Bone Anchored Hearing Aids (BAHA) for Single Sided Deafness: Adult Users Experiences of BAHA Provision and Services. A Qualitative Study

Research Commissioned by: The Oticon Foundation

Research Undertaken By: The Ear Foundation in collaboration with CLAHRC-NDL (Collaboration for Leadership in Applied Health Research and Care Nottinghamshire, Derbyshire and Lincolnshire).

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Executive Summary

The Ear Foundation was commissioned by The Oticon Foundation to conduct, qualitative research into service user experiences of getting and using a Bone Anchored Hearing Aid (BAHA). The commissioned research has two work packages. The first work package (reported elsewhere) explores the experiences of family groups of having a deaf child who uses a BAHA (either implanted or prior to implant on a headband). The second (reported in this document) investigates the views and experiences of adult users with Single Sided Deafness (SSD). Both of these work packages were carried out in partnership between The Ear Foundation and CLAHRC-NDL (Collaboration for Leadership in Applied Health Research and Care, Nottinghamshire, Derbyshire and Lincolnshire).

Qualitative, semi structured interviews were conducted with 12 adults who considered themselves to be SSD. The interviews aimed to explore experiences of the care pathway and the practical issues related to getting and using a BAHA device. Eleven of the interviews were conducted over the telephone and one was done face to face. All the interviews were audio recorded and fully transcribed. An SL24 form was obtained from the NHS research ethics committee and all participants were asked to complete consent forms. As all recruitment took place through The Ear Foundation research forum there was no further ethical review requirements.

Four key themes were resonant with the participants’ accounts:

- Being Deaf.
- Care Processes.
- Information and Support Needs.
- Using a BAHA.

The findings from the study demonstrate that adults with SSD valued the improved access to sound that a BAHA device gave them. Participants were clear that it did not return hearing to “normal” but the awareness of sounds on a side which had previously been “dead” had huge emotional, psychological and social impacts. Although many participants had an “instant” reaction when the sound processor was switched on, an adjustment period was necessary to become familiar with the BAHA and the sound it transmitted. Unfortunately, systemic failures were noted within health services, such as individuals becoming lost in the system, delays caused by funding problems and notes being unavailable for appointments. The report concludes with a number of recommendations for further research and professional and organisational developments.
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Introduction

Single Sided Deafness (SSD) affects approximately 9,000 new people in the UK each year. Causes of SSD include physical damage to the ear, compression of the hearing nerve and inner ear problems such as bacterial or viral infections and tumours (for example Acoustic Neuroma and Cholesteatoma) (Advisory Group for Single Sided Deafness, 2003). Bone Anchored Hearing Aids (BAHA) are one treatment option for individuals with SSD (Advisory Group for Single Sided Deafness, 2003). The benefits of BAHA devices in relation to objective audiological outcomes have received considerable research interest (Arunachalam et al., 2000; Cremers et al., 1992; Hol et al., 2010; Mylanus et al., 1995; Tjellstrom & Granstrom, 1994; Wazen et al., 2001) and despite the benefits of binaural hearing in sound localisation and improved speech perception in noise being well established; the use of hearing devices, such as BAHAs, for people with SSD has lagged behind. Wazen et al (2001) illustrated this using the analogy of how monocles replaced eyeglasses for sight disturbances. However, in the hearing arena the impact of unilateral deafness has often been minimised, despite evidence indicating that conceptual, vocabulary and speech deficits affect people with SSD (Flexer, 1995). Linstrom et al (2009) and Wazen et al (2001) have both demonstrated the short and long term efficacy of BAHA on objective and subjective measures of benefit. However, there have been very few studies which have looked at SSD patient experiences of using a BAHA device.

Research which has focused on the patient experience has explored satisfaction and dissatisfaction with BAHAs and has typically used questionnaires. The results from these studies have indicated strong support for using BAHA devices (Arunachalam et al. 2001; Bance et al., 2002; Dutt et al., 2002; Gillett et al. 2006; Lustig et al. 2001; McLarnon et al., 2004; Newman et al. 2008). However, satisfaction is only a small part of the patient experience and questionnaire based studies, by their very nature, do not provide the opportunity for individuals to reflect and discuss more complex personal material (Willig, 2001). To overcome these limitations Stephens et al (1995) utilised an open ended questionnaire and asked individuals using BAHAs to list the benefits and shortcomings of them. This allowed participants to raise issues which were important to them. However, this still did not allow for a thorough discussion of these issues with those who took part.

Qualitative research has been widely used to investigate the patient experience of healthcare and is now being utilised more in audiology (Knudsen et al., 2012). However, there is a dearth of qualitative research looking at patient experiences of using BAHA devices and given the contested nature of SSD and the use of BAHA devices for this population an investigation into the experiences of this group is timely. Therefore the aims of this were:

- To explore the experiences of adults with SSD of the care pathway related to obtaining and using a BAHA device.
- To explore the benefits and challenges of having and using a BAHA device.
Methods

Research Design
The research study utilised an exploratory, qualitative design. Data were collected between October and December 2011 using individual, semi-structured interviews. Participants were asked if they had a preference for either a face to face or telephone interview. One participant specifically requested a face to face interview; the rest were contacted by telephone.

