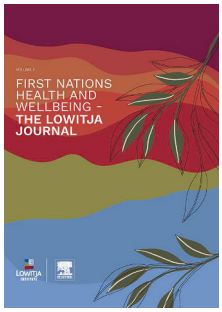

Original Research

‘This isn’t good enough’: Aboriginal caregivers’ perspectives on the pathways to support young children with otitis media and related hearing problems

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Abstract

Purpose This qualitative study aimed to explore the perspectives of Aboriginal parents and caregivers of children who have had ear health and hearing problems on: 1) supporting their children’s hearing health and language development; and 2) their experiences of ear health and hearing pathways, including audiology and speech language pathology (SLP) services. This study privileged the lived experience of Aboriginal caregivers to help health professionals and service providers understand more about how to build on family strengths.

Methods An Aboriginal research leadership team provided oversight for the study. Interviews were conducted with Aboriginal caregivers using the yarning method, an Indigenous research method, to privilege the voices of caregivers and prioritise relationality. Interviews were transcribed then analysed using reflexive thematic analysis, with project team collaborative yarning used to construct the final themes.

Main findings Interviews were conducted by an Aboriginal researcher with five Aboriginal caregivers in an inner regional urban New South Wales community and by non-Indigenous researchers with three

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Aboriginal caregivers in two remote Northern Territory communities. Three key themes were identified across the interviews: 1) Problematic pathways; 2) Caregivers having to be proactive; and 3) Caregiver recommendations. Sub-themes identified for theme 1 were: siloed services; lack of (appropriate) services; lack of clear messaging. Sub-themes identified for theme 2 were: advocating for their child; implementing strategies; finding help; advocating for other families. Sub-themes identified for theme 3 were: regular checks; more services; culturally respectful services; more information and education.

Principal conclusions Given the complexity of ear health and hearing pathways, Aboriginal caregivers had to strongly advocate for their children and other children in their communities. Consistent with previous studies, this suggests that significant changes are needed to support caregiver proactivity and ensure that the onus does not continue to solely rest on caregivers. Caregivers in this study described using a range of prevention and support strategies with their children with ear and hearing problems and provided recommendations for health services. Healthcare professionals can build on these strengths to assist families (including while they wait for specialist services) in ways that are culturally responsive and family centred.

Keywords: Aboriginal caregivers; Aboriginal children; Otitis media; Ear health and hearing pathways; Yarning method; Reflexive thematic analysis

Highlights

- Since ear health and hearing pathways are often complex and difficult to navigate, caregivers are having to be proactive in supporting their children with otitis media (OM) and related hearing loss.
- Caregivers identified problems, sought care and strongly advocated for their children, even though they were dismissed at times by health and education professionals. They implemented strategies to help prevent OM, as well as strategies to enable their child to hear and communicate more easily when they had OM. They found help, especially from community, family and friends, and advocated for and supported other families.
- Caregivers' recommendations for improving pathways include regular scheduled ear health and hearing checks, more services, culturally respectful services, and more information and education about pathways, otitis media and hearing for health and education professionals as well as families.

Introduction

Aboriginal and Torres Strait Islander children experience some of the highest rates of persistent otitis media (OM) globally (World Health Organization 2021). This prevalence relates to social determinants of health that are legacies of colonisation and ongoing coloniality, including racism, and disempowering government policies, economic disadvantage, difficulty in accessing affordable and culturally appropriate healthcare, and access to adequate housing that supports good health (Delacy et al. 2020; Shannon et al. 2022; Sherwood 2013; Watego et al. 2021).

Persistent OM causes long-term auditory deprivation in early childhood (Menzies School of Health Research 2020), with negative impacts on hearing and

communication-related development, education and social and emotional wellbeing (Bell et al. 2021; Campbell et al. 2022; James et al. 2025). Effective identification and care that mitigates negative impacts requires a range of primary, allied and specialist health services; however, evidence indicates that delays and sometimes long wait times can be common along the pathways to care (Australian Institute of Health and Welfare 2023).

Caregivers' experiences of ear health and hearing care for their children should inform improvements in service delivery, ensuring that the healthcare and information are appropriately tailored (Campbell et al. 2022). However, the perspectives of caregivers, especially Aboriginal and Torres Strait Islander caregivers, are under-represented in this research. Previous qualitative studies have considered the perspectives of caregivers supporting children with OM, including 17 studies considered in a systematic review (Chando et al. 2016) as well as others (e.g. Johnson, 2024; Russell et al. 2003; Stephens et al. 2020). However, few studies have specifically focused on the perspectives of Aboriginal and Torres Strait Islander caregivers (Campbell et al. 2022; Harkus et al. 2021; Jeffries-Stokes et al. 2004; Jones et al. 2018; Lau et al. 2024).

This study aimed to help address this gap by exploring the perspectives of Aboriginal caregivers of children (aged 12 and under) who had experienced persistent OM and related conductive hearing loss (CHL). The study explored their perspectives on 1) how they support their children's hearing health and language development; 2) experiences with ear health and hearing pathways, including audiology and speech language pathology (SLP) services. The study was led by an Aboriginal research leadership team (ARLT) and was motivated and informed by their knowledge of their communities and by the comments of Aboriginal caregivers during previous studies conducted by some of the authors (Harkus et al. 2021). It aimed to privilege the lived experience and expertise of Aboriginal caregivers by conducting interviews using the yarning method (Bessarab and Ng'Andu 2010; Kennedy et al. 2022). In doing so, this project sought to recognise and respect the wisdom of Aboriginal caregivers as 'agents of their [and their children's] health and wellbeing' (Shannon et al. 2022) and learn from them about how service providers can best support them and their children.

Methods

The ARLT (MK, TR, TM, TLR, JB) provided oversight to ensure that Aboriginal leadership, perspectives and ways of knowing were prioritised at all stages of the research. An Aboriginal and Torres Strait Islander researcher (JN) assisted with interpretation of the analysis and editing of the manuscript. Their disciplinary training included social science/social work (MK), health and medical sciences (TR, TM, TLR, JB) and bioethics (JN). Non-Indigenous researchers in the team sought to be self-reflexive and to listen to and learn from the members of the ARLT and the Aboriginal participants. Non-Indigenous researchers included IOK, CK (linguists); SH, MW (paediatric audiologists); JK (educator and musicologist); VM (epidemiologist and SLP), all with experience working respectfully with Aboriginal and Torres Strait Islander colleagues and communities. Ethics approval for the study was granted by 1) the Aboriginal Health and Medical Research Committee of New South Wales (NSW) Human Research Ethics Committee (Ref: 1857/21); 2) Menzies Top End Human Research Ethics Committee (Ref: 2021-4139); 3) Hearing Australia Human Research Ethics Committee (Ref: 2021-20). Informed consent (written or audio-recorded) was

sought from participants for participation in this study only and not for any future or secondary use of data.

