

**AN INVESTIGATION INTO THE EXPECTATIONS OF MOTHERS OF
CHILDREN WITH COCHLEAR IMPLANTS**

Jennifer Lynne Perold

**A dissertation submitted to the Faculty of Logopaedics, University of Cape
Town, in partial fulfilment of the requirements for the degree of Master of Audiology**

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DEDICATION

for the parents of cochlear implant children.

**May we, as audiologists, better understand your
journey in our pursuit of service excellence.**

DECLARATION

I, Jennifer Lynne Perold, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise), and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Date

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ABSTRACT

There is a paucity of research examining the expectations of parents whose children have received a cochlear implant. The process of implantation is fraught with expectations, and in order to ensure continued parental interest and motivation, it is important to have insight into and understanding of these expectations, as well as the factors which influence them. This study aimed to investigate the pre- and post implant expectations of mothers whose children had received a cochlear implant, as well as the possibility of changes in their expectations with duration of cochlear implant use. It also aimed to examine satisfaction of mothers with the cochlear implant, and the influence this had on expectations. A qualitative research methodology was used in the form of in-depth interviews. Eight mothers of prelingually deafened children who had not yet started formal schooling were interviewed. The data obtained from the mothers was transcribed verbatim and then analysed according to a detailed qualitative analysis procedure. Important findings emerged which detailed the changing expectations based either on hope or knowledge over time. These expectations were influenced by many variables, including the mothers' response to the deafness of the child (i.e. the grief reaction), anxiety and stress, performance outcomes, satisfaction, and expectations of others, including family and friends. Numerous theoretical and clinical implications emerged from these findings, including the dynamic nature of expectations, as well as the impact these have on the importance of ongoing counselling of mothers whose children use cochlear implants.

KEY WORDS: cochlear implants, children, outcomes, expectations, satisfaction, counselling.

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1. INTRODUCTION

“Before floating up into the sky with a balloon in search of honey,
make sure the bees you are looking for are the right sort of bees”.

(Powers, 1996)

In recent years cochlear implants have proven to be an effective and reliable method of treatment in both postlingually deaf adults and children, and congenital and prelingually deaf children who are unable to obtain meaningful benefit from conventional amplification (Lenarz, 1998). Measurement of the success of implantation has largely focussed on improvements in speech perception within the clinical situation (Dorman, Dankowski, McCandless, Parkin, & Smith, 1990; Fryauf-Bertschy, Tyler, Kelsay, Gantz, & Woodworth, 1997; Hogan, 1997; Ito, Takagi, Kawano, Takahashi, & Honjo, 1995; Waltzman, Cohen, & Shapiro, 1992), and improvements in speech production and language skills (Coerts & Mills, 1995; Grogan, Barker, Dettman, & Blamey, 1995; Tye-Murray, Spencer, & Woodworth, 1995; Tye-Murray, Spencer, & Gilbert-Bedia, 1995). Studies have all demonstrated significant improvement in performance levels as compared with pre-implantation abilities. However, objective results of hearing tests quantifying prosthesis performance need to be backed up by information regarding user satisfaction before a device can be regarded as successful (Cunningham, 1990; Cunningham & Stoeckert, 1992; Giles et al., 1997).

Knutson, Tyler, Schartz, Hinrichs, Gantz, and Woodworth (1991) and Giles et al. (1997) suggest that in order to obtain a more well-rounded understanding of the success of implantation, and because of the great variability in post-implant audiological outcomes, other indices of change should also be considered when evaluating the success of cochlear implantation. Various studies have been conducted on adults examining satisfaction and psychological outcomes. These studies have found significantly increased ability to communicate and communication confidence, as well as improved psychological well-being and quality of life in adults (Knutson et al., 1991; Kou, Shipp, & Nedzelski, 1994; Maillet, Tyler, & Jordan, 1995; Spitzer, Kessler, & Bromberg, 1992). Quality of life changes and satisfaction with a device should perhaps be considered an integral component in evaluation of the effectiveness of the device.

However, not all implantees are satisfied with their implants, as levels of performance vary considerably (Summerfield & Marshall, 1995). Furthermore, the set of expectations which the implantee has developed prior to implantation will have an important impact on post-implant satisfaction levels. Maillet et al. (1995) did not find a strong correlation between measures of satisfaction and clinical measures of speech recognition ability. Satisfaction was found to rather be closely related to ability to communicate within natural settings. This finding was similar to that of Zwolan, Kileny, & Telian (1996), who found that although a group of prelingually deafened adults (who had been implanted as adults and are generally not considered good candidates for implantation) performed poorly on traditional speech perception tests, they were highly satisfied with the device and used it regularly. Vidas, Hassan and Parnes (1992) found that performance for children in structured settings (i.e. testing and therapy sessions) was not in agreement with performance in unstructured settings (i.e. classroom and home environments). Kou et al. (1994) and Vidas et al. (1992) suggested that the use of speech perception tests alone to assess performance was inadequate. It would therefore appear that measures of success are not directly related to performance within the clinical setting, and in order to more fully evaluate outcomes of implantation it is necessary to develop and include other methods of measuring outcomes.

The process of cochlear implantation is surrounded by expectations (Hogan, 1998). The set of expectations which the implantee has developed prior to implantation will have an important impact on post-implant satisfaction levels. The implantee, as well as all individuals involved with the future implantee, develop a set of expectations about how the person will perform with the device. These expectations are often formed around the media hype about the “miracle of the bionic ear”. Hogan (1998) suggests that it is this “miracle metaphor” that is so often responsible for inappropriately high expectations. It is possible that dissatisfaction with implant performance may be related to inappropriate user expectations, and that pre-implant expectations have not been met. It is essential that, prior to implantation, and indeed as an integral part of post-implant counselling, candidates and their parents (in the case of children), are well prepared in terms of what to expect from the implant. Inappropriate expectations may lead to disappointment, frustration, and perhaps a loss of trust in the clinical program (Downs, Campos, Firemark, Martin, & Myres, 1986; Tye-Murray, 1993). Furthermore, these feelings may result in a loss of

enthusiasm and poor compliance with the follow-up visits. Ultimately, the client may end up rejecting the implant altogether.

A few studies have been conducted examining whether implanted adults are satisfied with their cochlear implants, and thus, indirectly, whether expectations have been met. The majority of these studies have used questionnaires to obtain information about satisfaction regarding various outcomes. Giles et al. (1997) found that, within most categories of performance, users were satisfied and generally expectations had been met or exceeded. They stressed the need for ongoing counselling during the rehabilitative process to address areas where users felt disappointed with results (i.e. where expectations had not been appropriate, e.g. music). Tyler (1994) used an open-ended questionnaire methodology to obtain information from adult users about expected advantages and disadvantages from their cochlear implant. Generally more advantages than had been expected were realised. Hogan (1998) has suggested that rehabilitation services for deafened adults tend to focus too much on the medical model, and need to pay more attention to psycho-social, and particularly expectations issues. He suggested the use of a qualitative methodology to investigate “process issues, i.e. what happened to a person’s life following implantation” (Hogan, 1997: 162).

Predictors of performance are particularly useful when addressing the issue of expectations of prospective implantees. Lenarz (1998) and Summerfield and Marshall (1995) confirmed previous findings of factors useful for predicting greater ability to understand speech and other sounds in adults: 1) shorter duration of deafness; and 2) more useable residual hearing (an indication of auditory nerve survival (Gantz et al., 1988)). Expectations regarding implant outcomes also play a significant role in the satisfaction experienced by users (McKenna & Denman, 1993). When addressing issues of appropriate expectations, Hogan (1998) suggested stressing the physiological process of implantation in that the physical confines of the auditory system (e.g. damaged auditory nerve) and of the device limit the extent of sound which can be delivered to the brain. The technology should not be seen as a “cure” for the deafness, but as a means of improvement in everyday oral communication. Furthermore, the hype surrounding the “switch-on” day needs to be carefully addressed. Particularly in the case of prelingually deafened children, where they have not heard before, parents should not expect a “miracle” of sudden

understanding of speech.

Hogan (1998) found that over a period of time, expectations in adults drop off steadily over the first year of implantation, before beginning to steadily climb again. He obtained qualitative information from a series of subjects whom he interviewed, and was able to obtain detailed and insightful information about their changing expectations as regards implant performance in a wide range of areas. Particularly useful and personal information was obtained about psychosocial issues, which often tend to be neglected in the management of implantees. It would not have been possible to have obtained such detailed information had quantitative research methods been used (e.g. closed-set questionnaires). Hogan (1998) stressed that the information acquired through this means demonstrated the high expectations and differing needs adults have when they approach implantation. These expectations and needs must be addressed within the rehabilitation process in order to optimise satisfaction and achieve the best possible outcomes.

More controversial than implantation in adults, where it has generally been highly successful (Rose, Vernon, & Pool, 1996), is the issue of implantation in children. Significant differences exist between children in their ability to use auditory input with a cochlear implant. Profound deafness acquired before basic spoken language skills are established (prelingual) has far more severe consequences than deafness acquired after the establishment of these skills (postlingual) (see footnote 1) (Boothroyd, 1993; Lenarz, 1998). Vernon and Alles (1994) stressed that prelingually and postlingually deafened children should be seen audiologically and linguistically as two distinctly different groups. Children who have been postlingually deafened (i.e. after the acquisition of speech and language) have been found to perform better than prelingually deafened children (Nevins & Chute, 1997; Dowell, Blamey, & Clark, 1995; O' Donoghue, 1996). Dowell et al. (1995) found that for children with acquired hearing losses, performance is most likely affected more by duration of deafness than age of onset. These children are likely to obtain open-set word recognition faster than prelingually deafened children (Nevins & Chute, 1997).

(Footnote 1: Boothroyd (1993) has defined prelingual deafness as falling into 2 categories: congenital and early - birth to 1 year; late - 1 to 3 years. Postlingual deafness occurs after the age of 3 years).

The congenitally and prelingually deafened child is at a considerable disadvantage because their exposure to speech and language has been considerably delayed. Bertram (1995) and Lenarz (1998) suggest that this results in understimulation of auditory and related neuronal structures, which makes the development of auditory perception based on electrical stimulation more difficult. If cochlear implantation is performed after the completion of the critical phase for acquisition of language, outcomes will be poorer than for children implanted at an earlier age (Lenarz, 1998). Duration of deafness and age at implantation are therefore two critical variables in prediction of outcome and success - the shorter the duration of deafness the better the result and the faster the progress (Brackett & Zara, 1998; Dowell et al, 1995; O'Donoghue, 1996). O'Donoghue (1996) found that for congenitally deaf children the best results were obtained when they were implanted before the age of 5 years. Fryauf-Bertschy et al. (1997), Dowell et al., 1995 and Tyler, Fryauf-Bertschy, Kelsay, Gantz, Woodworth, and Parkinson (1997) also found that prelingually deafened children implanted before the age of 5 years obtained significantly better speech perception scores than children implanted after the age of 5 years. Tye-Murray, Spencer and Gilbert-Bedia (1995) obtained similar results in terms of speech production skills - prelingually deafened children implanted before the age of 5 years showed greater benefit than children implanted after the age of 5 years. Clinical experience has shown that congenitally deaf children will most likely have near-normal speech and language acquisition in the long term if they are implanted before the age of four (Lenarz, 1998). Duration of deafness and age at implantation are therefore critical variables in determining performance outcomes for congenitally and prelingually deafened children.

Dowell et al. (1995) reviewed results obtained on 100 children using the Nucleus 22-channel cochlear prosthesis in order to obtain information about predictive factors for speech perception results. Factors associated with better scores, in addition to those already discussed, were useful pre-implant residual hearing or progressive hearing loss, and experience with the implant. With consistent use of the cochlear implant over time, speech perception and production abilities continue to improve (Fryauf-Bertschy et al., 1997). Speech perception performance is inherently unpredictable in children, and many other factors may also affect performance, such as home environment and additional handicaps (Dowell et al., 1995). Other factors are partial electrode array insertions, ossified cochleas, Mondini deformities (Nevins & Chute, 1997), amount and

consistency of auditory input (i.e. use of the device) (Dowell et al., 1995; Frauyf-Bertschy et al. 1997), learning disability / central auditory processing disorder (Isaacson, Hasenstab, Wohl, & Williams, 1996; Lenarz, 1998), the support of classroom teachers and commitment and collaboration by the implant team and the parents (O'Donoghue, 1996; Bertram, 1995; Bray, Neault, & Kenna, 1997). Other factors include behaviour, compliance, and ability to be conditioned.

An appropriate educational environment for the child is related to performance ability based on the above factors, and therefore an oral/aural environment is not necessarily suited to every child (Dowell et al., 1995). However, an oral/aural educational placement correlates with better speech perception scores and speech intelligibility. Bertram (1995) has stressed that in order for congenitally deaf children who are implanted at an early age to achieve nearly normal language development, parents must realise that adequate hearing experience and intensive auditory-verbal education are essential requirements to achieve this goal. He goes on to say that "the involvement and the participation of the parents are the main prerequisite for successful education of these children" (97). Continued commitment and motivation of the family for many years after implantation is therefore essential.

Fryauf-Bertschy et al. (1997) stressed that prelingually deafened children who obtained open-set word recognition were consistent users of the device, and that these improvements had occurred over a period of time. Children who did not use the device consistently did not perform as well, and many eventually became non-users of the device. The authors suggested that despite counselling regarding the slow development of auditory skills, some children and their parents lost interest in the device because of slow progress. These children tended to be children implanted over the age of 5 years. A study done by Rose et al. (1996) found that 47% of children in schools for the Deaf in the U.S.A. were no longer using their devices. Most of these children were using manual communication. The authors suggested that reasons for these apparent failures be further investigated. By obtaining information from parents of implanted children about their responses to and expectations from the cochlear implant, one would be able to obtain some insight into possible reasons for this apparent loss of interest in the implant. Furthermore, by obtaining information from parents about the performance of children in their natural settings,

one would be able to supplement results of objective test scores.

Results obtained in children are variable and often unpredictable, although trends have emerged as to likely better performers (Dowell et al., 1995). It is therefore essential that a profile of each child be obtained (Hellman, Chute, Kretschmer, Nevins, Parisier, & Thurston, 1991), and that all the issues which may affect outcomes be addressed when counselling parents about expectations. The decision as to whether to opt for a cochlear implant rests with the parents as well as the implant team, and because the implant is relatively new and highly technical, parents frequently have unrealistically high expectations of future performance. Family and friends often believe that an implanted child will hear normally and should understand everything (Kelsay & Tyler, 1996). Unrealistically high expectations are likely to have a negative impact on the child's development and on the family's adjustment to the device. Unrealised performance outcomes may lead to increases in levels of parental stress (Purdy, Chard, Moran, & Hodgson, 1995), which may influence the extent of parental involvement. When inappropriate expectations are not adequately addressed, parents may become disillusioned with results and progress, and may become ambivalent about the device (Kampfe, Harrison, Oettinger, Ludington, McDonald-Bell, & Pilsbury III, 1993). Kelsay and Tyler (1996) stressed that inappropriately high expectations of parents increased the likelihood that implant use would be discontinued due to lack of parental support. Expectations that are too low may limit the child's performance outcomes as parents may never challenge their child to listen or develop good auditory and speechreading skills (Tye-Murray, 1993).

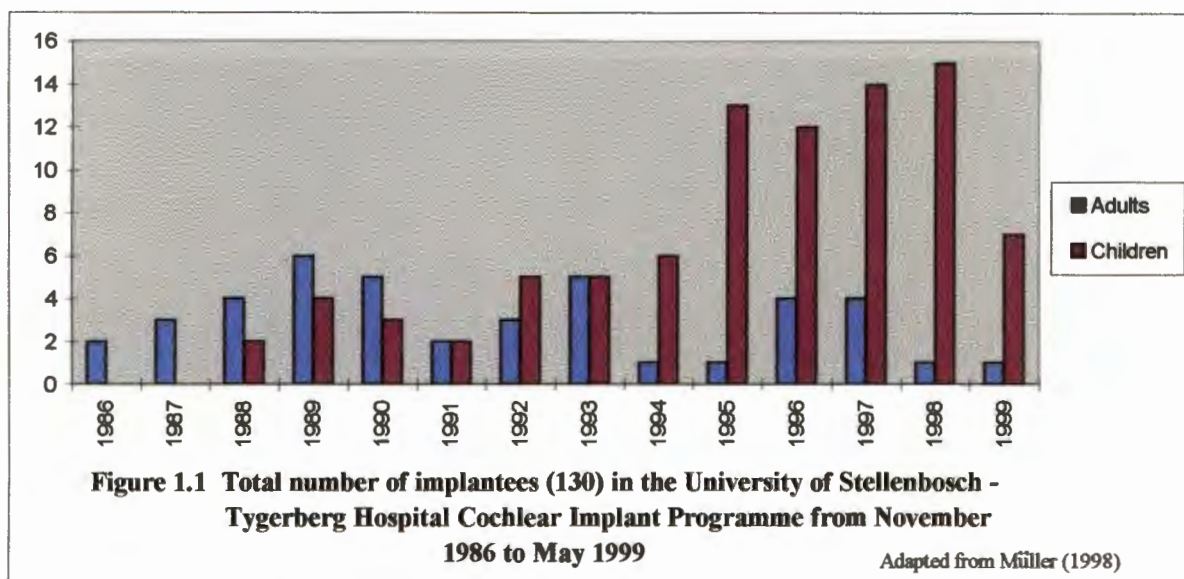
Crary, Berliner, Wexler, and Miller (1982) and Hogan (1998) found that expectations in adult implantees change over time, and that within the first year after implantation expectations drop before beginning to steadily climb again. Therefore counselling needs to be ongoing in order to discuss concerns and longer-term outcomes. It would be extremely useful to examine whether these changes in expectations over time applies to parents of implanted children. Parents may be highly enthusiastic in the initial stages, but may become disillusioned when expectations are not being met. This would present the danger of non-compliance with the programme as well as a lack of commitment to the programme and process. If expectations over time are not appropriate, it may be necessary to provide additional counselling to parents with regard to longer-term

results and outcomes. Ongoing counselling is particularly important where progress is slow (e.g. with a child who has a longer duration of deafness) and speech production changes are not as marked as perceptual changes. Parents need to be informed that this is to be expected. They need to recognise that small steps in progress are meaningful, and that time is required for the development of auditory perceptual skills (Bertram, 1995). Parental commitment and involvement are vital to success, and therefore their expectations should be appropriate over time. They also need to recognise that post-implant demands are considerable in terms of time, therapy commitments, financial demands, ongoing mapping and maintenance of equipment.

Prior to their child receiving an implant, adequate informational and emotional counselling should be provided. Kampfe et al. (1993) suggest that emotional counselling be provided to help parents come to terms with the child's deafness. This is important so that the implant is viewed as being able to provide the child with additional auditory input, rather than removing the deafness. Their motives for wanting the implant for their child need to be fully explored and addressed during pre-implant counselling. Educational counselling, where factual information is provided about the implant, should reduce the strength of unrealistic expectations. Both types of counselling should not be limited to pre-implant counselling, but should be ongoing. Very often, progress is slow and initially changes in performance are small. Parents need to recognise this and maintain appropriate expectations. Parents need to understand the implications of implantation and have expectations that are relevant to their particular child. This is particularly important in view of the fact that levels of performance and rate of progress vary considerably in this population (Fryauf-Bertschy et al., 1997; Wyatt & Niparko, 1993). In order to adequately address these issues, it is of great importance to have an understanding of the expectations of parents from the cochlear implant prior to as well as after implantation. Other factors which need to be addressed in the counselling process are educational implications, opposition of the Deaf culture to implants in prelingually deafened children, and ethical issues. All of these issues affect future expectations and levels of satisfaction with their child's progress, and need to be understood by parents.

Appropriate expectations are of such importance that decisions about implant candidacy may be based on such information (Kampfe et al., 1993). Parental commitment, attitudes and

involvement are vital factors in overall long-term success. In light of the fact that increasing numbers of young children are receiving cochlear implants (Lenarz, 1998), this knowledge has come to be of even more fundamental importance since the commitment required from parents is even greater. Furthermore, the time scale of parental commitment is also increased. Because very young children tend to spend more time at home than in the structures and routine of school, commitment of the parents to the therapeutic requirements and intensive auditory-verbal communication is of even greater importance than for older children. Figure 1.1 (adapted from Müller, 1998) demonstrates the increasing trend towards implanting children in South Africa. This reflects the worldwide trend of the increase in children as opposed to adults receiving a cochlear implant.



There is a paucity of research in the area of expectations of parents whose children use cochlear implants. Parents' evaluations and observations about their child's cochlear implant will provide an indication of their level of commitment and support. It is of vital importance to know about the realisation of parental expectations over time and their levels of satisfaction with the device. Kelsay and Tyler (1996) devised an open-ended questionnaire where parents were asked to list advantages and disadvantages associated with their child's cochlear implant use pre- and post-implant use. In order to ensure continued commitment by the parents, they need to be satisfied

with performance outcomes. Cunningham (1990) obtained information by means of a closed-ended questionnaire regarding satisfaction of parents of children who had been implanted with the 3M/House device (see footnote 2). Both studies obtained similar results regarding satisfaction with performance outcomes in terms of awareness and discrimination of sound, and speech perception and production. In neither study did parents discuss changes in behaviour and psychological well-being of the child as a result of implantation. Furthermore, the effects of performance outcomes on the parental expectations over time were not investigated.

Cunningham (1990) emphasised that parents were in a unique position to comment on real-life performance of their children, and that they should be seen as a valuable resource to improve our understanding of cochlear implants in children. Their evaluations and observations are valuable in assessing overall benefit of the cochlear implant, as well as finding out whether clinical results can be generalised to performance in everyday settings. Furthermore, parents' evaluations and observations indicate whether they will continue to provide the necessary support for the effective use of the implant. It takes time and effort on the part of parents to ensure that the device is used consistently and serviced, as well as to attend rehabilitative programs on a regular basis. It is essential that parents' motivation and interest is sustained in the long term. Their evaluations of the implant and their child's performance and progress are closely linked with their levels of satisfaction with the device. If pre-implant expectations were appropriate, parents are more likely to be satisfied with results, and therefore continue to be committed to the process of rehabilitation.

“The sense of success or failure is largely determined by goals, aspirations, and expectations” (Lewin, Dembo, Festinger, & Sears, 1944, in Kampfe et al., 1993: 298). It is therefore important that the expectations parents have from a cochlear implant are realistic. If parents experience a sense of success after implantation of the device, they will be more likely to maintain the

(Footnote 2: The 3M/House device is one of the earliest cochlear implant systems. It employs a single channel of stimulation (i.e. one electrode usually placed outside the cochlear -usually on the round window). Only the grosser aspects of the speech signal are conveyed by this type of device - spectral and temporal information).

schedule of (re)habilitation required for optimal progress of their child, as this feeling of success will provide positive reinforcement for ongoing use. Audiologists therefore need to have an in-depth understanding of these goals, aspirations and expectations parents have for their child, not only prior to implantation, but also over the long term.

To the best of the author's knowledge, no studies have been conducted examining to what extent parental expectations have been met for children implanted with multiple channel cochlear implants. In order to ensure continued commitment from parents, it is necessary to know whether pre-implant expectations were appropriate, and whether they are being met over time. This knowledge would provide indications as to satisfaction levels of parents with the cochlear implant, and therefore insight into likely levels of parental involvement and support of their child. Without these, the performance outcomes of the child will be jeopardised. Furthermore, increased pressure will be put on the cochlear implant programme as greater demands will be made for more frequent monitoring of the child's progress as well as maintenance of the device.

Professionals working with implanted children need to know about expectations and satisfaction of parents, as well as the factors which may contribute to the type of expectations parents may experience. It may be necessary to tailor counselling to meet these needs, and to adapt the type and extent of counselling to meet changing needs of parents over time. Commitment from parents needs to be consistent over the long term, as the children are reliant on their parents for long-term success. Professionals therefore need to ensure that parents do not lose interest. Parental enthusiasm and involvement are such a vital factor in the overall progress of the child, that appropriate management of their expectations, hopes and concerns should not, and must not, be overlooked.

In order to promote the continued success of cochlear implantation in children, it is therefore considered necessary to obtain insight into parental expectations and satisfaction both prior to and after implantation. The purpose of this research is therefore to investigate these issues in order to obtain a deeper understanding of the factors influential in parental commitment to and involvement with the implantation of their child. Counselling plays a crucial role in continued success of cochlear implants, and without this knowledge it would not be possible to address

these issues adequately.

The specific aims of this study are to examine the pre- and post-implant expectations and satisfaction of mothers with regard to the process of cochlear implantation in their child, as well as to investigate whether expectations and satisfaction change over time.

