Development of parent experience-based information resources for families of children aged 0-4 years with mild/unilateral deafness

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Contents

1 Project team

Kay Confait, Parent Partner, Bristol, UK.

Hannah Cooper, UCL Ear Institute, Faculty of Brain Sciences, University College London, London, UK and Audiology Department, Royal Berkshire NHS Foundation Trust, Reading, UK.

Jamila Dorner, UCL Ear Institute, Faculty of Brain Sciences, University College London, London, UK.

Amanda Hall, Department of Audiology, College of Health and Life Sciences, Aston University, Birmingham, UK and Audiology Department, University Hospitals Bristol and Western NHS Foundation Trust, Bristol, UK.

Katie Ireland, Audiology Department, Oxford University Hospitals NHS Foundation Trust, Oxford, UK.

Helen Pryce, Department of Audiology, College of Health and Life Sciences, Aston University, Birmingham, UK.

2 Executive summary

Introduction

The newborn hearing screening programme in England was set up to identify childhood deafness in both ears, of a moderate or greater degree. However, children with mild bilateral or unilateral deafness are also identified through the hearing screen, and there are challenges and uncertainties in diagnosis and management specific to these types of deafness. This can make decision making challenging for parents.

To find out what challenges are faced by parents of young children with mild and unilateral deafness we first undertook a research study to gather their experiences. We then used the data from the research study to develop resources for parents to address their key concerns and information needs, to be used within and outside of paediatric audiology.

Research methodology

We interviewed 17 parents of children aged 0-4 years old with mild or unilateral deafness. We asked them to describe their experiences of having a young child with mild or unilateral deafness including diagnosis, decision making about management and influences on decision making, experiences of equipment and technology and any advice they would give to other parents.

We coded the interviews to pick out key information as well as similarities and differences across parents' accounts. We grouped codes into categories that represented broader themes, and we then looked at how the categories linked to each other. Finally, we developed a theory to explain the experience of parental decision making for their child's mild or unilateral deafness.

Key findings

The key finding was that parents went through a complex process of decision-making and that they faced a great deal of *uncertainty* when it comes to understanding and managing their child's mild or unilateral deafness. Factors that enhanced or mitigated this uncertainty include *external constraints*, such as whether hearing devices or educational support were available locally; *parents' trust and compliance* with medical advice; and *parents' skills and values*, such as their ability to seek additional information if their information needs were not met.

Parents negotiated uncertainty by going through a process of *learning to notice* changes in their child's behaviours or speech which could reinforce or cast doubt on the diagnosis. They also engaged in processes of *trade-off actions*, such as comparing their perceptions of their child's hearing with evidence provided by professionals. Both processes led to decisions on how to manage their child's deafness, which was typically either to 'maximise hearing' or 'wait and see'. These decisions were either in opposition with professionals, in compliance or in concordance with professionals. The decisions they made led to parents *preparing futures* for their children and family, but as parents faced new challenges or changes in circumstances over time, such as progressive hearing loss or transitions such as starting nursery, this required their ongoing negotiation of uncertainty.

Conclusions

Parents experienced many uncertainties around their child's mild and unilateral deafness, and we have modelled how parents manage this uncertainty. Our model highlights where information and support could be improved, including professional communication of uncertainty, implications and manifestations of mild and unilateral deafness, and shared decision making to support the trade-off actions that parents make.

Based on these conclusions we have developed video experience-based resources for parents to support their negotiation of uncertainty and to aid decision making around these key areas. These will be made available through the National Deaf Children's Society website.

Recommendations

- Professional bodies to develop guidelines for management of mild bilateral and unilateral deafness in young children.
- Development and implementation of training and support for professionals on communicating uncertainty and practising shared decision making.
- Evaluation of the video experience-based resources to assess whether they reduce parental uncertainty.

3 Background

3.1 UK Newborn Hearing Screening Programme

The universal Newborn Hearing Screening Programme (NHSP) in England was established in 2006 to detect bilateral moderate to profound bilateral (in both ears) deafness at birth (Wood et al., 2015), although the inclusion of 'bilateral deafness' as part of the target condition has subsequently been removed (NHS England, 2024). There is a strong evidence-base of the impact that bilateral moderate or greater deafness has on language and communication development, education and quality of life (Davis et al., 1997), and strong evidence that NHSP leads to earlier intervention and management of deafness in children (Davis et al., 1997; Ching et al., 2017; Yoshinaga et al., 2021).

Within England, due to the set-up of the screening programme, children with other types and configurations of deafness are also identified, although outside the remit of the original NHSP (Bamford et al., 2005). These include babies with mild deafness (in both ears) and unilateral deafness (any level of deafness in one ear and typical hearing in the other ear), both sensorineural and conductive (either permanent or due to conditions such as middle ear fluid). Clinical management of these babies is challenging for several reasons, and there are uncertainties along all parts of the clinical pathway, which can make discussions around prognosis, and decision making about management challenging for parents and clinicians.

3.2 Clinical uncertainties in diagnosis of mild deafness

Mild deafness can be particularly challenging to diagnose in infancy. Following referral from NHSP the auditory brainstem response (ABR) test is used to assess infant hearing. The ABR test is an objective measure and involves assessing the response of the infant's hearing nerve in response to frequency specific sounds. However, ABR testing does not give exactly the same results as behavioural hearing testing which is carried out as children get older. This is important to note as the ABR in infancy is used to predict a child's later behavioural hearing testing. Studies have shown that the ABR typically overestimates behavioural hearing for normal hearing and mild deafness (meaning that results for ABR may be poorer than behavioural hearing testing) and underestimates behavioural hearing for moderate or greater hearing (Gorga et al., 2006). A study by McCreery et al., (2015) examining ABR test results of infants and young children showed that of those identified with mild deafness on ABR, approximately one-third have hearing thresholds within the normal range on behavioural measures. This results in greater uncertainty around later hearing levels when explaining results to parents and deciding on management, particularly whether

to start active management, e.g. hearing aids, immediately or wait until there is greater certainty about diagnosis.

3.3 Uncertainties about the impact of mild or unilateral deafness

It is unclear from research evidence whether mild or unilateral deafness has an impact on a child's development. There are limited high quality studies evaluating the impact of mild bilateral hearing loss on a child's life: Ching et al., (2017) studied a cohort of children with mild hearing loss identified through newborn hearing screening and showed their global language at age 5 was below the expected level for their age. Moore et al., (2020) measured hearing and a range of outcomes in 1638 primary school children and showed those with mild hearing loss performed more poorly on cognitive measures of reading ability, but there was no difference in terms of their communication and listening. Wang et al., (2019) studied a cohort of Australian children some of whom had bilateral slight/mild hearing loss and found small differences in performance on sentence repetition, teaching reported learning and physical quality of life. By contrast Wake et al., (2006) in a large survey of around 6000 Australian primary school children found no difference in language, reading, behaviour or quality of life for those with mild hearing loss compared to those with normal hearing.

There have been more studies that have examined the impact of unilateral deafness in terms of speech and communication development, listening effort and fatigue, as well as education and behaviour, and several systematic reviews have been published. As for mild hearing loss, these also show a picture of unclear evidence in terms of whether unilateral deafness impacts on speech and language development (Anne et al., 2017). It is possible that some children are more impacted than others, but with the existing evidence available, it is not possible to predict which children are at risk. This is particularly challenging when children are very young as difficulties may not be apparent due to their developmental stage e.g. a baby with unilateral deafness who has not yet reached the developmental stage of turning their head to a sound of interest will not be able to show the expected difficulties with localisation of sounds.

It is also important to recognise that a diagnosis of mild or unilateral deafness may conflict with parents' experiences with their child as they may respond to many sounds (e.g. Fitzpatrick et al., 2016; Lin et al., 2022). It may also be the case that the acoustic environments of babies with mild or unilateral hearing loss mean that they do not have any difficulties e.g. they may be in a quiet environment close to their caregiver for much of the

time. This may mean that difficulties are only present when their environment changes e.g. when they go to nursery or to school.

3.4 Uncertainties about the impact of intervention

It is unclear from research evidence whether interventions such as hearing aids are beneficial for children with mild or unilateral deafness. There are a range of outcomes from observational and clinical review studies with some children gaining benefit from interventions and others showing no benefit. A randomised control trial (RCT) is the best way to measure the effectiveness of an intervention but there have been no completed RCTs for mild or unilateral deafness in infants and children. There may be good reasons for this as highlighted by Sung et al., (2023). They carried out a feasibility study for an RCT in Australia to investigate hearing aid intervention for bilateral mild hearing loss but were unable to recruit enough participants. Subsequent qualitative research with families identified that the RCT method raised ethical concerns due to the potential negative consequences of not offering early amplification for some children, and therefore impacted on the feasibility of delivering the study. Similarly in England, an NHS trial was funded in 2001 to examine the effectiveness of hearing aid fitting for mild/moderate hearing loss identified through the newborn hearing screen but was discontinued due to difficulties with recruitment (NIHR, 2001).

