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**This is the author version of an article published as:**

Ching, T. Y., Saetre-Turner, M., Marnane, V., Scarinci, N., Choik, C., Tulloch, K., & Sung, V. (2022). Audiologists' perspectives on management of mild bilateral hearing loss in infants and young children. *International Journal of Audiology*, 61(9), 752-760.

© 2021. This is an Accepted Manuscript of an article published by Taylor & Francis in *International Journal of Audiology* on 9/8/2021, available online <https://doi.org/10.1080/14992027.2021.1961170>

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**Audiologists' perspectives on management of mild bilateral hearing loss in infants and young children**

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## **Audiologists' perspectives on management of mild bilateral hearing loss in infants and young children**

**Objective:** Universal newborn hearing screening programs have led to early identification of infants with congenital mild bilateral hearing loss (MBHL). The current lack of evidence-based protocols to guide audiological management of infants with MBHL has led to clinical equipoise about fitting of hearing aids. The purpose of this study was to increase understanding about the perspectives of pediatric audiologists on factors influencing their management of MBHL in infants and young children.

**Design:** A qualitative descriptive research methodology involving semi-structured interviews with audiologists.

**Study sample:** Twenty-three pediatric audiologists in diagnostic and rehabilitation settings in Victoria, Australia.

**Results:** Three main themes that influenced management were identified. These include: (1) evidence, or the lack of it, influences audiologists' practice; (2) audiologists recognise the need to be fluid; and (3) family characteristics and parents' perspectives. 'Audiologists delivering family-centred practice' was identified as an overarching theme across these factors.

**Conclusions:** Audiologists recognised the importance of adopting a family-centred approach in their management of MBHL in infants and young children. Embodied in their practice was the acknowledgement of limited evidence, the consideration of multiple child and family factors, and the incorporation of perspectives of parents and families in adopting a fluid approach to provide individualised services.

**Key words:** mild bilateral hearing loss, young children, audiologists, audiological management, qualitative research

**Acronyms and abbreviations:**

AAA - American Academy of Audiology

MBHL – Mild Bilateral hearing loss

PTA – Pure tone average

UNHS – Universal newborn hearing screening

## **Audiologists' perspectives on management of mild bilateral hearing loss in infants and young children**

Permanent childhood hearing loss occurs in about 3-4/1000 births when all degrees of hearing loss are considered (Prieve & Stevens, 2000; Watkin & Baldwin, 2011). Implementation of universal newborn hearing screening (UNHS) programs have led to identification of infants with the target condition of significant bilateral hearing loss of moderate or greater degrees soon after birth, often with incidental detection of unilateral hearing loss and mild bilateral hearing loss (MBHL). Whereas there is now cumulative evidence on the negative impact of moderate or greater degrees of permanent childhood hearing loss on developmental outcomes and the benefits of early intervention (Ching et al., 2017; Kennedy et al., 2006; Yoshinaga-Itano, 2003), much less is known about the impact of MBHL on development and even less on the potential effects of the timing of intervention. Paediatric audiologists are faced with a new population of infants with MBHL for whom there is limited evidence to guide best practice (McKay, Gravel, & Tharpe, 2008).

MBHL can be defined by a three-frequency pure tone average (average of the hearing thresholds at 0.5, 1, and 2 kHz; PTA) between 20 and 40 dB HL in both ears or pure tone thresholds greater than 25 dB HL at two or more frequencies above 2 kHz in both ears (Yoshinaga-Itano, Johnson, Carpenter, & Brown, 2008). The prevalence has been estimated to range from 8% to 23% in primary school children (Elbeltagy, 2020; Wang et al., 2018).

Current knowledge about the impact of MBHL on child outcomes has largely drawn on studies of late-identified children, typically diagnosed around school-age in the pre-UNHS era (Fitzpatrick, Whittingham, & Durieux-Smith, 2014; Tharpe, 2008).

The findings are mixed, and it does not appear to be possible to predict performance outcomes on the basis of audiometric hearing thresholds. A review by Tharpe (2008) suggested that some children with MBHL demonstrated lower academic performance (Blair, 1985) and poorer vocabulary (Davis, Elfenbein, Schum, & Bentler, 1986), experienced greater difficulty listening to speech in the presence of background noise (Crandell, 1993), and demonstrated deficits in social skills (Bess, Dodd-Murphy, & Parker, 1998), compared to typically hearing peers. On the other hand, a population-based study by Wake et al (2006) showed that on average, children with MBHL performed no differently to their typically developing peers on measures of expressive and receptive language, reading skills, behaviour and parent- and child-reported quality of life, but showed some deficit in phonological short term memory. Dokovic et al (2014) reported a comparison of developmental abilities of 144 children with MBHL with 160 children with normal hearing at age 7 to 11 years. On average, the measured abilities of both groups were within the normal range. Relative to the normal-hearing comparison group, children with MBHL showed delays in auditory discrimination, auditory memory, visual discrimination, sensory integration, concept formation, and morphosyntactic abilities. Lewis et al (2015) found that children with unilateral or MBHL and their normal-hearing peers performed at or near ceiling on sentence recognition in a simulated classroom environment. However, children with hearing loss performed more poorly than those with normal hearing in a comprehension task.

