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ORIGINAL ARTICLE

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

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Aim: To identify the barriers and facilitators for timely detection and optimal management of otitis media (OM) in Aboriginal children in a primary care setting from the perspective of carers of Aboriginal children.

Methods: A qualitative, Aboriginal co-designed, participatory action research study with interviews and focus groups in a large town in the Kimberley, Western Australia. The Consolidated Framework for Implementation Research informed stakeholder group identification and interview framework development. Data underwent thematic analysis using NVivo software.

Results: Thirty-two carers of Aboriginal children participated. Key barriers identified for the detection of OM were limited information about OM provided to carers and carers feeling disempowered to express their concerns. Key facilitators identified were the provision of health information through health promotion and the use of culturally secure resources. Having a culturally secure clinical environment was identified as essential, with Aboriginal Health Workers playing a vital role in clinical care. No barriers to management of OM in primary care were reported. Facilitators included health care practitioners (HCPs) emphasising the importance of completing antibiotic course and the clinic providing necessary medications.

Conclusions: A culturally secure health promotion strategy with health promotion teams, campaigns and resources is needed to increase community awareness of OM signs and symptoms and facilitate appropriate health seeking. It is essential that the local Aboriginal community co-lead and co-develop these initiatives to ensure the unique wisdom and knowledge of Aboriginal people are captured. HCPs and the clinic effectively facilitate management of OM by providing medications and emphasising completion of antibiotics.

Key words: Australian Aboriginal and Torres Strait Islander peoples; child; otitis media; primary health care; qualitative research.

What is already known on this topic

1 Despite significant public health measures to reduce otitis media (OM), First Nations children in Australia have amongst the highest rates of OM and associated hearing loss in the world. Childhood hearing loss has life-long consequences.
2 Long-term health trajectories can be improved if OM is detected in a timely way and be managed effectively in primary care.
3 Detection and management of health conditions is hindered by complex cultural and socio-economic factors that interlink with health system factors.

What this paper adds

1 The lack of effective culturally and locally relevant health promotion regarding OM is the biggest barrier to carers of Aboriginal children in seeking appropriate health care.
2 Carers prioritised empowerment with knowledge and resources through culturally secure health promotion.
3 There is a need to implement co-designed culturally secure health promotion with resources to increase community awareness about OM.

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First Nations children in Australia have amongst the highest rates of otitis media (OM) in the world.[1] OM is the most common cause of hearing loss in children,[2] leading to speech and language delay, learning impairment and psycho-social difficulties, all of which hinder education outcomes.[3] The World Health Organisation classifies the rates of chronic suppurative OM in Australian First Nations children as a 'massive health problem' requiring 'urgent attention'.[4]

The proportion of First Nations children in Australia experiencing OM is disproportionately high, with up to 91% of children under 3 years of age being affected.[5] Despite public health measures to address OM,[4,5] First Nations children in Australia are 2.9 times more likely than their non-First Nation peers to have OM or hearing impairment,[6] and experience OM at an earlier age, higher frequency, and with greater severity.[7]

OM is a common reason for children presenting to primary health care.[6] In the Kimberley, a remote region in the northern part of Western Australia (WA), visiting ear, nose and throat (ENT) specialists and challenges of coordinating ear health screening services, accentuate the central role of existing primary care services for First Nations children with OM. In Australia, First Nations consists of Aboriginal and Torres Strait Islander people. However, in some regions, such as the Kimberley, the preferred term by local communities is Aboriginal, hence this is the term we will use in this manuscript when referring to the Kimberley population. Local Aboriginal community members raised the need to improve their children's ear health after witnessing the positive outcomes of a similar study that explored the barriers and facilitators pertaining to chronic wet cough.[8]

Long-term health and social trajectories can potentially be improved if OM in children can be detected in a timely way and be managed effectively in primary care.[3,9,10] However, for First Nations children in Australia, detection and management of health conditions are hindered by complex cultural and socio-economic factors that interlink with health system factors.[8] Such factors can be considered within a conceptual framework to study health service delivery such as the Consolidated Framework for Implementation Research.[11] This study represents the first stage of an implementation science study aimed at improving the ear health of Australian First Nations children by exploring the perspectives of carers on the barriers and facilitators to the timely detection and optimal management of OM in a primary care setting.