The difficulties of conducting an RCT in this area, and therefore the lack of high-quality evidence, mean that clinicians have to rely on observational evidence, which is more likely to be biased. For example, data is more likely to be gathered and available from parents and children who are finding an intervention beneficial; those who are not finding it beneficial are more likely not to use a device, attend clinic or to provide data.

The best quality observational data that is available is from studies that have used natural variation in roll-out of screening programmes within a country to conduct “natural experiments”. These types of studies have less bias (participation in newborn hearing screening is due to geographical location or time, and not due to factors related to the child or family). The Australian Longitudinal Outcomes of Hearing Impairment (LOCHI) is a recent example of such a study. The LOCHI study examined whether there was any benefit of early hearing aid fitting on global language at age 5, and whether this varied according to the severity of hearing loss. They found a clear benefit of early hearing aid fitting for bilateral severe and profound losses, a benefit (but reduced) for moderate and no benefit for early hearing aid fitting for mild hearing losses (Ching et al., 2017). Carew et al., (2018) examined

Australian data across four systems of hearing loss detection from 1991 to 2010 and concluded that although mild hearing losses are now identified and managed earlier through NHSP, the expressive (not receptive) language scores of these children are below normative values and this has not changed over time.

For unilateral hearing loss, recent systematic reviews have been published. A review of the impact of hearing device use on auditory outcomes identified limited studies with the results showing a trend to improvement (Appachi et al., 2017); a review of quality of life (measured using standardised questionnaires) found varied evidence as to whether interventions improved quality of life (Nicolas et al., 2021); while a review of academic outcomes highlighted the lack of evidence of benefit (Romano et al., 2024).

Several studies highlight critical periods of brain development and the impact of mild and unilateral hearing loss (Calcus et al., 2019; van Wieringen et al., 2019), with van Wieringen et al., (2019) concluding the need for early intervention with hearing devices for unilateral hearing loss. However, it is important to recognise that hearing aids and other devices are not perfect systems and can introduce distortions in sound quality and timings, the effects of which are unknown for infants and children with mild and unilateral deafness. They also come with challenges such as managing daily wear and battery safety, ensuring a good fitting mould, and potentially managing feedback (Lin et al., 2022). Other intervention options may include different types of technology such as a bone conduction hearing aid, CROS aid or remote microphone, however some of these may be impractical for small children. There is also the option of active monitoring without technology intervention to see whether problems develop as a baby grows.

3.5 Current guidelines for mild and unilateral deafness

Clinical guidelines for the management of children with mild and unilateral deafness are limited both in the UK and internationally. Where guidelines exist, they highlight the lack of evidence but do not provide options for management, advocating an ‘individualised approach’ which is unclear in meaning (BSA, 2021). This lack of guidelines can lead to substantial variation in management within and across services with the potential for clinicians to make decisions based on their own preferences. Lin et al., (2022) highlighted that parents of children with mild hearing loss from within the same service in Australia were getting different options for management from clinicians and Hall et al., (2019) noted variation across services within the UK for managing conductive hearing loss in infants.

There is also variation internationally in how different screening programmes manage mild and unilateral deafness. In a European-wide survey, Busse et al., (2021) identified that of 47 programmes, only half fitted hearing aids to children with unilateral deafness despite it being the target condition for most programmes. There was also variation in the fitting of hearing aids to mild deafness, with aids "fit when a HI exceeds 30 to 40 dB HL (in 25 out of 41 programmes), though the range varied across programmes from >=21 to >=60 dB HL" Busse et al., 2021, p827).

Walker et al., (2017) looked at service delivery for mild hearing loss in the USA. They advocated for early hearing aid fitting for children with mild deafness whilst at the same time acknowledging the weak evidence for this course of action.

3.6 Decision making in the context of uncertainty

Uncertainty is widespread throughout healthcare, and it is recognised that this can lead to difficulties for healthcare professionals when giving advice to patients (Scott et al., 2023). The uncertainties that have been outlined in the previous sections mean that audiologists experience difficulties advising families about management as no good quality evidence exists to guide practice (Ching et al., 2022). This in turn may lead to parental uncertainty due to ambiguity and lack of information, advice and professional guidance as well as potential uncertainty around their child's diagnosis. Making decisions is therefore challenging in these circumstances, for both parents and professionals.

3.7 Aims of the project

The aims of this project were to develop an online parent experience-based resource to support person-centred care for parents of infants and young children (0-4 years) identified with mild and unilateral deafness (sensorineural, permanent conductive or temporary conductive due to middle ear effusions), specifically to:

- Support parents of infants and young children with mild or unilateral deafness in understanding and making decisions for their child's deafness.
- Improve clinical care for infants and young children with mild or unilateral deafness through developing tools to improve shared decision making in paediatric audiology.

To find out the challenges that parents face we first undertook a research study to gather parent experiences. We then used the data from the research study to develop resources for

parents which addressed their key concerns and information needs, to be used with and outside of paediatric audiology.

Our research questions were:

1. What are parental experiences of the identification process and subsequent management of mild or unilateral deafness for their children (age 0-4 years)?
2. What are parental views and information needs on the management options and interventions for children aged 0-4 years with mild or unilateral deafness?

4 Participants and methods

4.1 Approach

Grounded Theory is a qualitative research methodology designed to generate theories directly from data. Unlike quantitative research methods that start with a hypothesis, grounded theory begins with data collection and allows the theory to emerge from the data itself. The key components of grounded theory are outlined below.

1. The first stage is to begin data collection, typically using semi-structured interviews, which give respondents more room to explore the questions asked by the researcher This is a flexible process which evolves as the study progresses.
2. Coding is used to break down the interview data into manageable pieces and assign labels, known as codes, to the pieces. There are two main types of coding:
    a. Open coding – this is the initial phase where the data is broken down and examined for similarities and differences.
    b. Axial coding – this involves reassembling the data in new ways by making connections between codes.
3. Categorisation is the next stage which involves grouping codes into categories that represent broader themes or patterns in the data.
4. Theory development is then explored with codes being grouped and developed into a theory that explains the experiences being studied. This involves looking at relationships between categories to understand a phenomenon and identifying the core category which is common to all data and provides an explanation of the variance within the data.

Grounded Theory works within a specific framework, or structure, which guides the research process:

- An inductive approach is used which means that the research starts with observations, such as interviews with participants, and uses these observations to propose theories. This is different from traditional research which often starts with a theory or hypothesis to be tested.
- Grounded Theory uses an iterative process where data collection and analysis happen at the same time and influence one another. This means that the data collection is continuously refined based on the ongoing analysis.
- Theoretical sampling is used. Researchers select participants based on the emerging theory development in order to refine the categories. Participants are not selected at random.
- Data are constantly compared with the emerging categories to identify patterns and variations.
- The process continues until no new insights are gained from the data which suggests that the theory is well developed and comprehensive. This is known as theoretical saturation.

4.2 Ensuring quality in the research

We used a number of methods to make sure our research was of high quality. Reflexivity is an important part of Grounded Theory and requires complete openness about decisions that are made in the research process. We were reflexive throughout the process and those of us with clinical audiology backgrounds reflected on our clinical roles and preconceptions we may have about the management of children with mild/unilateral deafness. Our parent partner was also involved in discussions about the data collection and analysis process. The researcher who conducted the interviews was an experienced qualitative researcher and anthropologist, but she did not have a background in audiology. This meant that she was unbiased from that perspective in terms of her interactions with families and the data analysis process.

4.3 Ethical approval

The study was approved by the UCL Research Ethics Committee (project ID: 12585/009) and by the London – Harrow Research Ethics Committee (IRAS ID 313595). Informed consent was given by all participants. Data were stored in compliance with the European Union's General Data Protection Regulation (2016/679). Personal identifiers were removed for analysis.

4.4 Recruitment

Parents or carers of children with mild or unilateral deafness age 0-4 years were eligible to take part in the study. Study information was disseminated to potential participants via qualified Teachers for Deaf Children and Young People and through three NHS participant identification centres (Royal Berkshire NHS Foundation Trust, Reading; University Hospitals Bristol and Weston NHS Foundation Trust; Kent Community Health NHS Foundation Trust). Study information was sent out via National Deaf Children's Society family mail outs. Information was also posted on National Deaf Children's Society and UCL Ear Institute social media sites.

