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WHEN EXPECTATION MEETS EXPERIENCE: PARENTS' RECOLLECTIONS OF AND EXPERIENCES WITH A CHILD DIAGNOSED WITH HEARING LOSS SOON AFTER BIRTH

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Abstract

Objective—To examine parents' recollections of and their experiences with bringing up a child diagnosed with hearing loss at a very young age.

Design—Based on the analysis of informal parent discussion groups, four open-ended questions were formulated to solicit information about parents' expectations following diagnosis, as well as experiences and challenges when raising a child with a hearing loss.

Study Sample—Forty parents of children, aged between three to five years, who were diagnosed with hearing loss before the age of three years.

Results—Parents' responses revealed strong support for early intervention, high expectations for their child's development, and desire for information tailored to individual needs. Parents also reported anxiety relating to their perceptions of the significance of consistent device usage on their child's development. Further concerns arose from their observations of the difficulties experienced by their child in real-world environments despite consistent device usage, and their perception of their child's language delay despite early intervention.

Conclusions—The findings point to a need to support parents to form realistic expectations based on current knowledge. Implications for clinicians to provide improved management of children with hearing loss are discussed.

Keywords

Parents' expectations; Childhood hearing impairment; early intervention; early diagnosis; outcomes

Studies of hearing impairment in children have generally focused on its impact on children's outcomes with a view to identifying predictive factors that may enable improved clinical and educational intervention. However, the effect of hearing loss in a child on their wider family, and the needs of parents dealing with the impact of their child's hearing loss have received relatively little research attention. In many cases, parents of children diagnosed with hearing loss are expected to, and do take on the multiple roles of newly-conscripted rehabilitation experts, educationalists, and language therapists for their child. The varied demands of these roles, coupled with parents' lack of prior experience leave them highly dependent on hearing professionals for information on how best to support their child. A clearer awareness and understanding of parents' perspectives on their child's hearing loss and early development

could enable hearing professionals to provide support in a way that better meets the needs of parents.

Previous research has shown that in the case of a failed hearing screening, parents' initial responses to an unexpected report of the presence of hearing loss in their child include surprise, sadness, and concern (Kurtzer-White & Luterman 2003; Yoshinaga-Itano & DeUzcategui, 2001; Young & Tattersall, 2007). Questions naturally arise in parents' minds as to what may have caused the hearing loss, the likely impact on their new family member, and options for overcoming this unexpected development (Calderon & Greenberg, 1999; Corcoran et al., 2000; e.g., DesGeorges, 2003; Kurtzer-White & Luterman, 2003). Two studies examining parents' experiences following newborn screening have been conducted with Canadian (Fitzpatrick et al., 2007) and UK (Tattersall & Young, 2006; Young & Tattersall, 2007) families shortly after their child's diagnosis with hearing loss. Structured interviews allowed parents to discuss the impact of the new diagnostic procedures, and their understanding of the potential benefit that it might bring. Both of these studies reported that despite the associated grief, newborn hearing screening leading to early diagnosis was viewed as a positive experience that provided an opportunity for important early intervention and rehabilitation assistance. Furthermore, parents noted that early detection would improve prognosis for their child's language and educational development, allowing their child to attain "normal" outcomes. Parents showed high expectations that early detection and intervention would be a key factor that enabled their child to achieve like a child with normal hearing.

The timing of the majority of these studies however is in the period shortly after diagnosis has occurred, a time when many families are likely to feel understandably unprepared about the reality of any impact of their child's hearing loss.

Conversely, retrospective studies such as Minchom and colleagues (2003) which have reported parents recollecting receiving only low levels of support at the time of diagnosis are confounded by high variability resulting from 11 year birth range of families surveyed. This includes likely large differences in age of diagnosis and rehabilitation, but also the way in which service provision may have varied across the time span, and across health services.

A very different situation now exists for families receiving a diagnosis of hearing loss for their child, particularly in Australia. As for many countries, the implementation of universal newborn hearing screening (UNHS) makes it possible for the majority of families to access early detection and intervention services. Further the unique provision of hearing rehabilitation services through a single, government funded, agency in Australia means that all families receive a highly standardised level of care.