Eligibility included Aboriginal caregivers of children aged 12 years or younger who had some history of OM-related ear health and hearing difficulties, and who had some experience with audiology and/or SLP services. Recruitment was purposive, via the social and community networks of MK (NSW) and IOK and JK (Northern Territory [NT]), with participants invited to participate by MK, IOK and JK. Some caregivers were invited by other caregivers to contact the researchers (word of mouth and snowball methods). Five mothers and three grandmothers participated. Most participants worked in, or had family who worked in, health or education contexts. Participants were provided with participant information and consent forms before the interview. Interviewers (MK, IOK and JK) discussed these forms, as well as information about reimbursement (a $50 gift card), beforehand with the participants. The ARLT determined that the process and reimbursement were appropriate and in line with ethical research practices.

Interviewers used the yarning method, an Indigenous research method, that privileges caregivers' perspectives and the importance of relationality and researcher reflexivity (Bessarab and Ng'Andu 2010; Kennedy et al. 2022). The yarning began with social yarning to establish relationships, followed by research topic yarning to explain the research (these phases of the yarn were not recorded). Once caregivers were satisfied that their questions had been answered and gave their consent to be part of the research and to be audio-recorded, audio-recording began, and the research yarning phase commenced, following a yarning guide with broad topics of enquiry, rather than a strict set of questions. Each yarn went for no more than 90 minutes, and the recorded research yarning sections went for between 24 and 45 minutes. Aboriginal researcher, MK, who is experienced in the yarning method, mentored IOK. Non-Indigenous researchers JK and IOK have both worked for over 15 years with the remote NT communities taking part in the study, where Elders have taught them how to engage respectfully. In these communities, research assistants were unavailable due to COVID-19-related timing constraint challenges, so IOK and JK conducted the interviews. Participants were reimbursed for their time with Visa gift cards.

Members of the research team (IOK and MW) transcribed the audio-recordings for familiarisation. The transcripts were emailed to or talked through with caregivers to ensure that they accurately represented their words (or translations of their words in the case of some sections in Aboriginal languages) and that there were no errors or parts they would like taken out. The transcripts were then de-identified and shared with the research team as part of familiarisation, which is the first process in a reflexive thematic analysis approach (Braun and Clarke 2006; 2019). Two researchers (IOK and MW) performed the initial inductive coding then iteratively drafted candidate themes through discussions with other project team members. In line with the project team's commitment to relationality and ensuring that Aboriginal and Torres Strait Islander perspectives and ways of knowing were prioritised, the project team had collaborative yarning meetings to review the coding and construct the final themes.

Results

During 2022, MK conducted one-on-one interviews with five Aboriginal caregivers in an inner regional and urban NSW community. In parallel, IOK and JK conducted interviews with three Aboriginal caregivers in two remote NT communities (IOK had planned to

recruit five caregivers in the NT but was unable to within the project timeframe). 'Community' here is defined in a broad geographical and sociocultural way. Not all caregivers regularly attended their local Aboriginal community-controlled health organisation (ACCHO); the local health organisation was transitioning to be an ACCHO in one community. Interviews were conducted face-to-face (F2F), except for three, which were conducted via Zoom (www.zoom.com), which was the caregivers' preference. These details are provided in Table 1. Detailed demographic details are not provided to protect the anonymity of participants.

While one of the original foci of the research was on caregivers' experiences of audiology and SLP services, caregivers wanted to discuss ear and hearing health pathways more broadly in the yarns. After coding the transcripts and conducting collaborative yarning, three key interrelated themes that captured the main patterns of meaning were identified: 1) Problematic pathways; 2) Caregivers having to be proactive; 3) Caregiver recommendations. These themes are outlined (with illustrative quotes) in Table 2 and discussed in the following sections.

Participant ID	Relationship to child	NSW/NT	F2F/ Zoom	Interviewer/s
C1	Mother	NSW	F2F	MK
C2	Mother	NSW	F2F	MK
C3	Mother	NT	Zoom	IOK and JK
C4	Mother	NSW	Zoom	MK
C5	Grandmother	NT	F2F	IOK
C6	Mother	NSW	F2F	MK
C7	Grandmother	NT	F2F	IOK
C8	Grandmother	NSW	Zoom	MK

C, caregiver; F2F, face to face; ID, identification; IOK, Isabel O'Keeffe; JK, Jodie Kell; MK, Michelle Kennedy; NSW, New South Wales; NT, Northern Territory.

Table 1: Details of participants and interviews

Theme 1: Problematic pathways

As caregivers recounted stories of their child's ear and hearing difficulties, they described how problematic the various pathways could be, given the range of services involved and the challenge of accessing services and clear information.

Siloed services

Caregivers described having to navigate many services, and their respective referral and entry processes, including general practitioners (GPs); paediatricians; audiology; SLP; ear, nose and throat (ENT); and the National Disability Insurance Scheme (NDIS). One caregiver's abbreviated narrative illustrates the multiple and fragmented services she had to navigate:

> *Went to the GP [...] spoke to the daycare [...] went back to [ACCHO name] got a referral, they sent us to the community speech [SLP service] [...] spoke to the school [...] took him for an autism assessment [...] we kept going to speech [SLP service] [...] I got a referral from my GP for [audiology service name] [...] spoke to the school again [...] [audiology service name] were good, they called us for another 6-month follow-up. And he was still showing fluid in that one ear, so then that's when I said, 'well, I want to go down the ENT pathway, I've had a referral from my GP from [ACCHO name] to go to [hospital name]' and through [ACCHO name], we're just still on the waitlist* (C1).

Many caregivers recounted the challenges of navigating the different parts of the pathways that were 'siloed', meaning there was no continuity of care:

> *There's like the whole kind of questioning to begin with, like 'is there a problem, isn't there a problem' [...] then you have to see another specialist and they have to ask other questions [...] every part [of the*

