

Faculty of Health Sciences

Kadadjiny Dwank

(listening, thinking and learning with your ears):

Otitis Media from an Urban Aboriginal perspective

Rosemary Walley

Student number: 09189953

This thesis is presented for the Degree of

Master of Health Science

of

Curtin University

December 2020

DECLARATION

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Human Ethics

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC0022), and from the WAAHEC, Approval Number # 737.

Signature 

Date ...15/07/2021.....

ABSTRACT

Otitis Media (OM), or middle ear disease, is a preventable infection which can have harmful lifelong effects. Aboriginal and Torres Strait Islander children suffer with OM, and in particular its more serious form chronic suppurative otitis media (CSOM), to a far greater extent than do their non-Indigenous peers. Although there has been considerable research undertaken on OM in Aboriginal communities, the majority of this has been quantitative, and of that research almost none has focused on urban areas despite the fact that most Australian Aboriginal people live in urban settings. As best could be ascertained, the current project is the first to be both qualitative and urban-focused.

The Kadadjiny Dwank (listening, thinking and learning with your ears) project therefore aimed to contribute to addressing this evidence gap. Qualitative information was sought which would both inform the establishment of culturally appropriate services for Aboriginal people in urban areas, and add benefit by providing the community with information about ear health.

To do this, it was essential that the research be conducted in partnership with local Aboriginal health organisations in two areas in Perth with large Aboriginal communities. The lead researcher, who is from the communities involved in the study, worked closely with key stakeholders in Kwinana/Rockingham and in Armadale, in Perth, Western Australia.

Community forums and focus groups were open to all interested Aboriginal community members from these areas. Participants shared their knowledge around what people know and do about ear infections, what they see as barriers to accessing care, and how OM impacts on the child and family. The research team adhered to a participatory action research (PAR) and an Indigenous research decolonising approach to encourage self-determination and shared ownership and power between team and community. Consultations followed Aboriginal ways of communicating, with all consultations with community members proceeding through ‘yarning’, which allowed participants to be comfortable with and involved in the process.

Transcripts of the consultations were coded, and key themes identified and analysed to accurately reflect the knowledge shared by participants.

Results from this project clearly showed that, in these Aboriginal communities, knowledge of OM and its effects were largely confined to those families who had a child diagnosed, or whose OM had progressed to the point of causing communication issues, behavioural problems, or difficulties at school. Much of the knowledge there had been gathered through family advice or support. The various stressors on families and on the child living with OM were canvassed by many participants. Participants identified a number of barriers to obtaining help through health services, ranging from fears of child removal due to past practices, institutional and personal racism, communication issues and misdiagnosis, to practical problems such as transport, lack of funds, and competing responsibilities. Community members proposed a range of solutions for the many issues raised in the consultations, foremost among them simply the provision of more and more useful information around ear disease.

In sum, the findings from this research project represent the voices of participants and, while limited to two locations in Perth, WA, its findings are broadly consistent with other research around OM in Aboriginal communities. It adds to the current literature highlighting the continuing destructive effects of colonisation and the social determinants of health on contemporary Aboriginal communities. In response to the needs expressed by consultation participants, it provides a number of recommendations for policy and practice in caring for Aboriginal children suffering with ear disease, supporting and educating families, and ensuring health services are responsive to the needs of the Aboriginal families in their care.

TABLE OF CONTENTS

DECLARATION	II
ABSTRACT	III
TABLE OF CONTENTS	V
ACKNOWLEDGEMENTS	VIII
GLOSSARY OF ABORIGINAL WORDS AND TERMS	IX
ACRONYMS	X
LIST OF APPENDICES	XI
CHAPTER ONE – INTRODUCTION	1
PROJECT OBJECTIVES.....	2
SIGNIFICANCE OF THIS STUDY	3
RESEARCHER STANDPOINT: PERSONAL JOURNEY.....	4
CHAPTER TWO – LITERATURE REVIEW	10
INTRODUCTION	10
EAR STRUCTURE AND FUNCTION	11
OTITIS MEDIA (OM).....	12
<i>What is it?</i>	12
<i>How do we get it?</i>	13
WHAT DOES THE RESEARCH SAY?.....	14
<i>Prevalence and burden of the disease</i>	14
<i>Qualitative research around OM</i>	20
<i>Risk Factors</i>	23
<i>Social determinants</i>	24
INDIGENOUS PERSPECTIVE/DECOLONISING RESEARCH METHODOLOGIES	33
CONCLUSION	36
CHAPTER THREE – METHODS	39
INTRODUCTION	39
METHODOLOGY	41
<i>Participatory Action Research</i>	41
<i>Indigenous Research Methods</i>	43
<i>Yarning</i>	45
<i>Ethics</i>	46

<i>Cultural Governance</i>	47
<i>Data Management</i>	47
PLANNING THE STUDY	47
SELECTING THE STUDY AREAS: WHY KWINANA/ROCKINGHAM AND ARMADALE?	49
INSIDER/OUTSIDER ISSUES	51
NYOONGAR COMMUNITY RESEARCH TEAM	52
INFORMING THE COMMUNITY	53
DATA COLLECTION	53
<i>Community Forums</i>	53
<i>Focus groups</i>	57
<i>First Time Mums</i>	59
<i>Elders</i>	61
DATA ANALYSIS	61
CONCLUSION	62
CHAPTER FOUR – RESULTS/FINDINGS	64
STUDY PARTICIPANTS	64
WHAT WE LEARNED	65
<i>What do families know about OM?</i>	65
<i>Barriers</i>	66
<i>Impacts of living with a child with OM</i>	79
<i>Additional stressors</i>	83
COMMUNITY SOLUTIONS	85
CONCLUSION	87
CHAPTER FIVE – DISCUSSION AND CONCLUSION	88
WHAT THE LITERATURE TOLD US	92
THE APPROACH USED IN THIS RESEARCH	94
WHAT WE FOUND	96
<i>issues with health services</i>	97
<i>issues with communication</i>	99
<i>Racism</i>	100
<i>Stress</i>	101
<i>Shame</i>	102
<i>Lack of awareness of OM</i>	103
COMMUNITY SOLUTIONS	104
STRENGTHS	105

LIMITATIONS	106
KEY MESSAGES.....	107
RECOMMENDATIONS	108
CONCLUSION	109
BIBLIOGRAPHY	111
APPENDICES	124
APPENDIX A – WAAHEC APPROVAL	124
APPENDIX B – CURTIN UNIVERSITY HREC APPROVAL.....	125
APPENDIX C – INFORMATION SHEET	127
APPENDIX D – KADADJINY DWANK CONSENT FORMS	129
APPENDIX E – COMMUNITY FLYER.....	131
APPENDIX F – COMMUNITY FOCUS GROUP QUESTIONS.....	132
APPENDIX G – LETTER OF SUPPORT	136

ACKNOWLEDGEMENTS

I acknowledge my mother Mrs Theresa Walley a Whadjuk Elder, my husband Danny Ford, my two sons Daniel and Jonathan, my beautiful grandchildren, my sisters Charmaine, Cheryl and Doreen, and my good friend Antonia Hendrick. They have all been my inspiration throughout this journey and gave me the strength to believe in myself, to stay true and to not give up.

Without the Armadale, Kwinana and Rockingham Aboriginal Community Elders, Families, *Moorditj Koort and Boojari Yorgas* this research would not have happened. I was fortunate to be guided and supported by a team of advisors who have helped shape the project to be what it is. My supervisors come with extensive expertise in OM, academic research methods (both qualitative and quantitative), and also research in an Aboriginal context. The expertise among my supervisors is diverse and extensive, both in content and in Indigenous research methodology.

I thank my supervisors Professor Steve Allsop, A/Professor Deborah Lehmann, A/Professor Michael Wright, and A/Professor Peter Richmond, who have given me guidance and support in making effective decisions on the methods and methodologies for the *Kadadjiny Dwank* research project. I also have had support from my husband Mr Danny Ford who has provided cultural guidance and advice throughout the life of the project. Researcher/Speech Pathologist Victoria Stroud provided academic guidance and support throughout the project and has assisted in the writing of this thesis. Dr Lynn Roarty provided academic and editorial support in the final 18 months of completing the thesis. I acknowledge Curtin University for providing scholarship support for me to undertake this thesis and Telethon Kids Institute for providing me with accommodation and financial support. I also acknowledge Dr Lea-Ann Kirkham and Wesfarmers Centre of Vaccines who provided resources and support to enable me to complete this thesis, and the Looking Forward Team at Curtin University.

GLOSSARY OF ABORIGINAL WORDS AND TERMS

<i>Babbingur Mia</i>	<i>Friendship, home</i>
<i>Bibbulung Gnarneep</i>	<i>Solid Kid</i>
<i>Blackfella</i>	<i>Aboriginal</i>
<i>Boojari Yorgas</i>	<i>Pregnant Women</i>
<i>Djaalinj Waakinj</i>	<i>Listening and Learning</i>
<i>Elders</i>	<i>Aboriginal Elderly or Seniors</i>
<i>Kadadjiny Dwank</i>	<i>Listening, thinking and learning with your ears</i>
<i>Minditj Kaart-Moorditj Kaart</i>	<i>Sick head, Strong head</i>
<i>Moorditj Koort</i>	<i>Good/Strong Heart</i>
<i>Nyoongar</i>	<i>Aboriginal person from the south west of WA</i>
<i>Yorga</i>	<i>Woman</i>
<i>Wajella</i>	<i>Non-Aboriginal people</i>
<i>Whadjuk</i>	<i>Aboriginal people whose country is Perth, WA</i>

ACRONYMS

ACAG	Aboriginal Community Advisory Group
ACCHO	Aboriginal Community Controlled Health Organisations
AMS	Aboriginal Medical Service
ADHD	Attention-deficit/hyperactivity disorder
AMA	Australian Medical Association
AIHW	Australian Institute of Health and Welfare
ANIFS	Australian National Infant Feeding Survey
CRE_ICHEAR	Centre of Research Excellence for Indigenous Children's Healthy Ears
HREC	Curtin University Human Research Ethics Committee
DCP	Department of Child Protection
PMC	Department of the Prime Minister & Cabinet
ENT	Ear Nose and Throat
NHMRC	National Health and Medical Research Council
NCAHS	North Coast Area Health Service
OM	Otitis Media
PAR	Participatory Action Research
PHC	Primary Health Care
STI	Sexually Transmitted Infection
TKI	Telethon Kids Institute
UAEH	Urban Aboriginal Ear Health
WAAHEC	Western Australian Aboriginal Health Ethics Committee
WHO	World Health Organization

LIST OF APPENDICES

Appendix A – Western Australian Aboriginal Health Ethics Committee (WAAHEC)
approval

Appendix B – Curtin University Human Research Ethics Committee (HREC)
approval

Appendix C – Kadadjiny Dwank Information Sheet

Appendix D – Kadadjiny Consent Forms

Appendix E – Community Flyer

Appendix F – Focus Group Questions

Appendix G – Letter of Support

CHAPTER ONE – INTRODUCTION

Poor ear health is a major issue for Aboriginal and Torres Strait Islander children. Otitis Media or middle ear disease affects 80% of Australian children before the age of four years (Kong & Coates, 2009; Williams & Jacobs, 2009). Among Aboriginal and Torres Strait Islander children, however, the data show that 73% are affected before they are one-year-old (Kong & Coates, 2009). It sometimes begins within weeks of birth and can persist into adolescence and adulthood (Closing the Gap Clearinghouse, 2014).

Otitis media can be asymptomatic until ear discharge is visible, which can contribute to late detection and result in long-term complications (Burns & Thomson 2013; Lehmann et al, 2008). This can have profound implications for a child's learning potential, which can lead to social and learning difficulties as well as behavioural problems at home and later at school. This in turn will impact on life as an adult in terms of having and maintaining relationships, connection to culture, and employment prospects. The persistence of the disease and its long-term effects appear to be due partly to a lack of awareness of the disease among parents, teachers and health workers, and partly to the lack of agreement about who is responsible for treating the disease and its effects (Chando et al 2016). Low socioeconomic status with limited access to health care may also be a factor affecting the association of adverse outcomes with otitis media.

A great deal of research has been undertaken regarding OM, however, most of the research relating to OM in Aboriginal people has focused on remote communities (see, for example, Edwards & Moffatt, 2014; Gibney et al, 2003; Kenyon, 2017), despite the fact that most Aboriginal Australians now live in urban settings, and this has been the case for many years. Data from the most recent Census of Population and Housing at time of writing show that, Australia-wide, in 2016 the majority (79%) of Aboriginal and Torres Strait Islander peoples lived in urban areas, and in

Western Australia almost three-quarters (72.6%) of the state's Aboriginal population did so.¹

With regard to Aboriginal and Torres Strait Islander children living in urban areas, very little work has been done on OM related issues. Williams and colleagues conducted an analysis of hearing screening data for middle ear disease in Aboriginal children in Perth from 1998-2004 (Williams et al. 2009). Some more recent research exists addressing issues around ear health and developmental risk in urban areas (Chando et al, 2020), however, this is not specifically focused on OM, and other researchers have noted that data "on the burden of OM in Aboriginal and Torres Strait Islander children living in urban areas are sparse" (Abbott et al, 2016, p. 2 of 10).²

In light of this, the *Kadadjiny Dwank* (*listening, thinking and learning with your ears*) project I report on in this thesis was conducted in partnership with local Aboriginal Health organisations in the Perth metropolitan areas of Kwinana/Rockingham and Armadale. The research explored community questions around what people know and do about ear infections, the barriers to accessing care, and how OM and hearing loss impact on a child and their family.

PROJECT OBJECTIVES

The overall objective of the *Kadadjiny Dwank* project was to collect the information needed to enhance awareness about otitis media and its consequences within urban Aboriginal communities, and to assist in establishing optimal culturally appropriate ear health services for Aboriginal people living in urban areas. The project's aim was to help maintain the delicate function of the middle ear that enables a child to hear the sounds of his/her mother and carers, of the surrounding environment, and to hear about and participate in culture. The project had addressed three broad questions:

¹ See

<https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Aboriginal%20and%20Torres%20Strait%20islander%20Population%20Article~12>. Accessed on 17 July 2020.

² Available at: <https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-016-1247-y>

- What do people know and do about ear infections?
- What are the barriers to accessing care?
- How does OM impact on the child and family?

Capacity building occurred concurrently with this project by supporting a birth cohort study that was established in the metropolitan area to monitor ear health in young children. Information gathered within this project will assist in preventing middle ear infections and ensuring optimal treatment for young children.

SIGNIFICANCE OF THIS STUDY

A recent systematic review (Chando et al, 2016) identified only one qualitative study on OM undertaken among Indigenous populations worldwide, namely the above-mentioned study conducted in the WA Goldfields (Lehmann et al, 2008). In their submission to the public hearing in reference to the Inquiry into the Hearing Health and Wellbeing of Australia in June 2017, Leach & Morris recognised the present study as one of a handful of "important and ground breaking" small studies around hearing health literacy among Aboriginal families (Leach & Morris, 2017, p. 13), and is the first qualitative study of OM to be undertaken in an urban Aboriginal community (see also Morris & Leach, 2009).

Information gathered around knowledge, individual and family practices, barriers, and the impacts of OM on the Aboriginal community will inform policy, support service providers, build the capacity of Aboriginal health professionals and researchers, and empower communities to better prevent and manage ear health in their children and in community. Findings will inform policy across Western Australia and more widely across Australia by feeding into the WA Child Ear Health Strategy, and through the Centre of Research Excellence for Indigenous Children's Healthy Ears (CRE_ICHEAR).

RESEARCHER STANDPOINT: PERSONAL JOURNEY

The primary aim of this qualitative research study was to provide an Aboriginal, and more specifically a Nyoongar³ perspective to better understand the impact of OM on the lives of Aboriginal children and families in the Perth Metropolitan area. The research was conducted on Nyoongar country, which consists of 14 clan groups in the South West region of Western Australia, with mostly Nyoongar participants, and with myself as lead researcher being Nyoongar. This being so, it was considered important to provide here some personal background to my motivations for undertaking this personal journey.

My name is Rosemary Walley. I am a *Whadjuk Yorga* (woman) from Perth, Western Australia. I was born in a town called Pinjarra, 86 kilometres south-east of Perth, and grew up in the Kwinana and Rockingham areas, just to the south of Perth. I spent most of my early childhood raised in bush camps along the Serpentine and Murray Rivers with my parents, three sisters and three brothers. When I was about four years old, my parents had a camp on the outskirts of Kwinana, later moving into a house in Medina. To me it was just a house; our real home was the bush amongst the plants, animals and living along the river catching fish and turtles. It wasn't until the late 1960's, after we moved into the house in Medina, that my parents slowly started to trust wajella's (non-Aboriginal people). We were the first Aboriginal family to live in Kwinana.

My mother is a member of the Stolen Generation, taken from her parents when she was six years old and placed in the New Norcia Mission run by the Benedictines. She was released from the mission when she was 16. Because of my mother's bad experiences in the mission, both she and my dad would hide us from white people in bushes or under the bed in a tin shack so the Native Welfare couldn't take us. The dogs would growl when they came close to the bed. My mother was very afraid that we would also be stolen from her just like she was from her mother.

³ I acknowledge there are many ways to spell Nyoongar; for the purposes of consistency, this spelling will be used throughout this thesis.

My father was born in the Moore River Native Settlement but he and my nan returned to family in Pinjarra when he was still a baby. My other family members weren't so fortunate: they were all taken away to the New Norcia Mission and came back with broken spirits. My parents and other family members' experiences have left me with a strong understanding of the impact of past government policies on my family and community, the disconnection from culture, family, land, language, lore and spiritual beliefs. This legacy is still there today of pain, suffering and distrust of the system and of white people. My parents' courage and resilience to keep us safe has given me a strong cultural and spiritual connection to land, family and community. This has given me the cultural guidance and direction to ensure the *Kadadjiny Dwank* Research Project method and methodologies are culturally safe and appropriate during the life of the study.

In 2013, I completed a Bachelor of Applied Science (Indigenous Community Management) at Curtin University. This course introduced me to academic research methods and gave me the basic tools and confidence to pursue research – and particularly research from an Aboriginal perspective. Planning and preparation for research in an Aboriginal community context needs to be robust and rigorous and it also needs to be culturally safe and appropriate. The following year, I was given an opportunity to work at the Telethon Kids Institute as a research assistant working on a mental health project led by a Nyoongar man. This further improved my knowledge and experience in research, and further emphasised for me the importance of doing research 'blackfella way', the right way for our mob.

When I was first approached in 2016 to do a Masters on the topic of otitis media, my first reaction was "Otitis what"? I had no idea what that was. The first thing I did was to google OM to gain some understanding and knowledge about the disease. The more I researched OM, the more I learned about how it affects Aboriginal children, and how they are disproportionately affected by it.

I learned that there is limited data published on the risk factors for OM in urban Aboriginal communities in Western Australia. Nor was there much information

about the disease from the perspective of an urban Aboriginal person. The vast majority of research on OM has been carried out in remote areas of Australia. Differences in access to health services, language groups and environment mean one cannot extrapolate findings from rural to urban settings. So, in 2016, I enrolled in the Masters of Philosophy course at Curtin University.

I have been assisted by the advice given by my family. I have three sisters, each of whom have different life experiences, and all three have shared their experiences with OM so that I could learn more about the disease and its impact on Aboriginal families both in urban and in regional and remote environments.

One of my sisters is a grandmother who has shared with me her observations and interactions with children in community with OM, and the effects she understands the disease to have had on the children themselves, their mothers and wider family and community members. I had the opportunity to sit and listen to one young mother from this community, who is the mother of a two-year-old boy diagnosed with 'glue ear'. She was stressed, exhausted and needed lots of support and help from both family and community to manage her son. She told me:

Aunty, I can't even do my shopping or go to the park and get anyone to babysit him... He would run everywhere and wouldn't stop and I thought he was just being a naughty boy but later I realised he couldn't hear my voice.

She told me she recalls giving him smacks because of this and now she feels bad about it. Her biggest fear was that he wouldn't be able to start school in time because of the ongoing effects of OM for his health, learning ability and social behaviour.

My other two sisters have been employed as Aboriginal Health Workers for many years and have experience with OM through their work. One sister has lived in Kalgoorlie for over 20 years and has worked for more than seven years as an Aboriginal Health Worker in a remote area. Working as part of an outreach team checking infants and kids' ears for middle ear disease or OM on a regular basis, she has extensive experience of the impact of OM in remote and regional areas. We have

had many conversations on her knowledge and experiences, especially about consequences of OM and how it affects a child and his or her family if not detected early in life. She has always stressed the need to ensure kids have regular ear check-ups from infancy to when they start school so that they can hear and learn without complications both before beginning formal schooling and once at school.

My third sister has worked as an Aboriginal Health Worker in both urban and remote communities for over 25 years. In the last 15 years, she has worked in Community Child Health. She has identified OM in kids and supported parents through the process of caring for their child. We yarned about ear health from an urban perspective and her biggest concerns are for mothers with babies who are not accessing mainstream local community health services, such as ENT and audiology clinics, or just for regular check-ups. She feels strongly that mainstream services are not culturally safe and appropriate for Aboriginal families.

The more I spoke to my family about OM the more I realised that I had had no idea that my own family were impacted by their experiences of living with OM. Listening to their stories, and recognising there was little research to guide us, I realised I needed to explore and investigate what was happening in an urban environment regarding OM in Aboriginal children. Having a very close family with a lot of knowledge and experience in OM, I was confident in taking on the challenge of research into OM from an urban perspective.

I felt strongly that the way in which to get it right from an Aboriginal perspective was to first explore with the community the appropriate research questions for the project. As I am not a health worker and have not worked in community health, I thought it was important that I seek the guidance and knowledge of the community.

The planning and preparation for the community engagements was done with careful deliberation. I had to work closely with key stakeholders in two communities. For Kwinana/Rockingham, I worked closely with the team at Moorditj Koort, a Nyoongar Well-Being Centre in Kwinana that provides care for the Kwinana and

Rockingham communities. In these communities, Kwinana and Rockingham, two locations were used: the community forum was held at the larger community centre, while the focus groups, with smaller numbers of participants, were held at the community health centre, Moorditj Koort.

For Armadale, I needed to connect with the team at Boojari Yorgas. They have extensive knowledge of the community needs for maternal care from health services, and were also able to connect local families to the project. The community focus group and forum were held at the local community centre, which is the local hub for Aboriginal families attending community events. This was the perfect location, providing a safe environment for participants willing to meet and share and offer information for the project.

The thesis has five chapters inclusive of this Introduction.

Chapter Two is a review of the literature around otitis media, covering issues such as: the medical definition of otitis media and its causes and effects; the prevalence of OM; and, the risk factors, including the social and cultural issues affecting Aboriginal children and their families, involved in contracting OM and then in receiving culturally sensitive effective care. The review also surveys the literature around decolonising methodologies and Indigenous perspective to situate the methods used in this qualitative research project.

Chapter Three discusses the research design and methods used in the research undertaken for this project, and covers each stage of the preparation and planning, implementation, and administrative steps taken by the research team in eliciting the views of the community participants. This chapter provides information on the processes for cultural governance, ethics approval, and data management and analysis.

In Chapter Four, I present the results and findings from the community meetings, focus groups, and First Time Mums groups who participated in the project. This

chapter discusses who were the study participants, and what did we, as a research team, learn from them. Participants offered information around what they knew about OM, what were the issues, barriers, and stressors they confronted when living with a child with OM, and solutions they suggest would assist them in overcoming these issues and in ensuring their children receive adequate health care.