In order to obtain the information required for the purpose of this research, a qualitative methodology was employed. The use of in-depth interviews was chosen as the means by which the researcher would obtain information from respondents. It was felt that in order to achieve the richness and depth of information required, the use of questionnaires and a quantitative methodology (such as employed in other studies examining satisfaction issues) would not provide the type of information sought.

The methodology adopted in this research is rare in this field of study. To the best of the author's knowledge, no previous research in this particular area using this particular methodology has been conducted. Although several studies have proposed the inclusion of subjective information related to implant benefit, such as the use of questionnaires (Giles et al., 1997; Tyler, 1994), none have used a qualitative methodology using in-depth interviews as a means of obtaining information. The specific use of this methodology is supported by the need for the inclusion of subjective information as a means of examining implant benefit.

Zwolan et al. (1996) stressed the importance of using subjective methods (such as questionnaires) to obtain information about benefit and satisfaction. Several studies have used close-ended questionnaires to evaluate benefit and satisfaction in adults (Spitzer et al., 1992; Knutson et al., 1991; Cunningham & Stoeckert, 1992). However, although the use of close-ended questionnaires as a means of obtaining information regarding satisfaction is useful, they are limited in that the questions and issues raised are determined by the researcher. Tyler (1994) suggested that the use of open-ended questionnaires allows individuals to describe the issues that are important to them, as opposed to close-ended questionnaires which contain a pre-defined and hence a limited set of issues. Furthermore, close-ended questionnaires generally consist of specific response categories provided for obtaining information about specific issues suggested by the clinician, with little

option for obtaining more detailed information about the identified and other issues which may be important to the respondent. However, the response categories employed even in open-ended questionnaires are, to a certain extent, determined by the researcher. The extent of responses are also limited to the type of questions asked. Therefore, even the use of open-ended questionnaires (as used by Tyler, 1994), does not provide the depth and breadth of data that can be obtained about these issues by means of a qualitative methodology using in-depth interviews. Far richer information could be obtained by allowing respondents to shape their responses and feelings about issues that are important to them. These may or may not be issues which have been raised on questionnaires.

In-depth information is more readily obtainable by using qualitative research methods. This is often the most suitable approach when the aim of the research is to obtain detailed and insightful information about what people think (i.e. their attitudes and expectations) of particular events or issues (Skinner & Van Der Walt, 1997). The use of in-depth interviews about the subject to be probed provides the respondent with the opportunity to provide personal and detailed responses. The researcher approaches the interview with a list of points to be covered in the interview. These points provide direction, but should not inhibit other points if they appear important during the course of the interview. The points to be covered are not necessarily presented in a set sequence, and each point can be the beginning of a series of probing questions. The less structure, the greater the level of spontaneity allowed (Skinner & Van Der Walt, 1997). Furthermore, the use of a qualitative type of methodology enables the researcher to obtain information regarding responses to events over time. Therefore, this type of methodology would be particularly useful as a means of obtaining information about expectations over time.

Since the purpose of this research is to examine expectations of parents of young children, informants selected for this study were mothers of prelingually deafened children who had not yet started formal schooling. By restricting the age range of children, the central focus of this study centred around expectations related to communication issues rather than expectations related to schooling and educational issues. It was also felt that the needs of parents of younger and older children would differ, and it was therefore decided to limit the age of the informants' children. Furthermore, since the trend is towards implanting younger children (children under

the age of two are now considered for implantation (Lenarz, 1998)), it was felt that it would be more relevant to direct the focus of this study to a younger age group.

Numerous clinical and theoretical implications emerged from this study. Interesting and relevant clinical implications emerged in terms of changing counselling needs over time in relation to both expectations from the cochlear implant, as well as parental responses to the deafness of their child. Indications are that the variation in the type and extent of counselling required over time by parents would be of great therapeutic significance in terms of reducing parental anxiety associated with specific unrealised performance outcomes.

“While science requires objective measures of the efficacy of a therapeutic procedure, phenomenological (that is, experiential) evidence is often ignored. Since recipients of treatment are exclusively concerned with how it will alter or improve their lives, their perception of therapeutic effects cannot be excluded from the pool of data used in the final assessment of the worth of a technological development”.
(Wexler, Berliner, Miller & Crary, 1982: 59)

2. METHODOLOGY

This section presents the aims, methodological design, informant selection criteria, and description of subjects used in this study. In addition, the data collection procedures are described.

2.1 AIMS

1. To examine the pre- and post-implant expectations of mothers whose children have received a cochlear implant.
2. To determine whether their expectations change over time - i.e. with duration of implant use.
3. To determine whether mothers are satisfied with the outcomes of the cochlear implant.

2.2 RESEARCH DESIGN

In this study a qualitative descriptive research design was employed.

Qualitative research methods enable the researcher to study selected issues in detail and depth. Use of these methods increases the understanding of the situations and cases studied. Predetermined categories of definition and analysis of issues (as in quantitative methods, such as the use of closed-set questionnaires) constrain the researcher in terms of the depth, openness and detail of enquiry (Patton, 1990). Since qualitative research is performed within the context of the respondent's life, it can produce results which directly represent what the person feels. Since the results obtained are descriptions of real situations rather than statistical measures, the results obtained are often more relevant, meaningful and accessible (A. Levett, personal communication, July 31, 1998; Marshall & Rossman, 1995; Miles & Huberman, 1994; Skinner & Van Der Walt, 1997). Furthermore, since the overall aim of this study is to explore respondents' deeper understandings of lived experiences within their own particular frames of reference, the method used to obtain the necessary information enabled the researcher to gain access to the respondent's views and experiences, as expressed in their own words (Minichiello, Aroni, Timewell, & Alexander, 1990; Patton, 1990). This method of obtaining this information

needs to have flexibility in its design and method of obtaining information. Design flexibility is a crucial feature of qualitative research methods, and the specific design used in this study meets this requirement (Marshall & Rossman, 1995; Miles & Huberman, 1994).

Furthermore, since it is assumed that the nature of expectations over time is a dynamic process, characterised by changes according to duration of implant use and performance over time, the use of a qualitative research methodology is uniquely positioned to evaluate these changes (Levett, 1998). Miles & Huberman (1994: 1) state that “with qualitative data one can preserve chronological flow, see precisely which events led to which consequences, and derive fruitful explanations”.

Multiple cases were employed as part of the research design of this study. Miles and Huberman (1994) state that multiple cases (as opposed to single case studies) add validity and stability to findings. Furthermore, by using multiple cases one is able to identify trends and highlight differences across cases (Marshall & Rossman, 1995; Patton, 1990). This research design facilitates the use of the constant comparative method of analysis of data, where the information obtained is compared across cases and interviews (Glaser & Strauss, 1967, in Mason, 1996).

2.3 INFORMANTS

2.3.1 Sample size

Eight mothers were selected according to the selection criteria used for their children. This smaller sample size was selected due to the method of data analysis and the scope of the study.

In qualitative research, there are no rules for sample size (Minichiello et al., 1990; Patton, 1990). Qualitative enquiry typically focuses in-depth on relatively small sample sizes which have been purposefully selected (Miles & Huberman, 1994; Patton, 1990). “Sample size depends on what you want to know, the purpose of the inquiry, what’s at stake, what will be useful, what will have credibility, and what can be done with available time and resources” (Patton, 1990: 184). When the aim of the study is to seek an open range of experiences, it is more appropriate to use a

smaller sample size (Miles & Huberman, 1994). Since statistical inferences were not to be made from the data, a particular sample size was not required (Abramson, 1990).

2.3.2 Informant selection criteria

*** Informant:**

The person interviewed was restricted to the mother of the child. Hadadian and Rose (1991) found that the majority of deaf children in their study had more contact with their mothers (62%) than with their fathers (27%). These authors found that fathers' and mothers' attitudes towards their children's deafness did not differ significantly, but questioned the generalisability of their findings due to their small sample size. As has been previously discussed, attitudes towards deafness have an important influence on expectations. It was therefore decided to restrict interviews to the mothers.

Furthermore, in all the cases used, the mothers spent considerably more time with the implantees than did the fathers. It is felt that they possibly had a better understanding of their abilities than did the fathers.

Mothers were selected according to the selection criteria applied to their children. These were as follows:

*** Prelingually Deafened Children:**

All informants were required to be mothers of prelingually deafened (i.e. before the age of 2 years (Boothroyd, 1993)) children. Postlingually deafened children progress faster and obtain open-set speech recognition faster than prelingually deafened children. Furthermore, speech and language skills are already established in postlingually deafened children. Because of these major differences in performance skills within these two groups, it was decided to examine issues of expectations of mothers of prelingually deafened children only in order to address more uniform categories of performance.

*** Educational Level of Child:**

All informants were required to be mothers of children who had not yet begun formal schooling. Since expectations about levels of performance change over time (i.e. once a child enters school the focus of expectations will change to scholastic performance), it was decided to limit this study to children who had not yet started formal schooling. Parental expectations of this group of children are more likely to be focused on auditory awareness, and speech and language development.

*** Home Language:**

All informants were required to use English as their home language. Due to the nature of the study and the interview design employed, it was particularly important that the interviewees and the interviewer used the same language (Joubert & Katzenellenbogen, 1997).

*** Duration of Cochlear Implant Use:**

All children were required to have used the implant for a minimum of 3 months. This was to ensure that mothers would have had sufficient experience with the cochlear implant. None of the children had used the implants for more than two years since they were required to not have begun formal schooling.

2.3.3 Informant consent

Consent was obtained from all mothers who were interviewed. Prior to the interview, they were provided with a written explanation of the nature and purpose of the research, and what was required of them. Explanation about the purpose of the research was kept deliberately vague so as to avoid any bias or preconceptions (Minichiello et al., 1990). It was explained to respondents that they had been asked to take part in the study so as to obtain information regarding their views and experiences in order to carry out the research. Permission to video record the interview was obtained in writing. They were informed that the interviews were to be entirely private and confidential, and that their names would not be linked to anything that they may say. Furthermore, they would be free to discontinue the interview should they wish to do so, and in so doing their child's treatment and care within the cochlear implant programme would not be

prejudiced.

In addition to informant consent, written consent was also obtained from the following people:

1. The Chief Medical Superintendent of Tygerberg Hospital - that the interviews be conducted on the premises and with the patients who are managed by the Cochlear Implant Programme.
2. The heads of the departments under which the Cochlear Implant Programme falls (Speech Pathology and Audiology Department, and the Ear, Nose and Throat Department).
3. The head of the Cochlear Implant Programme.

2.3.4 Description of informants' children

All subjects were obtained from the University of Stellenbosch - Tygerberg Hospital Cochlear Implant Programme, Cape Town. This is one of three implant centres in South Africa - the other two are at Pretoria University and the University of the Witwatersrand, Johannesburg. Only one centre will be used for data collection due to the scope of the study, and so as to ensure a standard approach of one programme. The Nucleus 22 and 24 system cochlear implants are used at this centre. This unit has been operational since 1986, and up to May 1999 (130) patients have been implanted. Of these (42) are adults and (88) are children.

The biographical information of the children of the mothers interviewed is displayed in Table 2.1 below.

Table 2.1 Biographical characteristics of children.

subject	Sex	etiology	age at onset of profound deafness	age at diagnosis profound deafness	age fitted with hearing aids	age at implant connection	duration of deafness prior to connection	duration of implant experience
1	F	viral	15 mths	18 mths	1 yr 7 mths	3 yrs 1 mth	1 yr 10 mths	1 yr
2	F	congenital / ear infection	< 1 yr	15 mths	18 mths	3 yrs	2 yrs	1 yr
3	F	viral / chronic OM	< 2 yrs	2 yrs 6 mths	2 yrs 10 mths	5 yrs	4 yrs	3 mths
4	M	rhesus	birth	11 mths	11 mths	4 yrs 4 mths	4 yrs 4 mths	1 yr
5	F	rubella	birth	3 wks	1 mth	3 yrs 2 mths	3 yrs 2 mths	2 yrs
6	M	unknown	birth	2 yrs	2 yrs 2 mths	3 yrs 7 mths	3 yrs 7 mths	5 mths
7	F	unknown	birth	3 mths	6 mths	4 yrs 6 mths	4 yrs 6 mths	18 mths
8	M	genetic	birth	18 mths	19 mths	3 yrs 3 mths	3 yrs 3 mths	3 mths

Mothers of eight prelingually deafened children participated in this study. Age at cochlear implant connection ranged from 3 years to 5 years, and averaged 3 years 8 months. Duration of experience ranged from 3 months to two years, and averaged 11 months. Children who had used the implant for longer than two years had entered formal schooling, and were therefore not included. Children were selected with particular ranges of implant experience (i.e. 3 months, 6 months, one year, 18 months and two years) so that insight could be obtained into responses of mothers at that time, as well as over different periods of time. In addition, a child with a multiple handicap was included, as it was felt that the information obtained from this mother would add an interesting dimension to the findings. The nature of the research design allowed

for the inclusion of this unusual case.

Biographical characteristics are presented in Table 2.1, which provides a list of subjects' sex, etiology, age at onset of profound deafness, age of diagnosis of deafness, age fitted with hearing aids, age at cochlear implant connection, duration of deafness prior to connection, and duration of cochlear implant experience. Two of the children had been implanted with CI-22 systems (numbers 5 and 7), and the rest of the children had CI-24 systems. The stimulus mode used by the CI-22 children was BP+1, and the CI-24 children MP1+2. All subjects used the SPEAK coding strategy. Full electrode insertions had been obtained in all the children, and there were no surgical or mapping complications. All the children lived at home - six were local patients and attended the Carel du Toit Centre, Tygerberg Hospital. The Carel du Toit Centre consists of a parent guidance, nursery and pre-school programme which follows an oral approach to communication. Two of the children commuted to the programme on a regular basis (every three months). Of these two children, one attended a satellite branch of the Carel du Toit programme, and the other was at home. All children used oral communication at home and at school. One child (4) had cerebral palsy, the other children had no additional handicaps.

2.4 PILOT STUDY

A pilot study was undertaken for the following purposes:

1. In order to ensure appropriateness of the methodology, i.e. a qualitative method of enquiry using in-depth interviewing as the method of data collection.
2. To refine the style of interviewing so as to facilitate a free flow of information.
3. To confirm that the themes raised in the interview guide were appropriate.
4. To estimate the time required for each interview.

The pilot study was conducted with two post-graduate Masters Speech Pathology students, and two mothers of implanted school-going children (i.e. who did not fit the subject selection criteria). The one child was postlingually deafened attending a mainstream school and the other children were prelingually deafened twins attending a local oral school for the Deaf.

Based on the pilot study interviews, the researcher was made more aware of the following issues:

1. Interview style

- * To keep vocabulary and language simple.
- * To avoid the use of dichotomous questions.
- * To make questions deliberately vague.
- * To maintain an open-ended style of questioning (avoid question-answer format). This was particularly noticeable with the students, and perhaps this problem arose because of their limited knowledge of the “lived” experience of being a mother of an implanted child.
- * To be aware of not interrupting respondents.
- * To avoid use of the specific word “expectations” so as to avoid bias or preconceived answers. Instead, questions were to be phrased “is that what you thought would happen?”, or “could you tell me about how things turned out compared with how you thought it would be?.”

2. Interview themes

- * The interview process began with a more open-ended question about the entire process so that the subjects would be able to generate their own themes. This was in line with A. Hogan’s (personal communication, July 14, 1998) suggestion. The interview guide would then be used to cover themes not covered by the respondent but identified by the researcher.
- * It was decided to exclude certain questions (such as performance and expectations thereof in structured versus unstructured settings) as it was felt mothers would not have sufficient experience and knowledge of these issues.

3. This methodology was considered to be extremely valuable in obtaining information which would not have been able to be accessed via a standardised type of questionnaire. This was particularly so for the two mothers interviewed.

4. The duration of the interviews for the students were 20-30 minutes, and for the mothers 45

minutes to one hour. It was felt that the duration of interviews for the mothers were more representative as they had “lived” the experience.

2.5 DATA COLLECTION

2.5.1 Underlying principles

2.5.1.1 In-depth semi-structured interview as means of data collection

A semi-structured in-depth interview using an interview guide was used as the method of obtaining data from respondents.

An in-depth interviewing approach allows the researcher to gain a deeper understanding of the informant’s perspectives and thoughts on their experiences and situations as expressed in their own words (Minichiello et al., 1990; Patton, 1990). It is a useful way of obtaining large amounts of data quickly (Marshall & Rossman, 1995).

Predesigned, structured instruments may not include important phenomena as experienced by the respondent, and the risk is therefore that these may be overlooked (Breakwell, 1995; Miles & Huberman, 1994). A structured interview approach entails a list of standardised questions which are carefully ordered and worded in a detailed interview schedule (Minichiello et al., 1990). The disadvantage of this is that the themes are identified by the researcher, thereby relying on his/her perspectives and biases.

Unstructured interviews (also referred to as an informal conversational interview) (Patton, 1990) rely entirely on spontaneous generation of questions within the context of a conversation. This type of approach generates much superfluous information which comprises the power and efficiency of analysis (Miles & Huberman, 1994).

The use of a semi-structured or focussed interview, where an interview guide is used, provides a more valid description of the respondent’s perceptions than would a structured interview

approach. An interview guide within the context of a semi-structured interview allows for themes which are pertinent to the research questions to be discussed, as well as any other issues deemed to be pertinent to the respondent (Breakwell, 1995). The topic guide therefore guides which questions are to be asked, but no particular sequence of questioning is adhered to (Minichiello et al., 1990). The guide thus provides a framework to ensure that areas identified in the literature and from clinical experience of the researcher are covered, but flexibility is maintained where respondents are free to discuss any other pertinent issues (A. Hogan, personal communication, July 14, 1998; Patton, 1990). A topic guide is used only to the extent to which it prompts the researcher to recall key issues to be investigated, and that all relevant topics are included in the interview. It should not be used in the form of a questionnaire. Reliance on fixed questions may result in the researcher not listening to the content of responses analytically, and this may result in implications of what has been discussed being overlooked (Millward, 1995). The wording and sequence of questions are adapted to specific respondents within the context of each interview.

This method of data collection ensures that sufficient information is obtained as pertaining to the research questions and any other issues relevant to respondents. It is also an efficient method in terms of time, accessibility, and cost to both researcher and participants. These are important factors to consider in terms of meeting criteria against which a qualitative research strategy would be judged (Marshall & Rossman, 1995).

2.5.1.2 Principles of interviewing techniques

The researcher followed guidelines suggested by A. Hogan (personal communication, July 14, 1998), Patton (1990), and Minichiello et al. (1990) for the purpose of obtaining valid, unbiased responses during interviews. When conducting qualitative research, it is important that questions are open-ended, clear, singular and neutral. The researcher aimed at responding in a non-judgemental, empathetic way with an attitude of positive regard.

Interviewing techniques employed included probing for

1. clarification (e.g. “what you are saying now is important and I want to make sure I am understanding exactly what you are saying...”),

2. elaboration (e.g. “I think I’m beginning to understand...”)

Both verbal and non-verbal probes were utilised.

Transition statements were used, after discussion around particular themes had been completed, in order to maintain conversational flow (e.g. “We have been discussing x, now I would like to discuss y”).

Silences and pauses were used to let the person know that more information was required on a certain topic, or to allow the person to regain composure when necessary (Patton, 1990).

A. Hogan (personal communication, July, 14, 1998) stated that the key to good interviewing is the skilful use of pause or silence.

Topics to be explored were introduced in a general conversational manner (A.Hogan, personal communication, July 14, 1998). This method of probing was used so as to avoid any possible bias, and to encourage respondents to express ideas spontaneously in their own words (Oppenheim, 1992).

The types of questions included opinion, experiential, feeling, knowledge, and background questions (Patton, 1990). Questions were set within a time frame when specific themes were discussed - past, present and then future. This method provided useful information about how perceptions and expectations changed with time.

Issues that arose that needed further management or specific attention were written down and attended to outside of the interview context. This enabled the researcher to address certain ethical considerations in that the respondent stood to gain from the interview (Marshall & Rossman, 1995; Patton, 1990).

It was decided to only use one interviewer for all the interviews. Patton (1990) suggests that it is up to the researcher to decide on this - using more than one interviewer can either increase or reduce the reliability and validity of the data. The risk is that different interviewers have different

interviewing skills and techniques, have different relationships with respondents, and have different levels of knowledge and insight. The researcher has a relationship with all respondents, has clinical experience and knowledge of the programme, and is experienced in counselling. Marshall and Rossman (1995) suggest that of paramount importance in qualitative research are interpersonal skills and the relationship the interviewer has with the participant. It was therefore decided to maintain a standard approach to all the interviews.

2.5.2 Materials

As mentioned previously, the method of data collection used in this study was in-depth interviewing. This is a method extensively used in qualitative research methods for collecting data (Marshall & Rossman, 1995; Minichiello et al., 1990). An interview guide was prepared in advance where themes from the literature and clinical experience of the researcher were identified. Specific questions around these themes were generated in order to provide some structure to the interview. However, these questions were merely to serve as a prompt to ensure that all relevant issues as identified were included in the interview. They were not followed in a fixed order, and the wording of questions was changed as deemed necessary for each respondent. Therefore, a number of core themes of focus questions were identified, and these were followed up with exploratory questions depending on respondents' responses (A. Hogan, personal communication, July 14, 1998). The interviews all began with an open-ended question relating to the mothers' general impressions of the cochlear implant.

All interviews were conducted by the researcher.

Core themes identified were:

1. Discussion of general progress and expectations in the broader sense.
2. Switch - on (connection) period.
3. Expectations of family and friends.
4. Expectations for specific areas of performance (e.g. perception of everyday sounds, speech perception, speech development, language development, reliance on lipreading, ability to hear and recognise music).

5. Behaviour of their child.
6. Relationship with their child.
7. Terminology and technical aspects.
8. Time commitments.
9. Future expectations.

(See Appendix A for interview guide).

2.5.3 Setting

All interviews were conducted in the Speech and Hearing Clinic, Tygerberg Hospital. This is the location of the Cochlear Implant Programme. This setting was selected for the following reasons:

It is accessible, therefore entry of all participants was possible. The children attended this clinic on a regular basis for mapping, evaluation and counselling. The Carel du Toit Centre is within the hospital grounds, and therefore all mothers were able to conduct the interviews with minimal inconvenience. All mothers participated in interviews while their children were in school.

These characteristics of the setting fulfilled all the criteria of an ideal setting in which to conduct this type of research (Marshall & Rossman, 1995).

Interviews all took place in a quiet room, which was sound-proof and free of interruptions. Children of mothers were not present during the interviews in order to avoid distractions and interruptions.

2.5.4 Time

The length of the interviews ranged from one hour to one and a half hours.

2.5.5 Interview recording and equipment

All interviews were videotaped with a Bosch Bauer VCC 526 AF video camera recorder. It was essential that the entire interview conversation was accurately recorded so as to facilitate accurate transcriptions of the data afterwards. Furthermore, the video recording allowed for observation of non-verbal information and gestures, as well as visual cues when auditory information was poor.

The camera was set up in an unobtrusive place (in the corner of the room on a small table). After a few minutes of the interview, subjects reported afterwards that they had forgotten about the presence of a camera.

The use of recording equipment so that note-taking is not required allowed the interviewer to focus her full attention on the interviewee.

2.6 TREATMENT OF DATA

2.6.1 Transcription of data

All interviews were transcribed verbatim. This included the entire verbal and non-verbal exchange between interviewer and interviewee. This was done according to recommendations by Minichiello et al. (1990) and Patton (1990) that full transcriptions are the most desirable to obtain in terms of detailed analysis of data, and for future replications or independent analyses of data. Contextual information was included as it can influence the way in which text is listened to and interpreted.

Transcriptions were all completed by the researcher. The major advantage of this is that it familiarises the researcher with the data, so at the same time as transcribing the process of data analysis begins (Minichiello et al., 1990).

After transcribing the data, the video tape was replayed and the transcribed data checked for

errors. Each interview took on average 10 - 12 hours to transcribe, and 90 hours in total.

2.6.2 Storage of data

Fieldnotes were maintained concerning each interview contact. These fieldnotes were written on the same day as the interview, and notes were kept as to any thoughts or ideas the researcher may have had outside of the interview setting. This process has great value in contextualising the interview process, as well as documenting emergent ideas in the data. This is the first stage of data analysis, and data collection and data analysis should go hand in hand (Marshall & Rossman, 1995; Minichiello et al., 1990; Patton, 1990). Fieldnotes are reflective notes speculating about themes which may have arisen during the interview, connections between pieces of data within particular interviews or across interviews, and reflections on methodological, sampling and ethical issues (Minichiello et al., 1990).

Fieldnotes were divided into separate files as suggested by Minichiello et al. (1990):

1. Transcript file - this included the transcription of the interview (the raw data), with comments in the margins by the researcher which were made during the transcription process, and a covering page. Information on the covering page included all information relevant to the study (e.g. biographical data, number and date of interview, and length of interview). This information was obtained prior to the interview from the clinical files of the subjects. All information was confirmed with the mothers prior to interviews.