There is some evidence from recent studies on early-identified children with MBHL. Fitzpatrick et al (2015) compared auditory and communication development in a group of 55 children with unilateral or MBHL to that in a group of 45 normal-hearing children up to 4 years of age. Based on parent reports, there were no significant

differences between the two groups on two auditory development measures at any age, except for one auditory questionnaire (Children's Home Inventory for Listening Difficulties, Anderson & Smaldino, 2011) at ages 3 and 4 years on which children with normal hearing obtained higher scores. Also, there were no significant differences between groups on any language outcomes measure at any age. In a similar vein, parent and teacher ratings of auditory, social and behavioural skills of 11 children with MBHL demonstrated that the children with MBHL were functioning at age 5 to 9 years like their peers with typical hearing (Nassrallah, Tang, Whittingham, Sun, & Fitzpatrick, 2019). A recent study revealed no significant difference in vocabulary size and reading outcomes between children with MBHL and their hearing peers at grade 4, but the former group obtained lower scores in listening comprehension and morphology than the latter (Walker, 2020).

The limited information about the consequences of early-identified MBHL and the mixed findings on its impact have been reflected in clinical recommendations (Walker, Spratford, Ambrose, Holte, & Oleson, 2017). The Pediatric Amplification Protocol of the American Academy of Audiology (AAA) (American Academy of Audiology, 2013) recommended that each child should be evaluated on a case-by case basis, and the Joint Committee on Infant Hearing Supplement (Muse et al., 2013) recommended enrolling children with MBHL in early intervention services if they qualify, and emphasised on the need to carefully monitor children's developmental outcomes. Accordingly, Bagatto and Tharpe (2014) proposed a decision support guide that considers hearing loss configuration, ear acoustics, device characteristics, and child and family factors to assist clinicians compile information in making decisions about hearing aid fitting for children with MBHL under five years of age. More recently, an

audibility based approach that accounts for ear canal acoustics to determine hearing aid candidacy was proposed (McCreery et al, 2020). Although the AAA pediatric amplification guidelines recommended hearing aid provision to children with MBHL (American Academy of Audiology, 2013), there are no evidence-based guidelines for when to fit hearing aids.

What is known about the potential benefits of early hearing aid fitting for infants identified with MBHL is limited and the success of amplification is variable (Winiger, Alexander, & Diefendorf, 2016). There is some information suggesting that use of hearing aids could be beneficial for some school-aged children with MBHL (Walker et al., 2015; Walker, 2020) whereas others did not show a benefit with hearing aid usage for children with MBHL or unilateral hearing loss (Porter, Sladen, Ampah, Rothpletz, & Bess, 2013). Some parents of young children with MBHL were positive about the benefits of amplification, but others noted uncertainties about benefits from hearing aids (Fitzpatrick et al., 2016; Walker et al., 2017). The uncertainty regarding the effects of amplification for infants and young children with MBHL is consistent with the observation of higher occurrences of no hearing aid fitting or nonuse of fitted devices for children with MBHL relative to those with more severe hearing loss (Fitzpatrick, Durieux-Smith, & Whittingham, 2010; Walker et al., 2013).

Although the existing guidelines and the decision support tool are helpful, there is no systematic protocol in terms of amplification and intervention options other than diligent monitoring and parent education. Audiologists need to inform parents of the potential impact of MBHL, and the different amplification and intervention options and their relative benefits and harms for their child in clinical decision making. However, uncertainties about potential positive and negative effects of amplification for infants



and young children with MBHL (Lin et al., 2021; McKay et al., 2008; Winiger et al., 2016) have posed challenges to audiologists and families that need to make decisions about whether to proceed with amplification after diagnosis of MBHL in infants. There were no studies that explored perspectives of audiologists on management of MBHL in infants and young children. The purpose of this qualitative study was to increase understanding about the perspectives of pediatric audiologists on factors influencing their management of MBHL in infants and young children. Complementary investigations into parents' perspectives are reported separately (Lin et al., 2021). An increased understanding of the audiologists' and parents' perspectives will contribute to devising tools and protocols to improve hearing service delivery to families of infants and young children with MBHL.