Chapter Five analyses and discusses the main findings from the research, as well as the strengths and limitations of the research approach. It then discusses some of the key findings in conversation with other research in this field. Finally, this chapter presents the key messages drawn from the research and offers some ways forward for practitioners and other researchers in the field.

CHAPTER TWO – LITERATURE REVIEW

INTRODUCTION

Otitis media (OM) is an umbrella term for a number of related conditions caused by inflammation of the middle ear. It is one of the most common pediatric diseases in young children worldwide, and in high-income countries a major reason for why medical advice is sought, antibiotics are prescribed, and surgeries are undertaken (Schilder et al, 2016; Chando et al, 2016, Lehmann et al, 2008).

For Aboriginal and Torres Strait Islander people, especially for young children, ear health is a significant issue. Gunasekera and others, reporting the results of a survey of Australian Aboriginal Medical Service (AMS) practitioners, found that "Aboriginal children experience earlier, more frequent and more severe OM than other children" (Gunasekera et al, 2009a, p. 425). More recently, in their 2017 report card on Indigenous health, the Australian Medical Association (AMA) noted that rates of chronic otitis media in Aboriginal children are among the highest in the world (AMA, 2017). For some young Aboriginal children, contracting OM can occur within weeks of birth; however, the disease often can be asymptomatic until ear discharge, developmental delays in areas such as speech or social integration, or impaired hearing are noted (Lehmann et al, 2008).

In this chapter I explore the literature around otitis media (OM) to outline why this research project is an important contribution to the very limited existing qualitative research focused on knowledge of OM from the perspective of Aboriginal people living in urban areas – giving them the chance to speak and hear their voice. The review first examines the medical and epidemiological literature to understand what OM is, how it is contracted, and its prevalence. It then discusses the available qualitative research around OM, and the literature around the burden of the disease, including the range of risk factors and existing barriers to quality care for Aboriginal children in Western Australia. I also review literature around the qualitative methodologies that provide the rationale for the methods used in this study.

EAR STRUCTURE AND FUNCTION

To begin, a brief explanation of ear structure and function is necessary to provide an understanding of how otitis media (OM) is contracted and of how it affects hearing.

The ear is structured in three parts: the outer or external ear, the middle ear, and the inner ear. The external ear comprises the pinna, the ear canal, and the tympanic membrane or ear drum. The middle ear, an air-filled space behind the tympanic membrane, contains the malleus (or hammer), the incus (the anvil), and the stapes (the stirrup) - collectively known as the ossicles. The inner ear contains the fluid filled hearing organ, the cochlea, and the vestibular system, the semicircular canals that are associated with balance (Munir & Clarke, 2013).

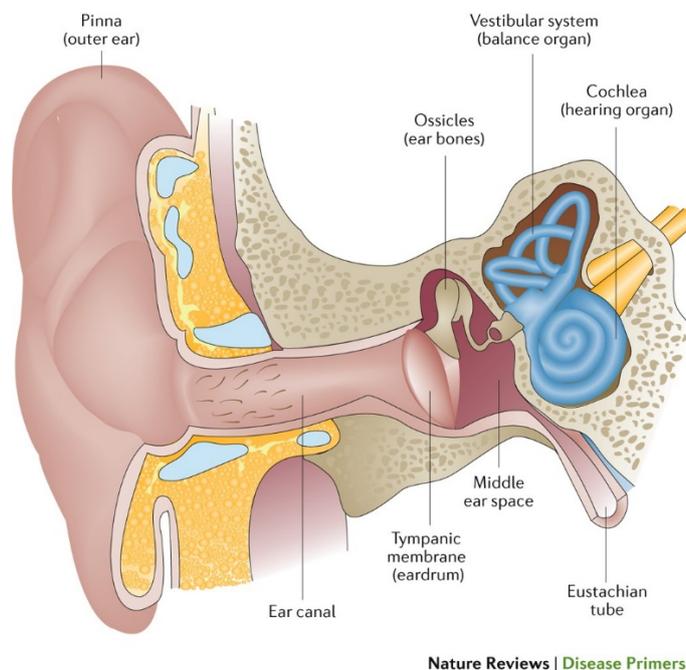


Figure 1: Structure of the ear.⁴

Each component of the ear is involved in the process of hearing: sound travels from the pinna through the ear canal to the ear drum (the tympanic membrane) and the malleus (hammer) attached to the eardrum, picking up vibrations which are then transmitted to the incus (anvil) and the stapes (stirrups). These vibrations are then

⁴ See <https://www.nature.com/articles/nrdp201663>. Accessed on 15 June 2020

sent to the cochlea, causing the fluid inside it to ripple and to form a wave, which activates the hair cells inside to move. This results in electrical signals that are then carried by the auditory nerve to the brain, which converts them into sounds we are able to recognise.⁵

OTITIS MEDIA (OM)

WHAT IS IT?

Otitis media is an inflammation of the middle ear that starts with an infection caused by a virus or a bacteria. Figure 2 below shows an image of a healthy ear contrasted with an image of an ear affected by OM:

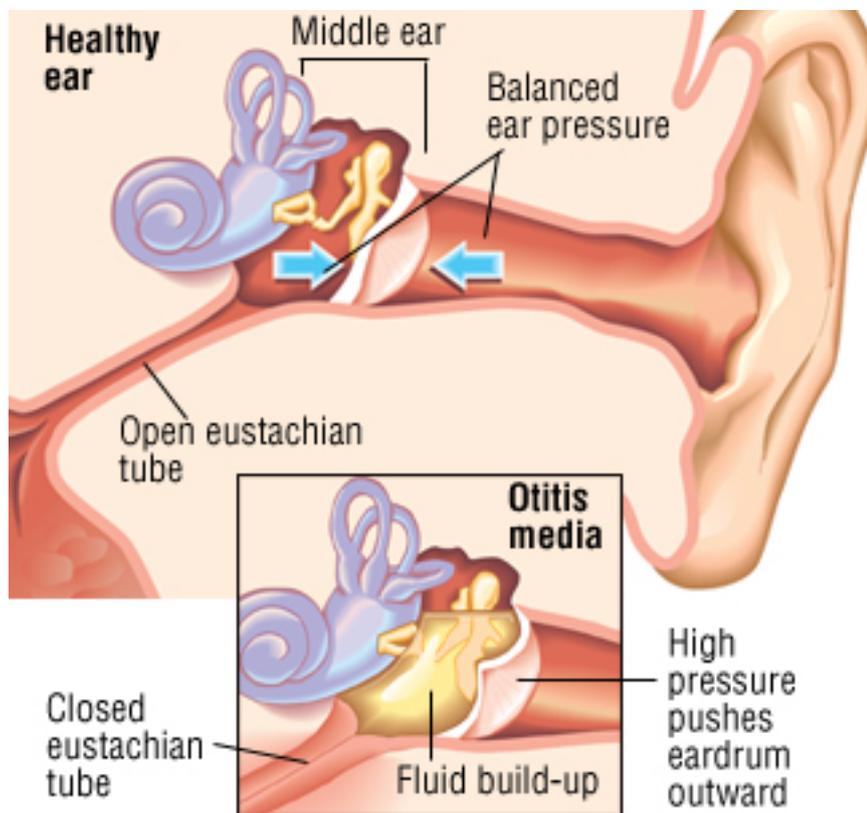


Figure 2: Image of a healthy ear/otitis media affected ear⁶

⁵ See <https://www.nidcd.nih.gov/health/how-do-we-hear>

⁶ https://www.health.harvard.edu/a_to_z/middle-ear-infection-otitis-media-a-to-z

There are a number of forms of OM. Among them, are:

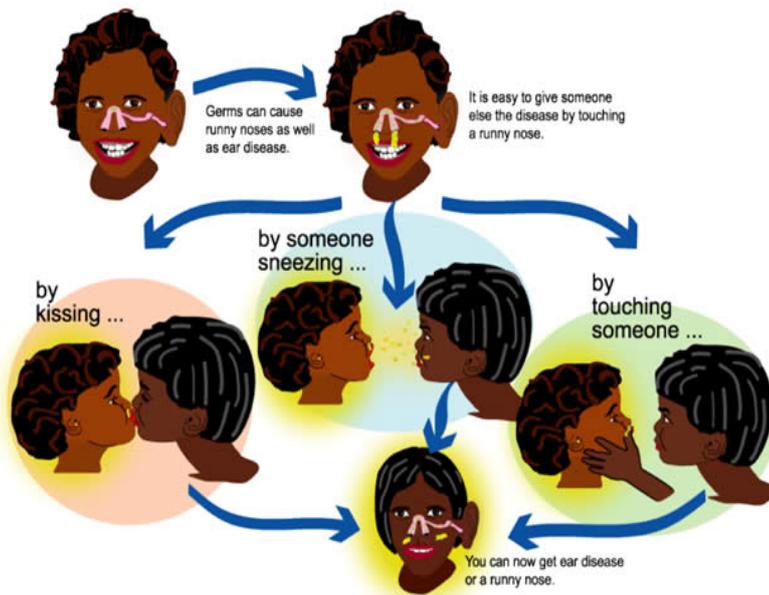
- Otitis media with effusion (OME), where there is presence of fluid behind the eardrum. No acute symptoms. This form is sometimes called ‘glue ear’.
- Persistent or chronic otitis media, with effusion. In this form, fluid is present in the middle ear for more than three months with no symptoms or inflammation.
- Chronic suppurative otitis media (CSOM), where there is persistent perforation of the ear drum and persistent discharge (see Government of South Australia, 2017) .

HOW DO WE GET IT?

OM usually starts with a cold or a sore throat caused by bacteria or a virus. Bacterial infections are responsible for the majority (up to 70%) of cases, and viruses for around 30% of acute cases of OM (Cripps & Otczyk, 2006).

Globally, the three main bacterial pathogens are *Streptococcus pneumoniae* (pneumococcus), *Haemophilus influenzae*, and *Moraxella catarrhalis*, with geography influencing the dominance of individual strains. Viral causes of OM include those responsible for the common cold (for example, rhinovirus, coronavirus, adenovirus), and the flu, or influenza virus (Ngo et al, 2016).

Figure 3 below shows how the various germs that can cause OM can be transmitted from person to person.



Developed by the Menzies School of Health Research Ear Health and Education Unit 2006

Figure 3: Routes of infection⁷

WHAT DOES THE RESEARCH SAY?

PREVALENCE AND BURDEN OF THE DISEASE

Otitis media is one of the most common of all childhood ailments worldwide. It is an illness that most children will endure at least once in their early years, with both a worldwide and an Australian prevalence of 80% of children affected by some form of the disease by the time they reach three years of age (Gunasekera et al, 2009b, Gribben et al, 2012, Kong & Coates, 2009, Vergison et al 2010, Mahadevan et al, 2012, Monasta et al, 2012). Over twenty years ago, the global prevalence of chronic suppurative otitis media (CSOM) was noted as an important and continuing public health problem, resulting in a call for more research into all aspects of prevention, treatment, training and service delivery for OM generally (WHO, 1998). More recently, the WHO has noted chronic otitis media with effusion as among the significant causes of a rising prevalence in hearing impairment, deserving of "appropriate and well-coordinated global action" (Davis & Hoffman, 2019).⁸

⁷ See https://www.menzies.edu.au/page/Resources/Transmission_of_otitis_media/. Accessed on 16 July 2020

⁸ See <https://www.who.int/bulletin/volumes/97/10/19-224683/en/>. Accessed on 16 July 2020

While OM affects most children to some degree, compared to their non-Indigenous peers it affects more children from Indigenous backgrounds, at a younger age, more regularly, for longer, and with more serious forms of the disease (Coleman et al, 2018; see also Sibthorpe et al, 2017). The WHO, in their 1998 report, stated:

Children in many Indigenous communities suffer from chronic ear disease, in particular otitis media, at rates that well exceed the 4% threshold at which a disease is regarded as a major public health problem (p. 2).

In their systematic review on OM in Indigenous children, Coleman and colleagues noted that "up to one third of Greenlandic and Alaskan Inuit, Native American, and Australian Indigenous children have or have had chronic suppurative OM (CSOM)" (p. 2). Maori children from rural areas have also historically been shown to have high rates of CSOM, and Gribben and others note a study published in 2010 which showed that Maori and Pacific Island children had higher rates of hospital admissions for OM than did other children in the study sample (Gribben et al, 2012).

Children from cultural groups such as Bedouin, Fijian, Thai, and Nepalese have also been reported to have very high rates of middle ear disease (Thomson, 1994). Thomson suggested that Indigenous children of peoples "adapting rapidly to industrialized life in other countries [than Canada] also have epidemics of severe otitis media" (p. 1946). She concluded that they are impacted more greatly by OM "in times of cultural disintegration" and that such epidemics recede as the population adapts to cultural changes (p. 1946).

Bhutta (2015) suggested that the high prevalence of OM in Indigenous children may be the result of evolutionary factors. He noted that there is evidence of OM being present in modern humans for many thousands of years, and that, instead of OM becoming rarer through the process of evolutionary natural selection, it endures due to the disease's complexity and high heritability:

... [the] evolutionary forces that drive human susceptibility to middle ear inflammation therefore cannot be considered in isolation but, rather, exist in

complex interplay with the evolutionary forces affecting colonization, survival, and pathogenicity of bacteria living in the nasopharynx (p. 93).

Bhutta presented a table summary of published data that documents increased prevalence of OM in Native American, Inuit, Maori and Australian Aboriginal children, showing prevalence rates for AOM and CSOM of up to 30% in some groups, and a range of between 1.5 to 5 times higher than in populations of 'white children' in developed countries (p. 100). He concluded that the high rates of OM in Indigenous populations may be due to European colonization creating a 'disruption' in their ecology and the consequent more recent exposure to the infections that cause OM, to which European and African populations have been accustomed for a much longer period of time (p. 102).

It is clear that OM has a greater impact on Indigenous children than on non-Indigenous children around the world, including Aboriginal and Torres Strait Islander children here in Australia. There is evidence that bacterial colonisation associated with OME and acute OM happens very early in life in Aboriginal children (Leach et al, 1994; Brophy-Williams, 2019). Thornton and colleagues (2017) noted that "the rates of OM reported for Australian Aboriginal children are the highest in the world" (p. 1). In their submission to the Australian Parliament's Standing Committee Inquiry into hearing health and wellbeing, Leach & Morris (2017) also stated that Australia's Aboriginal children have the highest rates of OM of any other group of people in the world, and are at greater risk of subsequent hearing loss than their non-Indigenous peers, with consequent developmental delays and lifelong detriments across every aspect of life (pp. 4-5). The WA Department of Health (2013) supported this, stating that "Australian Aboriginal children have the highest prevalence (up to 70% in remote communities) of CSOM in the world" (p. 6).

Kong & Coates (2009) described the differences between Aboriginal and non-Aboriginal children experiencing OM and its complications as "disproportionately high; up to 73% by the age of 12 months" (p. S39). They further indicated that while most non-Indigenous children will generally be over any OM-related ailment within three days, Indigenous children may go on to suffer recurrent acute OM (RAOM),

leading to chronic otorrhoea, and CSOM. Whether from remote or urban settings, Aboriginal children tend to endure otitis media not only at higher rates but also at an earlier age, more often and more severely (p. S40; see also Jervis-Bardy et al 2014). Despite finding that Australian Aboriginal children have higher hospitalisation rates for OM, Westphal et al (2019) note that they have fewer surgical procedures than their non-Indigenous peers. These differences indicate that causes and treatment approaches for Aboriginal children need to be separately considered from those appropriate for their non-Indigenous peers.

There are relatively few studies focused on prevalence in Aboriginal children living in urban settings. Williams & Jacobs (2009) noted that "[h]igh rates of otitis media have been found in Aboriginal children living in rural, remote and urban areas" (p. S69), referencing an analysis of hearing screening data conducted between 1998-2004 for Aboriginal school children in Perth. This study indicated alarming rates of occurrence of OM in this population, with middle ear disease evident in just over 40% of children at first screening visit. Study authors noted that even though the rate is lower than rates reported in many studies of Aboriginal children in rural and remote areas, where rates of more than 90% have been recorded, they are considerably higher than those reported for non-Aboriginal populations (Williams et al, 2009).

In her unpublished PhD thesis, Bibbulung Gnarneep (Solid Kid) (2003), a longitudinal study of a population based cohort of urban Aboriginal children in Western Australia, focused on the determinants of health outcomes during early childhood for these children, Sandra Eades stated that:

There are few reported longitudinal cohort studies, which describe the health of Aboriginal and Torres Strait Islander children living in their communities, and none which focus on urban Aboriginal and Torres Strait Islander children (p. 39).

Whilst her study was not about the impact of OM, it does highlight that there is a lack of research from an urban perspective.

More recently, data collected from a birth cohort study in the Perth Nyoongar community project, *Djaalinj Waakinj* (listening talking), between 2017-2019, investigated the prevalence of OM and risk factors among urban Aboriginal children from 0 to 12 months. This research study examined results from the ear examinations from otoscopy⁹ and tympanometry¹⁰ from babies at the ages of 2, 6 and 12 months, identifying the prevalence of OM as 39% of children having evidence of middle ear fluid at age 2-4 months, and 52% of children at 6-8 months. These authors noted that to their knowledge their study was the first prospective cohort study with the aim of determining prevalence and risk factors associated with OM in Aboriginal infants living in an urban area (Swift et al, 2020; see also Richmond, unpublished thesis, 2019).

Queensland Health explained the concept of burden of disease as:

Burden of disease is a measure of population health that aims to quantify the gap between the ideal of living to old age in good health, and the current situation where healthy life is shortened by illness, injury, disability and premature death.¹¹

The various forms of middle ear disease place a significant health burden on individuals affected. The research literature notes that worldwide it is both the most common cause of sick children visiting a doctor, and in developed countries the major reason for antibiotic use. Vergison and colleagues (2010) noted that in these countries "infants and toddlers spend a mean of 42 days on antibiotics in the first year of life and 49 days ... in the second year" (p. 195).

The level of burden differs for children living in developed as compared to developing countries, and as between Indigenous and non-Indigenous children in countries around the world and can be related to the form and persistence of the disease (Acuin, 2004, Vergison et al, 2010; see also Gunasekera et al 2009b, Falster

⁹ The use of an otoscope to look into the ears.

¹⁰ A test providing information about the presence and quantity of fluid in the middle ear through the changing of air pressure to measure movement in the eardrum.

¹¹ See <https://www.health.qld.gov.au/research-reports/population-health/burden-disease>

et al 2016, Thorne et al, 2019). Both acute OM (AOM) and the more serious condition chronic suppurative OM (CSOM) are widely discussed as contributing to hearing deficits which can lead to difficulties and poorer outcomes across the life course in areas such as cognition, language development, behavioural issues, family and social functioning, education, and employment prospects (see, for example, Acuin, 2004; Brouwer et al, 2005; Lehmann et al, 2008; Williams et al, 2009; Mackenzie & Smith, 2009; Vergison et al, 2010; Davis & Hoffman, 2019). CSOM in particular is overwhelmingly more likely to occur in children living in developing countries (Acuin 2004) or in Indigenous children within developed countries. The disease burden and consequences for these children are substantial and often lifelong.

Between 2006 and 2016, the Australian Bureau of Statistics Census of Population and Housing reported that the number of people identifying as Aboriginal and/or Torres Strait Islander increased from 2.3% to 2.8% of Australia's total population. Over the same time period, the proportion of children aged 0-14 years decreased from 40% to 34% of the Indigenous population,¹² comprising less than 1% of the country's total population.

In this context, in 2008 it was estimated that Indigenous children accounted for 12.8% of all new cases of OM in Australia (Kong & Coates, 2009) and 10 years later the Australian Institute of Health and Welfare (AIHW) noted that:

In 2011, the rate of burden (measured using disability-adjusted life years—DALYs) from hearing loss in Indigenous children aged 0–14 was 12 times as high as for non-Indigenous children (69.4 and 5.6 DALYs per 100,000 population, respectively). Similarly, the rate of burden from otitis media in Indigenous children was 8.5 times as high as for non-Indigenous children (41.9 and 4.9 DALYs per 100,000, respectively) (2018, p. 6).

On the question of the economic burden of hearing loss from all causes including OM, in a recent editorial published in the WHO Bulletin, it was said that hearing loss

¹² See <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Aboriginal%20and%20Torres%20Strait%20Islander%20Population%20Data%20Summary~10>

that had been left untreated placed a considerable economic burden on global society, at an estimated cost of US\$750 billion (Davis & Hoffman, 2019).¹³

The WA Department of Health's Otitis Media Model of Care (2013) cited an Access Economics study conducted in 2009 as estimating the burden of disease in Australia for OM as:

... 5,717 disability adjusted life years (DALYs) for the first five years of life, and the cost of wellbeing was estimated to be between \$1.05 and \$3.49 billion. This same study estimated that productivity and other non-health financial costs in Australia for people with OM to be \$67 million in 2008 and the cost of lost productivity of carers of children with OM was \$189 million. ... for some communities with very high prevalence of OM, the burden associated with absence from school and associated poor educational outcomes is much higher (page 12).

In this same report, the direct health costs for Australia were estimated as between \$85 and \$163 million, approximately 10% of which related to costs of care for Aboriginal Australians. Based on population, it was estimated that the cost for managing otitis media in Western Australia's Aboriginal population would be between \$1.1 to \$2.1 million. It was further noted, however, that this was likely to be an under-estimate due to higher health costs in remote areas of the state (WA Department of Health, 2013, p. 12).

QUALITATIVE RESEARCH AROUND OM

In 2016, Chando and colleagues (2016) published a systematic review they had conducted of qualitative studies on parental views around caring for a child with OM. They identified just 17 studies from six countries which met the inclusion criteria: five from the United Kingdom; four from each of the United States and Canada; two from Australia; one from New Zealand; and, one from Iceland.

The systematic review described seven themes which emerged from these 17 studies of parental experiences and perspectives of caring for a child with OM:

¹³ See <https://www.who.int/bulletin/volumes/97/10/19-224683/en/>

- diminishing competency (guilt over failure to identify symptoms, helpless and despairing, fear of complications, disempowered and dismissed);
 - disrupting life schedules (disturbing sleep, interfering with work, burden on family);
 - social isolation (stigma and judgement, sick consciousness);
 - threatening normal development (delaying growth milestones, impairing interpersonal skills, impeding education);
 - taking ownership (recognising symptoms, diagnostic closure, working the system, protecting against physical trauma, contingency planning);
 - valuing support (needing respite, depending on community, clinician validation); and,
 - cherishing health (relief with treatment success, inspiring resilience)
- (Chando et al, 2016, pp. 1300-1301).

Chando and colleagues note that parents can find managing and caring for a child with OM very challenging. In support of this statement, they cite the disruption to their lives by needing to arrange and attend multiple necessary medical appointments, and the concerns raised by reoccurrence of the disease, which can lead to worries over the value of treatment, child development and to parental self-doubt.

Just two of the studies included in their review explicitly focused on Indigenous families. One was a Canadian study on the management of OM in North American First Nations culture (Wuest, 1991), and the other was an Australian study around barriers to treatment adherence in the Kalgoorlie-Boulder area of Western Australia (Jeffries-Stokes et al, 2004).

Wuest (1991) took a grounded theory approach to understanding how First Nations American families managed the care of a child with persistent OM with effusion (OME), conducting unstructured face-to-face interviews with parents (some of whom were not themselves First Nations people) of North American First Nations children living in the St John River Valley in New Brunswick, Canada. These First Nations families took an approach to the disease informed by culture, and influenced by a range of factors which encompassed the autonomy of the child, and ultimately aimed

at becoming experts. Once this had been accomplished, the parents in this study spoke of rearranging roles and responsibilities; negotiating with the health and school systems; and, minimising the effects on the child (pp. 12-13).