The current study focuses on parents receiving diagnosis during the early period of UNHS programs. Unlike many of the previous mentioned newborn hearing screening studies, parents participating in this study are beyond the early period during which they were reacting to a diagnosis of hearing loss. For the most part, their children have already received audiological and educational intervention services and the parents have had the opportunity to spend some time experiencing the impact of hearing loss and on their child's development. This study, therefore, allows investigations to go beyond an examination of parents' initial expectations and to assess parents' experiences over the first few years following diagnosis. The aim of the study was to investigate parental experiences of receiving a diagnosis of hearing loss for their young child, in the context of a reasonably high standardised service-provision model. It is hypothesised that parents' recollections of their expectations about diagnosis and early rehabilitation/intervention, may be similar to

those experiences previously reported in the literature, but mediated by their subsequent experience of parenting a young child with hearing impairment.

Method

This evaluation was conducted within the context of a population-based study designed to examine the efficacy of early intervention by prospectively measuring the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI; Ching et al., 2010).

Participants

Families participating in the LOCHI project, whose children were under the age of five years, were invited to respond to a questionnaire. In order to maintain anonymity, participants were not asked questions that could be used to identify them (e.g. postcode, gender, age).

Materials

The questionnaire was based on the issues raised by parents in a previous discussion group activity during the LOCHI project, (See National Acoustic Laboratories, 2009). During these informal sessions, parents' reflections led to discussion of similar topics across the different groups. These included the timing of diagnosis and their subsequent responses, their experiences and decisions regarding amplification and intervention options, and the impact on their family and parenting techniques. Four open-ended questions were formulated for the present study, to gather more information about these topics. Parents were asked about their recollections of the diagnostic process, their preferences regarding screening/identification age, and their current experiences parenting a child with a hearing impairment. Parents were also asked what support they believed would further assist them and their family.

Procedure

Ethics approval for the study was granted through the institutional human research review committee. Surveys were mailed to parents participating in the LOCHI study with directions for them to be completed and returned by mail. The survey was also made available online for interested participants to complete in this form. Invitations to participate were included as part of a regular newsletter update to families, not as a directed request to respond.

Results and Preliminary Discussion

A total of 40 parents responded to the survey. From the responses received, it was possible to identify that the respondents were parents of 18 male and 19 female children, with no known information about the children of the 3 remaining respondents available. Parents' responses were collated by question number, and content analysis was used to identify and extract significant themes or issues.

1a) Please describe your immediate response when you found out about your child's hearing loss

Two overarching response-types were identified. The first was significant grief-related responses. The second was feelings of comparative acceptance/relief for those families where the diagnosis of hearing loss was contrasted against additional (sometimes life-threatening) medical concerns.

Grief Responses—Overall, responses included 38 references to grief-related emotions. Parents recalled that their initial reaction to the diagnosis was one of “shock” or of being

“stunned”, which was mentioned 13 times by parents. Other related emotions included confusion, grief, denial, disbelief, and sadness. Seven parents reported strong levels of grief (including “devastated” or “heartbroken”) indicating the significant and dramatic emotional impact that diagnosis can have on families at the time. One response, “*Devastated, of course*” indicates the parent’s expectation that this level of emotional response would be common to all families in their situation.

In the context of their current experience, parents expressed difficulties when their child was perceived to be falling short of normal language outcomes for their age, and a number also commented on ongoing concerns in relation to school enrolment or attendance. For many in the current study, the imminent start of schooling had awakened fresh worry, “*Will have more worries when he is at kindergarten and at school*”; “*Always worry that they are not developing at or within “normal” limits. Will they be ready for school?*”.

Relative Acceptance—Strong feelings of grief were recounted by many parents, but not all. For seven parents, comparisons were made to the child’s preceding or co-existing health concerns, and initial reactions to their child’s diagnosis included feelings of relief or acceptance in comparison to other difficulties faced by the family. Contrasted against other (sometimes life threatening) co-existing conditions, these parents reflected that they had viewed hearing loss as a relative minor concern, believing it to be easily treatable.

“I felt comforted that there are lots of things we can do to help our son with his hearing loss, but the fear I had of him never being able to walk and talk was unbearable” (Mother of a child with suspected risk for CP and epilepsy).

However, parents’ recollections of diagnosis here show a (perhaps common/understandable) lack of awareness of the realistic impact of hearing loss and an overestimation regarding the likely efficacy of rehabilitation options “*I was concerned, but knew we could get a hearing aid to fix the problem*”.

1b) Where did you go for support?

It should be noted that for at least one parent, hearing loss was not seen as an outcome needing assistance or that should be met with despair. Rather, as a Deaf adult, hearing loss was viewed as something the parent was comfortable with, that was normal, and carrying few negative expectations “*...my daughter is the fifth generation of Deaf families; had no needs for support*”.

