

A qualitative review of parents' perspectives on the value of CAEP recording in influencing their acceptance of hearing devices for their child.

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Abstract

Objective: To obtain a parental perspective on how audiological tests, including recording cortical auditory-evoked potentials to speech sounds (CAEP), influenced their uptake of hearing devices for their infant.

Design: A focus group was established of parents of hearing-impaired children. A facilitator explored how audiology tests influenced their understanding and management of hearing loss in their child and their acceptance of hearing aids or cochlear implant referral. The views were transcribed and thematic analysis was used to understand key topics.

Sample: Eight sets of parents participated. Their children had been enrolled in an audiology pathway that included CAEP testing. The sample included 6 children who were aided, 1 child who was going through the implant assessment and 1 child who was implanted.

Results: Parents reported that it was important for them to understand the test results because this influenced acceptance of hearing aids and cochlear implant assessments. Seven sets of parents had not understood ABR results whilst 6 reported that CAEPs had helped them to understand their child's hearing and need for intervention.

Conclusion: Compliance with early hearing aid use and referral for cochlear implant depends upon parents' understanding of their infant's hearing loss by including CAEPs in the audiology pathway.

Introduction

Babies born in the UK are screened for hearing loss through the newborn hearing screening programme (Davis & Hind, 2003). Those requiring diagnostic assessment are referred for auditory brainstem response (ABR) to estimate the degree of hearing loss. If hearing aids are required, then the prescription gains are also derived from these results. At this age parental observation of the behaviour of infants to sound is often ambiguous and so the ability of families to understand the impact of the hearing loss largely depends upon information provided by the audiologist and hearing support team. Optimal day-to-day use of hearing aids depends on the commitment and determination of parents to place the hearing aids on their child, and to provide a good listening environment and spoken language input. This can only be achieved if families understand the impact of hearing loss and the importance of using amplification which provides access to speech (Muñoz et al, 2015). In those with a more severe loss the age at cochlear implantation is an important factor in determining speech and language outcomes (Sharma A et al, 2002; Nicholas et al, 2008). Ching et al (2013) in their prospective study of three-year olds found that better outcomes were associated with a younger age at cochlear implant switch-on. Other studies support this and report that children implanted within the first year of life can achieve age appropriate spoken language (Holman et al., 2013; Dettman et al., 2016). The possibility of achieving better outcomes in children who are implanted in infancy has encouraged the promotion of very early implantation (Sharma S et al, 2017). However, parents need to be able to make informed decisions which require a good understanding of the severity and implications of their child's hearing loss, and the options that are available to them.

The recognition of hearing loss and the subsequent use of hearing devices by the family impacts upon the deaf child's language development. Watkin et al (2007) who explored language ability in 120 children with Permanent Childhood Hearing Impairment (PCHI) and reported that family participation correlated positively with language development. Holzinger et al (2011) quantified the effect suggesting that 60% of the variance in speech and language outcomes was explained by family-related factors. Thus, we can predict that the use of hearing aids may be less effective when parents do not understand the implications of their child's hearing loss or the purpose of hearing aids thus compromising management. Munoz et al (2015) reported the challenges faced by parents for achieving consistent aid use. The challenges they found was inconsistent hearing aid use, expectations not addressed by audiologist, lack of hearing aid benefit and psychosocial challenges. The children enrolled in their study had been issued with hearing aids for some 15 months, but as toddlers one-third were still wearing them for less than 5 hours a day. Walker et al (2015) in a longitudinal study of 290 children found that although the majority of children had been identified neonatally, the mean age of hearing aid fitting was 11 months and in those aged less than 2 years, over half were wearing their hearing aids for less than 4 hours a day.

Punch et al (2016) reported a retrospective review of 83 infants with PCHI, who were fitted with hearing aids based on CAEP results that were used to determine prescriptive targets according to the Australian national protocol. Their findings indicated that professionals believed CAEP testing had a positive impact on the effectiveness of hearing aid provision and that CAEP testing was well received by parents as a counselling tool to help reassure them that the hearing aid was providing sufficient amplification. This led to integration of CAEP testing into the Australian routine infant hearing aid fitting program.

