63-77); Tyler (1990:282-289); Carol (1995:18-21); Cunningham (1990:375-381); Smith et al (1998:840-850); Osberger et al (1993:186-203); Nicholas (1994:181-198); see also paragraph 4.6.1.7).

It is clear that the cochlear implant does not only improve communication, it also improves and normalises relations in the family. Members of the family grow closer together. This correlates with the studies of Wexler et al (1982:59-61). They did

research on the psychological effect of the cochlear implant. After the implant the close relatives say that they are more at ease with regard to matters of safety, the patient is perceived to have fewer episodes of emotional distress, communication is easier, the patient seems to understand much more, the patient is a better speech reader and can modulate his or her voice more successfully, the relatives are less frustrated due to improved communication, both the patient and the relative experience less emotional tension.

b. Feelings of parents

Parents feel very pleased that their child can hear after the implant. They have no regret, they feel relieved and happy (Interview 1,2,3; Questionnaire 1,2,3,4,5,6,7).

The fact that parents express such positive feelings indicates that the implant has made a positive impact on the family. The relations between parents and all the children will be more relaxed and normal. Family life will improve.

The one mother said that she has mixed emotions. According to her she sometimes “feels sad for her child, and sometimes happy”. She finds it difficult to explain the “joy you feel in your heart when you see your child look up at a tree and point at a bird that is singing”. She says: “For us with deaf kids, every time they say and hear something different we are so excited and want to scream so that the whole world can hear that our child has said a new word ... it is a wonderful feeling” (Questionnaire 2). Another parent said: “I feel she is special” and that she (the mother) enjoys the closeness of their relationship (Questionnaire 6).

A father said that it is comforting to know that they as parents are doing the best to make life easier for their child. He said: “Perhaps I am still harbouring an unlogical feeling of guilt concerning my daughter’s handicap”. This might also relate to unfinished business in the parent’s road of accepting the child’s hearing loss. Will a parent ever be able to accept his child’s handicap totally? The final word on unlogical feelings and feelings of guilt is not yet been said and requires further study.

Two of the questionnaires report that parents tend not to think about their own feelings – they want to go on with life “as normal as possible” (Questionnaire 1,4).

This may be a cause for concern and the professionals (psychologists) should pay attention to it.

A father said that the deafness had initially a straining effect on the marriage, but after the implant, they have grown closer together. He said the implant has improved relations in the family (Questionnaire 8). According to another mother, the cochlear implant did not have a beneficial effect on her relationship with her husband, they got divorced (Questionnaire 5). This cannot be linked directly to the cochlear implant. This marriage might have been not too stable before the implant. Yet, the cochlear implant may have increased tension in their relationship. According to research in this field, cochlear implants do not contribute to the frequency of divorce (Kahyap, 1986:35; Moores, 1996:141).

Mothers report that they had to be a lot stronger for their child's sake (Questionnaire 1,3,5). This points to the stress related to deafness with or without the cochlear implant (cf. Kashyap, 1986:35, Quittner et al, 1991:95-104). Quittner agrees that parental stress does not disappear after the cochlear implant.

Some parents do not regard their children as deaf anymore after the implant (Questionnaire 1,2,7).

c. Effect on the deaf child

The cochlear implant has a significant effect on the deaf child. The following was mentioned:

In general parents said that their child is not isolated anymore and acts as if part of the world (Questionnaire 1,2,3,4,5,6,7,8; Interview 1,2,3). Children hear much better after the cochlear implant (Questionnaire 1,2,3,4,5,6,7; Interview 1,2,3).

One teenage daughter said she does not feel that she is deaf now that she has the cochlear implant. According to Maillet (undated:31-48) the cochlear implant makes a significant positive change in the quality of life of patients. Lansing et al (1990:63-77) also describe improvement in feelings and attitudes concerning hearing loss and a deaf person's ability to communicate verbally.

The hearing-impaired child is more capable of expressing their feelings after the implant than before (Interview 1,2,3; Questionnaire 3,4,7). This is definitely a positive development. The fact that the child is more able to express feelings towards his family will enhance the bonding with parents. There will be an improvement in emotional bonding between the children as well. This will contribute to the fact that the child will feel part of the family, will experience more emotional security and will inevitably develop a better self-image.