Themes	Sub-themes	Illustrative quotes
Problematic pathways	Siloed services	*Every part [of the pathway] happens in like a siloed section, there isn't that kind of continual understanding and respect of what that patient or family is actually going through* (C6).
	Lack of (appropriate) services	*Given that otitis media is so high in our community, the facilities available are just not enough* (C4). *You could tell the difference between a culturally respectful environment and just a clinical environment [...] the type of people that you have at the desk, the questions that they ask* (C4).
	Lack of clear messaging	*With the [child health record] and your needles and things like that, there was no mention about I should be getting his ears checked* (C1). *It's not like they [health] had a guide or anything around hearing* (C2).
Caregivers having to be proactive	Advocating for their child	*Gotta keep pushing ENT doctors and hearing [services] to like do something for their ears* (C3). *I was constantly being dismissed [by the GP], to the point of me going in with like research on otitis media printed off* (C4).
	Implementing strategies	*We did the 6-week [SLP] program [...] I just had to watch him, how he kind of played [...] what I thought he could hear [...] how he would speak back to me [...] and we would read books to try and, you know, get his words up!* (C1). *I just give him like hug and keep him calming down and then I ask him again* (C3).
	Finding help	*It was more community; it was more like family and friends that were more helpful than anything* (C6). *[The local ear health worker] explain it to them [caregivers] like in [local] language and also in English* (C3).
	Advocating for other families	*We've had friends that have had their kids in similar situations and [...] we've been able to help advocate for them, to make sure they don't go through what we went through as well* (C4). *I help and support them, you know, mums, like: 'you need to take him to clinic to get checked'* (C3).
Caregiver recommendations	Regular scheduled checks	*The health system should be like 'here's your hearing booklet, make sure you get hearing checks regular'* (C2). *It should be a health check [...] I think it should be like the same as they say 'book your kid in for a dental check every 6 months', it should be a hearing check as well [...] I wouldn't have known [about ear and hearing issues] and I work at [hospital name]. Imagine how many other young mums wouldn't know!* (C1).
	More services	*An improvement would be having a [ENT] clinic at [ACCHO name] every month, not every three months [...] given that otitis media is so high in our community* (C4). *They [visiting audiology service] should come often* (C5).
	Culturally respectful services	*I really think there needs to be just discussion prior to it [hearing assessment] [...] like have an Aboriginal health worker or something like that, like I think some type of like cultural connection checking would be like really beneficial [...] I would've liked a heads up, like, it's not a great feeling when you can hear something and your kid can't!* (C6).
	More information and education	*I think having like as much information as possible. I think it would've been nice for them [audiologists] even maybe do [...] like a quick role play [...] instead of them be like 'ok, mum, come sit down' and that's it and [...] we're in and then they're [audiologist] like back turned, writing [...] no like respect for [...] what that means for your kid* (C6). *It's working to educate our doctors across the district, what otitis media is, but also educate our families as well* (C4). *That hearing mob when they come, they should explain like more [...] or make a community meeting* (C7). *Needs to be educated to mob [Aboriginal people] and to schools [...] I don't know how many conversations I have to have with the teachers [...] 'do you think maybe she has a speech issue going on and a hearing issue going on'* (C2).

Table 2: Themes with illustrative quotes

pathway] happens in like a siloed section, there isn't that kind of continual understanding and respect of what that patient or family is actually going through (C6).

As the above quote shows, the way that services can be siloed creates challenges for caregivers having to repeat the story about their child's ear and hearing difficulties to different health professionals. Although

many of the caregivers described experiences of their local ACCHO helping to coordinate the complex range of services (e.g. visiting ENT and SLP services) and referrals, some caregivers also accessed private services when they could, attempting to reduce wait times:

> *I booked in to see a private ENT at that point [...] because I think it was like another huge wait to see the ENT specialist to come back to [ACCHO name], I can't remember how long the wait was then, but it was just too long, I just wanted to get on top of it before he [my child] started school* (C6).

Lack of (appropriate) services

It was evident from the narratives of caregivers that there was a lack of appropriate and accessible services – and even a lack of any services. Caregivers described how this lack led to long wait times and other access challenges related to the costs of services, costs of travel and caregivers needing to take time off work to attend appointments. Caregivers in NSW pointed out that wait times had been exacerbated during the COVID-19 pandemic, when visiting services and F2F appointments had been suspended for a period:

> *Given that otitis media is so high in our community, the facilities available are just not enough* (C4).

In addition to the access challenges, some caregivers had found that some services were not culturally safe or welcoming:

> *The first one [SLP] they set me up with was in town [...] Like I'm a single mum, I work, that's impossible for me to do! [...] and if you missed them, then that was your speech session done, you missed out [...] when we rocked up there [...] it wasn't culture one, like it wasn't a blackfulla one [...] [the SLP] wasn't very friendly and [...] I don't wanna talk about my kids in front of my kids! I don't want them to think there's things wrong with them! [...] I can't work a day now cos I have to do this for 10 weeks! [..] And the waiting list is huge!* (C2).

In contrast, some caregivers described culturally safe and helpful services at their local ACCHO compared with more 'clinical' environments elsewhere:

> *Being referred to an ENT that works out of an Aboriginal service was a massive benefit. For us we already had a place of comfort within [ACCHO name] [...] Going to Dr [ENT name]'s private rooms [...] you could tell the difference between a culturally respectful environment and just a clinical environment [...] the type of people that you have at the desk, the questions that they ask* (C4).

Lack of clear messaging

Caregivers' narratives emphasised the lack of clear messaging around ear health and hearing support available, and how to navigate the system. Several caregivers described their frustration at the lack of information about OM, hearing and the need for ear health and hearing checks:

> *I said [to the audiology service] 'is this [OM] [...] common in Indigenous kids?' but they didn't really know. So then that's when I went back to [ACCHO name] and they said 'it's actually like the most common thing in Indigenous kids', which I had no idea about!* (C1).
>
> *There's not really a pamphlet that says 'my child has otitis media, what does that mean?'* (C4).
>
> *With the [child health record] and your needles and things like that, there was no mention about I should be getting his ears checked* (C1).
>
> *It's not like they [health] had a guide or anything around hearing* (C2).

Theme 2: Caregivers having to be proactive

Caregivers narrated how they identified their child's ear health and hearing problems and the care and support they had to advocate for. In many of the caregivers' narratives, health and education professionals had not identified children's OM or hearing problems and had even dismissed caregivers' concerns. Caregivers emphasised that being proactive and advocating for their children was about wanting the best for their children now and their futures:

> *I used to tell them [health services] get this done for my kids so they can hear and speak well, you know, in the future!* (C3).
>
> *They are our babies and they are the future* (C1).

Advocating for their child

Caregivers described challenges identifying OM (because it is often asymptomatic) and related hearing issues and differentiating these from developmental concerns. They recounted how family members might think a child was just 'ignoring' them (C7), 'just pretending' not to hear (C5), or being 'naughty' (C2, 6) or 'stubborn' (C6). One caregiver described a teacher saying that the child was 'being silly' (C7). However, caregivers had noticed and become concerned about their child's difficulties with hearing, listening, communication and speech:

> *I knew that he wasn't a naughty kid. I knew [...], he wasn't ignoring, like I could see like him trying to process things and it not quite working and I think that's such a frustrating thing. And we are just so lucky right that we got onto this when we did, so it didn't go to school age, and he didn't get labelled that naughty kid* (C6).
>
> *He wasn't hearing properly or responding to us or his sister* (C4).
>
> *Like he couldn't talk, like he was just pointing [...] I said 'oh something going on with their ears'* (C3).
>
> *I would of never been to [audiology service name] if I wasn't worried about [child name]'s speech* (C1).

For many caregivers, once they had concerns, they were still unable to get diagnoses or care for some time. Caregivers described having to strongly advocate for their children in the face of failures in ear health-related care, including being dismissed by health and education professionals or having to push for action:

> *I was still like keep like humbugging [continually asking] hearing team mob to check on his ears like every like 2, 3 months' time and, you know, they ended up find out that he had a fluid behind his ears [...] Gotta keep pushing ENT doctors and hearing [services] to like do something for their ears* (C3).
>
> *Went to the GP, they more or less just went through the [child health record], said he was fine. I spoke to the daycare, they said his milestones were fine [...] Like he's had a speech delay and if I wasn't active on that he wouldn't have had any appointments* (C1).
>
> *I was constantly being dismissed [by the GP], to the point of me going in with like research on otitis media printed off and being like 'I think this what he has, like, can you tell me if that's the case!'* (C4).