Mehta et al (2017) reviewed data for an inner city UK clinic following the introduction of CAEPs into the infant audiology assessment pathways. They observed an earlier age for cochlear implant referral for severe-profound hearing loss, and also an earlier age of amplification for infants with mild-to-moderate hearing loss compared to a cohort of children assessed prior to the introduction of CAEPs in the pathway. They hypothesised that the important change for those infants with a mild-to-moderate hearing impairment arose in part because the CAEP recordings enabled parents to be better informed about both the effect of the hearing loss and the impact of hearing aids.

Mehta et al (2017) and Punch et al (2016) used a system that measured CAEP responses to speech sounds presented from a loudspeaker placed in front of the child. Three speech sounds with a spectral emphasis in the low, mid and high frequency regions were used (Van Dun et al, 2012). The CAEP test can be conducted with and without hearing aids to demonstrate the impact of amplification on the child's detection of speech sounds. With this approach parents can hear sounds of different frequencies and levels and can understand how quiet or loud they are. The CAEP recording to speech stimuli enables parents to observe their child's recorded responses with and without hearing aids and this can be used as a counselling tool enabling parents to make informed decisions about their child's needs.

As stated earlier, we hypothesise that the reduction in age at intervention with hearing devices reported by Mehta et al (2017) was in part due to the use of CAEP recordings to help audiologist aid mild-to-moderate hearing losses and for parents to better understand their child's hearing loss and to engage with the use of the hearing devices that were available to

them. To further investigate this particular hypothesis a focus group of parents was held to explore how different elements of the infant audiology pathway influenced parent's understanding of their child's hearing loss, which specific aspects were most important and whether this empowered them to make hearing device choices.

The infant clinical audiology pathway

The study took place in the paediatric audiology department in an inner city UK clinic. All the infants referred from neonatal hearing screening were placed on a post-screen diagnostic test pathway which included ABR and unaided CAEP recording. The post-screen diagnostic tests were undertaken by experienced paediatric audiologists. The initial audiological assessments were followed by hearing aid fitting with the recording of aided CAEPs to determine the effectiveness of the amplification. All the children identified with a hearing loss were offered regular follow-up appointments with continued assessment which consisted of visual reinforcement audiometry (VRA) using the Ling 6 sounds and eventually conditioned play audiometry. Identification of PCHI prompted immediate referral for parental support and educational counselling and guidance. Peer-to-peer support was given by a parent support worker (PSW) with experience as a parent of a deaf child. Parental counselling and guidance was provided by a specialist teacher of the deaf (TOD). Both supportive services were undertaken within the home and in a centre run by the Early Support Team for families of deaf and hearing-impaired children.

Methods

Ethical Considerations

The study was registered as a service evaluation with the Hospital Research and Development department: registration number 1275. Written consent was taken from the

parents to participate in the focus group and for the facilitator to make audio-recordings of the discussions and to record any comments that were made by the group.

Selection of focus group participants

Parents were identified through a purposive selection process to include families whose children had been identified with a bilateral PCHI by the Newborn Hearing Screen Programme and who had been managed by an audiology pathway that included the recording of aided and unaided CAEP. Although not necessarily the first language of the home, 15 families who could speak English were invited by letter to participate in the focus group. The invitation was subsequently followed up by contacting the families with a text message. The invitation requested that when possible both parents or a parent and another primary carer attend the focus group. Very often decisions are made by the primary carers away from the clinical appointment and it was considered desirable to include the views of those decision makers who may not have been able to be present at pivotal audiological assessments. To facilitate the attendance of working members of the family the focus group was conducted in the early evening. Ten families responded to the invitation but two were not able to attend on the date of the focus group. Single parent and same sex parents were invited but did not attend. The group therefore consisted of the mother and father of eight children, 16 parents in total. The demographic details of the group participants are detailed in table 1.