Sample/Participants
A purposive sample of participants were recruited to the study using The Ear Foundation’s Research Forum. This forum comprises of a database of individuals who have identified themselves as being interested in research. Participants were recruited from across the United Kingdom and to be included in the study, they needed to fulfil the following criteria:

1) Be aged over the age of 18 years.
2) Be Single Sided Deaf (SSD).
3) Have a BAHA device for their single sided deafness.
4) Be able to give informed consent to take part in the study.
5) Be able to speak English.

Twelve participants fulfilled the above criteria and agreed to take part.

Data Collection
Data were collected via individual, semi-structured interviews. These were conducted either face to face or over the telephone. The same topic guide was used to facilitate the interviews in both settings. All the interviews were audio recorded and immediately initial reflections and analytic notes were documented separately. Prior to the interviews commencing the research process was explained to the participants and it was explained that there were no right or wrong answers. Participants were reminded that they could refuse to divulge any details which they did not wish to discuss and that their current care would not be affected by taking part in the study. At the end of each interview participants were given an explanation regarding what would happen next to their information and it was reiterated to them that they could contact the research team should they have any further questions. A copy of the interview topic guide is included in Appendix One.

Research Ethics
A SL24 form was obtained from the NHS Research Ethics Committee prior to the study commencing (dated 4th September 2011, see Appendix Two). As all participant recruitment was completed through The Ear Foundation rather than the NHS and no medical records were accessed, further approvals were not required. Whilst 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 (Appendix Three) was emailed to individuals when they were first
contacted. For those participants who were interviewed over the telephone; a consent form was posted to them and they were asked to return it via a self addressed envelope. Consent was taken by the researcher at the time for the face to face interview. Participants were reminded that they could withdraw their consent at any time and they could ask for the audio recording equipment to be switched off at any point. All participants were assured that their information would be kept confidential and that the raw data would be anonymised as soon as practicable after the interviews were completed. The interviews varied in length from 120 to 45 minutes.

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 involved going 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. Computer Assisted Qualitative Data Analysis Software (CAQDAS) was not used to manage this process. Instead the transcripts were colour coded using standard word processing packages and different documents were created for each theme. The analysis process resulted in four main themes related to the experiences of adult BAHA users with SSD.

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 of the interview guide, the views of other researchers who had conducted projects within the subject area were obtained. Some of the questions were removed or rephrased following this input. Credibility was also increased by discussing preliminary findings with other members of staff at The Ear Foundation and researchers at CLAHRC-NDL. An experienced researcher in the subject area was also asked to review the transcripts and comment on the themes emerging from the data to ensure they were consistent with their experience. This allowed emergent themes to be questioned and alternative viewpoints to be discussed. 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 twelve individual interviews, eleven of which were conducted over the telephone and one face to face. Of the twelve participants six were female and six were male. Table One summarises the demographics and diagnostic features of the sample. All of the individuals interviewed had the BAHA implanted; none were using it on a headband.

Four main themes were identified in the participants’ accounts which describe their experiences of BAHA devices:

- Being Deaf.
- Care Processes.
- Information and Support Needs.
- Using a BAHA.

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 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.

Being Deaf

Only two of the participants in the study were born with congenital hearing losses, the others described a process of becoming deaf. For some this process was instantaneous, for example by experiencing a bomb blast during the Second World War:

“Well I should explain how it started. It was a bomb blast during the war. The bomb landed across the other side of the road from where I was looking out of the window and the blast obviously made me deaf.” (P011).

Whereas for others it was a gradual process over several years, in some cases complicated with other symptoms such as dizziness or falling over:
“I used to do yoga and I started to realise that when other people were holding their pose you know standing on one leg or whatever, the balancing poses, I just could not hold the pose. I would wobble.” (P005).
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Table One: Demographic and Diagnostic Characteristics of the Participants Involved in the Study
For those individuals who had acoustic neuromas or cholesteatomas the decline in hearing may have occurred gradually but the treatments offered led to an individual becoming SSD overnight:

“Yes. Yes. Yes it was because although my hearing had been deteriorating I’d still had some hearing there and so I suddenly came out of the operation with all the hearing gone... You suddenly think oh my God... I don’t hear my foot move, I don’t hear my hand move so much, you’re just not so aware and I suppose it’s because the body is not hearing itself, in a way its cut out that side.” (P005).

Participants described a range of reactions to being SSD. For some individuals it was not an initial priority, it was more important to them to have the tumour removed from their brain:

“But when you’ve got an, albeit benign, tumour growing in your head then the decision is made; you are going to have it removed. And one of the consequences of that was losing my, completely, my hearing.” (P003).

Others described a physical sensation of being dead on one side. There were also descriptions of the social and psychological impact of deafness, for example feelings of increased isolation and withdrawal and decreased confidence:

“I used to go to a French class and I could hear the teacher because you know she was used to projecting her voice but when we were reading round the class, I couldn’t hear some of the people. Especially as it got further away from me and I did have difficulty keeping my place. I eventually gave that up and I was very sad about it, I just wasn’t coping.” (P006).

To come to terms with SSD, a range of coping strategies and adjustments were made by individuals to their everyday lives. This was true for all the participants whether they became deaf or had problems from birth. For some individuals this involved relatively simple techniques to manage social interaction, for example sitting in the right place in restaurants to be able to hear the conversation. Others described how hearing loss had impacted on their life choices such as the subjects they studied at school and the careers they eventually pursued:

“I used to sit in the front row of the school right in front of the teacher so that it was the easiest way to hear. I would obviously read rather than listen because I could, the subjects I studied were what I could
read rather than what I could listen to. And from a work point of view, the work I chose was work where I was rarely dealing with people.” (P011).