One caregiver stressed the additional challenges of advocating for children in situations of shared care arrangements because of the lack of an effective system for identifying and tracking management of ear health and hearing issues in primary healthcare, shifting the onus for these on to caregivers:

> *Because they're [my grandchildren] in a situation of shared care it's sometimes hard [...] to know what's happened or what's been treated on the other side [of the family]. If there's issues with communication or the relationship isn't amicable, at times, it's hard to actually get that stuff right* (P8).

Implementing strategies

Caregivers described a range of strategies they used to help prevent OM, as well as strategies to enable their children to more easily hear and communicate when they had OM. Preventative strategies included encouraging nose blowing, washing hands and faces, and trying to avoid swimming or to wear a swimming cap in the river. Strategies for communication included ensuring that the child can see their face when they speak; telling others they may need to speak louder, talk slower or be closer to the child; and getting the child's attention before speaking with touch or hand signs. Strategies to enable children to learn and use language included repeating words and encouraging children to copy and use words:

> *Learning new words, it was me kind of focusing and like repeating sounds and then getting him to, like repeat sounds before he would do a word* (C6).

Other strategies that caregivers described included activities encouraged by SLPs, such as reading with children and asking them about what they were doing:

> *We did the 6-week [SLP] program [...] I just had to watch him, how he kind of played [...] what I thought he could hear [...] how he would speak back to me [...] and we would read books to try and, you know, get his words up!* (C1).

Caregivers also described emotional support strategies for when their child was frustrated:

> *I just give him like hug and keep him calming down and then I ask him again* (C3).

Finding help

Caregivers reported finding help, particularly from community, family and friends who had previous experience with ear health and hearing problems and services:

> *It was more community; it was more like family and friends that were more helpful than anything* (C6).
>
> *My brother has ear problems as well and my mum [was] saying 'you know, if it keeps getting bad, his [your child's] ear drums will burst, and he could possibly have like hearing damage when he's older* (C4).
>
> *It's only through my cousin's kid who's had ENT issues [...] she could pick up on a lot of resemblance [with my child], at the similar age* (C1).

Caregivers had found some help from supportive health professionals. This included explanations from health professionals about what OM was, support to access services and health services following up and making appointments 'fun' for the child:

> *Like it was really good, they [the audiologists] explained it [...] that it's like when you're swimming in an inground pool or something like that and you get water in your ear, that's how [Child name] is feeling every day* (C1).
>
> *I was lucky with the NDIS plan [for child's speech delay] because [...] they [NDIS workers] would help me get her [my child] into the speech [SLP services], and the ENT* (C2).
>
> *They [audiology service] rang for a follow up which was good, cos I work, time gets away [...] He [my child] is pretty good when he goes to [audiology service] cos they make it fun. Like it's all a game and things like that* (C1).

Some caregivers, however, described how they had been reluctant to ask for help at times because of feelings of shame:

> *I didn't ask for a lot of help because I was so shame that it just kept happening* (C4).
>
> *As a first-time mum, you blame yourself. 'Why's this happening to my kid? What have I done wrong? […] Oh my god, can he [my child] even hear me?'* (C1).

Yet these same caregivers had still strongly advocated for their children in the face of these internal challenges as well as external challenges, such as being dismissed by health and education professionals.

Advocating for other families

As well as advocating and supporting their own children, caregivers had also helped other families whose children had OM and hearing difficulties. Caregivers had helped other families to understand more about ear health and hearing problems, pathways and the available support:

> *We've had friends that have had their kids in similar situations and both my husband and I are like 'this is what you have to do, like this is how you get in quicker' […] we've been able to help advocate for them, to make sure they don't go through what we went through as well* (C4).
>
> *I help and support them, you know, mums, like: 'you need to take him to clinic to get checked'* (C3).
>
> *[The local ear health worker] explain it to them [caregivers] like in [local] language and also in English […] she came and then explain to mums while I was running the FaFT [Families as First Teachers playgroup]* (C3).

Theme 3: Caregiver recommendations

Caregivers made a range of recommendations based on their experiences of supporting their children and navigating the complex ear health and hearing pathways. This included recommendations for improving the pathways with regular checks and more services (and reducing the onus on caregivers to be proactive) as well as recommendations for culturally respectful services and the provision of more information and education. Caregivers were not directly asked to give their recommendations, but these came up in the yarns as caregivers reflected on what they thought had or could have helped them and their child. Each of the key recommendations are discussed below as sub-themes.

Regular checks

A few caregivers expressed the idea that having regular ear and hearing checks, like dental checks, 'should be' the norm. They explained that this would have helped them and/or would help other caregivers, such as other young mothers with less knowledge of ear and hearing health:

> *The health system should be like 'here's your hearing booklet, make sure you get hearing checks regular'.* (C2)
>
> *It should be a health check […] I think it should be like the same as they say 'book your kid in for a dental check every 6', it should be a hearing check as well, if it is such a high percentage in Indigenous people. I wouldn't have known [about ear and hearing issues] and I work at [hospital name]. Imagine how many other young mums wouldn't know!* (C1)
>
> *Like that's something that you do annually [health checks], might be nice to have that [ear health and hearing] on his [my child's] file and flagged, like that doesn't get brought up very much.* (C6)

As the quotes above illustrate, caregivers thought that regular checks would have helped to 'bring up' ear health and hearing issues and ensure that the onus was on the health system rather than on caregivers having to be proactive.

More services

Given the lack of (appropriate and accessible) services discussed above, caregivers had recommendations for more regular services, particularly for more regular visiting services, and for screening in accessible places for families.

> *An improvement would be having a [ENT] clinic at [ACCHO name] every month, not every three months [...] given that otitis media is so high in our community.* (C4)

> *They [visiting audiology service] should come often* (C5).

> *[Ear health and hearing] screening in homes and [...] the preschool [...] community days [...] but it's gotta be linked to those [health] records eventually* (C8).

Culturally respectful services

Caregivers also described the kind of culturally respectful service provision they had found helpful or would have found helpful. This included services where staff were 'friendly and welcoming', 'reassuring' and 'sensitive' to the needs of the child and caregiver (C4). Clear explanations from health professionals were also valued. One caregiver also described the need for 'cultural connection checking', the importance of Aboriginal health workers and 'individualised care' (C6):

> *Staff [at audiology service] were really friendly and welcoming [...] the way they explained stuff and reassured, the types of questions they asked they were culturally respectful, which was nice. They were sensitive to the fact that he was a boy that had been through a lot in a small amount of time. And that mum was at her wit's end, and she just wanted help!* (C4).

> *I really think there needs to be just discussion prior to it [hearing assessment] [...] like have an Aboriginal health worker [...] some type of like cultural connection checking would be like really beneficial [...] I would've liked a heads up, like, it's not a great feeling when you can hear something and your kid can't* (C6).