Methods

Qualitative research study using semi-structured interviews and focus groups with local parents and carers (hereafter termed carers) of Aboriginal children, co-designed with Aboriginal people and utilised a combined Aboriginal Participatory Action Research and Implementation Science approach (PAR/IS).[12] Local Aboriginal community members contributed to conceptualisation of the research, development of the semi-structured interview guide and participated in conducting interviews, data analysis and reporting. The Aboriginal Health Council of WA, in addition to regional and local Aboriginal Medical Services, provided consultation throughout the study design. Ethical approval was granted by Western Australian Aboriginal Health Ethics Committee (HREC 774) and Child and Adolescent Child Health Service Ethics Committee (RGS 4136).

The study was conducted in a large town in the Kimberley region, in northern WA, which serves as the regional medical hub. This town has a population of 15 000, where Aboriginal people comprise 28% of the population[13] and has one Aboriginal Community Controlled Health Service (hereafter 'clinic'). Interviews were conducted at an Aboriginal family playgroup or within a non-medical community setting.

Individual interviews and focus group discussions were conducted between 10 June 2021 and 30 July 2021.

Any carers of Aboriginal children living in the study town were eligible participants. Qualitative data were analysed by following a reflexive thematic analysis process. Further details on methodology, including sample size, interview guide and development, data collection and data analysis, are detailed in the supplement.

Results

Forty-one people were approached by interviewers and nine people declined to participate. All participants that declined were presumed carers that were approached outside the clinic and either indicated lack of time or did not provide a reason.

Thirty-two carers were interviewed. Participant demographics are included in the Table S2. Two focus groups (11 and 10 participants respectively) were conducted. One carer participated in both a focus group and an individual interview.

Findings

The key barriers and facilitators were organised into themes: (i) knowledge, (ii) beliefs and attitudes, (iii) perceived skills of clinicians and (iv) clinic processes and environment. The thematic map illustrating the classification of themes, subthemes, and codes is shown in Figure 1.

Barriers to timely detection and optimal management of OM

Knowledge

Health literacy. All carers interviewed, excluding those that were also HCPs, reported that they had never received information about ear health before and were unaware of ear health resources:

> I didn't know that pulling on ears was a sign. If I knew, I would have picked it up sooner. (C18).

Ear health literacy of carers varied. Most carers were aware that ear health was important, but they were unaware of the signs of OM, or the implications of untreated OM. Some carers reported knowledge of ear infections from lived experiences.

*OM symptom awareness*Carers reported a sense of normalisation of OM symptoms due to its high community prevalence:

> I have two little ones … they have runny ears sometimes. My sister-in-law has a child with runny ears, it's part of our population really. (C14).

Carers described situations where if a child appeared not to be listening, it was frequently attributed to the child misbehaving, rather than possible hearing impairment:

> Think it's the child's behaviour or it's someone else's' problem. They just say, 'That kid got no ears' and 'They're the naughty kids.' (C8).