In this paper, we report a qualitative descriptive study that explored audiologists' perspectives on management of MBHL in infants identified with hearing loss via UNHS.

## **Method**

### **Study setting**

This study was conducted in the state of Victoria in Australia, where UNHS was implemented in 2005 reaching >95% coverage by 2012 (Ching & Leigh, 2020). In Australia, UNHS is carried out by state-wide authorities (Victorian Infant Hearing Screening Program in Victoria), but hearing habilitation services for children with hearing loss under the age of 26 years is provided nationally by the sole government-funded service provider, Hearing Australia, according to national protocols (King, 2010); at no cost to families.

## **Study Design**

This study adopted a qualitative descriptive research methodology, which sought to understand audiologists' perspectives on managing MBHL. Qualitative description is a suitable research methodology when the aim of the research is to provide clear answers to questions of clinical practice or policy (Sandelowski, 2000).

## **Participants**

Rehabilitative and diagnostic audiologists were invited to participate in this study. The inclusion of both diagnostic and rehabilitation audiologists in the study was deemed important given their involvement in the ongoing diagnosis and management of MBHL, with the potential to add different perspectives in different aspects of the journey. A letter of invitation was sent via email to eligible audiologists at Hearing Australia and in the hearing screening services network. If an opt-out from further contact was not received within 10 days, researchers contacted each individual audiologist to provide further information and seek consent. Participants provided written informed consent for participation. The research protocol and methodology were approved by Institutional Review Board.

Participants were 23 audiologists (all female), with 3 working in regional and 20 in urban services. The majority of audiologists reported working in rehabilitation (n = 12, 52.2%), diagnostic audiology (n = 8, 34.8%), or both rehabilitation and diagnostic audiology (n = 2, 8.7%), with one audiologist working as an early support service facilitator, providing support and assistance to families of children who receive a positive result following UNHS. Fifteen audiologists (65.2%) reported working in the public sector, and seven in the private sector (46.7%). The experience of the audiologists in the current practice setting at the time of enrolment varied from 9 years

or less (n = 9, 39.0%), 10 to 19 years (n = 10, 43.0%) to 20 years or more (n = 4, 17.0%).

## **Procedure**

After enrolment, a research audiologist who was not involved in management of children arranged to conduct an individual in-depth semi-structured interview with each participant, either face-to-face or over the phone. The interviews were conducted in 2018 to explore audiologists' personal experiences, their opinions, and perspectives about factors influencing how they manage MBHL in infants and young children. An interview guide (Appendix 1) was used to ensure thoroughness and consistency across interviews, with adaptations to the wording and ordering of questions based on the flow and nature of information provided by the participant. All interviews were audio-recorded (median duration: 28 minutes, interquartile range: 21-37). The recordings were transcribed verbatim by a third-party professional transcription service. The transcripts were de-identified prior to analysis.

## **Data analysis**

The interview data were analysed using inductive thematic analysis (Braun & Clarke, 2006) by two researchers (MST, CC) with training and support from researchers experienced in qualitative research methods (TC, VM, NS). The researchers first familiarised themselves with the transcripts by reading and re-reading the responses and noting down initial ideas for later coding (Braun & Clarke, 2006). Initial codes were generated across all transcripts systematically, with the research question in mind. The primary research team (TC, MST, VM, NS) met regularly to review the analyses at several time points to discuss the emerging codes, themes, and subthemes. Themes and

subthemes were modified depending on whether the data showed a clear pattern. If the data did not form a distinctive category or there were not enough data to support it, the theme was merged with another theme or removed (Braun & Clarke, 2006). Some larger themes were separated into additional subthemes to allow for clearer interpretation of the data. All codes were reviewed by the team and verified for reporting.

## Results

‘Audiologists deliver family-centred practice’ was identified as an overarching theme across three themes that described factors influencing audiologists’ management of children with MBHL. The three themes include: (1) evidence, or the lack of it, influences audiologists’ practice; (2) audiologists recognise the need to be fluid; and (3) family characteristics and parents’ perspectives.