The transcript file was typed, with the text centred towards the middle of the page with wide margins for comments on interviewing techniques and ideas about responses. Initials were used to identify the speaker, and lines were numbered to facilitate data analysis.

2. Personal log - this included an account of personal impressions of the informants, methodological notes about processes and interviewing techniques used, and analytical notes as to initial questions used and whether they needed to be revised in future interviews. Ethical issues were also addressed in the personal logs kept. This log enabled the discovery and

development of new ideas, as well as facilitating the process of data analysis and theory building (Minichiello et al., 1990).

3. Analytical log - this included noting issues that arose during the interview process that were not included in the interview guide. Maintaining a record of these assisted in guiding future interviews and reviewing previous ideas. A log was also maintained as to appropriacy of themes identified and particular questions asked in the interview guide. For example, questions related to specific performance issues and expectations thereof needed to be modified according to duration of implant use (e.g. speech development issues were different for 3 months versus 2 years post-implant children). Questions asked were therefore developed, refined and reformulated over the course of data collection (Minichiello et al., 1990). Identification of new themes or concepts were also recorded in the analytical logs. By doing so flexibility of research design is achieved (Lincoln & Guba, 1985).

This process of maintaining fieldnotes enables the researcher to organise and reflect on information obtained over the course of data collection (Minichiello et al., 1990).

2.6.3 Analysis of data

The aim of content analysis is to create order out of the mass of raw data obtained, to reduce the data to manageable proportions (Breakwell, 1995), and to find meaning in the information collected (Minichiello et al., 1990).

The data was analysed within the context of the research questions, but additional information obtained during the interviews was included in the analysis. Breakwell (1995) suggests that the research questions should act as a prism through which the data is viewed.

The data was analysed inductively, based on the data processing method of the constant comparative method proposed by Glaser and Strauss (1967, in Lincoln & Guba, 1985). Inductive analysis can be defined as “making sense of field data” where the theory grows out of the raw data (Lincoln & Guba, 1985: 202). This inductive search for categories, themes and patterns was

guided by the research questions identified at the beginning of the study.

The method of data analysis which was followed was based on procedures suggested by a variety of authors. These procedures will now be described below.

2.6.3.1 Organisation of and familiarity with the data

During the process of data collection, initial analysis of the data was performed where logs were maintained (as discussed previously in 2.6.2). Comments were recorded in the margins of the transcripts regarding concepts or incidents emerging in the data collection phase (Ely, 1991; Patton, 1990). By doing this emerging data was tested for completeness (Lincoln & Guba, 1985), so that in subsequent interviews possible modifications could be made based on findings of previous interviews. For example, in an initial interview the difficulty of resolving issues related to acceptance of deafness emerged as a theme, and this was then introduced into the interview guide as an area to be explored. This method allowed for testing the divergence of data where “fleshing out” of initial categories occurred (Guba, 1978, in Patton, 1990). The following criteria were applied during this process:

- * extension (building on known information and filling in the gaps);
- * bridging (making connections between known information, clearing up anomalies and conflicts);
- * surfacing (proposing new information that appears to fit and then verifying it).

The data was organised according to suggestions by Patton (1990) and Minichiello et al. (1990). Three copies of the original transcript were made, and the original maintained for safekeeping. The copies were used for cutting and pasting in the process of sorting the data (Minichiello et al., 1990). Emerging categories were sorted into separate files.

Minichiello et al. (1990) suggest that the process of intensive data analysis should not begin until the author is completely familiar with the data. This involves reading and re-reading the notes several times.

2.6.3.2 Initial data classification

Ely (1991) proposes that the first step prior to creating categories from the raw data is to establish the smallest chunk of narrative that can be called “meaning units”. Strauss and Corbin (1990) refer to the first part of the data classification process as “open coding” where phenomena are named and coded.

A provisional “start list” of codes was created prior to commencing with data classification. This list was devised based on the conceptual framework, topic guide and list of research questions (Miles & Huberman, 1994). This facilitated prevention of data overload. During ongoing analysis this initial list was modified and added to as found necessary.

Sentences were analysed in order to identify concepts (words which are grouped together to indicate particular ideas) (Minichiello et al., 1990). Sentences are the most useful to focus on in this initial classification as they are the most fundamental, generative and valuable unit of analysis (Ely, 1991; Lincoln & Guba, 1985; Minichiello et al., 1990; Strauss & Corbin, 1990).

The data was carefully read through and examined on a sentence by sentence basis in order to identify phenomena. Strauss and Corbin (1990) refer to phenomena as discrete ideas, incidents or events. Phenomena are identified by asking the question “what is this data referring to?” (Strauss & Corbin, 1990:100). These phenomena were given names or labels. During this initial classification process, incidents were compared with incidents, so that similar phenomena were given similar names. These names were generally descriptive labels which explained what the unit or phenomena was about. These initial names were written in the margins on the original transcript (Patton, 1990). The concepts or labels were grouped according to those that seemed to fit together, and given a label that was suitable for the entire group of concepts. Those that did not fit together were separated. Links were searched for between these phenomena, and they were compared and contrasted. When appropriate, labels were changed and moved. Subsequent transcripts were analysed applying phenomena / labels previously identified. Where indicated new labels were given, and previous transcripts re-analysed in terms of these new phenomena (Ely, 1991).

This first step in content analysis is therefore where the various kinds of data are labelled and a data index is established (Patton, 1990). Strauss and Corbin (1990:62) refer to this process as “fracturing the data”.

2.6.3.3 Generation of categories and themes

Once particular phenomena had been identified, those that appeared to belong together or relate to the same content were grouped together in categories. Those that did not appear to fit together were assigned separate categories. This was done in order to organise the data and reduce the number of units (Ely, 1991; Strauss & Corbin, 1990). The names assigned to these categories were more abstract than those given to concepts, but sufficiently clear to remind the researcher of the essence of the concepts to which they referred (Lincoln & Guba, 1985; Strauss & Corbin, 1990). In this way relevant segments of the data which related to particular themes were grouped together (Minichiello et al., 1990). Minichiello et al. (1990) and Miles and Huberman (1994) suggest that codes should be related to the research question and fit into a conceptual scheme.

Categories were developed in terms of their properties and dimensions. Strauss and Corbin (1990) suggest that these characteristics form the basis for creating relationships between categories and sub-categories. The types of categories were developed according to suggestions outlined by Bogdan and Biklen (1982, in Minichiello et al., 1990: 296):

1. Setting or content codes (pertaining to general information on the setting, topic or subjects).
2. Definitions of situation codes (how informants define the setting or particular topic).
3. Perspectives held by informants codes (how they think about their situation).
4. Process codes (activity over time, and perceived change occurring in a sequence or stages).
5. Events codes (specific events).
6. Strategies codes (ways people accomplish things).
7. Relationship and social structure codes (regular pattern of behaviour and relationships).

Once the coding categories had been identified, a letter was assigned to each category contained on the list (Minichiello et al., 1990). These letters were written in the margins of the transcripts

(opposite margins from phenomena labels) to represent phenomena identified.

Categories were then examined for convergence, as suggested by Lincoln and Guba (1985).

Categories were examined and judged by two criteria:

1. Internal homogeneity - the extent to which data grouped in distinct categories are similar or hold together.
2. External heterogeneity - the extent to which differences in categories are distinct.

The set of categories was then examined for possible relationships among categories by working back and forth between the data and classification system. This allows the researcher to verify the meaningfulness and accuracy of placement of data within certain categories (Patton, 1990), and to review categories for possible overlap or dual contents (a particular piece of data was coded in two or more separate categories (Ely, 1991; Lincoln & Guba, 1985). Minichiello et al. (1990: 298) refer to this as “double coding” - where the “same data set can be classified under different code categories”.

The categories generated were then examined in terms of their completeness (Lincoln & Guba, 1985):

1. Filling in - adding new codes as new insights and ways of looking at the data emerged.
2. Extension - ensuring that codes previously assigned to particular categories were appropriately coded.
3. Bridging - making connections between different codes.
4. Surfacing - identifying new categories and verifying their existence.

When all of the incidents could be readily classified, the categories were assumed to be saturated. They were then prioritised in terms of factors such as their salience, credibility and uniqueness (Patton, 1990).

Minichiello et al. (1990) suggest that categories should be organised into files and sub-files. Each category was assigned to separate category sheets, and data relevant to that particular category

was cut from a copy of the original transcript and pasted on the category sheet. Where relevant the same sets of data were allocated to different category sheets (hence the need for several copies of the original transcript). Each set of data which was cut from the copy contained the following information: the identification label for each informant, the coding category, and the page and line number from where it was obtained.

Themes were developed out of the sets of categories which had been identified. Themes can be considered to be statements of meaning that run through all or most of the pertinent data. Their impact is primarily emotive and factual (Ely, 1991).

2.6.4 Procedures adopted to enhance credibility and trustworthiness of research

The following criteria, as adopted from Patton (1990), were used in order to ensure credibility and trustworthiness of the design and analysis procedures.

1. Rigorous techniques and methods for the collection and analysis of data.
2. Credibility of the researcher.
3. Philosophical assumptions of the research design.

These criteria are explained in more detail below:

2.6.4.1 Techniques for collection and analysis of data

Lincoln and Guba (1985) argue that the traditional constructs of internal and external validity, reliability and objectivity are inappropriate for qualitative research. They propose that more suitable constructs for establishing the trustworthiness of qualitative research are credibility, transferability, dependability and confirmability.

*** Credibility**

The use of interviews with multiple informants, the achievement of saturation of themes and

phenomena, and the acquisition of multiple responses to the same questions as identified by the researcher in the interview guide, contribute to the validity of the study (Miller & Kirk, 1986; Minichiello et al., 1990). However, Miller and Kirk (1986: 31) point out that it is not possible to control all the possible variables that may be present at the time, and that the researcher is “at the mercy of the world view of his or her subjects”.

All children met the required subject selection criteria, therefore the quality and credibility of the data was ensured.

Methods and subjects used in this study have been carefully described and contextualised. By doing so boundaries have been placed around the study (i.e. the parameters are identified). Lincoln and Guba (1985) state that in so doing the credibility, and thus the validity of the research is sufficient.

*** Transferability / generalisability**

A study of this nature is only generalisable if exactly the same set of conditions is applied to the second study as to the first, as well as the same set of population parameters and settings (Lincoln & Guba, 1985; Patton, 1990). A. Levett (personal communication, July 31, 1998) argues that no study of a qualitative nature can ever be replicated as every interchange is influenced by both participating interlocutors. Although the style and content may differ within different interactions, no one interchange is more “true” than another.

For the purposes of this study, data based on interviews with mothers was used in analysis. Their personal perspectives on their lived experiences of having a child who had received a cochlear implant was required. Marshall and Rossman (1995) state that when the purpose of the study is to uncover and describe the respondents’ perspectives, it is their subjective view that matters. Where more objective assumptions are required, triangulation of interview data with data gathered through other methods should occur. Triangulation is a strategy to enhance generalisability (Patton, 1990). This is defined as “the act of bringing more than one source of data to bear on a single point” (Marshall & Rossman, 1995: 114). However, the use of a single

method of data collection does not mean that the study is weak (Patton, 1990).

Certain techniques to enhance generalisability and trustworthiness were utilised:

- a. The sampling method used ensured a variety of information-rich cases. Multiple cases enable the strengthening of precision, validity and stability of findings (Miles & Huberman, 1994).
- b. Saturation of emergent themes and phenomena was achieved.
- c. The literature was used as supplementary validation of findings. Strauss and Corbin (1990) state that the literature can be used as a secondary data source, where findings can be confirmed or it can be explained where they differed.

*** Dependability**

Personal and analytical logs were maintained for each interview. These ensured design flexibility where questions were modified or changed over the period of data collection as indicated by responses of participants. In this way the changing conditions which arose in this research paradigm were addressed. De Poy and Gitlin (1994) refer to this method of enhancing rigour of the research as conducting an audit trail. The essence of qualitative research creates problems with replications of such studies, and thus the concept of “reliability” in terms of quantitative paradigms is not possible (Levett, 1998; Marshall & Rossman, 1995; Minichiello et al., 1990).

*** Confirmability**

This construct equates to the construct of reliability (the objectivity of the researcher) (Marshall & Rossman, 1995). Levett (1998) argues that qualitative research is by its very nature not reliable as interviewing styles, relationships with participants and analysis of data are inherently subjective. Thus the natural subjectivity of the researcher will shape the research (Marshall & Rossman, 1995).

Various strategies were instituted in order to minimise bias in interpretation. An audit of data collection and analytic strategies was implemented (in the personal and analytical logs). This

method of enhancing the rigour of the research is referred to as reflexivity (De Poy & Gitlin, 1994; Finlay, 1998), where self analysis occurs on both a personal and methodological level. This includes analysis of the researcher's interviewing techniques and style for personal biases. The researcher should ensure that leading questions are avoided and responses are objective and non-judgmental. Thorough notes were kept on each modification, as well as modifications of the interview guide and the rationale behind these decisions. All collected data was kept in a retrievable and organised form so that it could be accessed if needed.

Reliability in the context of qualitative research can be attained by thorough and careful documentation of research procedures (Miller & Kirk, 1986).

2.6.4.2 The researcher

“Because the researcher is the instrument in qualitative inquiry, a qualitative report must include information about the researcher” (Patton, 1990: 472).

*** Credibility**

The researcher has many years of clinical experience in the Tygerberg Hospital Cochlear Implant Programme as a clinical audiologist. Personal connections are that the respondents either have children who are being managed by her, or who are known to her. This could potentially have created a problem in that mothers may have felt that they were not free to be honest about any dissatisfactions they may have had. However, the interviewer stressed to them prior to the interview that their responses would not in any way interfere with their management. An open, trusting relationship was present with all respondents, and it is not felt that this personal involvement was a negative factor. The fact that they were open about difficulties they had experienced was viewed by both participants as positive in that the rationale for the interview was in order to improve services offered. The insight into the programme as well as personal experiences was felt to be beneficial.

This knowledge and professional experience was a valuable source of what Strauss and Corbin

(1990) refer to as “theoretical sensitivity”. This added to credibility and rigour of data analysis and interpretation as the researcher had an awareness of the subtleties of meanings of the data. This theoretical sensitivity was further enhanced by the extensive reading done in the literature and other publications (e.g. biographical accounts).

*** Perspectives**

The researcher has clinical and theoretical knowledge of expectations before and after implantation. The interview guide was drawn up on the basis of this knowledge. However, it was not assumed that this knowledge was complete - this was the rationale for using semi-structured interviews in order to gain knowledge about the respondents’ perspectives.

*** Intellectual rigour**

In order to establish whether the categories, explanations and interpretations of the data made sense, the researcher returned to the data over and over again by reading and re-reading the transcripts, as well as watching the video recordings repeatedly. This was done to ensure that analysis and interpretations of the data really reflected the true nature of the phenomena (Patton, 1990).

*** Philosophical assumptions of the research design**

The argument for use of a qualitative research design has been presented.

Thus, all possible attempts within the scope and nature of this study were made in order to enhance rigour, credibility and trustworthiness of this research.

3. RESULTS AND DISCUSSION

The findings which emerged out of the thematic analysis of the interviews conducted with the mothers will now be discussed. Table 3.1 below depicts the five major themes which emerged from the interviews.

Table 3.1 Themes which emerged from the interviews

RESPONSE TO DEAFNESS Coming to terms with deafness Coping with a deaf child
DECISION TO IMPLANT AND EXPECTATIONS
EXPECTATIONS RELATED TO COCHLEAR IMPLANTATION OVER TIME Pre-implant Switch-on Honeymoon Despondency Breakthrough
FUTURE EXPECTATIONS
COUNSELLING NEEDS

A brief overview of the themes which emerged will now be discussed. This will be followed by an in-depth discussion of each theme.

The **emotional responses** of the mothers to the diagnosis of the **deafness** of their children, as well as their responses over time to the deafness, emerged as an important theme. These emotional responses were intimately interlinked, and had an important influence on expectations. Many mothers revealed having had great difficulty accepting the permanence of their child's deafness, and the grief process continued long after implantation. It became apparent that over time, as emotions see-sawed during the process of adjustment to the implant and coming to terms with the time it takes for marked progress to become apparent (particularly in terms of the development of speech and communication skills), many mothers revisited their

emotional responses to the many issues related to their child's deafness. In order to work with and understand the expectations of parents, it is necessary to have insight into the possible origins and dynamics involved in the development and strength of expectations (Kampfe et al., 1993). It was found that emotional responses to deafness continued to have an impact on expectations from the cochlear implant over time. It was therefore felt that this theme was of great importance, not only in terms of expectations from the cochlear implant, but also in terms of the management of these difficult times by the clinician and other team members involved in the post-implant management of the child. The difficulty of **coping with a deaf child** was also an important component of this theme, particularly when examined post-implant. High rates of behavioural difficulties are found among hearing-impaired children which lead to an increase in parenting stress and difficulties in communicating with their children (Quittner, Thompson-Steck, & Rouiller, 1991). The lack of ability to respond to sounds in general and to the mother's voice affects the mother-child relationship (Vernon & Andrews, 1990). The trend that emerged from the interviews was that all mothers spoke of an improvement in behaviour and communication, which resulted in their children being easier to manage. This in turn resulted in an improvement in their relationship with their child.

The second major theme identified was that of the **decision to implant**. This decision arose after it became apparent that the lack of auditory responsiveness and therefore poor development of speech, meant that an alternative to hearing aids needed to be sought. During this decision-making process, expectations regarding outcomes were discussed at length. Expectations formulated were based on knowledge gained from the pre-operative counselling, and particularly from observing other implanted children in the school. An important source of knowledge and support in the decision-making process was that of the support structures provided by other mothers of implanted children. The primary motivation for the implant was that mothers did not want their children to communicate by means of sign language - all mothers wanted their children to receive a cochlear implant so that they would attain improved hearing ability and therefore be able to learn to speak.

The primary theme was that of **expectations** from the cochlear implant. It was not possible to discuss specific expectations as an overall theme as these changed and developed with the

passage of time, and at certain periods expectations became primarily driven either by hopes or by knowledge. It was found that there was a trend towards hope-based versus knowledge-based expectations at different periods after the switch-on, and that as levels of anxiety about performance increased, so did hope-based as opposed to knowledge-based expectations. These trends were separated into time periods. These time periods differed in length for different mothers, depending on satisfaction with outcomes. A model was developed by the author which demonstrates the trends which emerged in terms of these changing expectations over time. During periods of high levels of anxiety, many mothers revisited their difficulties regarding the issue of “deafness”, so that this theme re-emerged at different points after the switch-on. Ditchfield (1992) suggests that stages of grieving are not time linked - the time period depends on the way in which parents react to a current situation. Moog (1986, in Downs et al., 1986) also suggests that parents never really fully “accept” their child’s deafness, and that throughout their lives there are different stages of acceptance. This became apparent during the time period examined in this study, in that many mothers appeared to experience a process of “adaptation” to their child’s deafness, rather than an “acceptance” of it. As noted by Ditchfield (1992), feelings of sadness about having a “handicapped” child are experienced over a considerable period of time, but these feelings tend to be periodic rather than continuous, occurring mainly during periods of increased stress. This was evident in that during stressful times during the course of adjustment to the cochlear implant, mothers appeared to experience heightened emotions related to the grieving process. These emotions impacted on their expectations from the cochlear implant. It was therefore necessary to examine the theme of expectations in terms of a dynamic rather than a static concept.

Following on from this theme, was the issue of **expectations for the future**, which included speech / communication outcomes, schooling, hopes for future integration into “mainstream society”, and other fears or concerns. It was particularly interesting to note that there was a definite trend towards not wanting their children to be mainstreamed. Mothers were particularly concerned about the large class sizes, and that teachers were not sufficiently trained and would not have the time or resources to cope with having a hearing-impaired child in their class. They all hoped for either a small class within the mainstream, and if this was not possible, for placement in an oral programme school for the deaf.

The importance of examining **counselling needs** emerged. Counselling of parents of hearing-impaired children should be ongoing and sensitive to changing needs (Atkins, 1994; Downs et al., 1986; Luterman, 1987). Some mothers identified specific needs in terms of content and style of counselling. This theme examined these needs, and discussed practical suggestions made by mothers. In addition to the particular needs expressed by mothers, many implications regarding counselling arose across all the themes. These will be discussed in detail under clinical implications.

3.1 RESPONSE TO DEAFNESS

A theme which emerged strongly across all the respondents was that of the reaction to and coping with the deafness of their child. Many issues arose out of this theme, most of which are beyond the scope of this study. Although this theme was not initially identified as a separate issue to raise during the interviews, it became apparent that mothers' expectations over time were integrally related to their emotional status regarding the child's deafness. It is felt that the themes which arose out of expectations from the cochlear implant cannot be discussed without taking into consideration the responses of mothers to the issue of their child's deafness. The ability to cope effectively and constructively with a permanent disability can only begin after the family are fully aware of the irreversibility of the condition and of the full range of its effects (Vash, 1982, in Vernon & Andrews, 1990). This suggests that until the mother has come to terms with her child's deafness, hope-based expectations that the cochlear implant will provide the child with normal hearing will predominate (even though perhaps not expressed as such). The very possibility of a cochlear implant may rekindle hopes for a hearing child (Kampfe et al., 1993). These authors further suggested that audiologists need to be aware of these emotions, and also of the variables influencing the strength of unrealistic expectations. These variables should be taken into consideration on an ongoing basis during post-operative management by the cochlear implant team. Use should be made of support structures such as other mothers who have had the same experiences. All mothers reported that they had found this type of contact to be extremely beneficial in terms of facilitating more realistic expectations for future outcomes, as well as for coping with emotional difficulties during times of anxiety related to unexpected outcomes. They were able to identify with these mothers as they had all "*travelled the same path*" (M7).

3.1.1 Coming to terms with deafness

The grief reaction, based on the model developed by Kubler-Ross (1969), is a fluid process, which cannot be divided into mutually exclusive areas. Her model was based on the grief process of terminally ill patients, and included (1) denial, (2) anger, (3) bargaining, (4) depression, and (5) acceptance. However, stages of grief continue in various forms throughout the child's life (Luterman, 1987; Kampfe et al., 1993; Downs et al., 1986), so that the issue of "acceptance of a child's deafness" is perhaps in itself a fallacy - does a parent ever really "accept" it? Pray (1996) suggests that a more appropriate term to use would be "adaptation". Parents may revisit various grief stages during the rest of the child's life, and these are usually initiated by certain stresses or anxieties, such as educational decisions. Over time parents adapt to the idea of their child's deafness and adopt various coping strategies. The success of these and the type of strategies employed usually depend on the personality of the person and the presence and severity of other stressors in that person's life (Quittner et al., 1991). An examination of these other factors is beyond the scope of this study. The stages of grief experienced by the mothers will be explored during this thematic analysis, particularly in terms of finding solutions to the child's deafness where a cochlear implant is considered. This was usually considered the next option after hearing aids, and was seen as a last resort to help the child "learn to speak" and function within the mainstream of society.

Denial is one of the most important of the coping mechanisms in reaction to the diagnosis of deafness. This initial denial gives parents an opportunity to mobilize their energies and move forward. However, it must be followed by an acknowledgement of the reality of the disability and a period of mourning for constructive management of the problem to begin (Vernon & Andrews, 1990). This response emerged as a clear trend, in that the initial response to being told that their child was deaf was a strong sense of denial, and they spoke of seeking a second or third opinion.

"I didn't want to believe it. I knew there was something wrong because she wasn't responding. I thought maybe just an infection or something you know. I thought maybe the doctor would give her medicine and treatment and fine...I went and see another doctor then" (M1).

Although there was often a suspicion that something was wrong as the child was not responding to auditory stimuli as they should have, the initial response to the diagnosis was one of disbelief. The hearing problem was temporary and would be resolved with medical intervention.

"I didn't want to accept in the beginning. Not at all...And I said to (audiologist) he's not hearing-impaired, he's fine, he's just got a problem with his ear infection...and I didn't believe her" (M8).

"...I couldn't wait (for my appointment)...cos I wanted to make sure there was nothing wrong with my child that the doctors could fix" (M1).

A reaction of **shock** to the diagnosis and permanence of deafness is well-documented (Luterman, 1987). He suggests that the emotion of shock is a self-protective mechanism, much like denial. Words such as "terrible, shock, devastated, pain" were used to describe feelings on diagnosis. Although all mothers suspected deafness, the finality of the permanence of the deafness still came as a shock, together with a sense of **disbelief**.

"They told me...that she's totally deaf - I don't want to believe - it was like someone had stabbed me you know. I thought I was going to die that day because it was so tight. That pain. I've never felt such pain (crying) in all my life. I said to the man it's not true what he's telling me" (M1).