In Questionnaire 1 the mother reports that their child begins to understand the importance of speech in order to be understood.

According to almost all the questionnaires and interviews, the child is less frustrated and therefore there are less tantrums after the implant (Interview 1,3; Questionnaire 1,2,3,4,5,6,7). Fenster (1988:225-234) describes the frustration and temper tantrums of the hearing-impaired child.

Almost all the parents in this research said that their children became more independent: They would stay over with friends (Questionnaire 2,3,4,5,6,7; Interview 1,2,3), do things for themselves (Questionnaire 2,3,4,5,6,7; Interview 1,2,3), and as one father said, "he (the child) can make up his own mind" (Interview 1). The mother in Questionnaire 1 said that their child has always been independent. Being independent is valuable and an important asset in a cochlear implanted child's development. When a child can function independently, it contributes to a good self-image and more confidence, which will eventually help the child to reach self-actualisation. This will give parents satisfaction, decrease their stress and help them to carry on normally.

It upsets the child if the cochlear aid is not working, because then they cannot hear (Questionnaire 1,2,3,4,5,6,7). One child said he feels very happy with his implant, although he feels shy when having to change his battery in front of other people. Although there are a few frustrations, it can be coped with, as the majority is of a practical nature.

d. Normality

According to parents, things feel much more normal in the house after the cochlear implant. They have the same expectations of all their children, including the hearing-impaired child (Interview 2,3; Questionnaire 2,3,6,7).

Children using the cochlear implant can be called from another room in the house, and can be called from outside (Interview 1,2,3; Questionnaire 1,2,3,4,5,6,7). Shea et al (1994:70) proves that children with a cochlear implant can detect speech at normal conversational loudness thresholds post operatively. Fenster (1988:225-237) describes the complexity of communication with a deaf child.

Parents reported that their hearing-impaired child can now have a fight, is able to argue and can discuss things with you (Interview 2,3; Questionnaire 1,2,3,5,6,7). The whole family has a better quality of life. Mom and dad can have a normal conversation (Interview 1,3). The fact that the child can hear environmental noises like the doorbell, the telephone, birds, motorcar hooters, the sound of traffic, makes life much easier.

This development is in sharp contrast with the situation before the implant. Deaf children's behaviour influences their parents' behaviour. Having a deaf child in the family necessitates the family to change (Questionnaire 3). A family has to change in the way they communicate, more demands are made on the family's time as communication is slower and much more complicated (Questionnaire 1,2,3,4,5,6,7; Interview 1,2,3) (cf. Quittner et al, 1991:96). On the other hand, Fisiloglu et al (1996:234) argue that the functioning of families with deaf and hard of hearing children is not different from the functioning of families with hearing children.

e. Effect on parents

There are certain feelings that are experienced repeatedly – even after the implant. One mother with a teenage daughter reported that the trauma of taking her child to school for the first time was in a way repeated when this child had to return to school after a long holiday. The child was nervous and felt unsure of herself and the mother experienced stress and felt sorry for the child (Questionnaire 3).

Some parents say that they have benefited from having a deaf child with a cochlear implant. Now they have a better understanding of other people with disabilities, they have more empathy with the disabled and are interested in other disabilities (Interview 1,2,3; Questionnaire 1). One mother said that they did not know anything about deafness previously and this was a new challenge in their lives. As their knowledge about deafness improved, they were able to inform their friends and the community. Through this process, they even gained a lot of new friends (Questionnaire 6). This correlates with Fisiloglu's research where it was found that the stress in families is not necessarily a negative force, it can be an occasion for growth (Fisiloglu et al, 1996:234).

According to parents, the cochlear implant changed parents' whole outlook on life (Interview 2,3).

The cochlear implant had a definite effect on the financial situation of the people in South Africa (Questionnaire 1,2,3). In this country there is no National Health Service and parents have to afford the implant themselves.

Other financial matters such as the cost of batteries, the cost of residential courses and the cost of a deaf au pair were mentioned (Questionnaire 6). Travelling expenses to the cochlear units are also a factor (Questionnaire 4). One mother (Questionnaire 5) said that there were no financial implications with regard to the cochlear implant. In South Africa spare parts are still expensive (Questionnaire 8).

f. Effect on siblings.