For other parents, the responses indicated that they utilised a range of support and information. Six parents described accessing the internet after receiving the diagnosis to search for information. Six parents also mentioned turning to family members for practical and emotional support.

Unsurprisingly, the most commonly mentioned contact was with audiologists or audiological services (21 responses). However, parents’ responses were mixed in regards to their perceptions of the appropriateness and level of support provided at the time, with half mentioning a perceived lack of information provision. Ten parents made some reference to the value or the quality of the support they received from hearing professionals, but were evenly split between reporting positive support “*We were always left in the loop and informed*” (P1), and reporting inadequate support, “*We weren’t given any information so I searched the internet. We were also not given any support, however our families helped us*”.

The provision of an information booklet designed for families of children newly diagnosed with hearing loss “*Choices*”¹ was perceived differently by families receiving it. For some, this information was a positive experience “*[Service provider] were fantastic. We used the*

'Choices' booklet to contact [relevant agencies]'. For others however, the same printed material was perceived to be inadequate. *"The audiologist who told us about the hearing loss gave us a 'Choices' booklet, that was it, no other information was given so I had to find my early intervention program myself"*.

2 At what age was your child's hearing loss identified? Some parents have expressed a wish that their child's hearing loss had been identified earlier/later. How do you feel about this and why?

Twenty-six parents reported having had a child diagnosed early (before six months) and nine having had a child diagnosed later (up to three years). A number of participants also expressed a specific preference regarding the timing of screening and diagnosis citing parent-based and child-based concerns (shown in Table 1).

Parents who reported a preference for an earlier diagnosis (regardless of the time that their child was diagnosed) discussed this in relation to the ability to access earlier intervention and rehabilitation, and their beliefs that this would lead to better outcomes for their child. For some parents, responses indicated that they associated early intervention with an expectation of the attainment of "normal" developmental outcomes, *"The sooner the better - it allows intervention and provides assurances of steady learning and development"*. Furthermore, a number of comments centred on a strong desire to remove any uncertainty that a delay in diagnosis had created, or may have led to.

Although the majority of parents stated they preferred early diagnosis, about 18% of parents' responses expressed a preference for later diagnosis. Parents cited concerns about bonding difficulties, and indicated a desire to have more time to adjust to being the parent of a newborn before additionally responding to a diagnosis of hearing impairment.

Some parents who expressed a personal desire for a later diagnosis simultaneously noted that early access to intervention which early diagnosis afforded was considered to be more important than the perceived emotional costs. *"It was difficult to hear the news...but I did consider it a blessing as... you can start to deal with it"*.

It is important to note that in some of these cases, the desire for a "later diagnosis" did not necessarily mean a delay of many months or years. For some parents who received a negative screening result within days or a week of giving birth, "later" may simply refer to a time that had allowed them sufficient time to firstly adjust to the arrival of the baby, *"I felt it was too young [early] as I was dealing with a new baby as well as one that was deaf"* (Child screened at 1 day).

3 What do you find easy and/or difficult with your child's use of a hearing aid and/or cochlear implant? and 4 What are some of the day-to-day challenges when caring for a child with a hearing loss?

Parents' responses about the difficulties or challenges they currently faced encompassed both emotional and physical (or practical) challenges. Only six parents reported experiencing no difficulties.

Practical Challenges—The most common difficulties, expressed by 17 parents, related to device usage and the difficulty of keeping the hearing aids or cochlear implants on their child. Difficulties included devices falling off (sometimes due to perceived design flaws);

¹The "Choices" booklet is a publication distributed by the provider of hearing rehabilitation services in Australia. Current versions of the publication (and state-by-state supplements can be accessed at <http://www.hearing.com.au/fact-sheets>

devices being pulled off by the child and, sometimes, devices being chewed/mouthed. These were often tied to concerns about the perceived subsequent (negative) impact on children's development.

A related concern by seven parents was their need to remain vigilant as a way of avoiding anxiety associated with the thought of the loss of a device e.g., “[hearing aid] *needs constant checking so it doesn't fall off*”. One parent further commented at their distress when criticised for not trying hard enough to keep the devices on the child, despite insisting they had implemented (unsuccessfully) all the advice offered by their audiologists “...*clearly we were being grossly misunderstood*”.

Some parents expressed a difficulty with device failure or breakdowns, especially if the subsequent repairs took longer than they considered appropriate; others commented on the need for families to always have batteries charged or on hand. Further, a few parents also reported frustration over not being able to tell if a device was working (e.g. flat batteries, broken device). This was particularly worrisome for parents when the child was young and unable to tell parents if the device stopped working.

