The Views and Experiences of Families on Bone Anchored Hearing Aid use with Children: A Study by Interviews

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This study qualitatively explores the views and experiences of families on obtaining and using a bone-anchored hearing aid (BAHA) device. A semi-structured interview format was used to collect responses from 10 families from different geographical regions of the UK. Findings indicate how the use of BAHA was valued by families. Although participants identified that BAHA devices improve both the clarity and directionality of sound, the most consistently reported benefits related to social, psychological, and educational functioning. BAHA devices were perceived to give children the opportunity to interact with others reducing isolation and improving self-esteem and self-identity. However, the findings also demonstrate that BAHA devices are not without challenges. Responses identified how professionals need to provide accurate information to families to aid them with the complicated decision-making process they are working through in deciding whether to have a BAHA or not. Managing the expectations of what BAHA devices can and cannot do is vital to ensure that families are able to make a fully informed decision. The availability of appropriate advice, information, and support (including peer support) is an important part of this process. Families involved in this study were clear that in many circumstances there were system errors in relation to their care package and these experiences can have a negative impact on their experiences of the device itself.

Keywords deaf children, hearing loss, bone conduction hearing aids, users’ perspectives, families’ perspectives, qualitative research

Introduction

Fortnum et al. (2001) identify that more than two children a day are born in the UK with significant and permanent hearing loss. The introduction of newborn screening...
programmes, allows for the early identification and referral for treatment of children at a very young age (Snik et al., 2008). However, even before the routine screening of newborns, Kuhl et al. (1992) discussed the importance of early intervention for lessening the impact of hearing loss on the child, their family, and the wider society. Kochkin (2000) argues that left untreated, individuals with hearing loss are more likely to report depression, anxiety, and paranoia. They are also less likely to participate in organized social activities when compared to those using hearing aids (Kochkin, 2000). Mohr et al. (2000) calculated that severe to profound hearing loss is expected to cost society $297,000 over the lifetime of an individual. Lifetime costs for people with a prelingual onset exceed $1 million (Mohr et al., 2000). This indicates that early identification and intervention with deaf children can have a substantial payback across health, education, and other services (Mohr et al., 2000).

Hearing aid use is therefore associated with significant improvements in social, psychological, emotional, and physical aspects of the lives of deaf people (Hagr, 2007). However, for some hearing impairments the use of air conduction hearing aids has been problematic, if not impossible. For this group, bone-anchored hearing aids (BAHA) are possibly the only satisfactory solution. The first patients were implanted with BAHAs in 1977 and the device became commercially available in 1987 (Tjellstrom & Granstrom, 1994). Since their introduction, Cochlear (2010) estimate that more than 50,000 people worldwide have received a BAHA device. Researchers such as Arunachalan et al. (2000), Cremers et al. (1992) and Hol et al. (2010) have demonstrated the benefits of BAHA devices on a range of objective audiological outcomes. Short- and long-term efficacy has also been shown in studies conducted by Linstrom et al. (2009) and Wazen et al. (2001).

There has also been a plethora of studies which have explored patients’ satisfaction with BAHA devices. Typically, these studies have utilized a questionnaire design and have indicated strong support for using BAHA devices (Lustig et al., 2001; Dutt et al., 2002; McLarnon et al., 2004; Gillett et al. 2006; Newman et al., 2008). However, satisfaction with the device relates to only one part of the patient experience and there is a dearth of research which explores the practical aspects of getting and using a BAHA for children and their families. The device itself is closely related to the overall care package received and the support available within both health and education services. Although organizations such as the National Deaf Children’s Society (NCDS, 2010) have produced guidelines related to the care pathway, it is not clear how closely individual experiences mirror these (NCDS, 2010). Similarly, there is a lack of research into the pragmatic and practical issues associated with having a child who uses a BAHA. These research questions can only be explored using qualitative methods. Qualitative research has been used extensively to explore patient experiences of healthcare, including within audiology (Knudsen et al., 2012). Given the potential impact to the individual child and their family as well as to society more widely of early intervention with appropriate technology for hearing impairment, this study aimed to explore the experiences of children and their families of the care pathway related to obtaining
and using a BAHA device and explore the practical issues related to BAHA use for children and families.

**Methods**

**Research design**
The research study utilized an exploratory, qualitative design. A SL24 form was obtained from the NHS Research Ethics Committee prior to the study commencing and an ethical review of the study was conducted (Appendix 1). While fulfilling the ‘procedural ethics’ requirements is essential to the delivery of a successful research project, there are other dimensions to ethical conduct which relate to a researcher’s practice (Guillemin & Gillam, 2004). To ensure participants were able to give informed consent a participant information sheet and consent form was emailed to individuals when they were first contacted to take part in the study.

**Sample/participants**
For the purposes of the study the term participant is used to refer to the families who were involved. In some cases this refers to an individual parent, for others this is a family group interview with the child/young person present. A purposive sample of families was recruited to the study using The Ear Foundation’s Research Forum. Table 1 summarizes the characteristics of the children involved in the study.

