

2021 Podcast Series

Podcast 2. Anisa Visram. *“Babies and hearing aids: why parents struggle and how to help”*

This text is an edited transcript of a recorded podcast.

Hello and welcome once again to a ManCAD / British Academy of Audiology podcast. You might well know that ManCAD stands for Manchester Centre for Audiology and Deafness and that we are located at the University of Manchester in the UK.

I am Gabrielle (Gaby) Saunders. I'm a Senior Research Fellow at ManCAD and I moderate these podcasts.

We always try to address the topics pertinent to the practice of audiology but also want to make sure that they are relevant to audiologists, researchers and anyone interested in hearing and hearing loss.

We will record a new podcast each month each one will be about 20-30 minutes long and we will post the audio recording along with a transcript on our University of Manchester webpages.

You can find information on the ManCAD website.

<http://research.bmh.manchester.ac.uk/ManCAD/Podcast/>

On to today, Anisa Visram from ManCAD will be discussing **“Babies and hearing aids: why parents struggle and how to help”**. Her knowledge about the topic arose from a study she and other colleagues conducted here in Manchester and from working closely with parents and their young infants with hearing loss over the last 5 years

Anisa is a Research Fellow in Audiology. Her research interests include improving clinical practice in paediatric audiology, auditory evoked potentials, and improving outcomes with hearing devices. Before we start our conversation, I'm going to pass you over to Anisa who will tell you a little more about herself

Anisa: Thank you very much for having me. I started out doing my PhD in Audiology here in Manchester. I then moved to North Wales where I did my clinical training to be a clinical audiologist and worked in North Wales as a paediatric audiologist. After that I moved back to Manchester where I have been working as a researcher in ManCAD for last 5 years with a focus on clinical projects in paediatric audiology.

Gaby: Today we're going to be talking about a study that Anisa and her team conducted looking at some of the challenges faced by parents of deaf babies when it comes to maintaining hearing aid use. Anisa, can you first set the scene of the study for us:

Anisa: We know 1 in 1000 babies born with permanent hearing loss, mostly to hearing parents. So the idea of hearing aids and hearing loss is very new to the parents. Consistent hearing aid use is really important for children to get quality language input and then developing language skills. Ideally we want to see three things:

- the ideal is that a child wears their hearing aid all waking hours
- the hearing aid is set up properly to match the child's hearing loss well
- the child is getting a lot of good quality language input at home and school

If we can achieve all these things we know that children are getting everything they need for good language development and won't be at a disadvantage compared to their peers with normal hearing.

Gaby: Sounds straightforward enough, what are the issues?

Anisa: Parents in reality face significant challenges in getting their children to wear their hearing aids all waking hours. Previous studies have shown that young children are probably only ever wearing their hearing aids on average for around 4-5 hours a day.

We also know from previous studies that generally hearing aid use tends to increase with age: as the parents get into better routines, as the children are awake for longer, all these sorts of things contribute to increasing hearing aid use. But we also know that consistent hearing aid use from the very beginning is really important for language development. This is why we want to help support parents from a very early age to maximise the number of hours their children are wearing their hearing aids. So the first thing is about trying to understand more about the challenges those parents face.

Gaby: So, what did you do to look at this?

Anisa: We designed a study using survey data. We asked parents of babies with hearing loss of their experiences at two different times. First off when the babies were very young, soon after they had the hearing aids fitted, when their babies were 3-7 months old, and again a few months later to see how things had changed. We also looked at how many hours a day the infants were wearing the aids using hearing aid data logging. One of the good things about the study, we were able to travel around the UK collecting the data. We actually recruited families from 53 different NHS Trusts from all around the UK, so we have a really representative sample, know we were getting to the important issues. We visited them at their homes, making participation possible and simple even at this time which can be difficult for parents.

Gaby: What were the key findings?

Anisa: One of the really interesting things we found was that hearing aid use actually decreased over time for these babies. They were using the hearing aids less when they were a little bit older than when they first had them fitted. That's despite the fact that as the children are a little bit older they were awake for longer and so in the terms of the effect of percentage of waking hours that they were wearing them, that meant that the decrease over time was even stronger.

Gaby: That's surprising since you said earlier that studies have shown that hours of daily use tended to increase with age. Why do you think your findings differed?

Anisa: When we looked closer, one of the effects we found was the effect was strongest with children with more profound losses. Children with worse hearing loss were more likely to show a reduction in hearing aid use than children with milder losses. We don't know exactly why this is but we can make a couple of educated guesses. This may be because the parents felt the hearing aids were not giving any benefit, and the ones with more profound hearing loss would be on waiting lists to have cochlear implants so perhaps the parents are just thinking the hearing aids are no use, we will just wait for the cochlear implants.

Another issue was that parents reported slightly different things when the children were really young and when they were a bit older. One of the things they always highlighted when the kids were a bit older was having more and more problems with the children pulling their hearing aids out of their ears. One really obvious barrier to consistent hearing aid use that did get worse as the children got older.

Gaby: That sounds problematic. Is it?