This reaction highlights the importance of not providing too much information during this first session, as shock overrides the ability to process any other information. The person who has explained the diagnosis to the mother should be empathetic, recognise the validity of her feelings and be supportive. It is important to allow parents time to grieve, and to talk about how they feel about the deafness. Parents should be allowed to express their feelings openly and without fear of being judged. If too much information is given during this time of high levels of anxiety, which limit cognitive ability, feelings of panic are likely to arise (Luterman, 1987). He suggests that this is a time for dealing with parent's questions rather than providing too much information, and that people are generally ready for information when they can formulate questions. Many parents find it beneficial for the audiologist to focus on ability rather than disability, and this approach helps them maintain a more positive and constructive attitude in the early days after diagnosis (Roush, 1994).

Another mother spoke of the sense of **devastation** and **depression** (which manifested in

physical symptoms) she experienced on being told of her son's deafness.

"So she said no, (he) is profoundly deaf. So that's when the day I couldn't wake up from the bed...I couldn't bend my knees...and my chest was like - I don't know how you get a heart attack but that's how I was. I couldn't lift myself out of the bed. So I was in hospital for a week" (M6).

The sense of denial can continue on into much later stages, such as is demonstrated by a mother who had still not accepted the finality of her daughter's deafness even after a considerable period of time.

"Sometimes when I think about it, although we got her into the school and things, it probably still didn't ... dawn on me that she's different to normal children. And I expected her to be as a normal child" (M7).

Denial continued long after her child had been fitted with hearing aids and enrolled in a programme for hearing-impaired children. These feelings returned after her child had been implanted, which demonstrates the fluidity of the grieving process. This response highlights the need for the team members to be aware of the need to counsel mothers on an ongoing basis in terms of their emotional response and stage of grieving.

Audiologists need to have insight into the various stages of the grieving process and be empathetic to mothers' needs. Understanding of the stage of grieving experienced would assist the audiologist to be better equipped to counsel mothers regarding the decision-making process of cochlear implantation. The unrealistic expectations as expressed by M7 are an important factor in examining expectations from a cochlear implant. Parents need to have adapted to their child's deafness and have accepted the reality of the situation in order to be able to have realistic expectations from the cochlear implant and their child's future abilities. Factors motivating parents to pursue the option of a cochlear implant need to be identified early in the process of evaluation, so that disappointment and anger do not occur when unrealistic expectations are not met (Kampfe et al., 1993).

Feelings of denial, shock, as well as **confusion** and **panic** are well expressed by the following mother:

"I don't want to talk about hearing aids, you just told me that terrible news. 'Oh, but your

daughter is deaf. I thought I heard wrong. Excuse me? Oh no, she's totally deaf, just like that. And I says what? Oh, I just grabbed (child) away from there - she was still lying in bed there sleeping, I just grabbed her away and run...I went to see another doctor then" (M1).

Feelings of **anger** usually emerge after the child has been diagnosed as being deaf. This anger can be directed at the clinician or doctor "...are you really a specialist...you're not fit to be on that chair"(M6), to feelings of anger towards the child or parent herself: "I was angry she couldn't hear, I was angry at myself...cos I had been in touch with rubella. You know. That sort of guilt story. I did feel guilty. I took it out on her that she couldn't hear - I got cross with her that she couldn't hear" (M5).

Anger and **guilt** are common reactions during the grieving process. Myerson (1983, in Luterman, 1987) sees guilt as being self-directed anger that the parent could have, or should have done something to prevent the deafness. Luterman (1987) suggests that guilt can result in a lack of trust in professionals and their competency. This was evident in that this mother felt anger and resentment at the audiologist and teacher involved in her child's therapy after she had received hearing aids.

"and here was this girl saying you must do this with your child, and speak to your child like this, and don't do it this way but do it this way. And I sort of got my back up. And I thought who are you to tell me how to treat - it's my child. Don't tell me what to do. I got my back up. ...and I think I was still sort of aggro about the whole thing. Upset and aggro and um all of the rest of the emotions that go with it. ...when I look back now she was in the best hands" (M5).

This reaction, although to a lesser extent, continued much later after her child had been implanted, when this mother questioned the audiologist's competency. This occurred during the first few days of programming her child's cochlear implant when her child was not responding as she had expected. It is important for audiologists and teachers to be aware of the possibility of these feelings of anger and resentment. Parents may feel they have lost control, and may subconsciously resent others for having to show them how to communicate with and teach their child. This anger can also manifest at later stages after the child has received a cochlear implant when the child's performance outcomes do not meet parental expectations (Kampfe et al., 1993). Dissatisfaction with outcomes can cause feelings of anger. Luterman (1987) stresses that this

anger should be externalised, and should be seen as a useful emotion. If turned inwards it becomes depression, and this emotion is not in the best interests of the child. Professionals involved in the management of deaf children need to be ready to deal with anger in their relationships with parents, and encourage parents to express these feelings.

Luterman (1987) suggests that many parents respond to their child's deafness with indignation that such a thing should happen to them. Feelings of guilt and bewilderment were also evident. *"why did this have to happen? ...did I do something wrong? Did me or my husband do something wrong? And God's punishing us? But why my child you know - why not me?...so small innocent child you know..."*(M1).

"You see all these kids that are all fine and talking, and you think but why us? You actually think to yourself what have we done?"(M7).

Some parents try to alleviate the pain of deafness by thinking that the deafness is not that bad. *"I'm glad she's got her sight...and she's got all her feet, her arms you know, nothing wrong with that. Right, she's got the hearing loss, but it's not as bad if you see crippled children...and then you know in a way I thank God it was just her hearing"* (M1).

Vernon and Andrews (1990) refer to this as "reaction formation". Luterman (1987) suggests that this is an ineffective strategy in that it does not allow the mother the right to grieve or feel pain. Only once grieving has occurred can a parent become effective in dealing with the habilitation process. Dealing with the deafness is most constructively faced when there is a realistic awareness that it is a loss of an important sensory modality (Vernon & Andrews, 1990). The loss of this modality has major ramifications, and will mean that parents will need to re-address their expectations and hopes for the future of their child. In doing so parents are more likely to have realistic expectations from the cochlear implant.

Kubler-Ross (1969) identified the final stage of the grief reaction as being **acceptance**. However, as Luterman (1987) points out, acceptance is not devoid of grief.

"I learn to live with it, but it's hard still to accept" (M8).

"I became used to the idea" (M5).

These comments suggest that mothers do not really ever "accept" the deafness, but rather adjust

to it.

"...but the fact is I don't really accept his deafness. I mean I'm living with it, but I don't really accept it. Because it's not something we wanted - it's just that it came.. Because I mean maybe someday out there...miracles do happen...like maybe he's just gonna hear one day, or something like that" (M6).

It would appear that this mother was still in denial as she still hoped for a miracle that would "take away this deafness". Her hope, as opposed to her knowledge, was that the implant would provide this miracle cure. Despite having knowledge about performance outcomes and having spoken to other parents and having observed implantees, she still secretly hoped for a miracle. This further stresses the importance of the audiologist having insight into responses of mothers to deafness, being empathetic to these hopes, and assisting in the development of appropriate expectations based on knowledge rather than hope. Time needs to be spent with parents counselling them as to their response to the deafness.

Even after the child has been enrolled in a special school and has been wearing hearing aids for a length of time, mothers may still have difficulty accepting their child's deafness.

"...and then she used to play and things and the children used to just stare at her, or they used to make fun of her. I used to cover up a lot for that. And that made me more determined that my child was going to be normal, or as close to normal than anything else"(M7).

Coming to terms with deafness includes recognising that the child is "different", and being able to cope with comparisons with normal hearing children and comments from strangers. Mothers experienced hurt and anger when confronted with these issues, and these feelings need to be expressed and shared. Emotional responses of mothers need attention during the management of their child, as they can stand in the way of effective habilitation and realistic expectations for their child (Kampfe et al., 1993).

There was an exception to the trend of mothers having difficulty with the issue of adjustment to their child's deafness. One mother realised that in order to be able to move on in a constructive manner she would have to put her feelings of anger behind her.

"...you learn to accept it...because if you just keep on thinking why, why, why, it's just not worth it. It's happened and you just live with it" (M8).

An exception to the overall trend of response to the diagnosis of deafness was that of the mother of the child with multiple-handicap. This child had been seriously ill for most of his life up to and after diagnosis of the deafness. Her response appeared not to be one of devastation, but rather a calm acceptance of the deafness and a systematic approach to dealing with it.

"...he just didn't respond. And suddenly you just know...that your child can't hear. And we took him...he did the brainstem, and then we tried the hearing aids and we started from there" (M4).

The severity and type of reaction to diagnosis of deafness is complex and unique to each family, and can depend in large part on previous experiences and expectations (Luterman, 1987). It is possible that in this case, the severity of her child's other problems, many of which were life-threatening, resulted in her having always had low expectations for him. Her response, rather than being one of denial, anger and indignation, was that she would do anything she could in order to alleviate the situation. The diagnosis of deafness was perhaps seen as just another challenge which she had to face. The process of beginning with habilitation was the next logical step in the sequence. In the other cases, where their children were in all other senses "normal", expectations for their children were initially high, and a diagnosis of deafness forced a sudden lowering of these expectations. This may be a reason that mothers of previously "normal" children found it so much harder to accept the diagnosis. This disparity in reactions stresses the need to approach each family on an individual basis in determining their counselling needs (Luterman, 1987).

It is important to explore parental reactions to their child's deafness in order to recognise which stage of the grieving process the mother is experiencing when discussing the option of a cochlear implant. The stage of mourning the parent is experiencing has an important influence on the parents' expectations from implantation. For example, if they are in a stage of denial, they may be seeking a miracle cure to their child's deafness (Kampfe et al., 1993). Therefore, their motives for wanting the implant for their child need to be fully explored and addressed during the pre-implant counselling stage.

It has been suggested that implantation should be delayed if parents have not come to terms with their child's deafness, and that depending on the parents' response to their child's deafness certain children should not be considered candidates for implantation (Kampfe et al., 1993).

However, such a decision based on parental grieving is controversial. It has been proven that the earlier a child is implanted the greater the performance outcome (Brackett & Zara, 1998; Fryauf-Bertschy et al., 1997; Waltzman, Cohen, Gomolin, Shapiro, Ozdamar, & Hoffman, 1994). One questions whether it is ethical to compromise the potential for success of a child when making candidacy decisions based on parental grieving. As has been seen, the grieving process can continue for years, with episodes of denial, anger, guilt, and other emotions resurfacing at various points in the child's life. Furthermore, how does one ever really know the full extent of grieving in a person? There is great variability in coping strategies, and perhaps it would be more appropriate to adapt the counselling approach and depth according to the emotions the parent is experiencing at that particular time. This should apply to both before and after implantation, so that clinicians and team members are constantly aware of the variables which could precipitate a return to a particular stage of grief. These may occur during periods of anxiety resulting from perhaps disappointment in performance outcomes, where expectations based on hopes as opposed to knowledge are not met, or when their child responds in a different way from which other children may have responded (e.g. during the switch-on process).

It is essential to not limit the clinical focus to habilitation and management of the child. Mothers have emotional responses and stresses which need to be ventilated - their emotional crises need to be stabilised in order to them to function optimally. A mother spoke of her desperate need for help in dealing with her emotional crisis:

"It was always on the child. And because we only had parent guidance once a week it was focussed totally on (her)...I was so desperate to meet other moms in my situation"(M5).

Although support groups were arranged by the social worker, she felt that they needed to be comprised of mothers of a similar language and cultural background, and who were in a similar predicament to hers. She experienced a desperate need to have an outlet and sympathetic ear to how she was feeling about the deafness.

"...so at each meeting we had they decided about how to collect funds. So nobody was talking about feelings or anything like that...so I think a support group is very important" (M5).

The provision of a support group for families is highly valuable (Luterman, 1987). They offer an excellent means of providing learning and emotional support as the family goes through the

grief process. Luterman (1994) states that there is no greater gift that a professional can give to parents than support groups. They are the one place where parents feel they can be understood and where their experiences can be shared by each telling their own stories. The needs and benefits of sharing feelings in an empathetic environment are important in enhancing the ability to cope constructively with a deaf child (Vernon & Andrews, 1990). They suggest that groups be made up of parents with a little as well as a lot of experience in deafness. Support groups should not only be provided after the child has been diagnosed as being deaf, but also after the child has received a cochlear implant. Over and above the sharing of emotional responses, they are invaluable as a means of gaining knowledge about longer-term performance outcomes. This would also assist parents in having reinforced and expanded knowledge and understanding in terms of expectations from the cochlear implant.

3.1.2 Coping with a deaf child

Parenting stress is greater for parents of profoundly deaf children as a result of high rates of behavioural difficulties, such as being impulsive, easily distracted, and non-responsive to auditory stimuli (Quittner et al., 1991). There are frequently problems with discipline, accomplishing daily routines and communicating with their child.

A trend which emerged for all the mothers interviewed in terms of dealing with the deafness was that of the impact of the deafness on their child's behaviour. They all felt that the difficulty they had in communicating with their child had a negative impact on their relationship with their child. The lack of responsiveness to their mother's voice and other auditory stimuli can also have a detrimental effect on the mother-child relationship (Vernon & Andrews, 1990). Parents need help in dealing with the behaviour of their children. Mothers reported strong feelings of frustration and anger, and spoke of the enormous difficulties they experienced in communicating with their child and dealing with difficult behaviours. Most mothers described their children as being wild, biting, fighting, screaming, having severe tantrums, very very naughty, frustrated, tense, strained, crying, frightened, and aggressive.

"...he couldn't let us know what he wanted...And I think the more frustrated he got the more frustrated we got. And you actually lose your patience so much more...it was like a

rollercoaster” (M8).

Mothers were often torn between being firm with their child, and yet feeling sorry for them because they were unable to express what it was they wanted. In this way the disciplining of their children became ineffective, leading to a sense of not being able to cope with their behaviour and lack of communication. This was a great source of stress to the mothers.

“She used to scream a lot. I don’t know if it was frustration, um, like often I wouldn’t be able to understand her...the two of us used to fight terribly...because I was frustrated...I used to come here to school in the mornings and cry by (the teacher)...I said to (her) I can’t manage this anymore...because I didn’t know how to handle it” (M7).

Lack of communication was also an important detrimental factor in the relationship between the mother and her child.

“when your child couldn’t hear anything you couldn’t - it didn’t really feel like you’ve got a child that you can talk to...it seemed so abnormal...you try and you’d do visual things and that. But it’s not the same. But I used to often think - oh, I’d love to talk to her” (M2).

“...before there wasn’t much communication. It was a lot of small talk and actions” (M3).

This frustration at the lack of ability to communicate effectively with their child and thus develop a close, satisfying relationship was an important factor in the decision to choose the option of a cochlear implant for their child. A trend that was evident was that mothers wanted their children to hear their voice, and they wanted to hear their children say “mommy”. These comments indicate the desperate need mothers felt for a closer relationship with their children.

This lack of communication and its impact on the mother-child bonding process can manifest from very early in the cases of an early diagnosis of deafness.

“I used to watch the other moms in the clinics. The babies used to watch their mother’s eyes when they were feeding. (My baby) always watched my lips from the word go. And ja, it was very upsetting cos the moms in the clinics would be talking and coochicoo over their babies. And I just went into an absolute lapse of silence...and the more they said to me here at the school “talk to your baby, it’s important”, the more I thought why should I talk to her, she can’t hear me. So I never spoke to her, or very, very little”.

This mother had previously spoken of her sense of anger at herself and her child for being deaf,

and this anger seemed to manifest in **depression**. This mother became incapable of talking to and bonding with her child as a result of these feelings.

An enormous strain is introduced into the relationship between a mother and her newly diagnosed deaf child (Luterman, 1987), and a very early diagnosis of deafness is highly likely to negatively affect the parent-infant bonding process. Stokes and Sinason (1992) suggest that having a baby who is damaged in some way usually evokes a reaction of rejection. There has been an increasing emphasis placed on the importance and possibility of diagnosis of deafness in neonates with the advent of otoacoustic emissions (Johnson, Maxon, White, & Vohr, 1993). An important issue to consider with this development is just how important is it audilogically to make such an early diagnosis (i.e. 3 weeks, or even as a neonate, as opposed to 3 months). A mother with a newly-born child has usually been through a period of emotional turmoil, and she should be allowed to enjoy her baby for a certain period of time. The first few months of carefree parent-child affection should not be lightly sacrificed (Luterman, 1987), and professionals should not impose their anxieties on the family. A slightly later diagnosis would allow a normal bonding process to take place, and perhaps alleviate the shock and pain of diagnosis as parents may have within themselves become suspicious about a hearing problem. However, Luterman (1987) stresses that diagnosis should preferably rapidly follow any parental concern about hearing status.

M5, whose child was diagnosed as being profoundly deaf at the age of three weeks, felt the early diagnosis had had a negative effect on her attitude towards her child.

“If we’d found out maybe a little bit later I think I would have been far more natural with her. I would have spoken more to her. I probably would have been totally normal just like everybody else. There wouldn’t have been that strain. It would have been easier on me if we hadn’t found out so early” (M5).

The intensive habilitation process can also have a detrimental effect on mother-child relationships. The time commitments required from parents after implantation is usually greater than for when their child used hearing aids. Cochlear implants increase rather than decrease the amount of time required for aural habilitation (Kampfe et al., 1993). In a study of parents of

children with Downs Syndrome it was found that mothers assumed the teacher role far more often than did the fathers (Stoneman, Brody, & Abbott, 1983, in Bailey, Blasco, & Simeonsson, 1992). Luterman (1987) found that in families with deaf children the child-rearing responsibility of the mother is increased. This requirement of mothers can affect the parental roles as well as the mother-child bonding process. This occurrence is expressed by the following mother:

"...she used Daddy as her playmate and couldn't wait for Daddy to come home - he would hold her and love her and play. And I was more - we must get working" (M3).

"and here we were not doing all the normal things a mother does with her baby" (M5).

It is important to recognise the importance of this bonding process, and not to expect too much from mothers in terms of formal carryover of language-learning activities from schools. Many mothers find this difficult as they feel that they are not "teachers", and it does not come naturally to them. However, mothers are natural teachers to their children (McConkey, 1985), and we should not lose sight of this. We need to recognise their need to be primarily a "mother" to their child, and not have too high expectations in terms of carryover and homework activities at home. In particular, working with a profoundly deaf child can be very frustrating, since progress is so slow.

"And I couldn't imagine working harder with her because it was...onto the unpleasant. Cos I was getting nowhere, and one day she'd be happy, and progress and imitate, and the next day she wouldn't. And it felt as if yesterday wasn't even there" (M1).

Luterman (1987) suggests that as the child shows progress, the parents' relationship with the child improves as their self esteem increases. Parents need to see results of their efforts. When expectations about performance outcomes are met parents have a greater ability to give affection. Mothers initially have certain expectations after fitting their children with hearing aids. When these expectations or hopes are not met, they may delay making decisions regarding future outcomes (i.e. sign language or a cochlear implant) as they continue to perhaps deny the reality of the lack of progress.

"...we still had hope she would benefit from the hearing aids..we just sort of procrastinated all the time, we just sort of waited for progress and waited for progress. And there was basically nothing happening" (M7).

Furthermore, when progress is so slow or not apparent, mothers may become disillusioned with the course of management for their child, and their expectations of outcomes drop.

"I always thought she will never hear my voice" (M1).

"I mean I wasn't sure if he would ever say a word. When you have a deaf child you think they're never going to say anything" (M4).

It was generally at this about stage that the option of a cochlear implant became a reality.

3.2 DECISION TO IMPLANT AND EXPECTATIONS

The principal selection criteria employed for children to be considered candidates for cochlear implantation is that no benefit has been obtained from prolonged hearing aid use over several months. Typical aided behavioural thresholds are in excess of 60dBHL bilaterally (O'Donoghue, 1996). A lack of progress with hearing aids was evident for all the children, and referrals for cochlear implantation resulted from this lack of progress.

"...because she wasn't progressing they suggested a cochlear implant" (M2).

A distinct trend that emerged in terms of motivation for seeking a cochlear implant and expectations from it was that mothers felt there was no alternative if they wished for their children to learn to speak. None of the mothers were in favour of the sign language option, and felt that if their child wished to learn sign language and become part of the Deaf culture, they could do so in the future. By providing them with the opportunity of obtaining improved hearing skills by means of a cochlear implant, they would be provided with the opportunity of being part of mainstream society in that they would be able to learn to speak. The primary motivation was that they wanted their children to talk.

"So then I had to put in my mind a cochlear implant because I want the best for my child...I had no choice...if she had to carry on with the hearing aids, the strongest that they could have been, and the frustration wouldn't have stopped. And she would have learned sign language then. And it's not what I wanted...I don't want that - I want her to hear my voice. I want her to say "mommy"...I mean I want her to talk" (M1).

When it becomes apparent that hearing aids are not providing enough auditory information for

the development of speech skills, a choice needs to be made in terms of the mode of communication which the child will follow - signing or speech.

"...we'd heard of the cochlear - we thought if you've got two choices then rather let her speak you know...we thought okay, we've got no choice" (M5).

During this early stage of developing expectations from the cochlear implant, it is important that parents are exposed to a variety of outcomes in other implanted children. In this way their knowledge about the range of possible outcomes would be ensured. Although parents may foster secret hopes that their child may be different (Kampfe et al., 1993), if their knowledge is based on repeated observations of outcomes, meetings with other parents of children with short and longer-term durations of implant use, and repeated confirmation from the team members about realistic expectations, knowledge-based expectations will be strengthened and will be more likely to predominate. Furthermore, it is important that during this pre-implant assessment stage the audiologist should attempt to establish the stage of grieving which the parent may be experiencing. Counselling should be directed towards resolving possible unstable emotional states, and addressing the possibility of denial of the deafness. Parents in denial may have expectations that the cochlear implant will restore their child's hearing (Kampfe et al., 1993).

An exception to the above trend was in the case of M4. It was important that her child just benefit more from a cochlear implant than from hearing aids. Her expectations were therefore lower than those of the other mothers. She was not sure of exactly how much more the implant would provide, but as long as it was more than the hearing aids she would be satisfied. She felt that an implant was the only alternative.

"He could hear banging and that...we knew it wasn't enough. So I knew we had done what we could with the hearing aids...it was the only other way for him to get hearing. So even if he never spoke we had to give him that chance...and you can hope that he will start talking...when you have a child that has anything wrong with it, you will do whatever you can to make it just a little better...you just worry about the next step, and you know that he's already 4, and that is the next step...I had to give him that chance you know" (M4).

Another trend that emerged was that hearing aids would have been the first option in the minds

of all mothers, and they would have preferred these to a cochlear implant.

" [we] weren't really all that keen on the implant. We always just hoped and prayed that she would do all right with hearing aids. That she would be able to talk with the hearing aids...so [the audiologist] said the only alternative really is a cochlear implant " (M2).

A few mothers spoke of fears about the higher technological level of the cochlear implant, and felt that they may have some difficulty managing to deal with this on a day-to-day basis. They felt that hearing aids were easier to work with and maintain. This issue of fears and concerns about various aspects of cochlear implantation was evident in levels of uncertainty about their decision. Various issues seemed to be a source of concern to different mothers, and in most cases the decision was not an easy one.

"...we were undecided...it was such a big thing and such a big decision.....we hope that (she) doesn't have to have the implant...but it was just because you're afraid of the unknown " (M2).

Many mothers spoke of their fears of the surgery, and some in fact procrastinated and delayed the decision on the basis of these fears.

Other fears included the child falling and damaging the implant, cosmetic concerns of the child wearing an external device with cables, and fears that the implant was a foreign device in the head and could malfunction causing brain damage, and that failure could mean that further surgery may be required. There were also fears that it would not work with their child, despite evidence of success in other children.

"Would it really work as it did for the other children...some of them were much younger when they were implanted. So they had a shorter period without language and stimulation...and I thought she's going to take so much longer...it didn't happen then (with hearing aids), so what chances are there it's going to happen with the implant?" (M7).

One mother was afraid that her child would not accept the device.

"My biggest fear was that she wouldn't ever wear it. Because she wouldn't wear hearing aids" (M5).

Other fears expressed were that the child would lose the remaining hearing in the implanted ear, and uncertainty about whether they should wait for further improvements in technology. This

issue of fears continued after implantation, and will be discussed further under the themes of “expectations from the cochlear implant” and “future expectations”.

Early implantation (<5 years) and shorter duration of deafness result in faster progress and better performance outcomes for prelingually deafened children (Fryauf-Bertschy et al., 1997; Waltzman et al., 1994). Some mothers expressed anger and disappointment that their child had not been referred earlier when it became evident that there was poor progress with the hearing aids.

“But then how come I wasn’t told about the cochlear - my child isn’t talking” (M3).