In summary, being SSD was described by participants as having a large effect on every aspect of their physical, psychological and social wellbeing. The majority of the participants became deaf and needed to adjust to what this meant for their future. It impacted on some of the fundamental decisions individuals made about their career and lifestyle choices.

Care Processes
Obtaining a diagnosis and acknowledgement from healthcare professionals that there was a problem with hearing was difficult for many participants. For the individuals with acoustic neuromas and cholesteatomas there were multiple trips, often over several years before they were referred to other services for scans, diagnosis and treatment:

“Yes I had loss of hearing in that ear and probably about 11 years beforehand I’d been to the Doctor and said I’m not hearing as I should be and she just and it wasn’t even a proper hearing test really, with the nurse at the GPs and then when I saw her said oh well you know you’ve got some hearing loss but you know ask people to speak up and your hearing does decrease as you get older.” (P001).

Having a diagnosis did not necessarily speed up the process to getting a BAHA. Individuals who had been SSD since birth or childhood had not had access to hearing technologies. They had been told there was nothing which could be done to help them:

“They just said that basically that I’d been born congenitally deaf and they didn’t use that word, they said you were born deaf in that right ear, there’s nothing we can do about it and basically you’ll have to put up with it for the rest of your life.” (P010).

Those participants who had perforated ear drums and experienced excessive amounts of discharge from the ears had tried out numerous hearing aids and surgical treatments before having a BAHA offered to them:
“They referred me to the Consultant, they gave me some grommets to try and relieve pressure, it didn’t work. Since then I’ve had six operations on my ear and I now haven’t got much middle ear left at all. I had a perforated eardrum which they finally managed to sort out when I was, well it was last year 2010 when I had an operation on that. So consequently I’ve got virtually no middle ear and that’s how I lost sound with all the operations and things.” (P008).

Participants highlighted that within the NHS there is not a holistic and integrated approach to care. People are segregated based on their ailments and this meant that the dots were often not joined up between an individual presenting for one particular problem and how this could be impacting on their overall health and wellbeing. Hearing impairments, in particular, were not perceived as an ongoing health problem and so was not discussed when individuals had appointments and checkups for other problems. Only one participant was referred by their General Practitioner for a BAHA, other participants reported that their General Practitioner did not have any awareness of what the devices were. Deafness was very much perceived to be an “invisible disability”:

“I mean you tell people don’t you, you know, just to let you know I’m deaf and they remember for about five seconds. And then you’re left thinking I’m deaf so what more can I say? And you just think, Oh God and I think that’s the problem, it’s because you don’t look any different. I think blindness is probably, in a way a disability that we assume, we see that more because that person obviously can’t see it and so it is easier to see. But deafness is harder because people just forget and in their daily life they haven’t got time to remember you’re deaf.” (P005).

Even within specialist centres, participants reported communication difficulties and a lack of joined up working between different parts of the system. Surgeons failed to communicate with audiology departments, medical notes were not in the correct department for visits and the move of the BAHA centre from one hospital to another led to delays and one individual “getting lost in the system”:

“But when it went to September and I didn’t hear anything I was in contact with the surgeon’s secretary on a regular basis and then eventually I went to my audiology department and it was in a centre in [place name], I went to see the Chief Audiologist and I said look I’ve been waiting such a long time and she was really shocked that I’d been waiting that long. It was so long I think they’d forgotten about me.” (P010).

The relationship with the surgeon doing the operation to implant the BAHA was important to participants in the study. Individuals described with pride that the surgeons they saw were “international experts” in the field. They discussed the importance of having confidence in that person
and being concerned if on the day of the operation if it was someone different with no explanation given:

“Well when I went to the hospital I didn’t even see the Doctor who you know Mr [name] he was not the surgeon who was going to operate on me... I was just a bit surprised you know. There was never an explanation as to why he didn’t do it or who the person was who did it. You know he never said he was used to doing the job or otherwise.” (P011).

A significant part of the relationship with healthcare professionals was managing the expectations of what a BAHA would and would not be able to give an individual. Participants stated that they knew that it could not return hearing to “normal”. Some individuals were also aware that because they had no Cochlear on their deaf side they would not regain directional or stereo hearing. However, some participants did describe feeling a little disappointed that the BAHA had not lived up to what they had expected:

“I had this hope that I would get a degree of directionality which would allow me a degree of subconscious filtering, which means even in a noisy environment I would have a better chance of erm, hearing that which was important. And I expected a dramatic improvement, which I’ve erm, err, it fell short of my expectations, let’s just put it that way.” (P003).

A key part of the care process was obtaining funding for the BAHA. Participants were aware that BAHAs were not part of the core NHS service and permission had to be obtained from funding panels before the operation could go ahead. In most cases participants did not know which organisation or person made the funding decisions. Although all the participants in the study had obtained funding for an initial BAHA, many were not clear how many years they would need to wait to get an upgrade if they would get one at all. One participant had been explicitly told that he would not receive an upgrade and would have to look into whether he could be part of a trial to have a better device:

“I have been to see them at [hospital name] after they gave me the processor and I did have a go at them but the audiologist informed me that basically because of funding issues they can’t give me the latest one. What she did say was that she would look into if there is a trial of them... she was saying that if there is a trial and there is a new processor what the audiologists have to go through is training for that. So sometimes they need guinea pigs to sort of test that with them as well so you might be able to get on that way.” (P010).
In summary, the care process that participants reported was not a simple, linear one. The hidden and invisible nature of deafness and the confounding issues associated with some of the causes of hearing loss often meant long delays for individuals in obtaining a diagnosis and access to BAHA devices. The participants’ accounts also emphasise the importance of the relationship with the care team particularly the surgeon involved in the operation. Last minute changes in personnel led to anxiety for individuals. Participants also identified that there were communication difficulties between different parts of the care pathway which had a negative impact on their overall experiences.