**Data collection**
Data were collected via semi-structured interviews and these were either conducted individually or in family groups. The same schedule was used for all the interviews and they were audio recorded. Written field notes were also made during the interviews. Immediately after the interviews, initial reflections and analytic notes were documented. A copy of the interview schedule is included in Appendix 1.

**Data analysis**
All the interviews were audio recorded and transcribed verbatim. Thematic content analysis was then used to interrogate the data (Green & Thorogood, 2004). This method involved several steps. First, the typed transcriptions were read through in their entirety several times, so that a sense of the whole narrative could be obtained. The next stage was to go through the transcripts in detail to identify meaning units, which were then grouped together without losing the original context in which the statements were made. These grouped units were consolidated with codes and compared on the basis of similarities and differences between them. They were then consolidated into tentative themes.

**Validity and reliability/rigour**
Rigour within the research process was judged using the criteria of credibility, dependability, and transferability (Lincoln & Guba, 1985). To ensure the credibility
## Table 1

**Characteristics of the Participants**

<table>
<thead>
<tr>
<th>Participant no.</th>
<th>F001</th>
<th>F002</th>
<th>F003</th>
<th>F004</th>
<th>F005</th>
<th>F006</th>
<th>F007</th>
<th>F008</th>
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<tr>
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<td>2 years</td>
<td>12 years</td>
<td>15 years</td>
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<td>4 years</td>
<td>4 years</td>
<td>3 years</td>
<td>6 years</td>
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<td>Conductive hearing loss</td>
<td>Bilateral microtia</td>
<td>Congenital conductive hearing loss</td>
<td>Conductive</td>
<td>Sensori-neural</td>
<td>Microtia and atresia</td>
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<td>Unilateral: left ear</td>
<td>Unilateral: left ear</td>
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<td>6 years</td>
<td>3–4 months</td>
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<td>Birth</td>
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<td>Age when Given a Baha</td>
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<td>6 years</td>
<td>1 year</td>
<td>11 years</td>
<td>14 years</td>
<td>13 years</td>
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<td>3 months</td>
<td>8–10 months</td>
<td>4 years</td>
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<td>Current Baha Status</td>
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<td>Soft headband</td>
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<td>Soft headband</td>
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<td>1</td>
<td>2</td>
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of the interview guide, the views were obtained of other researchers who had conducted projects within the subject area. Credibility was also increased by discussing preliminary findings with other members of staff at The Ear Foundation and researchers at CLAHRC-NDL. The audio recording of the interviews and verbatim transcription has increased the dependability of the findings as there is a clear audit trail which demonstrates how themes have evolved. Writing notes throughout the research process has also allowed for reflection and ideas which could influence the research process to be articulated and made transparent. The transferability of the findings to other contexts was enhanced by making links with the wider body of knowledge in the subject area, using direct quotations as part of the analysis process and providing as much background information relating to the study participants as possible.

**Findings**

The findings are based on ten family interviews, seven were conducted individually and three in a group situation. Four main themes were identified in the participants’ accounts which describe their BAHA journey:

- the impact of deafness
- experiences of the care pathway
- making an informed choice: weighing up the benefits and challenges
- Getting and using a BAHA.

These themes were a result of subthemes being grouped together as part of the analysis process, this is summarized in Table 2.

Quotes are used throughout the narrative to illustrate and provide lived examples of the concepts being discussed. Any changes which have been made to maintain

<table>
<thead>
<tr>
<th>Main themes</th>
<th>Experiences of the care pathway</th>
<th>Making an informed choice: weighing up the benefits and challenges</th>
<th>Getting and using a BAHA</th>
</tr>
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<tr>
<td>The impact of deafness</td>
<td>Accessing hearing technology</td>
<td>Finding information</td>
<td>Using a BAHA: try before you buy</td>
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<tr>
<td>Experiences of the care pathway</td>
<td>Knowledge of BAHA outside of specialist centres</td>
<td>Getting practical advice: the importance of peer support</td>
<td>Having patience</td>
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<tr>
<td>Making an informed choice: weighing up the benefits and challenges</td>
<td>Communication with professionals</td>
<td>Managing expectations</td>
<td>Accessing sound: benefits and difficulties of everyday BAHA use</td>
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<tr>
<td>Getting and using a BAHA</td>
<td>Funding a BAHA</td>
<td>Having a choice of BAHA manufacturer</td>
<td>Changes to the design of the device</td>
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<tr>
<td>Decision-making processes</td>
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</tbody>
</table>

**TABLE 2**

THE MAIN THEMES AND SUB THEMES FROM THE ANALYSIS PROCESS
confidentiality are highlighted. The themes are presented sequentially in an ordered and discrete manner to aid reading. However, they should not be seen as representing a hierarchy or as mutually exclusive categories. In reality, participants described a process of constant movement between themes and the different parts of the BAHA journey.