Potential participants were directed to fill in an online form to express interest in the study and a basic eligibility check was carried out (age of child). A member of the study team then contacted interested families by email with further details about the project and a link to a consent and demographics form was included. Once participants had filled in the consent form a date for an online interview was arranged. Basic information about families was collected in order to describe the group and ensure that the group was diverse in terms of the age of the child, type of deafness, geographical location, ethnicity and relationship to child (mother or father).

4.5 Qualitative interviews

All interviews took place on Microsoft Teams and were video and audio recorded. Interviews were carried out by Jamila Dorner with supervision from Helen Pryce who is an experienced qualitative researcher. A topic guide was developed by the study team to explore participants' experiences of having a child with mild or unilateral deafness (Appendix 1). Jamila asked parents to describe their experiences of having a young child with mild or unilateral deafness including diagnosis, decision making about management and influences on decision making, experiences of equipment and technology and any advice they would give to other parents. Jamila asked open questions and allowed parents to lead the discussion, with minimal influence on their responses. The analysis took place alongside the interviews: after each interview, the transcript was explored for themes which were present in that interview and in previous interviews. The topic guide was then amended or expanded to explore new themes in the next interviews. Interviews lasted between 45 to 75 minutes.

4.6 Participants

A total of 40 people filled in the screening form and 24 people consented to be interviewed. Eighteen interviews were conducted. Six people who consented did not respond to emails about arrangements for interviews. One interview (participant 9) was excluded from the analysis due to inconsistent responses and poor quality of recording. This left 17 transcripts which were analysed.

Table 1 shows participant characteristics.

All participants but one were from England with one participant from Northern Ireland. Parents were from a range of educational levels and ethnicities (not reported here to preserve anonymity). Children's age ranged from 5 months to 4 years old. Mild or unilateral deafness was identified at birth or within 8 weeks after the birth.

4.7 Reasons for not participating

Although we did not systematically seek or collect this data we had some conversations with parents while giving information about the study. Anecdotally people told us that they did not have time to participate or had no concerns about their child.

4.8 Data analysis

Several steps are used in Grounded Theory to analyse data, and these were followed in this study. Following data collection, 'open coding' of transcripts was used to break down each conversation into smaller parts and label them with codes which describe what each part is about. 'Axial coding' was then used to group the codes into categories and look at how they related to each other. This process continued alongside the interviews and the findings from the ongoing analysis directed the topics explored in the subsequent interviews. Open coding was carried out by Jamila, with Helen coding a sample of transcripts. Jamila and Helen discussed and compared codes and developed the axial codes together. The codes were then used to identify key categories which the team developed into a theoretical framework to describe the experiences of parents.

Table 1 participant details

Participant number	Relationship to child	Age band	Parent education level	Child's position in family	Mild/unilateral deafness	Child uses hearing aid/CI
1	Mother	18-24	Postgraduate degree	Only child	Unilateral	Yes, in one ear
2	Mother	25-34	Undergraduate degree	Only child	Unilateral	No
3	Mother	25-34	College/vocational training	2nd born	Unilateral	No
4	Mother	25-34	Undergraduate degree	Only child	Unilateral	Yes, in one ear
5	Mother	25-34	Postgraduate degree	Only child	Unilateral	No
6	Father	35-44	Postgraduate degree	Only child	Mild in one ear mild-moderate in other ear	Yes, in both ears
7	Father	35-44	College/vocational training	2nd born	Unilateral	No
8	Father	35-44	Undergraduate degree	Only child	Unilateral	Yes, in one ear
10	Mother	25-34	Undergraduate degree	Only child	Unilateral	Yes, in one ear

11	Father	35-44	Postgraduate degree	Only child	Mild bilateral	No
12	Mother	25-34	Secondary school	Only child	Unilateral	No
13	Mother	35-44	Postgraduate degree	Only child	Unilateral	Yes, in one ear
14	Mother	25-34	College/vocational training	3rd born	Unilateral	No
15	Mother	35-44	Undergraduate degree	2nd born	Unilateral	Yes, in one ear
16	Mother	35-44	Undergraduate degree	2nd born	Unilateral	Yes, in one ear
17	Mother	35-44	College/vocational training	1st born	Unilateral	No
18	Mother	25-34	Undergraduate degree	Only child	Unilateral	Yes, in one ear

5 Findings

5.1 Overview of the model

We investigated the experiences of parents regarding the identification and management of their infants and pre-school children with mild or unilateral hearing loss. The key finding was that parents face a great deal of uncertainty, and this is the core category in our data. We have modelled how parents negotiate that uncertainty in relation to decision making for their child (Figure 1).

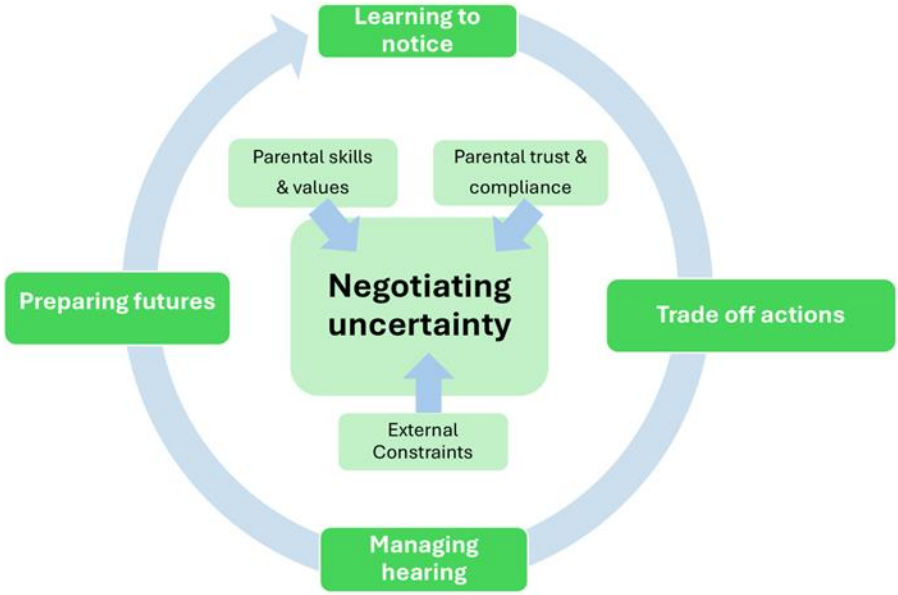

Figure 1: Model of how parents negotiate uncertainty about mild and unilateral hearing loss in their pre-school children

We examined contrasting cases or negative cases (a key component of Grounded Theory methodology). Uncertainty remained a key factor for all participants unless the level of hearing loss was deteriorating to become bilateral and more severe as evidenced by participants whose child had a progressive hearing loss or developed glue ear in their hearing ear. In those latter cases, the process of decision making then became straightforward.

There were three categories that feed in to *negotiating uncertainty*, and these are components that can enhance or mitigate uncertainty in decision making. For example,

external constraints, relates to lack access to some technical interventions due to geographical locations or NHS eligibility criteria, which reduces the degree of uncertainty with parents advocating for their child to access more technological support (e.g. hearing aids, BAHA or CI). *Parental trust and compliance* with medical advice reduces the degree of uncertainty whenever parents valued and privileged medical evidence (e.g. audiogram, statistical evidence). Another factor is *parental skills and values*, which relates to parents' ability to seek additional information when their information needs were not met, which can mitigate or enhance uncertainty as they may agree with or challenge medical authority.

In our model, parents negotiate uncertainty by engaging in a process of *learning to notice* any changes in their child's behaviours or speech which could reinforce or cast doubt on medical discourse. They also engage in a key process comprising complex *trade-off actions*, such as comparing their perceptions of their child's hearing with the evidence provided by the professionals and the audiogram. Both processes lead to specific decisions regarding ways of *managing hearing/deafness,* whether they prefer to 'maximise hearing' or 'wait and see', whose outcomes aim at *preparing futures.*

The category *preparing futures* can feed uncertainty as parents faced new challenges and monitored their decisions over time as their children experienced educational transitions (e.g. starting school or nursery) or unexpected changes in circumstances (e.g. progressive hearing loss).

These categories are described in more detail below.

5.2 Negotiating uncertainty

Negotiating uncertainty is the core category in our data and is present in each account. There were a range of uncertainties that parents described in our data. Parents were uncertain about what mild or unilateral deafness meant; they were uncertain about what was the right thing to do for their child; and they were uncertain about whether interventions would help or, if used, whether the interventions were helping.