The effect of the cochlear implant on the life of the deaf child will definitely have implications for the siblings in the family.

In this study the siblings never gave the impression that having a sister or brother with a cochlear implant created problems for them as individuals (Questionnaire 3,8; Interview 3).

According to Israelite (1986:47) and Atkins (1987:32) little empirical data exists on siblings of a hearing-impaired child. Murphy (1979:352) also mentions the lack of professional interest and investments in the literature concerning the siblings of handicapped children. Atkins (1987:34) lists specific concerns of brothers and sisters. Among them are the individual roles within the family, quality and quantity of parental attention, responsibilities, health, extent of and understanding of hearing loss, type and quality of communication, discipline, expression of feelings, personality, temperament, developing and maintaining one's own identity, pressure to achieve, behavioural expectations, dealing with rudeness from other and information needs. All these may be problem areas when having a hearing-impaired child.

In the discussions with siblings as well as in the questionnaires none of these problems appear. The cochlear implant makes life easier for the other children in the family. One younger sister said that it is always a problem if the cochlear implant is not working. Then they have to tap the hearing-impaired sister on the shoulder to get her attention. "Then I have to look at her face again.... if I want to speak to her" (Interview 3). As communication is easier for the siblings, they experience their life as more normal.

A younger sibling tends to feel sorry for the hearing-impaired child whereas teenagers do not feel specifically sorry for this child. A teenager feels that the hearing-impaired child gets enough attention and does not really need more (Interview 3). This can be an indication of jealousy. One teenager sister, however, said that she is worried that the hearing-impaired child would not be able to cope in the high school (Interview 3). A teenager brother said he knows that it is difficult for the hearing-impaired child, but it is much easier in life for her than for other hearing-impaired children without a cochlear implant (Questionnaire 3).

The educational psychologist can assist siblings in coping with existing worries about the implanted child. If possible the sibling can be involved in the direct rehabilitation process of the child. This might help siblings to feel they are actively involved in helping the child.

Younger as well as older siblings said that their friends understand their hearing-impaired brother or sister's speech and that they do not have any problem with their friends (Interview 3; Questionnaires 1,3). According to them, their friends accept the hearing-impaired child in a normal way and act in a normal way to him or her.

Parents said that the older brother had to understand the complicated situation of having a hearing-impaired child in the family at a very early age. Although it does not seem to be a problem for the child, the mother is aware of the high demands on the older children to cope with the situation (Questionnaire 3). One parent said that the other siblings had to learn to cope with less attention, although the parents try to maintain the balance (Questionnaire 8).

Parents should be guided and helped not to expect too much of the siblings with regard to the hearing-impaired child. Siblings should get enough information to be able to understand the situation. If siblings experience that they are trusted with information and allowed to co-operate as a team, their self-esteem will be enhanced.

5.5 Conclusion

There is a remarkable consistency in the experience of the parents and siblings as reported in the questionnaires and interviews. There is also a consistency in these results and the research results as portrayed in the scientific literature. Yet, it is not only general tendencies that are noteworthy, but also the unique and individual responses. In this field of study, respect for the uniqueness of every person and every family is of the utmost importance.

Table 10: Psychological aspects

Psychological aspects of the deaf child after the cochlear implant

- not isolated anymore
- feels part of the world
- does not feel deaf
- more capable of expressing feelings: bonding with parents and siblings
- experience emotional security; will develop better self-image
- less frustrated
- more independent
- good self-image
- more confident; better chance to reach self-actualisation
- feels happy

The above-mentioned have a direct correlation with the following
psychological aspects of siblings after the cochlear implant:

- life is easier, more normal
- communication is easier
- some feel sorry for the deaf child, some not
- sometimes there may be indications of jealousy, although not severe
- have to understand the complicated situation of hearing impairment at a very early age
- have to cope with high demands
- have to cope with less attention from parents
- co-operating as part of the rehabilitation team enhances their self-esteem

Psychological aspects of parents after the cochlear implant:

- feel pleased
- positive impact on whole family
- better relations between parents; closer together
- better relations between parents and children
- family life improves
- comforting to know that you have done the best for your deaf child
- continuing stress: had to be stronger for their child
- satisfied
- can carry on normally; family life is more normal for example, discussions, arguing, fights
- have the same expectations for the deaf child as for the other children
- conversation is normal
- conversation between parents can be normal

Chapter 6: Guidelines for parents

The aim with this chapter is to give practical guidelines to parents. The researcher makes use of information gained through the literature study, interviews and personal experience. It is presented in an abbreviated form that can be handed out to parents. When parents consider a cochlear implant for their child, the amount of available literature is sometimes overwhelming. They will appreciate compact guidelines that are to the point and that will not take too long to read.