**The impact of deafness**

**Emotional responses to child’s deafness**

Participants described the impact deafness had on their families’ lives. For all the families involved there was no forewarning that their child would have a hearing impairment, antenatal checks did not identify any difficulties. When parents realized that there was or could potentially be a hearing problem they described a range of feelings including devastation, disappointment, shock, and sadness.

I was devastated I felt completely sick. I thought oh my God it’s just something that happened to people who missed hospital appointments. Completely and utterly overwhelmed. (F001).

Six families had children with Microtia and the deformed outer ears were identifiable at birth. Having microtic ears provided a visible cue to a child’s difficulties and parents expressed discrepant views about whether this was beneficial. For four of the families it was positive as it allowed for support from birth:

I think because [childs name] condition was so obvious it was a good thing, I’ve always said it was a good thing because it meant we got sort of the support that we needed from day one. (F008)

Whereas for others (two) there were concerns that it could lead to stigma and discrimination:

I think you are always paranoid that someone is staring at you, and this or that or is it the shape of her ears. Can they see this? Can they see that? (F009).

**The challenges of single sided deafness**

Five families had a child with a unilateral hearing loss. Single-sided deafness posed specific problems for the participants. Two participants described difficulties in obtaining a diagnosis and once this had been given they were told that there was nothing that could be done as they still had ‘one good ear’:

It was through the health visitor and then they referred us to the ENT consultant. And they did a brain stem test because they thought she was too young to be able to do the big test accurately. And after that they just said that’s it we don’t do anything for single sided deafness, go away. (F006).

**The impact of deafness at school**

Two children were labelled as having behavioural difficulties by teachers. Schools often emphasized strategies such as sitting in the right place or facing the teacher;
however, the difficulties experienced by children with hearing impairment in group situations was often not acknowledged. One parent fought to have their child identified as ‘deaf’ in order to gain access to the support that was required:

So you know that’s why I’m pleased we got the statement for [child’s name]… You know the National Deaf Children’s Society family officer said to me that she wasn’t aware of anybody else in the country with a unilateral hearing loss that has got a statement. (F004).

As well as effecting educational performance, deafness was described as having an impact on every aspect of a child’s health and wellbeing. Two participants described children being more physically tired (in comparison to other children). All of the participants discussed the social and psychological effects such as reduced self-confidence and self-esteem, increased social isolation and in some cases being bullied at school:

In the summer holidays she just broke down and it all came out about how much she was being bullied, how she felt stupid because she didn’t know what other children had done and you know known and she didn’t know the letters of the alphabet, I mean and this is a really bright child we are talking about… and it was stuff like the children used to make L signs like that with their hands and they used to call her [child’s name] loser, that was her name in class. And it is just not good enough. I mean I know children are children and but at the end of the day she was being bullied really because she was deaf. (F004).

In summary, participants described a huge range of impacts that having a deaf child had on their family. Parents had strong emotional responses when they first realized there was a problem and establishing a diagnosis was problematic for some people. The invisible nature of deafness often hindered the process of diagnosis, although the presence of visible cues such as Microtic ears was sometimes perceived to be beneficial to accessing help. Others, however, were concerned about the possibility of stigma. The impacts of deafness could be wide ranging across the physical, psychological, social, and educational spectrum.

**Experiences of the care pathway**

**Accessing hearing technology**

Overall the majority of participants (nine) stated that they were pleased with the BAHA device and to be able to access technology which would have a large impact on their children’s quality of life and wellbeing. However, they spoke at length about their experiences through the care pathway in terms of gaining access to BAHAIs and also the ongoing support package they received. Participants described a complex network of professionals involved in the management of their child’s deafness and using a BAHA device. This included individuals within statutory health, social, and education services. Unfortunately, eight of the families described
systemic communication problems within statutory services. Three parents explicitly outlined how the onus was on them to chase services and make sure appointments were organized on time. In some situations they outlined how they would have to contact an organization multiple times to ensure their family’s needs were met:

So you know in three months time I’ll be back on the phone, are we on the waiting list? Why aren’t we on the waiting list? Can you call me back? And then I will just mark it in my diary every three days to call them and bug them. And in the end it will be easier for them to give in than to deal with me every two or three days. But it shouldn’t be like that. I mean not all parents have the time or necessarily, have you know, have the opportunity to get on the phone every few days. (F003).

**Knowledge of BAHAs outside of specialist centres**

All the participants reported that outside of specialist centres there was often poor knowledge of BAHA devices with individuals being given inaccurate information about where to go to get help or what to do if the device broke. Parents expected that professionals such as teachers of the deaf and speech and language therapists should be able to offer help; however, in four cases they were not able to. Two families also reported that

General practitioners and practice nurses found treating any problems they had with the BAHA or the abutment site difficult:

Yeah we’ve had that with the practice nurse. I couldn’t get a dressing put on it. She wouldn’t touch the swelling she was worried about it. Touching it. (F006).