Information and Support Needs
Participants identified two different types’ of information and support needs related to getting a BAHA. The first was termed “clinical information” which was provided by healthcare professionals. This related to diagnostic information, giving and receiving test results and descriptions of BAHA device. Participants identified that this information was often given to them clearly and appropriately. The second type of information and support was linked to the experience of what it is like to have a BAHA. This related to practical questions such as: what is the operation like? How long will I be off work for? Will it hurt? How do I clean the site? What difference does it make? Participants stated that although they could ask healthcare professionals these questions they felt “silly” doing so and wanted to be able to talk to someone with a BAHA about their experiences:

“You feel silly asking these really silly questions, like how do I wash my abutment? You know, how do you keep that clean? And you know, there are things like how do you screw it in.” (P010).

Face to face peer support from others with a BAHA was not available for the participants (some had been told this would be arranged for them but did not come to fruition) and so they used other means to find the required information. Individuals stated that they watched YouTube videos of the operation and joined online support groups, such as BUSK and those on FaceBook:

“Yeah BUSK. That’s right. And that was brilliant when I was getting fed up with waiting and being told one thing and then another and everybody saying things. And then I was having problems with it healing, I’d come home so frustrated…you can ask them different questions… I’d be posting a fed up post, I suppose frustrated or whatever. And at one point [name] sent me an email…she said if I wanted to send her a moaning personal email she was happy for me to do that.” (P001).
Although the internet was a valuable resource, it was also recognised that too much information could be a problem and one participant stated that he advised others in a similar position to himself to avoid American websites:

“The other thing that I was told was not to go on the American websites because you go in the American websites and too much information is a dangerous thing and they are a bit potty over there.” (P009).

It was also highlighted that more information needed to be disseminated to professionals outside of specialist centres. Participants felt that this would assist the diagnostic and referral process as well as facilitate increased support for individuals who already have a BAHA:

“Yes it would be jolly nice if my GP was on the receiving end of updates to be able to say hey there’s this wonderful thing that’s available for your patients, have you got anyone who is suitable?” (P003).

In summary, participants identified that they needed two different types of information and support in relation to BAHA devices. The first was the technical and clinical information which health care professionals provided. The second related to peer support and the need to learn from the experiences of others. As meeting face to face was often not an option, participants utilised internet forums and support groups to obtain the information they needed. Professionals outside of specialist services also needed more information to be able to diagnose and refer appropriately and to also provide support to those who have a BAHA device implanted.

**Using a BAHA**

Just as participants described a social, psychological and physical reaction to becoming deaf, they also outlined a holistic response to having a BAHA. The BAHA was perceived to impact across the biopsychosocial spectrum of an individual’s health and wellbeing. Participants reported a reduction in feelings of isolation, in being physically tired and feeling more able to engage with social interaction. Individuals also described having a greater sense of personal safety and awareness of others around them. Examples given to illustrate this were being out jogging and negotiating traffic:

“But really the difference it has made for me is, well personally is just huge, absolutely huge. I think physical safety as well, when I went out jogging I didn’t used to hear people coming up behind me and I was a bit conscious of that and I’d be turning round to look and see if somebody was there you know, if I was on a dark road or something and now I’m well I could honestly I mean I don’t know if there’s
somebody there or not but I know I could hear them. But I think it just improves your confidence. Again you go into any kind of social situation and I am confident that now if I don’t hear actually hear other people in the room would know I’d be hearing and that’s because of the problem with the noise level is too high or something. It’s not down to me, its the general level.” (P008).

There were some discrepant opinions related to experiences of using the BAHA to listen to music. Whilst one participant was “moved to tears” following attendance at a concert after having the BAHA implanted, another found that they were unable to listen to music as the BAHA distorted the sound too much:

“I would have to say that listening to music is a, was a disappointment, I would listen to the music, actually I play the trumpet and my interest in listening to music has dropped significantly... The frequency response for the BAHA, is quite rightly, and I think understandably focused on voice which means that the bass response is absolutely awful. If am sitting in the car and I listen with my good ear I can hear all the bass notes, with a finger in my good ear and I listen just through my BAHA with the rhythm section and the bass section disappear altogether and I can understand that because it is right and proper that the primary objective is to provide one with the ability to communicate rather than being entertained... Interestingly enough I’ve met somebody else with a BAHA to whom music is desperately important and she connects her BAHA to her MP3 player and goes absolutely over the moon. But maybe she doesn’t have any in the rhythm and bass section, I don’t know.” (P003).