“...we should have been advised earlier...I just feel that my child has lost out so much because she could have been done a lot earlier” (M2).

It is essential that early referrals occur as soon as it becomes evident that the child is not deriving meaningful benefit from hearing aids. Professionals involved in working with deaf children should therefore be educated regarding cochlear implants and when they should consider referring.

A general trend which emerged from the interviews was that one of the most important factors in the decision to provide their child with a cochlear implant was seeing the success of it in other children and speaking to their parents.

“And then eventually uh, we started speaking to the parents of these children, and what it did for them...I couldn’t believe what we saw then you know. Their progress and the fact that they could hear so well. And um, then we sort of started watching their progress...slowly but surely it seemed more real and more promising. And then it was a question of how are we going to raise the money. We were then ready - we’d worked through all our anxieties and apprehensions about it” (M7).

By seeing outcomes of implantation in other children, mothers felt that they had been provided with “proof” of the potential outcomes.

“You’ve got to see other children. Because if you were to go by what doctors say you don’t know because you’re listening to them, and yes, maybe they’re right, but you haven’t got any evidence” (M4).

In addition to providing information about outcomes, parents are an important source of emotional support.

"...talking to people...it really helped. It really did help. Talking to parents that have been through the whole thing" (M7).

Some mothers described the decision to proceed as being influenced by the following:

"Rather have it done and know that it didn't work, than never have it done and say you should have...we were between the devil and the deep blue sea" (M7).

"...if your child is deaf and you could help your child and make life better for your child, you just want to do the best for your child. You're going to do it anyway - it's the natural instinct of the parent" (M8).

It would appear from the general trends which emerged at this time that mothers had certain expectations from implant performance, and these expectations were primarily based on their knowledge obtained from counselling, observation of performance in other implanted children, and speaking to other parents. Most mothers expressed many fears, but ultimately their desire for the expected outcomes of implantation outweighed these fears.

It is therefore important when advising and counselling parents prior to their child being implanted, that any fears and concerns are addressed by the team members. Parents need to be encouraged to develop their own questions prior to implantation. The type of questions asked by parents may also provide useful insight into the extent of their knowledge, and the level of realistic expectations. Furthermore, contact with other parents and the opportunity to observe and meet other implanted children with a variety of performance outcomes is vital in addressing issues of expectations of progress and success, as well as potential difficulties associated with the process of obtaining and using a cochlear implant.

3.3 EXPECTATIONS RELATED TO COCHLEAR IMPLANTATION OVER TIME

When asked about expectations from the cochlear implant, a trend that emerged was that the mothers spoke about their expectations with reference to outcomes, and found difficulty discussing expectations in isolation. It became apparent that various performance outcomes resulted in mothers becoming aware of different aspects of the child's development and progress over time. Most of their pre-implant expectations had been focussed on whether their child would be able to hear and would learn to speak. With the passage of time, new issues and challenges emerged. For example, a trend emerged where unexpected responses to the switch-on (such as rejection of the new sound by the child) resulted in many mothers becoming anxious about whether they had made the correct decision. A variety of new fears and concerns emerged at this time, and for some mothers this resulted in a return to various grieving stages related to adaptation to the permanence of their child's hearing loss.

Another difficult time was what has been labelled a "despondency" period, where outcomes related to the development of speech were slower than anticipated. During these times, the trend was that mothers became more anxious, which resulted in the re-emergence of expectations based on hopes as opposed to knowledge. Mothers often had difficulty in coping with these new issues and challenges in terms of their original expectations. This may have occurred as many of these issues had not really been considered and thoroughly understood. As will be elaborated on at a later stage, issues such as knowledge, hopes, stage of the grieving process, level of satisfaction and emotional states are some important variables that affect the ability to cope with these new challenges. The audiologist needs to be aware of these variables so that the management of mothers is sensitive to changing needs and is also relevant to individual needs.

The following model (Figure 3.1) was developed by the author to depict the trends which emerged of the changes and variability of knowledge-based and hope-based expectations, and the influence which anxiety and satisfaction levels had on these types of expectations. These variables are considered in relation to outcomes of performance over time. This graph is based purely on qualitative findings from interviews, and does not attempt to quantify levels of expectations or outcomes.

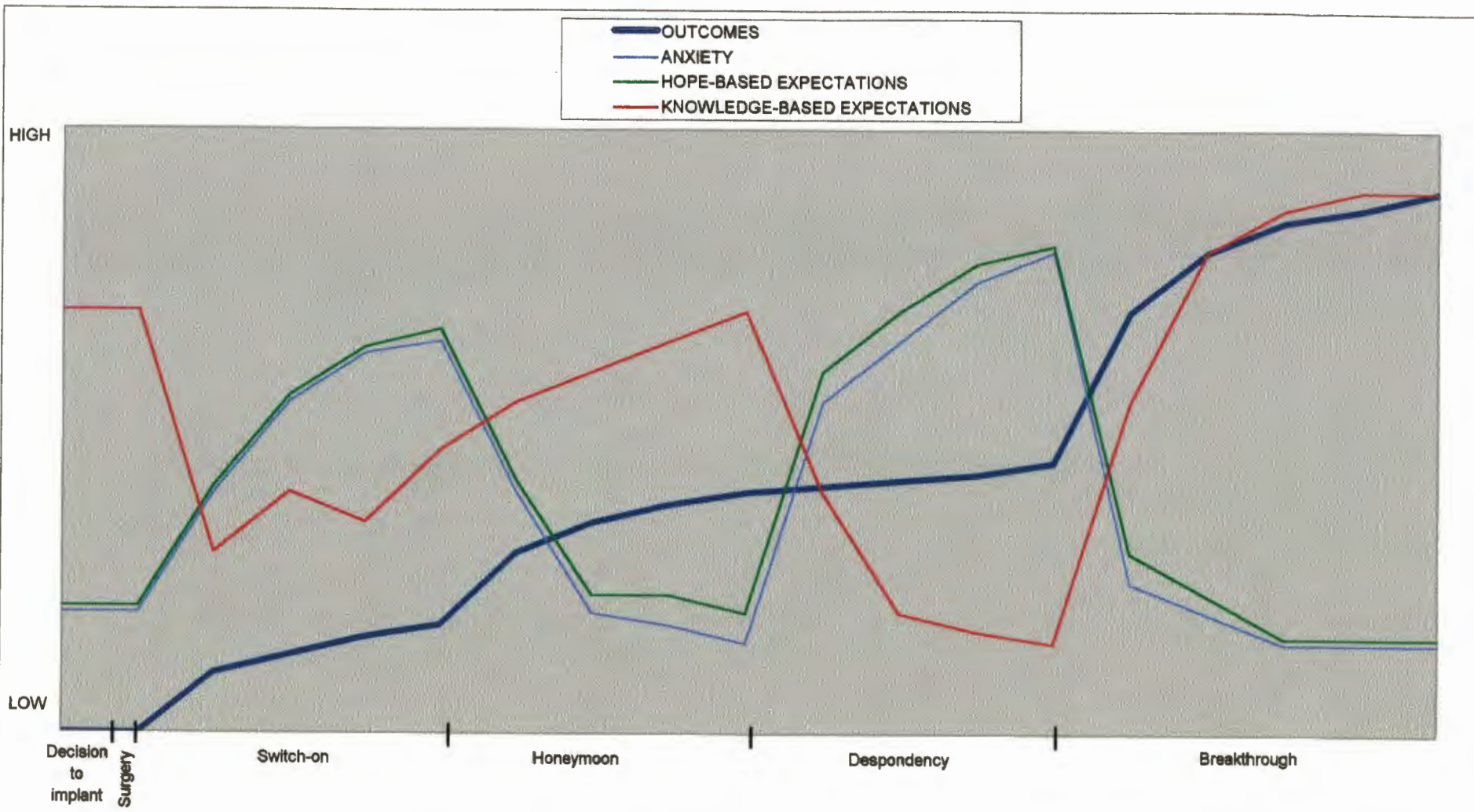


Figure 3.1 Changes in expectations over time based on hope or knowledge in relation to performance outcomes

An important pattern of divergent expectations which emerged was that as anxiety levels rose, so did hope-based as opposed to knowledge-based expectations. Hope-based expectations were those expectations based on mothers' more hidden wishes for performance outcomes. These hope-based expectations were generally emotionally driven. An example of a hope-based expectation was that the child would be switched-on and would hear normally, and that the development of speech would occur soon thereafter. Knowledge-based expectations were those which were as a result of counselling from the cochlear implant team members, speaking to mothers of implanted children, and from observing other children who used cochlear implants. During periods of anxiety, where outcomes were not as expected or as hoped for, these hope-based expectations superseded knowledge-based expectations. The extent of hope-based expectations seemed to depend on the mothers stage of grieving. The less they had adjusted to the loss (i.e. the greater the denial), the more hope-based expectations predominated over knowledge-based expectations. As a result of this trend, it became apparent that the influence of the grieving process was an important factor to consider when providing a child with a cochlear implant, as well as when considering parental responses over time to the performance outcomes. Mothers who were still in denial about their child's loss became more anxious when expectations were not met, and this led to less reliance on their knowledge about performance outcomes. An exception to the trend was M4, who appeared to have adjusted to her child's deafness, and remained relatively unanxious about performance outcomes because her expectations remained driven primarily by knowledge.

There were two distinct periods which appeared to be driven by hope as opposed to knowledge based-expectations. These were during the "switch-on" period, and after what has been termed the "honeymoon" period, namely the "despondency" period. The terms for these periods were developed by the author. The honeymoon period occurred after the switch-on period, where the child's performance improved markedly, more in terms of listening skills. During this time, levels of anxiety dropped, satisfaction levels were high, and expectations about performance outcomes were based on knowledge. However, when speech development did not noticeably occur after a certain period of time, mothers' anxiety levels rose again - performance outcomes were not meeting their expectations based more on hope than on knowledge. Once again, hope-based expectations began to predominate, and knowledge about outcomes assumed less

importance. However, once the child began to use speech in a meaningful way (for example, saying “mommy” consistently), anxiety levels dropped sharply, satisfaction increased, and knowledge-based expectations once again came to the fore. This period has been termed a “breakthrough” period.

It can therefore be seen from the model that mothers experienced similar anxieties and trends in types of expectations at particular times, but the time scales of these phases varied, depending on performance outcomes. There are important implications which arise from these findings in terms of counselling both prior to and after implantation. The audiologist would be able to predict and understand the processes the mother may be experiencing at various times post-implantation, as well as be able to prepare her for the possibility of stressful times. The model also suggests that there are critical times where counselling assumes more importance than perhaps mappings and evaluations. Furthermore, by using this model, mothers would also be able to understand that what they are feeling at particular periods of time is a normal reaction, and that the difficult times will pass. This interpretation should assist in lowering levels of stress and anxiety. It has been seen that the greater the anxiety level, the less the ability to process information cognitively, and to allow expectations to be guided by knowledge rather than by hope. The audiologist and other team members should perhaps strive for increased reliance on knowledge-based expectations and lowering of levels of anxiety. Although responses are individual and depend on many other factors (such as personality, coming to terms with deafness, outcome potential of the particular child, and the presence of other stressors in that person’s life), referring to the trends identified may be helpful in identifying and contextualising problems when they arise. The model proposed by the author suggests that the pattern of responses of mothers over time is a normal reaction, and it is perhaps unreasonable to expect mothers to always have only knowledge-based expectations predominating. However, by using this model of the responses of other mothers, it may assist in reducing their anxiety, and thereby reducing the extent and duration of hope-based expectations.

The phases of performance outcomes and the relation of expectations of these outcomes were divided by the author into several stages. This division arose out of the mothers’ descriptions of expectations over time.

3.3.1 Pre-Implant

This theme was previously discussed in the theme of “decision to implant”. During this time parents are provided with extensive counselling by the various team members, and are in regular contact with other mothers and children. Constant access to implantees is available to mothers who have children in the school, so that they are able to observe performance outcomes over time. This allows for high levels of knowledge-based expectations, which predominate at this time. Emotional levels are maintained at relatively lower levels, and hopes or unrealistic expectations thereby also reduced.

At the time of surgery emotional levels increase, and the focus was on fears of the surgery rather than outcomes of implant performance.

3.3.2 Switch-on

The period referred to is the time during which the electrodes are activated, and usually occurs over a period of approximately two to three weeks. A trend that became evident at this time was that together with a rapidly increased level of anxiety, emotion and excitement, came unrealistic expectations based on hope.

“I was excited. I wanted to know that my child could hear. I thought as soon as she switch on she could hear everything now - me or you - you know, that was my idea, and that she could hear perfectly afterwards” (M1).

This surge of hope-based expectations seemed to occur despite having the knowledge of possible outcomes from the switch-on. This same mother later explained that she knew and understood from previous counselling what would happen (although she did contradict herself).

“I didn't know what to expect. It was just the first day and she wasn't going to respond straight away and so we had to work with her...” (M1).

A similar pattern was evident for other mothers.

“You know with the switch-on we expected to see weird and wonderful things...and when they switch them on and they do nothing, and you think “huh, what a let down”. You know cos you're

expecting them to come up with hundreds of new things. Like "ooh mommy, I can hear" type of thing. But I mean, you've just got to take them at their own pace" (M2).

A common reaction of the child to the new auditory stimulus is more likely to be a negative than a positive reaction. While anticipating and hoping for excitement and a sudden change in auditory responsiveness, mothers were often dismayed when their child displayed a negative reaction.

"I didn't expect the shock she experienced - I didn't expect her to hit the roof. I did expect her little eyes to light up, and point to her ear or something. I didn't think she'd cry and scream. But (another implantee) did...so did (another implantee). But I think it would have been better if she had sat on my lap and I gave her a squeeze...It was not at all what I expected. But it was okay. I wasn't devastated" (M3)

This demonstrates that although this mother had the knowledge that a negative reaction could occur at the switch-on, she still did not expect it and hoped for a "joyful" response.

Although there was a certain amount of knowledge related to the expected outcome with the switch-on, it appears that, despite this knowledge, when there was an unexpected response anxiety increased. There was a high level of hope-based expectations at this time, and although mothers attempted to keep referring to their knowledge, their anxiety stood in the way of allowing it to maintain a greater influence on their feelings. There was therefore a fluctuation of the different types of expectations and of emotional levels during this time. There is usually a great deal of "hype" related to the switch-on, and media coverage of cochlear implants frequently refers to "the bionic ear". This may be an important factor in the determination of higher, more unrealistic expectations where a "miracle" response could perhaps be hoped for (Hogan, 1998; Kampfe et al., 1993). Parents need to remember that this will be the first exposure their child has had to sound, and generally will not know what to make of it. Reactions of fear and rejection of the new stimulus are common. Unlike in adults, where they have a frame of reference of sound, newly switched-on children will take a period of time to acclimatise to the new input.

A good example of how the initial dominance of knowledge-based expectations becomes superseded by hope-based expectations when outcomes are not as expected is demonstrated by

the following mother. She initially spoke of her knowledge-based expectations when asked about the switch-on period.

"...she said her child took two weeks. So I sort of realised...and every time she must be mapped or the electrodes put on, cos they weren't all switched on at once. So to me it was quite logical that she's not going to hear everything, or hear instantly...we knew that it's going to be gradual" (M2).

She then later went on to explain what she had hoped from the switch-on.

"I think that you sort of think that your child is going to show a big response on that first day, and you know that they'd sort of look and say - I mean (she) couldn't talk - but you expect like a very big response" (M2).

When the outcome of the switch-on process did not meet her hopes, her anxiety levels rose.

"...and you know like you sit there waiting, and (the audiologist's) turning, turning - and you think (intake of breath) it's not working - she's doing nothing, and like you're convinced it isn't working. You get so worked up, and you get so worried...it's not working and then you'd have to have the implant again. You'd have to go through it all over again" (M2).

Her anxiety levels rose further when her child appeared to still not be benefitting from it within the next few days, and she then lost sight of her knowledge-based expectations.

"...she became very frightened, of anything..I found it very worrying - extremely worrying...that she didn't want the implant. That it would never come right. Because I said how can a child wear an implant and it's frightening her to such a degree that she can't be normal?" (M2).

When this reaction continued over the next few days, new fears and concerns arose and her knowledge-based expectations dissipated.

"I was thinking is she ever going to get over this?...she doesn't want it on, she doesn't want to hear...I used to get so cross. I used to say "you know, we paid all this money and she doesn't want to hear...she wants to be deaf" (M2).

These feelings may indicate a level of anger and guilt about implanting her child. There is strong opposition from the Deaf community to implantation of young children, who feel that this is denying them a place within the Deaf culture (Tyler, 1993). Lane (1993, in Fryauf-Bertschy et al., 1997) argues that cochlear implants do not provide children with enough hearing to become part of the hearing world. However, Tyler (1993) goes on to say that about 90% of deaf children are born to hearing parents, and that most of these parents wish to facilitate spoken

communication with their children. When hearing aids are unable to provide sufficient auditory information for the achievement of this, cochlear implants are seen as the answer. Cohen (1995) suggests that deaf children of hearing parents only become members of the Deaf community once their parents place them in that community, or when the child voluntarily decides to enter it. Parents can only hope that they have made a correct decision in terms of the future for their child, and M2 became afraid at this time that she and her husband had not made the correct decision in providing their child with a cochlear implant.

A similar response was obtained from a mother whose child tried to crawl away from the sound. Her anxiety increased when her child responded in this manner to the new sound, and with this increased anxiety new fears arose.

"I felt distraught - because I didn't know whether he was going to accept it. We thought that that was it and that was what he was going to have to live with" (M8).

With this increased anxiety level, this mother's knowledge that this type of response could occur became overridden by new fears. At the time she interpreted this negative response as being a permanent reaction to sound by her child.

The trend was therefore that mothers went into the switch-on with knowledge-based expectations predominating.

"I wasn't expecting a response - I understood that you wouldn't say to her "(child) can you hear me?" and she'd say "yes mom I can". I knew that"(M5).

However, although this mother had felt secure in her expectations based on her knowledge, when the switch-on did not go as anticipated she also became highly anxious, and fears arose.

"...the switch-on day was horrific. Everything went fine electrode by electrode. And then when (audiologist) did the switch-on she screamed, pulled it off her head, she cried, she wouldn't put it back on again...I phoned (audiologist) that night...I said "I told you, we've wasted our money, she won't wear it"...we thought we'd wasted our money and our time."(M5).

She reported that she had had mixed feelings on that first day - excitement that there had been a response, but upset that the response had been so negative. She had found herself questioning the capability of the clinician *"how does she know it's going to be alright?"*. These feelings reflect high levels of anxiety. Counselling mothers prior to the switch-on needs to include the

variety of responses likely to occur and the child's likely progress after a period of time. However, it would appear that despite knowledge about the variety of possible responses, this rapid emergence of fears is an unavoidable reaction. It may help mothers to be able to ventilate these feelings with the audiologist, as well as share them with other mothers whose children have been implanted.

Thus it can be seen that when outcomes did not match hope-based expectations, some mothers found themselves faced with new challenges and fears, such as that the child would reject the implant, or that the device had not worked with their child. Hogan (1998), in a study examining expectations and the adjustment process to a cochlear implant in adults, referred to this period as the "reconciling of reality" (in press). He found that the feelings of excitement and anticipation associated with the switch-on are usually met with disappointment when the new sound is not as expected, and there is a variable period of adjustment to the quality of the sound. The same principle could be applied to parents of newly switched-on children when their expectations of outcomes are not satisfactorily met. Because of the extent of the negative reactions usually associated with the switch-on by prelingually deafened children, the sense of disappointment may be even more severe. Unmet expectations can be an added source of stress (Hogan 1998), and these increased levels of stress can lead to a dropping off of knowledge-based expectations and increase in fears and anxieties.

As can be seen from all the cases documented, none of the children responded in a positive manner to the switch-on. Generally they were afraid and rejected it. The trend was that although mothers knew that a negative reaction was likely, they still felt emotionally unprepared for a negative reaction.

"...so the only thing we were not informed of was the fact that she could get a fright and not want to wear it" (M2).

When expectations are based so strongly on hope that knowledge becomes insignificant, mothers are likely to be bitterly disappointed with the outcome of the switch-on process. They may become unrealistic about the outcomes and deny the lack of existence of what they were hoping to witness. This type of response occurred in one mother and was an exception to the general

trend which emerged.

"I just expected the switch-on and (he) will just talk...I mean I thought maybe there's a miracle out there...I was told and I saw (what was going to happen). But I said maybe there is a God out there was just going to answer me...it was just one of my secrets...I mean I knew what's going to happen, and I said no maybe something out there is just going to say ooh, (child) talk" (M6).

These comments are of great concern, as this mother, despite being informed and having the knowledge about likely outcomes, did not make use of this knowledge. Her expectations appeared to be unrealistic and based entirely on her hope-based, emotionally-driven expectations. What was interesting is that it did not appear that her anxiety levels increased when these unrealistic expectations were not met. She reported that her reaction to his unexpected response was:

"I didn't really think anything about it. Because it was just one of my secrets" (M6).

This suggests that, in certain cases, no amount of counselling about expected outcomes prior to switch-on can change a certain type of mindset. The possible implications that can be drawn from this are that this mother was still in denial about her child's hearing loss. She also appeared to be in denial regarding his lack of response according to her expectations. This case highlights the importance of the adjustment to the child's deafness as being integrally related to the issue of expectations. When asked about the outcomes of the switch-on period, this mother avoided answering in a factual manner, concentrating rather on the emotions of the great excitement experienced.

"We were all very excited at the way everything was going...It was like the dream that we had just come true"(M6).

"...everybody phones...and we say ja, (child) can hear" (M6).

It would therefore appear that her reaction to her child's response was still one of denial, and in order to obtain a more factually-based response from her would require a great deal of probing. She did finally admit that her child was not in fact hearing as well as she had hoped.

"...because when he was switched on he never used to respond to anything, and the words wouldn't come out...only the music, that's the only thing he'll hear" (M6).

Even the way in which she expressed this appeared to show a lack of insight in that she expected the words to "come out". In this case, the previously discussed issue of candidacy related to

parental expectations needs to be considered. If expectations are so unrealistic that outcomes can never match these, it is possible that parents may end up rejecting the implant (Kampfe et al., 1993). It is a difficult ethical decision to make in terms of longer-term benefit of the child and parental input. It is therefore important to spend time alone with mothers discussing issues such as these, and professional counselling may be indicated in certain cases.

The general trend which emerged during this switch-on period was therefore one in which knowledge-based expectations were initially high. However, many of the mothers appeared to foster secret hopes that their child would respond in a positive and meaningful way. When outcomes were unexpected and did not meet these secret hope-based expectations, anxiety levels rose sharply. Together with these increased anxiety levels came new fears and concerns. There was a sharp reduction of reliance on knowledge-based expectations and increase in hope-based expectations.

3.3 Honeymoon

This period usually occurred soon after the switch-on, when the child began to respond to a variety of new sounds, and often became more vocal (although not intelligible speech). There was therefore a marked improvement in performance outcomes during this period. With this improvement in performance, satisfaction increased, anxiety levels dropped and mothers became more realistic in their expectations, which were again primarily knowledge-based. Knowledge-based expectations therefore predominated over this period. It has been referred to by the author as a “honeymoon” period as it was a time of high levels of satisfaction and low anxiety. The distinct trend was that mothers were pleased with outcomes. The difference from when the child wore hearing aids to using the cochlear implant made this difference in performance more noticeable, in that the child was beginning to respond to environmental sounds, which most of them had previously not been able to do. With high levels of satisfaction with outcomes based on improved auditory responsiveness, knowledge-based expectations played an important role in that mothers relied more on these during this period. An important trend at this time was that outcomes were as expected.

“I think a couple of weeks after the implant - or a week - she ran to the phone. You know, when

she had hearing aids - she couldn't hear. She couldn't hear a thing. It was just so wonderful to be able to call her and she can turn around because she can hear you. Or if the phone rings she can look around and run and answer the phone...It was about what I expected. Cos (another implantee's mother) was saying (her child) could hear fat sizzling in the pan. I was waiting for those milestones and it happened" (M2).

As a result of the outcomes being as expected, it meant that anxiety levels were low, and there was application of knowledge-based expectations. These high levels of satisfaction were related to the ability to respond to softer environmental sounds than anticipated. This meant that sometimes expectations were exceeded.

"Her response was far more than we expected. Far better...we didn't expect her to hear sirens down on the Main road...distance...birds...we actually thought she'll never hear that. Cos I mean it's really soft...the fridge when it shudders...the kettle or oven as it warms up...frying...far more than we expected" (M5).

The ability of a child to localise and detect everyday sounds is the most immediate benefit after implantation. Where children had previously not benefitted from hearing aids for long periods, the magnitude of this difference in sound perception is extremely gratifying for parents (O'Donoghue, 1996). This relatively dramatic improvement was found to be a major factor in the general reduction in anxiety levels and the re-emergence of expectations of performance outcomes based primarily on knowledge. The memory of poor performance with hearing aids as opposed to results being obtained with the cochlear implant contributes significantly to high levels of satisfaction.