Mum and Dad used to clean it every day and I think when I went to Uni I had to keep that up. I did go to the nurse, they weren’t as good at cleaning it as my Mum and Dad were. I think Dad had to come with me to the nurse as well, to show them how to clean it… I think at Uni the nurses were a bit reluctant. (F002).

Within mainstream education parents were shocked at the lack of understanding shown by some teachers in relation to deaf children. One parent stated that it had been documented in her daughters records that she ‘used deafness as an excuse’ for poor behaviour in the classroom. When parents experienced these difficulties and attitudes it often lead them to lose confidence in the professionals and services they were receiving:

Unfortunately what we then still encountered was, well she’s got one ear and she’s just not listening. And in fact I got hold of her school records and they, its actually on there and I quote, from them, from memory because I’ll never forget it ‘class teacher feels [child’s name] uses her deafness as an excuse…’ we actually had her withdrawn from school in September. (F004).
Communication with professionals
As well as problems between different elements of the care pathway, participants also expressed concerns about how professionals within specialist services communicated with them. Six parents reported that audiologists failed to explain clearly what test results meant. They also failed to empathize with parents regarding the practical difficulties they experienced, particularly in relation to getting small children to wear the BAHA. One parent stated they had received letters which contained inaccurate information about their child. These participants reported that they had no doubt that the audiologists they were working with had a good academic grounding, characterized by statements such as: ‘they have read all the books’ but they lacked the interpersonal skills to build relationships with the families they saw. One family also complained that there was a lack of basic deaf awareness during consultations. This family also highlighted the integration of the experience of care with having positive view of the BAHA device itself. It was clear within this account that the two elements were closely linked together:

If there had been more co-ordination and each knew what the other was doing sort of thing and working together you’d have a far more favourable impression of it wouldn’t you, and maybe a bit more deaf awareness. Because when you talked they kind of sat with their back to you. (F006).

Funding a BAHA
One aspect of the care pathway that all the participants discussed was funding. There was huge geographical variation in whether families could easily obtain funding for one or more BAHA devices. One participant stated that they had no difficulties in obtaining funding for two BAHAs from their local Primary Care Trust (PCT) but they were now also accessing services elsewhere for cosmetic reconstruction and they did not fund two devices. They were concerned that by seeking specialist support elsewhere they would lose the opportunity to have two BAHAs. Another participant stated that their daughter was given one BAHA from being only a few weeks old and had huge benefits from it. However, their local PCT had refused to fund two devices despite this being identified as a clinical need. Some participants expressed concerns that because their child was struggling to decide whether to have a BAHA that by the time they had decided the opportunity would no longer exist due to budget cuts. Participants expressed frustrations that funding decisions appeared to lack a transparent process and were often made without talking to the clinicians or families involved:

Because these are real people who decide what, whether you get the funding or not, they don’t know the person who is getting the hearing aid or not getting the hearing aid. They don’t know, they don’t really have much experience in how severe deafness is and how bad it can impact on you and just hearing, knowing that I could have the chance of hearing things I’ve never heard before and for them to say no, it just sort of, yeah I do... I felt let down.
Because you expect someone who makes those decisions to know, the severity of actually going through..., research just how bad the hearing loss of that person is and research how much it will benefit them. And you'd expect them to do that, but they didn't really. They just based it on the information they got, they didn’t go and ask questions, ask my Doctors, my Audiologists, they didn’t ask and they didn’t even ask us (F005).

In summary, the BAHA device is only one aspect of the care package a family receives. Although the technology is crucial to improving a child's hearing the care pathway and route through services has a vital role to play. Professional attitudes and interpersonal skills can have a lasting impact on families’ experiences of using a BAHA device. While the participants in this study have some positive things to say about the service they have received, a lack of transparency and a systemic failure to communicate adequately dominates their accounts.

Making an informed choice: weighing up the benefits and challenges

Finding information

Deciding to have a BAHA was a complicated decision for families to make. It involved an analysis of the benefits and challenges to the child and this relied on families having access to comprehensive advice, so that the choice was fully informed. In some cases (three) statutory services were able to answer all the questions participants had and gave them written materials which they could look through. However, in many cases (six) the only information which individuals had was what they could find out for themselves through the internet. Parents also stated that while being giving leaflets was useful, it was often difficult to find the time to read them and they were not necessarily written in language suitable for a lay person. One participant stated that it would be helpful to have a summary document or ‘idiots guide’ to BAHA particularly near the beginning of the process:

What would I have found useful? I think a really short Dummies guide because giving somebody a stack of leaflets, it’s just you know I don’t have the time and half the time you file them away and forget about them. So you know something really short, really punchy, what it is, how it can help your child, trouble shooting guide, that sort of thing and then further web addresses or whatever should you want to find out more (F003).