In most cases, parents noted that many of the difficulties experienced (when their child first received hearing devices) was “a phase”, stressful at the time, but ultimately one that would pass. In total, nine parents contrasted ease of device use now against previous difficulties. It is encouraging that a number of parents noted that monitoring device usage had become easier over time, e.g., “*Now that our daughter is 20 months she keeps her aid in almost all the time, which is very nice!*”

Emotional Challenges—A common theme was continuing frustration, both child- and parent-based, as reported by eight participants e.g., “[*with emerging language skills – that are quite delayed from chronological age*], *dealing with and managing our child's frustration [is a challenge]*”. Some parents presented concerns over behavioural issues, such as children “failing to listen” by facing away, or not responding to verbal directions appropriately. Parents indicated that they could not be sure if this was normal childhood misbehaviour needing no specialised response, or the result of a hearing loss leading to maladaptive behaviours and thus a cause for concern.

Parents also expressed current difficulties with managing their child's speech and language problems. Some mentioned being unsure about what parts of conversation their child missed hearing, and feeling stressed that they needed to navigate their child's way through communication with others. “*When people are speaking to them I have to repeat it to them again because they misunderstand what they are saying*”. Parents also noted the need to alert or remind others of these issues in interactions with their child. “[we need to challenge] *assumptions [by others] that ears are now normal*”.

Another issue raised by parents was the need to continually remember that their child still has a hearing impairment. Parents perceived that, regardless of the device (hearing aids or cochlear implants) used, their child continued to have difficulty in background noise “*number one challenge is noise in the playground and the inadequacies of aids in this situation*”, needed to have someone physically gain their attention before talking, and were reliant on visual cues in situations when the device was removed, “*bath time and water play is hard when you have to remove the device... need to rely on gesture alone*”.

Discussion and Implications for Clinical Management

Parents' expectations and experiences

The parents' recall of their initial reaction to their child's diagnosis of hearing loss found in this study is consistent with those reported in other reports. This included experiencing grief relating to the loss of an expected future or shared experiences with a child (distinct from death-related grief; see Kurtzer-White & Luterman, 2003). Also, there were concerns that early diagnosis may have adversely affected parents' ability to get to know their newborn without worry or sadness (discussed also by Luterman & Kurtzer-White, 1999; Fitzpatrick, Graham et al., 2007). In the case of children with additional needs, the diagnosis of hearing loss was inconsequential (see also, Fitzpatrick et al 2007). The present study further found that the initial grief continued over time as parents observed delays in their child's development relative to other hearing peers over the first few years of life.

Parents' initial expectations reveal a belief that hearing loss can and will be relatively easily and effectively managed by early fitting of hearing devices, and that early intervention will be associated with better speech, language, and educational outcomes. These expectations are consistent with those reported previously (Fitzpatrick, Graham et al., 2007; Young & Tattersall, 2007). Some parents who had experienced late diagnosis expressed a belief that delayed intervention was the primary (if not the only) cause of any speech and language deficits exhibited by their child. The present study also found that device usage appeared to be one of parents' biggest concerns. Parents believed that any amount of time their child was not wearing hearing devices that were functioning consistently would be detrimental to their child's auditory experiences, with potentially severe consequences for development.

Thus, parents have expectations that early intervention coupled with high levels of device usage will ensure that their child will develop like a child with normal hearing. Such expectations may be misguided when considering that multiple factors influence developmental outcomes of children with hearing impairment, and the effect of timing of intervention is small compared to other demographic factors relating to the individual child and family (Ching et al, 2013).

The importance of early intervention for a child diagnosed with hearing loss must not be understated. Not only does it provide auditory stimulation so that neural connections may be formed effectively to support the child's speech and language acquisition (Kuhl et al, 1992), it also facilitates interactions between the child and the family and its environment. Early diagnosis has been described as beneficial in allowing parents extra time to make decisions and explore options for their child's habilitation (Luterman & Kurtzer-White, 1999). However, care must be taken that parents do not experience an unnecessarily high sense of urgency (and related anxiety) about accessing such options and that their expectations are realistic in relation to their individual child's situation. Perpetration of the belief that early intervention equates to normal development may serve to place unnecessary guilt or pressure on those families where early intervention does not occur, or fails to provide such outcomes. Provision of evidence-based information to families needs to be balanced in such a way as to provide the good news of what early intervention can do, within a realistic framework.