Our data emphasised that *negotiating uncertainty* was an ongoing, dynamic process with decisions being revisited over time. Parents made several decisions and changed their approach ('maximise hearing' or 'wait and see') towards the management of their child's hearing loss as their child developed and new evidence arose, as the educational context

changed with transitions to nurseries/schools, or with changes in circumstances affecting the level of the hearing loss (e.g. experiencing episodes of glue ear).

The whole process of *negotiating uncertainty* in decision making operated within an overarching framework characterised by tensions between the lifeworld and the medical world as parents' views and perceptions were often conflicting with medical discourse. Parents believed to 'know their child best' and advocated for their child based on their own research for additional information and their personal values (e.g. fearing stigma vs valuing disability, valuing scientific evidence vs challenging medical discourse).

> *'I think it's like reading stories of other parents cause then you see it from their perspective. Cause I think doctors and NHS like it's very medical, isn't it, which is obviously what their job is.' (P2)*

> *'Meeting with other parents you realise that it's not just a one size fits all, every child is different. They've all got different levels of hearing loss. They all have different technology, and you just need to find what fits you really.' (P3)*

As a result, our data highlighted that some parents were compliant with medical advice whereas others were challenging medical protocols and the 'one-size fits all' approach depending on *parental trust and compliance* as well as *parental skills and values*.

5.3 Parental trust and compliance

The category *parental trust & compliance* relates to how parents dealt with uncertainty depending on their trust and attitudes towards medical discourse and the kind of evidence that they valued: whether this was scientific evidence, such as statistics and explanations of child brain development; or evidence from their child such as their ability to respond to sound, and their speech development.

When parents trusted medical discourse, they tended to show compliance.

> *'I didn't want her to miss out on anything. And they say that with the hearing aid, especially if you're going to introduce it, you're best off to introduce it sooner rather than later in order to ensure the brain connections all get sorted out. So we went down the road of getting her a hearing aid.' (P15)*

When they privileged their own observations of their child, they tended to challenge the medical stance.

> *'He clearly likes engaging with sound, and therefore we're going to, obviously we're going to wait and see how that materialises in terms of what kind of assistance he might need, if any'. (P11)*

Those quotations show how parents negotiated uncertainty by privileging different forms of evidence and how these influenced going down the 'aided' or 'non-aided route'.

5.4 Parental skills and values

Parents in our sample came from a range of educational backgrounds and had a variety of professional experiences and social capital to draw on. As a result, some parents were able to read scientific evidence around hearing loss, to access clinical guidelines, or to secure additional fundings.

> *'I went through all the standards of Radio Aid that were available on the NDCS, the technical standards, the research that was quoted, especially for example in Scandinavian countries […] So then I created a case saying that if the interventions are done at the right age, all the support, which is very expensive later on, will not be required.' (P6)*

Some were confident in challenging authority figures, questioning the need for a hearing aid or equally contesting the lack of options available for managing their child's unilateral or mild hearing loss.

> *'Sometimes I wish I wasn't a [health professional]. I think, you know, you see things, you know, working in the NHS and yeah, it has helped cause obviously I think if I hadn't been like aware…or being on the Internet or on these like forums… the doctors, I don't think they would have brought up the subject of a Cochlear implant.' (P4)*

Some parents described how their professional background influenced their confidence in health and educational services. They followed the medical advice they were given, having confidence in professionals to know the correct approach to take.

> *'I'm a [public sector worker], so I don't know. I think maybe as a person I'm quite assertive and maybe that's what made me so comfortable about my decisions and I obviously I work in the public sector, so I have confidence in the public sector that in the end, you know, the NHS and the professionals are professionals for a reason and*

that's why… I have confidence in what they're telling me is right because I know that they have the qualifications, the training.' (P13)

Other parents described how they were led by their own views on what was best for their child, were sceptical and challenged the medical views.

'I feel like I've had to harass them [the professionals] a little bit, like in a nice way, as best I can cause I know you get nowhere by shouting at people but you know, I don't think it's a lot to ask for them to consider maybe a unilateral loss on a case by case basis.' (P4)

These quotations have highlighted two mechanisms through which parents negotiated uncertainty: by trusting medical discourse or by challenging it on the basis that they 'know their child best'.

5.5 External constraints

External constraints affected access to technological interventions (e.g. hearing aid; BAHA; radio aid) and educational supports (Teacher of the Deaf; BSL courses for parents). Parents described NHS and education system constraints which meant that their preferred intervention choice might not be available or may not be the standard practice in the service they were under. This included lack of access to technological interventions such as cochlear implants, with some parents aware that outside the UK other countries are fitting cochlear implants to children with unilateral deafness. Parents also described a lack of access to hearing devices in some places, with some services not fitting hearing devices for unilateral deafness and others fitting them as standard.

'He [audiologist] basically said they didn't like to give any aids to unilaterally deaf children.' (P10)

The rationale given for these system constraints and lack of availability of interventions was the lack of scientific evidence.

'Because they said that there was no evidence that it would help.' (P3)

They described the need for special funding in some cases.

'And they had to make a case that she has a BAHA bone anchored hearing aid on a soft band.' (P14)

In terms of education, some parents described not getting pre-school support or not getting support to learn sign language. Some parents felt that these system constraints were related to the fact that their child was not 'really deaf'.

> *'Probably easier if the child is 'really deaf'. Then you've got all the options. But if it's just partially, I think, you're kind of pushed aside.' (P10)*

> *'A lot of the time, but because, oh, you've got one good ear. Oh, that's only temporary. There's no support.' (P14)*

Parents recognised the difficulties in decision making due to the level of hearing loss their child had and the potentially lesser impact of mild and unilateral hearing loss compared to greater degrees of hearing loss. For some, they felt their decision making would be easier if their child was profoundly deaf.

> *'I think if your child has a unilateral loss or a mild hearing loss, I think that's when it's trickier to make the decision because they might hear fine and they might do well and they might be able to access all the speech sounds.' (P16)*

5.6 Learning to notice

Parents described their child's hearing loss as an 'invisible disability' that has 'no fix'. This made decision making about the management of their child's hearing loss a difficult process during which parents experienced an overwhelming sense of guilt, responsibility and uncertainty.

> *'I think it's hard and I think hearing loss because it's like you know it's it's an invisible disability and obviously so many things that happen physically to your children you know you've been through yourself. You know you break a leg or cut yourself and things like that, but you've been through it. You know how it feels and you know what works, whereas you don't with hearing loss.' (P16)*

Parents reported difficulty in making decisions without input or feedback from the child due to their child's young age. In the absence of their child's feedback parents engaged in a process of learning to notice using their new knowledge gained from audiology appointments (e.g. audiogram about their child's hearing) and from additional information seeking (e.g. reading scientific journals, joining social network with other parents) to observe and interpret their child's responses to sound and development of speech.

> *'I do notice it now, she's a bit older… in busy environments, she will struggle to pick up that, to focus. So say if you're talking to her but you're not right in front of her, and*

I was to call her name, she would struggle to hear where that voice was coming from.' (P13)

There was variation in how parents perceived their child's hearing loss, related to how their child responded to sound or developed speech. This linked to whether parents perceived that a technical intervention was required. There was often a sense of difference between the parents' observations of their child and the explanation provided by audiologists and other professionals about their child's hearing loss.

'We know he can hear, hear a lot. We communicated that to them. I would say they weren't really that open to our experience which is really…You know which I think has a firm basis.' (P11)

'If he hadn't had the newborn screen, I don't think we would have ever known, because I think he speaks better than she [his sister] did at the same age.' (P3)

The parents whose children were babies or infants talked about wanting their child to be able to 'speak for themselves', which can be thought of in terms of both having autonomy over decision making as well as making age-appropriate communication progress.

'It's quite hard to know until she starts talking and communicating… It's quite hard to know what's right.' (P2)

5.7 Making trade off actions

Parents described how each child was different and that they, as parents, knew their children best. Unless their child could express their preference, the parents engaged in various trade-offs between medical advice and their own observations of their child to decide about a course of action and whether a technical intervention was needed. To do so, they often networked with other parents and researched information online when their information needs were not met. This led some parents to challenge the medical views (e.g. NICE guidelines) when no management was offered for mild/unilateral deafness.

Whether parents valued medical advice, or their own observations, this explained how the trade-off was made.

'There were many times that I feel like 'oh' like 'he can hear!'. Like 'he's fine!', you know. But then I kind of think about the information I've been given and I'm like, well, because, it's unilateral, I understand that one ear does work. It may seem to us that

he's hearing everything, so you know, but really he's not accessing the same sounds that we're having.' (P1)

The outcomes of those trade-off actions were that some parents preferred to 'maximise hearing' by providing a hearing device early on. Others however preferred to 'wait and see' how their child developed.