Getting practical advice: the importance of peer support

Participants also reported that there was a failure to answer what they termed ‘practical’ questions; professionals did not seem interesting in dealing with these concerns which were often a priority for families. ‘Practical’ was used to refer to a range of different issues associated with having a BAHA. Parents spoke of a need for strategies to use with younger children to persuade them to wear the BAHA and of the dissatisfaction they felt when professionals just told them to ‘keep trying’ (two
participants). The practical issues associated with the operation, for example, how long it would take and how long a child would need to be off school were also cited as questions which parents felt unable to discuss with professionals. On family stated that they were given no information related to the aftercare of the abutment site:

And I think some preparation for just after the operation on how to look after what is quite a significant wound. Looking after this thing when you’ve never ever seen one before. And the first time you do see it you think, is it meant to look like that. Well they don’t tell you, they didn’t tell us anything about it or how to deal with it. We were just left. (F006).

To obtain information related to the practical aspects of having a BAHA, all the participants spoke of the value of peer support and the use of online forums, support groups, and the work of third-sector organizations. None of the participants had contact with other families or children with BAHAs through statutory services, despite being told that this would be organized for them. Participants stated that being able to have contact with other children or families who had gone through the same process as them were important as this offered them the opportunity to ask the questions which they felt unable to articulate to health-care professionals. One of the young people interviewed stated that it was contact with another teenager who had a BAHA which had convinced her to try it. Similarly, another participant stated that if her daughter could meet someone else with a BAHA she might be more willing to persist with wearing it:

They did suggest that they could get in touch with a child with it who’d had the operation but actually it didn’t come to fruition... and I think if we’d been about to have some kind of contact I think that might have encouraged her... but I don’t know I mean I think if she knew other people who wore it she’d be fine. (F004).

As participants could not access peer support through statutory organizations they looked to online forums (in particular the Microtia Mingle Facebook page) and third-sector organizations and support groups to fill this need. The forums and groups not only helped them to find out information from others who were ‘further down the line’ than they were, it also allowed them to share their experiences and to help others. This altruistic function of peer support was important to parents and there was some regret that there were not more opportunities to meet other families in similar situations:

I think just through speaking to other parents in similar positions and actually the older members that have, that can speak for themselves I suppose. And just people, speaking to people who, have..., are kind of behind you, so had all the questions I had, like maybe a year or two ago, and are feeling that I could offer advice. (F007).
Managing expectations
As well as ensuring families are given accurate information about BAHA devices, it
is vital that professionals manage their expectations about what it can and cannot
do. One family stated that they were told a BAHA could restore normal hearing
and subsequently were disappointed with the outcome following implantation.
They stated that they felt the professionals involved had misled them and this
meant they have started to question all the advice they had been given:

No I’m not very confident in them… You need to seriously consider where you’d
have the procedure done… are they doing a lot of them? And have they got the
knowledge… I think it’s certainly worth going to a centre where they’ve got a
lot more expertise than where we went… But I don’t know how you find that
out though. Or where you’d find information on who is best at doing it… It
would be nice if we could find out some information about the surgeons who
perform the BAHA and how often they are having to do revision surgery just
in case there is a link between the skill of the surgeon and the way it is
done… yes and the location of the implant as well maybe that makes a differ-
ence. (F006).

Having a choice of BAHA manufacturer
All the participants were asked if they had been offered a choice of BAHA in terms of
either a particular model of the manufacturer. Only two participants were aware
that there were different manufacturers, the others had all assumed there was
only one. Families who had existing knowledge or who had undertaken research
had in some cases been able to request a particular model (two families), but the
remaining participants assumed that the professionals they were seeing would
give them the most appropriate device. Some parents (three) noted that there was
a culture that if they did not ask for something they were unlikely to get it:

I think it will be, if I see something I will need to mention it or I will ask or bring
it up… I can see why it’s done. Money. On the other hand if it’s better then it’s
wrong that it should be those that are in the know and can do the research are
the ones who get it… but when you’re in that position you do it. But there’s just
no consistency anywhere about who gets what or what should be the standard.
(F009).

Decision-making processes
Participants also raised the issue of who within the family unit actually made the
decision to go ahead with having a BAHA fitted. Two parents indicated that at a
certain age (approximately 12 years) they felt that the young person should make
the decision themselves. They were not happy to force something on them which
they may regret or resent later. Nine parents suggested that the earlier children
could have access to BAHAs the better. As well as an improvement in social, edu-
cational, and psychological outcomes, children grew up being used to hearing
through the BAHA and parents were happier to make a decision on behalf of a child the younger they were. Two parents identified that the peer pressure and desire to fit in during early teenage years meant that having a BAHA at this time was particularly difficult for some young people:

And that’s the thing for me with the BAHAs is that I think if [child’s name] had the opportunity to try one when she was very young, I think she would have had it. She would have got used to it and we wouldn’t have had all the image issues. Whereas now she is at that stage where she’s starting to develop, you know she wants her hair in a certain way, it’s got to be combed in a certain way, whatever you know. And all those sorts of things and she’s not you know she’s just a straight forward hard working child. She’s not an over the top one but she doesn’t want to be marginalised because of something. (F004).