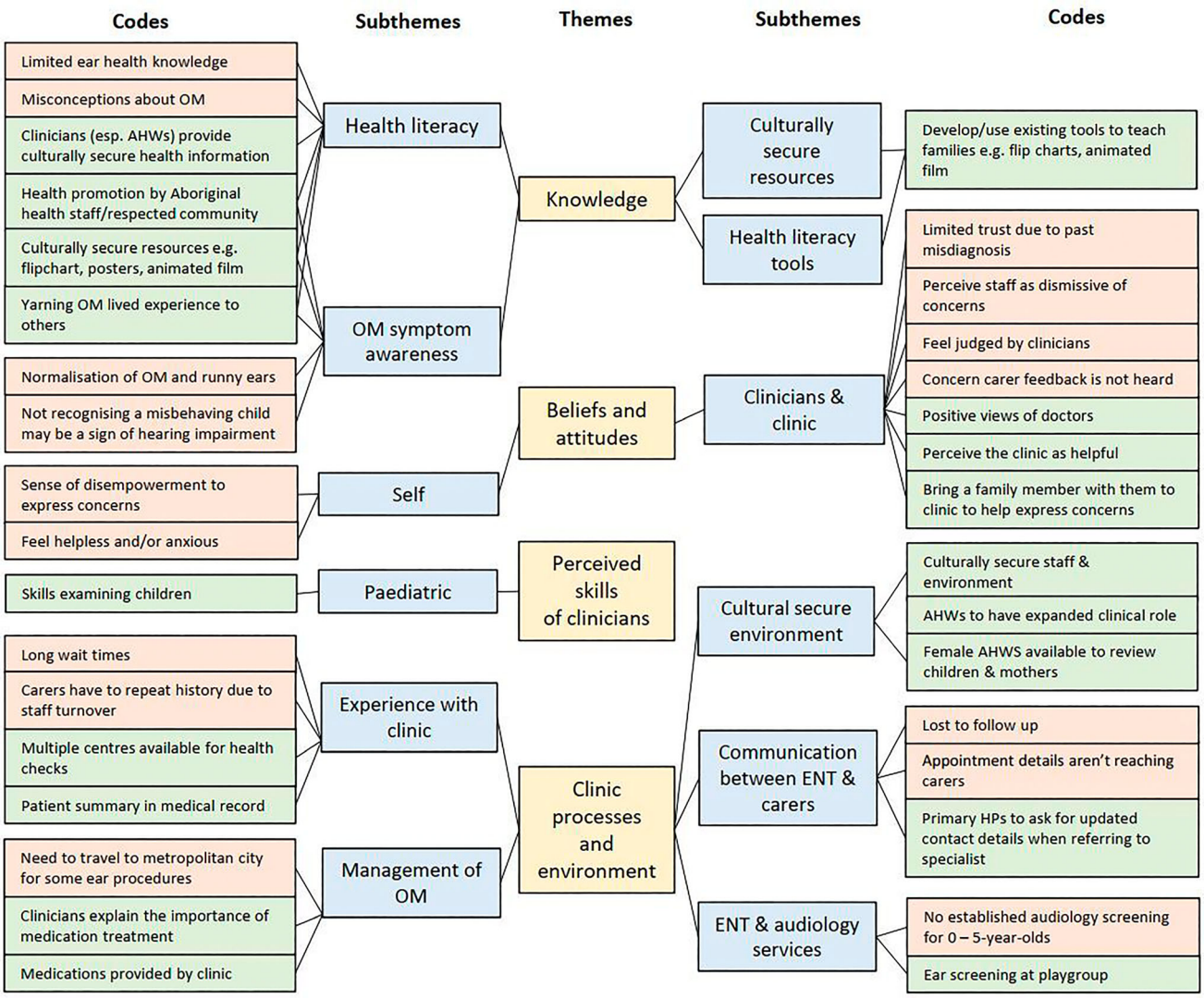

Fig. 1 Thematic map of themes, subthemes and codes. Red = barriers; Green = facilitators. AHWs, Aboriginal Health Workers; ENT, ear, nose and throat; OM, otitis media.

Beliefs and attitudes

About self, HCPs and clinic. Carers reported experiencing anxiety when bringing their children into clinic and feeling a sense of disempowerment to express concerns about their child, as they perceived that their concerns get dismissed:

> I get choked up (when I bring child to clinic). (C6).

> We just get told it's teething. (C8).