Individuals also describing varying reactions related to whether the BAHA facilitated directional and stereo hearing. Some participants reported that they had been lucky enough to regain directional hearing whereas others were disappointed not to have achieved this. For participants directional hearing was linked to whether they still had a functioning Cochlear on their deaf side. It was not clear where the participants had obtained this information from, but it seemed to give some reassurance:

“I was told that some people got back some directional capability and that raised my hopes. I've had it for two years now and I've been through the physics and it’s not possible. The only people who can have any clear benefit in terms of stereo performance is people who have got two cochlears. You have to have two cochleas in order to be able to use the brain to be able to get any sort of stereophonic filtering if you've only got one, you've got no mechanism for differentiating between left or right.” (P003).
Participants clearly articulated their initial reactions to having the sound processor switched on. For all the participants this was an emotional experience which allowed them to hear sounds which they had been missing. Often it was the ordinary or everyday which led to profound reactions for participants:

“When I actually had the sound processor implanted on the abutment I actually cried as I walked home from that, from the hospital I know it sounds daft but to hear on the left side was amazing, to hear footsteps on my left side, to hear traffic as I walked up and down the road, to hear the wind in the trees and it was like on my God I didn’t realise how much time I’d spent dead.” (P005).

Despite the initial reaction to the BAHA, participants stated that it required an adjustment period to get used to listening through it and the sounds and sensations it produced. For one participant this involved working out its optimum capabilities:

“I’ve done trials at home with a blindfold and my wife going round with a, you know, banging a glass, to see whether in that there was any, any way in which I can guess where the sound is coming from. And if I exclude all other clues, there is no question that there is no directional thing at all and I guess that is the biggest fundamental loss that one suffers and you’re never going to get that back.” (P003).

Participants also suggested that getting the BAHA sooner may reduce the time it took to adjust to it. As individuals would not get used to hearing on only one side. One participant was told that there was a hearing memory and it was important to wear the BAHA to trigger this:

“And [name] did say that in wearing it, the more that you wear it the better and he was determined that I understood that if you don’t do anything that there is a hearing memory and so if I’d left it twenty years then having a BAHA it wouldn’t do any good, because perhaps the brain would have forgotten how to hear on that side.” (P005).

Despite the positive response to the BAHA participants did identify challenges with using it. There were some difficulties with the site of the abutment:

“I went to my audiologist and she said there was some swelling around it, the abutment, and also the abutment wasn’t sticking out very far, so in fact part of the processor was touching my head so of course was sending feedback. So what she did was she put on an extra long abutment, they can unscrew the
one bit of it and put on an extra long abutment. And also when she did that it improved the feedback.” (P010).

Individuals also described how the sound processor could break down and if the specialist centre where they usually had their appointments did not have a loan BAHA available they could be without one for a few weeks:

“I've actually have had it taken away because it was when I had to have it serviced because they hadn't got loan device, which is rare at Manchester I might add, so I have gone a period without it and it was terrible. I can't describe it.” (P009).

On a day to day basis the main challenges identified were using the BAHA in group situations and settings where there was a lot of background noise such as busy restaurants. On these occasions participants reported that the BAHA amplified all the surrounding sounds rather than just the focus of attention, for example the person speaking:

“Now you are talking about the bubble, one of the problems of being deaf in one ear is say if you go into a noisy environment like a restaurant and you can't participate in the conversation around the table, you end up becoming part of what I call, the bubble. You sit there on your own and you just don’t avail yourself and that still exists... in group situations, meetings workshops and yes all the rest it is fine but put me in a public place like a bar, a restaurant that is very busy and it does have its limitations”.

Other areas which participants thought could be improved in terms of the design of the device included the addition of Bluetooth, reducing the amount of feedback experienced when something touched the BAHA, the small buttons which were difficult to use and altering the shape of the device to be less obvious:

“The present one the buttons are a bit small but that's a different issue entirely, it's just they're very small and I've got arthritis in my hands and my hands are fairly big, so I can't operate it, with it on, I have to take it off.” (P011).

Despite the challenges of using a BAHA and the adjustment that was necessary to get the full benefits of hearing through it, participants were clear that they did not want it to be taken away from them.
Participants attributed their happiness to it and when they were asked directly what would happen if it was taken away from them, strong emotional reactions were provoked:

“Well first of all you’d have to get to me and I’d chop your hand off. But I would miss the freedom it gives me and the freedom it gives me with regards to not having to go through the regular routine of to dry my ears.” (P012).

In summary, getting and using a BAHA impacted across the physical, social and psychological domains of an individual’s life. The descriptions of BAHA use suggests that the devices become part of the individual and the thought of losing it produces an emotional reaction. Although participants reported positive effects on their physical health (a reduction in tiredness) and also their social interactions, there were also some discrepant views about what the BAHA could and could not do, for example stereo and directional hearing. Making the device less obvious, having Bluetooth capabilities and less feedback were common areas for improvements in the design.
Discussion

The path to having a BAHA is lengthy and the findings from this study indicate that for people with SSD this could take even longer. The descriptions from participants indicate that obtaining an accurate diagnosis and appropriate referral to specialist services could take years. Six of the 12 participants had either a Cholesteatoma or an Acoustic Neuroma and the other symptoms associated with these may have influenced the diagnostic process (Mayo Clinic, 2012). For example the symptoms of dizziness and hearing loss could be attributed to other conditions such as Menieres Disease. However, this study has also demonstrated that there is a lack of knowledge and awareness within primary care settings related to SSD its causes, symptoms and management options. Schneider et al (2010) in an Australian study found similar results when they concluded that the levels of identification and management of hearing loss were relatively low in a General Practitioner population.