In summary, coming to a decision to have a BAHA was not always an easy one for families to make. It involved a complex process of considering the benefits and challenges relating to a BAHA and how much of an improvement it would bring to a child’s functioning in relation to the practical implications of the operation and the aftercare required. To make this decision, families need accurate information from health-care professional and their expectations managed of what a BAHA can and cannot do. Peer support and learning from the experiences of others can in some cases be the deciding factor. Health-care services also need to be aware that relatively young children may be making the decision about whether to have a BAHA device themselves and so the information they are given needs to be understandable by them. Currently, there is a lack of awareness related to the different types and manufacturers of BAHA devices and families on the whole do not appear to have a choice over what they are given.

**Getting and using a BAHA**

**Using a BAHA: try before you buy**

Of the ten families who participated in the interviews, four had children who had been implanted with a BAHA device. The others were using a BAHA on either a soft or hard headband. Having the option to ‘try before you buy’ was seen to be one of the benefits of a BAHA:

And the best thing about it is that you can try it before you go ahead... you’re able to put one on because you weren’t sure at all to begin with until you put one on and then you put it on and you went, amazing! Didn’t you? And you never looked back from there really... yeah you don’t have to have surgery to try it on a headband. (F005).

Participants reported that using the BAHA on a headband led to improvements in what they or their child could hear. They stated that health-care professionals told them that the impact of having the BAHA implanted would be even greater. Three of the four children or their parents with implants agreed with this:
I think the main reason I wanted to go ahead with it was that [name] said it sounded better and I have to say I didn’t like having it on the headband because it put a lot of pressure on my head...now I don’t have that problem. (F005).

However, one family did not find this to be the case. Following the attachment of the sound processor to the abutment no difference to hearing was noted. This family felt that the promise of the implant being better than the headband had influenced their decision to go ahead with the operation but had also heightened their sense of disappointment at the result. The family stated that there had been no ‘light bulb’ moment when the sound processor was attached and it was not clear what differences in hearing they should be expecting:

After they operated... [child’s name] quite soon knew and was expressing disappointment... well all the audiologists made out that it was amazing and that it would bring back like normal hearing. But then it didn’t. I couldn’t tell any difference when I first put it on... I didn’t know what I was supposed to be hearing. (F006).

Having patience
One family spoke of the need for ‘patience’ with a BAHA in relation to both the aftercare of the implant site and learning how to listen using it. It was identified that the brain needed to be taught to listen in a different way

you just have to be patient with it, because it’s not the hearing aid, it’s your brain actually getting this information and knowing what to do with it. And knowing how to identify what this information is. And it’s just, it’s not you getting used to the hearing aid it’s your brain getting used to the information that it’s getting passed through from the hearing aid. (F005).

Accessing sound: the benefits and difficulties of everyday BAHA use
Whether the BAHA was being used on a headband or had been implanted the majority of families (eight) reported that the device gave them better access and improved the clarity of sound. Physical, social, psychological, and educational impacts that deafness had on children were also reduced. Three parents also reported that they felt there was personal safety elements to using a BAHA as children were more aware of traffic noise then they had been previously. However, participants also reported difficulties in using BAHAs in noisy situations such as restaurants or at parties or outside when it is windy:

The clarity of the sound is just so much better... sometimes it’s still difficult when you’re in a crowd or outside, I do still struggle to hear people speaking over background noise. And especially outside in the wind, that’s always the biggest concern that I can’t hear outside when it’s windy. (F002).
One participant stated that she purposely removed the BAHA in these situations as it was so difficult to use it. Two participants stated that their child associated the BAHA with school and there was a reluctance to wear it at home:

She just refused to wear it and because it vibrates she just didn’t want it. It was a real struggle to get her to, she used to pull it off all the time, she didn’t like it at all and now she kind of associates it with school so she will wear it to school but when she’s home she doesn’t like to. (F007)

Changes to the design of the device
All the families identified practical design issues with the device which in an ideal world would be alleviated. All the participants stated they would like smaller, less bulky devices which were more robust and waterproof. Feedback was also cited by the majority of participants (eight) as a problem. Other areas which were criticized included the buttons being too close together which made altering the settings difficult and one participant stated there was no on/off switch and so the only way to turn it off was to remove the battery. The six families who were using the BAHA on a headband complained that they caused sore patches and described them as ‘girly’ and ‘babyish’. In relation to the sound quality, two participants stated that it would be helpful if background noise could be filtered out and greater emphasis given to voice recognition. It was identified that the technology was developing at a rapid rate and that in future BAHAs may have changed beyond recognition. However, all the families were unclear about the process for getting an upgrade and whether in the current economic climate they would be offered one. One family also cautioned against getting a brand new device as they ‘often have teething problems:

I got the BAHA and it wouldn’t switch on… and it took the Doctors a while to get it to switch on. And then ever since that first BAHA this is my third, which I got last week, because with that one they sent it away and then I got another one… and then there was a problem with the switch on that one but I got another one which actually I found alright… that’s the problem with a new device it can have a few teething problems. (F005).