Additionally, some carers also reported having limited trust due to past misdiagnoses and feeling judged by doctors:

> Often feel that the professionals are looking down on you. (C5).

Experience with clinic. Carers reported long waiting times due to high demands on the clinic. Carers also described that the clinic experienced high staff turnover which caused carers to have to retell their child's history, causing them to relive the trauma of bad experiences:

> We don't feel welcome at clinic. There is overturn of staff … We have to relive the grief each time. Telling them the same story. (C3).

Clinic processes and environment

Management of OM. Multiple carers expressed that the travel required to the closest city for operations for children with recurrent OM was a barrier to optimal care as only one parent was financially subsidised to attend with the child:

> … What about my other kids? Who is going to look after them? (C19).

Communication between ENT and carers. Carers reported experiencing difficulties with receiving communication from specialists regarding appointments due to outdated contact details, resulting in missed appointments.

ENT and audiology services. Carers reported that there were no screening services for pre-school children, highlighting a gap in services in the age-group most vulnerable to OM.[14]

Facilitators to timely detection and optimal management of OM

Knowledge

Health literacy. The overarching facilitator identified was to empower families with culturally secure health information through health promotion teams, campaigns, and resources.

> Use health promotion! (C29).

Carers expressed that if they were equipped with appropriate knowledge, then they would be empowered to seek help. Various methods for health promotion were suggested e.g., community groups, placing information resources (e.g., posters) in strategic locations around the community, and social media.

Culturally secure resources. Carers emphasised the importance of ensuring that health promotion and resources were culturally secure and relatable to families:

> It's about the story… If you don't relate, then it's lost its meaning… Have a template of facts then each local mob be involved to make it [the resource] their own. (C13).

Carers wanted to hear the lived experiences of families, and suggested use of images that families could relate to serve as an analogy for explaining OM:

> Trochus shells is really good. People relate to them. (C28).

Health literacy tools. Carers identified that having a visual flipchart would facilitate HCPs explaining ear health:

> Flipchart with clear pictures like this one [Chronic Lung Sickness Flipchart][15] is a good idea. (C15).

Belief and attitudes

About clinicians and clinic. Carers perceived the clinic to be helpful and capable:

> They [HCPs] can do a lot, check kids' ears to see if there's an infection. (C23).

To help carers express their concerns, carers bring a family member with them to clinic:

> I need to bring my mum with me to talk. (C6).

Perceived skills of clinicians

Paediatric. Carers identified that clinicians with paediatric skills facilitated examining children's ears:

> They've never let anyone look in their ears before without kicking and screaming. (C7 while observing her child being examined by a paediatric doctor).

Clinic processes and environment

Culturally secure environment. Carers emphasised that provision of culturally secure care was an essential factor in their decision to attend clinic:

> People want to come to [clinic] because it's more culturally appropriate. (C12).

Carers also expressed their desire for AHWs to play a more significant role in children's assessments, such as examining ears.

Experience with clinic. Carers suggested having a summary for each child in their medical record to reduce carers repeating the child's history.

Management of OM. Carers identified their management of their child's OM was improved if HCPs explained that the importance to finishing the antibiotic course and the clinic provided the medications.

Communication between ENT and carers. Carers suggested that primary HCPs check contact details at appointments to facilitate specialist appointment letters reaching carers.

ENT & audiology services. To facilitate screening of pre-school aged children, carers suggested that audiology services could attend playgroup:

> It's good here at the playgroup. They can also see other kids do it [have their ears checked]. (C7).

Discussion

Carers recognised that a lack of health promotion and education about OM in children and difficulties in effectively expressing their concerns to HCPs, were the key barriers to timely detection of OM. Carers identified provision of ear health information in a culturally secure way, with health promotion resources, as the key facilitators to timely detection. No barriers to the OM management in primary care were identified, however, carers reported difficulties in accessing ENT specialist care due to limited services in their town, compounded by difficulties with receiving communication from ENT regarding appointments. Carers recognised that OM

management is improved due to improved adherence to treatments if HCPs emphasised the importance of finishing the antibiotic course and the clinic provided the medications.