6.1 Decision making and the time before the operation

It is very difficult to decide whether or not your child should have an implant -

Remember:

- Professionals are aware of the complexity of this decision and have experience in guiding parents through the process.
- Professionals are eager to assist.
- Professionals are ready to give information.

Hints:

- Discuss your child's health and hearing problem with a medical doctor. (ENT, GP)
- Get all relevant information about the following issues:
 - the Cochlear implant and how it works.
 - the operation – where will it take place.
 - how long your child will be in hospital.
 - whether the parents may stay with the child in hospital.
- Get statistical data about the effectiveness of cochlear implants.
- Get information about the screening process.
- Discuss feelings like anger, fears, frustrations and other emotions with an educational psychologist. The Doctor, audiologists, speech therapists and other professionals have to focus on their field of specialisation and will not have time to help with these problems.
- Get into contact with children with cochlear implants and their parents.

- The possible candidate for the implant should be part of the decision making process (where possible).
- Prepare your child as well as possible for the operation.
- Prepare siblings and grandparents to know what to expect after the operation.
- Find out about the situation after the operation for example:
 - How long does it take before the stitches are removed?
 - What is expected of you with regard to the wound?
 - When do you have to go for the first “mapping session”?
 - How regular should you go for mapping?
 - How can you help your child in the meantime (before the “switch-on”)?

6.2 The operation

Remember:

- The surgeon is a specialist and is trained specifically to do this operation.
- Everybody who works with your child wants the best for him or her.
- If you and your child are well prepared for the operation, your child will feel safe and calm.
- Your child will be very sleepy for a few hours after the operation.

Hints:

- Pack your child’s favourite soft toy.
- Leave something special (a gift) for the siblings at home for the time you’re going to be in hospital with your child.
- Pack something to keep yourself busy during the long hours of the operation. You can even do some shopping or window-shopping to fill the time.

6.3 After the operation

Remember:

- Your child won’t be able to hear directly after the implant.
- Your child will have to go for a “mapping” session and the aid should be “switched on” before he or she can hear anything.
- Your child’s ability to hear is only starting now. He or she will need time, intensive auditory training (learning to listen) and a lot of encouragement.

- Your child will be tired after the operation. He or she may not appreciate too much fussing.

Hints:

- Do not frustrate your child by testing his or her hearing too frequently.
- The auditory training must go hand in hand with language input – for example, if you hear an aeroplane, listen with your child to the sound, but also provide (say) the language “I can hear an aeroplane”, or “the aeroplane is flying high” (the speech therapist will be able to give good advice).
- Parents need to be aware of potential frustrations. Your child may feel frustrated because he or she is anxious to be able to hear.
- Parents will need a lot of patience. When you want to “work” with your child, your child may not be willing to. Always keep in mind that he or she is just a child.

6.4 General guidelines

- Teach your child as soon as possible to take responsibility for this aid:
 - He or she has to know how to switch the aid on and off.
 - He or she has to be able to change batteries.
 - He or she has to tell when the aid is not working or when it is dysfunctional.
 - He or she has to know where to put the aid when it is not used - it should be kept where pets (dogs) cannot reach it.
 - He or she should not swim, take a bath or shower with the aid.
- If your child is young parents should visit the child’s school. The functioning and appearance of the aid should be discussed with the teacher as well as the children at school.
- The parent as well as the child should always have spare batteries. It is a good idea to have an extra cable available.
- Clean the aid regularly.
- Keep the aid away from water.
- Your child should wear a “medic alert” bracelet or necklace to give information about the implant and the prohibition of electro-surgery, diathermy, MRI and electro-convulsive ionising radiation therapy.