In Australia, Jeffries-Stokes and colleagues (2004) conducted structured face-to-face focus groups and individual interviews with Aboriginal people of the Kalgoorlie-Boulder area in Western Australia, exploring the burden of OM and its impact on children and their families. It identified a number of issues around caring for a child or children with OM, among them that parents have many competing demands on their time, and that treatment often has to be shared amongst family members other than the child's parents. The authors noted that the intensity of caring for and treating OM can lead to "families becoming resigned to a child's chronic ear discharge" (Jeffries-Stokes, 2004, p. 258). That OM is often asymptomatic and therefore not always checked for during health visits, and specialist services are not always available when they are needed, were also identified as concerns and as barriers to effective treatment and positive outcomes.

A more recent qualitative study of parents' experiences with acute otitis media (AOM) was undertaken by Meherali and colleagues (2019). This was a Canadian study undertaken in the large urban centre of Edmonton, Alberta. There is no indication that First Nations families were included in this study which, like that of Chando & colleagues discussed above, also identified seven themes from the semi-structured interviews it conducted with 16 parents recruited from a pediatric emergency department:

- frequency of AOM;
- symptoms experienced by children and parents;
- symptom management strategies used by parents;
- parent's beliefs about AOM;
- parent's satisfaction with treatment prescribed by physicians;
- the effect of AOM on family's quality of life; and,
- parent's information needs about AOM (p. 53).

RISK FACTORS

Kong and Coates (2009) provided a table separating the risk factors for otitis media into host-related and environmental causes, and further noted the level of evidence available to support each separate category of risk:

Risk factor	Comment	NHMRC level of evidence* ¹⁸
Host-related		
Age	Highest incidence between 6 and 11 months	A
Sex	Slightly higher preponderance among males	C
Ethnicity	Indigenous children are at increased risk of earlier and more severe disease	A
Premature birth	Increased risk	C
Allergy	Link noted, but pathways unclear	D
Immunosuppression	Subtle immune deficiencies often noted in recurrent acute otitis media	A
Genetic predisposition	Familial clustering noted	A
Craniofacial abnormalities	Increased incidence in children with cleft palate, Down syndrome and craniofacial anomalies	C
Adenoids	Infected adenoids or tissue increases risk more than size of adenoids	C
Gastro-oesophageal reflux	Link noted, but further study required	D
Environmental		
Daycare or overcrowding	Higher incidence with daycare attendance	B
Siblings	Increased risk with older siblings	B
Upper respiratory tract infection	Viruses predispose to otitis media	B
Seasonality	Increased incidence in winter months	D
Cigarette smoke exposure	Increased risk	B
Breastfeeding	Has a protective effect	C
Socioeconomic status	Variable but generally increased risk with lower status	C
Dummy (pacifier) use	Increased risk after age 11 months	B

NHMRC = National Health and Medical Research Council.
 *NHMRC levels of evidence: A = body of evidence can be trusted to guide practice. B = body of evidence can be trusted to guide practice in most situations. C = body of evidence provides some support for recommendation(s) but care should be taken in its application. D = body of evidence is weak and recommendation must be applied with caution.

Figure 4: Risk factors for otitis media (adapted from Kong & Coates, 2009, p. S41)

In relation to host-related or biological risk factors, Australia’s Aboriginal children have been shown to have, at an early age, “multiple strains of bacterial pathogens at high density that persist longer” (Wiertsema & Leach, 2009). Some recent literature noted that there is evidence for a genetic predisposition to otitis media (Burns & Thomson, 2013; AIHW, 2014; Santos-Cortez et al 2018), and researchers now have access to new genomic technologies with which to analyse the bacterial communities present in Indigenous children suffering with OM (Jervis-Bardy et al, 2017). Research shows that Aboriginal mothers experience higher rates of pre-term and low birth weight babies than do non-Indigenous mothers (McNamara et al, 2018; Clarke & Boyle, 2014).

SOCIAL DETERMINANTS

The social determinants of health have been described by the World Health Organisation (WHO) as:

... the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries.¹⁴

It is well known that the health of individuals is impacted by many factors. According to a report by the Australian Institute of Health and Welfare, factors such as “income, education, conditions of employment, power and social support act to strengthen or undermine the health of individuals and communities” (AIHW, 2016, p. 1). These and other interconnecting factors involved in the determinants of health were depicted in this diagram from the Royal College of Physicians and Surgeons of Canada’s guide to *Defining Societal Health Needs* (2012):



(Royal College of Physicians and Surgeons of Canada, 2012, p. 7)¹⁵

¹⁴ See World Health Organization (2020). Social determinants of health. Accessed on 17 June 2020 at: https://www.who.int/social_determinants/sdh_definition/en/

¹⁵ Source: Health Canada, “Health and Environment: Critical Pathways,” *Health Policy Research Bulletin*, Issue 04, Octo

Despite Australia being regarded as a modern affluent first world country, Aboriginal and Torres Strait Islander people still feature as being among the most disadvantaged and unhealthy groups in the nation and globally. The evidence shows that they experience poorer health outcomes and lower life expectancy than their non-Indigenous peers, with higher rates of preventable disease, emergency presentations, hospital admissions, and maternal and infant death (McNamara et al, 2018; Clarke & Boyle, 2014). Social disadvantage, social risk factors, and intergenerational trauma from colonisation and the impact of dispossession and forced family separation are all contributing factors to this unacceptable burden of morbidity and mortality (Fairthorne et al, 2016; Paradies, 2006, 2016; McNamara et al , 2018; Salmon, 2018, DeLacy et al, 2020).

In relation to OM specifically, the reasons for the high rates in Aboriginal children are complex and multifactorial (Lehmann et al, 2008). Living conditions such as overcrowding, bottle-feeding, poor nutrition, passive smoking, the presence of older children in the house (who may contract and bring home the virus from child care, kindergarten, preschool, or school), inadequate sanitation and lack of running water have all been noted in the research literature as contributing risk factors (Reid & Trompf, 1991; Couzos et al, 2001; Kong & Coates, 2009; Senate Community Affairs Committee Secretariat, 2010).

Jacoby and colleagues (2011) found that the risk of carriage of bacteria responsible for OM increases with each additional member in both Aboriginal and in non-Aboriginal households. For Aboriginal children living in larger houses, however, the risk was reduced. This study further found that males had a higher risk of carriage of each of the three strains of bacteria, and that exclusive breastfeeding was protective against carriage of *S aureus*.

The most current recommendation from Australia's National Health and Medical Research Council (NHMRC) is for exclusive breastfeeding until an infant is 'around six months' old, and the continuation of breastfeeding after the introduction of solid foods 'for as long as the mother and child desire' (NHMRC, 2013). The most recent

Australian National Infant Feeding Survey (ANIFS) 2010 found that rates for exclusive breastfeeding were similar for Indigenous and non-Indigenous babies up to one month of age; however, they declined sharply for Aboriginal infants over time, with just 7% exclusively breastfed by six months old, compared with 16% of non-Indigenous infants (AIHW, 2011). There are a range of well-known personal and social factors affecting whether and for how long a woman will breastfeed her child. For Aboriginal women, additional barriers exist related to culture, service delivery, and to the ongoing harms from past colonial and government practices (see Brown et al, 2016; Reibel et al, 2016; Krahe, 2016; Kildea et al, 2012, 2016, 2018; Jones et al, 2017, 2018).

At present there are no published data specific to risk factors for OM in urban Indigenous populations. There are, however, similarities and differences in the prevalence of risk factors between metropolitan Perth and the Kalgoorlie-Boulder region of Western Australia which have been reported. For example, in their 2008 study, Lehmann and colleagues found that, although mothers in Kalgoorlie were less likely to be employed and more likely to live in larger households, infants resident in Perth were regularly exposed to tobacco smoke at higher rates than were those living in Kalgoorlie (Lehmann et al, 2008).

Further, the majority of Aboriginal people in the Goldfields belong to the Wongutha group, while the original Aboriginal people in the Perth metropolitan area are Whadjuk Nyoongars and there are many different groups living in the urban area. Hence one cannot extrapolate directly from findings in regional areas, as living conditions, and social supports such as access to health care, educational and employment opportunities all differ.

Service availability and delivery

Australia's health system was ranked second only to the UK in a 2017 study of 11 health systems in the developed world (Schneider et al, 2017). It encompasses primary, secondary and tertiary levels of care, delivered by public and private service providers through a combination of care pathways: primary health care; specialist services; hospitals; and, health promotion (AIHW, 2018). Access to and delivery of

services is, however, uneven across the general population for a number of reasons including cost, location, and availability of service. There is considerable research literature addressing these issues with specific reference to Aboriginal people (Kelly et al, 2014; Green et al, 2016; Jersky et al, 2016; Dossetor et al, 2019).

Research undertaken by Wright and colleagues (2013) identified that language was a huge barrier for some participants visiting a health professional for any condition. In particular, where the doctor or other health worker had a very strong foreign accent, people said they were unable to understand or interpret what was being said to them during their visit. This caused major problems for participants with a child suffering from otitis media or an earache. When the doctor was explaining the illness to the parent/carer they didn't know what they were talking about, leaving the participant confused and frustrated, resulting in parent/carer unable to take proper care of the child at home. The other problem was that the participant did not know how to express or explain themselves, creating a two-way language barrier impacting both parties involved, and resulting in anxiety, confusion and frustration for the participant.

Other research focuses more particularly on the further barriers which exist for Aboriginal people around a lack of cultural safety and sensitivity within mainstream services (Hayman et al, 2009; Ou et al, 2011; Freeman et al, 2014; Young et al 2016; Vallesi et al, 2018; Harfield et al 2018; Carman et al 2019), and communication problems due to switching between 'Aboriginal and non-Aboriginal ways of being' (Ralph, 1997; McConvell, 1988; McConvell & Meakins, 2005), which are often worsened by issues such as racism and shame.

Racism

Racism is widely recognised in the literature as one of the social determinants of health which have a detrimental effect on both the physical and mental wellbeing of Aboriginal Australians. The issue of racism in the health system is strongly addressed in the Commonwealth Government's (2013) *National Aboriginal and Torres Strait Islander Health Plan 2013-2023* which states in the *Vision* that '[r]acism has been identified as a social determinant of health' (p.8). The Plan goes

further, calling for ‘a culturally respectful and non-discriminatory health system’ as one of the key principles underpinning the strategies deriving from the plan (pp. 14-15).

Larson and colleagues (2007) noted that racism, where it occurs, is both interpersonal – between individuals – and institutional, where Aboriginal Australians derive less benefit from the ‘policies and practices carried out by government and other institutions’ than do non-Aboriginal Australians (p. 322). This study reported that there is a ‘consistent association’ between racial discrimination and a range of health outcomes, including poor health, hypertension, and heightened stress (pp. 322-23).

In a 2012 paper, Priest and colleagues looked at the social determinants of health and the strengths and challenges for Aboriginal (Koori) children in an urban area of Victoria. They noted that both historical and contemporary racism has an impact on the health and other challenges faced by Aboriginal children (p. 165). Their qualitative findings were that racism is a daily occurrence for some children, and that this places a burden also on parents, or other carers, to ensure that their children were protected as much as possible from the negative effects this could have on their spirit and sense of identity (p. 169). Of particular note is a quote from a participant in this research who stated that:

Look purely the health workforce itself is highly racist, and that’s historical, and that’s been passed down. That hasn’t been broken yet (p. 169).

Participants in this research identified a number of strategies to protect their children from racism in various situations. These included ensuring that the child felt accepted and loved, proud of who they were, felt secure, supported, and connected to family and to community (p. 169).

Vicki-Ann Ware (2013) outlined that there is a significant international literature addressing hesitancy to access health services where there is a colonial history and

record of past injustices. She suggested that this exists even where health services are easily accessible. She went on to note that the impact of a colonial past can lead to:

... fear, due to forced removals of children or relocation of families ... (and) ongoing individual, institutional and systemic racism. Some health services fail to deliver care to all without discrimination. It has been found that, compared to non-Indigenous clients with the same medical needs, Indigenous clients were about one-third less likely to receive appropriate medical care across all conditions (p. 7).

Yin Paradies (2016) also discussed the effects of racism on health in the context of the many harmful 'predominantly historical' practices attributed to colonisation, noting that the impact of colonialism on the health of Indigenous peoples is now well-recognised (pp. 83-84; see also Fisher et al 2019).

A survey conducted by Kelaher and colleagues (2014) focused on experiences of racism and the effects it had on the mental health of Aboriginal Australians in Victoria. Results from this study showed that, those experiencing racism – either within a health setting or in non-health setting – were at greater risk than those not experiencing racism for suffering “high or very high psychological distress”. Among all those who experienced racism, however, psychological distress was increased for those who encountered interpersonal racism in health settings (p. 44).

Shepherd and colleagues (2017), in their study on the impact of racial discrimination on young Indigenous children, aged 5-10 years, found that it was detrimental and that “prolonged and more frequent exposure ... that starts in the early lifecourse can impact on multiple domains of health” (p. 1). With particular regard to racism and OM, research undertaken by Smith and Boss (2010) on the treatment of otitis media in children in the United States of America concluded that “Racial/ethnic and socioeconomic disparities exist for the prevalence and treatment of children with OM” (2010, p. 2306). Durey (2010) recognised a number of strategies, similar to those noted by Priest and colleagues (2012), as useful in overcoming the deleterious effects of racism. Among these are ensuring a strong connection to country and community, feeling safe, and having dignity.

Shame

While the issue of shame consistently emerges in the literature as a key issue, it is rarely unpacked or examined in detail. The feeling of shame expressed by Aboriginal people has also been identified as a barrier to accessing (and possibly being retained in) health care (Maher 1999). Due to the substantial impact shame has on preventing some Aboriginal people accessing health care facilities, it is important to understand what this phenomenon is.

Potter-Efron (2002) defined shame as “a painful sense of one’s basic defectiveness as a human being” (pp. 1-2). Potter-Efron describes the primary feelings of shame as including: identifying as inadequate; deficient; defective worthless; exposed; and/or, disgraced. Shame is so painful because it involves the individual’s total self-image; their central identity; their whole self. He states that shame is a spiritual issue, since it causes people to question “the reason and meaning of their lives” (p. 5). This description of shame and how it affects people resonates for Aboriginal people as these are many of the feelings that occur for them in their dealings with health services and health professionals.

There are many possible causes for feelings of shame. It can result from a person being singled out for attention, losing the security and anonymity of their immediate social group, not knowing the correct way to behave, or being forced to act in a way that does not conform to their social and spiritual obligations (Maher 1999).

Additionally, shame can be caused by a perception of being talked down to, harsh judgments of different parental expectations and child-rearing practices (Scrimgeour & Scrimgeour 2008), poor self-esteem leading to a lack of confidence in accessing services (Hayman et al. 2009), and low levels of literacy and numeracy (NCAHS 2009). Shame is arguably a chief reason many Indigenous people do not attend non-Indigenous specific health services (Maher 1999). Baker and colleagues (1996) found that “patients with low literacy harbor a deep sense of shame”, and that such shame is “reinforced by hospital staff who become frustrated or angry when someone cannot complete a form or read instructions” (p. 329).

‘Shyness’ is another recurring theme in the literature and is closely related to shame. It is a reluctance to interact with Western health services due to feeling threatened by the perceived social distance and power between the client and professional service providers (Barwick 2000; NCAHS 2009). It can also manifest as a reluctance to expose particular body parts in front of non-Indigenous service providers, particularly where they are of the opposite gender (Finn et al. 2008). Aboriginal people may display a similar reluctance to exposure in an educational context or to undertake any kind of performance in public unless they are confident of their knowledge or ability in these spheres (see Harrison, 2011; Hughes et al, 2004).

Colloquially, shame is often conflated with guilt, humiliation, embarrassment, feelings of inadequacy, unworthiness, being unliked, awkwardness, fear of leaving the group/individual perceived expectations and shyness. All of these colloquial meanings infer internal, psychological manifestations of shame (McKnight et al, 2018, p. 3).

Potter-Efron acknowledges that shame should not be always thought of as a negative emotion. In fact, “when ... experienced as temporary in duration, moderate in intensity, and point towards corrective action” (Potter-Efron, 2002, p. 1) shame can motivate people to make improvements in their approaches to various elements of life. One reason for this is that shame helps the individual distinguish between right and wrong (Madanes, 1997). The degree to which shame is necessary varies with the culture of the society (see Lutwak, Razzino, & Ferrari, 1998). For example, in Japan, shame-prone and self-effacing behaviour tends to be given positive functional value and is actively promoted by Japanese society, whereas in the United States the exhibition of shame and the showing of one’s vulnerability, tends to be prohibited (Okano, 1994). Thus, what is critical is the level of shame that an individual experiences. Potter-Efron (1989) suggested that there is a shame/pride continuum. At the negative end of the continuum is overwhelming shame, which is characterised by feelings of not being as good as others, being controlled by others, and perceiving pressure to fail. Loader (1998) noted that “too much shame results in a sense of the self as fundamentally flawed, and can lead to lifelong problems in living” (p. 44).

Delayed detection and diagnosis of ear infections

The Australian Institute of Health and Welfare's Health Performance Framework for 2017 noted that, although the rate of GP management of ear issues in Indigenous children is almost the same as the rate for non-Indigenous children, "the prevalence of ear disease is almost 3 times as high" (p. 69). This report further noted that:

Hearing loss, especially in childhood, can lead to linguistic, social and learning difficulties and behavioural problems in school. Such difficulties may reduce educational achievements and have lifelong consequences for wellbeing, employment, income, social success, contact with the criminal justice system and future potential (p. 69).

In the same year, the Australian Medical Association (2017) released a report card on Indigenous health, in which they specifically addressed the impacts of OM in Indigenous communities. Observing that "Chronic otitis media among Australia's Aboriginal and Torres Strait Islander infants and children is not a hidden or unknown health problem" (p. 3), the AMA said that "its effects are significant 'life sentences' of disability" (p. 3).

Just over a decade ago, Williams & Jacobs (2009) explicitly stated that:

Children who sustain a hearing loss before the age of 12 months, the optimal period for development of the sound system, are at higher risk of long-lasting consequence of otitis media. Children whose hearing loss during this period is relatively greater and lasts longer are at the most risk of lasting consequences (p. S70).

This study is one of the few studies that has commented on the early literacy skills of urban Aboriginal children. It found that children with otitis media had significantly poorer phonological awareness, reading and spelling skills than their peers who did not have otitis media.

It is clear, then, that early detection and treatment of OM is extremely important to ensure that Aboriginal children do not progress to the more severe or chronic stages of the disease. However, it appears that screening has been mostly conducted amongst school children (see, for example, Gunsasekera 2011; Su, 2019). Similarly, Williams & Jacobs (2009) pointed out that the classroom, which is often a noisy

place, would cause difficulties in processing spoken information for children with hearing issues. The literature on this issue discussed here shows that it may be too late for children with OM to be detected only at school age.

In sum, there are a number of social issues, entwined with health policy, treatment and management, which are impacting upon the hearing health of Australia's Aboriginal children. In this regard, the AMA (2017) stated very clearly that:

... the AMA believes it is time for clarity about the range of chronic otitis media related social impacts on the Indigenous population and to recognise that these impacts are of an entirely different magnitude and range to those experienced by the non-Indigenous population (p. 6).

INDIGENOUS PERSPECTIVE/DECOLONISING RESEARCH METHODOLOGIES

The literature around Indigenous perspectives in research and decolonising methodologies is replete with the recognition that Western ways of doing research with Indigenous peoples has not, in the past, been of benefit to them. Instead, it has served to further embed colonialist and racist assumptions and attitudes, and to neglect other ways of achieving the aims of the research (for example, Rigney, 2001, 2006; Saunders et al, 2010; Sikes, 2013; Peltier, 2018; Rix et al, 2018; D'Antoine et al, 2019). Rix and colleagues (2018) noted that "Australian Indigenous peoples ... have witnessed two centuries of being 'over-researched' with no prior consultation, permissions sought or any form of post research feedback or positive outcomes" (p. 7).

Traditional research methodologies are, however, now being challenged as more and more Indigenous researchers emerge in the academic world. Porsanger (2004) summarised the emergence of Indigenous Research Methodologies as:

... a body of indigenous and theoretical approaches and methods, rules and postulates employed by indigenous research in the study of indigenous peoples. The main aim of indigenous methodologies is to ensure that research on indigenous issues can be carried out in a more respectful, ethical, correct, sympathetic, useful and beneficial fashion, seen from the point of view of indigenous peoples (pp. 7-8).

Rigney (2001) proposed that Indigenous research is “informed by three fundamental and interrelated principles”, the third of which is to privilege Indigenous voice:

- Involvement in resistance as the emancipatory imperative in Indigenist research
- Political integrity of Indigenist research
- Giving privilege to Indigenous voices in Indigenist research” (p. 41-42).

Similarly, Fast & Kovach (2019) discussed what they called the “three key dimensions of Indigenous research: the role of community in relationship to geographic spaces; the function of our own story as researchers as integral to a relationship with community; and the ethic of reciprocity in community-research relationships” (p. 22).

These principles embrace the importance of an approach to research with and for Indigenous people that involves privileging their voices, and acknowledging and valuing their culture, experiences and knowledge. Juanita Sherwood, in her 2010 thesis “Do no harm: decolonising Aboriginal health research”, framed her research within her own journey as both participant and researcher to “grow a new approach to Indigenous health research” (Abstract). Sherwood found that the colonial structures and strategies of research discourse have been and are still problematic and injurious for Aboriginal people, silencing their voices and suppressing their knowledge. She concluded by proposing a ‘way forward’ which includes utilising a decolonising framework in research, and support for researchers in building Aboriginal health research that is collaborative with community and includes Aboriginal ethics and Aboriginal voices (p. 293-294). She specifically noted the importance of Elders to this process, stating that “The roots of the tree are the supports that hold the learner ... these roots are the Elders and the Mother” (p. 293; see also Sherwood, 2013).

Cindy Peltier (2018) similarly suggested that the researcher has special responsibilities that include inherent responsibility, respect for, and accountability to “all my relations – those who came before me, those who are still in this realm, and those who are yet to come” (p. 3).

According to Cornel Pewewardy (2019), “[T]he concept of applying Indigenous research methods aspires to be a reconstructive and locative educational and social justice idea” (p. 151). Along these lines, Margaret Kovach (2009), in discussing how Indigenous researchers may approach academic research, noted that they are in a position to choose to place their tribal epistemology at the centre of what they do. She further proposed that Indigenous researchers may serve as a “bridge”, as they are in an academic space whilst also embodying Indigenous knowledge systems (p. 58).

This notion of a ‘bridge’ between the two ways of seeing is taken up by Cindy Peltier, who discussed the concept of ‘Two-Eyed Seeing’ as a frame – as a bridge between Indigenous and participatory methodologies (2018; see also Martin, 2012). In a similar vein, Bartlett & colleagues described Two-Eyed Seeing as:

... the gift of multiple perspective treasured by many aboriginal peoples ... to see from one eye with the *strengths* of Indigenous ways of knowing, and to see from the other eye with the *strengths* of Western ways of knowing, and to [use] both these eyes together, for the benefit of all (Bartlett, Marshall & Marshall, 2012, p. 335).