Although technology may provide benefit in specific circumstances, comments indicate that parents may hold many expectations about habilitation that fail to be met by experience (e.g. effectiveness of hearing aids; Sjoblad et al, 2001). Parents recognise that difficulties with communication continue to exist, and feel that it is not always beneficial that their child be treated as, or compared to, a hearing child. This mismatch between high expectations and experiences may serve to generate frustrations and place additional stress on families.

Parents' comments highlighted a number of areas where they perceived that their child's hearing loss continued to carry adverse impacts, despite receiving early intervention and persevering with device usage. Further, some parents admitted they did not feel confident in dealing with or adequately prepared for situations where their child's hearing devices required removal or were not functioning. The question must be raised as to whether parents' early expectations are realistic (or reasonable), and if not, how they can be more appropriately shaped, and their concerns addressed.

Practical Guidelines for Helping Parents

Parents expressed a desire for more information than they have received. It should be noted that parents' recollections of support, as discussed here cannot be compared against the actual type and amount of support actually offered by providers.

Regardless, any perception that support is lacking is likely to impact as much (if not more) on parents' wellbeing as the reality of the support levels offered (Ross et al., 1999). In some cases increasing parents' awareness and perceptions of support available may be as useful as attempts to improve levels of support.

The finding that parents require more information and support is not new, but the quest for these to be tailored to meet parents' needs as their child grows is cause for modifications of clinical practice. Individual factors will vary the quality and quantity of information needed by parents, making it impossible to put forward a single solution that fits all. Rehabilitative efforts may benefit from a semi-structured interview format to be used by clinicians to identify the varied needs of individual families and monitor parents' understanding of the information provided. The approach may include questions specifically directed at clarifying parents' key concerns at each appointment/stage of habilitation, providing information in a format that parents prefer, and giving reassurance regarding the actual likely impact of any short-term difficulties on reaching their own long-term objectives.

It is also important to remain aware that when parents are experiencing grief emotions, they may be particularly prone to seek out positive advice and focus only on this. Care must first be taken to understand what parents are hoping to achieve for their child, and look for ways to support rather than supplant any efforts they are making to do so. Some measures that are designed to help direct individualised habilitation include the Family Expectations Worksheet (FEW, Palmer & Morner, 1999) and the Client-Oriented Scale of Improvement for Children (COSI-C, Lovelock, unpublished).

The finding that a source of grief and frustration for parents is seeing that hearing devices are not effective in noisy situations may be addressed with technology and appropriate counselling. It is known that young children need a higher signal-to-noise ratio (SNR) than older children or adults for understanding speech (Gravel et al, 1999; Jamieson et al, 2004; Blandy & Lutman, 2005); and younger children need an improved SNR more often than anyone else as they rely on the auditory input for acquiring speech and language. The use of wireless systems will significantly improve signal-to-noise ratio (SNR) in noisy places. Where use of such systems is logistically not possible, directional microphones in hearing aids will help in situations when the listener faces the talker (McCreery et al, 2012). Evidence on look behaviour of young children in conversational situations suggest that they orient towards the talker, and are therefore likely to benefit from directional microphone technology fitted to their personal hearing devices. No child is too young to use the technology, as the benefits apply irrespective of the age of the child (Ching et al, 2009). It would also be beneficial to provide training for families and children on communicative strategies in real-life situations to maximise the benefit of the technology provided to them. For a child with hearing loss, access to auditory information is a pre-requisite for speech

development. A pro-active approach that evaluates the effectiveness of amplification for the child is not only clinically motivated best practice, it is also useful in building rapport with families and helps to alleviate anxiety of parents especially when validated report tools that directly involve the parents, such as the Parents Evaluation of Aural/Oral Performance of Children (PEACH, Ching & Hill, 2007) or the Infant-Toddler Meaningful Auditory Integration Scale (IT-MAIS, Zimmerman-Phillips et al, 1997), are used. The appropriateness of hearing aids should be checked regularly and especially when changes in hearing loss or in the child's life occur.

The question of how better to encourage speech and language development for children is more difficult to address. Current knowledge suggests that socio-economic factors and maternal education, rather than age of intervention, significantly impact on children's development (Ching et al, 2013). It will be necessary for professionals to join forces to maximise auditory input, optimise auditory training, monitor progress, introduce alternative intervention options if necessary, and promote language development activities that meet individual children's developmental needs as early as possible.