> *Maybe individualised care is missing or something [...] just the discussion around like 'what's happening? Where are we at?' Like what are we expecting? Do we understand? Do we have all the information? Is there something that they could do around like providing more information or support?* (C6).

More information and education

Caregivers recommended more information for families about what to expect in appointments and across the pathway. This included 'what it actually means to get grommets [...] how big that is to let your kid go under [anaesthetic]' (C6) and health professionals having 'respect' for how difficult children and caregivers might find grommet surgery and other health appointments:

> *I think maybe they [the audiology clinic] could've maybe explained what was to be expected [...] send out an information thing or tell me over the phone* (C1).

> *I think having like as much information as possible. I think it would've been nice for them [audiologists] even maybe do [...] like a quick role play [...] instead of them be like 'ok, mum, come sit down' and that's it and [...] we're in and then they're [audiologist] like back turned, writing [...] just that no like respect for [...] what that means for your kid* (C6).

> *That hearing mob when they come, they should explain like more [...] or make a community meeting [...] and explain* (C7).

One caregiver suggested the creation of an app with information about ear health and hearing that could also assist caregivers making the right appointments with health services:

> *You could create this hearing app for mob that has all your information on there, can make special appointment if your kid's facing this* (C2).

Caregivers also recommended more education about ear health and hearing for GPs and educators, as well as for families:

> *It's [about] working to educate our doctors across the district, what otitis media is, but also educate our families as well [...] Unless a doctor specialises in it [OM], they don't really know, so there's more education that's needed [...] we need to talk about this chronic health condition even more as a part of their developing education* (C4).

> *Needs to be educated to mob [Aboriginal people] and to schools [...] I don't know how many conversations I have to have with the teachers [...] 'do you think maybe she has a speech issue going on and a hearing issue going on'* (C2).

Discussion

The three overarching and interconnected themes highlight the complexity of ear health and hearing pathways, the degree of caregiver proactivity currently required to navigate these pathways and the recommendations that caregivers had for improvements in pathways and services. These research findings add to the small but growing body of research on the perspectives of Aboriginal and Torres Strait Islander parents and caregivers on supporting their children's ear health and hearing.

The recommendation of some caregivers to have regular ear health and hearing checks is a new and important finding from this study. It provides initial evidence that families may find new primary healthcare recommendations for six-monthly ear health checks for Aboriginal and Torres Strait Islander children aged five years and younger to be acceptable and feasible (Harkus et al. 2023). However, further research is needed to scope the implementation of these checks in an effective and culturally responsive way with Aboriginal community-controlled primary healthcare services and Aboriginal and Torres Strait Islander people 'at the forefront' (Kennedy et al. 2022) of this research.

This study highlights that the onus is still on caregivers to have to be proactive to receive effective care. This aligns with related themes from previous studies presenting Aboriginal and Torres Strait Islander caregivers' perspectives on caring for children with OM (Campbell et al. 2022; Harkus et al. 2021). These studies have noted the importance of 'caregiver work on behalf of their child' (Campbell et al. 2022) and 'carer recognition of signs of ear health and hearing problems' and 'parent and carer action-taking', similarly concluding that 'the onus for identifying ear health and hearing problems often rests with Aboriginal and Torres Strait Islander parents and carers' (Harkus et al. 2021). Previous studies have also noted challenges for caregivers in recognising symptoms of ear health and hearing problems (Campbell et al. 2022; Harkus et al. 2021; Jeffries-Stokes et al. 2004) and being dismissed by health professionals (Campbell et al. 2022). Consistent with previous findings, this study found that caregivers also identified problems by observing children's listening and talking behaviours (Harkus et al. 2021).

The strategies discussed by caregivers in this study align with previous studies relating to prevention (Jeffries-Stokes et al. 2004) and supporting children (Jones et al. 2018; Lowell et al. 1995; Walsh 2020), including the use of home languages, sign language or gestures. By learning about and building on the existing strategies and strengths of caregivers and their families, health and education professionals may be able to better assist caregivers and their families to support children with OM and hearing difficulties, even while they face long wait times for services. This approach is consistent with the principles of best-practice family-centred care (FCC) (Epley et al. 2010) and the calls for FCC in SLP (Staley et al. 2020), audiology (Ng 2022) and other health services more broadly (DiGiacomo et al. 2013a; DiGiacomo et al. 2013b). FCC also needs to be culturally responsive and safe, as outlined in the Indigenous Allied Heath Australia's (IAHA) Cultural Responsiveness in Action framework (Indigenous Allied Health Australia 2019). Specific methods that may assist practitioners to be culturally responsive include 'yarning' methods in SLP (Lewis et al. 2017) and 'clinical yarning' more broadly (Lin et al. 2016).

Previous studies have noted the difficulties and complexities of ear health and hearing pathways, including accessibility and wait times (Campbell et al. 2022; Department of Health and Ageing 2010; Harkus et al. 2021; Jeffries-Stokes et al. 2004). That these remain unchanged across 20 years of studies highlights the urgency of systemic reforms so that the major public health concern of OM and related hearing issues are addressed. Reducing the complexity of ear health and hearing pathways requires major structural changes (e.g. coordination across services and sectors, greater availability of ENT services, regular ear health and hearing checks in primary healthcare), and clear communication regarding the availability of support services and ear health and hearing more broadly (Harkus et al. 2023). However, this should not prevent immediate actions that could improve caregiver experiences, such as more friendly, welcoming and culturally responsive services for families, as outlined in the IAHA's framework (Indigenous Allied Health Australia 2019). Caregivers provided concrete recommendations (see Table 2, theme 3), many of which echo calls from previous studies for more information and education for both families and clinicians (Australian Department of Health and Ageing 2010; Campbell et al. 2022; Harkus et al. 2021; Hearing Australia 2017).

Strengths and limitations

One strength was the use of yarning, an Indigenous research method, that privileged caregivers' perspectives and the importance of relationality and researcher reflexivity (Kennedy et al. 2022). As an experienced Aboriginal researcher proficient in yarning and with strong pre-established community relationships, MK's interviewing allowed caregivers to feel culturally safe and able to share detailed and personal stories. MK also provided mentoring for IOK. Another strength was the inclusion of caregivers from both inner regional urban NSW and remote NT communities, since they provided perspectives from different contexts. It was also a strength to have the study led by an ARLT who ensured that Aboriginal and Torres Strait Islander perspectives and ways of knowing were prioritised.

One limitation of the study was that it did not capture the full extent of the challenges that caregivers may face, since the eligibility criteria required participants to have some experience with audiology and/or SLP services. Additionally, many of the participants had worked in health or education contexts and/or had assistance from family or friends with experience or

employment within related health services. ARLT members and several participants mentioned their concerns about other caregivers who may have greater challenges navigating ear health and hearing pathways. While the small number of participants may be considered a limitation, the study did not aim to produce quantitative, generalisable results, but to produce rich, qualitative data to explore caregivers' experiences and perspectives. These data provide in-depth insights into the ways that caregivers support their children with ear and hearing difficulties, as well as the challenges navigating and accessing support services and their perspectives on what culturally safe services look like. While some of the caregivers' perspectives may relate to specific contexts, many of their insights and recommendations are consistent with other studies and can inform structural changes to ear health and hearing pathways, and models of culturally safe research and service delivery.