Anisa: There are problems but we can understand and address better. For children with profound losses some people may be tempted to say that they are not hearing anything so what does it matter? We still really want to be encouraging the children to wear their hearing aids as much as possible. We know that any tiny little bit of sound that gets through will help to make sure that the auditory pathways to the brain are stimulated. That means when they do go on to have cochlear implants this tends to lead to better outcomes. Still really important for children with profound hearing losses.

Looking at other issues around hearing aid use. In a separate survey we have been asking parents about their experiences recently during COVID lockdown. That's been interesting in that it's suggested that about 1/3 of children seemed to be wearing their hearing aids less during lockdown when they are not going to school. So this could be another pertinent issue right at the moment which is just adding in extra difficulty for parents trying to achieve consistent hearing aid use.

For all children, all degrees of hearing loss, all ages, we know that if they are just not using hearing aids then quality language is not getting through, not getting to the brain, just going to lead to slower development of language and of education. So it's really important.

Gaby: I suppose getting that message across to parents who think my child is profoundly deaf they need a cochlear implant, why bother? I could see that could be a huge barrier. Were there any other major findings you want to share from the study?

Anisa: Reassuringly there were certain things that parents were really good at. Basic hearing aid management skills like changing batteries, inserting ear moulds, they were really confident with those things. There were some things they struggled with, the more complex skills of troubleshooting hearing aids, doing listening checks they just weren't as competent with. We also asked parents about what information they wished they have had that they didn't or where they felt they were lacking in information.

In the early days it was really information about clearing the hearing aids and doing listening checks, they were the things they were just lacking complete information on soon after the hearing aids were fitted. When we went back and asked them again a few months down the line the focus was more about keeping hearing aids in the ears of the children and about the higher skills like how to retube ear moulds. So the information needs did change over time.

They also spoke about specific barriers to consistent hearing aid use, one of these we have already talked about, pulling the hearing aids out. Also some factors about the hearing aids themselves, e.g. frequent feedback or aids not working properly and other factors that were more to do with personal circumstances, such as distractions of other children in the home and difficulty getting into a routine. So we learned quite a bit about what kind of barriers the parents have got to hearing aid use.

Gaby: It's interesting to me because I am more familiar with adults and it seems the same, that adult new hearing aid users can do the basic skills but troubleshooting etc. Maybe that says that audiology as a field needs to find better ways to explain some of that to everyone. Not all these issues are specific to older adults, not specific to parents of children, it's a broader problem.

Anisa: We have been much focussed on paediatric audiology and children but you are absolutely right that some of it will extend out and just be relevant to new hearing aid users of any kind.

Gaby: Earlier you talked about the fact that most babies born with permanent hearing loss have hearing parents and so the parents know very little about hearing loss. This sounds like a major problem but also something that with planning and counselling could overcome. Can you talk more about that?

Anisa: One of the challenges lies in getting all the important information about hearing and hearing loss across to parents, at a time when they are likely to be feeling a bit confused and a little bit vulnerable. We did ask parents a bit about their experience of receiving information at this time. About a third of parents reported they felt overwhelmed by the information given to them in the audiology clinic about hearing loss and hearing aids. So something to be sensitive towards.

Whilst a lot of them did feel overwhelmed most, but not all, still wanted to get all the information straight from the beginning. 85% of parents said that. That's interesting in itself as it means that perhaps one in 6 or 7 parents would benefit from getting the information gradually. So it's just about being aware of the difficulties the parents maybe under emotionally at that time and the different experiences that might be appropriate for them in the clinic. We also asked them about what extra information they would have wanted at this time when hearing about the babies hearing loss and the specific things they said they would have liked; more information to help understand what their babies could and couldn't hear; information about peer support, more detail about the ongoing management plan.

These are all things that can be addressed with e.g. use of hearing loss simulators; a lot of hearing aid fitting software will include hearing loss simulators or you can just get some simple online implementations you can look them up on YouTube which is really great for helping parents understand. Information about local and national support groups such as NDCS, and clear written information about the ongoing plan helps to make sure that they don't necessarily have to take everything in all at once but they have information to refer back to.

We know how we can get information across to parents but we also know just because they receive that relevant information they may not necessarily go on to develop the necessary skills in hearing aid management. And just because they have the skills to manage hearing aids, they may not always put them into practice. There may still be broader wider barriers in terms of their personal circumstances, situation, beliefs, and motivations that stop them being able to use the hearing aids as much and well as we'd like.

Gaby: Have you thought about some solutions to some of these problems?

Anisa: First off we make efforts to make sure they have the rights skills and knowledge and we have talked about some of these already. The benefit of repetition, people don't always take things in on the first hearing. Also just checking in with parents over time to make sure you are addressing any gaps in their knowledge or skillset. We know that's not always enough. We need to make sure parents have belief in their abilities to use the hearing aids and that they understand the importance of using the hearing aids so that they are motivated to actually do it and that really requires specific and personalised interventions and we think that we can use evidence based behaviour changing techniques to develop these interventions to get some really good outcomes.