### **Overarching Theme: Audiologists delivering family-centred practice**

Audiologists described how they were open to families about the lack of evidence to guide intervention, flexible in meeting the needs of the child with MBHL, holistic in their approach to management of MBHL, and considered family choice and family strengths in providing individualised services. The following example quote illustrates this overarching theme:

*You know, if your child was severe or profoundly deaf, then I could give you a good recommendation about what we know is going to be the best way to go forward, but for your child..., because your child has the mild hearing loss, there’s not clear evidence about which way you should go. So we’re much more guided by you [family] and what you want to do. [P23]*

## **Theme 1: Evidence, or the Lack of it, Influences Audiologists' Practice**

Analyses of the transcripts revealed that audiologists' management was strongly influenced by the lack of evidence to guide best practice. As such, they drew on their own knowledge and experience. This theme incorporated three subthemes: (1) lack of research evidence; (2) drawing on personal knowledge and experience; and (3) consideration of individual child characteristics and needs.

### ***Lack of Research Evidence***

When reflecting on their experiences managing infants and young children with MBHL, multiple audiologists described it as being difficult and a 'grey area' [P7] when compared to making decisions regarding the management of more severe hearing loss. As such, audiologists also reported that they lack confidence, and felt '*being a bit wishy-washy ... in appointments*' [P9]. Many audiologists commented that their management decisions were not evidence-based because current clinical protocols '*... are the least strongly indicated protocols*', and that "*a lot of it feels like it's learned on the job*" [P2]. Audiologists often explained to families the lack of research evidence to guide management:

*I would probably talk to them ... that there are options for amplification devices or if they wanted them, but there is a grey area and we don't have a lot of concrete evidence either way. [P4]*

### ***Drawing on personal knowledge and experience***

The lack of clear evidence on the effectiveness of fitting hearing aids to infants with MBHL has possibly led to concerns by audiologists regarding the potential

negative effect of fitting hearing aids, as “*you don’t want to cause more harm than good*” [P3].

*The likely benefit that they’re going to be getting from their hearing aids with a mild hearing loss, it doesn’t really outweigh the anxiety and stress that it might cause a family to try and manage hearing aids. If it’s a more moderate to severe hearing loss, then I think, well, unfortunately, you kind of have to risk stressing out the family, you know, because this baby needs to be hearing ... I feel a bit more comfortable kind of putting the family through that stress, I guess, because I know that it’s really benefitting the baby. [P9]*

An audiologist recounted how personal clinical experiences in managing MBHL has led to increased confidence in adopting a watchful waiting approach:

*I think I’m a bit more okay with waiting. I think early on ... you fear if you do nothing, you’re not doing the right thing or that you’re not helping these kids if you haven’t put hearing aids on ... you might be doing something wrong, whereas over time, obviously, in observing and seeing more cases of kids with mild hearing loss, both infant and older, you get, I suppose, a little bit more comfortable with the idea of waiting and monitoring and not necessarily proceeding with fitting. [P16]*

On the other hand, some audiologists felt ‘*more comfortable*’ advising parents to consider the fitting of hearing aids, despite the uncertainty about ‘*what’s best for their child with mild hearing loss*’ [P14]. The audiologists reasoned this as being a ‘cautious’ approach to the management of MBHL:

*I tend to err on the side of caution in terms of assuming that if some children are impacted by it and some are not, that I have to assume with every child that there's a chance that they are the child who will be impacted by it. [P21].*

Some audiologists made a clinical judgement about not fitting devices to infants with MBHL on the basis of their knowledge about hearing and hearing aids:

*I think that hearing aids for a mild hearing loss are not necessarily beneficial, yeah, absolutely, because they only give a small amount of volume and if you're one-to-one, I don't think it makes a huge difference. [P10]*

A number of audiologists also expressed concerns about occluding the child's ears by “*blocking up the ears with ear moulds*” [P15] or “*that occlusion which we're potentially causing*” [P8] when fitting a hearing device. potential emotional harms of fitting hearing aids on a child's family and the negative impact the fitting may have on bonding:

*I think for the really young ones, I think I have a preference for not aiding and it's just because it's so – it's so hard to show that it's worthwhile, and I think sometimes it causes just a lot of undue suffering for the families. [P2]*

*...and I think there's a lot to be said as well for letting the parent and the baby just bond in those first couple of months, in particular, without having extra stressors added on of appointments and moulds and all the rest of it that goes with it. [P19]*

Audiologists also mentioned potential social and educational impacts of fitting hearing aids to a child with MBHL:

*I guess there are two ways to look at hearing aids. One is that they give you sound that you don't otherwise have, and that's a good thing. The other is that they "mark" you in some way and that can be a negative. So either in terms of social interactions with children and adults, but also, you know, educationally ... people might look at that child and think "I don't expect so much of that child because you've got a hearing loss. I don't expect so much of you". [P23]*

### ***Consideration of individual child characteristics and needs***

Both diagnostic and rehabilitation audiologists noted that their management decisions were influenced by the child's absolute hearing levels at different frequencies. Some audiologists had specific ranges in mind that shaped their management strategies:

*So, you know, if it was 25 (dB), no, I wouldn't (fit a hearing aid). If it was 35-40 at more than one frequency, I would. [P17]*

*So I think if it were the more extreme version of a mild loss, then I would go ahead with the hearing aid fitting, and if it was just a borderline becoming a mild loss, then I would probably wait to watch language skills development to see if there is a delay present. [P20]*

Although many audiologists reported that they generally would not recommend hearing aids for a child with MBHL, they indicated that hearing aids might be beneficial for children with additional needs:

*All those predictive factors of how a child's language and communication skills will develop, so if there's another disability or any other sort of comorbidities going on, if there are any learning difficulties, not good support at home in terms*



*of language development, then those would be factors I would say, given the same audiogram, would push one (to get hearing aids) rather than another. [P20]*

Audiologists in diagnostic services would also consider the aetiology of the hearing loss when considering the timing of referral for intervention:

*So, ... if they suspect a particular type of hearing loss, like a CMV infection or vestibular aqueduct as a cause of hearing loss, they [diagnostic service] would like - they like us to monitor a lot, whereas if it's not a hearing loss where we suspect any change, we would then just monitor them for a behavioural test. So, you know, eight to 10 months. [P10]*

## **Theme 2: Audiologists Recognise the Need to be Fluid**

An excerpt from an audiologist encapsulates this perspective: “*There is no one-size-fits-all approach to audiological management of mild (hearing loss)*” [P19]. When managing infants and young children with MBHL, audiologists recognised the importance to be fluid and the need to adjust strategies as more information became available. This theme consisted of two subthemes: (1) actions guided by watchful waiting; and (2) meeting the child’s changing listening needs.

### ***Actions Guided by Watchful Waiting***

Audiologists described varying clinical practice ranging from continual monitoring to immediate referrals for rehabilitation or to immediate fitting of hearing devices.

Some audiologists recounted how they would prefer to collect more information before making referrals to rehabilitation services. While some referral processes were

not differentiated, “*if it’s a sensorineural loss, they’re referred to [Government hearing service]*” [P18], some audiologists noted that they would prefer to monitor cases of MBHL before referring: “*it’s the ones that are really mild where we hold on to them for a little bit longer and wait to see that behavioural assessment*” [P7]. Audiologists explained the importance of not being passive during the watch and wait stage “*so that you’re not just being reactive*” [P23].

A diagnostic audiologist described how she would continue to monitor children whose families decided not to take up a referral to a hearing rehabilitation service:

*.... So they might just say “Well, look, I’m happy not to take a referral at this point”. I will see them in probably two or three months and then keep on seeing them through until I can see that - how they’re doing, basically, functionally with their hearing, and if they’re developing - you know, if they’re babbling and moving on through up into word development and so forth. So we sort of hang on to them along the way.* [P23]

Some audiologists considered that the early diagnosis of MBHL “buys time” for collecting additional information about the child:

*So you know, when you’ve got that moderate or greater loss where you know that the babies aren’t hearing what they should be right now you feel that sense of urgency to move everything along very quickly. Whereas with a milder loss you do feel as if there is a, you know, a little bit more time up your sleeve.* [P17]

Some audiologists were clear on the need to obtain information about a child’s behavioural responses to sounds and their development to guide management and habilitation:

*If it's a very, very mild hearing loss, then I might be, like, "Well, let's just check this again once they're starting to develop language" ... especially once they're able to do behavioural testing as well. So once they get to the seven/eight months you can actually get them to turn to sounds and that gives you a little bit more of a feel for is it impacting them when they're starting to develop speech and language ... So you want to keep a close eye on them. [P3]*

*It's just always re-evaluating at each appointment where they're at and if there's a challenge or if they seem to be doing well and ... making it clear to the parents as well that it's not something set in stone and ... it's fluid. [P6]*

### ***Meeting a child's changing listening needs***

Audiologists considered aiding more readily as the child grows:

*When they're very young, parents normally talk to them in very close-up distance. So there is a grey area that they think "Should we go ahead now or should we wait a bit longer?", when the baby grows up and starts walking around and the distance from the speaker is getting longer, then they might need hearing aids at that time. [P11]*

Audiologists were driven in their management strategies by the complexity of the child's everyday listening environment, with childcare, kindergarten, and school being seen as 'challenging environments... where those mild losses would have more of an impact and where the hearing aids would help' [P16].