Those whose preference was to 'maximise hearing' decided to 'try something' because they associated this with a way of 'doing your best for your child' or giving them 'the best start'. They described a sense of duty or 'job as parent' clashing at times with some parents' fears about stigmatisation (depending on the type and design of the aid) and bullying behaviours.

'There was never any uncertainty for us that [name of child]., wearing some support for her hearing, wouldn't be an advantage, but it was just about…Well, I think the beginning for me it was people seeing my baby with her hearing aid and her ear, the way it looks…' (P13)

Parents engaged therefore in two different types of trade off actions both cognitive and emotional.

5.8 Managing hearing/deafness

This category related to what parents did to maximise hearing and communication and minimise the impact of the hearing loss, including the use of technical devices and educational strategies.

This was influenced by *external constraints* such as the nature of the interventions available for mild and unilateral deafness, and the systems in which they were delivered. Indeed, we observed a lack of consensus in the medical discourse which involved offering a hearing device early on ('maximise hearing'), monitoring hearing ('wait and see') or not offering any management on the basis that the child can hear ('one ear is enough'). This meant that there were discrepancies between audiology services across the nation, which affected options for management and decision making.

'I didn't feel like I had a choice. I mean, it kind of was, you know, he's got a hearing loss. Um, here's the hearing aid. Um, I didn't feel like I could say no, but at the same time I wouldn't have wanted to say no because I want the best thing for him.' (P1)

‘They explained that it was very much led by us, so if we wanted to try something, we could, but they wouldn't push anything on us. If there was something that we decided we would like to try, then we could, but we decided not to and that we would just see how things go.’ (P3)

‘I don't think it's a lot to ask for them to consider maybe a unilateral loss on a case by case basis instead of just shutting the door in your face, saying ‘No, sorry you've got hearing in the other ear. Yeah, he'll be fine. He'll adapt.’ (P4)

Parents had differing values and attitudes to deafness which influenced their decision-making regarding *managing hearing/deafness*. Some expressed fear of stigma or discrimination, for example where deafness was taboo in their home country, whereas others had positive attitudes for example where they felt there was good support for people with additional needs. Some felt it was important to have a visual reminder to others through a hearing aid that their child was deaf to increase awareness and help with communication of those interacting with their child.

‘It's good [the BAHA] because it's visual. So anyone can look at her and they know she is deaf and they will know.’ (P16)

While some parents welcomed such visibility and described how they had transformed hearing devices into fashion accessories, others felt that hearing devices had an unappealing design that could stigmatise their child.

‘I hate the softband. Anyway, I think it looks like a bra strap, but that's just the way they have to be designed.’ (P13)

Parents reported how the type of hearing device had influenced their decision since these were non-invasive, did not require surgery and were therefore non-permanent. This gave their child options to continue or stop wearing them in the future.

Parents described how they acted depending on their child and family’s personal circumstances.

‘I don't know every child, like I said, is different and everyone's lifestyle is different so I think maybe, if [name of child] had been going to nursery earlier from a younger age, I probably would have considered a hearing aid.’ (P5)

‘And my view is very much of it, ‘deal with things as they arise. Don't make a problem that isn't necessarily there.’ So because with [name of child] we haven't seen any real

challenges at the moment, I don't feel there is the need to try and make him do something he might not be as comfortable with.' (P7)

Many felt a time pressure to act, feeling their child's development was at stake, whether that was in relation to missing out on sounds, or in terms of their child's brain development.

"And they say that with the hearing aid, especially if you're going to introduce it, you're best off to introduce it sooner rather than later in order to ensure the brain connections all get sorted out. So we went down the road of getting her a hearing aid" (P15)

'I think with a unilateral deafness, it's by the time they are 3 or 4. And like I said, I just feel time is against us at the minute cause he's 1 now.' (P4)

Those whose children were older did not feel a time pressure to act if their child's developmental milestones were met.

These factors influenced how decisions about the intervention were made. Parent-led and medically-led decisions involved a sense of conflict. The parents may not have felt listened to. They might not have been asked about their preferred course of action. They may have been overwhelmed with conflicting information or felt their information needs were not met.

When the intervention was parent led, the parents challenged the medical views and opted for a different course of action than the one recommended by the professional, or the professional left the decision making entirely in the hands of the parent without supporting them in the process.

'One audiologist that we saw once was like 'oh it's time that you need to like sort of make a decision. Is this something that we want to do?' And I thought 'oh I thought we were just...going with the flow and see what happens?' (P3)

When the intervention was medically led, parents did not feel that the decision was their own but followed the recommendations of the professionals. They did not feel that they had options.

'I didn't feel like I had a choice. I mean, it kind of was, you know, he's got a hearing loss. Um, here's the hearing aid. Um, I didn't feel like I could say no, but at the same time I wouldn't have wanted to say no because I want the best thing for him.' (P1).

'So the only thing they really told us at the hospital was, 'umm, he's going to have to sit at the front of the class whenever he's older in school because he only can hear in one ear.' But then they also said that he won't benefit from any hearing aids or anything like that. They haven't actually explained why they just said he won't benefit from [an aid] and that's it. (P12)

Concorded involved a higher degree of satisfaction with the decision and preferred course of treatment. Parents felt in control with their decision but also in agreement with medical advice. Information was shared by professionals.

'We'd always been quite open to, you know, we'd always have like the open discussions with them [audiology].' (P16)

Managing hearing/deafness also comprised a range of additional educational strategies aimed at 'maximising communication'. For example, parents reported enrolling in BSL courses, valuing audio-verbal and speech therapies, nurturing a bilingual home and privileging one-to-one activities when their child was a baby/infant.

5.9 Preparing futures

Uncertainty remained for many parents as they were unsure whether a hearing device was helping or whether the other ear was compensating in the case of unilateral deafness.

'[It's] Hard to know, because obviously you're you sort of think well, is she using the hearing aid or is it just the other ear working harder?' (P15)

They also described their worries regarding further potential deterioration of hearing. Whilst some expressed ongoing worry and growing uncertainty, others felt confident about the future.

'So his speech is delayed…so I'm not sure how the hearing aid is helping him' (P10)

'People just keep telling me that he might lose his hearing in his left ear and that freaks me out. So I have to not think about it because I can't control it.' (P17)

'I mean, we're happy with [child's name]…. How she's at the moment with her speech and development, her language. So no, I think actually, if we went back in time and we were presented with the same situation, I don't think we would have changed anything.' (P16)

The idea that the process of negotiating uncertainty and decision making evolves over time was also clear in our data: parents made several decisions influenced by educational transitions, such as starting school, or when there were unexpected circumstances affecting their child's hearing loss such as an episode of glue ear.

Parents who had good access to information and support felt confident about the future in contrast to those who had to battle for support.

> *'It's not as bad as I thought it was going to be when we were first told when he was sort of four weeks old. When he was four weeks old, I was really scared and worried. And actually the older he gets, the less worried about it I am.' (P3)*

6 Discussion

Our main finding was that parents experienced many uncertainties around their child's mild and unilateral deafness, and how they managed this uncertainty was related to whether they valued and trusted medical discourse or were guided by their own observations and evidence from their child. This informed the trade-offs that parents made as to whether to intervene with amplification or wait and see. It informed whether decisions that parents made were in opposition with professionals, in compliance or in concordance with professionals.

6.1 Professional advice and communication of uncertainty

Parents in our sample were given a range of differing advice on the best management strategy for mild and unilateral deafness. Where the decision about intervention for mild and unilateral deafness was medically led, some parents were given no options and no information that enabled them to make informed choices. The geographical variation in service provision for mild and unilateral deafness, both within and outside the UK, added to the uncertainty for parents. This demonstrates a clear need for national professional guidance to address regional differences in service provision and advice giving.

There is a strong need for professionals including audiologists and Teachers for Deaf Children and Young People to be able to better communicate uncertainty to families. Uncertainty is highly prevalent across healthcare and a variety of recommendations for how to communicate uncertainty have been made in the literature, however, most also lack an evidence base (Medendorp et al., 2021). The most common advice for healthcare professionals is to ensure that communication is individualised but there is little guidance on

how to do this in practice (Medendorp et al., 2021). Our study shows the importance for professionals to understand the views of families and to work together to come to a decision that is congruent with their values and beliefs.