- Keep on giving your child new language.
- STAY POSITIVE !!!!!

6.5 The following literature is recommended

- Nottingham Paediatric Cochlear Implant Programme. Undated. *Information booklet*. Nottingham: Circus Design.
- Robbins, A.M. 1994. Guidelines for Developing Oral Skills in Children with Cochlear Implants. *Volta Review* vol 96, no 5, p 75 – 82.
- Scottish Cochlear Implant Programme for adults and Paediatrics. Undated. *Information for Patients*. Kilmarnock: Dept. Medical Photography & AV Services. Crosshouse Hospital.

The Cochlear Clinic at Crosshouse Hospital, Kilmarnock (Scotland) has the following information booklets available for patients and their families:

- “I’m going for a Cochlear Implant Assessment”
- “The Scottish Cochlear Implant Programme for Adults and Paediatrics”
- “Switch-on. What happens?”
- “Paediatric Cochlear Implantation. Post Operative Advice.”
- “Cochlear Implant preliminary Questionnaire”
- “Paediatric Audiology Assessment Aims”
- “.... gets a Cochlear Implant at Crosshouse Hospital”
- “Deaf children and cochlear implants”

The National Deaf Children’s Society (United Kingdom) also distributes the following worthwhile literature:

- “Deaf Children and Cochlear Implants Leaflet”. This is an introduction for anyone who is interested in Cochlear implants and deaf children.
- “Deaf Children and Cochlear Implants”. This is a well-balanced booklet that covers the issues facing parents when considering a cochlear implant for their child.

6.6 How do I help the siblings?

Parfit, 1975:19-20 discusses the needs of siblings. She says that the ways we can help the siblings depend to a great extent on their age in relation to the handicapped child. The needs of the siblings are threefold:

- **Need for information**
 - Do not hide the existence of deafness from the siblings. Deafness and its complications should be explained to the other brothers and sisters.
 - Help the children to know how to tell their friends and their teachers about the hearing-impaired brother or sister.
 - As the children grow older, discuss the following with them:
 - Possible genetic implications.
 - They have to participate in the discussions about future plans for the deaf child.
- **Need for emotional help**
 - The younger the child, the more intuitive and physically reassuring must the support be. The father may help to provide more support and give extra individual time and attention to the other siblings.
 - Emotional reactions like jealousy, feelings of guilt in some or other way, can be brought into the open through discussion and conversation.
- **Need for education**
 - The older siblings can be shown what they can do to help with the training of the hearing-impaired child.
 - Encourage the sibling to find activities that are appropriate.
 - Older siblings can be actively involved in the use of developmental toys, games, or speech and language training. The siblings will feel that their help is really important and that they are special.
 - Older siblings should know the basic facts about the cochlear implant. They usually feel proud to explain these things to friends.

If the whole family is involved in the training of the hearing-impaired child, the best educational psychological environment is created.

Chapter 7: Conclusions, findings and recommendations

7.1 Introduction

The cochlear implant is a radical intervention in the life of the hearing-impaired child and his or her family. The purpose of this study was to identify and interpret the educational psychological effect of the cochlear implant on the hearing-impaired child's family. It is the wish of the researcher that this dissertation can be of practical value. The chapter with the guidelines can be used as a booklet for parents. Professionals may also benefit from it.

7.2 Conclusion and findings from the literature study

The literature study is done to give a broad base of information about deafness and its effect on the deaf child and his or her family. Without such a frame of reference, it would not have been possible to identify the effect of the cochlear implant. In this frame of reference, prominence is given to the physiology of the ear (cf. Figure 1), the classification of hearing loss (cf. Table 1) and the aetiology of deafness (cf. Table 2). In the literature, the effect of deafness on the family is described in detail (cf. Table 5 and Table 6). The effect of the cochlear implant on the family, however, is not adequately dealt with in the literature.