*If they're in child care and not in a relatively quiet environment of at home with mum, I'd be more inclined to mention that to mum, that child care is a noisy*

*environment and that, perhaps, we need to go and find out about whether the child needs any help and trial something. [P21]*

A child's entry into school was viewed as another critical time-point to re-consider the child's auditory needs due to the increased noise levels and the importance of adequate hearing for learning in the school environment: "*They may have difficulty, particularly academically in the classroom, being able to follow full auditory streams of information, particularly once the noise levels get up in the classroom as well*" [P20].

Audiologists considered the varied acoustic environments that a child is in as they increase in age. Some were of the view that hearing aids would be of benefit "*probably from kinder ... so when, you know, it becomes more difficult to actually control the acoustic environment and there's that much more going on. So, yeah, depending on the setting*" [P13].

### **Theme 3: Family Characteristics and Parents' Perspectives**

Audiologists described how management of MBHL was often '*driven by the parents*' [P10]. They considered (1) family circumstances and priorities; (2) perceived parent wishes and attitudes; (3) external influences and societal pressures on families; and (4) other professionals' opinions.

#### ***Family Circumstances and Priorities***

Audiologists noted that every family situation is different, and priorities relating to other areas of the child's life may be seen as more important than the diagnosis of MBHL:

*... they've got so many other things going on, how important is (fitting hearing aids) in the grand scheme of things right at this very minute ... [P19]*

*So if there are other factors influencing a child's health... perhaps, it's not the highest priority for the child and the family if they have other needs or considerations. Is it appropriate, you know, to introduce another intervention? [P5]*

Family circumstances also impacted upon audiologist management in a positive way:

*So another child who had a very mild loss, just high frequencies from memory, and the mother was a speech therapist, so I felt he was going to get pretty good language support and also very instantaneous recognition when there was language delay happening, so she was happy to hold off. [P20]*

### ***Perceived Parent Wishes and Attitudes***

Parent-led management was apparent during the referral process, as indicated by one diagnostic audiologist: “*our protocol is to recommend an [hearing service provider] discussion at the parents' discretion*” [P20]. In a similar vein, other diagnostic audiologists described the influence of children's parents on their management:

*I suppose the parents - the parents' acceptance of a hearing aid would be a big one. Some parents will - I find are very keen to do something and I feel that has a big impact on whether I will refer or not, and other parents are very - are happier to wait. [P7]*

As there is limited evidence on the timing of amplification on outcomes of children with MBHL, audiologists believed that the provision of hearing aids has to be primarily a ‘family’s decision’:

*we want to listen to where the family’s at and where they’re - what they’re thinking with the hearing loss as well. [P3]*

Audiologists refrained from influencing a family unless the family specifically sought their professional guidance:

*I try to let them make their own decision, .... You know, it’s not uncommon that they’ll say “Well, if it was your child, what would you do?” [P23]*

Some audiologists would recommend hearing aid fitting if a family “*really want to just do something, it makes them feel better to be doing something*” [P9]. Another audiologist recounted:

*...and I guess to some extent for a parent who’s worrying, understand they’re doing what they can do, you know, as much as they can do. I think that’s not to be understated. The worst thing for a parent is to be told something’s wrong and there’s nothing we can do to help. [P21]*

In contrast, some audiologists reported that they preferred not to go ahead with hearing aid fitting if the family was not ready:

*If they’re reacting pretty badly, then I would be waiting and just not rushing forward with the sort of concept of amplification like I would with a severe or profound loss. [P20]*

### ***External Influences and Societal Pressures on the Family***

Audiologists reported that some families presented with preconceived ideas shaped by cultural pressure and opinions from extended family members about what would be best for their child. One audiologist described this pressure on families:

*I think when it's mild, family and society's opinions do become much more of a concern because the fact is there's a chance we could do without it and there's not the overriding concern of "This child really won't develop as we want them to without a hearing aid". [P21]*

Parents expressed concerns about the negative impact of hearing aids and stigma:

*Obviously, their family and their cultural background will have huge influences and their own experiences of anyone with hearing aids or their own experiences of anyone being bullied in the playground. I've had, you know, a number of families where their own experiences at school have been quite negative, whether it's glasses or hearing aids, whether it's themselves or whether it's someone else, and they're just very concerned that they'd be doing something negative, yeah, for their child. [P14]*

*I think that's probably a difficult one for them because everyone's concerned about image and cosmetics, and all of that social stigma stuff. So if they don't have to do it they're probably less inclined to. [P22]*

*... some families felt that their babies were being stigmatised by the look of a hearing aid [P17]*

### ***Other Professionals' Opinions***

Rehabilitation audiologists described how other professionals' opinions influenced parents' attitudes towards management of their child's hearing loss:

*... the diagnostic centre that they attended talked/spoke to them about the hearing loss as well and its implications and have said, you know, the child may just need to be monitored at this stage. [P16]*

Audiologists noted that some parents attended their appointments having already made decisions about amplification, or changed their mind as they received information. In some instances, advice from other professionals caused conflict between audiologists and parents:

*A lot of kids end up enrolled with [early intervention service] and attending groups and things through them, but then they get a lot of pressure put on them by the agencies because it's like they have the expectation of, like, "Ooh, why aren't they wearing hearing aids? Like, why didn't you choose hearing aids?" and stuff as well. So then we get the other question coming back from the parents that are enrolled with early intervention saying "Well, they say that he should have hearing aids. Like, why are you saying that he shouldn't have hearing aids?" [P2]*

*I do find that sometimes they get told by maybe the ENT or their paediatrician that "Oh, yeah, you need hearing aids", and they'll refer for hearing aids which kind of annoys me because I've already, you know, had a bit of a discussion with the family about whether or not they're ready to proceed. [P9]*

One audiologist described how advice from multiple sources can be difficult for families, and also affected her own management:



*So sometimes they get a lot of conflicting information and I think that's one of the biggest challenges, is that everybody has got an opinion and they're not evidence-based opinions, they're just opinions. So, yeah, and so it makes it hard for us to keep everything going in, like, a straight sort of direction. [P2]*

## **Discussion**

This study was aimed to increase understanding about audiologists' perspectives in managing early-identified MBHL in infants and young children. Based on thematic analyses of interview transcripts of 23 pediatric audiologists in diagnostic and rehabilitation service settings, three main themes were identified: (1) evidence, or lack of it, influences audiologists' practice; (2) audiologists recognise the need to be fluid; and (3) family characteristics and parents' perspectives. An overarching theme of 'audiologists delivering family-centred practice' underpins all of these factors.

Family-centred practice is a philosophy and model of service delivery that recognises the importance of families being the central focus of healthcare services, and emphasises the importance of individual family wishes, strengths, and needs (Epley, Summers, & Turnbull, 2010). Family-centred practice has been recognised as best practice for the management of children with hearing loss (Ekberg, Scarinci, Hickson, & Meyer, 2018). Across the data, it was clear that audiologists recognised the need to apply an individualised approach when working with families, with "family-driven care" an essential component to management of this complex area of practice. The application of individualised family-centred services to children with MBHL is particularly important given the limited scientific evidence to support clinical management. Specifically, an evidence-based approach supports consideration of individual patient needs and characteristics (Hoffmann, Bennett, & Del Mar, 2017), a

central tenant of family-centred practice (Epley, Summers, & Turnbull, 2010), and a theme discussed by the participants in this study as strongly influencing their management.

In the area of hearing loss, Moeller and colleagues (2013) identified 10 specific principles for implementing family-centred practice with children with hearing loss and their family, including: (1) early, timely, equitable access to services; (2) family-provider partnerships; (3) informed choice and decision making; (4) family social and emotional support; (5) family-infant interaction; (6) use of assistive technologies and supporting means of communication; (7) qualified providers; (8) collaborative teamwork; (9) progress monitoring; and (10) programme monitoring. Analysis of the data clearly showed that audiologists value the importance of working in partnership with families to manage a child's MBHL, and supporting families to make informed decisions about hearing aid fitting and ongoing care. Further, the audiologists considered individual child and family characteristics in ensuring that they were respectful of individual family differences and choices (Moeller et al., 2013). In particular, the final theme "the perspectives of parents drive audiological management" aligns very clearly with the provision of family-centred practice, and respecting the family as the key driving force for selection of management strategies, with fluid decision-making responsive to the changing needs and abilities of the child and the family over time (Moeller et al., 2013).

Consistent with a family-centred care approach, participants also discussed how they considered parent emotions and well-being when providing recommendations and guiding ongoing management of the MBHL. The provision of information in order to inform family choice and decision-making is not only mandated by Government hearing

services, but also in line with Moeller et al's (2013) recommendations for informed choice and decision making and family social and emotional support. Importantly, informational counselling has implications for reducing family distress and uncertainty that often surrounds the initial diagnostic period (Meinzen-Derr, Lim, Choo, Buyniski, & Wiley, 2008).