Likewise, Ruth Nicholls (2019), a non-Indigenous researcher who conducts research with Indigenous peoples, stated that “... the counter-colonial voices of Indigenous peoples are now well-articulated in ethics and methods literature” (117), and supported the position that this research process requires that the lived experiences and knowledge of Indigenous people is recognised as the central component in the process, suggesting that the most effective way of conducting such research is through a “reflexive process of collaborative ‘sense-making’” (p. 124).

Central to this process for Aboriginal people is the process of ‘yarning’. According to Walker and colleagues (2014), “Yarning is a conversational process that involves the sharing of stories and the development of knowledge. It prioritizes indigenous ways of communicating, in that it is culturally prescribed, cooperative, and respectful” (p. 1216). Of specific relevance for this current research, they further note that “... yarning as a research method is appropriate for community-based health research with indigenous Australian women” (p. 1217).

Dawn Bessarab and Bridget Ng'andu (2010) described yarning as containing three aspects, encompassing four different types:

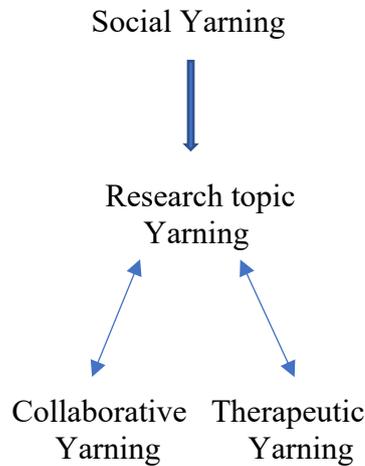


Figure 5: Adapted from Bessarab & Ng'andu, 2010, p. 40.

Each of these types of yarning contribute to the relationship building that is necessary for successful connection between researcher/s and participant/s. Social yarning 'lays the groundwork', research topic yarning signals a change in the conversation to becoming more serious', therapeutic yarning provides the participant with the ability to incorporate their particular life story into the research topic, and collaborative yarning provides for the folding into the process of a back and forth conversation between researcher and participant.

Bessarab & Ng'andu proposed that yarning is of benefit to researchers, because it assists in the development of in-depth discussions with participants, within a "relaxed and open manner" that allows for the collection of rich data. Its strength, they say, "is in the cultural security that it creates for Indigenous people participating in research", concluding that it has "a legitimate place alongside other western research methods" (p. 47).

CONCLUSION

The literature highlights a number of risk factors for otitis media in children, most of which are influenced by social determinants and fewer simply biological. There is some evidence for a genetic predisposition to otitis media, and some additional risk

here for Aboriginal babies who are at higher rates of being pre-term or low birth weight babies. The majority of risk factors are, however, social risk factors. These include living conditions – overcrowding, poor nutrition, and passive smoking. Breastfeeding rates are lower for Aboriginal than for non-Indigenous babies, and breastfeeding is noted as being protective for a range of issues including otitis media.

As recently as 2017, Australia’s health system was ranked second in the world- however, as the literature notes, service availability and delivery is uneven across the population, and for Aboriginal people there are further issues related to communication, cultural sensitivity and safety within mainstream services. Racism, both interpersonal and institutional, are widely discussed as having detrimental effects on Aboriginal people, while shame is known to prevent some Aboriginal people from accessing health care facilities (and/or possibly being engaged beyond an initial contact), in particular mainstream services where they may feel uncomfortable, embarrassed, or misunderstood.

Alongside these barriers to quality and effective care, the literature highlights issues for Aboriginal children around delayed detection and diagnosis, even though prevalence among these children is significantly higher than in non-Indigenous children. To some extent, this is because of the higher prevalence of asymptomatic OM in these children, partly because, as some qualitative studies have shown, parents can become resigned and cease to mention ear health during child health checks. It is also in part because most screening checks take place amongst school children and this is often too late for many Aboriginal children who may have been suffering with OM since shortly after birth.

The critical ingredients to successful research with Indigenous people, and methods that will underpin this study have been well covered in the literature review described above. Decolonising research methodologies are discussed as key to conducting research with and for Indigenous people, providing for ethical conduct which privileges the participants’ voices and acknowledges and values their culture. This involves Aboriginal ways of communicating through a process of ‘yarning’,

which can be social, collaborative, and therapeutic for those involved and allows participants to be comfortable with and involved in the research process. Indigenous research methods include the notion of ‘Two-eyed seeing’ (see Bartlett et al, 2012; Martin, 2012) which blends western and Indigenous ways of knowing to the benefit of all, with Indigenous researchers serving as a bridge between the cultures.

In sum, the literature shows that there is a range of health and social issues impacting on the ear health of Aboriginal children. These have a considerable effect on the quality of life for child, family, and community. The long-term consequences for the child can be severe across a range of measures, not only in terms of health but also socially, educationally, and professionally. This is unacceptable in any country but especially one rich in resources which prides itself on its health services such as Australia. And yet there are very few qualitative studies with Australian Aboriginal peoples on this issue, and none that were located for this literature review focused on Aboriginal children living in an urban area. The literature firmly supports the kind of research that has determined as a priority for this project. There is a need for qualitative work with Aboriginal people and Elders, that is conducted by Indigenous researchers, and that is culturally secure, and respectful. Such research will provide knowledge around how children and families deal with otitis media, opening the way for a better understanding of how health services in an urban environment can better address their needs.

CHAPTER THREE – METHODS

INTRODUCTION

To date, most of the limited research about otitis media (OM) and Aboriginal people has primarily been focused on the impact of OM in remote communities. My intention was that the Kadadjiny Dwank research project was to instead focus on urban settings to explore whether OM impacts in similar ways on Aboriginal people living in these areas to how it impacts people who live remotely. That is, to ask the question: do Aboriginal people living in towns and cities have the same types of issues with OM as do Aboriginal people who live in regional and remote communities?

The name of this research project *Kadadjiny Dwank* was provided by a local Nyoongar Elder from the Kwinana community: *Kadadjiny* means 'thinking, listening and learning' and *dwank* means 'ears' in the local Nyoongar language. The Elder also gave permission to use her design of a bird for any related promotional material.

The research questions for the project were focused on otitis media (OM) from an urban Aboriginal perspective. The questions were:

- What do people know and do about ear infections?
- What are the barriers to accessing care?
- How does OM impact on the child and family?

This chapter will outline the methods used to explore and examine these research questions.

Two locations in the Perth metropolitan area were selected from which to gather data. I live in one of the locations chosen for the study and this was major reason for the selection of the sites for the study. The sites, Kwinana/Rockingham and Armadale and located within the city of Perth. It was my intention that the Aboriginal people of the Kwinana/Rockingham and Armadale regions have their voices heard, and that this activity would inform approaches to improve services for

Aboriginal children and others who suffer ear disease. It is expected that findings from this research will contribute to the knowledge base around OM and its impact on Aboriginal people living in urban settings.

The remainder of this chapter will describe how the research was conducted: the research approach; how the community was engaged and recruited; what methods and methodology were used; how data were managed and stored; and, how ethical issues were addressed.

As an Aboriginal person from the communities chosen for the study, I was keen for there to be as much Aboriginal, and more specifically Nyoongar, ownership of the research as possible. Given that the research was conducted on Nyoongar country, with mostly Nyoongar participants, and myself as the researcher being Nyoongar, I believed, and there is some research basis to this position, that as many of the team as possible also should be Nyoongar.

Bearing in mind the widespread recognition in the literature that research "has been used as a tool of the colonization of indigenous peoples " (Porsanger, 2004 p. 107; also see, for example, Scheurich & Young, 1997), it was important that the community see Nyoongar people front and centre in the process and implementation of the research. The project followed Indigenous ways of knowing and doing around research, ensuring a decolonization process that encourages self-determination and cultural governance for control, and partnership with the project to allow for community and researcher to share power (Wright, 2011; Porsanger, 2004).

The research acknowledged and recognised community's knowledge, wisdom, lores and customs to ensure the study was undertaken in a culturally respectful and reciprocal manner (Nakata 2002). For me, this enabled cultural security and safety for Aboriginal people to attend forums and focus groups (Coffin 2007), whilst also showing the Aboriginal community that Aboriginal people are competent and capable as researchers.

METHODOLOGY

PARTICIPATORY ACTION RESEARCH

This research is about engaging the Aboriginal community in a way that empowers them to raise issues from their knowledge and experiences about OM and of how the disease is being addressed in their local area. The principles of Participatory Action Research (PAR) enunciated below not only empower community but also each individual to have control and self-management over their lives to ensure long term quality of life within their homes and community (Cox et al, 2014). These principles underpinned the overall research approach for this study.

PAR methodology emphasizes collective inquiry grounded in experiences and social history that encourages collaboration, to seek support and guidance, to educate, ensuring involvement from participants, thus enabling change on social or environmental issues (see, for example, Rigney, 1997; Moreton-Robinson, 2000; Tuhiwai-Smith, 1999, 2003; Battiste, 2007; Wright, 2011; Bessarab & Ng'andu, 2010). Stringer (2014) described action research as “a systematic approach to investigation that enables people to find effective solutions to problems they confront in their everyday lives ... In doing so it also seeks to build a body of knowledge that enhances the well-being of the people involved” (p.1). That is, all participants act collaboratively with the research team in the whole process of inquiry, including the conclusions, to resolve the particular issue or problem.

Chevalier and Buckles (2013) provide a visual explanation of PAR in the Venn diagram in Figure 1 below:

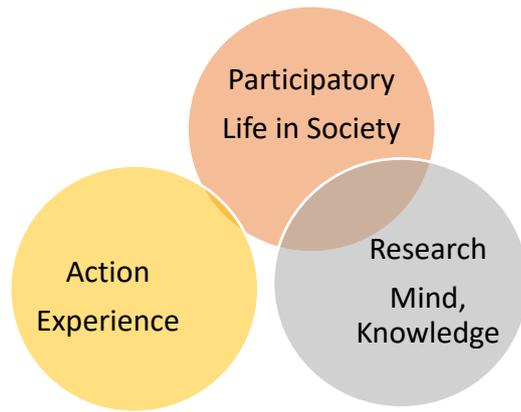


Figure 1. PAR Framework (Chevalier and Buckles, 2013, p.10)

Baum (2006) noted that PAR varies from other approaches of health research as it is based on reflection, data collection, and action that aims to improve and reduce inequities by including the people who will take actions to improve their own health. So, while action research is not the answer to everything, it has its advantages in research contexts and processes such as those to be undertaken in this study (Stringer, 2014).

While still considered relatively novel in public health research, PAR complements Indigenous research contexts where family, community obligation and commitments are recognised as core values (Rigney, 1997; Moreton-Robinson, 2000; Tuhiwai-Smith, 2003). This is not to say that PAR is the only approach for Aboriginal and Torres Strait Islanders and other marginalised groups. Porsanger (2004) is clear that Indigenous ways of doing research on Indigenous issues “are not meant to compete with, or replace, the Western research paradigm; rather, to challenge it and contribute to the body of knowledge of indigenous peoples about themselves and for themselves, and for their own needs as peoples, rather than as objects of investigation” (p. 105). In the context of this study, it was important for the community to feel that they were not only providing information during the research process, but also to have a feeling of ownership of the research – that it was about them, it involved their input, and had relevance for them.

In sum, there was no doubt for me as lead researcher that PAR with its origins and values as a research methodology was ideal for this research project. PAR as a methodology, as agreed by Whitman and others (2015), and by Wright (2011), gives the community a voice – and the means for that voice to be heard. In the spirit of PAR as discussed above, it is hoped that this research, using a method that does indeed give voice to the community, a voice that will be heard and will assist in improving the quality of care around management of OM in young children in an Aboriginal urban setting.

INDIGENOUS RESEARCH METHODS

The research methodology for the *Kadadjiny Dwank* research project aimed to accommodate those cultural norms and historical factors pertaining to Aboriginal people which distinguish them from the broader dominant society. The research process needed to incorporate Aboriginal ways of doing research. Porsanger (2004) summarises Indigenous Research Methodology as:

... a body of indigenous and theoretical approaches and methods, rules and postulates employed by indigenous research in the study of indigenous peoples. The main aim of indigenous methodologies is to ensure that research on indigenous issues can be carried out in a more respectful, ethical, correct, sympathetic, useful and beneficial fashion, seen from the point of view of indigenous peoples (p.107-108).

Porsanger further suggests that research approaches from an Aboriginal perspective must take into account Aboriginal people's interests, experiences and knowledge and incorporate "the principles of respect, reciprocity and feedback, which are crucial for indigenous methodologies" (p. 113). The sharing of responsibilities between researcher, community and family is important to ensure all problematic issues are resolved appropriately. The sharing of power enables community to lead and have control within the project so as to encourage a co-design for the study. The important principle of reciprocity is the emotional engagement that encourages building relationships, such as friendship, which required the researcher to be genuine, truthful and being transparent throughout the life of the project (Sofaer, 2014).

It is important to note here that, similar to the way in which PAR is regarded with scepticism by some scholars in mainstream research, Maiter (2008) pointed out that reciprocity is not often seen as important in health-related research whether it's to share data, feeding back to participants or to engage on an emotional journey, the researcher may feel it's not required or needed, their objective is to collect data and leave (Sofaer 2014). Wright (2011) argued that "Indigenous research and participatory action research can work together if there is the recognition that the Indigenous world-view is different" (p. 32), and that Indigenous researchers are conscious of decolonisation and validating Indigenous knowledge (see also Wright et al 2015).

Reciprocity was noted as a key principle in Eggins' diagrammatic attempt to capture key themes relevant to an Indigenous Research Approach, as shown in Figure 2 below:

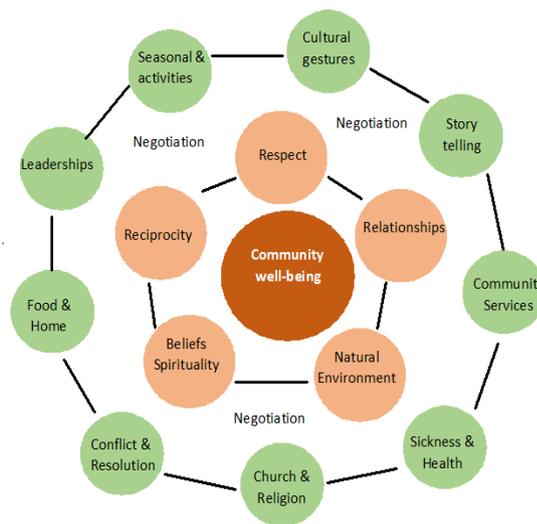


Figure 2:
Community Themes Relevant to an Indigenous Research Approach (Eggins 2011).

Smith (1999) identified that Indigenous methodologies tend to approach cultural protocols, values and behaviours as an integral part of methodology. She also mentioned that there are two important outcomes of reciprocity that are not always addressed by scientific research which are to do with 'reporting back' to the people and 'sharing of knowledge' (p. 15). It was vital that the research encompass reciprocity as a methodology throughout the data gathering, and as lead researcher I endeavoured to maintain an exchange of knowledge and experiences between the

team and community participants during all community events. Whilst the Aboriginal people in this study live in an urban context, Aboriginal ways of doing and thinking are still prevalent in their lives. The protocol of reciprocity certainly remains a strong practice today and needed to be factored into this research.

YARNING

Yarning as a formal research process (Bessarab & Ng'andu, 2010) was used throughout this project as a culturally safe and respectful tool to create a cultural practice of introduction and ongoing contribution.

Wilson (2001) emphasised that by adopting Indigenous research methods, such as yarning, we will better meet Indigenous communities' expectations and incorporate Indigenous values, beliefs, and ways of knowing, thus facilitating research that is respectful, collaborative, and relational. Similarly, Bessarab & Ng'andu (2010) have said that yarning complements Indigenous ways of doing things and it provides a sense of cultural security as a positive for Indigenous people to participate in research. The researcher and the participants become "knowers and learners in the process" (p. 47).

Yarning suits Aboriginal people's communication styles and the way they can relate to each other. Nyoongar and other Aboriginal people will talk about who your mob are and try to find that common connection, be it family or country or an activity such as football, especially if they don't know each other. According to Bessarab & Ng'andu the rules and protocols for conversation differ between cultures. As with other Aboriginal cultures across Australia, conversations between Nyoongar people are respectfully guided by the protocols around 'yarning', which is the sharing of information and of stories. Bessarab & Ng'andu describe it as:

Yarning in a semi-structured interview is an informal and relaxed discussion through which both the researcher and participant journey together visiting places and topics of interest relevant to the research study. Yarning is a process that requires the researcher to develop and build a relationship that is accountable to Indigenous people participating in the research (2010, p. 38).

The Nyoongar facilitator for the community consultations and the focus groups (other than the focus group with the Young Mums) was able to quickly build a rapport with the participants as many were known to him, which led to a safe and trusting environment. The facilitator then used the focus group questions as a guide to manage the focus groups in a conversational manner that very much enabled yarning to occur where narratives and stories could be heard, and everyone contributed. It appeared semi-structured, as described by Bessarab & Ng'andu, but it was structured and on-topic. By the end, all the focus group questions were covered, all stories were heard, and everyone was able to have a say. The approach in this study was entirely consistent with yarning as described by Bessarab & Ng'andu. As a research process, yarning worked very well with the Aboriginal groups in this research project.

ETHICS

The study was approved by the Western Australian Aboriginal Health Ethics Committee (WAAHEC) (Appendix A) and the Curtin University Ethics Committee (Appendix B). The researcher sought informed consent, and participants were offered referral to support services as needed. All data collected were de-identified to ensure confidentiality and secured in a locked location within the Telethon Kids Institute systems with only a few authorised people with access to the files. All forms such as questions, consent forms, and information sheets were approved by the supervisors, WAAHEC, and the Curtin University Ethics Committee prior to being used for the research project. Amendments were reviewed by community consultants, and the supervisor and ethics teams.

At the commencement of forums and other events, participants were asked for their consent for any photos featuring them to be taken and for their consent for the conversations to be recorded. All community forums and focus groups were digitally recorded. Examples of the information sheets and consent forms can be found in Appendix C and Appendix D respectively below.

CULTURAL GOVERNANCE

To ensure Cultural Governance for this research project an Aboriginal Community Advisory Group (ACAG) was formed in June 2017, and was still active until early 2019.

The ACAG, which included Elders, workers and younger people, provided cultural guidance, support and governance to the project. All members were Aboriginal people residing in the study areas. The ACAG also supported dissemination of findings and advice on how best to address the findings of the study. There were eight meetings, with four taking place in 2017 and four in 2018.

DATA MANAGEMENT

Recordings and transcriptions were stored in a locked cabinet at Telethon Kids Institute (TKI) and later at Curtin University, and consistent with NHMRC guidelines will be kept for a minimum of seven (7) years until 2025. University protocols to ensure confidentiality of data were rigorously followed. Data files are password protected and only accessible to the lead researcher. Public presentation of results only occurred after approval of the Aboriginal Community Advisory Group.

PLANNING THE STUDY

The initial planning of the study was undertaken with the team from the Telethon Kids Institute (TKI), as well as the Urban Ear Health Research Team, and supervisors from TKI and from Curtin University. The research plan included engaging Aboriginal people living in urban areas to explore with them the issues they experience with respect to OM and ear health. Community forums and focus groups were the research methods used to capture community narratives of lived experiences. The data from the forums and focus groups were then analysed to capture the common themes that emerged from the discussions.

In order to engage with the communities of the Armadale and Kwinana/Rockingham areas it was agreed to hold a community forum in each location. This would serve the multiple purposes of informing the community of the research, seeking general endorsement from community (in concert with the ACAG), and recruiting participants for further research activities such as focus groups.

It was also necessary to engage and seek the support of local Aboriginal organisations and other health agencies. Endorsement for the research by these local Aboriginal groups was made possible by building upon existing relationships within both communities. Their endorsement of the research encouraged community people to be involved and assisted in the recruitment of participants for focus groups, and especially in identifying families with children who had experienced, or were experiencing, OM.

Moorditj Koort ('good heart') is a local Aboriginal Health and Wellbeing Centre aimed at supporting all aspects of the wellbeing of the Aboriginal and Torres Strait Islander people who reside in the Kwinana and Rockingham areas. They currently provide Ear Nose and Throat (ENT) services for community. In Armadale, the Champion Centre hosts community-based programs, playgroups and service agencies for Aboriginal people. Each organisation was approached by the *Kadadjiny Dwank* research team to seek their endorsement and support for the project.

Prior to the commencement of the project in Kwinana, the *Kadadjiny Dwank* research team met with the Moorditj Koort Chief Executive Officer and provided a detailed overview of the project. Given its importance to the local Aboriginal community the CEO readily agreed for the organisation to support the project and provided a letter of support to that effect (Appendix G). The Champion Centre Aboriginal Reference Group also supported the project; they provided the venue for the Armadale community forum. Obtaining endorsements from local community organisations also satisfied ethics requirements both from the Curtin University Human Research Ethics Committee (HREC) and the Western Australian Aboriginal Health Ethics Committee (WAAHEC).

Community forums and focus groups were deemed culturally safe and appropriate as the data collection method for the project. It also allowed for the sharing of knowledge and service information, providing support and guidance to the Aboriginal people who participated in the research. As already noted, an Aboriginal Community Advisory Group (ACAG) was formed from the Armadale, Kwinana and

Rockingham areas. Members were selected from the Community Forums and they provided cultural and procedural guidance for the project. The ACAG provided a mechanism for an appropriate in giving feedback on the progress of the study. Many of participants who attended the focus groups were enlisted through the community forums facilitated by the research. As to be expected, the community members who attended the community forums had direct personal experience of their children having otitis media; they were able to yarn about their lived experiences of living with OM, the barriers they faced and how they coped with their child living with OM. With participants' permission, all focus group conversations were recorded and transcribed. The data from the transcripts were then analysed for key themes running through the various conversations of each focus group. Details of these processes are discussed below.

SELECTING THE STUDY AREAS: WHY KWINANA/ROCKINGHAM AND ARMADALE?

The Kwinana/Rockingham and Armadale areas are suburbs on the outskirts of the southern urban sprawl of Perth, Western Australia (as shown in Figure 3 below). Both locations have a significant population in the lower socio-economic groups. Both locations also have a relatively large population of Aboriginal people from which to recruit participants for this research project.

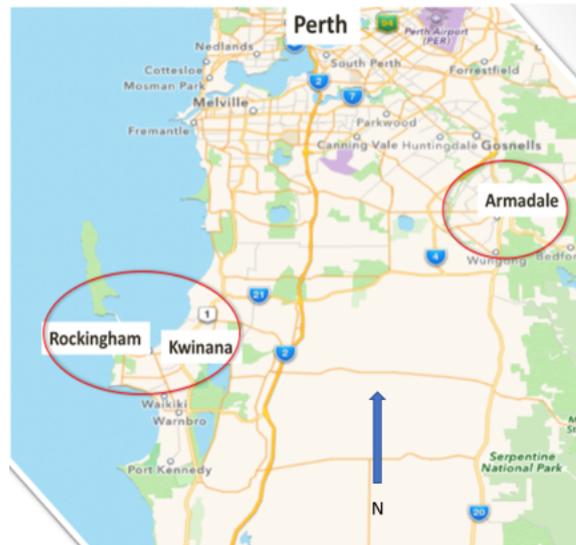
The geographic areas chosen for inclusion in this research study have large, active Aboriginal communities. At the date of writing, the most recent figures for the location and numbers of people who identified as Aboriginal and/or Torres Strait Islander in the study areas from the 2016 Census of Population and Housing were:

- **In the Kwinana** area, which lies about 40 kilometres south of Perth, 1,405 people.¹⁶
- **In the Rockingham** area, which lies about 48 km *south* of Perth, 2,567 people.¹⁷

¹⁶ <https://profile.id.com.au/kwinana/indigenous-keystatistics>

¹⁷ https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/LGA57490

- **In Armadale**, which is located 28 km on the south-eastern edge of Perth, 2,035 people.¹⁸



Google map of Perth

Figure 3: The above map indicates the locations of both study areas in relation to the central Perth CBD.¹⁹

Kwinana and Rockingham are generally regarded by the Aboriginal people from the two suburbs as inseparable, as being one location. Rockingham has a secondary hospital and an Aboriginal mums' support service, Babbingur Mia. As noted earlier, Kwinana has an Aboriginal health service - the Moorditj Koort Aboriginal Health and Wellness Centre - and an Aboriginal community centre, the Medina Aboriginal Cultural Centre. Armadale also has a secondary hospital that employs Aboriginal liaison staff and offers the *Boodjari Yorgas* program for women who are pregnant. Armadale also has a local government resourced Aboriginal community centre that offers a range of social and post-natal programs for women with newborns.