Luckily enough we have a project underway at the moment funded by NDCS (National Deaf Children's Society) looking at this. Ciara Kelly a post-doc in Manchester is working on it now. First she is doing interviews and questionnaires with parents and hearing professionals to help better understand these broader barriers to consistent hearing aid use. Using this to design and test interventions to help parents maximise hearing aid use, from the very beginning when their children are first diagnosed and fitted with hearing aids.

Gaby: This intervention you are talking about. What do you think it will be?

Anisa: We don't know exactly what it will be yet as that's what the ground work of exploring the barriers is about. We do know there has been a similar intervention has been described in the literature by Ambrose et al 2020. They described an intervention aimed at parents and toddlers with low hearing aid use. They developed a personalised intervention whereby they did structured interviews with the parents to find out exactly what their personal barriers were and used that to build in these interventions. Really quite personalised in addressing the specific issues concerned, whether it was negative beliefs, a lack of self-belief. They had real success. They had three parent-infant participants in the study and they all showed increased hearing aid use. That use did persist at least for one month after the study though it wasn't tested further than that.

We will probably be using some similar aspects of that kind of intervention but there are some differences as well. One of the things was that intervention was quite intense and involved home visits over several weeks. We might look at something where we are able to perhaps reduce but also increase the scope of participation and making sure it's viable to put into practice. Using remote practice to do some of the sessions and the other important thing is we are trying to target parents of children who are younger and have just been fitted with hearing aids to get straight in there with these good habits that the parents can get into and we also want to make sure we follow it up over a slightly longer timespan so we know if the benefits persist.

Gaby: That makes a lot of sense. When is that going to start?

Anisa: Ciara has been on the project for the last few months so she is well underway and will probably be getting in touch with some hearing professionals soon to get some input to this. So it's happening.

Gaby: So I want to take you back to something. You alluded to travelling around the UK collecting data on that first study. Can you tell us more about that?

Anisa: This study with the survey data was a bit opportunistic because we were travelling around to visit families for a different study where we were looking at doing aided EEG. So either cortical evoked potentials or auditory steady state responses. This is essentially for babies who are 3-7 months old wearing hearing aids, trying to find out if we can use objective techniques to see if the hearing aids were working appropriately and if the children were hearing speech through their hearing aids. Because we were trying to access a wide range of children we ended up with this project whereby we built a mobile research unit – a van with a soundproof booth in the back that we could drive to families' homes to do the testing outside their homes. What that meant was that it improved participation. We have already said that the parents are already under huge amounts of stress and have got different priorities in their lives with young babies so just being able to park up outside their house meant it was a lot easier for them to take part. We just realised that accessing all these children from all over the country we had the

opportunity to get a bit of extra value and get a bit of information about how the parents were coping with hearing aids at the same time.

Gaby: That's really wonderful. I understand there are new plans for this vehicle in the future?

Anisa: We have just gotten funding to look at a project investigating persistent auditory consequences of COVID. People may have seen in the media some attention has been given to the possibility that one of the long term consequences of COVID is effects on the auditory system. We will be looking at that in a lot more detail. The idea is to recruit 100 participants who have had COVID and 100 participants who have not had COVID who have been hospitalised over the last year and do a whole bunch of different hearing tests on them to try to delve into if there is a long term effect on hearing and if so, what parts of the auditory system are affected. That will be underway very soon. Just exciting and really important question.

Gaby: What is the key message you would like listeners to take away from this podcast?

Anisa: Keeping hearing aids in children's ears is hard work for parents, especially when it's all new to them. Start off by appreciating that. But acknowledge that it is important to keep hearing aids on children's ears, so it's worth putting the effort in to try and make sure that it's done. This means making sure that as well as making sure parents have the knowledge and skills to manage hearing aids, we need to look at what the broader challenges affecting them this could be about beliefs and personal circumstances. Maybe they think 'the hearing aids don't help'; 'it's not that important and I have other priorities'. Really discovering what those broader issues are and addressing these in an individual way that's what will lead to more consistent use and better outcomes for those children.

Gaby: It's a really important message. Let's hope we can change behaviour and it seems to me that it simply comes down to an understanding on the part of the parents that their behaviour have consequences down the line that they may be unaware of.

Anisa: Exactly and that's what we think using these behaviour change techniques can just be a really good way to understand it and address it and it's just supporting parents really.

Gaby: All it remains for me to do is say thank you Anisa for your time and sharing your thoughts.

If the audience have any follow up questions, feedback or share ideas for future topics please contact me.

You can send me an email. Gabrielle.Saunders@manchester.ac.uk

I hope you enjoyed this discussion and are going to come back to the next podcast. Until then farewell and stay well.

References:

- Ambrose, S. E., Appenzeller, M., Al-Salim, S., & Kaiser, A. P. (2020). Effects of an Intervention Designed to Increase Toddlers' Hearing Aid Use. *Journal of Deaf Studies and Deaf Education*. <https://doi.org/10.1093/deafed/enz032>
- Visram, A., Roughley, A., Hudson, C., & Munro, K. J. (2020). Longitudinal Changes in Hearing Aid Use and Hearing Aid Management Challenges in Infants. *Ear and Hearing*.