Although not directly relevant to the aims of the study, all the participants spoke in depth about their experiences of becoming SSD. SSD was found to impact on every aspect of an individual’s health and wellbeing. This corroborates findings from studies such as Hallberg and Carlsson (1983) and Hetu and Shannon (1988) as well as extending the evidence base by focusing specifically on the SSD population. Many of the participants discussed the difficulties associated with social interaction and in particular withdrawal from group situations. Like Linstrom et al (2009) the participant accounts indicate that the impact of SSD on their health and wellbeing was minimised by others. The prevailing attitude that individuals described was that by still having “one good ear” their hearing difficulties was not an ongoing health problem.

Studies such as Arunachalan et al (2000), Barbara (2010) and Ho et al (2009) have all reported improvements in objective quality of life measures when individuals have received BAHA devices. The findings in this study also support this. The participants’ descriptions indicate that improved self esteem, self confidence and less isolation resulted following being given a BAHA device. However, despite the positive feedback participants did also discuss challenges with using the device, for example experiencing feedback, problems with wind noise, difficulties in noisy or group situations and keeping the abutment site healthy. Given the rapid pace of change in amplification technology it is concerning to note that these issues have been documented in the literature over 15 years ago (Stephens et al., 1996).
However, even if the technology is improved the access to it for people with SSD through the NHS is not a clear process. The interviewees were drawn from across the UK and their accounts suggest a wide geographical variation in the service they have received or will receive in the future. Participants spoke of the desire for a holistic approach to their health needs and satisfaction with the BAHA relates to both the care package received as well as the technical capabilities of the device itself. The current fiscal climate within the NHS and the proposed changes to health care commissioning processes (DH, 2010) may mean that services become further fragmented and access to the latest BAHA technology becomes even more limited for individuals with SSD.

One aspect of the care package which participants consistently found to be lacking was access to peer support and being able to meet people who share similar experiences to themselves. This was particularly the case when participants were making the decision about having a BAHA. The literature which connects health and social relationships is growing. It has been argued that peer support can facilitate individuals to try out difference coping strategies and can also be a safety net in case things go wrong (Spencer & Pahl, 2006). Although opportunities for peer support within statutory care were lacking, participants found contact with BAHA users through other means for example internet forums and social networking sites such as FaceBook. Although it could be assumed that social interaction through the internet is in some way lacking in comparison to face to face contact, research by Gershuny (2003) and Licoppe (2004) dispute this. Both of these studies demonstrate that active and supportive social networks can be developed and maintained through web based means (Gershuny, 2003; Licoppe, 2004).

Participants described immediate reactions to the sound processor being switched on; in particular being able to hear noises which they had not consciously realised they were missing. Despite this initial reaction participants also identified that there was a period of adjustment required to learn how to listen with the BAHA and to work out what its capabilities were. Participants identified that the BAHA did not give them “normal” or natural hearing and it took time to get used to the sound it produced. This indicates that a period of rehabilitation may be beneficial to individuals following the attachment of the BAHA sound processor. Whilst the need for rehabilitation after Cochlear implants, for adults and children, has been widely reported in the literature (for example Pedley, 2006; Ross 2007), there is a dearth of literature related to rehabilitation following a BAHA. The participant accounts suggest that this could be a useful area for further clinical and research developments in the future.

For the participants in this study the BAHA became part of them and was associated with a strong emotional response, particularly when the possibility of losing it was raised during the interview. The machine-human interface and how the body and self are effected, has been widely researched within the medical sociology field. Although not specific to hearing technologies, Timmermans and Berg (2003) argue that medical technology influences how bodies are socially identified and personally experienced.
As identified in the participant’s accounts, a BAHA is therefore not just a hearing aid. It becomes part of the individual and is intimately linked to their sense of self. The embodiment of a BAHA and the attachment a person has to it may lead to a discrepancy between the individual and the health care provider. Without an understanding of the relationship an individual has to the device, health care professionals may unwittingly offend or upset a patient by assuming that a BAHA is purely a technological aid.

**Limitations of the Study**

The participants were recruited through the research forum on the Ear Foundation website. As with any self selecting sample there may be a bias in terms of who volunteers to be involved in a study and who does not. Some participants in the study stated during the interviews that they worked in a voluntary capacity as BAHA advocates for one of the manufacturers. Whilst these participants were able to identify problems both with the devices and with the care packages they received it is possible that they were not talking with their own voice. Their role may have influenced how they articulated and described their experiences and made them more willing to take part. All the participants were also over the age over 45 years; it is not clear whether the experiences outlined in this study also reflect those of younger adults. The study was only able to include people who were fluent in the English language; it is possible that non-English speakers have very different experiences of BAHAs to those outlined here. For some participants this was the first opportunity they had been given to express their thoughts and feelings about the service they had received. This may have lead to a cathartic response whereby some participants are overly positive or negative in their accounts of their experiences. The retrospective, self report nature of a one off interview means that this process can only ever gain a snapshot of the participants’ experiences and feelings at any given time.
Conclusions and Recommendations

Taking the above limitations into account, this study has produced some illuminating and important findings relating to the experiences of adult BAHA users with SSD. BAHA devices represent the potential of the latest technological developments in the field of hearing. The access to sound that they facilitate is highly valued by those who use them. The strongest impact users reported was on their social, emotional and psychological wellbeing. BAHA devices allowed them to become more engaged with social interaction and developed confidence in users. Physical tiredness was also reduced as participants did not have to use so much energy trying to listen to their surroundings. However, BAHA does not represent a magic wand returning “natural”, stereo hearing to individuals. Although there was often an instant reaction when the sound processor was switched on, there was also a period of adjustment required to learn how to listen with the device. This indicates that a period of rehabilitation may be beneficial to new BAHA users.