6.2 Acknowledging potential disbenefits of intervention with hearing technology

Our finding about the time pressures and expectations of action are similar to those identified in research investigating parents of deaf children and their experiences of newborn hearing screening (Young et al., 2007). The evidence on the benefits of early intervention with hearing aids is strong for deaf children with moderate or greater bilateral deafness (Ching et al., 2017), but Young et al.,(2007) identified the implications of starting intervention as early as possible requires good support to deal with this early knowledge. However, there is evidence that early intervention with hearing aids is not time critical for mild deafness, with data from Ching et al.,(2017) showing no impact on global language at age 5 on early versus later intervention for those with mild hearing deafness (note that this study did not include measures of skills that may be challenging for children particularly with unilateral deafness such as localisation of sounds). It is also important to consider that hearing aids are imperfect devices that introduce distortion and noise and can be ineffective when there is a high level of background sound. We have not been able to find reference to this lack of evidence for early intervention with hearing aids for mild deafness in any patient literature and it is therefore likely that there is inconsistency in the way this uncertainty is communicated to parents, as demonstrated in our study.

Within the field of medicine, the concept of overdiagnosis has been described in relation to identifying problems that were never going to cause harm (Brodersen et al., 2018). Within the concept of overdiagnosis, ‘overdefinition’ describes where the category expands to include patients with ambiguous or mild symptoms (Brodersen et al., 2018). Overdefinition could be argued to fit mild and unilateral deafness given the current evidence base. The implication of overdiagnosis and overdefinition as described by Brodersen et al.,(2018) is that it can lead to overtreatment. Having good evidence for interventions is therefore key. Unfortunately, mild and unilateral deafness are hard to study using the conventional randomised controlled trial approach, as previous studies have shown that parents and clinicians do not consent to be randomised (Sung et al., 2022).

The Lothian report and the subsequent review of paediatric audiology services in the UK demonstrated issues with poor practice within the sector which had led to late diagnosis of children with deafness. It is therefore likely that in this context audiologists are becoming

increasingly risk averse and feeling that it is better to intervene than not. Lin et al.,(2022) reported that most parents of young children with mild deafness in their sample felt it was “better to try than not” (page 503) and were recommended hearing aids by most audiologists (this study was carried out in Australia). Parents in their sample did not remember being told about the potential negatives of hearing aid fitting. They also noted the potential burden of attending appointments and using hearing aids, and the feelings of frustration and guilt felt by parents when challenges arose. This is seen similarly in adult audiology, where only recently are the patient burdens of hearing healthcare and managing hearing loss being understood (Smith et al., 2024). There has been limited investigation in relation to the burden of paediatric hearing health care on parents and carers, although some recent work investigating the challenges of hearing aid use in infants showed that parents experience difficulties in the early months following fitting and beyond (Visram et al., 2021). Archbold et al.,(2015) identified the lack of an audiology care pathway for children with mild/moderate deafness and the need for more parental information and support.

6.3 Challenges with the terms mild and unilateral deafness

We also identified important perceptions around the terminology and labelling of mild and unilateral deafness. The use of the term ‘mild’ deafness may inadvertently under-emphasise the potential impact of deafness for some families, as was described by Haggard and Primus (1999) twenty-five years ago or be unhelpful for understanding the implications for their child (Fitzpatrick et al., 2016). There are other ways of describing deafness and there is evidence showing that using different explanations of mild deafness can lead to parents selecting different intervention options (Sapp et al., 2023). This can include using simulations of deafness and a measure of the amount of speech a child can hear, known as the Speech Intelligibility Index or SII (McCreery et al., 2020; Sapp et al., 2023). Another way would be to share with parents some concrete examples of how mild or unilateral deafness may affect their child’s daily life as a way to bridge the gap between the medical world and the parents’ lifeworld.

6.4 Shared decision making and the resources required

In clinical situations where there is a lack of evidence or evidence is ambiguous, and therefore there is uncertainty about what is effective, shared decision making is appropriate (Pryce and Hall, 2014). Shared decision making enables parents to weigh up the advantages and disadvantages of the potential options including no action, and consider their own values, preferences and circumstances as part of the decision-making process.

There may be disadvantages to any suggested intervention as well as advantages, and these will depend on individual family circumstances. In the case of mild and unilateral deafness there is the added complication that the impact of different management options on infant development are likely to be unknown. This can make decision making particularly difficult in the early months and years before key developmental milestones can be assessed.

To enable shared decision making, parents require high quality information and support to negotiate the challenges and uncertainties of making decisions about mild and unilateral deafness for their young child. Tailored resources can provide answers to the range of frequently asked questions which parents typically have, based on the evidence that is available and setting out the pros and cons of different options.

6.5 Recommendations for future work

The evidence base for managing mild and unilateral deafness is weak and obtaining the evidence through research on the effectiveness of interventions is difficult. Future work should involve:

- Developing guidelines for the management of children with mild and unilateral deafness. This could include taking an action research approach to development as undertaken recently in relation to developing services for long COVID (Greenhalgh et al., 2024)
- Developing and collecting standard outcome measures for all levels of deafness including mild and unilateral deafness to enable national service evaluation of interventions and outcomes. Models for this exist in other health conditions of childhood e.g. the CRANE (Cleft Registry and Audit Network) Database for children with cleft palate.
- Utilising existing health national databases in order to facilitate national evaluation and research on childhood deafness, including mild and unilateral deafness, and linking to the recently created NIHR Health Informatics Collaborative for Hearing Health (Mehta et al., 2024)

There is also a need to ensure that children with mild and unilateral deafness are acknowledged as belonging to part of the spectrum of deafness so that parents and families do not feel excluded from options and conversations.

6.6 Limitations

Several limitations in this study are apparent. We set out to interview parents of children with unilateral and mild deafness but only two out of 17 had mild deafness with the rest being unilaterally deaf. We also aimed to find representation from across the UK but we were unable to recruit any participants from Wales or Scotland. Although two of the children of the parents we interviewed had additional needs beyond deafness it would have been interesting to expand to children who had intellectual disability and other needs.

6.7 Clinical recommendations

This project has revealed insights into the decision-making processes that families use for their child with mild or unilateral deafness and the ways in which they navigate uncertainty. In terms of information needs, and improvements in management, we propose the following recommendations:

- **The use of the term 'mild' deafness is unhelpful.** Researchers and clinicians should work towards a different model of description for deafness and there are examples of how this might be done in the literature (e.g. Sapp et al., 2023).
- **Improved explanations of mild and unilateral deafness are required.** This could include simulating a particular child's deafness (particularly helpful for mild deafness but potentially more difficult for unilateral) and ensuring clear information about why children with mild or unilateral deafness respond to many of the sounds in their daily lives.
- **The time burden for parents should be acknowledged.** The time investment of parents to manage their child's mild or unilateral deafness (including appointment attendance, management of devices such as hearing aids, applying for funding, etc.) is substantial and should be balanced with the lack of evidence that interventions currently offered are beneficial.
- **Professionals to value parent preferences in decision making.** There is a need for professionals to understand and value parent preferences when discussing management options, and to engage fully in shared decision making. Training or time may be needed for this to be implemented effectively. Other professionals such as health visitors are often involved in supporting parents and also need access to appropriate training on deafness.

7 Resource creation

7.1 Introduction

Parents require high quality information and support to negotiate the challenges and uncertainties of making decisions about mild and unilateral deafness for their young child. Our second aim for this project was therefore to create resources to help parents of newly diagnosed mild or unilaterally deaf young children with decision making.

One way of providing decisional information is through patient experience-based resources, such as Healthtalk Online https://healthtalk.org/. This type of resource provides information about common health conditions based on patient stories around key themes, which have been identified through rigorous qualitative research and this is the approach we have taken in our resource creation.

7.1.1 Health experience resources

Health experience-based resources can play a key role in person-centred care (Locock et al., 2013) and it is increasingly common for patients to use online health experience information (Ziebland et al., 2016). Resources based on patients' experiences can have a number of benefits beyond solely information delivery. When delivered online, the mechanisms of benefit for patients include: finding information about their health condition; feeling supported when knowing others have similar health experiences; knowing how to navigate health systems and services based on experiences of others; helping with self-management through others' personal stories (Ziebland and Wyke, 2012).

A Cochrane review examined the effects of Interactive Health Communication Applications (IHCA), which are web-based packages combining health information with social support, decision support or behaviour change support, for people with chronic disease (Murray et al., 2005). The review examined a wide range of IHCA for different diseases with the findings showing positive effects on knowledge, social support and clinical outcomes. Online patient experience websites can also help health professionals understand what patients think of the care and treatments they receive, what works and what doesn't (Kidd and Ziebland, 2016). They have also been successfully used in accelerated experience-based co-design of health services (Locock et al., 2014).

7.2 Resource creation

Our initial proposal included the creation of parent videos in collaboration with the National Deaf Children's Society. When exploring resource creation with our participants, our core team and our steering group, audio podcasts were also suggested as a potential source of information for new parents. There are important considerations to be made for each medium which are summarised in Table 2.