¹⁸ <https://profile.id.com.au/armadale/indigenous-keystatistics>

¹⁹ Adapted from [https://www.google.com/maps/place/Perth+WA/@-32.0186637,115.8443538,11.49z/data=!4m5!3m4!1s0x2a32966cdb47733d:0x304f0b535df55d0!8m2!3d-](https://www.google.com/maps/place/Perth+WA/@-32.0186637,115.8443538,11.49z/data=!4m5!3m4!1s0x2a32966cdb47733d:0x304f0b535df55d0!8m2!3d-31.9505269!4d115.8604572)

[31.9505269!4d115.8604572](https://www.google.com/maps/place/Perth+WA/@-32.0186637,115.8443538,11.49z/data=!4m5!3m4!1s0x2a32966cdb47733d:0x304f0b535df55d0!8m2!3d-31.9505269!4d115.8604572)

INSIDER/OUTSIDER ISSUES

I grew up in the Kwinana area and so I am very familiar with that location and with Rockingham; and living not far from the Armadale area I am also familiar with that area and people. This helped build relationships and trust within a short period of time. This familiarity, together with the presence of significant Aboriginal populations and Aboriginal Community Controlled Organisations (ACCOs) in these communities, was expected to facilitate the research in a two main ways:

- I would know many of the people in the two locations and the likelihood of recruiting participants would therefore be enhanced; and,
- many of the Aboriginal workers in the local ACCO's are known to me.

Of course, such familiarity can contribute to other challenges. While there are advantages in this in terms of access, there are also the potential issues of bias and influence. As a Whadjuk Aboriginal woman working closely with the community I have deep connections and strong relationships with the Aboriginal communities selected for the study. As expected, doing research in my own community, I have experienced many challenges and these I have considered and noted.

Reflecting on my unique position in this research project, I have been informed by the concept of insider/outsider as it has been discussed and described by Kerstetter (2012), and others (see, for example, Kanuha, 2000; Serrant-Green, 2002; Dwyer & Buckle, 2009). Kerstetter notes that within the framework set out by Dwyer & Buckle "all researchers fall somewhere within the space between complete insiders and complete outsiders" (p. 101).

Thus, for a researcher, the notion of insider/outsider is a little more complex than simply being one or the other, and the positionality of the researcher is dependent upon a range of variables, including the characteristics of the researcher and of the research itself (Kerstetter, 2012). Familiarity with the concepts of insider/outsider discussed in this literature has made me conscious of my role and any influences I may bring with me, to ensure that these do not unduly impact on the research and its outcomes.

NYOONGAR COMMUNITY RESEARCH TEAM

In keeping with both the principles and intention for this research project it was agreed that the project should be Aboriginal controlled and directed. It was, therefore, imperative that not only should the team be Aboriginal, but identify as Nyoongar as the project was being conducted on Nyoongar country. Whilst the research project had non-Aboriginal team members involved, from the Urban Ear Health Research Team, it was important that the local Aboriginal community recognise the project was being led by Nyoongar people. This is consistent with the advice and approach embraced by Wright et al (2013). When writing about the *Minditj Kaart-Moorditj Kaart Framework* they noted that:

An important component of the Framework is the visible presence of Nyoongar cultural leadership, a feature also echoed in the research team itself, namely through the presence of the Nyoongar lead researcher, Nyoongar Elder and Nyoongar consultant ... (p. 54).

The current project engaged Nyoongar people as both facilitator and notetaker. The lead researcher is herself, Nyoongar. By having the Nyoongar team enabled a culturally safe environment that allowed participants to feel both comfortable and safe. The facilitator and notetaker attended the two community forums and the three focus groups together with the lead researcher.

It was also agreed that it would be more appropriate that the focus group with the *First-time Mums* be facilitated by a female. Creating a safe environment that allowed young mums to talk more freely without being shy or embarrassed was a priority. The lead researcher facilitated these sessions. The safe space allowed mums who were breast-feeding to do so without feeling uncomfortable or embarrassed..

The digital audio recordings were transcribed and cleaned by Nyoongar people to ensure consistency and accuracy of Nyoongar words and their meanings spoken during the sessions. This allowed for any inconsistencies to be corrected. It was agreed that the person/s transcribing and checking be Nyoongar so as to ensure cultural integrity of the data was maintained.

INFORMING THE COMMUNITY

It was agreed that the project would use a flyer to promote the project to the community (see Appendix E). The flyer was designed to both attract the attention of community members and key stakeholders, and to recruit community members to attend the community forums. The flyer included information about the research project, and details of how to become involved. It provided details on how to attend the community forums and how to contact the lead researcher for further information.

The draft flyers ideally should have been approved by an Aboriginal Advisory Group (the ACAG) to check that they were culturally appropriate and fit for purpose; however, the advisory group had not been established at this stage of the project. As a result, the flyers were developed by the lead researcher with input from supervisors – which included a senior Nyoongar academic. The process was iterative with the intention of ensuring clarity around the communication of the key points related to the project. It was important that the flyer be written at an appropriate level to cater for a range of reading skills. It needed to be simple, clear, and informative, and constructed and organised in a manner to avoid any confusion – to offer clear communication to all interested within the communities. For example, talking about 'ear problems' rather than 'otitis media' ensured that the focus and purpose of the project was very clear to people reading the flyers.

General agreement was given that the flyers were culturally appropriate, and consistent with the key communication issues and aims. The flyers inviting community members and key stakeholders to attend the community forums and learn more about the project were then distributed throughout Armadale and Kwinana/Rockingham to key people and organisations.

DATA COLLECTION

COMMUNITY FORUMS

The community forums were open to all Aboriginal people in the community who were interested in ear health. Participants at community forums included Elders, representatives from community organisations/Community Health Centres (Aboriginal Health Practitioners), parents and grandparents. Participants were

interested to be given more information about ear disease and were eager to share their experiences and concerns around the ear health of children in their community.

Participants were recruited for the forums by the following ways:

- community members and others who responded directly to the flyers;
- persons associated with the lead researcher who had asked to be involved;
- persons who were known or were clients of an ACCHO and were then invited by the ACCHO worker/s to be involved; and,
- the technique of ‘snowballing’, where participants already involved, suggested attendance to other likely community members who they thought might be interested in being involved.

The Moorditj Koort Aboriginal Health and Wellbeing Centre greatly assisted in promoting the community forum for the Kwinana/Rockingham area. This forum was held in a meeting room at a local community centre in Kwinana. As noted above, Moorditj Koort provide ENT services for community members in the Kwinana area, and so the forum was promoted by staff for families of children living with middle ear disease. Moorditj Koort staff contacted the families who they knew had children with middle ear disease and invited them to attend the community forum. Potential attendees were provided with the flyer, which included my details as lead researcher, and contact details if they had any concerns or questions prior to the event. This process allowed participants to make an informed decision about attending the forum.

A similar approach was adopted for the Armadale forum, which was held at the Champion Centre. The Centre is a well-known location for the local Aboriginal community. Staff of the Centre assisted with promotion of the forum and by contacting people who would most likely attend.

A community forum was held in each location to inform the potential participants about the research project, and to seek their (informed) endorsement. If support for the project was apparent, details were provided for their attendance at focus groups and for their expression of interest to join the Community Advisory Group.

As has been noted above, one of the advantages of the researcher coming from one of the communities where the research was undertaken, was that there was already knowledge of those communities and that relationships and trust were already established. This assisted with making contact with local Aboriginal organisations to set-up meetings to introduce the project and the researchers. It must also be recognised, however, that this can also be a limitation, where familiarity may mean not picking up on some interactions because of habit or of how people fit into their familiar roles. This makes it possible for the unfamiliar and the unexpected to be unrecognised or overlooked.

The community forums in this study were used to:

- inform and explain the study and the research questions to community members;
- provide information to families about OM, what it is and how it affects children and families;
- provide an opportunity for community members to share stories of how OM affects them and their children and families, voice their opinions, concerns and solutions around OM in an informal manner;
- seek support for the research project; and,
- recruit participants for focus groups.

The community forum in Kwinana was attended by 15 Aboriginal people, made up of community people, workers and Elders, and the forum in Armadale had 10 attendees from a similar mix of backgrounds. Attendees were thanked for being a part of the forum and an Elder provided a Welcome to Country. This was followed by introductions between all and allowed an opportunity for people to ask questions or make comment. The principles of participatory action research (PAR), reciprocity and yarning were applied to the community forums in each of the study locations. In line with these principles, all participants were given the opportunity to say who they were, where they were from, how long they had lived in community, and what they would like to get out of the day. This was undertaken before any information about the project was provided to encourage participants to feel safe and comfortable,

facilitating their contribution to the forums and focus groups. As well, often in these types of community meetings, people will make statements about issues that may not be related to the purpose of the meeting. To some extent this needs to occur as it encourages people to talk/take part, while still ensuring that attention is paid to the original purpose.

Following this, a power-point presentation outlined the purpose of the forum and explained the research project, including who was involved. Attendees were then able to ask further questions and indicate whether they would like to be involved further in the project.

Reciprocity is important when conducting research with Aboriginal people (Wright, 2011). Therefore, refreshments were provided at all events, to ensure the giving back to the community for their participation and generosity. It also helped with conversation and allowed for people to feel more congenial, relaxed and helped to maintain their energy levels for the period of the event.

Reciprocity was also facilitated by providing information when questions were asked and by providing health advice if sought.

The Urban Aboriginal Ear Health research team was present at both community forums. This team was made up of both Aboriginal and non-Aboriginal researchers, and included specialists such as an Audiologist, allowing for people who attended the forums to have their ears checked and be provided with information about any issues they may have. In this way, one simple ingredient of reciprocity was realised – inviting people to talk about ear health was complemented by the opportunity to have personal ear health assessed. Similarly, other medical professionals with the Urban Aboriginal Ear Health team were able to respond to questions that required medical knowledge and provide information around current understandings about the causes and consequences of OM. The research team had the requisite expertise to explain medical terminology, the workings of the inner ear and to dispel various myths about the disease. This process of sharing and giving back to community was reciprocity as

a research method in practice, contributing to the research being more meaningful and effective for the community.

At the conclusion of the study, a final community forum was held in Kwinana to inform and seek feedback from the community and other health services providers for the project. The forum provided the opportunity for members of the community to ask questions and offer suggestions for the recommendations and solutions for ways forward. The community was assured that the study would contribute to improving access to ear health services in their area.

FOCUS GROUPS

Focus groups have been shown to be useful for the researcher as an exploratory data collection method proven effective for gathering quality information from a small number of people where group interaction is well-organised (Masadeh, 2012) and to "gain valuable information on language or behavior specifics" (Threlfall, 1999, p. 103).

Focus group participants were recruited from the community forums, through word of mouth from community members, and by the Aboriginal organisations asking individuals with OM in their families if they would like to be involved. Focus groups participants included Elders, young mothers, representatives of community organisations, parents and grandparents. The majority of participants were women. Some focus group participants had also attended community forums and were keen to learn more about ear disease and help address some of problems they had faced in their own experience.

Each focus group comprised a group conversation between those attending (12 and 8 in the community focus groups, and 3 for the First Time Mums group), and followed a semi-structured script of questions to discuss what they thought, felt and knew about OM. Prior to using the focus group questions the researcher workshopped the questions with two Community Aboriginal Health Workers/Practitioners to ensure the questions were respectful and safe for participants as well as relevant to the

research study. No issues of concern were identified (the question protocol can be found at Appendix F).

Focus groups were formed for each of the two study regions. A third focus group (discussed below) was conducted solely with young mothers as a specific cohort with small children to gauge their level of knowledge and understanding of OM. The focus questions were based around the research questions to explore what was happening in their community and how it impacted on child, family and community.

As with the forums, attendees were thanked for taking part, and an Elder provided a Welcome to Country. This was followed by introductions between all and allowed an opportunity for people to ask questions or make comment. The focus questions that were used in the focus groups were:

Introductory comments: Let's yarn about ear infections - your understanding about them, what do you know about them? And issues you may have around them.

Prompt: experience hearing loss e.g. Fred Flintstone or fingers in ears?

Note: the reference to Fred Flintstone here refers to a three minute animated educational video located on YouTube that demonstrates hearing loss. The animated video uses characters from the Fred Flintstone cartoons. The video clip is used to highlight hearing loss as part of discussions in the focus group sessions.

What do you know and do about ear infection or OM?

1. Has anybody had an ear infection or had a family member with ear infections, poor hearing, or speech difficulties?
2. How do you recognise ear infections in children?
3. What do you do when a child has an ear infection?
4. What has worked / not worked for you?

Worked: *(Prompts: prevention, treatment, who to go to (particular ear health providers), AHW to talk about prevention as and when appropriate (reciprocity))*

Not worked: (*Prompts: barriers to accessing care or what stops you/family from going to the doctor or health care centre; transport; cost; wait lists; cultural/respect*)

5. How do ear infections/OM impact on child and family? (*Prompts: impacts on our children, this may include difficulty hearing and bad behaviour. These can also affect families*)
6. Does anything need to change to improve ear health in community? (*Prompts: service providers, prevention, community, family. What do you think needs to happen to enable change? / How would you like to see ear health services in community change?*)
7. What is working? How do we maintain it?
Final prompt: Anything else?

FIRST TIME MUMS

In addition to the whole of community focus group, it was planned to have a separate session with younger first-time mums, all aged in their mid-20s, who had children with OM. The participants for this group were mainly enlisted by Moorditj Koorditj who approached them to see if they would be involved. It was felt that a younger first-time mums' group might have different stories and experiences from those of older people, given they might have a young child currently with OM in their care. This space provided an intimate environment for new mums to share experiences and knowledge on ear health. Some young women can be shy and reluctant to share their stories amongst others, including Elders and grandmothers. First time mums appreciated having a private and safe space to share their experiences and to ask their questions. It was felt important to capture this data. The First-Time Mums focus group was held at Moorditj Koort (good heart) Aboriginal Health and Wellness Centre and involved participants who had only given birth to one child, but may have been caring for other children at home.

Attendees were thanked for taking part, and an Elder provided a Welcome to Country. This was followed by introductions between all and allowed an opportunity for people to ask questions or make comment. The questions for the first-time mum's group were adapted from the focus group questions outlined above to reflect the fact

that they had a small child in their care. Again, the focus questions were based around ear health. The First Time Mums questions were again presented and explored through yarning, as was done in the other focus groups. As was noted above, it was deemed more appropriate for the facilitation of the First Time Mums focus group be facilitated by a female and was therefore undertaken by myself as both a female and lead researcher.

The questions used for the First-time Mums focus group session were:

1. What do you know about *otitis media* (*prompt ear infections*)?
2. Are you able to tell if your baby or child has got an earache and/or infection and if so what would you do about it?
3. What do you understand about the Newborn Hearing screen? Was your baby's hearing checked at birth in the hospital or in community? How did this make you feel?
4. Have you had your baby's ear checked? Can you tell us about your experience? Where do you get your baby/child's ears checked?
5. Have you received information about ear health? (*prompt: what information were you given? From where?*) What did you learn from it?
6. What has worked / not worked for you and your baby/child?

Worked: (*Prompts: Prevention: how do we stop kids getting ear infection/ treatment; Who to go to (particular ear health providers): talk about prevention as and when appropriate (reciprocity); Family support*)

Not worked: (*Prompts: barriers to accessing care or what stops you/family from going to the doctor or health care centre; transport; cost; wait lists; cultural/respect*)

7. Has ear infections/OM impacted on you and your baby/child and/or your family? (*Prompts: impacts on our children, this may include difficulty hearing and bad behaviour. These can also affect families (stress)*)
8. How do you feel when you take your baby to the doctors or Community Child Health Centre for ear and hearing checks? (*Prompt: if your baby has had ear infection, what did you do, what did the nurse/doctor do or say/ were you happy with the treatment? How did you feel?*) Did you know where to go next?

9. In your opinion, what is the most important thing that could change to improve ear health in community? (*Prompts: service providers, prevention, community, family; What do you think needs to happen to enable change? / What changes would you like to see for ear health services in the community?*)?

Participants from both the community forums and focus groups gave their permission for the sessions to be audio recorded and to have photos taken.

ELDERS

Elders are the governing body of the community. Elders have the authority in providing cultural support and guidance for family and community. Their role is vitally important in providing the formal cultural support for family and community. The Elders' attendance at project events was necessary as their presence and guidance (for researchers and community) provided the cultural authority for the research. Elders attended *Kadadjiny Dwank* events, and were members on the Aboriginal Community Advisory Group for another ear health project, the 'Urban Aboriginal Ear Health Program'.

DATA ANALYSIS

Three Focus Group transcripts provided the primary source of material upon which thematic analysis was conducted. The audio recorded information was transcribed, cleaned and stored in NVivo, a qualitative data analysis computer software program. NVivo has been designed for qualitative researchers working with text-based and/or multimedia information, where deep levels of analysis on small or large volumes of data are required.²⁰

The transcripts were coded individually by the lead researcher and a colleague from the Ear Health Team at the Telethon Kids Institute. Themes were identified, discussed and matched to the research questions; key themes were then identified. In order to accurately honour the voices of our participants, we ensured that the process

²⁰ See <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>

of analysis was organised in such a way as to accurately reflect their lived experiences and knowledge as it was shared with us.

The data were also checked manually to ensure themes were accurately reflected from the source material. Checking manually ensured that the key themes identified from community discussions were accurate.

Investigator triangulation was used to support the analysis. Analyses were conducted via two groups and individual work. The first group consisted of the lead researcher and a colleague experienced in data analysis in pre-coding key themes from NVivo. The second group were from a research team from Curtin University and the Telethon Kids Institute who have extensive experience in qualitative methods and analysing data using the NVivo system. Three pre-coding sessions were held to discuss the emerging key themes of the transcripts. The second team provided the support and expertise on pre-coding transcripts to help identify key themes. This process provided the rigour and validation of key themes from the transcripts using NVivo. Research team discussions were held around the data analysis process and about how conclusions were reached. Care was taken to structure coding around the research questions.

CONCLUSION

The Kadadjiny Dwank qualitative research project's method and methodologies were based on a Nyoongar worldview. The three main research processes for this project were:

- Yarning.
- Participatory Action Research (PAR).
- Reciprocity.

These research processes enabled Aboriginal control of the research, which contributed to the building of respectful relationships, inclusiveness, empowerment, cultural governance, cultural security, and the following of cultural protocols. The integrity of the research was guided and ensured by the ethics code of conduct from WAAHEC and the Curtin University Ethics Committee through the duration of

the project. This validated the rigour of the research and also included management and security of the data and analysis to protect the participants.

The researcher also took into consideration the impact of past policies and practices of oppression and segregation that have left a legacy of distrust, disempowerment and a sense of hopelessness for Aboriginal people. The undoing of past discrimination and the entrenched attitudes and perceptions of today will require a decolonization approach such as is taken in this research, ensuring that Aboriginal people are listened to and heard, to deliver a strong voice for community to bring about change for Aboriginal people accessing mainstream services to combat OM in community.

CHAPTER FOUR – RESULTS/FINDINGS

Findings from the research project were extracted from the data collected and analysed by the qualitative data analysis software program NVivo,²¹ which identified key themes from the research that took place in study areas Armadale and Rockingham/Kwinana areas. The results were based on the research questions:

- What do people know and do about ear infections?
- What are the barriers to accessing care?
- How does OM impact on the child and family?

These themes come from the voices of the Aboriginal community.

STUDY PARTICIPANTS

All community members who participated in the *Kadadjiny Dwank* project were from the urban Aboriginal community in Kwinana, Rockingham or Armadale. Participants attended one or more of Community Forums and Community Focus Groups as shown in Table 1 below.

Activity	Location	No of participants
Community Forum	Kwinana	15
	Armadale	10
Community Focus Group	Kwinana	12
	Armadale	8
	First time mums	3

Table 1: Activity, location & participant numbers

Data collection activities came from a sharing of information, which respects the cultural value of reciprocity of giving and taking. Hearing about lived experiences was critical to understanding what it was like for families who live with a child with OM, to understand how it impacts the child and the family, and what families go through on a daily basis.

²¹ See <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>

WHAT WE LEARNED

WHAT DO FAMILIES KNOW ABOUT OM?

Mothers with children who had a family history of middle ear disease knew more about the disease than did other family members who had not had experience of the disease. For example, participants who had lived experience of OM reported recognising symptoms of OM as pain, pus/runny ears, pulling or scratching of the ear, blocked ear/nose, deaf or not responding, or, having a temperature, and they linked it to having the flu.

Most families reported, however, that they only really knew about the effects of OM once a child had been diagnosed. That is to say, at this time they began to recognise in their children developmental delays, such as being slow to speak, inability to communicate, behavioural problems, and difficulties with engaging with family or friends, or with teachers and peers once they were at school.

Early in the discussions it was apparent that many young mums had minimal knowledge about what constituted good ear health. They recounted how much they relied on family for advice and support and, if required, for reinforcement of the need to take their baby to either a general practitioner or to hospital. They spoke about the importance of how knowledge is communicated among and between family members, including aunts and grandparents when their babies were sick. They were eager to share their stories and to learn more about ear health. Recent experiences were still quite traumatic and fresh in their minds. Discussions in both focus groups, through the sharing of ideas and stories, apparently offered a rare opportunity to listen and learn from their peers and to increase their knowledge about ear disease and what preventive actions they can take. This element of the research indicated that meeting together as peers in this way may be more effective than just providing health sheets for families.

Young mothers and those without a family history of ear disease reported not knowing what otitis media was; what were the risk factors; what were the

consequences for a child's development, or what to do if their child had ear problems. *"It's just an earache, it will go away"* was a statement by one participant.

One young mum shared that when her daughter *"... was 3 months she was sick and wouldn't settle. Doctor said next day she had earache. I had no idea"* [that her child was suffering from an earache].

Another young mum, who works for a local health and wellbeing organisation in ear health said, *"No, I can't tell [if baby's got an earache]... I just assume it's a flu, she hasn't pulled ears so I think she's right. If it's red it's infected, right?"*

A few participants knew about preventing ear disease by, for example, blowing the nose and eating fruit/good diet. One recipient wanted to know why some children get it more than others. Some participants reported *"not getting it [the ear] wet"* or monitoring the ear or *"keep an eye on it"*.

Generally, though, participants said they would seek medical advice, or advice from a community health worker or family. Participants clearly relied on doctors for treatment and medication:

... I took her straight to the doctor, gave her antibiotics and it's cleared up and she's better. Keep my eye on it all the time now...