 Unfortunately, systemic difficulties have been highlighted with the care packages provided; obtaining a diagnosis was extremely problematic for some individuals. Although participants reported receiving good clinical information from health care professionals; practical advice and support was lacking and often had to be sought from internet forums. The need for peer support was also identified as an area to be developed further. Interviewing participants from across the UK also identified geographical variations in service provision, particularly in relation to funding decisions and individuals having access to updated technology as it becomes available. It is also not clear on what evidence funding decisions are made; there is a need for this process to become more transparent.

From the experiences of the participants in this study a number of recommendations can be proposed for future service developments, support and more research:

1. The lack of knowledge regarding BAHA provision outside of specialist services needs to be resolved. General Practitioners and Service Commissioners need to have information disseminated to them in appropriate formats to raise awareness and to assist in decision making.
2. A central repository of reputable sources of information needs to be available to users with SSD. This could include lay language summaries of research evidence, web sites and user forums.
3. Improved communication between different parts of the health care system and communication strategies for assisting users to stay up to date with progress.
4. The implementation of standard guidelines and criteria regarding the provision of BAHAs for people with SSD to reduce geographical variation.
5. The development of peer support and buddying systems for individuals at each part of the BAHA process.
6. The provision of psychological support for individuals considering a BAHA and immediately afterwards to assist with adjustment process.
7. The development of a rehabilitation programme post-implant to aid individuals with adjusting to listening through a BAHA. This could include the psychological support outlined above.

8. A larger scale research study into the experiences of individuals with SSD and BAHA use. This could include the use of standardised instruments to assess the psychological and social impact.
References


Appendix One: Interview Topic Guide

1. Can we start by talking about your hearing difficulties? In your own words can you describe how your hearing difficulties developed?
   a. How did you realise you had a hearing problem?
   b. Were you born deaf or did it develop over time?
   c. How did your hearing loss affect your life?
   d. Can you remember how you felt at this time?
   e. When you first saw a health care professional can you remember what information you were given?

2. Have you 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?
   c. 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?
   d. If someone else suggested that you have a BAHA, how did you feel about this?

4. How were you referred for a BAHA assessment?
   a. Who did the referral?
   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. What about the assessment process – how long did it take?
   e. Did you have a choice about which make of BAHA to have fitted? How did you make your choice?
   f. Do you feel you should or could have been offered a BAHA hearing aid sooner?
   g. How did you feel about the prospect of having a BAHA fitted?

5. How did you prepare for the operation?
   a. Did you do anything to prepare for the operation?
   b. Can you remember what you were feeling at this time?

6. Immediately after the BAHA was fitted, what did you notice?
   a. Can you describe how you felt when the sound processor was fitted and you heard sound for the first time?
   b. How was this sound different to other hearing aids?
   c. Can you remember any immediate benefits? Or problems?

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

8. How long did it take you to adjust to the BAHA?
9. What about now, what are the major benefits now? For example environmental sounds, communication, television and radio, relationships, work, family friends

10. Have you experienced any problems with the device?
   a. Have you ever had any problems with abutment? Any infections or has it become loose?
   b. If you have had problems what is your experience of getting things put right?
   c. Do you get regular upgrades of the sound processor or do you have to wait until it breaks down?
   d. Are there any changes you would like to see in the design of the device?

11. Does the BAHA do more or less than you hoped?
   a. Are there any things that you find difficult about using your BAHA?

12. Do you feel it has changed any of your relationships either positively or negatively?

13. To finish, what advice would you give to somebody who was considering a BAHA and experiences Single Sided Deafness?
04 September 2011

Dr Imran Mulla,

**Full title of project:** Views and experiences of individuals with single sided deafness (SSD) using bone anchored hearing aids (BAHA)

Thank you for seeking the Committee’s advice about the above project.

You provided the following documents for consideration:

- BAHA Proposal

This document has been considered by the Chair.
I enclose a copy of our leaflet, “Defining Research”, which explains how we differentiate research from other activities. Dr Carl Edwards has advised that the project is not considered to be research according to this guidance. Therefore it does not require ethical review by a NHS Research Ethics Committee.

*Dr Carl Edwards stated ‘the study is of people as members of your organisation/database and not NHS resources’*

This letter should not be interpreted as giving a form of ethical approval or any endorsement of the project, but it may be provided to a journal or other body as evidence that ethical approval is not required under NHS research governance arrangements.

However, if you, your sponsor/funder or any NHS organisation feels that the project should be managed as research and/or that ethical review by a NHS REC is essential, please write setting out your reasons and we will be pleased to consider further.

Where NHS organisations have clarified that a project is not to be managed as research, the Research Governance Framework states that it should not be presented as research within the NHS.

Yours sincerely

**Miss Jessica Parfrement**

*Committee Co-ordinator*

E-mail: jessica.parfrement@nottspct.nhs.uk

Enclosure: NRES leaflet – “Defining Research”

Invitation to take part in the study

The Ear Foundation specialises in user and family led research. This is an important area for study as it allows us to understand the practical issues associated with having a hearing impairment. We can also find out how easy it is to access health services. Most importantly by talking to those who experience hearing impairment we can learn about the social, emotional and psychological impact it has on everyday life both for individuals and their families/carers. We are interested in identified those outcomes which are of importance to you and aim to use this information to influence the care provided in the future. We would like to invite you to take part in this study as we feel your experiences will make a valuable contribution to our understanding in this area.