"We never imagined that he'd be able to hear as nicely as he does. Cos with hearing aids it was extremely difficult to get him to turn to his name...everything took longer with hearing aids. But with the cochlear his listening skills have got so good...it's actually taking him so much quicker...he still gets frustrated, because he still doesn't yet have the vocabulary. But it's got better than what it was" (M8).

The primary focus at this time is on outcomes related to auditory responsiveness rather than the development of speech skills, and there is reliance on knowledge-based expectations over this period.

“We were told two months for him to turn around to his name. Because every child is different. They just said to us don’t expect too much. And we didn’t. We actually had prepared ourselves to a degree where well, if he’s not doing it now, he will do it in time. Don’t rush it...our expectations were not to expect too much in the beginning” (M8).

Good performance outcomes result in knowledge-based expectations sometimes being exceeded, with the result that anxiety levels remain low as there is satisfaction with the progress being made.

“They told us it would actually take a month or two for him actually to respond to (his name). And he responded to it within two weeks. While we were here with the switch-on he started to respond...What he’s done is far greater than what we did expect” (M8).

This demonstrates the variability in performance outcomes for the different children. Performance outcomes influence anxiety levels, which in turn are influenced by expectations. It should be noted that this child had some residual hearing pre-operatively, and therefore had a greater auditory awareness than some of the other children. Zwolan, Zimmerman-Phillips, Ashbaugh, Hieber, Kileney, & Telian (1997) found that children with more pre-implant residual hearing (i.e. with some auditory experience) exhibited significantly better speech recognition skills within the first year following implantation than children with less auditory experience. This would explain why this child progressed at a faster rate than did others (e.g. responding to his name soon after switch-on).

M5 reported the most encouraging moment she had had as being:

“The first time when she came and told me the battery was flat...then we knew for sure she was hearing” (M5).

This event occurred before this child began to speak. This implies that at this time this mother was experiencing a honeymoon phase based primarily on the progress of her child’s hearing skills rather than being concerned about the beginning of speech.

The mother of the child with a multiple handicap continued to rely on knowledge-based expectations. She was highly satisfied with the way her child responded in the period after his switch-on, and again the focus of satisfaction was on the improvement in hearing skills as

opposed to the development of speech.

"... he responded fairly quickly to sound, obviously not talking and all of that...because all the children I've seen, it's taken a while...so my expectation wasn't that they would be talking cos I had actually seen that they weren't yet" (M4).

Children of two of the mothers interviewed had been switched on for 3-4 months. These mothers were still in the "honeymoon phase" when interviewed. The following mother's child had been switched on for 3 ½ months:

"Even though she's not hearing perfectly, she really did relax. And became happy...I think in the second week she said a couple of words that were nice and clear...she can hear the birds far away...she'll say "listen, birdie"...she hears a lot of high pitch - she hears that well" (M3).

The words to which this mother was referring were part of the child's limited vocabulary prior to the implant. The improvement in her child's happiness was an important factor in this mother's satisfaction with outcomes.

However, she had some feelings which were not as positive during this time.

"Also words she knew before sounded so different she just didn't get them. Like she didn't know her name at all...I was amazed that she didn't know her name - (audiologist) explained to me afterwards why - she said remember that it sounds so different. I expected her to talk soon. Yes, because she wants to talk...I am in a bit of a hurry...no, she's progressing well...I want her to say sentences more spontaneously - when I want them to be said. Not when she wants to...But it'll come." (M3).

Although she was a little concerned at the lack of spontaneous output, her expectations remained knowledge-based and she did not, at this stage, become anxious about her unfulfilled expectations. She also did not become anxious about unexpected outcomes (such as not responding to her name) and relied on previous knowledge and knowledge which she had obtained at the time. However, there was perhaps an element of hope-based expectations as she wished for faster progress in speech development. At this stage, despite this, she maintained realistic expectations in that she knew it would take time. These feelings were evident in the following:

"The little words she does say are clear. Sometimes not - she still gabbles a lot. She's talking

with gabbling, and then she says one clear perfect word. And then you know that you're on the right track with her...But that gap between understanding and speech is great...I'm not expecting too much from that. I'm very happy she understands so much -I'm amazed" (M3).

During this honeymoon period, it is possible that with good performance outcomes in terms of auditory responsiveness, mothers become so excited at these improvements that they begin to lose sight of the time period required for the development of auditory skills and understanding of language input.

"Now I can chat to her. I don't have to make sure she's listening...when we go for walks I'll just chat away, and ask her a question every now and again just to make sure she's listening to me...but it's easier - definitely easier" (M3).

Comments such as these should alert the clinician to perceptions of performance that are unrealistically high, and perhaps indicate an element of longing for more normal communication with their child. This type of comment may also suggest the re-emergence of denial about the reality and permanence of the hearing loss. It is possible that when perceptions become more reality-based, disappointment may occur. It is important that the audiologist be attuned to comments such as these, as they may signal the need for further counselling about emotional response to the hearing loss, as well as about expectations in terms of performance outcomes in terms of the time periods.

A similar pattern was evident to a much greater degree for M6, and was more of an exception to the trend seen for the other mothers. Her expectations of outcomes were unrealistic. Sometimes mothers have still not come to terms with the fact that they have a deaf child, and still hope for a "miracle" (Kampfe et al., 1993). In the case of M6, her hope versus knowledge-based expectations fluctuated during the period after the switch-on. Although she reported that she was satisfied with the way in which her child's hearing and speech skills were developing, she still hoped that her child would suddenly start talking. Her perceptions of the outcomes of her child's performance were unrealistic.

"...he's no more hearing-impaired. Because he can talk now" (M6).

However, she contradicted herself when speaking about expected outcomes, expressing both realistic and unrealistic expectations at the same time.

"maybe he's just gonna hear one day...even if he doesn't talk a lot or whatever, as long as he can hear a bit and say a few words...I've accepted that part of it" (M6).

Comments such as these indicate a possible state of emotional turmoil, where she is having great difficulty reconciling the permanence of the hearing loss.

Her reports of the outcomes of his progress were also contradictory.

"the words are really coming out - if he wants milk he says something and then I'll know it's milk. But if he wants his coffee or something he'll take it and perform a little. He'll bang on the table" (M6).

This is evident again of the turmoil which she is experiencing - her hopes are so strong that they cloud her judgement of his performance. The examples which she provided to demonstrate the appearance of words are in fact not examples of speech. Her understanding of his limitations was also poor.

"I talk to him just normally, like there's nothing wrong with him" (M6).

This statement again could be an expression of her denial of his deafness, and desire for him to be a hearing child.

The clinician would need to be aware of conflicts such as these, and prepare herself as well as the mother for the possibility of a rejection of or dissatisfaction of the implant.

It is therefore important during this honeymoon period to ensure that mothers are realistic in terms of the way their child is responding, for example *"She understood just about everything"* (M3). If these perceptions are unrealistic it is likely that disappointment will occur. When progress is not as fast as they would like to imagine, the following period, where hope-based expectations again predominate (referred to as the "despondency" period), will be one of high levels of anxiety. The clinician should provide feedback about performance noted during the clinical situation, and the teacher and speech therapist would also be able to provide important information to the mother regarding outcomes in the classroom and therapy situations. At the same time it is important to respect the mothers' perceptions and input regarding performance outcomes. The mother is the person who spends most time with the child, and sees the child in a variety of more natural settings. When there is a disparity in perceptions about outcomes, mothers may see the professional's perceptions and expectations as being too low.

"...and what frustrates me the most is often when she does things at home, and I come to school and I tell them about it and she doesn't perform...they know that she's not progressing. But I know what she's performing at home...and I felt that they thought I was telling lies" (M7).

These statements have important practical implications. It is vital that the mother's perceptions be respected and valued. Possibly a balance between perceptions needs to be sensitively sought between the mothers and the professionals. It may help to ask the mother to provide concrete examples about performance, as well as provide the mother with concrete examples, in order to ensure that her perceptions are based on fact and are not an emotional response. It has been seen that when anxiety levels are high, there is poorer assimilation of knowledge. It may be expedient to first deal with the emotions the mother may be experiencing, and to then provide counselling providing information to promote knowledge-based expectations.

As was previously discussed in the theme "coping with a deaf child", parents of deaf children frequently have difficulties with behaviour and attention problems. A trend that emerged during this time period was that with the improvement in hearing ability there was an improvement in behaviour and attention, which resulted in a reduction in mothers' stress levels.

"He listens so nicely. Which is great. I mean that's made the burden for me so much better" (M8).

This stress was also lessened due to the fact that communication had improved between them:

"He can actually understand me" (M8);

and that her child's behaviour had improved.

"I find it easier...now...I can see a difference in him. He...doesn't get so frustrated so quickly" (M8).

A trend which emerged across all the time periods was that of the usefulness of comparisons of performance with other implantees. Although the mothers had been told by teachers and clinicians' not to compare the performance of their child with others because of the great variability in outcomes, they all did so. They felt that doing so assisted with their knowledge-based expectations, and helped reduce anxiety when their child was progressing at a slower rate than they had hoped.

"I knew it would take a while. Because (another implantee) had had hers already a year I think

when I met her, so I knew that it would take a while...my expectation wasn't that they would be talking cos I had actually seen that they weren't yet" (M2).

"...I saw the other kids, how slow they were, ...it didn't really bother me after that" (M7).

By comparing outcomes with other children, mothers felt that when outcomes were similar to those of other children, they were ensured that they were "*...on the right track*" (M8).

It would appear that comparisons with other children is beneficial in terms of reducing anxiety levels. A useful method of consolidating knowledge-based expectations is observing other implantees. Parents should be exposed on an ongoing basis to a variety of performance outcomes in other children (Kampfe et al., 1993). Observing other children seems to have an important effect of reducing anxiety about slow progress, and in particular the slow onset of the development of speech. The lowering of anxiety assists parents in avoiding the situation where hope-based as opposed to knowledge-based expectations predominate.

An exception to this trend was in the case of M1. She did not seem to experience this honeymoon period as her expectations were focussed on waiting for her child to start speaking. After being disappointed in the response to her switch-on, in the time which followed she became despondent at the lack in progress in terms of imitating speech and developing spontaneous speech.

"...she was responding to sound and everything, but...you just want to hear your child talking" (M1).

She went straight into a period of despondency, where hope-based expectations predominated.

As can be seen from the model proposed, the honeymoon period therefore signals a phase where satisfaction is high and outcomes occur according to knowledge-based expectations. Hope-based expectations and anxiety levels do not increase to a significant level where they begin to cloud knowledge. During this time, the improvement in auditory awareness in comparison with previous performance with hearing aids was the focus of the mothers' source of satisfaction. An exception to the trend was that if outcomes are different from expectations (e.g. not beginning to talk), anxiety levels remain high and new fears arise. When this happens knowledge-based expectations may be disregarded.

3.3.4 Despondency

This period was characterised by a sense of despondency arising from concern that although their child was hearing, they had not started to speak. Although mothers did refer to their knowledge-based expectations during this time, they were overshadowed by increasing levels of anxiety and hope-based expectations. Thus, as can be seen in the model, for this period where outcomes appeared to plateau, there was a marked increase in anxiety as a result of hope-based expectations not being met. With these increasing anxiety levels and predominance of hope-based expectations, knowledge-based expectations played a less important role in guiding general expectations of performance outcomes. This trend was similar to the pattern seen during the switch-on period.

The development of speech production occurs hand-in-hand with the development of auditory perception. However, acquisition of meaningful, intelligible speech and language only occurs after the development of basic auditory perceptual skills. These both occur at a faster rate when the child is implanted before the age of 5 years (Brackett & Zara, 1998; Fryauf-Bertschy et al., 1997). The development of speech production is reliant on two important factors - maturation, and the fact that the child has to have attained sufficient experience using a cochlear implant (Tye-Murray, Spencer, & Gilbert-Bedia, 1995). This implies consistent use of the device. These authors suggest that the auditory information received from cochlear implants via an electrical signal begins to enhance speech production skills after an average of 34 months experience. Kiefer, Gall, Desloovere, Knecht, Mikowski and von Ilberg (1996) have reported that, after cochlear implantation, the acquisition of auditory processing skills seems to follow a pattern similar to that found in normal-hearing children, starting with sound detection and pattern perception, and then progressing over various levels of speech identification up to speech recognition. All children in their study achieved high levels of open-set speech recognition. They stressed that the time course of this pattern may take several years (Kiefer et al., 1996). However, Brackett and Zara (1998) found that, for children implanted before the age of 5 years, open-set speech perception was attained by 24 months. Nevins and Chute (1997) stress that improvement in speech production occurs at a much slower rate than speech perception. Tobey and Hasenstab (1991) found that although significant increases in speech intelligibility occur

after the first year of implantation, changes in the mean length of utterance do not occur for a considerably longer time.

All the mothers knew that the development of speech production would take a long period of time as their children had to first develop adequate speech perception skills. However, the trend which emerged during this phase was that hopes for meaningful speech became more important to them than the gradual improvement of auditory perceptual skills. They appeared to lose sight of the fact that development of adequate speech perception skills was a prerequisite for the development of speech, and that the development of perceptual skills occurs over a relatively long period of time in prelingually deafened children (Miyamoto et al., 1994).

Although mothers had knowledge about the time it takes for the normal course of development of perceptual skills, reliance on this knowledge diminished when hope-based expectations for faster progress were not met. More unrealistic expectations based on hopes tended to dominate this period. There was a trend of poor implementation of knowledge about the time course for the development of auditory perceptual skills. The following are examples of this increasing sense of despondency.

"I believe there's a difference in sound...we had to start like from the beginning again. That's why she couldn't recognise the sounds or anything...I was thinking maybe a month or two, and then she would get used to the sound because it's different sound from the hearing aids to the cochlear implant, and then that everything is going to be easy, fast...At first it was a bit hard and we thought oh - start all over again, we'll never get there. We also think when will she hear and we can't wait until the day she'll start - not hear - we know that she can hear - but repeat or start imitating the sounds and that" (M1).

"I knew exactly what the sequence of events was going to be and what the expectations were going to be from the programme and from the teachers and everything..they did tell me it would take a year for - it's sort of accumulating all the information and things, and then after the year...they should start benefitting maximally from it...it was just...but my child is going to be different...she was a go-getter from the beginning...she was determined, and I was determined. And therefore she's going to be better than what they expected" (M7).

The acquisition of speech became of overriding importance during this period, and the importance of the time and maturational factors for the acquisition of speech seemed to become inconsequential.

"Because in the beginning it was going very slowly - it does you know...in those six months you didn't see much progress... So let me say within the first six months you do feel the child's never going to start talking...in the beginning you do feel a bit despondent, you feel impatient. You just want her to start saying words. And um, it actually it does take a while, before they actually start saying words" (M2).

Mothers may feel a desperate need for the establishment of a closeness in their relationship. M1's overriding desire was:

"I actually couldn't wait until she said - I just wanted her to say "mommy"... (crying)" (M1).

When expectations were not met and anxiety increased, new fears arose.

"you just feel like you know it's going to take time and all that. But you can't actually believe that they're going to talk until they do start saying something. You know, cos you always have that fear in you that it's not going to work. She can hear, but it's not going to work - she's not going to learn to speak...You know it's worked on other children who are speaking and it does take time, but you've still got this secret little fear. My child isn't going to speak. You can't actually believe that they're going to speak, although they tell you they will speak. It's just a natural fear that. And that's why you anxiously wait for that day when they actually start saying something...so I'd say the first six months are really slow...you aren't sure yet what the child's actually going to say or do" (M2).

The acquisition of speech is viewed as "proof" that the implant has been successful. Although this mother did refer to her knowledge several times, she did not seem to be able to dispel her increasing fears.

Parental disillusionment is common after the rapid restoration of hearing after implantation because the acquisition of intelligible speech is frustratingly slow (O'Donoghue, 1996). The trend that emerged was that mothers became despondent about having to "start all over again". This raises the issue as to whether they felt emotionally drained after the build-up to the switch-on, and the excitement of the switch-on process. During the honeymoon phase, they may have

put a lot of time and energy into working with their child, and this feeling that they were working so hard and not seeing the results they hoped to see may have contributed to their feelings of despondency. Parents need to see results of their efforts and to be reinforced by their child (Luterman, 1987).

Some mothers did not seem to really understand the parallel development of auditory perception and speech production, and the fact that speech production was dependent on certain basic auditory perceptual skills.

"I thought like she's got a cochlear implant (crying) - now she can hear - now she should talk after you, you know. I thought it was like an um, someone teaching you something and then you say it straight away. And it took long - for her to start repeating and imitating and that - it actually took very long...I was worried - very worried- in the beginning. Though everybody says it takes time and that, you want to see your child talking" (M1).

These comments are of some concern as her insight into the acquisition of speech appears to be poor. She seems to be under the impression that the development of speech has the same principle as "teaching a parrot to talk" - if you say something often enough the child will be able to say it too. She also felt an inordinate pressure to work with and teach her child, and her perception was that the more she "drilled" her the faster her development would be. Her knowledge of the anticipated time it would take before the onset of meaningful speech production seemed to lose significance to her. Together with this increase in anxiety came new fears that it was perhaps her fault that her child was not progressing faster.

"We must work very hard, and I was working hard and sometimes she wasn't repeating, she wasn't imitating and I just thought no, it's not working with my child. Sometimes you feel down you know - is it your child? Is it your fault?...I used to feel guilty myself - sometimes I think maybe it's because I'm not spending enough time with her. I thought maybe if I just focus on (child), work on (child), talk with (child) all the time she will learn quicker. But it didn't happen. So at one stage I was feeling a bit down...I thought what must I do next - I thought at one stage it's my fault..." (M1).

Parents are usually told that they will need to work very hard with their children to ensure progress. All the mothers felt that they had appropriate expectations in terms of the time

commitments required. However, when providing this information about time commitments to mothers, it should be remembered that feelings of guilt can arise if not all the mothers' time is devoted to working with her child, and they may even feel that it is their fault that the progress they expect is not happening.

"I thought maybe I'm not spending enough time with her - I used to feel guilty - you know like I didn't have my afternoon free just for (child)" (M1).

It is possible that for some mothers who may feel an overriding sense of responsibility for progress, the time commitments required from them may be a contributing factor in the increasing anxiety and sense of despondency. Mothers need to feel that they can have time to themselves and for their other family commitments in addition to working with their children and stimulating their speech and language. This mother felt guilty if she did not spend every spare moment with her child. This kind of pressure is likely to lead to a further increase in anxiety. As has been seen, high levels of stress and anxiety cloud cognition, and ability to draw on knowledge. Quittner et al. (1991) found that parents of children with cochlear implants experienced high levels of stress resulting from the time commitments required, and often felt the need to get away and to have time for themselves.

The clinician and teachers need to be aware of encouraging the mother to be a mother to her child and not just a teacher. As mentioned previously, mothers are natural teachers (McConkey, 1985), and this natural mother-child relationship should be encouraged. The situation should also be avoided where the mother begins to feel guilty for slower progress. Counselling needs to be ongoing about the development of auditory skills and at which point their child is in this development.

During this stage there is therefore an increase in more unrealistic expectations based on hopes. It is not always easy for a mother to admit to these unrealistic hopes, and the skill and insight of the clinician would be an important factor in determining what the mother is truly feeling. It would be beneficial to both the mother and to the child if these hopes could be verbalised. However, mothers may not easily open up to these feelings.

"I kept it in...because no matter what they tell you, you still have your own expectations" (M7).

Expectations of family and friends are often unrealistically high. Kelsay and Tyler (1996) found that family and friends often believe that a child with a cochlear implant will be able to hear normally and understand everything. This finding was supported by the interviews with these mothers. One mother reported that these unrealistically high expectations influenced her own expectations, so that she became anxious because, as her family and friends commented, her child wasn't responding faster.

"...then they'd say "but she's not responding"...maybe that also influenced my expectations. Because they kept saying that, now why isn't she responding...they didn't realise that it would be a slow process. And they indirectly made me start doubting" (M7).

This highlights the need to involve extended family and closer friends in pre-operative counselling.

Support structures during this difficult time would be beneficial, so that other mothers who had felt the same during this period could reassure mothers experiencing anxiety and despondency about unmet expectations. This may assist in reducing anxiety. A clear trend across all time periods was the use and benefit gained from the sharing of information and emotions with the other mothers of implantees. Support structures play a very important role in assisting in reducing emotional distress (Dunst & Trivett, 1990), and could also play an important role in expanding knowledge of outcomes during different time periods. The following are some comments by various mothers about the importance of communicating with other mothers:

"We talk and learn a lot from each other" (M3).

"I got a lot from the other mothers" (M4).

"You just want to know if you're on the right track" (M8).

This period was therefore characterised by a sense of despondency arising out of the slow progress apparent in performance outcomes. These were primarily related to the slow onset of speech. At this time, expectations were primarily based on hope, so that knowledge-based expectations became far less important to mothers than their hopes. With this sense of despondency, anxiety levels increased as to whether expected outcomes would ever be met, so that the trend was that mothers began to fear that the implant may be a failure. Together with these new fears, stress levels increased in terms of required time commitments and expectations

from family and friends. Some mothers once again began to experience a sense of sadness and sometimes guilt about their child being different from other hearing children. During this difficult time, the audiologist needs to be aware of emotional states regarding deafness and the coming to terms with longer-term outcomes. Use should be made of support systems of other mothers who have passed through this period, so that much the same type of benefit can be gained as when parents supported each other over the grief process of their child's deafness.

An important insight was shared by M7 as to the effects of having unrealistic expectations and the influence of these on anxiety. She displayed good insight into her feelings at this time, and her advice to other parents with children to be implanted was:

"...don't put your expectations too high...because I will tell them this is what I did. And I was very disappointed when I set my own standards. And the child only progresses exactly as the programme says. You will only see proper results after a year, basically" (M7).

3.3.5 Breakthrough

A trend which emerged from the interviews that signalled a move out of the despondency phase into the next phase was linked to the onset of the beginning of intelligible, meaningful speech. During this phase there was a marked reduction in anxiety about performance outcomes. This reduction in anxiety paralleled a marked decrease in reliance on hope-based expectations and the re-emergence of reliance on knowledge-based expectations. Many mothers referred to this as being a turning point for them, hence the use of the term "breakthrough" to represent this period. Other factors which were seen as being important in reducing stress and anxiety levels were improvements in the behaviour of and in their relationship with their child, as well as improved communication between mother and child. Mothers no longer felt so anxious about performance outcomes, and felt re-invigorated to continue. Although emotional levels were high as a result of satisfaction, there was no apparent anxiety and stress associated with this period.

"So at one stage I was feeling a bit down. And then I relaxed a bit, and all of a sudden a week after all of a sudden boom - she started talking and saying words...and then it gave me more - not courage - it was like I had to charge the battery again and start all over again - now I must

work with my child all over again. It did work...and so it's a joy now. We can see progress now, and even my husband is so thrilled...she can say a lot of words, and special "mommy" now...now she goes "where mommy" if she doesn't know where I am (crying)" (M1).

Great excitement is usually experienced with the onset and rapid progress of speech, as well as with the improvement in pragmatic (turn-taking) and therefore communicative capabilities. These factors have a positive influence on the child's behaviour, and mothers reported finding it easier and more rewarding to work with their children. Previous feelings of anxiety about the possibility that the device was a failure, which are sometimes experienced during the despondency period, usually dissipate. The onset of speech confirms that the device has been successful, and that the decision to implant their child was the correct decision.

"...when she started - I knew it's alright. She's learning new words, and she's saying new words...but even every step. When they're on with one word then you can't really believe when they put two words together - when they say "where mommy?". It's something great...you get so excited for everything that they say - when it comes to three words you get so excited. Everything they say you have to tell a hundred people.." (M2).

Rapid changes in the quantity and quality of vocalisations begin about a year after implantation (O'Donoghue, 1996). He reported that of children implanted below the age of 5 years, at two-years post-implant about 60% of the children were using speech effectively in their everyday communication. This figure had reached 91% at the three-year stage. Furthermore, speech intelligibility continued to improve. Sometimes expectations are exceeded, and this leads to high levels of satisfaction. The mother of the child who had been implanted for the longest period of time (two years) reported that her expectations had by far been exceeded in many areas of performance.

"They told us it would take between two and five years for her to start talking. They warned us it would be a long sort of process. It's only going on two years now in October. So it started before the two years...maybe about 16 - 17 months - she's really taken off...I never realised it would be so fast...her response was far more than we expected" (M5).