Insert table 1 around here

Both the number of participants not born in the UK and the number who did not speak English as their main language was substantially higher than the overall UK population, but typical for London, where the clinic was based. The proportion who had passed through a course of higher education was the same as the national average. Half of the parents participating in the focus group had high or secondary school qualifications gained in the UK, or the equivalent achieved in their country of birth. This was only marginally lower than the national average, but characteristic of the local resident population (UK profiles, 2017).

The eight children all had a bilateral PCHI. Their age when the focus group was held ranged from 6 to 36 months with a mean of 16.3 months. The severity of their PCHI was categorised using the British Society Audiology (BSA) descriptors as mild (20 to 39 dB HL), moderate (40 to 69 dB HL), severe (70 to 94 dB HL) and profound (>95 dB HL), using the average of the better hearing ear at octave intervals from 500Hz to 4000 Hz. The degree of hearing loss and other characteristics of the 8 children are detailed in table 2. The median four-frequency hearing loss of the eight children was 61 dB SPL in the better hearing ear. The children were categorised using their hearing loss from the initial hearing aid fitting appointment. Seven children had a bilateral symmetrical PCHI with two having a sloping high frequency loss. The remaining child had a profound loss in one ear with a moderate loss across the frequency range in the other.

Insert Table 2 around here

Focus Group

The focus group was held during a single evening session. It took place in a quiet room in the centre where the children had been assessed. The group's facilitator was the first author of this paper and the paediatric audiologist who had assessed the children. The families sat

around a small table allowing the participants to see each other. The facilitator explained the procedures to the group. It was emphasised that individual families had their own understanding, knowledge, experiences and viewpoints, and that all differences would be respected. Approximately 30 minutes were spent with the families introducing themselves and sharing their experiences about their child's diagnosis, level of hearing and use of hearing devices (hearing aids or cochlear implants).

The facilitator then explained that the aim of the group was to explore the parents' views of how the different clinical audiology tests had affected their understanding of the child's hearing and how it had guided their management of the hearing loss. The discussions aimed at exploring how the tests had influenced their use of the hearing aids and, when appropriate, how they had affected their decision to engage with further cochlear implant assessments. Leading questions about individual tests were avoided with the participants being asked to mention anything at all that they had found helpful. The facilitator used the information offered by the parents to further guide the discussions and to explore their perspective on the value of the different tests. References by the parents to specific audiological tests, assessments, events and support that they had received were recorded and if not clear the facilitator encouraged participants to give more details. All 6 of the following general questions were asked with the discussions being audio-recorded. Parents were encouraged to speak freely about topics and expand on information. Once the introduction has completed the remaining session lasted for approximately 40 minutes.

1. How confident are you about describing your child's hearing loss and could you describe your child's hearing loss for the group?
2. Do you know how your child's hearing loss will affect his/her hearing of speech and what effect that will have on them?

3. Can you remember any of the appointments/events that helped you to understand your child's hearing needs?
4. Which part of the process/appointments did you find most helpful to understand your child's hearing loss?
5. When did you feel your child needed hearing aids? What helped you realise that?
6. Do you know what your child can hear with and without their hearing aids?

The questioning prompted a wide range of discussions with the facilitator balancing the discussions and encouraging less confident contributors so that all opinions were heard. Parents had the opportunity not to answer the questions and at times were asked to discuss their responses.

Data Analysis

The audio recordings were transcribed by the first author verbatim, for use in a thematic data analysis. Thematic analysis is a method used for identifying, analysing and reporting patterns (themes) within data (Braun and Clarke 2006). The qualitative research software NVivo 10 (www.qsrinternational.com; qualitative software) was used to assist with data handling, organisation and coding. The thematic synthesis was conducted in three stages:

1. familiarisation with data: free line-by-line coding from the focus group,
2. the organisation of these 'free codes' into related areas to have general themes,
3. defining and naming themes and report writing.