In summary, using a BAHA on either a headband or as an implant made a large impact in many areas of a child’s life. Physical, social, psychological, educational, and personal safety impacts were all reported. Families’ experiences in using BAHAs have enabled the identification of numerous practical considerations related to the design of the device which if addressed would make them more user friendly. It has also been highlighted that there may not be an immediate impact or ‘light bulb’ moment when a BAHA is implanted and the sound processor switched on. Children (and their parents) need to be patient and learn how to listen and use the device for maximum benefit.
Discussion

The families in this study identify that having a deaf child has a huge impact on the quality of life of the individual as well as the family unit as a whole. It was not something that could prepare for as there were no antenatal signs that the child would be deaf. This is not surprising given estimates that 90 per cent of deaf children are born to hearing parents (Moores, 1987). Feher-Prout (1996) suggests that parents experience a grief reaction to the diagnosis of a deaf child and the family unit as a whole needs to undergo an adjustment process to learn to cope with the situation. Deafness was perceived to be multi-dimensional and impact on a child’s social, psychological, and physical functioning.

Participants differed in their views about whether the visibility of conditions such as Microtia had a positive or negative impact on their experiences of accessing services and obtaining a BAHA, in comparison to other more ‘invisible’ forms of deafness. While some parents felt that a visible cue (such as Microtic ears) had led to them accessing services and support from an early stage, others were concerned about the stigma associated with physical disabilities. Having and wearing a BAHA also made the deafness more obvious to others. Issues of invisibility and visibility have a complex relationship with long-term conditions. Whereas those who have visible disabilities have no choice but to disclose their condition, the invisible nature of other illnesses means that symptoms and difficulties can go ignored or minimized (Joachim & Acorn, 2000). The number of participants in this study makes it difficult to make generalizations about the experiences of children with Microtia versus those with a less obvious hearing impairment. However, having a visible indication of deafness did appear to facilitate access to BAHA devices earlier. It was also those children who had no visible cues that experienced more negative reactions from others such as being labelled as having behavioural problems in school.

As identified above deafness impacts on several aspects of a child’s health and well-being. Despite quality standards being devised by organizations such as the National deaf Children’s Society (NCDS, 2010), many participants described systemic communication failures within the care pathway. A lack of appropriate information and poor communication between different parts of the care pathway were the most frequent complaints. Many participants felt the onus was on them to chase up appointments and to keep up to date with the latest developments and research to ensure that they have access to the most current BAHA technology. Having accurate information is vital to making an informed choice (Department of Health, 2009). The Department of Health (2009) states that parents must be provided with balanced information on an ongoing basis about their child’s development, so that any choices they make are fully informed. Unfortunately, the findings from this study suggest that this is not happening on regular basis within the BAHA care pathway.

The question as to who makes the decision about having a BAHA was also raised by the participants. While parents were happy to be the decision makers for young
children, older children and teenagers often made their own choices about whether to wear or have a BAHA. Self image and self identity were particularly important for this group of young people. Parents felt that if a young person had access to a BAHA from a young age this would be less of an issue than for those individuals who had the implant for the first time in early adolescence. Kirk (2010) explained how children construct and negotiate the use of medical technology in their lives and their interactions with peers are crucial to this process. The presence of a device such as a BAHA reinforces a young person’s difference in comparison to those around them and represents a constant threat to their identity (Kirk, 2010). This indicates the importance of providing peer support for children and their parents so that young people can interact and share experiences with other BAHA users and also that early implantation is beneficial as it allows a young person to integrate the BAHA into their identity from an early age. It also suggests that when professionals are presenting information to families they need to be aware that it may be the child and not the parent who is making the decision about whether to have a BAHA and so it needs to be in a format that they will understand.

For the majority of participants observable differences were noted in a child’s behaviour following being given a BAHA, whether implanted or on a headband. Improved social interactions, concentration at school, and more confidence were all reported. These findings support those of researchers such as Arunachalan et al. (2000) and Barbara et al. (2010) who found improvements in objective quality-of-life measures following implantation with a BAHA. However, despite the positive feedback participants did identify challenges with using the device. Keeping the headband on young children was difficult; the headband rubbed some children and caused sore patches; experiencing feedback and difficulties in group or noisy situations were all discussed. Stephens et al. (1996) identified similar issues to these more than 15 years ago; given developments in technology it is concerning that these difficulties are still being raised.

A further issue that participants raised was that using a BAHA required patience and a period of adjustment to get used to its capabilities and the sound it made. This was prevalent even for those individuals who had an instant reaction to the BAHA being implanted and the sound processor switched on. While the need for rehabilitation has been noted in relation to cochlear implants, and there is a great deal of resources available for those with implants, it is not highlighted within the BAHA pathway (NCDS, 2010). It is possible that a programme of rehabilitation and links to educational services post implant could lead to even better outcomes for children and could also assist those who are disappointed with the device to establish what has or has not worked so well for them.