BARRIERS

These following stories tell of the challenges families face when considering going to health services, and we define these as the barriers confronting families in accessing the quality care that may support their child, increase the likelihood of diagnosis and, reduce the possibility of OM having long term health impacts on a child. Table 2 below summarises key themes from participants of Kadadjiny Dwank focus groups reported as barriers to accessing health care.

Table 2: Identified barriers to families accessing health care

Key theme	Description
Impact on child	How otitis media impacted child's life
Impact on family	How otitis media impacted family's life
Racism	How they were treated; being judged; intergenerational trauma felt by past experiences of health care services; bad memories; fear
Shame	How they felt (shy, embarrassed, afraid and judged)
Misdiagnosis	Includes misdiagnosis within the PHC system - not identifying or misdiagnosing OM
Dysfunction of health services	Experiences of Primary Health Care Services not being available or not working for people. Also systems not working together to support families. Includes lack of cultural understanding
Community /Cultural safety	Providing a culturally safe place/environment for people to come together either as a health service or within community
Issues of communication – two-way language barriers	Primary Health Care workers not able to understand or not listening to what the mother/carers are saying/meaning - or vice versa the family/carer not understanding what the Primary Health Care worker is saying
Normalisation of ear disease in community	About what to do and who to see; understanding disease and associated behaviour in children
Disempowerment	Participants feeling they were unable to challenge people perceived to be important, or those in positions of power

Participants in this research project shared their experiences of the issues that create barriers for families accessing services.

Colonialism, negative stereotyping and racism

Shame

Shame was another common theme that emerged from the study. Participants shared their lived experiences of how they felt during and after visiting the doctor's or after home-visits by non-Aboriginal people. They talked about what made them feel shame. Shame was identified as being vulnerable, being alone with no support for them, or that shame could lead to feeling judged or a feeling of being inadequate.

Shame is an emotion, of feeling shy, embarrassed, afraid, inferior, inadequate, that can be influenced by a range of factors, but in this context particularly because of feeling or being judged because of your race. These feelings also come from feeling disempowered, exposed to feeling inadequate or inferior.

Shame, for both adults and children, may be because they have, or are perceived to have, a disability and they don't like the image of wearing something like a hearing aid which shows they have a disability:

I'm supposed to wear [hearing aids] when I was in my twenties, I was shame. I wouldn't wear it, it's the shameness of it because of people, you know your own family will call you names.

Sometimes sitting silent, or not asking questions can also be an indication that the person is feeling 'shame'. This may be a barrier to accessing care because families and carers may feel uncomfortable or embarrassed about how they are treated or being judged, looked down on. Participants relayed stories such as:

... I get shamed when I can't hear and I've got to say to the doctor excuse me I didn't hear you. I hate that, so I'm looking at my daughters and my husband cause they are my ears ...

Or there is a more silent shame:

... sometimes they (the doctors) judge young mums, we say we need help but they judge us. I've got a good GP so I'm lucky. Sometimes young mums get shame ...

... I think people hide it. I think even some of the people that are asked ... just say no.

Another observation is that people just nod their heads because it's too shaming to ask questions, because "... you don't understand":

... probably a lot of those ladies out there (in community) think that there is no support and they might be shamed to come this way (accessing mainstream services) ..."

As a solution, this participant reflected that "...maybe their aunty say [she will] come along to this ...", to stop young mums from feeling shame and as offering support. So the Aunty, in this case, would encourage them to go to a [mainstream health services] and not make them feel shame about going.

Another young mother related her experience of feeling judged as less competent by a health worker because of her young age and Aboriginality:

... she [non-Indigenous nurse] was always nagging in the wrong way, she was judgemental, she was judging me cause I wasn't ready right then and there ... she had her nose [up] at me. The Indigenous nurse ... she'd always come around and like she was completely different... sometimes they just judge young mums when they're saying something's wrong with my baby and they don't listen coz they're young so it's kinda like ... young mums get shamed.

This nurse's attitude, behaviour and actions made the young mum feel uncomfortable, from being judged, and feeling that the nurse had "her nose [up]" at her. She stated her belief that young mums, when treated in these ways, can feel shamed and disrespected. This can present further barriers to seeking, accepting or remaining in services which are there to provide support. A less dynamic and assertive young mother might have been shamed to such an extent that she disengaged with the health service.

As a solution an Elder at one of the focus groups encouraged young mums to speak up if they don't understand:

... don't be frightened to ask questions because part of our culture is that we don't ask questions ... But ask questions ... it doesn't matter if they sound silly or not but you gotta know coz we don't know a lot of things.

Misdiagnosis/failure to diagnose

Families also reported feelings of helplessness around misdiagnosis or late detection of OM at the primary health care (PHC) level, and frustration that they felt unable to challenge the doctor because they did not know enough about the disease or what was happening to their child. As a result, they may leave the surgery with their child's ears still not treated. This led to further stress and frustration, knowing that their child continued to suffer. Some mothers talked about their anger toward the doctor because the doctor had failed to help their child.

A majority of people spoke of their experiences of Primary Health Care services as not being available or working for them, and also of systems not working together to support families. One young mum explained how stressed and frustrated she was by the PHC system:

Just how much I had to go through and not only what I went through it's just how long it took me to pick it up and how many doctors I went to, and I seen like three different doctors and that was back when I was ... staying ... at my dad's. So I was out there for about three years then I returned back to Rockingham so yeah out there it was pretty hectic. You could tell something was wrong and every time I explained to the doctors they just [said] "Oh no, it's fine, he'll be right, [or] he'll grow out of it". Handballs more or less, yes, so three different doctors, three different surgeries.

Another mother told of her child being misdiagnosed by a doctor:

... I went when she was 4 months, her breathing wasn't normal, he just said take her home and take antibiotics, Nan said take her hospital, hospital said she had bronchitis and we had to stay in hospital for four days...

Once diagnosed, another mother expressed relief at being able to explain behaviour issues. As described by this grandmother, families also reported stories that once a specialist was involved things seemed to flow and work for them, indicating the main barrier they experienced was at the Primary Health Care level:

I don't think the local GPs have got proper knowledge of what's going on with a child ... they're not specialists. If I never seen this Irish fellow at Moorditj Koort ... [we would never have known what was wrong]... Everything he said was pinpoint to what was going on ...

People related instances of issues arising where people were not given information or where it was not shared between medical professionals:

I couldn't tell about the bone, so we had to wait til she got sick ... It's up to the doctors and the specialist to make sure they tell us.

Families rely heavily on the doctor's diagnosis to know something is wrong and then what to do about it. Some families reported not knowing about the diagnosis:

No, I wasn't happy with how they treated me. He was diagnosed [in] 2015 by the ear bus at school and they didn't tell me. It was two years between when they diagnosed him and ... I found out [in] 2017. I've had the same number this whole time. They didn't call me or tell me ... And I think at the time, the child health nurse referred him over so we didn't go through the doctor ... he's ... in speech therapy now because he's just not getting it and we've only just been referred to an ENT. But there is a giant wait list. ... also I've just found out ... that he's actually deaf in one ear and I wasn't told. The speech therapist actually told me ... where the doctor should have told me, there was no communication.

Participants also indicated some lack of cultural understanding:

Yeah well, she's like, judgemental. Yeah, I was just about to say felt like in a way she was judging me like I'm not ready right there and then or this, this, and when I was ready for them to come around and take me or pick me up I'm waiting for them and they never came so ...

It could have been identified a lot earlier, I couldn't tell about the bone so we had to wait until it was bad. The health system needs to be more caring for Aboriginal people and listen to us. I hated it. I couldn't hear but I was too shame to say I couldn't hear that so I look at my daughters cause they are my ears.

Other stories related to negative experiences, for example:

Well it ... didn't stop it, coz it kept going but she [had] to have all these operations ... the doctor told me only when she was a woman that it destroyed, ruined her ears. That she shouldn't have [had] all those operations. So why didn't they tell us back in those days? ... I guess they only just found out ... operations don't really do a lot of good for certain people.

Not all GP's fail to detect middle ear in Aboriginal children, some get it right and when they do it makes a huge difference for a child to get treatment immediately. These parents couldn't have been happier when the doctor was able to diagnose OM. They praised their local GP for diagnosing OM in their child's ears at age two, and were impressed by how quickly they had fast tracked the child to see a specialist:

... they had to make sure my son was fast tracked because of his age, he was over two by the time so... they had to make sure he was fast tracked so he was pretty good like and that was all through the normal GPs and the normal team, without the help [of the] the health community and Indigenous. It was alright. I was really impressed how they made sure he was fast tracked.

Community /Cultural safety

Another barrier identified by Elders at the focus groups was the issue of community members feeling safe within community. A group of Elders indicated that some families had existing unresolved disputes with families of health service staff or other patients and, as a consequence, feared for their safety when attending the health service. It was suggested that health services should actively address such barriers to access:

They wouldn't come because ... feuding or whatever else goes on in the community you know. I think it's up to the services ... there's a need to [address this] ... we all should work together.

Another Elder confirmed:

That's right. That's one big issue we got here in Kwinana is we got to come together as one community.

This reflects feelings of discomfort or lack of safety. This may be a reality in community and services should manage and address this by consulting with families, and providing options and choices; for example, offering services at more than one location. A non-Aboriginal person or an Aboriginal person from outside community can be important here because they can approach the issues without bias and, as was noted by one Elder:

Doesn't have to be a blackfella but someone that understands you.

One mother pointed out that families need to feel safe and respected, and as a result of that, comforted that they are getting the best approach:

They might not be trained or understand the difference between others and Aboriginal health so they should be more aware of - cultural awareness.

Issues of communication

Two-way language barriers, where Primary Health Care workers are not able to understand or are not listening to what the mother/carers are saying/meaning or vice versa, were an identified issue. That is to say, the family/carer does not understand what the Primary Health Care worker is saying or about the process for which tests are being done, and the implications are not explained:

I'm just disappointed the doctors never heard my concerns ... they just look over him and [said] all good off you go ... it took about three different doctors, different surgeries ... and yeah the last one [did] like a health check.

This example relates to a mothers' frustration in feeling that her concerns were not listened to. She persisted in following her instincts, knowing that her son's behaviour wasn't right until finally a doctor did a full health check on her child to identify an issue with his hearing.

Another issue that was raised during the First Time Mums focus group related to the Newborn Hearing Screen and how results were delivered to the young mum:

She told me my daughter was unresponsive on one side ... and that got me upset ... I cried ... I thought she was deaf ... Then [later] another nurse come and told me she passed [the hearing test].

The first nurse in this situation appears not to have clearly explained the process of the screen to this mother, causing her to feel some distress until she was reassured by the second nurse who clarified the test process and results.

Another problem is language, either not understanding what the doctor or nurse is saying, or trying to interpret what's been said, which can lead to confusion, and an inability to take in instructions of what the doctor or nurse had just said. Participants found this problem especially when the doctor or nurse had just arrived in Australia and had a strong accent, which added a further layer of difficulty, and could be very hard to make sense of:

... I told her that some doctors I went and seen had a bit of the accent and I couldn't understand them so they could have been, um, telling me he had the ear problem but due to their accent I couldn't, kinda didn't really understand what they were saying so they could have said something back then and me not understand - but she was fully English, proper English and she understood and checked it up and told me and yeah, she told me like, what's the steps next and put him on the wait[ing]list...

Mothers also discussed the information that is provided in brochures. They joked about the amount of material they are given upon the birth of a child, and that may not be read by young mums:

I just got brochures, the language is okay, [I] just flicked through them. I never really read [them].

They agreed that:

Information is there if we needed it but I guess we didn't really look into it.

This raises an opportunity to improve the way information is delivered to young mothers and parents, as some Elders pointed out:

Language - our people get upset if we can't understand language or jargon they use, they just ignore them [the doctor] and say yes or nod. Take that word up there, 'Otitis Media', how many people understand it? They don't know it's ear infections.

Sometimes I say to the doctor 'I can't understand what you are talking about' ... even if ... the doctor is speaking plain English, [it's] the jargon they ... use.

The language. The language, there that's a big barrier, I'm saying we can't understand people when they're talking.

So it makes you wonder if the doctors do know how to go about treating Aboriginal people. Do they ... really know? Coz Dr ... when they talk to you, you can't understand what they are talking about.

Participants also noted that sometimes with school health check-ups, especially with ear check-ups, that where they are unable to get in contact with the parent the school will send a note home with the child. Participants said that a note has a high risk of getting lost or of parents being unaware of the note being sent out.

Cost of services was another example of communication failure and a barrier identified in discussions. This issue was seen to be a failure on the part of primary health care services to adjust to the needs of Aboriginal people, many of whom are well known to be living in poverty:

You got three and a half thousand dollars to buy a hearing aid? I need one.

Another Elder shared her story:

I didn't like going to the doctor coz, yeah, but I had a clinic sister would come around, just to check on the kids. I couldn't afford ... the doctor.

Transport was also a recognised barrier to people attending appointments:

I find a lot of [problems] is transport. A lot of our mob haven't got transport.

Having services available was one issue – but access could be diminished by distance, public transport and of course the capacity to afford transport.

Disempowerment

Disempowerment was closely linked to communication issues by participants, and became an important key theme in the study. Participants identified two areas where they felt themselves to be disempowered:

- participants accessing services; and
- knowledge in general, and in particular having limited knowledge of the disease.

Some participants talked about how they felt when accessing services or visiting the doctor when their child is sick, especially when suffering from an ear infection. Families acknowledged that a lack of knowledge was a big issue in families not knowing how or feeling unable to challenge health professionals. Mothers expressed how powerless they felt being unable to challenge the doctor about their child's ears, leaving the surgery frustrated and disappointed:

... sad because it's part of your family that's suffering and you can't do nothing about it...

... [every] time I explained to the doctors they just, "oh no it's fine, she'll be right, or he'll grow out of it". Handballs more or less, yes, so three different doctors, three different surgeries ...

One mother who had become exhausted and stressed by her son's hyperactive behaviour explained how she could not leave him because she was fearful for his safety, and this had become a constant demand in her life. She blamed herself, and said it was the grandmother who noticed and insisted that something was not right and advised her to seek medical help:

[She said to me] There is something not right with this kid ... he wasn't talking at his age ... or walking and when he did ... she kinda [knew] something was off.

This mother did seek medical advice and told the doctor that her son was:

... hyper [as] he would just run wild so I asked the doctor does he have ADHD cause he was always running [around and not] because he had ear problems ... I was actually asking them something like that [worry about ADHD medication and not fixing his ear up] ... coz he was always running a lot but it ended up being the ear problem ...

This story illustrates the importance of family members in helping identify when something is not right and encouraging the mother to seek medical advice:

With my son, my Mum actually noticed something ... before I did ... Mum, she actually made me pay more attention that he wasn't talking at the same level as [his sister].

One great grandmother talked about her experience when she had to leave her son at the hospital when stolen generation was still happening, and of how it still affects her today and of how powerless and scared she was:

... little fella [baby] with us he got sick and I took him to the doctors, he had to go to the hospital immediately. When I rung up to say is he ok to come home and they said no he's not coming home, so I ran up the road crying to my grandfather - I still get very emotional and so we went to [hospital]and we said no we are taking this baby home, you're not sending him away. It was a bit scary. Took me a long time to even like say that story...

Her husband's response was "So those stress and trauma are still with her ...".

Bad experiences with accessing services such as hospitals can leave a lingering impact that can take a long time to get over. For parents/carers, going to the doctors or community health centre can be a traumatic experience, leaving them powerless and, for some, unable to keep going:

... Sometimes I gave up, I don't want to go to the doctor anymore.

Participants spoke of disempowerment in terms of lack of knowledge and lack of accessible information. They felt health professionals should have explained or given them more and better information: what does it look like, how does it impact a child, how do we manage it, how do we recognise ear problems, and can we prevent it from happening to our kids.

Normalisation of ear disease in community

This disease, that can sometimes start within weeks of being born, most commonly starts with a cold or a virus, as a result of which parents/carers often did not realise their baby was also suffering from an earache. The disease can also be an asymptomatic, showing no symptoms of middle ear disease, making it even more difficult for the parent/carer to know that their child has contracted OM. The disease will sometimes only show itself once fluid starts to discharge from the ear, or inflammation in the ear will cause pain for child, causing the parent/carer to act by going to the doctor, unaware that fluid build-up has already occurred before any visible discharge. In this way, over time parents/carers become too familiar with constant earaches, not knowing that it is causing hearing problems.

One parent's comment was "*it's just an earache nothing to worry about*". One mother spoke about her experience of being unable to recognise that her son was suffering from middle ear disease:

He never complains but when he's in so much pain 'mum, mum, hurting' that's the only way I know, because he is the type of kid that doesn't tell you, but if he's in a lot of pain he will tell me, usually it's his ears...

First time mothers were asked a question: When your baby has got an earache, can you tell? Some responses were:

... no, I can't [tell].

... when my daughter was three months, she was sick and wouldn't settle. Doctor said next day she had earache, I had no idea.

... I always just assume it's a flu, she hasn't pulled ears so I think she's right. If it's red, it's infected, right?

This is also an issue amongst doctors as described in stories above in the misdiagnosis section such as: *“the doctor hadn't identified that this child had anything wrong. They didn't say anything”*. Responses like, *“he'll be right or he'll grow out of it”* suggest an issue of normalisation of ear disease amongst doctors/primary health care workers. Families also talked about community health nurses, *“..the home visit nurses checked general health but not ears, they come out but [did] not do ear checks”*.

IMPACTS OF LIVING WITH A CHILD WITH OM

Families talked about coping and managing a child with otitis media and how it impacted their family. They described the stresses on families and individuals as encompassing a number of issues, some examples of which are included below.

Some families expressed being overwhelmed with managing appointments going in all directions from doctor, ENT specialist, hospital, and for some, speech therapists and counselling for kids with behavioural problems. This could also mean going from one end of town to the other, causing financial stress, and stress on both child and parent, especially when there is more than one child and the other children are all at school:

... everything is busy and you forget about appointments and forget about things...

Another participant told of the stress created for parents and other family dealing with a child with behavioural problems:

It took the whole family to contain him, and make sure he [was] safe. [I've even] locked him in the toilet. I get really stressed out.

Others spoke of the heartbreak of watching their infants and children suffering with the effects of OM:

Baby was up all night. It's heartbreaking knowing your baby is upset and in pain.

As they get older sometimes it's very difficult to hear children who are deaf as well because they speak very softly ... they become isolated ...

We have a little granddaughter, she was always very quiet and um, she had hearing problems and she had to wear [hearing aids] and it took her forever to wear [them] to school ...

Lack of information/lack of understanding of information

One young first time mother shared her anxiety around hearing the results of her Newborn Hearing Screen: *"I cried when they did my daughters' [screen] cause she didn't respond ... at first I thought she was deaf, it was tragic ..."*

The Purple Book

The purple book is the colour of a book that is given to mothers for every child born in Western Australia in which to keep records of baby's development and immunisations, together with other health information for that child. People had some comments in relation to the use of this book:

The purple book is good and all but sometimes you lose pages or you can misplace them - who cares about the book you know; we forget about it a lot. They do have questions in there that's supposed to thing [help] but most people aren't worried about it.

Yeah coz in the purple book there's a gap. Yeah coz I got mine there's actually, you get the main ones, the main stages the new-born the first three days or something so for each three days or something like, then they got like a couple week two, four or something then six weeks and then it just keeps jumping that gap. So what I was trying to figure out is what gap did he get missed out on in terms of when it happened.

The child's lived experience of OM

Participants shared their own personal experiences of having OM as a child. One participant with a history of ear infections, said she:

... couldn't do swimming lessons ... or go swimming. When mum took us all I had to sit out and watch all the other kids swim ...

And:

I liked to go to school but I missed quite a bit coz I was [having] operations and stuff. As an adult I had an operation, what was it called ... a reconstruction ... they said it was a bone that had kinda broken away due to the infection[s].

One mother told a story of how she observed otitis media impacting her child's wellbeing, emotionally and physically, which included behavioural and developmental problems causing stress on the child:

.... He wasn't you know at the language development stage where he should have been, and then it wasn't until primary school where he started speech therapy and, he still has speech therapy now and with that, you know, the teacher thinks he's got behavioural problems Yeah my kid, my son is actually in the Education Support Unit at school because he has a severe speech delay and he's been diagnosed with intellectual disability now as he is so far [behind]. My son is in the education support, when he was in mainstream he was so far behind, basically a wasted year of school, he wasn't doing anything.

Delayed diagnosis

This same young mum told us that, because of the delayed diagnosis for her son:

... [it] wasn't until primary school he [my son] started speech therapy and [is] still in speech therapy now ... I felt like a shit mum, especially being a Health Worker. Feel like you're falling through the cracks yourself.

Another participant noted that, in general a child with undiagnosed or delayed diagnosis for OM will:

[Get] behind in school ... gets frustrated and misses a lot of school

And of course, getting behind in school can have a lifelong impact on a child, associated with a range of other problems and disadvantage.

Social problems

Image is important for young people. Looking 'normal', 'perfect', smart or cool helps build confidence and self-esteem. Children with hearing aids are at greater risk of being teased, which may result in bullying:

... when you are talking about kids wearing... you know, having things in their ears if they're going to school and other kids might, you know... know [they're] deaf so they call them names ...

Children who are teased and/or bullied may be at risk of not wearing their hearing aids, since some would rather put up with being deaf than being 'shame'. Bullying can have its own impact on wellbeing:

... sometimes .. they become isolated ... because of the labelling, the name calling and so they keep to themselves.

My nephew would isolate himself and get frustrated.

Other participants also noted that there were issues of frustration for other children in playing with a child who is unable to hear.

A participant at one of the focus groups who works in the criminal justice system linked hearing loss with the courts:

Hearing issues impact on behaviour and then you know sometimes lead onto the justice system ... there are all sorts of different reasons why someone might be struggling ... mental health ... or coming off a substance, but sometimes you can see that there is [just] a hearing thing.

Comments such as this by one of the Elders reflect the quality of life impact of OM:

... it comes back to learning with the schools, not just education but whole life skills. You know, how to survive daily.

This Elder acknowledged the importance of learning beyond the school. Schools offer some support if the resources are available. But this comment is about the person, it describes more than a disease and comments on the impact of hearing loss on a child's personal life and development of social skills.

ADDITIONAL STRESSORS

People also spoke of some additional stressors that people had to cope with. These included one grandmother talking about the impact of separation due to distance from services. She said:

... we lived in the country, for them to do anything to [her daughter's] ears we had to bring her down to Perth and leave her here ... so she got a bit of an attitude out of that.

[Facilitator]: Feeling of abandonment? [Grandmother]: *The result [has added to] the separation in the family.*

Other stressors mentioned were worrying about long term use, or constant use, of antibiotics, and financial issues.

In sum, when many other issues are faced by families each day, ear problems can be a low priority, as described by this young mum:

... a lot of Aboriginals are in survival mode and they're just trying to get through week-by-week, day-by-day, so they don't see little things like ears ... they are still trying to get through all the big issues that are coming up. So that's a big issue that affects everybody.

Racism

And finally, racism was strongly identified in the data as a common theme and a significant stressor for participants accessing mainstream services within an urban environment. Negative stereotyping was a major issue, cited frequently by participants, demonstrating how the experience had impacted on how they felt and whether they went to the doctor. They talked about their bad experiences whilst visiting a health centre, a doctor or home visits, of being judged and ill-treated, which led to feeling humiliated, helpless, anger and hurt, all because of being of who

they are and what race they belong to, just for being black. An Aboriginal health worker gave an example of possible racism, abuse of power and agency regarding child removal represented by inexperienced non-Aboriginal health professionals undertaking home visits:

... I always say firstly we are going to see the person not the house, then if it's a child we're seeing that child first and cultural awareness like, a lot of them come in and they're just like, you can see them looking around looking to see if the house is dirty. We have to pull them up or they will ring DCP you know, when we get back. That, that really shits me...