The parental discussions were wide-ranging and recurrent themes that were identified in the dialogue related to the parents' feelings about their child's hearing loss and their views of the support they had received. For the current study a "top down" (theoretical or deductive)

thematic analysis was employed, and the coded data was organised into general themes that related to the discussions that were held about the clinical audiology tests with associated sub-themes of similar response by different parents focussing on how the tests had affected their understanding and management. Illustrative content was extracted from the transcribed text and is presented using quotations and includes the child's gender and age at the time of the focus group. The facilitators explanatory text is added to the transcribed text in brackets. Individual family members reinforced a unified view and therefore numeric analysis was by family rather than by parent.

Results:

The analysis of the parental discussions topics are presented in order of where they fall in the infant audiology pathway.

Auditory Brainstem Response

The parents discussed the ABR, but 7 of the 8 families felt quite negative about the test (table 3). Almost all had found it too long and although they had been shown the results by the audiologists and had them explained, they had failed to fully understand them. Two parents discussed the difficulties they had in “getting their heads around” lines shown to them on a page. Despite careful explanations by the audiologists the results were not meaningful to them. Another father asserted that his family's lack of understanding of the implications of the ABR test results had significantly hindered their engagement with further audiology appointments.

Insert Table 3 around here

An example of one parent's comment:

"..... it was our first audiology appointment, our child would not sleep, (we) had to come back to have the test repeated. We had no faith in the test until we came back and had all the other various tests done with the puppets (here parents were referring to the VRA with speech sounds)"(Parents of 12 month old boy)

"The first hearing test (the ABR) was so difficult that we didn't come back to any follow-ups.....because of this we didn't discuss hearing aid fitting until the PSW came to our home" (Parents of 15 month old boy)

Cortical Auditory Evoked Potential

All 8 families made positive comments about the usefulness of the CAEP test in helping both the understanding and management of their child's hearing loss (table 4). Seven of the families stated that the CAEP recording helped them to understand the potential benefit of hearing aid use. They commented that the CAEP test gave them increased understanding of the impact of the hearing loss and this encouraged them to agree to the trial of hearing aids. It also helped those families whose children demonstrated no aided CAEP benefit to consider the need for their child to be referred for cochlear implants. Some families discussed the initial difficulties they had encountered in recognising the presence of a hearing loss. At home, they had observed their baby responding to sounds and to their name being called. However, the CAEP test demonstrated their child's inability to hear the quiet speech sounds, and because they were themselves able to hear the sounds played through a loud speaker they were able to understand their child's level of hearing.

Insert Table 4 around here

Associated comments from the parents:

“The speech test that our child underwent when she was about 4 months, we could see from the results that she required the aids, without this we would not have agreed to go ahead with the hearing aid fitting.” (Parents of 6 month old girl)

“I also found the sticky pad test (identified as CAEP by the facilitator) useful in understanding what speech sounds my child can produce and being able to relate this to her hearing loss. As my child has a mild loss if we were not shown these test results I would not have believed the hearing loss, we would have not proceeded with the hearing aids.” (Parents of 24 month old girl)

Two of the 8 children had sloping high frequency hearing losses, and in both families the demonstration that their infants were unable to hear speech sounds with spectral emphasis in different frequency regions helped both their understanding and management. It also helped one parent appreciate the need to tune her child’s hearing aid.

“I was able to understand my child’s hearing loss when he had the test (the CAEP) without the aids. He could hear the other sounds but not the /t/. Now I could understand why he was turning to things at home and why we didn’t think he needed hearing aids.” (Parents of Male aged 12 months)

“I found it useful when hearing aids were tuned because he could not hear the m sound. I also found the way the results are set out on the screen understandable.” (Parent of male aged 15 months)

Although all families offered positive comments about the CAEP tests, there were some additional unhelpful aspects of the test. The recordings achieved for the child with a moderate loss in one ear and a profound loss in the other, reflected the hearing in her better hearing ear, and this failed to help the parents understand the complexities of the asymmetrical PCHI. Two parents had additional negative observations. One remarked that the speech sounds used in the test were “very robotic”. Another family had found the CAEP recording process disappointing as no aided benefit had been shown. However, despite this reservation they agreed that the test had helped with their child’s subsequent cochlear implant referral. They said:

“My child has profound hearing loss. I found the CAEP test to be disheartening as it showed up that my child could not hear any of the sounds even with the aids, it made us feel like ‘what was the purpose of using the aids.’” (Parents of 12 month old boy)

Visual Reinforcement Audiometry

A small number of the families participating in the group recalled and commented on the VRA test with speech sounds (Ling sounds) that had been conducted at around 7-8 months. Three had found that it clarified the hearing loss and the benefit of using the hearing aids. They also commented that it re-enforced the earlier results of the CAEP test with two families preferring the VRA test because they were able to observe their child’s behavioural responses to sound. Not all the comments were positive, and they are detailed in Table 5.

Insert Table 5 around here

Some of the comments were:

“We both felt that we came to terms with her hearing loss after the puppet test which showed us what she could hear with and without the aids. We could hear the speech

sounds from a loud speaker, which helped the process (the sounds parents were referring to were identified by the facilitator as the Ling 6 sounds). We could see when our child turned to speech sounds. We now know that the aids have been very helpful, and this has helped her speech. We use the sounds at home now to check the aids now” (Parent of 20 month old girl)

“My child hated the puppet test, every time they appeared she would freak out, need to think about using new puppets.” (Parents of 20 month old girl)

Supporting the Audiology Tests:

A theme that was identified by all parents was that they needed to understand the results of the audiology tests to engage with the available management options. However, this understanding depended upon the additional support that was given *outside* the test session. Even though the CAEP test gave them greater understanding during the session, not all the parents had been present at this appointment and most of those who had been commented that they had found it too difficult to fully understand the results and all the implications in the clinic. The parents had therefore valued the explanations and input of the PSW in the home. The consensus of the group participants was that without the input of the PSW the families would have “been lost” and they would have taken longer to decide on the aids and to make management choices. CAEP tests were used to make decisions about fitting hearing aids to two babies with a mild hearing loss. Both these parents revealed that they had only agreed to intervention after further discussions of the results in their home. The PSWs then acted as a bridge with the clinicians. The sub-themes relating to the importance of supporting the test results are detailed in Table 6.

Insert Table 6 around here

A typical comment regarding the important role of the PSWs in understanding the test results was:

“Susan Cordwell helped me understand the test results such as the sticky pad one (identified as CAEP on further questioning by the facilitator) and was good in explaining to both of us how the test fits with my child’s hearing loss”. (Parents of 20 month old girl)

Discussion

The focus group identified that both the audiological test and the support available affected the families’ understanding and management of the PCHI following confirmation by the Newborn Hearing Screen Programme. The test type and support influenced the adoption of hearing aids and when necessary the acceptance by parents that their child was a candidate for cochlear implants. The participants asserted that they needed to understand their baby’s hearing impairment before hearing aids were accepted and before they were regularly used in the home. Although ABR is used in the diagnostic assessment of hearing thresholds and in the estimation of the prescription gain for fitting hearing aids in infants, nearly all the parents contributing to the focus group reported that they had not properly understood or appreciated the worth of this test. Whilst it is professionally informative to use ABR for confirming diagnosis, the discussions held revealed that it is not easy to communicate this information to parents. Although the ABR tests had all been undertaken by experienced and clinically registered audiologists, the results had not conveyed the information that these parents needed to understand the hearing loss and therefore their adoption of hearing aids depended almost entirely upon their acceptance of the professional advice offered to them. This was difficult because most of the parents were not receptive by the end of the ABR test session.