Audiologists' knowledge of the potential effects of early diagnosis and hearing aid fitting on parents' emotions and parent-child attachment influenced their management of MBHL. Audiologists reflected on how this knowledge influenced the timing of hearing aid recommendations, especially given the potential for parents of children with disabilities to be at greater risk of developing insecure attachment (Howe, 2006). Allowing more time for parents to process the diagnosis may contribute to better informed decisions (Kampfe, 1989), but it may also increase parental stress arising from subsequent hearing aid fitting and ongoing hearing aid management (Kerkhofs & De Smit, 2013). On the other hand, delaying hearing aid fitting for children of families who prefer to fit hearing aids at the earliest possible time might lead to frustrations and a feeling that they weren't doing everything they could to help their children (Tudball, Fisher, Sands, & Dowse, 2002).

The absence of evidence-based management protocols and definitive evidence surrounding the timing and effectiveness of amplification for alleviating any potential negative impact of congenital MBHL in infants and young children likely contributed to variabilities observed in clinical practice (Porter, Bess, Tharpe, & Seewald, 2016). Importantly however, though not traditionally thought of as "evidence", the integration of clinical experience and patient preferences, along with traditional research evidence, forms an integral component of providing "evidence-based practice" (Hoffmann,

Bennett, & Del Mar, 2017). Even though clinicians' experience is invaluable in informing clinical decisions, this approach does not come without limitations as the use of anecdotal evidence brings a greater risk of bias and reasoning errors (Doyle et al., 2014). As summarised by a participant [P9], evidence on "*the long-term outcomes of ... hearing aid versus not hearing aid*" is crucial to guiding decision-making. Therefore, there is clearly a need for further research regarding the relative benefits and harms of hearing aid fitting and the timing of fitting on infants identified with MBHL and their families, and the ongoing development of processes and protocols to guide management.

### **Limitations and Future Directions**

The findings of this study have increased understanding of the factors influencing audiologists' management of MBHL, and the information they use to guide clinical practice. Though maximum variation sampling was used to recruit a range of audiologists with different levels of experience working in diverse sectors, the findings may not be generalisable across contexts where service delivery models might vary from that described in this study. To that end, we have specifically included diagnostic and rehabilitation audiologists to provide perspectives on ongoing management of infants diagnosed with MBHL. However, individual perspectives might differ for service providers that encompass diagnosis and hearing aid intervention in the one organisation. Future research could capture the experiences of a broader range of audiologists and other early interventionists working with children with MBHL and their families. In combination with a companion study on parents' perspectives and other studies on parents' needs ( e.g. Fitzpatrick et al., 2019; Walker et al., 2017), the

increased knowledge will contribute to practice guidelines that meet the needs of families and practitioners.

### **Conclusion**

Audiologists recognised the importance of adopting a family-centred approach in their management of MBHL in infants and young children. Embodied in their practice was the acknowledgement of limited evidence, the consideration of multiple child and family factors, and the incorporation of perspectives of parents and families in adopting a fluid approach to provide individualised services.

### **Acknowledgements**

The authors would like to thank all participants for their time and commitment to this study. We would like to acknowledge the assistance of Patricia Van Buynder in data collection, and Alison King and Peter Carew in supporting the recruitment for the study.

This study was partly supported by funding from the Garnett Passe and Rodney Williams Memorial Foundation awarded to VS and TC. This study was also partly supported by the Commonwealth of Australia through the Office of Hearing Services and the Murdoch Children's Research Institute Population Health Theme Funding. Research at the Murdoch Children's Research Institute is supported by the Victorian Government's Operational Infrastructure Support Program. VS was supported by Australian National Health and Medical Research Council (NHMRC) Early Career Fellowship [1125687] and a L'Oréal-UNESCO Australian & New Zealand For Women in Science Fellowship.

Part of this study was reported at the Australasian Newborn Hearing Screening Conference held in Australia, 21-22 March, 2019, "It's a grey area: the factors influencing audiologists' management of children with mild bilateral hearing loss".

### **Declaration of Interest Statement**

**Financial disclosure:** The authors have no financial relationships relevant to this article to disclose.

**Conflict of interest:** The authors have no conflicts of interest relevant to this article to disclose.

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## **Appendix 1: Audiologist interview guide**

### **Opening sentence:**

When you see a baby with a new diagnosis of bilateral mild hearing loss, what are your thought processes and what is your approach to counselling and managing the family?

### **Key Questions:**

1. How would you define a mild hearing loss?
2. How would you manage the baby?
3. What would you tell the family?
4. What factors help you decide on your management?
5. Do you think that hearing aids help these babies?
6. Do you think there may be any potential negative effects?
7. Where did you get the information to help you decide on what to do?
8. What do you think the evidence in managing infants with mild bilateral loss?
9. What would you advise a new audiologist in your role, who is seeing a baby with newly diagnosed mild hearing loss now?