The fear of having their children removed is a significant barrier as it will determine whether Aboriginal families will seek help. This Aboriginal Health Worker stated that the family will only allow the nurse to attend if “*she has one of us blackfellas with her*”.

Families also reported how they were treated. One young mother shared her story of being negatively stereotyped:

... [of going] to get my ear checked, [the doctor] sent me for a blood test. [The doctor] said it was for STD. I never been to a doctor about me ears again. ... [My] ears are still bad. [The doctor] never even looked in my ears. I went for me and my daughter. [The doctor] sent her away for nappy samples and me for blood test.

This doctor apparently stereotyped this young Aboriginal mother and her daughter by making an assumption that a sexually transmitted infection (STI) was the issue, which she felt was unrelated to her issue of having a sore ear. This tells a story about a doctor being perceived to be judging a mother and not explaining or being transparent about why he suggested a test for an STI, that is, the doctor needed to explain that STIs may link to issues that cause ear disease. She felt judged and shamed by the doctor questioning her and felt unable to challenge his diagnosis. These kinds of stories highlight the potential for misunderstanding and issues around poor communication.

Participants also said that, “*We work better with our own kind, you start to open up*”, “... attitude is a big think you know ...”, while also acknowledging that “[It] *doesn't have to be a blackfella but someone that understands you*”. Participants felt as Aboriginal people that they were treated differently to non-Aboriginal people, that they were negatively stereotyped and that this racism perpetuated the colonialism of the settler population. For families with children suffering from otitis media or middle ear disease, accessing mainstream services can be a traumatic experience and some will only go when the disease is severe.

COMMUNITY SOLUTIONS

Participants of focus groups suggested ideas or solutions that would address some of the barriers to their accessing health care services. For example, one Elder said that:

We used to have a very good relationship with our local community health who would come as soon as there was something the matter with any of our children so they had a good relationship with the Nyoongar people that were in the community at the time, and they used to come ... and [give] a whole community workshop where they did actual ear inspections [and] everything ... it's amazing how things are found when you do have a workshop and [health] check.

As was noted above, participants spoke of the disempowerment that accompanies lack of knowledge and of insufficient easily-understandable information from health professionals. Many participants commented along these lines:

... some more information and about kids and their ears. My foster child got grommets in her ears and I don't know too much about it, so, yeah and then what I can do to prevent things from happening with infections...

... but there's not enough info, they don't explain what you should do and what's next. There's not enough information...

Others said they looked forward to receiving useful information out of the community forums or focus groups to help fill this gap:

... I just hope to get some information [middle ear disease] from today...

... I want to get more information to provide to other mums who are dealing with the ear infections with their toddlers...

Participants noted that families find it hard to get to appointments, either because they don't have a car, or if they do they don't have money for petrol, or because bus services are not readily accessible. Offering outreach services or services in locations that are easy for community to access is very important.

Others discussed the idea of having a wellbeing day where community is invited to come and have a health check, ask questions, learn about health and how to keep themselves and their families healthy. A young mum suggested a need for:

More awareness ... more workshops ... they'd be good during pregnancy [and/or] doing ... an antenatal program for Indigenous mums.

Another community idea that was discussed during focus groups was around the importance of family. One Elder highlighted this by posing the questions:

... who's your first teacher? ... Your mother is your first teacher. Who's your best carer? Your mother. ... The first person who brought you into the world was your mother, and you wouldn't be here without ... your mother.

Other participants acknowledged that mothers need to be supported to have more confidence to follow their instincts and be encouraged to be good mums, reinforcing the notion that *"a healthy baby will come from a good mother"*.

Some people talked about the role of extended family as being like a helpline. This conversation took place between Elders, who said, *"that's our culture, we got extended families that can help, look after grandchildren ... we do it because that's our culture"*.

Another solution from a young mum was the need for Indigenous Health Nurses who understand Aboriginal culture, with the suggestion that there should be a greater emphasis on cultural awareness training and skills in health care workers:

Having the Nyoongar support makes a big difference. I had to go get his immunisations updated, so yeah, just got a checkup and all that, letting them know my concerns.

It appears from these comments that the community would highly value friendly two-way conversations and clear verbal explanations, preferably from Nyoongar health professionals, about issues concerning their own and their child's health.

CONCLUSION

This research identified key themes relevant to otitis media from an Aboriginal urban community context, in particular what people know and do about ear infections. The findings of this study suggest more research and greater flexibility in the health service sector is needed for a better understanding of the health needs of Aboriginal Australians living in urban settings, which in Western Australia includes almost three-quarters (72.6%) of the state's Aboriginal population.

Participants provided the research with solutions they believed would assist in combating otitis media in community and addressing some of the barriers to accessing mainstream services. These included cultural awareness for doctors and other health staff, the presence of an Aboriginal health worker at every appointment, and doctors being trained to specifically and regularly check for OM in Aboriginal children's ears. There was a need to encourage and provide opportunities to increase awareness and understanding of OM for Aboriginal parents and families. This would help families to ensure their babies have regular ear checks at the local community health centre or during appointments with doctors.

In conclusion, the stories shared by participants in the focus groups and during interviews have demonstrated the many ways in which OM and hearing loss has impacted families and individuals. It is very clear that the life-long consequences of OM for Aboriginal children, families, and community are real and can be devastating. All Aboriginal families are entitled to healthy ears. Beyond the clinical care and management, supporting and educating families should be part of standard practice. The findings from this research support the importance of early detection and treatment of OM to ensure that Aboriginal children have a strong start to life.

CHAPTER FIVE – DISCUSSION AND CONCLUSION

This chapter discusses the key themes that emerged from the Kadadjiny Dwank research project, derived from the voices of the participants who talked about their lived experiences of otitis media (OM) from an Aboriginal urban perspective.

To capture the voices required knowledge and understanding of the Aboriginal world view, and of the impact of colonisation which has left a legacy of distrust and fear for Aboriginal people that still exists today. Knowing this, an Aboriginal research team was formed from community to provide the cultural security that was paramount for participants to be able to tell their stories without them feeling they were being judged or experiencing other negative emotions. Without the research team, the data would not be so rich, stories would not have been told, and therefore findings would not be evident to then shape policy and outcomes for children suffering from OM. The research literature highlighted the lingering impact of colonisation and dispossession of Aboriginal people that still exists today and which impacts on health, specifically OM, and whether and how support services are accessed. Failure to acknowledge and recognise this legacy, and not identifying it as a catalyst for systemic racism within the health services, will continue to delay the recovery from this disease in Aboriginal children.

To understand community, the research project took into consideration the community's spiritual, social and emotional needs as well as their physical safety, that also included connection to country (Coffin 2007, Williams 1999, Scott, Janke 2002, Davy 2017). Central to the project was to give individuals and the community their voice and to hear these voices. This required:

- Cultural protocols - community's lores and customs. This included a Welcome to Country that was done at all events respecting country and people.
- Cultural governance - key people in community such as Elders and other stakeholders who are the decision makers.

- Cultural security - ensure a safe and cultural place for all who attended forums and focus groups giving participants a sense of belonging.
- Cultural competence - maintain and sustain respect by acknowledging and respecting community's worldview from start to finish of the project.

This is represented in the following image, which was designed by the study author:



Figure 1: This became the project's cultural compass, a navigating tool to help steer the research in a respectful cultural manner in community. This approach was necessary and was a strength of the research.

The researcher understood the importance of working in partnership with community such as Elders, grandparents, carers, parents, young mothers and community workers. This required that power be equal: that is, for the researcher to share power; let go of power; and, hand over power. In short, this meant to empower, as demonstrated below, also designed by the author to represent the balance of power:



This process allowed the communities to embrace the research and to have ownership and control over it, which enabled a strong cultural foundation for the research, built on trust, respect and reciprocity. This reflects the six core values from the NHMRC guidelines for conducting ethical research with Aboriginal and Torres Strait Islander peoples, which identify spirit and integrity, cultural continuity, equity, reciprocity, respect, and responsibility to maintain and sustain trust, enforcing best practice at a national level Australia-wide.

Having a strong cultural foundation enabled key themes to emerge from the voices of the individuals and the communities, from their lived experiences of accessing mainstream services and living with a child suffering from OM – and the voices of Elders. These voices tell of racism and shame, but also of the resilience, courage and wisdom of the individuals, of families and of communities. Participants shared their stories on their understanding of OM and how it affected their children, themselves, their families and their community, and about how they were treated and how they felt when accessing health services in an urban environment. The participants talked about feeling frustrated and being helpless after coming from their appointments. They spoke about being dissatisfied with the services, especially when the disease was not picked-up/identified, or an explanation on the disease and appropriate responses/management, leaving their child to continue to suffer, causing more harm and stress with no clear understanding of what might be causing the symptoms and issues. Participants shared their pain and suffering so that their stories can be heard, but also to provide the research with solutions to address these problems to bring about change, not only for themselves but for other Aboriginal families suffering in the same way. They also gave insight into how things can work well and the positive impact this can have on the child and families.

Culturally secure methods and methodologies such as yarning and participatory action research (PAR), as noted in other research (see, for example, Maguire, 1987, Streubert & Carpenter, 1995, Baum et al. 2006, MacDonald, 2012), allowed the researcher to be inclusive with the community. This meant that community were part of the research, rather than having research ‘done to them’, and enabled them to feel

safe during the study while sharing their lived experiences of living with OM. This research approach acknowledged the power of yarning which includes storytelling and provided a voice, particularly for Aboriginal people whose voices have historically been silenced. This echoes descriptions of the colonising process from US feminist bell hooks:

[There is] no need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you I write myself anew. I am still author, authority. I am still [the] colonizer, the speaking subject, and you are now at the center of my talk (1990, p. 343).

Reciprocity was included by the simple acts of providing a safe place, of having experts provide advice at the meetings and the commitment to communicate their voices in recommendations for prevention activity and clinical practice as an outcome of this research. We suggest that the practice of reciprocity be taken beyond the individual level in conducting health research. Reciprocity is not only necessary to accomplish research in an ethical manner, but it is also illuminating, since the process of negotiating priorities and learning what study participants expect to obtain from cooperating with researchers reveals valuable cultural knowledge (Wax, 1982). Reciprocal research relationships provide the context for providing clear information about the outcomes of the study and the benefits to the community participating in the study.

A qualitative research method was used for this study that was culturally appropriate to help learn about and investigate Aboriginal participants' issues and experiences, which were explored around the research questions, based on their lived experiences on OM. For this to transpire, the researcher needed to understand qualitative research based on her review of the literature combined with her world view as an Aboriginal woman. The synthesis of these elements was used to develop an approach which helped gather in-depth data from participants to determine what is happening in their community with OM and how it affects them, their child and their family.

Otitis media is a significant problem around the world and a risk for all Australian children, but more so for Aboriginal children for whom it can sometimes occur within weeks of birth. Their suffering starts earlier and continues longer than for non-Aboriginal children. If not detected and treated early, it can cause hearing loss, leading to disability and long-term consequences which result in a poorer quality of life – if a person’s hearing is impaired this can impact their development, their educational capacity and attainment and of course social life. The literature review confirmed that there has been almost no research at all undertaken on Aboriginal children suffering with OM who live in an urban/city environment. There is an essential need for qualitative research in this area, particularly when the majority of Australia’s Aboriginal population live in cities and metropolitan areas.²²

WHAT THE LITERATURE TOLD US

A more in-depth and broader insight into OM at the national and international levels was required to be undertaken, all of which helped to structure the research questions around middle ear disease. The relevant literature for this research covered otitis media, colonisation, and a decolonisation method and methodology that provided guidance, knowledge and information for the researcher. This helped with the planning and preparation of the project to ensure cultural protocols such as cultural security and cultural safety were followed throughout the life of the project.

Research literature reviewed covered a range of topics relevant to the research, including:

- the structure and function of the ear;
- what OM is and how it is contracted;
- the burden of the disease, its prevalence, and the risk factors associated with it;
- a review of existing qualitative research on OM;

²² See <https://www.aihw.gov.au/reports/australias-welfare/profile-of-indigenous-australians>

- a discussion of the social determinants of health, with specific reference to those which have particular relevance for Aboriginal people such as racism and shame; and,
- discussions of the Indigenous perspective and decolonising research methodologies.

As well as some biological features, research has identified a wide range of risk factors for OM in Aboriginal children, such as poverty, overcrowding, homelessness, poor housing, poor nutrition, exposure to cigarette smoke and lack of running water, personal hygiene, premature birth, and bottle feeding, based on peoples living conditions and their location.

A recent Aboriginal research project in Perth in 2019, the Djaalinj Waakinj epidemiology study (Swift et al 2020), investigated the prevalence of otitis media in young Aboriginal children. This quantitative research confirmed that young children living in an urban environment also suffer a high prevalence of OM and are at an increased risk of being subjected to hearing loss at a young age. It highlighted the higher prevalence of middle ear disease in Aboriginal children and also that, in common with their peers in regional and remote areas, they are affected to a greater extent and for more extended periods compared with non-Aboriginal children.

The overwhelming majority of the research into this issue has been quantitative and focused on Aboriginal communities in rural and remote communities, both nationally and within Western Australia. This validated the necessity for a qualitative research project to be undertaken with an urban Aboriginal community in Perth. Especially an approach that included giving voice to individuals, affected families, Elders and the communities and to enable their voices to be heard and acted on.

Although Australia's health system is among the best in the world, researchers have noted significant issues for Aboriginal people in their encounters with health services (Dosssetor et al, 2019; Carman et al 2019; McConvell, 1988). Some of these have related specifically to questions of diagnosis, treatment, and service availability and access. Others were focused on the social determinants which affect health. Among these, communication, cultural safety, and institutional and interpersonal racism were all assessed and found wanting. This had led to Aboriginal people avoiding

mainstream health care facilities because of discomfort or feeling unwelcome and unheard (Larson et al 2007; Paradies, 2016).

The literature review supported the need for and importance of this type of research by confirming the extent of the problem of OM for Aboriginal communities in Australia, in terms of its prevalence, need and consequences.

THE APPROACH USED IN THIS RESEARCH

The literature that was reviewed with an Aboriginal, and specifically a Nyoongar worldview, provided information and guidance to the project team. The research literature around decolonising research methodologies, yarning, and Indigenous research methods, was central to the planning stages for this research, informing the approach taken throughout. These methodologies were then embedded within the project and their principles and practices were incorporated from beginning to end.

This allowed the project to be culturally effective and beneficial, working in partnership with the Aboriginal community. For this to happen, yarning and participatory action research (PAR) methods were applied. The project also took a reciprocal approach, to ensure participants were at a low risk of being exploited, and ensuring that their investment of time, knowledge and wisdom was to be used to respond to their needs.

The research project chose to have an Aboriginal notetaker and/or facilitator at focus groups and community forums because it was felt that to do so would increase the cultural security for participants. This ensured that the language and the context of participants' conversations and language nuances were captured, to ensure participants' views and voices were not lost or misinterpreted was essential. This required these roles be undertaken by Aboriginal people.

There were two community forums and three focus groups that provided the data for this research. Three focus group transcripts were needed to provide the primary source of material for thematic analysis. A Nyoongar transcriber transcribed all audio

recordings. The research questions helped us to capture the participants' voices which have informed the study's findings.

A triangulation process was undertaken to organise, examine, and analyse the data from participants. There were three stages required for data to be analysed and for confirmation of key themes identified from the study:

- first stage - The researcher uploaded the transcripts into a qualitative research tool, NVivo, and then extracted common themes consistent with the participant's stories. To ensure confidentiality their names were coded as required by the ethics approval process;
- second stage - Collaborating with another research team consisting of an experienced Senior Nyoongar researcher team leader, and two non-Aboriginal researchers based at Curtin University specializing in coding and analyzing data. This required two meetings and memos via email to confirm the validation of key messages was consistent; and,
- third stage - Key themes were categorised into relevant topics by the researcher and a non-Aboriginal researcher colleague to ensure there was consensus on the category placing, for example, racism, shame, dysfunction of services and stress, and so on.

For this research project to happen, it required the wisdom of the Elders, the strength of family, resilience of children, commitment and dedication of community and the spirit of country all in equal measure. The diagram below drawn by the researcher demonstrates the importance of community in research:



WHAT WE FOUND

The key findings of the Kadadjiny Dwank research project were derived from the analysis of the data from the participant's responses to the research questions:

- What do people know and do about ear infections?
- What are the barriers to accessing care?
- How does OM impact on the child and family?

These findings represent the voices of the participants describing how OM has impacted on their lives within an urban environment, and providing insight into the various barriers they face in accessing and obtaining respectful and beneficial care from the health services in their community.

While there are few studies that address similar questions in Indigenous populations, there are some similarities between the findings in this study with those examined in the systematic review conducted by Chando and colleagues (2016, see also 2020). In common with the views expressed by participants in this study, these authors noted that studies variously found that parental experiences and perspectives of caring for a child with OM included guilt and helplessness over failure to identify the symptoms or inability to help their child; a disruption of life schedules; concern over the threats OM poses to a child's normal development, social skills and inclusion, and a valuing of and need for community and health service support.

A summary of key findings of this study are discussed in more detail below, in conversation with the existing literature.

ISSUES WITH HEALTH SERVICES

Consistent with studies by others (Wright et al. 2013, Maher, 1999, Scrimgeour & Scrimgeour 2008, McKnight, 2020) this study revealed some families were reluctant to access health services based on how they were treated previously in terms of services not being culturally appropriate, racism, poor communication, and feelings of shame. Parents/carers felt they were being treated differently from non-Aboriginal people and were disenchanted when accessing health services for their lack of cultural understanding and awareness, and their attitude towards them. Such services generally were felt to be unable to accommodate people from a different culture, especially when one is from a minority group with a legacy of trauma and disempowerment from past policies that still impacts them today. These insights have also been noted by other researchers (for example, Hayman et al., 2009; Carman et al. 2019).

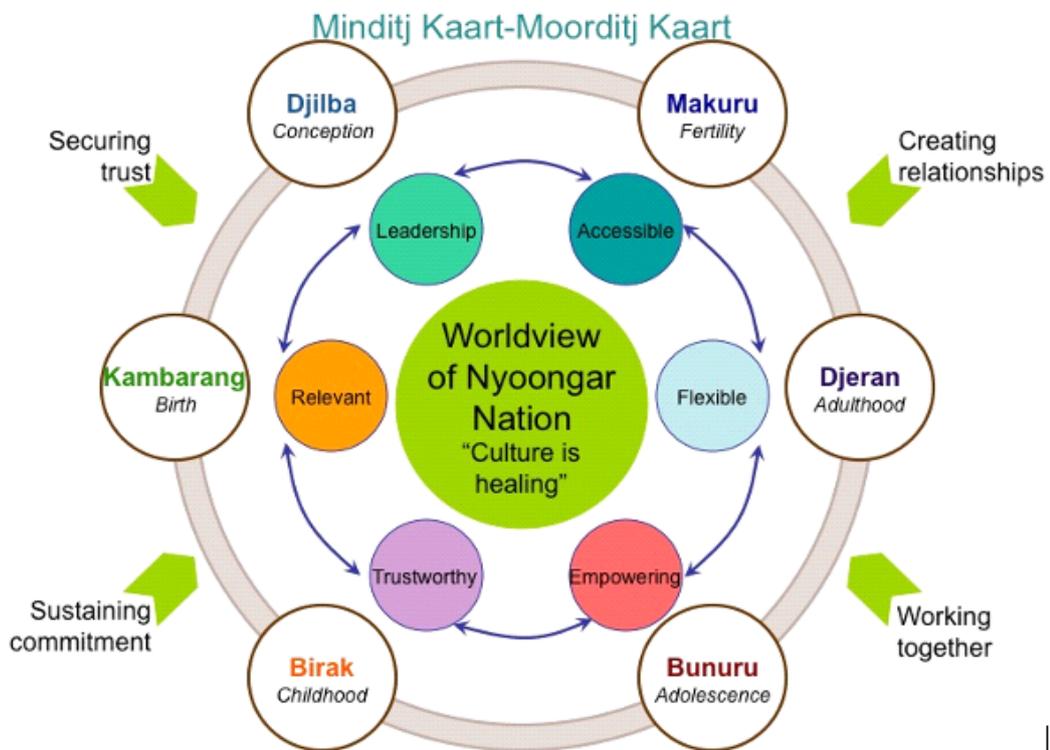


Figure 1. The draft *Minditj Kaart-Moorditj Kaart* (“Sick Head to Good Head”) Framework, featured six key attributes for responsive service delivery, endorsed by Elders group in 2013 (Wright et al, 2013).

Poor or delayed diagnosis was another key issue for some parents/carers with a child suffering from OM. For the child to see an Ear Nose Throat (ENT) specialist requires a referral from the doctor. A number of parents/carers complained that they needed to go to several doctors for a one to identify the cause of their child's suffering from abnormal behavior or constant earaches:

Just how much I had to go through and not only what I went through it's just how long it took me to pick it up and how many doctors, and I seen like three different doctors...

It appeared, at least from the perspective of the participants, that some doctors were not trained or skilled in identifying OM, and may not have appropriate equipment to confirm fluid in the middle ear, for example a tympanometry machine to check for middle ears disease instead of waiting for it to become visible, for example with a runny ear. Delays such as this can cause further damage to the child's ears and hearing, adding further stress on child and family.

So it makes you wonder if the doctors do know how to go about treating Aboriginal people. Do they ... really know?...

Parents/carers are left frustrated and angry, which impacts on their ability to challenge doctors, and disenchanted with the health services which reinforces their disinclination to attend unless a situation is urgent.

Study participant comments reflect other reports on delayed detection and diagnosis of ear infections in Aboriginal children (AIHW, 2017; AMA, 2017; Williams & Jacobs, 2009), which have foregrounded the importance of early detection and treatment of OM, and the significant impact of late detection for affected children.

In sum, study participants highlighted a number of barriers to accessing care, and how OM impacts on the child and family in the early years. The research emphasised what has been noted in prior research, that relying on screening at school is too late. These findings support those of the Kalgoorlie study by Jeffries-Stokes and colleagues (2004), who reported on a diminished sense of competency, guilt and helplessness among parents and carers accompanying a lack of knowledge and that they

were weary of the sustained treatment required. Barriers to accessing care and the timing of screening such as these identified in this study had previously been noted by others (Lehmann et al. 2008, William & Coates, 2009, Kelly et al. 2014, AIHW, 2018). Other factors, including cost, location, and lack of availability of services were also barriers to care, issues also noted by Kelly and colleagues (2014).

To overcome these problems, the participants suggested cultural awareness training would bring an understanding of a Nyoongar worldview (such as that described in the image below from the *Looking Forward* project), and having an Aboriginal worker there at all engagements, from doctor's surgery, to ENT specialist, audio testing and attending a speech therapist, to ensure cultural safety is provided and to give a sense of belonging and cultural understanding.

ISSUES WITH COMMUNICATION

For the child, participants spoke about difficulties with trying to understand their child's wants and needs because the child could not hear properly or understand what the parents/carers were saying. This could result in tantrums from the child, and stress for both the child and parent/carer. Some children, who were having trouble trying to talk, required a speech therapist to help them communicate at home and at school, in the hope of reducing stress for child and family.