A cross-disciplinary approach to providing intervention would allow parents to feel better supported in their decision-making following their child's diagnosis. While parents are likely to continue needing to visit a variety of hearing and educational professionals to discuss their child's rehabilitation, benefit may be found in providing the means for all professionals to communicate their findings and advice with each other. One suggestion may be the use of a "Communication diary" that is kept by the parent/child to allow each professional to make notes for sharing important information or changes about the child with others. Such a system would have the added benefit of providing parents with a written record of the many appointments and advice they receive from hearing professionals over their child's early months and years.

Caveats

Parental responses reported in the current study showed a strong emphasis on practical versus emotional challenges. This does not necessarily reflect the actual balance of concerns by parents, as being more worried about practical issues. Rather, it may be that parents feel more comfortable/capable of discussing practical-based issues (especially in an impersonal questionnaire format) that they may see as being able to be addressed by outsiders, than more personal emotional-based concerns. Further investigations using face-to-face interviews will be necessary to probe into some of the latter concerns.

Although some issues were mentioned by more respondents than others, this does not necessarily indicate that fewer participants were concerned about that issue overall. Rather, the issue may be something that many parents did experience at some time, but was not the most pressing issue, or one that occurred to them at the time when presented with the question.

It should be noted that the size of the sample reflects a potentially small response rate of surveys from the number of parents invited to participate. However, the context in which the survey was distributed (as part of a larger, ongoing, study) and the nature of the invitation (a non-personalised, general invite without subsequent follow ups) should be taken into account. Further, the decision not to collect potentially identifying information makes it difficult to determine the extent to which the sample reflects the wider population. Even though the limited information that could be gleaned from responses suggests that participants were from different regional areas and circumstances, with a good range of ages, the representativeness of the sample cannot be determined. The size of the present sample and the criteria for inclusion limit the ability to generalise response patterns as

indicative of the size of the concerns in the larger population. This will have to be examined in future research.

Conclusions

The present findings identify areas in which hearing professionals may modify clinical practice in light of research on parent experiences. The first relates to provision of information in a structured manner that is tailored to the varying needs of parents at different stages of their child's development. The second relates to potential alleviation of grief and anxiety of parents and frustrations of children by using state-of-the-art technology and providing training on compensatory strategies.

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Abbreviations

UNHS Universal Newborn Hearing Screening

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Table 1

Parent's preferences for later or earlier diagnosis

Preference:	Early (<6mths)		Late (>6mths)	
	Late (n=3)	Early (n=15)	Early (n=6)	Late (n=2)
Reasons given				
Parent concerns:	Parent felt too worried to enjoy baby; Parent felt cheated out of just enjoying time with newborn;	Parent in better position to provide support; Parent not left to worry about delayed speech;	Parent was left with question of onset time and "what ifs"; (For child with LVAS) Parent may have been more protective	Parent got to know newborn without sadness; Parent didn't think bonding was affected.
Child Concerns:		Child could receive hearing aids/ intervention earlier; better able to tolerate hearing aids; Child more likely to achieve better outcomes, earlier and better speech	Child was frustrated, angry, behind in schoolwork; speech would have been age-appropriate;	

Table 2

Parents' early and later experiences following diagnosis

	Early experiences after diagnosis	Later experiences
Grief	Shock, devastated	Triggered at developmental milestones – child's development not within normal range Triggered at important events – kindergarten, schooling
Underestimate impact of HL	Believe fitting hearing devices (hearing aids or cochlear implants) will fix the problem	Found that child continued to have problems in some real-life situations, despite device usage
Anxious about device management	Distressed when being criticised for not trying hard enough to keep devices in the ear; Worried about impact of non- use on child's development	Recognised that the initial difficulties with device management was a phase that will pass.
	Need to become more competent with trouble-shooting of devices	Children took responsibility for use of devices, could tell parents when devices were not working
Want information	Uncertain where to find help, need information presented in such a way that will meet their current needs	Need for information as the child grows and have different needs
Early diagnosis is good	Allows family to start to deal with the problem; Child can get early intervention and develop normal speech and language.	
Later diagnosis is good	Allows family more time to enjoy their new child; Allows family more relaxed opportunities to bond with their child.	Regret lost time- Even a few months later would be better to allow parents time to bond with their babies without worry or sadness.
Stress arising from difficulties in supporting their child with hearing loss		Frustrated with perceived delays in the child's speech and language skills Perceived inadequacies of devices in some real-life situations and observed children experiencing difficulties Dealing with and managing child's frustrations arising from communicative difficulties Not sure if child's misbehaviour or lack of response to verbal instructions was due to hearing loss per se Felt the need to remind themselves and others about their child's difficulties due to the hearing impairment Felt unprepared to be the advocate for their child with others