Recommendations for future research

Future research needs to consider how to support (and reduce the need for) caregiver proactivity, address complexities with pathways and respond to caregiver recommendations. This includes further research on the acceptability and feasibility of the new recommendations for the components and timing of regular ear health and hearing checks (Harkus et al. 2023), given the caregiver support for these checks evidenced in this study. Additionally, research is needed to co-design tailored information with and for families about the pathways and services, as well as health promotion and information about ear health and hearing for families and health and education professionals. Considering the perspectives of caregivers at earlier stages of the journey or in situations that would make accessing services more difficult (e.g. in locations with limited services or in situations of shared care or caring for foster children) could provide greater insights into the extent of the challenges that caregivers face. The perspectives of children and young people could be considered to better understand the impacts on them and what support is most helpful (McFarland and Dealtry 2017; Priest et al. 2017; Wilson and Wilks 2013). Further research on culturally responsive FCC (McCarthy and Guerin 2022; Strobel et al. 2022) and/or methodologies, such as clinical yarning (Burke et al. 2022), could strengthen the evidence base for the kind of care that caregivers recommended. This research would need to build on the expertise of Aboriginal and Torres Strait Islander researchers and health workers, and support and develop new Aboriginal and Torres Strait Islander researchers and health workers.

Conclusion

> *Like if I was a doctor or a boss or something, I'd probably go to a head meeting and say you know, 'this needs to change, this needs to happen and this isn't good enough' [...] but I'm not a doctor, and people aren't gonna listen to me cos I'm just one mum* (C2).

This study highlights the importance of listening to and responding to Aboriginal and Torres Strait Islander caregivers' experiences and recommendations to inform and improve health pathways, as well as culturally responsive and family-centred healthcare. This is especially important because this study and others have shown that caregivers are often dismissed or not listened to; yet the onus remains on families to identify problems, find support and navigate ear health and hearing pathways. By listening to caregivers and building on their existing strategies, healthcare professionals and researchers can seek to empower caregivers, while also working to change a system that, as one caregiver stated, 'isn't good enough'.

Heeding the recommendations from caregivers in this study for regular ear health and hearing checks, more (culturally respectful) services and more information and education (for families and clinicians) would help to improve pathways and reduce the need for caregivers to be so proactive. Additionally, by building on the existing prevention and support strategies that families use with their children, healthcare professionals can assist families in strengths-based ways to maximise children's communication and provide rich language environments for their children, even while they wait for specialist services, such as ENT services.

Author contributions

I. O'Keeffe was responsible for the design, drafting, acquisition and analysis of data, and editing of the manuscript. T. Rankmore, M. Ward and T. Manton were responsible for the design, analysis and interpretation of data, reviewing and editing the manuscript and contributing to the design of the manuscript. J. Nash was responsible for assisting with the drafting, interpretation of data, reviewing and editing the manuscript and contributing to the design of the manuscript. M. Kennedy was responsible for the design, acquisition, analysis and interpretation of data, providing analytical advice, contributing to the design of the manuscript and reviewing and editing the manuscript. T.L. Ridgeway, C. Kung, S. Harkus and J. Bennett were responsible for assisting with the design, analysis and interpretation of data, reviewing and editing the manuscript. V. Marnane was responsible for analysis and interpretation of data, reviewing and editing the manuscript. J. Kell was responsible for acquisition and interpretation of data and reviewing and editing the manuscript. T. Manton was responsible for the overall design, plans for acquisition, analysis and interpretation of data, reviewing and editing the manuscript and contributing to the design of the manuscript. T. Rankmore, M. Kennedy, T.L. Ridgeway, J. Bennett and T. Manton provided Aboriginal and Torres Strait Islander leadership for the project, along with J. Nash's leadership in the analysis and manuscript drafting and editing.

Declaration of interests

Associate Professor Michelle Kennedy is an Associate Editor of First Nations Health and Wellbeing - The Lowitja Journal, and Strategic Research Advisor at Lowitja Institute. All other authors declare no competing interests.

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Author biographies

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Trumaine Rankmore is a proud Wiradjuri man from Dubbo with family connections to Gomeroi and Ngemba nations. Trumaine has been working in Aboriginal health since 2012 and been an Ahpra registered Aboriginal Health Practitioner (AHP) since 2016. He commenced his Aboriginal health worker journey within an ACCHO, where he learnt the fundamentals of Aboriginal health. This experience provided him with the knowledge and skills to transfer across to now providing healthcare within a mainstream general practice. Trumaine also works part-time in ear health research at University of Newcastle, HMRI and Hearing Australia.

Jessma Nash is a Gudang and Meriam woman who grew up in Queensland. She is a researcher at the National Acoustic Laboratories (NAL), working in the area of Aboriginal and Torres Strait Islander paediatric hearing health, and a bioethicist working in health and aged care. She has worked on several NAL projects, including 'AmpOut: What determines the success of fitting amplification to Aboriginal and Torres Strait Islander children with persistent OM?' and '5,000 PLUMs: Assessing utility and efficacy of the PLUM listening skills checklist through analysis of over 5,000 sessions of care with young Aboriginal and Torres Strait Islander children'.

Meagan Ward is non-Indigenous audiologist and clinician-researcher who lives on Gadigal Land. Her current role is Clinical Leader (First Nations Services) at Hearing Australia. She has worked with Hearing Australia as a paediatric audiologist and with the Aboriginal and Torres Strait program doing outreach work across remote, urban and regional areas for decades. She has also been involved in several National Acoustic Laboratories projects, where she worked for several years as Clinical Lead Community Outreach in the Communication Sciences Department.

Michelle Kennedy is a proud Wiradjuri woman raised on Worimi Country. She brings over 16 years' experience working with Aboriginal and Torres Strait Islander communities across community development, social work and health research, and Indigenous ways of knowing, being and doing in health research practice. Michelle is leading national research in tobacco control, Aboriginal and Torres Strait Islander health research ethics and Indigenous methodologies. Michelle is Associate Professor and Assistant Dean Indigenous Strategy and Leadership at the University of Newcastle, Strategic Research Advisor at Lowitja Institute and Vice President for the Public Health Association.

Carmen Kung is a non-Indigenous researcher with a PhD in cognitive neuroscience. She has over 10 years of research experience across brain and language science, child development and hearing health, including Aboriginal and Torres Strait Islander children's hearing health. She has a strong commitment to undertaking strengths-based and

ethical research that supports the quality of life and health outcomes of culturally and linguistically diverse populations across the lifespan. Carmen is passionate about translating research findings into evidence-based recommendations and communicating research findings and recommendations to diverse audiences.