Table 2 Summary of considerations for video and podcast resources

	Video	Audio podcast
Deaf accessibility	Fully accessible including for BSL users.	Only accessible via transcript for BSL users and others unable to hear content.
Engagement requirement	Needs full focus to access.	Can access while doing other activities e.g. driving, walking with pram, household chores.
Length	Generally shortform (around 5 mins) so potentially depth of information limited.	Longform (around 20-60 mins) so can have multiple interviewees and in-depth information.
Content	Can show visual information e.g. hearing aid, ear anatomy. Option to have supporting information on hosting webpage.	All information must be described verbally. Option to have supporting information on hosting webpage.

After discussion we decided to make video resources for this project. Separate funding was used to also develop audio podcasts and this will also be described here briefly.

7.2.1 Videos

The themes identified from the research study were used to develop the structure of the video resources. The questions asked to parents were as follows:

- Introduce your child (e.g. favourite play activity, character, etc.) and tell us about their hearing/level or type of deafness.
- Describe when your child's hearing loss/deafness was identified. Was it through the newborn hearing screening programme (NHSP)? What were the signs?

- Discuss how you made decisions about your child's hearing (aiding or not aiding). What was challenging and what helped most? What did you find helpful after the diagnosis? Who helped? Was there a particular service, organisation or advice that you would pass on?
- How are things going now? How did you feel then and how do you feel now about your child's deafness?
- What advice would you have for other parents?
- Tailored questions depending on aiding/not aiding – e.g. your experience with technology (e.g. hearing aid; BAHA), preferred communication methods, and any self-adjustments you had to make.

An adult with mild hearing loss has also participated in a video to give families a different perspective. Questions asked for this video were as follows:

- How is work/daily life with your deafness?
- How did you feel as a child and how do you feel now.
- How did it affect your interactions with people/your friendships?
- How was is at school/secondary school/University for you?
- Have you practised/learned any sport/ instrument/drama?
- Did you wish you had an aid or no aid?
- What would you tell parents whose child has this type of deafness?

7.2.2 Podcasts

Although we decided not to pursue podcast production within this project, we have used separate funding to develop this further. Again, the qualitative research was used to develop the podcasts and it is hoped that the videos and podcasts will be complementary. Podcasts will be hosted by UCL and will be accompanied by transcripts and supporting information on a webpage.

We are currently making recordings for podcasts with the following chapters:

1. What does mild/unilateral deafness mean?
2. Wait and see or maximise hearing.
3. Prioritising your child as an individual.
4. Decisions evolve over time.
5. Confident about the future.

7.3 Next steps

7.3.1 Dissemination

- The videos and the podcasts will be launched at the British Academy of Audiology conference in November 2024. The National Deaf Children's Society is currently planning a marketing campaign to publicise the videos.

7.3.2 Evaluation

We plan to apply for further funding to evaluate the efficacy of both the podcasts and the videos.

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9 References

Anne S, Lieu JEC, Cohen MS. Speech and Language Consequences of Unilateral Hearing Loss: A Systematic Review. Otolaryngol Head Neck Surg. 2017 Oct;157(4):572-579. doi: 10.1177/0194599817726326.

Appachi S, Specht JL, Raol N, Lieu JEC, Cohen MS, Dedhia K, Anne S. Auditory Outcomes with Hearing Rehabilitation in Children with Unilateral Hearing Loss: A Systematic Review. Otolaryngol Head Neck Surg. 2017 Oct;157(4):565-571. doi: 10.1177/0194599817726757.

Archbold, S., Experiences of young people with mild to moderate hearing loss. Views of parents and teachers. 2015. NDCS. https://www.ndcs.org.uk/media/1827/ear_foundation_mild_moderate_hearing_loss_research.pdf Accessed 29.8.24.

Bamford J, Uus K, Davis A. Screening for hearing loss in childhood: issues, evidence and current approaches in the UK. J Med Screen. 2005;12(3):119-24. doi: 10.1258/0969141054855256.

BSA (British Society of Audiology). Guidelines for the Early Audiological Assessment and Management of Babies Referred from the Newborn Hearing Screening Programme 2021. https://www.thebsa.org.uk/wp-content/uploads/2022/10/OD104-98-BSA-Practice-Guidance-Early-Assessment-Management.pdf Accessed 29.8.24.

Brodersen J, Schwartz LM, Heneghan C, O'Sullivan JW, Aronson JK, Woloshin S. Overdiagnosis: what it is and what it isn't. BMJ Evid Based Med. 2018 Feb;23(1):1-3. doi: 10.1136/ebmed-2017-110886.

Bussé AML, Mackey AR, Hoeve HLJ, Goedegebure A, Carr G, Uhlén IM, Simonsz HJ; EUS€REEN Foundation. Assessment of hearing screening programmes across 47 countries or regions I: provision of newborn hearing screening. Int J Audiol. 2021 Nov;60(11):821-830. doi: 10.1080/14992027.2021.1886350.

Calcus A, Tuomainen O, Campos A, Rosen S, Halliday LF. Functional brain alterations following mild-to-moderate sensorineural hearing loss in children. Elife. 2019 Oct 1;8:e46965. doi: 10.7554/eLife.46965.

Carew P, Mensah FK, Rance G, Flynn T, Poulakis Z, Wake M. Mild-moderate congenital hearing loss: secular trends in outcomes across four systems of detection. Child Care Health Dev. 2018 Jan;44(1):71-82. doi: 10.1111/cch.12477.

Ching TYC, Dillon H, Button L, Seeto M, Van Buynder P, Marnane V, Cupples L, Leigh G. Age at Intervention for Permanent Hearing Loss and 5-Year Language Outcomes. Pediatrics. 2017 Sep;140(3):e20164274. doi: 10.1542/peds.2016-4274.

Ching TYC, Saetre-Turner M, Marnane V, Scarinci N, Choik C, Tulloch K, Sung V. Audiologists' perspectives on management of mild bilateral hearing loss in infants and young children. Int J Audiol. 2022 Sep;61(9):752-760. doi: 10.1080/14992027.2021.1961170.

Davis A, Bamford J, Wilson I, Ramkalawan T, Forshaw M, Wright S. A critical review of the role of neonatal hearing screening in the detection of congenital hearing impairment. Health Technol Assess. 1997;1(10):i-iv, 1-176.

Fitzpatrick E, Grandpierre V, Durieux-Smith A, Gaboury I, Coyle D, Na E, Sallam N. Children With Mild Bilateral and Unilateral Hearing Loss: Parents' Reflections on Experiences and Outcomes. J Deaf Stud Deaf Educ. 2016 Jan;21(1):34-43. doi: 10.1093/deafed/env047.

Gorga MP, Johnson TA, Kaminski JR, Beauchaine KL, Garner CA, Neely ST. Using a combination of click- and tone burst-evoked auditory brain stem response measurements to estimate pure-tone thresholds. Ear Hear. 2006 Feb;27(1):60-74. doi: 10.1097/01.aud.0000194511.14740.9c.

Greenhalgh T, Darbyshire JL, Lee C, Ladds E, Ceolta-Smith J. What is quality in long covid care? Lessons from a national quality improvement collaborative and multi-site ethnography. BMC Med. 2024 Apr 15;22(1):159. doi: 10.1186/s12916-024-03371-6.

Haggard RS, Primus MA. Parental perceptions of hearing loss classification in children. Am J Audiol. 1999 Dec;8(2):83-92. doi: 10.1044/1059-0889(1999/014).

Hall A, Pryce H, Bruce IA, Callery P, Lakhanpaul M, Schilder AGM. A mixed-methods study of the management of hearing loss associated with otitis media with effusion in children with Down syndrome. Clin Otolaryngol. 2019 Jan;44(1):32-38. doi: 10.1111/coa.13228.

Kidd J, Ziebland S. Narratives of experience of mental health and illness on healthtalk.org. BJPsych Bull. 2016 Oct;40(5):273-276. doi: 10.1192/pb.bp.115.052217.

Lin JJ, Gillam L, Smith L, Carew P, King A, Ching TYC, Sung V. Mild matters: parental insights into the conundrums of managing mild congenital hearing loss. Int J Audiol. 2022 Jun;61(6):500-506. doi: 10.1080/14992027.2021.1954248.

Locock L, Robert G, Boaz A, Vougioukalou S, Shuldham C, Fielden J, Ziebland S, Gager M, Tollyfield R, Pearcey J. Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement. Southampton (UK): NIHR Journals Library; 2014 Feb. https://doi.org/10.3310/hsdr02040

McCreery RW, Kaminski J, Beauchaine K, Lenzen N, Simms K, Gorga MP. The impact of degree of hearing loss on auditory brainstem response predictions of behavioral thresholds. Ear Hear. 2015 May-Jun;36(3):309-19. doi: 10.1097/AUD.0000000000000120.