The largest barrier to timely health seeking identified by carers was the lack of health promotion and education regarding OM. None of the carers (except those that were also HCPs) reported that they had received education on ear health. Limited health literacy is consistent with the known literature, the latest we could identify was a 2004 study exploring Aboriginal family perspectives on OM in another region of WA.[16] The findings also support studies that explored Aboriginal people's perspectives on other common health conditions[17,18] as well as utilisation of health services.[19] Normalisation of OM symptoms was common, with carers expressing this was due to high OM prevalence in the community and confirms findings from previous studies that high prevalence of a symptom may lead to normalisation.[17]

Carers expressed their struggle to effectively communicate their child's concerns to HCPs due to their own anxiety, which was further amplified by perception of doctors being dismissive of their worries regarding their child's ear symptoms. Communication gaps and clinicians dismissing concerns may be a pervasive issue across health for Aboriginal families, with similar reports discussed in other studies.[17,20] This highlights the importance of HCPs effectively communicating and ensuring families feel safe and concerns heard. Indeed, one study demonstrated that health seeking, medical management and health outcomes improved when communication, amongst other factors, were addressed.[8]

The overarching facilitator identified was to empower families with OM-specific health information. Carers wanted health promotion at community groups (e.g., playgroups), with community members sharing their lived experiences. The importance of narratives and storytelling is a well-recognised method to improve translation of Australian First Nations research into practice, but has been adversely impacted by colonisation and breakdown in family structure.[21] Carers also wanted visual resources (e.g., posters) and suggested using a culturally relevant analogy to help explain ear health. It was important that the carers could relate to the story behind the resources which highlights the importance of co-creation.[22] The significance of a community-based approach to health promotion is consistent with studies on the facilitators for individuals to seek help for their health.[16,17]

Carers attached importance to the clinic's ability to offer culturally secure care as a factor facilitating timely health-seeking. They recognised the critical role AHWs play in clinic and expressed desire to see an increase in AHW involvement, such as conducting ear examinations. This emphasis on culturally secure care and the vital role of AHWs to facilitate health care utilisation is consistent with findings from other studies.[17,23] Carers suggested that the primary HCPs could play a pivotal role as intermediaries between specialists and families. Their role could involve guiding families through the complexities of the health system and ensuring seamless communication of specialist appointments and relevant information. This suggestion aligns with a study conducted in New South Wales, which identified the importance of providing culturally safe navigation support for families.[20]

Limitations of our study include being a single site and potentially limiting generalisability to other locations. However, participants discussed their experiences in the wider region. The recruitment strategy may have over-represented families who engage with community and health services, potentially excluding those reticent to engage with services or who are limited by remoteness. Additionally, there is a possibility that carers may have experienced reluctance in discussing certain barriers such as socio-cultural influences on the detection and management of OM. Nonetheless, those participants who were engaged with health services expressed significant concerns, highlighting the need to improve ear health of Australian First Nations children.

Conclusion

Given the high rates of OM and the significant burden of ear disease in First Nations children,[1,4] urgent action is required to develop (using existing resources, where possible) and implement the community-identified strategies to empower families and facilitate timely detection and management by HCPs. To our knowledge, this is the first use of a combined PAR/IS approach to investigate such barriers in the Kimberley region. The local First Nations community must co-lead and co-develop these strategies to ensure they are well-informed by stakeholder findings.[24] Collaboration between researchers and the local First Nations community will ensure that latter's perspectives are incorporated into future health strategies, increasing the likelihood of successful knowledge translation.[24]

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

Data S1: Supporting Information.
Figure S1: Thematic analysis process.
Table S1: Interview template to document information pertaining to reporting qualitative research.
Table S2: Individual interviewee characteristics.