During this phase there was a marked reduction in anxiety, and knowledge-based expectations

predominated. Continued improvement in performance outcomes was an important factor in the reason for lowering of anxiety. Of particular interest was that although performance outcomes sometimes did not meet hopes (e.g. good articulation, faster progress in speech output), this mismatch did not lead to anxiety. Mothers made use of their knowledge to justify these mismatches. It would appear that the fact that their child was starting to talk was so significant to them that these types of issues assumed less importance. For example, although M2 was not entirely satisfied with the intelligibility of her child's speech, this did not cause an increase in anxiety levels again, as her expectations were once again based on her knowledge. She made use of this knowledge when hopes for higher levels of performance were not met.

"...with the speech I'm just a little bit disappointed that she doesn't speak a little more fluently. That her pronunciation isn't better - that she isn't speaking more clearly...I knew that they don't speak perfectly...because I'd seen the other children...I actually know it's a slow process. It's just that sometimes you want your child to speak, and you get impatient. You have to be realistic, and that I know" (M2).

The reduction in anxiety was an important factor in terms of the mothers' emotional well-being, and the clinician should not underestimate just how difficult the despondency period may be for mothers experiencing high anxiety levels.

"...it's a good feeling now. Cos before I had like - it was tight you know (indicating stomach) - tense here. I used to feel uptight every night like even when I used to go to bed at night. I used to think every night - oh, what can I do better tomorrow to help (child)?" (M1).

A similar response was seen for M7. The onset of speech, which was intelligible not only to her but also to her family and friends, was a great relief. This breakthrough led to a reduction in anxiety and stress and more realistic expectations.

"I'm very much less stressed now, very much less stressed. Because, I suppose, it's because I'm allowing the whole process to take its course now" (M7).

Quittner et al. (1991) found that parents of children with cochlear implants often experience greater levels of stress than parents of children with hearing aids. A possible source of stressors is the increase in time, emotional and technological demands after the child has been implanted. Furthermore, a lack of progress, despite hard work by parents, can also be a stressor, as they need

to see results of their efforts (Luterman, 1987). The combination of these factors, particularly if the parent bases expectations primarily on hopes for performance outcomes, can cause a great deal of anxiety. It has been seen how high levels of anxiety can cloud judgement, and cause a reduced reliance on knowledge-based expectations. This further stresses the need for the cochlear implant team members to be constantly aware of these issues, and be alerted to high anxiety levels in mothers. Counselling therefore needs to be ongoing throughout the habilitation process.

O'Donoghue (1996) reported that in the first year following implantation, there were improvements in the children's communication skills and in their behaviour. The findings of this study confirmed this in that another trend that became evident during this breakthrough period was the reported improvement in the behaviour of the children. Mothers reported that they were calmer, less frustrated, understood speech more easily and had improved concentration. They were more "interested", and had improved communication skills. What was particularly important was that together with these improvements in behaviour, there was an improvement in the mother-child relationship. The difficulties inherent in this have been discussed previously in the theme "coping with a deaf child". Examples of this were seen for the following mothers: *"What is nice is that you can talk to her, and you can actually have a little conversation with her now. Before when your child couldn't hear anything you couldn't - it didn't really feel like you've got a child you can talk to...I used to often think "oh, I'd love to talk to her now"...now I can do it - I want to cry...and if she didn't have the implant - oh - you can't actually imagine what it would have been like!"* (M2).

"She's changing also - more calmer, she's listening now, it's starting to be more normal now for her...she understands better now so it's easier to work with her...she's listening now, she's taking turns, it's so good with her...now that she understands what you say, she understand me as well now she's not throwing so much tantrums anymore" (M1).

This trend was also evident for M5. It should be noted that this is the mother who, prior to the implant, had withdrawn from communicating with her child, had experienced guilt and anger about her deafness and felt the mother-child relationship had been poor as a result of the deafness. She now felt rewarded by her communication efforts - it was no longer a waste of time talking to her child.

“Before there wasn't much communication...now because we can talk and she can talk to me...then I was constantly talking...and I sort of felt I'm not wasting my time - she can hear...so it wasn't a hassle to talk. I'm sort of more interested in her...I feel more like a mother to her now than before” (M5).

The importance of these comments should not be underestimated in terms of the mother's emotional well-being, the long-term potential for outcomes with this improved mother-child relationship, and also in terms of the psychological adjustment of the child in the longer-term. This highlights the importance of adequate communication between a mother and her child.

The process of coming to terms with having a child with a hearing loss is usually long term. Changing expectations from the cochlear implant can be an important part of this process as hope-based expectations, which are grounded in the hope for a “normal” child, gradually become replaced by knowledge. Expectations gradually become more realistic based on likely present and future abilities of the child. The implication which can be drawn from the model proposed, is that before a mother is able to assimilate information and incorporate this information into her knowledge-based expectations, her emotions and anxieties need to be addressed. The audiologist should also make use of the invaluable support structures and network of other mothers who have had similar experiences in assisting mothers reach this point. Hope-based expectations need to be replaced by knowledge-based expectations in order for realistic expectations to be formed. This in itself is part of the process of adapting to the child's deafness, and becoming realistic about future expectations.

“And then I realised that the children are different, their hearing levels are different and they each will progress at their own rate and things. And then only...learning started taking place. Because um I sort of had to hold back with my expectations...it was difficult to hold back...and then when it really happened and I did hold back it was like...she said this...it's unexpected. Like the other day she said to me “mommy, sit properly!”. And I mean I've never taught her that word...”(M7).

This mother interpreted this process of allowing her knowledge to influence her expectations of outcomes rather than her hopes as being that she “held back” on her expectations. In other words, she may have still harboured hope-based expectations, but did not allow them to dominate her thinking.

The breakthrough phase is an important turning point for mothers from an emotional point of view, as it usually coincides with coming to terms with their child's deafness. They also become more realistic in terms of long-term expectations for their child.

"...she doesn't have to be an academic. And before I couldn't do that...the only way I got to that point was by speaking to mothers here who had reached that point already. And I know that have been there where I am now. Where I was...and it's difficult, very difficult to get there..." (M7). She said that she had initially hoped that the implant would fulfil her secret hopes for her child to be different and be "normal".

"I hoped it would until I realised that when we were in the programme and things I thought no, man, this is not it because it's not happening. It's not happening, and it's not that there's something wrong with it, but it's something wrong with me hoping" (M7).

This realisation was a great breakthrough for her, and it was from this point onwards that she found it easier to focus on knowledge-based as opposed to hope-based expectations. She also found that her support structures were more appropriate with parents of deaf children as opposed to her colleagues at work with normal-hearing children.

"And it angers me when you meet people and they talk about their children. Or like I'd go to work and I'd say...(child) said the word "properly", or she can say /k/, and they'd say "oh, nice". You know - no excitement, nothing. They can't feel it with me you know...but when I do it at school, these mothers, they know exactly what I'm talking about...it's a different world there. I can identify with them (mothers at school) ...and now I've actually come to a point where at work...or with my friends I can say well my child is going to this school...But I can say it out loudly, do you know what I'm saying?"(M7).

Part of the process of coming to terms with the deafness of her child and future expectations was being able to identify with the other mothers of children with hearing loss. It is possible that her initial refusal to identify with mothers of deaf children reflected her own denial and rejection of her child's deafness. Her sense of isolation from mothers of normal-hearing children and feelings of anger at their lack of understanding of her needs and difficulties could only be resolved once she had reached this point of breakthrough where she found it easier to identify with mothers of deaf children. This example demonstrates the dynamic nature of the grief process attached to adaptation to deafness. This process is not time-linked (Ditchfield, 1992). The cochlear implant

team members need to be sensitive to this, and counselling about the adaptation to hearing loss should not be assumed to be completed once the mother initially appears to have come to terms with her child's deafness. It is highly likely that this issue will be revisited over and over again during the longer-term future of the child. It is also likely that the implantation of a child is in itself an instigator in this revisiting of the various emotions attached to the grieving process. This example of the dynamic nature of the grief process further highlights the importance of perhaps not delaying implantation based on the parents' stage of grieving. There will be re-emergence of various stages of grief after implantation, and it is highly likely that these feelings will re-emerge at later stages in the child's life. Moog (1986, in Downs et al., 1986) suggests that acquiring or not acquiring an implant is perhaps not the crucial issue - the concern is rather how one deals with the parents in relation to whatever assistive device is provided. An important consideration is the vital importance of much greater potential for good performance outcomes when a child is implanted at an early age. The consideration of acceptance of deafness as a criterion for selection is the responsibility of the cochlear implant team, and each child and family should perhaps be considered on an individual basis.

A summary of some of the major trends that emerged from this theme of expectations over time will now be presented.

The overall trend that therefore became apparent in terms of expectations over time was that there was a fluctuation of hope-based versus knowledge-based expectations over time. This pattern is graphically depicted in the model proposed. During the **“pre-implant”** period, knowledge-based expectations predominated, despite the presence of an element of hope for various performance outcomes. Anxiety levels were relatively low - mothers were more excited at the option of an alternative means of providing their children with the opportunity to learn to talk. The **“switch-on”** period was characterised by rapidly increasing levels of anxiety, which resulted in a decreased use of knowledge and increased reliance on hope-based expectations. This trend was even more marked in cases where outcomes of the switch-on were more disparate from expectations. With increased anxieties new fears came to the fore. The next phase (the **“honeymoon”** period) was characterised by decreasing anxieties as performance outcomes -

primarily in terms of auditory responsiveness - improved. This improvement was particularly apparent to mothers as the performance was so much better than with hearing aids. Levels of satisfaction were high, and knowledge-based expectations again dominated this period. However, after a period of time, as performance outcomes appeared to level off or reach a plateau, mothers became despondent about this apparent slowing down of performance. These feelings were primarily related to the non-appearance of speech. This period was referred to as the “**despondency**” period. This sense of despondency gave rise to increasing levels of anxiety, which resulted in the increase in unrealistically high hope-based expectations. During times of high emotions, mothers tended to disregard their knowledge-based expectations. This occurrence was probably also contributed to by the fact that insight was often poor as to the importance of the development of adequate auditory skills as a precursor for the development of speech. New fears arose during this time. Some mothers began to doubt the wisdom of having implanted their child. With this rise in new fears and concerns, emotional states clouded their knowledge-based expectations. This wave of emotion, as was seen during the switch-on period, resulted in mothers losing sight of their knowledge-based expectations. It was during this time that support structures became very important - particularly those of other mothers. Observation of other children’s longer-term performance was also an important factor in reminding mothers that this type of pattern was normal. The final phase identified was that of the “**breakthrough**”, which was linked to the onset of speech. The trend was that with the onset of meaningful speech production there was a marked dropping off of anxiety, which was replaced by high levels of satisfaction. Knowledge-based expectations increased sharply, and hope-based expectations did not seem to be a particular feature of this period.

Of the mothers interviewed, three were relatively shorter term (two 3 month post switch-on and one five months post switch-on). These mothers tended to still be in the honeymoon phase, and although occasionally hope-based expectations came into play, they were generally so pleased with the outcomes that their anxiety levels remained fairly constant at lower levels. However, one of these mother’s responses (M6) were of a different nature from the others. She remained highly emotional throughout the course of use to date, and responses to questions about performance were generally not factually-based. They were more emotionally-driven, and her statements were often contradictory. This mother was the most unrealistic in terms of expectations initially, and

she had great difficulty in dealing with her child's deafness. She still hoped for a miracle, and maintained high levels of anxiety. Her expectations fluctuated continuously between being hope or knowledge-based.

An exception to the overall trend observed was the response of the mother of the multiply-handicapped child (M4). She had originally not had high expectations for him, did not become highly anxious and feel that there was no real progress - she knew that this would happen with time. In her case, expectations based on hope were not really a feature of the pattern of expectations over time. This mother did not seem to ever really go through a despondency phase, rather passing straight from the honeymoon into the breakthrough phase. She was the only mother who consistently applied her knowledge gained prior to the implant about hearing aids and the development of listening skills in terms of the normal development of auditory perceptual skills.

"...how they work with the hearing aids. How they start with sounds, discriminating, localising. And I think it's kind of the same - we do the same thing with the cochlear. I think that everyone should be pretty prepared for the process...basically you've been through the programme with the hearing aids, they haven't worked, so you have quite a knowledge already...so you're building on a knowledge from years of experience" (M4).

She also applied this knowledge to the way in which her child responded to the switch-on.

" I think everyone makes a big thing of the switch-on...it doesn't happen like that...I knew it would take a while...I mean it's the same as with hearing aids - you have to learn to listen...so it's not something that you switch on and they can hear" (M4).

Her expectations for implant outcomes seemed to remain driven primarily by her knowledge-based expectations. As time went by, she did not appear to ever experience a sense of despondency, and her anxiety levels remained low.

However, a significant factor which needs to be taken into account with this mother is that her expectations from the outset were not the same as for the other mothers.

"I don't think we've expected very much of (child) because we've had so many disappointments. So I think our expectations are probably different to other children that are running around and that kind of thing. So for me it's been amazing.... He can hear...he's saying so many words...he's

doing so well...if you call him he can actually turn around. He can hear us! And respond!...It pretty much met my expectations, in fact it's even more than I expected. I think it's amazing" (M4).

Her expectations for performance outcomes were primarily centred around improved hearing ability, and that this would probably result in the development of some speech and language skills. She felt that the implant had more than met her expectations and that her child had benefitted from it. She was therefore satisfied with performance outcomes. However, an important factor to consider was that her expectations were lower than that of all the other mothers whose children were in all other senses "normal". These lower expectations may have had to do with the fact that her child had a multiple handicap. Although this exception to the trend may suggest that expectations of this type of child may be lower, one cannot draw assumptions from one case. This mother experienced a certain amount of frustration associated with the fact that she was required to spend a lot of time on other activities and therapies associated with her child's multiple handicap. Also, because of her child's limited motoric skills, the child was not exposed to as wide a range of inputs as for normal children. She felt that this may have resulted in slower progress than her child may have been capable of.

"...we spend a lot of time doing other things with him - there's so much to do with him. That if I had a child that just had a hearing problem I think he would progress much faster cos we could put all your input into that" (M4).

Decisions regarding candidacy for cochlear implantation of multiply-handicapped children rest primarily on medical criteria, and each case needs to be determined on an individual basis according to potential benefit they may obtain from additional auditory input (Lesinski, Hartrampf, Dahm, Bertram, & Lenarz, 1995). Furthermore, consideration should be given to what the expectations of outcomes are for the parents, and what their criteria are for success. In this case, despite the limitations of this child's physical abilities, and the extra demands placed on the mother for other therapies, she was extremely satisfied with performance outcomes, and felt that his performance had exceeded her initial expectations. Lenarz (1998) suggests that the additional auditory sensory stimulation provided by a cochlear implant can have a positive influence on additional handicaps because behaviour can be more easily controlled and communication developed.

It can be seen that when expectations continue to be based on knowledge, anxiety levels remain low (as in the case of M4). However, it would appear that this is not the normal pattern of responses over time. It is natural for hope-based expectations and anxiety to fluctuate over time, particularly during more stressful periods. During these times mothers become less reliant on their knowledge-based expectations, and hope-based expectations dominate. It has been seen that these times are highly stressful for mothers. Implications that can be drawn from these findings are that the cochlear implant team members need to be aware of these fluctuating levels of anxiety, and attempt to reduce anxiety levels. This may be achieved by encouraging mothers to discuss possible fears and concerns, as well as their hopes, in an accepting and non-judgmental manner. It may also be of benefit to mothers to refer to the model proposed in this study, so that they are able to see the normal pattern of expectations and anxieties other mothers experience at various time frames. This knowledge may assist in allaying anxieties, and encouraging the re-emergence of knowledge-based expectations.

3.4 FUTURE EXPECTATIONS

It is important to know what mothers' expectations are for the future of their child. They have implications for obtaining insight into the extent of adaptation to their child's deafness, as well as to how realistic their expectations are about future performance outcomes. These include outcomes related to speech and communication skills, as well as outcomes related to schooling options.

Future expectations were primarily centred around the improvement of **speech production and listening (i.e. communication) skills**. The trend was that mothers expected that their children would develop good speech and hearing skills, and would therefore be able to function almost as normal children. The mothers of children who had been implanted for a longer period of time, were so encouraged by the rapid progress of their child's speech that they assumed this growth would continue. They expected their children to speak intelligibly so that other people would understand them easily. Mothers of children implanted for shorter periods of time expected their children to be talking more spontaneously within a year. This is encouraging in that these mothers did appear to understand the time that would be required for the development of

improved speech production.

Some mothers expressed that they expected that they would be “like normal children”. One can hope that such an expectation is not an indication of an element of ongoing denial of the reality and permanence of the child’s deafness. However, one mother did clarify what she meant by “normal”:

“...if I look at (another implantee) the other day she was practising her consonants, and the last time I heard her speak it was quite unintelligible. And when she was doing her consonant recitation she was speaking so clearly I couldn’t believe it was the same child. So I hope (child) will follow the same pattern - that in another year or so she’ll be speaking just like that. And then I’ll be happy if she can just speak like that” (M2).

This highlights again the importance of using the longer-term performance of other implantees as a source of information regarding the development of appropriate knowledge-based expectations. Mothers need to be exposed to children with a variety of longer-term outcomes, not just the more successful ones. They also need to observe older children who have been implanted for longer periods of time, for example, children who are at school. Speech perception and production outcomes may thereby be easier to understand and anticipate, and expectations for the future can be formulated based on knowledge of other children observed first-hand.

An exception to the trend was M4, who was unsure of her future expectations in terms of speech, and did not seem ready to commit herself in terms of predictions of future outcomes.

“I don’t know how well he is going to learn to speak. I mean he’s doing really nicely now and I’m really happy...you can only really go on what you hear from (child) and sort of what someone who knows tells you. But you don’t really know, so we’ll have to wait and see” (M4).

Her expectations were lower than those of the other mothers, and she continued to rely on knowledge-based expectations rather than hope-based expectations, as had been the trend for her of expectations over time.

The majority of prelingually-deafened children implanted before the age of 5 years attain high levels of open-set speech recognition, but they will generally only begin to reach this stage of speech perception after at least one to two years of use (Brackett & Zara, 1998). With the

increased access to conversational level speech, spoken language skills improve. The majority of these children develop intelligible spoken language within three years (O'Donoghue, 1998). Furthermore, the shorter the duration of deafness, the faster the rate of progress (Miyamoto, Svirsky, Kirk, Robbins, Todd, & Riley, 1997). There are very few studies done on long-term (> five years) speech production and language outcomes in implanted prelingually-deafened children. Expectations of mothers regarding outcomes related to speech production were generally formulated based on their own child's progress as they saw it, and seeing results in children who had been using the implant for a longer period of time.

Another trend in terms of future expectations was that mothers saw the implant as providing their child with the opportunity to be **integrated into mainstream society**, and allowing them to have opportunities which they would not otherwise have had. They hoped for their children to grow up to be able to function independently - they did not want their children to be "left behind". This meant that their children would have the freedom to be able to do what they wanted in life.

"...that's all I want, so that she can be functional and that she can be integrated into society and that she could have an education. And people must be able to understand her, and she must make a difference" (M7).

Another very important issue which all the mothers referred to was that of **schooling**. It is a selection consideration for cochlear implantation that the children are placed into a school which encourages development of auditory and oral language skills (Erlor, 1996). Archbold, Nikolopoulos, O'Donoghue, and Lutman (1998) found that, of children who were in pre-school at the time of implantation, 53% had been mainstreamed two years after implantation. However, within the South African context, where the necessary support structures (such as special classes) are not usually available in mainstream schools, this option is not as readily available. The trend that emerged in this study was that mothers were concerned that their children would have difficulty coping in "normal" or mainstream schooling. Classes in mainstream schools usually consist of between 40 - 50 children per class. They were concerned that teachers would not be able to cope with the special needs these (and in fact most hearing-impaired) children have.

All the mothers only considered the option of oral schooling (mainstream or special) as the

decision that I would never because I won't subject her - especially with the classes being so big now - and um the rate of progress - she will get lost in the system. So she will definitely go to a specialised school" (M7).

This mother had spent a long time in denial of the hearing loss, and over the period of cochlear implant use and reconciling of hope-based and knowledge-based expectations, she had worked through her difficulties with adjustment to the deafness of her child. This process of coming to terms with the long-term reality of her child's deafness, and its implications in terms of life choices, were described as a final understanding that she should "...encourage her but not push her to a certain level or profession or anything. So however she develops. And pick up what her strong points are and explore that and go further into that" (M7).

She stressed the usefulness of the support structures of other mothers with implanted children in assisting her with the development of more appropriate expectations and hopes for the future.

Erler (1996) suggests that there is no perfect educational placement for a child using a cochlear implant, and that each child and its family represent unique abilities and requirements. Whatever educational placement is selected for an implanted child, the school will need personalised and ongoing training about cochlear implants. A vitally important component towards ultimate successful use of a cochlear implant is the support of classroom teachers (O' Donoghue, 1996). However, the decision is more complicated in South Africa, as mainstream schools generally have large class sizes and are frequently understaffed. Very few mainstream schools have adequate support structures to support the needs of implanted children. With their unique educational and management needs, it may in certain cases be a wiser option to place these children in oral schools for the deaf as opposed to mainstream placement (if the necessary support structures are not available in a particular mainstream school). It needs to be stressed that signing schools are a poor option for these children. Their performance outcomes in terms of speech production and oral language skills are poorer than if they were placed in oral programmes, where the emphasis is on the use of audition and spoken language. Implanted children who are placed in signing schools often become primarily dependent on a manual communication system, and many end up as non-users of the device (Rose, Vernon, & Pool, 1996).

A unique challenge lies in school placement of deaf children with multiple handicap. Each type of school would be with its advantages and disadvantages for that child, as each special school would be geared for a particular type of disability. The mother of the child with multiple handicap recognised this difficulty, but felt that the greater handicap would be that of hearing, and therefore communication problems. Her primary concern, however, was that the school should have a certain academic standard, as she wished for her child to have a good education. *"It will either be...(school for cerebral palsy)...I would prefer it if he went to a deaf school if he could physically go. If they would accept him. Cos I think that's his biggest disability - communication is much bigger than walking and stuff like that...But if he went to (school for cerebral palsy) I wouldn't be disappointed...they've got an academic standard...it's just that he'd miss out on the hearing, which I think is so important...if you can't hear that well you miss out on most of the lesson...so that's why for me a deaf school would be what I want"* (M4).

Other future expectations expressed by mothers were **long-term fears** of implantation. The issue of fears and concerns emerged at various stages over the duration of implantation, as well as prior to the implant. Some of the same fears re-emerged during discussion of this theme. Fears included failure of the internal device.

"I'm always worried if something's going to go wrong" (M2).

Other fears expressed were of the long-term ramifications of using an implant, especially because it was in the head

"...will she be able to carry that all her life inside her?" (M1).

and fears of possible long term brain damage.

"I hope in 20 years time they don't say it will lead to brain damage, or something...that does sometimes worry me" (M2).

3.5 COUNSELLING NEEDS

The final theme which emerged from this research was related to counselling needs. Counselling is recognised as a vital component of the audiological management service offered to clients (Clark, 1994). It can be divided into two primary areas - informational and adjustment or supportive counselling (Kaplan, 1986). Mothers only referred to informational counselling when

asked about their counselling needs. Many of them had felt overwhelmed by the vast amounts of information provided, particularly prior to the implant and during the early stages of the switch-on. They had felt that there was too much information to absorb at the time.

"...too many things at the time...at the beginning - the first days - I also got a bit confused"
(M1).

As has been previously discussed, high levels of anxiety can contribute to reduced ability to process cognitive information (Luterman, 1987). Perhaps it is necessary to consider alternative, more efficient methods of providing information to parents so as to ensure maximum understanding and retention of knowledge. Although it is always necessary to provide face-to-face counselling, there are other useful ways of providing information.

Most mothers requested a videotape which they could borrow to take home or make a copy of. M2 spoke of specific suggestions as to what such a videotape could contain:

"I couldn't even imagine what they were talking about...if we could perhaps have seen something - like a video or something - of how it works, what the implant looks like and things like that before the time. I actually think that's quite important you know. Maybe with the first session, you know now if your child is going to get a cochlear implant, that a video is set up of the procedure, this is what an implant looks like, and this is more or less what they do in the surgery, this is how they map - you know, just little inserts...this is the operation, then afterwards you go to your audiologist, and the speech therapy and things like that. To show you how the child improves...as a preparation of what's lying ahead" (M2).