The limitations to this study were that families recruited were a diverse group of participants in terms of their experiences and reasons for BAHA use. This has meant that not all participants were able to discuss fully every aspect of the interview. Participants were recruited through the Ear Foundation research forum. There is a possibility that those individuals with the strongest views (either positive or
negative) may be more likely to become involved in a study such as this and so skew the results obtained. Utilizing group interviews could also have impacted on the data obtained. Within the group situation individuals may have felt inhibited and unable to express their views and experiences.

Conclusion

This study has produced some interesting and fresh findings. BAHA devices represent the development and use of advanced medical technology with children. Families valued the access to sound, improved self-esteem and self-identity it gives children and reported the social, psychological, and educational benefits associated with its use. However, a lack of accurate information and support in the decision-making process was identified by families and access to appropriate professional assistance and peer support during this process would have been greatly appreciated.

By interviewing families across the UK, the geographical variation in service has been highlighted. This is a particular concern in relation to funding from NHS commissioning organizations for BAHA devices. Many participants described ‘the fight’ they have experienced to obtain funding and access to services for their children. From the participants accounts it is not clear to them on what basis funding decisions are made. However, given the variability of the process, it does not appear to be governed by either research evidence or best practice guidelines. Where this evidence exists it needs to be disseminated in appropriate formats for both funders and parents. Where there are gaps in the evidence base, research needs to be conducted to address this.

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References


Appendix 1: Ethics

Subjects were identified and recruited to the study through The Ear Foundation’s education and research forum, in compliance with normal Data Protection legislation. The study received scientific and ethical scrutiny by The Ear Foundation’s internal review process and no material ethical issues were identified. This opinion was supported by a local NHS Research Ethics Committee Chair; contact details available on request. A SL24 form was provided by the NRES Committee East Midlands – Leicester and states ‘This study doesn’t come under the purview of NHS R&D governance as the participants are not being identified through their NHS records or as part of any NHS treatment’.

Appendix 2: Interview schedule and data capture form

BAHA Families: Data Capture Form

Please fill in the following details. Where multiple options are available please cross through those which do not apply.

Childs Name: 
Childs Age: 
Diagnosis for left ear: 
Left Ear: 
Mild/Moderate/Severe/Profound 
Conductive/Sensori-Neural/Mixed 
Diagnosis for Right Ear: 
Mild/Moderate/Severe/Profound 
Conductive/Sensori-Neural/Mixed 
Do you have one or two BAHA devices? 
One/Two 
Age at Diagnosis of Hearing Problem: 
Age first received a BAHA device: 

BAHA Families Interview Schedule 

1. Can we start by talking about ——— deafness. In your own words can you describe his/her current hearing difficulties?
   (a) How did you realise s/he had a hearing problem? 
   (b) When you first saw a health care professional can you remember what information you were given? 
   (c) Can you remember how you felt at this time? 
2. Has ——— tried any other hearing aids? What were they?
   (a) What were your experiences with these? Why were they not successful? 
3. How did you first find out about the BAHA?
   (a) Did you research it yourself? Where did you find the information from? 
   (b) Did you talk to family, friends or other people who had BAHAs or whose children had BAHAs? 
   (c) Did a health or education professional first mention BAHA devices to you? Who were they? 
   (d) Was it easy to find out information? Is there any other information that you think should be provided for people when they are making a decision about having a BAHA device?
4. How was referred for a BAHA assessment?
   (a) Who did the referral? (Audiologist or ENT)
   (b) How long did it take from first referral to the actual operation/having the device fitted?
   (c) Were there any issues about funding the BAHA?
   (d) Did you have a choice about which make of BAHA to have fitted? How did you make your choice?

5. How did you prepare for the operation?
   (a) Did you do anything to prepare for the operation? What do you think understood about the operation?
   (b) Did you have any idea what was feeling at this time?

6. Immediately after the BAHA was fitted, did you notice any changes which indicated that s/he was benefiting from it? Did talk about what they s/he could hear?

7. Have you received any ongoing support from the hospital?

8. What about now, what are the major benefits for now? For example Environmental sounds, Communication, School, Television, Radio, Family and Friends

9. Has experienced any problems with the device?
   (a) How does let you know if there are any problems?
   (b) Have you ever had any problems with abutment (bit surgically placed into the cranium to hold the aid in place)? Any infections or has it become loose?
   (c) If you have had problems what is your experience of getting things put right?
   (d) Do you get regular upgrades of the sound processor or do you have to wait until it breaks down?
   (e) Are there any changes you would like to see in the design of the device?

10. What has been experiences of using the BAHA in school?
    (a) Have they reported any problems to you?
    (b) What has been the benefits?
    (c) Does use or need to use radio aid (FM system) in school? Are there any technological difficulties in linking the BAHA to an FM system in school?

11. Does the BAHA do more or less than you hoped?

12. Do you feel a BAHA should or could have been offered to sooner?

13. To finish, what advice would you give to somebody who was considering a BAHA for their child?
    (a) What do you think might think about this?

Notes on contributor

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