McCreery RW, Walker EA, Stiles DJ, Spratford M, Oleson JJ, Lewis DE. Audibility-Based Hearing Aid Fitting Criteria for Children With Mild Bilateral Hearing Loss. Lang Speech Hear Serv Sch. 2020 Jan 8;51(1):55-67. doi: 10.1044/2019_LSHSS-OCHL-19-0021.

Medendorp NM, Stiggelbout AM, Aalfs CM, Han PKJ, Smets EMA, Hillen MA. A scoping review of practice recommendations for clinicians' communication of uncertainty. Health Expect. 2021 Aug;24(4):1025-1043. doi: 10.1111/hex.13255.

Mehta N, Ribeyre BB, Dimitrov L, English LJ, Ewart C, Heinrich A, Joshi N, Munro KJ, Roadknight G, Romao L, Schilder AG, Spriggs RV, Norris R, Ross T, Tilston G. Creating a health informatics data resource for hearing health research. BMC Med Inform Decis Mak. 2024 Jul 29;24(1):209. doi: 10.1186/s12911-024-02589-x.

Moore DR, Zobay O, Ferguson MA. Minimal and Mild Hearing Loss in Children: Association with Auditory Perception, Cognition, and Communication Problems. Ear Hear. 2020 Jul/Aug;41(4):720-732. doi: 10.1097/AUD.0000000000000802.

Murray E, Burns J, See TS, Lai R, Nazareth I. Interactive Health Communication Applications for people with chronic disease. Cochrane Database Syst Rev. 2005 Oct 19;(4):CD004274. doi: 10.1002/14651858.CD004274.pub4.

NHS England. 2024. Newborn Hearing Screening Programme overview https://www.gov.uk/guidance/newborn-hearing-screening-programme-overview (Accessed 29.8.24)

Nicolas S, Gallois Y, Calmels MN, Deguine O, Fraysse B, Marx M. Quality of life of children treated for unilateral hearing loss: a systematic review and meta-analysis. Arch Dis Child. 2021 Nov;106(11):1102-1110. doi: 10.1136/archdischild-2020-320389.

NIHR. 2001. Interventions for mild to moderate permanent childhood hearing impairments identified by neonatal hearing screening - NIHR Funding and Awards. Accessed 29.8.2024

Pryce H., Hall A. The role of shared decision-making in audiologic rehabilitation. Perspectives on Aural Rehabilitation and Its Instrumentation. 2014; 21(1): 15-23.

Romano DR, Sindhar S, Yaeger LH, Lieu JEC. Academic Outcomes with Hearing Amplification Devices in Children with Unilateral Hearing Loss: A Systematic Review and Narrative Synthesis. Audiol Neurootol. 2024 May 29:1-9. doi: 10.1159/000539513.

Sapp C, McCreery R, Holte L, Oleson J, Walker E. Descriptions of Hearing Loss Severity Differentially Influence Parental Concern about the Impact of Childhood Hearing Loss. Ear Hear. 2023 Mar-Apr 01;44(2):287-299. doi: 10.1097/AUD.0000000000001280.

Scott IA, Doust JA, Keijzers GB, Wallis KA. Coping with uncertainty in clinical practice: a narrative review. Med J Aust. 2023 May 15;218(9):418-425. doi: 10.5694/mja2.51925.

Smith SK, Pryce H, O'Connell GB, Hussain S, Shaw R, Straus J. 'The burden is very much on yourself': A qualitative study to understand the illness and treatment burden of hearing loss across the life course. Health Expect. 2024 Jun;27(3):e14067. doi: 10.1111/hex.14067.

Sung V, Ching TYC, Smith L, Marnane V, Saetre-Turner M, King A, Beswick R, Iseli CE, Carew P. Mild matters: trial learnings and importance of community engagement in research for early identified bilateral mild hearing loss. Front Pediatr. 2023 Aug 8;11:1197739. doi: 10.3389/fped.2023.1197739.

Visram AS, Roughley AJ, Hudson CL, Purdy SC, Munro KJ. Longitudinal Changes in Hearing Aid Use and Hearing Aid Management Challenges in Infants. Ear Hear. 2021 July/Aug;42(4):961-972. doi: 10.1097/AUD.0000000000000986.

Wake M, Tobin S, Cone-Wesson B, Dahl HH, Gillam L, McCormick L, Poulakis Z, Rickards FW, Saunders K, Ukoumunne OC, Williams J. Slight/mild sensorineural hearing loss in children. Pediatrics. 2006 Nov;118(5):1842-51. doi: 10.1542/peds.2005-3168.

Walker EA, Spratford M, Ambrose SE, Holte L, Oleson J. Service Delivery to Children With Mild Hearing Loss: Current Practice Patterns and Parent Perceptions. Am J Audiol. 2017 Mar 1;26(1):38-52. doi: 10.1044/2016_AJA-16-0063.

Wang J, Quach J, Sung V, Carew P, Edwards B, Grobler A, Gold L, Wake M. Academic, behavioural and quality of life outcomes of slight to mild hearing loss in late childhood: a population-based study. Arch Dis Child. 2019 Nov;104(11):1056-1063. doi: 10.1136/archdischild-2019-316917.

van Wieringen A, Boudewyns A, Sangen A, Wouters J, Desloovere C. Unilateral congenital hearing loss in children: Challenges and potentials. Hear Res. 2019 Feb;372:29-41. doi: 10.1016/j.heares.2018.01.010.

Yoshinaga-Itano C, Manchaiah V, Hunnicutt C. Outcomes of Universal Newborn Screening Programs: Systematic Review. J Clin Med. 2021 Jun 24;10(13):2784. doi: 10.3390/jcm10132784.

Young A, Tattersall H. Universal newborn hearing screening and early identification of deafness: parents' responses to knowing early and their expectations of child communication development. J Deaf Stud Deaf Educ. 2007 Spring;12(2):209-20. doi: 10.1093/deafed/enl033.

Wake M, Tobin S, Cone-Wesson B, Dahl HH, Gillam L, McCormick L, Poulakis Z, Rickards FW, Saunders K, Ukoumunne OC, Williams J. Slight/mild sensorineural hearing loss in children. Pediatrics. 2006 Nov;118(5):1842-51. doi: 10.1542/peds.2005-3168.

White KR., Muñoz K. Screening. Sem Hear 2008; 29 (2): 149-158. Thieme Medical Publishers.

Wood SA, Sutton GJ, Davis AC. Performance and characteristics of the Newborn Hearing Screening Programme in England: The first seven years. Int J Audiol. 2015 Jun;54(6):353-8. doi: 10.3109/14992027.2014.989548.

Ziebland S, Powell J, Briggs P, Jenkinson C, Wyke S, Sillence E, Harris P, Perera R, Mazanderani F, Martin A, Locock L, Kelly L, Booth M, Gann B, Newhouse N, Farmer A. Examining the role of patients’ experiences as a resource for choice and decision-making in

health care: a creative, interdisciplinary mixed-method study in digital health. Southampton (UK): NIHR Journals Library; 2016 Nov.

Ziebland S, Wyke S. Health and illness in a connected world: how might sharing experiences on the internet affect people's health? Milbank Q. 2012 Jun;90(2):219-49. doi: 10.1111/j.1468-0009.2012.00662.x.

10 Appendix

10.1 Topic guide

After introductions and informed consent has been taken the interview will begin. Questioning will be open and largely guided by topics raised by the participants. The researcher will begin questioning by asking openly, ‘Can you tell me a bit about [child’s name] and his/her deafness?’ Based on the topics that the parent(s) raise the researcher will continue the conversation by asking questions such as:

- What happened next after your child’s deafness was identified?
- How did you go about making decisions about how to manage your child’s deafness?
- What were the effects of that?
- What was the main thing that happened?
- How did that influence your decision?
- What did you do/ investigate to make your decisions?
- What was the result of your decisions?
- How do you feel about that decision now?
- What would you tell other parents in your position?
- We are planning to develop information for parents in your position.
    - What do you think about this?
    - What do you think it is important to include?

If the participants do not volunteer topics, questions could continue along the following lines:

- Did the type of hearing loss [child’s name] has influence your decisions?
- Did the level of [child’s name] deafness influence your decisions?
- Did any other health professionals influence your decision?
- Did any other medical/ health issues influence your decision?
- Did your child’s teacher of the deaf have an influence?
- Did comparison to siblings influence your choices?
- Did comparison to peers influence your choices?

The researcher will close questioning by summarising and asking participants if there is anything else they feel has been missed or they would like to add. The researcher will then thank the participants and ensure they have contact details, should they think of any questions after the researcher has left.