Such a videotape would also have great use in terms of preparing extended family and friends as to what is involved in the implantation process. In this way it would be possible to ensure that expectations of families and friends are more realistic, or knowledge-based. Family and friends frequently have inappropriately high expectations from cochlear implants (Kampfe et al., 1993). Mothers reported finding it stressful and tedious having to explain to others on an ongoing basis why their child was not responding immediately, and why speech took so long to develop. It has been seen that unrealistically high expectations of families can also lead to increasing anxiety levels in mothers. Provision of informational videotapes may therefore also be a useful way of

reducing their anxiety. Kampfe et al. (1993) suggest that the use of videotapes may be an effective way of increasing the strength of realistic expectations in that a variety of performance outcomes could be shown to parents. As was discussed in the theme of expectations from the switch-on period, it would also be useful to expose parents to the range of possible responses to initial connection, so that the high levels of anxiety which were seen to result from negative, unexpected responses could be lessened. Furthermore, long-term performance examples of speech production and language outcomes would be beneficial in terms of assisting parents develop appropriate expectations of performance outcomes over time. McConkey (1985) suggests that videotapes are an excellent teaching medium. In particular, they are particularly useful for people who have greater difficulty understanding information presented through the written form, and they can be re-played as often as required, and at whatever time and locations suit the viewer.

Videotapes provided could include information regarding candidacy issues, prognostic factors in terms of outcomes, the stages of implantation and time commitments required in terms of programming and evaluation requirements. Information and examples of children regarding outcomes related to the switch-on period, as well as a range of longer-term outcomes of the children would be most useful in assisting parents develop appropriate expectations. Information regarding the more technical aspects of the device (how it works, troubleshooting, and terminology related to programming) would assist in reducing the technical difficulties and fears some mothers reported experiencing.

Some mothers suggested that parents be shown videotapes of switch-ons of other children so that they could see the range of responses. One mother had found that although sufficient information had been provided prior to the implant and switch-on as to what to expect, "*sometimes you don't take everything in*" (M2). Providing parents with a videotape of outcomes of a variety of other children could assist in decreasing the shock associated with an unexpected reaction from their child. It would also mean that the parents could watch the videotape at home in a relaxed environment, and that they could watch it several times over. Repeated exposure to the same information results in increased strength of expectations (Kampfe et al., 1993).

Videotapes are also a time efficient method of providing information about the various aspects of the cochlear implant. Although the need for counselling within and after the session with the child will always be an important aspect of management, it may be helpful for parents to hear the information again afterwards. It is difficult for parents to remember everything they are told (especially if their child is with them in the session as they are not really attending adequately). *"...sometimes (audiologist) would tell you what's going to happen, but sometimes you don't remember"* (M8).

Many mothers reported having difficulty, especially in the beginning, understanding the more technical aspects of the cochlear implant (for example, programming). Some mothers reported feeling embarrassed to ask questions about things they had not really understood.

"...I haven't got a very mathematical mind, technical mind. So I think it would need to be done more than once for me to understand fully" (M5).

It was also suggested that periodic workshops be held for mothers so that terminology and technical issues could be explained without interruptions or distractions. Some mothers even felt intimidated by having their husbands present as they felt that they could not ask "stupid" questions. Workshops would also be a useful time for providing a forum for mothers to share experiences and anxieties. They could fulfil a dual function of providing a forum for a support group.

Support groups are an extremely valuable adjunct to the therapeutic process (Luterman, 1987). They provide an effective forum for discussion of common concerns, and mothers can share strategies they may have developed for coping with common problems (Maxon & Brackett, 1992). Mothers could be encouraged to formulate their own questions to issues, rather than being provided with large amounts of information. It has been seen that only once parents are able to formulate their own questions are they ready to absorb new knowledge. Workshops, or group meetings, could therefore play an important role in fulfilling both informational and emotional needs of mothers. They could also assist the audiologist in obtaining information as to mothers' stages in their responses to deafness, as well as their expectations from the cochlear implant. It has been seen that the stage of response to deafness, the extent of hope-based expectations and levels of anxiety are important variables that need to be examined in order to promote reliance

on knowledge-based expectations of outcomes.

Some mothers interviewed reported that it was difficult to know what questions to ask. It would help for parents to observe a variety of other children at different stages post-implant and with a range of performance outcomes. It is important to speak to other parents during the evaluation and pre-implant counselling process, as well as post-implant, to assist parents in developing their own questions. Group meetings would also be a useful means of doing so. Furthermore, the type of questions asked provide the audiologist with an indication into parents' insight and expectations.

It has been seen from the theme of "expectations over time" that there are particular periods where hope-based expectations predominate. During these phases many mothers revisit various aspects of the grieving process related to their child's deafness. These times are linked to lower levels of satisfaction and higher levels of anxiety, and therefore mothers' ability to absorb much information during these times may be reduced. The implication of this is that during these periods the importance of counselling may take precedence over the child's programming needs, or at least suggest that more time needs to be devoted to counselling mothers in a session on their own. The application of the model developed would be useful in predicting when these more critical times, which require more attention to counselling, may occur. These times would be most likely to occur during the "switch-on" and "despondency" phases. It may also assist mothers to see the normal trends of emotions over time so that they can contextualise their own emotions. The combination of these two factors may play an important role in reducing anxiety, and thereby increasing reliance on knowledge.

4. CONCLUSIONS

In conclusion, in this study the pre- and post-implant expectations of mothers, as well as their expectations of outcomes from the cochlear implant over time, were investigated and documented. Furthermore, satisfaction with the device as an influential factor in terms of these expectations was considered.

A number of definite trends emerged from this study. The importance of the mothers' response to the deafness of their child emerged as having an important influence on expectations in general. Furthermore, the fluidity of the nature of the adaptation process was demonstrated by the re-emergence of stages of the grief process at particular stages over time. The type of expectations experienced varied, and were based either on hopes for particular outcomes, or on knowledge of likely outcomes. In addition, it was found that expectations were not static, but changed over time. The predominance of either hope- or knowledge-based expectations experienced at various stages post-implant were highly influenced by feelings of success and satisfaction with outcomes at the time. The model developed depicts this fluctuation in the type of expectations experienced over time in relation to performance outcomes and anxiety associated with these outcomes (see Figure 3.1).

Particular times post-implant were associated with high levels of anxiety, which were strongly influenced by feelings of dissatisfaction with performance outcomes at that time. When anxiety increased, there was a concomitant rise in expectations based on hope, and mothers appeared to lose sight of their knowledge of the expected outcomes at that stage. However, when their expectations based on their knowledge were confirmed by the child's performance at that time, there was a dramatic drop in anxiety and increase in satisfaction with outcomes. This resulted in a continued predominance of knowledge-based expectations. The sense of satisfaction was clearly linked with dramatic changes in levels of auditory responsiveness, and primarily with the emergence of meaningful speech. The onset of speech, improved communication and behaviour, and therefore improvements in the mother-child relationship, led to high levels of satisfaction. It was therefore clearly evident that the types of expectations experienced fluctuated over time depending on performance outcomes, satisfaction experienced with these outcomes, and anxiety

levels associated with the sense of satisfaction and success. Furthermore, there was a strong relationship between the predominance of hope- or knowledge-based expectations and satisfaction.

It was therefore clearly evident that expectations were ever-changing, and at various stages post-implant either hope- or knowledge-based expectations dominated. The factors influencing these changes have been elaborated on in detail in the results and discussion section. Hence it is apparent that it is impossible to separate expectations over time and satisfaction experienced. The model developed demonstrates the important findings that:

- i) expectations change over time, and should not be viewed as being static;
- ii) expectations based on hope or on knowledge of outcomes fluctuate over time, with either type of expectation dominating at particular time periods. These time periods are linked to particular performance outcomes.
- iii) there is a strong relationship between the type of expectations experienced (i.e. hope-based or knowledge-based expectations), and satisfaction with outcomes. The extent of satisfaction experienced is determined by the levels of anxiety associated with particular outcomes.

It should be noted that the changes, as depicted in the model, were not time-linked, and responses of mothers varied according to the outcomes of their particular child. As was discussed in the introduction, performance outcomes vary for different children according to various prognostic factors. Therefore, the rate of progress will be faster for some children than for others. This variability in progress means that the changes in the type of expectations experienced at particular times are different for different mothers. However, as was apparent from the findings of this research, the trend was that mothers experienced the same pattern of changes, although perhaps at different time periods post-implant. Furthermore, the extent of the responses were not based on any quantitative information, and merely reflected the depth of feelings as described by mothers.

An interesting trend was that during times of high anxiety levels and expectations based on unrealistically high hopes, many mothers spoke of issues related to the grieving process associated with their child's deafness. This highlighted the fluidity of the grieving process,

where the responses of mothers' to the deafness were revisited. However, during periods when expectations were based on knowledge of likely outcomes, feelings related to their child's deafness were focused on more realistic expectations, particularly in terms of future outcomes. This finding suggests that during these times when minimal anxiety and greater satisfaction is experienced, mothers demonstrated greater levels of adaptation to the deafness. Cochlear implant team members need to be aware of the likelihood of the re-emergence of grieving, and adjust counselling when indicated. Ongoing contact with other mothers and children who had been implanted was described by mothers as being extremely useful in reducing anxiety, as mothers were able to see that slow progress was normal, and that in the longer-term outcomes would be as anticipated based on their knowledge.

The importance of noting individuality among patterns of changing expectations and satisfaction was highlighted by the few exceptions to the overall trend found. Although there was a definite trend that expectations and levels of satisfaction and anxiety change over time (as has been discussed at length in the results and discussion), the few exceptions to this trend add strength to the principle of approaching each family and child on an individual basis. Each has their own needs, emotional requirements and each child's outcomes is influenced by particular prognostic variables.

It is believed that this model may be of much use when applied to counselling of mothers both prior to and after implantation. Its clinical application would provide the audiologist with a useful means of providing an in-depth explanation as to the likely outcomes over time in terms of performance, satisfaction, and the natural responses in terms of the types of expectations experienced. This knowledge would hopefully facilitate lower levels of anxiety during times of disillusionment and high anxiety, which should therefore mean that mothers would rely more on their knowledge of outcomes rather than their hopes. Use of this model could be extended in that it could be adapted to a layman's level. It could then be taken home and referred to on an ongoing basis, particularly during times of lower satisfaction and higher anxiety. It could provide mothers with a point of reference of their child's progress over time. In doing so they could continually contextualise their emotional responses, and thus reduce anxiety. The model could therefore be used by parents during times between contacts with the audiologist when there is

a greater need for reliance on internal resources.

Furthermore, the audiologist would be able to anticipate the type of emotions mothers may be experiencing at various stages based on the performance outcomes of the child. During times of greater anxiety it may be necessary to devote more time to counselling. It would be useful during these times to encourage mothers to discuss their feelings with mothers of children who have been implanted for longer periods of time. It is essential for parents to remain cooperative and motivated in the long-term. The model developed would be of great value in contributing to the longer-term commitment of parents because during times of high anxiety their feelings could be contextualised based on responses of other mothers. They would then be able to have insight into longer-term outcomes. In this way their long-term motivation and dedication could be encouraged.

In this study, unlike previous research in this field, the depth of emotions experienced by mothers over time, and the extent of satisfaction or disillusionment experienced during particular times after implantation was explored. It is essential for the cochlear implant team to be aware of these emotions, particularly during times of disillusionment, as ongoing cooperation and commitment from parents is essential to ensure continued success and progress of the child. Issues related to satisfaction and expectations are felt to have been addressed in more detail in this study than in previous research. This particular research methodology has allowed for a greater in-depth understanding of expectations from a cochlear implant and satisfaction over time. It has been seen that satisfaction and changing expectations are integrally linked, and cannot be separated. Other important issues related to expectations which were important to mothers were also identified in this research, and knowledge of these issues provided important insights into factors influencing the strength of different types of expectations experienced at different stages after the implant. It was only because of the particular methodology adopted that this extent of in-depth information could be obtained. It is believed that it would not have been possible to have obtained such insightful and in-depth information by using questionnaires.

It should be noted that this study was limited to prelingually deafened children who had been implanted before the age of 5 years. None of these children had developed any meaningful

speech prior to implantation. It would be valuable to undertake similar research using different selection criteria so that different groups of children (such as postlingually deafened children, or children implanted over the age of 5 years) could be investigated. Performance outcomes have been seen to differ according to these variables, and it is possible that the responses of the mothers to the progress of their children may differ from the results found in this study. The qualitative methodology approach has been seen to be extremely useful in terms of obtaining an in-depth understanding of the experiences of parents from the process of cochlear implantation. By applying the knowledge obtained from these different groups of implanted children (i.e. with different longer-term performance outcomes), the information obtained would be invaluable in terms of obtaining a deeper understanding of outcomes associated not only with clinical performance outcomes as perceived by parents, but also the realisation of their expectations and satisfaction.

It would also be of great value to undertake longitudinal research using a similar methodology to examine expectations over a longer period. In this research the longest time children had used their cochlear implant was two years. It would be useful to have an understanding of expectations of mothers when their needs have changed from focusing on the development of speech and language development to schooling and educational issues.

In section five the theoretical, clinical and research implications of this study will be discussed.

5. IMPLICATIONS

Numerous theoretical, practical and research implications emerged from this study.

5.1 Theoretical Implications

Some of the theoretical implications which emerged will now be discussed.

It is evident that mothers do not appear to “accept” the deafness of their child. Rather there is a process of “adaptation” to it, where feelings of grief are likely to re-emerge, particularly during times of increased stress and anxiety. A theoretical framework based on these varying stages of grief over time to the deafness of a child could thus be devised, demonstrating the fluidity of the grief process over time within this particular population.

The response to deafness is integrally connected with satisfaction with and expectations of performance outcomes. Audiologists working with children need to be constantly aware of fluidity of the grieving process, and the likely re-emergence of various grief responses during times of disillusionment.

Satisfaction and expectations are not static, and change according to outcomes and external influences (such as expectations from family and friends, as well as internal coping mechanisms).

The types of expectations experienced vary over time, based either on hope (which tend to be more unrealistic and related to response to deafness) or knowledge. The types of expectations experienced are influenced by satisfaction with performance outcomes.

Support groups and ongoing contact with other mothers and children who use cochlear implants have great value in terms of promoting knowledge of outcomes over time, sharing feelings and anxieties, and thus reducing stress.

In addition, this study demonstrated the tremendous value of using a qualitative methodology as a means of obtaining rich data concerning expectations and satisfaction over time.

5.2 Clinical Implications

Some important clinical implications emerged from this study:

- * The clinical application of the model developed is believed to be of potential value in terms of counselling parents regarding changing expectations and satisfaction with the device over time. It would assist them in understanding that their reactions during different periods are natural. This contextualisation of their responses and feelings would assist in reducing anxiety and disillusionment, and hence the predominance of hope-based expectations. It may also be of benefit to them to be able to admit to their hopes in an understanding and empathetic environment. The model would also be of value to the clinician by providing a means of anticipating difficult times mothers may experience and the possible re-emergence of a particular stage of grief regarding the deafness. The type and depth of counselling could thereby be modified as needed.
- * Audiologists working with implanted children need to have understanding of and insight into the normal responses to deafness of mothers. They should also discuss with the mothers their particular responses to their child's deafness. The stage of grieving has an important influence on the type of expectations mothers may have regarding performance outcomes in the short and longer term. Audiologists need to also be aware of the factors which may precipitate a return to a grieving period. The model would assist the audiologist in terms of being able to anticipate these times when the mother is more at risk for this occurring. During these times supportive counselling would be required. It would also be beneficial to provide support groups where these feelings could be openly discussed. During these times it would perhaps be prudent to spend less time on informational counselling until the emotional issues have been adequately addressed.
- * Parents need to more fully understand the normal course of development of auditory

perceptual skills. This development takes time and is an important precursor for the development of meaningful, intelligible speech. Understanding of this is critical to having insight into the process of progress with the implant over time. By providing this information on an ongoing basis, it may be possible to reduce anxiety of mothers that their child does not appear to be progressing. It is important for the clinician to counsel the mother alone (or in groups) on a regular basis in order to establish whether expectations are appropriate at particular time periods when these skills are developing. It is also important to obtain continual feedback about anxieties and concerns, so that the relevant issues can be addressed.

- * All team members should inform mothers on an ongoing basis regarding the development of skills and progress of the child, so that although visible outcomes may not be apparent (e.g. meaningful words), they can better understand their progress in terms of the development of listening skills. Furthermore, input from parents regarding progress and outcomes in the home environment is essential in providing a more rounded impression of results.

- * The use of videotapes emerged as a valuable means of providing information regarding outcomes (e.g. of the switch-on, and of the time it takes to acquire speech and language). They would also be useful in terms of showing to relevant family members and friends so that they could have more realistic expectations of outcomes based on knowledge of outcomes of other children. Mothers would then not be subjected to added stress where family and friends' unrealistically high expectations may influence their own expectations. It would also mean that the network of support structures could be extended beyond mothers of implanted children.

5.3 Future Research Implications

Numerous implications for future research emerged from this study, and these will be highlighted in this section.

Longitudinal research would be valuable so that knowledge could be gained about changing expectations as children enter formal schooling. The needs of parents change during different

phases of the child's life, and educational placement issues and longer-term schooling outcomes would assume more importance. It would also be useful to identify these issues in terms of management of these children and their parents.

Expectations and responses of mothers have been addressed in this research. It would be useful to identify the responses of fathers to the process. Research could therefore be aimed at addressing the possibility of changing expectations of fathers, as well as examining their responses to the deafness of their child.

This research has focused on parents' perceptions of implant outcomes and their responses to it. The child's future satisfaction is of utmost relevance, and it would be invaluable to obtain information regarding their perceptions of outcomes. This is particularly relevant in terms of the controversy surrounding implantation of young children. This type of research could be conducted with older children who have sufficient language skills and insight to be able to provide this type of information.

The group of children used in this study was restricted to prelingually deafened children who had not started formal schooling. Similar research could be conducted on other groups of children using different selection criteria. Children with more pre-implant residual hearing usually have some speech and language skills, and it is possible that mothers may not experience the same "despondency" period experienced by the mothers in this study. The same would in all likelihood apply to mothers of children with postlingual deafness. Furthermore, children who are implanted at a later age progress more slowly and do not usually achieve the same high levels of outcomes with regard to the development of speech and language, as well as educational outcomes. It would be useful to examine the patterns of changing expectations in these mothers.

It would be valuable to examine whether this model could apply to mothers of children who are fitted with hearing aids. This type of research could therefore be conducted on this group of mothers in order to obtain the same kind of information.

The issue of very early versus slightly later diagnosis of deafness was raised by one mother in

this study. A future research implication which emerges from this is to investigate the generalisability of her feelings. Would mothers whose children were diagnosed at a very early age have preferred to have had the opportunity to bond with their child before the diagnosis of their child's deafness? Would they have preferred to have had a diagnosis made only after they had become suspicious about the possibility of hearing loss? Furthermore, do outcomes differ to such an extent in children diagnosed as a neonate versus a diagnosis at 3-4 months that the continued emphasis on such early diagnosis is warranted?

“Parents are experts too. Help should begin with an understanding of what they believe, expect and need. This is the foundation for all efforts to help their child...”

(Parent's comment, Cunningham & Davis, 1985:1)

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7. APPENDIX A

INTERVIEW GUIDE

I am conducting this research in order to find out about your thoughts, feelings and experiences resulting from your child having received a cochlear implant. The reason I am interested in obtaining this information is so that suggestions and recommendations can be made as to ways in which the cochlear implant programme can be improved so that it is meeting the needs of parents of implanted children in the best way possible.

1. I wonder if we could start today by talking about how it has been for you from the time when you made the decision for your child to receive a cochlear implant.

Could you tell me about how things / it turned out compared with how you thought it would be?

2. General progress.

- * Describe how you feel about your child's progress since having received a cochlear implant.
- * How does this compare with what you thought it would be?
- * Tell me about how you felt in the early stages about having decided to give your child a cochlear implant. How do you feel now?
- * Tell me about whether you feel satisfied with the outcome of the implant.

3. Switch-on and initial period.

- * Tell me about the day of the switch-on.
- * Is this how you thought it would be?
- * Tell me about those first few days and weeks.
- * Is this what you thought would happen?
- * Do you think anything could have been done differently to prepare you?

4. Expectations of others.

- * Tell me about the expectations of other family members? Friends?

5. Expectations for specific areas.

We have spoken about your child's performance in a general sense. I am also interested in what you felt initially and feel now in terms of what s/he can do in specific areas as compared with what you thought s/he would be able to do.

What area do you think has shown the most significant change?

- * Sound perception (everyday sounds).
- * Speech perception.
- * Ability to understand speech with and without visual cues.
- * Reliance on lipreading.
- * Progress in speech development and intelligibility (ability of mother and others understanding what s/he is saying).
- * Progress in language development (vocabulary, putting words together to form sentences).
- * Ability to recognise and hear music.

6. General behaviour.

- * What do you think about his/her behaviour since having received the implant?
- * Is this what you thought would happen?

7. Relationship with child.

- * Tell me about your relationship with your child before and after having the implant.
- * Is this what you thought would happen?

8. Terminology and technical aspects.

- * Tell me about whether you feel that you have an adequate understanding of how the device works.
- * How do you feel in terms of your understanding of the terminology (such as mapping, stimulation mode, T- and C-levels).
- * What are your thoughts on what has been explained to you in terms of these areas, and whether these issues could be addressed differently in the future.

9. Commitment.

- * Tell me about your feelings about time commitments for therapy, mapping, and day-to-day maintenance.
- * Is this what you thought would be required?

10. Future expectations.

- * Tell me about what you think will happen in the future?
(Cover areas of speech and language, communication mode, educational placement).
- * Tell me about what do you really in your heart of hearts hope for your child?
- * Is this what you think will happen?
- * What are your concerns?

What has been the most difficult / encouraging time for you?

What advice would you give to other parents thinking about a cochlear implant for their child?

APPENDIX B

EXAMPLE OF TRANSCRIPTION WITH M5

Respondent: 1 It was always at a close sort of distance. And I sort of felt I'm not wasting
 2 my time - she can hear. So it wasn't a hassle to talk. Whereas before with
 3 hearing aids half the time I thought well she's not hearing, so why are
 4 you bothering? You're not allowed to let her lipread - at one stage we all
 5 had to talk (covering mouth with her hand) like this. I thought what's the
 6 point - she's not hearing, she's not responding. You know, it just seemed
 7 absolutely pointless. But after the implant, knowing that she could hear,
 8 seeing her reactions to sounds - every single sound that she heard she of
 9 course did this (pointing to her ear), said "what's that?". Um...and then
 10 again it was something to talk about, and to show her a picture of what it
 11 was. Um...so it's been easier, it's been a helluva lot easier.

ES:P
 ES:REL
 ES:TC
 S:PER

DEAF:HA
 DEAF:REL

ES:P-H

ES:REL
 S:PER

Interviewer: 12 So it hasn't been so much like "I'm working with you now"?...

AF:REL Respondent: 13 No- it's far more natural.

ES:REL
S:PER Interviewer: 14 Ja...

Respondent: 15 Far more normal. And some days I obviously do sit down and do
 16 homework with her, and some days I don't. And I don't feel bad about
 17 it because if we've gone somewhere she's with me - there's always
 18 language all the time. Especially in the car - that's like the best place.
 19 Cos you're confined to that little place. She talks the whole way to school.
 20 And the whole way home.

DEAF:REL
 ES:REL
 ES:TC
 ES:TC

ES:REL
 ES:HY/ES:S
 S:PER

Interviewer: 21 Really!

Respondent: 22 So we do a lot in the car. A helluva lot in the car.

Interviewer: 23 How does she hear and understand in the car?

Respondent: 24 She hears well...in the beginning she used to take the coil off in
 25 the car - probably the engine or something. She used to do that on the
 26 way home. I forgot about that - she'd take it off. Or if I had music playing
 27 in the car she'd take it off. And then I don't know, (audiologist) must

DT:H

ES: H
S: PES

1 I have adjusted something, and then it was fine. Now she talks in the car.

ES: P
ES: COMM

2 She can even sit in the back of the car and I can talk to her. There can

DEAF: REL
S: PER

3 be music on in the car and I can still talk to her. She hears all sorts

4 of sounds outside the car, and then she says "what's that? What's that
5 noise?".

Interviewer: 6 And is all of that what you thought would happen?

ES: P-S
COMM

Respondent: 7 They told us it would take between two and five years for her to start

8 talking. They warned us it would be a long sort of process. It's only going

9 on two years now in October. So it started before the two years - about sort

10 of - I can't remember now. Maybe about 16, 17 months - she's really

S: PER

11 taken off. And I feel that if they gave us a time limit of two to five years,

12 And she's doing this well now, and it's only going on two years, imagine

PE: COMM

13 what it'll be like in five years.

Interviewer: 14 So what are you expecting from her in five years?

COMM

Respondent: 15 To talk normally.

Interviewer: 16 Tell me more...

: COMM
: SP
S: PER

Respondent: 17 I'm not expecting her to talk like you and me. I'm expecting her to -

18 well, I thought there'd be a sort of like a monotone sort of sound. But

19 even now there's no trace of it. She copies pitches and sound of things

ES: P-S

20 exactly. Absolutely exactly. So she might not have that sort of monotone -

ES: P-S

21 which is one thing I expected.