Conversely, the recording of CAEP responses to speech sounds followed the initial diagnostic electrophysiological tests in the infant audiology pathway and this test was better tolerated. It had helped the parents to understand their child's hearing loss and the necessity for future audiological management. The demonstration of speech sounds that could and could not be heard was valued and it helped parents to realise the need for hearing aids. The CAEP results also demonstrated hearing aid benefit with a lack of gain enabling parents to accept that their child was a candidate for cochlear implant assessment. Without the use of CAEP, those parents of children with a milder hearing loss agreed that they would not have accepted management with hearing aids. The test had therefore helped them to make important management decisions with potentially long-term benefit to their child. However, once again the focus group participants highlighted the difficulties that parents had in assessing the outcome of the test during the clinical appointment. They hadn't always been able to fully take on board the demonstration or the implications of their child's hearing of speech like sounds in the clinic. Explanations and guidance offered outside of the clinical environment and within the home were appreciated by all the participating parents. This home support had helped the families move forward and engage with intervention. These discussions were particularly important for partners who wanted to be involved in the decisions being made about their child, but who had not been able to be present during the demonstrative clinical tests. The understanding the family gained from the discussions and explanations in the home empowered them to make the necessary decisions about early hearing aid use and if necessary to consider referral of their child for cochlear implant assessment.

Despite very early implementation of universal neonatal screening, the adoption of hearing aids for infants with mild-to-moderate losses has remained a continuing challenge (Mehta et al., 2017). Sjoblad et al (2001) investigated similar substantial delays between diagnosis and

hearing aid fitting across 45 American states and they identified 3 primary factors of concern for families in the early stages of their child's hearing aid use. These were uncertainty around the maintenance of hearing aids, the appearance of the device on their child and lastly not understanding the benefit for the child. In the early stages of the hearing device fitting, 65% of parents questioned the degree to which hearing aids were of benefit and 30% of parents requested better education on the sounds that the hearing aids could make audible. These parental concerns remain relevant. Walker et al (2015) in their more recent investigation of hearing aid use in 290 children concluded that inconsistent use in infancy and early childhood could be improved by an audiological demonstration of the benefit afforded by the hearing aids. Punch et al (2016) found that their recent introduction of the recording of CAEP responses to speech sounds provided this information for parents and that this test was therefore an effective counselling tool when hearing aids were fitted after the neonatal hearing screen. This finding was corroborated by the parents who made up our focus group.

Walker et al (2015) also concluded that parents needed individualised problem-solving strategies to help them in their use of hearing aids. This conclusion had also been reached by Muñoz et al (2015) in their investigation of the parent reported challenges of hearing aid use in young children. They emphasised the parental need for emotional support and when they surveyed 349 paediatric audiologists in the US, the majority recognised the need for paediatric audiologists to receive further training in counselling skills so that they could meet these emotional needs (Meibos et al., 2016). In the present study further discussions of the results of tests and their implications were undertaken within the home by a peer-to-peer support worker. This enabled decisions to be made by family members who had been unable to be present at the clinical tests. It also offered emotional support for parents as well as

individual pragmatic help for them in solving challenges they were facing with the hearing aid fitting. The parents participating in our focus group agreed that this input had been crucial to their understanding of the hearing loss, and to their management with hearing devices.

The reported study highlighted some aspects of the infant audiology pathway that can be developed to improve the parental understanding and management of their child's PCHI. The study had obvious limitations in that only 8 families participated in the focus group, and these families were those who were willing and able to attend. Walker et al (2015) found that the level of maternal education was an important predictor of hearing aid use in children. Although the London district where the focus group was held is generally an area of deprivation, the educational levels of the focus group were not atypical of those found in most other parts of the UK and in this respect, although replication with larger studies is required, the difficulties expressed by the reported focus group may be generalised. An additional limitation of the study was that the facilitator was an audiologist from the clinical practice that the parents attended. However the role of audiologist was not a central question for the group.

Conclusion

We had previously reported an earlier age of entry to intervention with hearing aids and cochlear implants following the inclusion of CAEP recording into the infant clinical auditory assessment pathway and hypothesised that this arose in part because the CAEP recordings enabled parents to be better informed about the effect of the hearing loss and the impact of hearing aids. We have analysed the discussions that took place in a focus group of parents whose infants had received the CAEP test following confirmation of their child's deafness

from the Newborn Hearing Screen Programme. The participants confirmed that recording of CAEP responses to speech sounds had enabled them to understand the impact of their child's hearing loss and the benefit of hearing aids. With help and guidance available from professional support they were empowered to make the management decisions required for their child.

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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