Sam Harkus is a non-Indigenous audiologist and clinician-researcher living on Gadigal land. She has worked with Hearing Australia in clinical roles and as Aboriginal and Torres Strait Islander program lead and has also worked in research at the National Acoustic Laboratories. Since 2019, Sam has worked on a range of projects with a common theme of equitable access to ear health and hearing care for young Aboriginal and Torres Strait Islander children, focusing on Aboriginal leadership and co-design and impact on policy and practice. This includes the development of primary health ear check recommendations for Aboriginal and Torres Strait Islander children.

Vivienne Marnane is a project coordinator at the National Acoustic Laboratories. She previously worked as research speech pathologist in the Communication Sciences Department and was involved in multiple research projects investigating the efficacy of early intervention and amplification, and the factors that affect short- and long-term outcomes for children with hearing difficulties. She has experience working on studies with a wide range of methodologies including longitudinal studies, qualitative and quantitative work.

Tanika Ridgeway is a proud Worimi woman from Port Stephens, and graduate of the University of Newcastle's Yapug pathway program now on the path to becoming a doctor through the Joint Medical Program. While studying, Tanika is working as an Indigenous Research Assistant at the University of Newcastle on a range of research projects including research ethics, tobacco control, ear health and cancer screening. Her goal is to provide access to appropriate and culturally safe medical services with Indigenous communities and to be part of achieving parity between Indigenous Australians and non-Indigenous Australians in the field of health.

Jessica Bennett is a proud Gamilaroi woman from Northern NSW. Jessica is a neonatal registered nurse at John Hunter Children's Hospital, PhD student at the University of Newcastle and a proud mother of three. Jessica has 10 years of neonatal experience and is conducting research to improve culturally safe Aboriginal health in neonatal settings through her PhD, 'The uncharted journey of Aboriginal health in the neonatal setting'. Jessica strives for equity and community engagement, while working to improve the health and wellbeing outcomes of Aboriginal and Torres Strait Islander children and families.

Jodie Kell is a PhD candidate at the Sydney Conservatorium of Music. Her research focuses on the dynamics of gender in popular music. As part of her PhD, she collaborates with the members of the Ripple Effect Band, a First Nations all-women rock band from Maningrida in the Northern Territory. Jodie has performed with the band across Australia and her research aims to draw out the ways in which the band uses contemporary music practice to express cultural knowledge and negotiate agency as women. Jodie works as a Senior Research Officer in the Sydney Office of PARADISEC, the Pacific and Regional Archive for Digital Sources in Endangered Cultures.

Toni Manton is a proud Gampingal woman from the Worimi nation. She has extensive experience working in the Aboriginal health sector in the Hunter New England

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References

Australian Department of Health and Ageing, 2010. Indigenous ear health research to inform social marketing campaigns: Final report. Accessed on 2 February 2024 at: https://www.circaresearch.com.au/wp-content/uploads/Consultation-and-testing-underpin-success-of-Indigenous-ear-health-campaign.pdf.

Australian Institute of Health and Welfare, 2023. Ear and hearing health of Aboriginal and Torres Strait Islander people 2023. Catalogue number IHW 282. Australian Government. https://doi.org/10.25816/5cbx-0z80.

Bell, M.F., Lima, F., Lehmann, D., Glauert, R., Moore, H.C., Brennan-Jones, C.G., 2021. Children with secondary care episodes for otitis media have poor literacy and numeracy outcomes: a data linkage study. Int J Environ Res Public Health 18 (20), 10822. https://doi.org/10.3390/ijerph182010822.

Bessarab, D., Ng'Andu, B., 2010. Yarning about yarning as a legitimate method in Indigenous research. Int J Crit Indig Studies 3 (1), 37–50. https://doi.org/10.5204/ijcis.v3i1.57.

Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qual Res Psychol 3 (2), 77–101. https://doi.org/10.1191/1478088706qp063oa.

Braun, V., Clarke, V., 2019. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health 11 (4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806.

Burke, A.W., Welch, S., Power, T., Lucas, C., Moles, R.J., 2022. Clinical yarning with Aboriginal and/or Torres Strait Islander peoples—a systematic scoping review of its use and impacts. Systematic Rev 11 (1), 129. https://doi.org/10.1186/s13643-022-02008-0.

Campbell, L., Reath, J., Hu, W., Gunasekera, H., Askew, D., Watego, C., Kong, K., Walsh, R., Doyle, K., Leach, A., Tyson, C., Abbott, P., 2022. The socioemotional challenges and consequences for caregivers of Aboriginal and Torres Strait Islander children with otitis media: a qualitative study. Health Expect. https://doi.org/10.1111/hex.13476.

Chando, S., Young, C., Craig, J.C., Gunasekera, H., Tong, A., 2016. Parental views on otitis media: systematic review of qualitative studies. Eur J Pediatr 175 (10), 1295–1305. https://doi.org/10.1007/s00431-016-2779-6.

Delacy, J., Dune, T., Macdonald, J.J., 2020. The social determinants of otitis media in Aboriginal children in Australia: are we addressing the primary causes? A systematic content review. BMC Public Health 20 (1). https://doi.org/10.1186/s12889-020-08570-3.

DiGiacomo, M., Davidson, P.M., Abbott, P., Delaney, P., Dharmendra, T., McGrath, S.J., Delaney, J., Vincent, F., 2013a. Childhood disability in Aboriginal and Torres Strait Islander peoples: a literature review. Int J Equity Health 12 (1), 7. https://doi.org/10.1186/1475-9276-12-7.

DiGiacomo, M., Delaney, P., Abbott, P., Davidson, P.M., Delaney, J., Vincent, F., 2013b. 'Doing the hard yards': carer and provider focus group perspectives of accessing Aboriginal childhood disability services. BMC Health Serv Res 13 (1), 326, 326. https://doi.org/10.1186/1472-6963-13-326.

Epley, P., Summers, J.A., Turnbull, A., 2010. Characteristics and trends in family-centered conceptualizations. J Fam Soc Work 13 (3), 269–285. https://doi.org/10.1080/10522150903514017.

Harkus, S., Caso, K., Hall, S., Kung, C., Manton, T., Murthy, S., Olive, G., Rankmore, T., Roberts, N., Ward, M., Kong, K., 2021. 'Sometimes they're gammin, playing tricks, but sometimes it's ears.' The perspectives of urban parents and carers of young Aboriginal and Torres Strait Islander children on their journey to diagnosis of persistent ear health and hearing problems. Public Health Res Pract 31 (5). https://doi.org/10.17061/phrp3152129.

Harkus, S., Marnane, V., O'Keeffe, I., Kung, C., Ward, M., Orr, N., Skinner, J., Kong, K., Fonua, L., Kennedy, M., Belfrage, M., 2023.

Routine ear health and hearing checks for Aboriginal and Torres Strait Islander children aged under 6 years attending primary care: a national consensus statement. Med J Aust 219 (8), 386–392. https://doi.org/10.5694/mja2.52100.