What is the purpose of the Study?

The Ear Foundation has reviewed the available research information related to BAHAs for people with Single Sided Deafness. Although there has been a steady increase in research in this area, there is very little which has explored experiences or identified the outcomes of importance to individuals with Single Sided Deafness who have had a BAHA device fitted.

The purpose of this study is to explore using interviews, the experiences of individuals with Single Sided Deafness (SSD) on the fitting, management and progress since being given a BAHA device. The findings from the study will provide information to health care services, service users and other professionals (for example teachers) on the experiences, outcomes and impact of BAHA use for families.

Why have I been chosen?

You have been chosen to take part in the study as you have previously indicated to us that you have a BAHA device and experience Single Sided Deafness. You have also shown an interest in being involved in our research programme by registering your details through the Ear Foundation’s Research Forum.
Do I have to take part?

Participation in the study is on a voluntary basis, you are under no obligation to take part. Whether you decide to take part in the study or not, will have no impact on the treatment you or your family members receive.

What will happen to me if I take part?

If you agree to take part in the study a researcher will arrange to come and interview you about your experiences. The interview will be organised for a date, time and place which is convenient for you. When the researcher visits you, you will be asked to sign a consent form to show that you have read this information sheet and are fully aware of what taking part in the study involves. They will then ask you some questions about your experiences of having a BAHA device fitted. If there are any questions which you feel uncomfortable answering, just let the researcher know and they will miss it out. The researcher will also ask if you are happy to have the interview audio recorded. This helps to make sure that your views and experiences are accurately recorded and reported in the study. If you are not happy to be recorded please inform the researcher.

What are the disadvantages/risks of taking part?

As this is an interview based study and no intervention is being delivered, it is a low risk study. However, exploring thoughts, feelings and experiences may lead to distress or feelings of discomfort if these were particularly negative. If you feel discomfort at any point during the interview process, let the researcher know.

What are the possible benefits of taking part?

Individuals often describe that the process of talking to others about their experiences has therapeutic effect. As well as being beneficial to you as an individual, we hope that your experiences will be able to provide information to health services about the experiences and impact of BAHA use for people with Single Sided Deafness. We aim for this to lead to the development of services and outcomes which are meaningful to those who use them.

Will my taking part be kept confidential?

Yes. However, should you disclose any serious criminal offences which has not been previously reported to the police or any maltreatment of children we are obliged to report this to the necessary authorities.

The audio recordings and interview transcripts will have all identifiable details removed as soon as possible after the data has been collected. Pseudonyms will be used in any written reports and on the transcribed interviews. The audio recordings will be password protected and stored on secure computer systems. The consent forms will be kept in a locked filing cabinet in a secure office, separate from the transcribed interviews.

What will happen if I change my mind about taking part?
You are free to change your mind about taking part in the study at any time. If you change your mind before the interview has taken place, it will not go ahead. If you change your mind during the interview all your previous answers will be erased from the audio recording in your presence. If you change your mind after the interview has taken place but before the data has been anonymised we will destroy all the information related to you. Once the data has been anonymised it will not be possible to withdraw it from the final analysis or reporting.

What will happen to my information after the study has finished?

All audio recordings and information held electronically will be archived in password protected files on secure computer systems. Hard copies of the transcribed interviews will be kept in locked filing cabinets in a secure office. The consent forms will also be stored in locked filing cabinets but these will be kept separately to the interview transcriptions.

Who has reviewed the study?

Dr. Carl Edwards (Chair, Leicestershire, Northamptonshire and Rutland Research Ethics Committee) has reviewed the research proposal and issued an SL24 form for the study.

Contact for further information.

If you would like any further information relating to the study to help you decide whether or not to take part, please contact any of the following people:

Dr. Sue Archbold (CEO, The Ear Foundation): sue@earfoundation.org.uk

Imran Mulla (Research Co-ordinator, The Ear Foundation): imran@earfoundation.org.uk

Dr. Nicola Wright (Researcher, The Ear Foundation): nicola@earfoundation.org.uk

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Telephone: (0)115 942 1985
Consent Form: Confidential

Title of Project: Bone Anchored Hearing Aids (BAHA) Single Sided Deafness: Adult Users views of BAHA use and services. A Qualitative Study

Please initial the box to confirm you have read the information.

1) I confirm that I have read the information sheet dated for the above study and have had the opportunity to ask questions and have these answered satisfactorily.

2) I understand that my participation is voluntary and I am free to withdraw consent at any time, without giving a reason and without my medical care or legal rights being affected.

3) I understand that the data collected may be looked by responsible individuals from the Ear Foundation and any other regulatory organisations for monitoring and auditing purposes to check that the research is being conducted to the highest standards.

4) I agree to being contacted in the future about further studies being undertaken at the Ear Foundation.

5) I understand that the data collected and subsequent transcripts are a gift. They can be stored anonymously and used by the Ear Foundation for future ethically approved research. The data will be held for no more than seven years.

6) I agree for my interview to be audio recorded and understand that all identifiable details will be removed as soon as is practicable after the interview has been conducted.

7) I agree that anonymised, verbatim quotations can be used in any reports written and publications produced.

8) I understand that should I disclose any information relating to serious criminal offences or child mistreatment that has not previously been reported to the appropriate authorities that the researcher may be obliged to do this.

Name of Participant

Signature

Date
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