Although the cochlear implant is still a fairly new aid for hearing-impaired people, there is already a wealth of information in the literature. It is interesting to note that the majority of studies is done by speech therapists, medical doctors, audiologists and technical persons. Only a few studies are done by psychologists. As a result, the majority of researchers describe technical data about the cochlear device, speech and language development and the technical aspects there-of (cf. Figure 5, Table 7, Table 8). Very little is found on the psychological aspects of the child (cf. Table 3). Even less is found concerning the psychological aspects with regard to the people (like the family) who are involved in the hearing-impaired child's life (cf. Table 5, Table 9). Although this study has endeavoured to explore this field, much more research can be done.

In the literature there is no mentioning of the concerns and fears that parents have while they are still in the process of deciding whether or not to give their child an implant. In fact, very little is mentioned concerning the emotions of the family, before or after the implant.

7.3 Conclusion and findings of the empirical study

In the empirical research, it was not possible to get sufficient statistical information to arrive at generalisations. It is nevertheless important to pay attention to the individual responses, as the researcher values the individual's views and feelings.

However, it is of significant value to know that most of the people who contributed to the study share more or less the same positive experiences about the cochlear implant. It is also clear that deafness has a radical effect on the child as well as the family.

All the respondents in the interviews and the questionnaires were very positive about the cochlear implant and its effect on the family. According to the respondents one of the most important issues after the cochlear implant is the fact that the situation in the family is normalised to a great extent. The researcher wants to emphasize this fact, because it gives an indication of the benefits of the cochlear implant with regard to family life (the hypothesis is confirmed).

In general the parents and the siblings were very keen to discuss the cochlear implant and its effect on the family. It was not always easy to keep the parents to the specific subject. It was obvious that most of the parents had a problem to come to terms with the way in which they were told that they have a hearing-impaired child. Although the researcher did not intend to focus on this issue, it was inevitable to have some discussion about this very delicate and sensitive matter.

There were also parents in this study who were too afraid to verbalise their expectations of their child. A few parents found it hard to discuss their own feelings. The majority of parents experienced the opportunity to discuss their child and the effect of the cochlear implant as therapeutic. The researcher realised how important it is to give parents the opportunity to discuss these issues in a context where there is no

stress involved - they do not have to make important decisions, they are not “working” with their child or making financial decisions.

Although the whole process implies a lot of stress, the researcher is convinced that it is experienced as worthwhile. The responses of the families (empirical study) and the literature reveal that the cochlear implant has a very positive effect on the total functioning of the family.

There are striking parallels between the results of the empirical study and the literature study – these two aspects have complemented each other.

7.4 Contribution of the study

The multitude of publications on deafness and the cochlear implant is systematised and summarised to a certain extent in this study. The publications that are relevant to this field of study, are identified and discussed. Some of the results of the empirical study were anticipated by the literature study, but the study also reveals some feelings and experiences of parents and siblings that were not previously described.

The implanted child, the siblings and parents may benefit from the study and it may be of value to professionals like the psychologists, speech therapists, teachers, audiologists, medical personnel and people who are part of the cochlear implant team.

The following contributions have been made to the specific field of research:

- The existing literature is systemised.
- Different tables were drawn up to serve as a synopsis.
- A questionnaire is developed to identify the effect of the cochlear implant on the hearing-impaired child’s family.
- Guidelines for parents of children with hearing impairment are given. The aim of these guidelines is to guide parents when they have to make decisions with regard to the cochlear implant for their child.
- Attention is drawn to specific feelings that are experienced by members of the family of an implantee.

7.5 Shortcomings of the study

Due to the limited number of questionnaires that were processed and interviews that were conducted it was not possible to arrive at generalisations. However the scope of this study did not allow more extensive research.

7.6 Recommendations for further study

It should be an interesting study to identify, measure and interpret the stress that parents experience before the implant.

In future research, attention can be given to the difficulty some parents experience in talking about their feelings.

It will be interesting to study the differences in the emotional effect of the traditional design and the new design of the instrument on the hearing-impaired child.

7.7 Conclusion

In a certain sense, deafness can lead to disorientation in the family of the deaf child. Due to the cochlear implant, the situation in the family can be normalised to a certain extent. The process of reorientation is complex. Although the families benefit from the cochlear implant, stress is not necessarily reduced. The child and the family still experience difficulty in coping with psychological adaptation as well as social, emotional and academic challenges. In this process, the role of the educational psychologist, as part of the team, is of the utmost importance and should not be underestimated (see Table 4).

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