Hearing Australia, 2017. Social research into hearing loss and amplification for Aboriginal and Torres Strait Islander children. Cultural and Indigenous Research Centre Australia.

Indigenous Allied Health Australia, 2019. Cultural Responsiveness in Action Framework - Indigenous Allied Health Australia, 3rd edition V8.

Jeffries-Stokes, C., Lehmann, D., Johnston, J., Mason, A., Evans, J., Elsbury, D., Wood, K., 2004. Aboriginal perspective on middle ear disease in the arid zone of Western Australia. J Paediatr Child Health 40, 258–264. https://doi.org/10.1111/j.1440-1754.2004.00360.x.

James, R., Machell, A., DeLacy, J., Stephens, J., 2025. Long-term outcomes of childhood otitis media and hearing loss: a systematic review. Speech Language Hearing 28 (1), 2420455. https://doi.org/10.1080/2050571X.2024.2420455.

Jones, C., Sharma, M., Harkus, S., McMahon, C., Taumoepeau, M., Demuth, K., Mattock, K., Rosas, L., Wing, R., Pawar, S., Hampshire, A., 2018. A program to respond to otitis media in remote Australian Aboriginal communities: a qualitative investigation of parent perspectives. BMC Pediatr 18 (1). https://doi.org/10.1186/s12887-018-1081-3.

Kennedy, M., Maddox, R., Booth, K., Maidment, S., Chamberlain, C., Bessarab, D., 2022. Decolonising qualitative research with respectful, reciprocal, and responsible research practice: a narrative review of the application of yarning method in qualitative Aboriginal and Torres Strait Islander health research. Int J Equity Health 21 (1), 134. https://doi.org/10.1186/s12939-022-01738-w.

Lau, G., Walker, R., Laird, P., Lewis, P., Kuthubutheen, J., Schultz, A., 2024. Identifying barriers and facilitators for the effective diagnosis and provision of primary health care for otitis media from the perspective of carers of Aboriginal children. J Paediatr Child Health 60, 505–510. https://doi.org/10.1111/jpc.16626.

Lewis, T., Hill, A.E., Bond, C., Nelson, A., 2017. Yarning. J Clin Pract Speech Lang Pathol, 19 (1).

Lin, I., Green, C., Bessarab, D., 2016. 'Yarn with me': applying clinical yarning to improve clinician–patient communication in Aboriginal health care. Aust J Prim Health 22 (5), 377. https://doi.org/10.1071/py16051.

Lowell, A., Budukulawuy, Gurlmangu, Maypllama, Nyomba, 1995. Communication and learning in an Aboriginal school: the influence of conductive hearing loss. Aust J Indig Educ (4), 1–7. https://doi.org/10.1017/S1326011100002039.

McCarthy, E., Guerin, S., 2022. Family-centred care in early intervention: a systematic review of the processes and outcomes of family-centred care and impacting factors. Child: Care Health Dev 48 (1), 1–32. https://doi.org/10.1111/CCH.12901.

McFarland, L., Dealtry, L., 2017. Hearing in the early childhood setting: children's perspectives. Aust J Early Childhood 42 (2), 105–113. https://doi.org/10.23965/ajec.42.2.13.

Johnson, J., 2024. Otitis Media: Parental perspectives and support needs. Capstones Scholarly Projects 138. Accessed on 12 January 2025 at: https://digscholarship.unco.edu/capstones/138.

Menzies School of Health Research. Otitis Media Guidelines for Aboriginal and Torres Strait Islander Children (version 1.1) [Mobile app]. Accessed on 2 February 2024 at: http://otitismediaguidelines.com.

Ng, Z.Y., 2022. Family-centred care in early intervention audiology and speech-language pathology services for culturally and linguistically diverse (CALD) families of children with hearing loss, in. Brisbane 1–234.

Priest, N., Thompson, L., Mackean, T., Baker, A., Waters, E., 2017. 'Yarning up with Koori kids' - hearing the voices of Australian urban Indigenous children about their health and well-being. Ethn Health 22 (6), 631–647. https://doi.org/10.1080/13557858.2016.1246418.

Russell, D., Luthra, M., Wright, J., Golby, M., Plastow, L., Marshall, M.N., 2003. A qualitative investigation of parents' concerns, experiences and expectations in managing otitis media in children: implications for general practitioners.

Prim Health Care Res Dev 4 (1), 85–93. doi:10.1191/1463423603pc135oa.

Shannon, G., Morgan, R., Zeinali, Z., Brady, L., Couto, M.T., Devakumar, D., Eder, B., Karadag, O., Mukherjee, M., Peres, M.F. T., Ryngelblum, M., Sabharwal, N., Schonfield, A., Silwane, P., Singh, D., Van Ryneveld, M., Vilakati, S., Watego, C., Whyle, E., Muraya, K., 2022. Intersectional insights into racism and health: not just a question of identity. Lancet 400 (10368), 2125–2136. https://doi.org/10.1016/S0140-6736(22)02304-2.

Sherwood, J., 2013. Colonisation – It's bad for your health: the context of Aboriginal health. Contemp Nurse 46 (1), 28–40. https://doi.org/10.5172/conu.2013.46.1.28.

Staley, B., Armstrong, E., Amery, R., Lowell, A., Wright, T., Jones, C., Taylor, L., Hodson, J., 2020. Speech language pathology in the Northern Territory: shifting the focus from clinicians to intercultural, interdisciplinary teamwork. J Clin Pract Speech Lang Pathol 34. https://doi.org/10.1080/22087168.2020.12370282.

Stephens, J.H., O'Keefe, M., Schembri, M., Baghurst, P.A., 2020. Parents need more support: a qualitative study of the experiences of Australian parents who are waiting for surgical intervention for their children with otitis media. J Patient Exp 7 (5), 717–725. https://doi.org/10.1177/2374373519883495.

Strobel, N.A., Chamberlain, C., Campbell, S.K., Shields, L., Bainbridge, R.G., Adams, C., Edmond, K.M., Marriott, R., McCalman, J., 2022. Family-centred interventions for Indigenous early childhood well-being by primary healthcare services. Cochrane Database Syst Rev 12 (12), Cd012463. https://doi.org/10.1002/14651858.CD012463.pub2.

Walsh, C., 2020. Falling on deaf ears? Listening to Indigenous voices regarding ear disease ('otitis media') and hearing loss (PhD thesis). Australian National University, Canberra, Australia.

Watego, C., Singh, D., Macoun, A., 2021. Partnership for justice in health: scoping paper on race, racism and the Australian health system. The Lowitja Institute, Melbourne.

Wilson, K., Wilks, J., 2013. Research with Indigenous children and young people in schools: ethical and methodological considerations. Glob Stud Child 3 (2), 142–152. https://doi.org/10.2304/gsch.2013.3.2.142.

World Health Organization, 2021. World report on hearing. World Health Organization, Geneva, Switzerland. Accessed on 2 February 2024 at: https://www.who.int/publications/i/item/9789240020481.