Poor communication was a further significant barrier to those discussed above for participants accessing health services. Results from the study identified that poor communication affected both child and parents/carers. Parents and carers said they found it hard to understand the medical language used to talk about OM or generally what the doctor was saying, which caused confusion and resulted in delaying and disrupting recovery for a child suffering from ear disease.

Sometimes I say to the doctor 'I can't understand what you are talking about' ... even if ... the doctor is speaking plain English, [it's] the jargon they ... use.

This also affected their overall relationship with the doctor or health services, with participants saying they were reluctant to attend or make an appointment, and that they only sought help when the child's suffering or condition was very serious.

These findings mirrors those of Wright and colleagues (2013) who identified that language was a substantial barrier for some participants visiting a health professional, and can cause major problems for participants with a child suffering with OM. This research also noted difficulties arising where the parent or carer has problems expressing or explaining themselves – a finding that supports views of the participants in the current study. In their Kalgoorlie study, Jeffries-Stokes similarly reported on communication issues between children and their parents/carers (2004).

RACISM

Racism was identified a key theme by participants. Participants shared their experiences of how they felt at being judged, stereotyped, and treated differently because they were Aboriginal. It was evident that racism is present in varying degrees within the health system and is one of the fundamental barriers for Aboriginal families accessing health services in an urban environment.

Racism as a determinant of health was recognised as a significant challenge for participants, due to it often preventing them from seeking medical attention immediately. This directly affects the child's health and wellbeing through postponed appointments and delayed treatment, potentially leading to further damage to the child's hearing and resulting in a poorer quality of life for the child.

Given that the health system is mostly designed for the mainstream population and not for minority oppressed groups, this systemic and structural racism impacts Aboriginal people trying to seek medical attention on a daily basis. There were concerns expressed by participants about home visits from non-Aboriginal people that left people feeling they were judged on their home living conditions. Failure to address issues such as systemic racism will continue to delay treatment and recovery for children suffering from OM.

These findings support the Australian Government's statement that racism is a social determinant of health (Australian Government, 2013), and the insights reported in various studies around racism as both interpersonal and institutional, with

detrimental effects on the health of those impacted by it (Larson et al., 2007; Priest et al., 2012; Ware, 2012).

STRESS

Stress was identified as a major problem for both child and family. The focus groups and forum participants revealed how stress impacts child and family on a daily basis, and specifically in trying to manage otitis media. Participants also talked about the need to attend many appointments in order to receive a diagnosis or treatment, which can be stressful for both child and parent. Visiting a doctor, ENT specialist, speech therapist or going to the hospital to have grommets can all be overwhelming for everyone involved, where just sitting in the waiting room with a child who cannot sit still or is having trouble listening can be very stressful for all. Participants also talked about the stress of trying to manage appointments during school hours when they have other kids at school, or their child often misses out on school because of needing to attend too many appointments. When asked for solutions to some of these issues, participants variously noted that outreach services or locating services closer to community would assist, as well as with the financial stress on families, trying to budget for such things as fuel and related costs – the whole process can be very expensive.

Participants spoke of witnessing their child stressing out because of their child's inability to express themselves or to tell them what they want, or because parents/carers are unable to understand what they are saying. Parents/carers talked about their child falling behind in school and the child getting distressed because they were failing to keep up with the other kids at school. Parents/carers also spoke of their child being stressed because other kids made fun of them, "sometimes ... they become isolated ... because of the labelling, the name calling", with another participant noting how their nephew would get frustrated with trying to be understood by the other kids and ending by isolating himself.

Parents/carers said they found it very stressful trying to keep their child safe at all times, because the child could not hear them, so there were increased risks that they

may run off and parents/carers either could not find them or spend the whole time running after them:

Aunty, I can't even do my shopping or go to the park and get anyone to babysit him... He would run everywhere and wouldn't stop and I thought he was just being a naughty boy but later I realised he couldn't hear my voice.

In sum, it was evident that families managing a child with OM were stressed, having to manage what they felt were too many appointments in order to obtain a correct diagnosis, dealing with communication problems with both the child and health professions, guilt at not being able to do more for their child, lack of knowledge of OM, and feeling disempowered in being unable to challenge doctors or health professionals. Each of these issues highlighted by participants in this study supported the findings of the Kalgoorlie study conducted by Jeffries-Stokes and colleagues (2004), highlighting a similarity in issues between metropolitan and regional areas and the lack of improvement over a considerable time period.

SHAME

Shame was identified by participants as another key issue from the findings. As was noted in the literature review, shame has been identified as a recurring issue and as a barrier to seeking help or entering treatment. Maher (1999) argued that it is among the chief reasons for Aboriginal people not attending mainstream health services. Most recently, McKnight and colleagues (2018) suggested that shame 'is often conflated with guilt, humiliation, embarrassment, feelings of inadequacy, unworthiness, [and] being unliked' (p. 3). Participants in the current study shared their lived experiences after visiting the health services and how they felt during and after their visits, of being judged, feeling disempowered, inadequate, inferior, or not clever enough ("dumb") with a lack of knowledge of OM, resulting in stereotyping that contributes to a sense of shame.

Participants also talked about the challenges of their child having to wear a hearing aid, that it can be shameful because they look and sound different from others. Shame goes beyond shyness or embarrassment; as participants described it, it is about being alone and about emotions around how they look, to how they are treated

and how they feel about how they are treated when visiting a health service, or in the general community.

These findings are consistent with those of Scrimgeour and Scrimgeour (2008), for example, around perceptions of being judged and talked down to, and with Potter-Efron's (2002) description of shame as a feeling of being exposed or disgraced. These feelings can be exacerbated by experiences of any lack of respect and cultural awareness from health staff, which in turn can contribute to poor assessment and inadequate diagnosis. Importantly, while other studies have touched briefly on shame (Maher, 1999, McKnight, 2020, Scrimgeour & Scrimgeour 2008), this study has demonstrated how, for young urban Aboriginal mothers, this is a significant factor acting as a barrier to care.

LACK OF AWARENESS OF OM

Participants in forums and focus groups were not aware that OM can be a disease which is not easily detected which will only show itself once discharge is noticeable or pain is making their child to suffer from an earache. Even then, they were not always aware of the severity of the disease, with many saying they had thought it was just an earache and therefore nothing to worry about. Participants said that they had felt incompetent and guilty as parents/carers because they had had no idea their child was suffering with OM, which had serious current and downstream implications.

Participants had become concerned at their lack of awareness or knowledge of OM, and their resulting inability to prevent the disease progressing to a more severe or chronic stage resulting in hearing loss, and leaving their child with a disability that would potentially impact them for the rest of their lives. They were eager to increase their knowledge to help to identify the signs of middle ear disease in their child's ears, to take earaches seriously, and to seek medical attention immediately to combat OM. These concerns expressed by study participants are comparable to those described by Chando and colleagues (2016), in their synthesis of themes across 17 studies. These authors found, similarly, that parents felt guilt over their failure to recognise the symptoms of OM, helpless and despairing at their inability to ease their

child's pain, and were keen to take ownership in learning to recognise symptoms, and managing their child's treatment regime.

As with the 2004 study by Jeffries-Stokes and colleagues, these findings confirmed that participants in this research had very little to no knowledge of OM or middle ear disease prior to taking part in the project. This would impact on their ability to make sure their child's ears are checked regular to combat OM or causing further damage to their hearing. As part of the project, material from medical journals, pamphlets, and manuals of OM were used to educate and bring awareness to the community about the disease and the consequences of OM for a child suffering from it – something which seemed to be important to and be valued by the participants - it gave participants an understanding and knowledge of what otitis media looks like, how it is contracted, how to respond and manage it, and how it impacts the child and family.

COMMUNITY SOLUTIONS

Ideas and solutions came from participants at both community forums and focus groups. These were innovative and possible, and quite simply excellent suggestions that were practical in their application and the suggested context (for example, conducting assessments such as when immunisation is provided or during recommended child health checks). They clearly have the potential to address some of the barriers identified, such as challenges in accessing health services, lack of knowledge and information on otitis media, and understanding of the impact on child and family. The suggestions included action research, enabling the strengths of communities to be highlighted, with solutions offered by communities who are best placed to know what might/does work:

- holding community workshops around all the elements of ear health;
- developing an App to manage the information and entries in the child's Purple Book – the child health record provided by WA Health to every child at birth;
- reporting on social media;

- giving handouts/brochure to all parents/carers, to provide an understanding of and support for OM;
- creating an animation / DVD for mothers and kids;
- educating families – especially noting the importance of educating pregnant mothers so they know about early intervention;
- having baby’s ears checked at the same time their immunisation is given;
- ensuring more information is included on OM in the Purple Book;
- ensuring parents have access to Aboriginal health workers at all times;
- outreach services delivered by Aboriginal community health workers; and,
- fast-tracking access to speech therapists, as waiting times are too long for a child.

Lack of awareness of OM by the participants was another problem as they were often not aware their child was suffering from OM and had little knowledge of OM. The dysfunction of health services and poor diagnosis of OM in their child’s ears also made participants feel frustrated and angry. This leads to a delay in accessing treatment and recovery resulting in the child continuing to suffer and being at a higher risk of a hearing impairment and permanent disability.

Findings of this research supported the importance of early detection and treatment of OM, in a culturally secure manner, to ensure that Aboriginal children do not progress to the more severe or chronic stages of the disease. Each of the findings is supported by, and itself supports and extends, the research literature around the risks of OM, its causes and its effects, and the journeys that Aboriginal families must make in navigating the health system and securing respectful, supportive and effective care for themselves and their children.

STRENGTHS

Kadadjiny Dwank (listening, thinking and learning with your ears) project is a partnership project that engaged and was guided by direction of local Aboriginal

Health organisations in the Perth metropolitan areas of Kwinana/ Rockingham and Armadale.

The strength of this study arose from the active role and ownership of participants in this process: in their courage to share painful and stressful experiences, and their resilience in overcoming racism and prejudice often experienced while visiting health services. But a strong solution focus was apparent - participants provided solutions to combat the problems that they face on a regular basis accessing health services. They not only took part in the study, but also became an active part of the research team, allowing community to embrace the research and to guide it to where it should be. The community's commitment and dedication to the study to bring about change for their children to have an enhanced quality of life was above and beyond the research team's expectations.

This research has potential significance for other First Nations communities in Australia and other countries, in method but also in its significance for change in health outcomes. To the best of my knowledge, it is unique in that there does not seem to be any other qualitative research, involving a full First Nation research team, on the experience of and impact of OM on Aboriginal people in an urban environment.

LIMITATIONS

Time became an issue during the study, with the research reliant upon community time which can mean not starting on time, or delaying research due to funerals or sorry business which may take a week or two before the research could get started again.

It is acknowledged that this is a small scale study conducted with the Aboriginal community in two geographical locations in Perth, Western Australia, which limits its generalisability to Aboriginal communities in rural and regional areas, and in other urban localities around Australia. Different practices may exist in other locations. Similarly, in studies of this kind, there can be a selection bias around participants – people who come to meetings might have particular experiences and

views that differ in some systematic way from those who do not come in. Whilst the findings are based on a sound approach, these limitations are acknowledged and do have implications for generalisability of the findings. Nevertheless, that the findings are broadly consistent with those obtained in other qualitative and quantitative research, as described in the wider literature around OM, suggests confidence in the findings.

KEY MESSAGES

Key issues arising from this research fell into three categories: personal issues for parents/carers; personal issues for children; and, structural issues with health services.

Personal issues for parents/carers and children included the stress created both by OM itself, and by contact with services where responsiveness, respect, and acceptable care were seen as lacking.

Parents/carers were left with a sense of guilt and incompetence as a result of their lack of knowledge and/or miscommunication (or limited communication) from health service staff, impacting on their ability to make informed decisions. There was also a perception of the power disparity between themselves and medical professionals, causing issues with engaging with services in general. Economic strain was also a key issue for many participants. This research noted, as a key feature, the dedication and commitment of participants to improve outcomes for their children.

For children affected with OM, the key issues as perceived by participants were: the impact of OM on their quality of life; their learning and social development; family and peer interactions and isolation due to hearing loss; and, the potential for lifelong challenge and disadvantage.

Key structural issues for services as noted by participants in this study included the perception, as noted above, that there was a lack of understanding and respect for Aboriginal people and their culture. The necessity for medical professionals to take extra time to ensure clear communication leading to understanding was a strong

thread through all consultations and focus groups. This study found similar evidence to Smith and Boss (2010) as discussed in the literature review – racial disparities exist for the prevalence and treatment of OM in children. Institutional – and in some cases individual – racism, encompassing such things as being quick to make judgments, inflexibility in the provision of care, and failing to truly engage with families and their concerns, were all implicated in mismanagement and misdiagnosis of OM in Aboriginal children.

The key issue arising from this research for parent/carers is the need to ensure that their children receive the dedicated, concerned, non-stigmatising and professional care that they are entitled to expect to receive.

A brief summary on the findings from the research will be shared back to the community. Community presentations on the research findings will be held in Kwinana/Rockingham and in Armadale, with community members and health professionals invited to attend. A paper will be prepared for submission to a refereed journal to inform the wider research community of the research and its outcomes.

RECOMMENDATIONS

Community participants proposed a large number of strategies which they felt would assist in achieving the goal of ensuring their children were protected from, or treated early for, OM, and which would enable them to live a healthy, full life with a positive future. The recommendations of this research study are to:

- build community education opportunities around health and wellbeing, for mothers, fathers and carers, but also for pregnant mothers so that they understand the importance of early intervention and have greater capacity and understanding to make informed decisions about their child's health and wellbeing;
- provide greater opportunities for local community to be involved as health professionals and acknowledge the importance of their role in engaging families and building understanding of key health messages;

- offer outreach into communities so that families have more access to advice as and when needed – families were an important source of information to parents/carers – it is important this is recognized in any strategy;
- restructure the Purple Book (and consider creating an App) to make it more accessible and more of an educational guide to support families;
- respect the competing demands on a family's time and provision of centrally located services so families have access to services all in one location and at the same time (a one-stop-shop), for example always have having baby's ears checked when they have their immunisations;
- provide access speech and language professionals, especially whilst waiting for referrals from other health services e.g. audiology or ENT;
- utilise social media as an opportunity for communication, not only awareness of OM but also in the use of videos that engage families in good health practices that are based and grounded in community values; and
- ensure that families and communities are kept informed of any new information related to otitis media or their children's health generally.

CONCLUSION

This project has been informed by respect for the emancipatory imperative, maintaining political integrity, and privileging the Indigenous voice. Its quality, validity and rigour has been situated within decolonising methodologies and an Indigenous perspective. The literature from other Indigenous researchers provided the foundation for a decolonisation process that enabled trust, respect, control and the ownership of research, so that the project could seek support, guidance, recruitment of participants, and governance from community.

Findings from the project support the significance of maintaining the integrity of community voices in the project's cultural governance, ethics, preparation and planning, implementation and administration, including data collection, management and analysis.

Taking families on the journey of healthy ears and good hearing is important. Beyond clinical care and management, supporting and educating families should be part of standard practice. Relying only on screening at school is too late. The findings of this study suggest more is needed in understanding the needs and values of Aboriginal Australians living in urban settings, which in Western Australia includes almost three-quarters (72.6%) of the state's Aboriginal population).

Failure to acknowledge and act on the social determinants of health implicated in the very serious issue of middle ear (OM) disease in Aboriginal communities as reported in prior research, and supported and extended in this qualitative research in an urban environment, will only cover the surface of the problem and not disturb the core, leaving a trail of unacknowledged and unresolved trauma for Aboriginal people.

BIBLIOGRAPHY

Abbott, P., Gunasekera, H., Leach, A.J., Askey, D., Walsh, R. & et al. (2016). A multi-centre open-label randomised noninferiority trial comparing watchful waiting to antibiotic treatment for acute otitis media without perforation in low-risk urban Aboriginal and Torres Strait Islander children (the WATCH trial): study protocol for a randomised controlled trial. *Trials* 17:119.

Acuin, J. (2004). Chronic suppurative otitis media. Burden of illness and management options. World Health Organisation, Geneva: Switzerland.

Australian Government. (2013). National Aboriginal and Torres Strait Islander Health Plan 2013-2023. Canberra: Australian Government.

Australian Institute of Health and Welfare. (2018). Australia's health 2018. 6.4 Ear health and hearing loss among Indigenous children. Australia's Health (series no. 16). Canberra: AIHW.

Australian Institute of Health and Welfare. (2017). Aboriginal and Torres Strait Islander Health Performance Framework (HPF) Report 2017. Web report, available at : <https://www.aihw.gov.au/reports/indigenous-health-welfare/health-performance-framework/contents/overview>.

Australian Institute of Health and Welfare. (2016). Australia's Health. Canberra: AIHW.

Australian Institute of Health and Welfare. (2014). Ear disease in Aboriginal and Torres Strait Islander children. Resource sheet no. 35 produced by the Closing the Gap Clearinghouse. Canberra: AIHW.

Australian Institute of Health and Welfare. (2011). 2010 Australian National Infant Feeding Survey. Indicator results. Canberra: AIHW.

Australian Medical Association (AMA). (2017). AMA report card on Indigenous health. A national strategic approach to ending chronic otitis media and its lifelong impacts in Indigenous communities. Available at: <https://ama.com.au/article/2017-ama-report-card-indigenous-health-national-strategic-approach-ending-chronic-otitis>, accessed 27 November 2020.

Baker, D.W., Parker, R.M., Williams, M.V., Pitkin, K., Parikh, N.S. & et al. (1996). The health care experience of patients with low literacy. *Arch Fam Med*, 5, 329-334.

Bartlett, C., Marshall, M. & A. Marshall. (2012). Two-eyed seeing and other lessons learned within a co-learning journey of bringing together indigenous and mainstream knowledges and ways of knowing. *Journal of Environmental Studies and Sciences*, 2, 331-340.

Barwick H 2000. Improving access to primary care for Maori, and Pacific peoples: a literature review commissioned by the Health Funding Authority. Wellington: Health Funding Authority.

- Battiste, M. (2007). Research ethics for protecting indigenous knowledge and heritage: Institutional and researcher responsibilities. In N.K. Denzin & M.D. Giardina (Eds.). *Ethical futures in qualitative research: Decolonizing the politics of knowledge* (pp. 113-132). Left Coast Press.
- Baum, F., MacDougall, C. & D. Smith. (2006). Participatory action research. *Epidemiology Community Health*, 60, 854-857.
- Bessarab, D. & B. Ng'andu. (2010). Yarning about yarning as a legitimate method in Indigenous research. *International Journal of Critical Indigenous Studies*, 3:1, 37-50.
- Bhutta, M.F. (2015). Evolution and Otitis Media: A Review, and a Model to Explain High Prevalence in Indigenous Populations. *Human Biology*, 87:2, 92-108.
- Brophy-Williams, S., Jarosz, K., Sommer, J., Leach, A.J. & P.S. Morris. (2019). Preventative and medical treatment of ear disease in remote or resource-constrained environments. *The Journal of Laryngology & Otology*, 133, 59-72.
- Brouwer, C.N.M., Maille, A.R., Rovers, M.M., Grobee, D.E., Sanders, E.A.M. & A.G.M. Schilder. (2005). Health-related quality of life in children with otitis media. *Journal of Pediatric Otorhinolaryngology*, 69, 1031-1041.
- Brown, A.E., Fereday, J.A., Middleton, P.F. & J.I. Pincombe. (2016). Aboriginal and Torres Strait Islander women's experiences accessing standard hospital care for birth in South Australia - a phenomenological study. *Women and Birth*, 29, 350-8.
- Burns, J. & N. Thomson. (2013). Review of ear health and hearing among Indigenous Australians. *Australian Indigenous Health Bulletin*, 13(4).
- Carman, R., Andrew, L., Devine, A. & J. Oosthuizen. (2019). Barriers to vaccination service delivery within general practice: opportunity to make a sustainable difference in Aboriginal child health? *Indigenous Health*, 43:6, 563-569.
- Chando, S., Craig, J.C., Burgess, L., Sherriff, S., Purcell, A. & et al. (2020). Developmental risk among Aboriginal children living in urban areas in Australia: the Study of Environment on Aboriginal Resilience and Child Health (SEARCH). *BMC Pediatrics*, 20:13.
- Chando, S., Young, C., Craig, J.C., Gunasekera, H. & A. Tong. (2016). Parental views on otitis media: systematic review of qualitative studies. *Eur J Pediatr*, 175, 1296-1305.
- Chevalier, J.M. & D. Buckles. (2013). *Participatory action research: Theory and methods for engaged inquiry*. London: Routledge
- Clarke, M. & J. Boyle (2014). Antenatal care for Aboriginal and Torres Strait Islander women. *Australian Family Physician*, 43(1): 20-4.
- Closing The Gap Clearinghouse. (2014). Ear Disease in Aboriginal and Torres Strait Islander Children. Resource Sheet no. 35.
- Coffin, J. (2007). Rising to the challenge in Aboriginal health by creating cultural security. *Aboriginal & Islander Health Worker Journal*, 3:3.

- Coleman, A., Wood, A., Bialasiewicz, S., Ware, R.S., Marsh, R.L. & et al. (2018). The unsolved problem of otitis media in indigenous populations: a systematic review of upper respiratory and middle ear microbiology in indigenous children with otitis media. *Microbiome*, 6:199, available at <https://doi.org/10.1186/s40168-018-0577-2>.
- Couzos, S., Metcalf, S. & R.B. Murray. (2001). Systematic review of existing evidence and primary care guidelines on the management of otitis media in Aboriginal and Torres Strait Islander populations. Report. Commonwealth Department of Health and Aged Care, Canberra.
- Cox, A., Dudgeon, P., Holland, C., Kelly, K., Scrine, C. & R. Walker. (2014). Using participatory action research to prevent suicide in Aboriginal and Torres Strait Islander communities. *Australian Journal of Primary Health*, 20:4, 345-349.
- Cripps, A.W. & D.C. Otczyk. (2006). Future Drugs, *Expert Review Vaccines* 5(4): 517-535
- D'Antoine, H., Abbott, P., Sherwood, J., Wright, M., Bond, C., Dowling, C. & et al. (2019). A collaborative yarn on qualitative health research with Aboriginal communities. *Australian Indigenous HealthBulletin*, 19:2, 1-6.
- Davis, A.C. & H.J. Hoffman. (2019). Hearing Loss: rising prevalence and impact. *Bulletin of the World Health Organization*, 97, 646-646A.
- Davy, C., Kite, E., Sivak, L., Brown, A., Ahmat, T. & et al. (2017). Towards the development of a wellbeing model for Aboriginal and Torres Strait Islander peoples living with chronic disease. *BMC Health Serv Res.* 17:1, 659-
- DeLacy, J., Dune, T. & J.J. Macdonald. (2020). The social determinants of otitis media in Aboriginal children in Australia: are we addressing the primary causes? A systematic content review. Division (Royal Australasian College of Physicians). *BMC Public Health*, 20, 492.
- Department of the Prime Minister and Cabinet. (2014). Aboriginal and Torres Strait Islander Health Performance Framework 2014 Report. 2.20 Breastfeeding practices 2014. Available from: <https://www.pmc.gov.au/sites/default/files/publications/indigenous/Health-Performance-Framework-2014/tier-2-determinants-health/220-breastfeeding-practices.html>
- Dossetor, P.J., Thorburn, K., Oscar, J., Carter, M., Fitzpatrick, J. & et al. (2019). Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions. *BMC Health Services Research*, 19, 758.
- Durey, A. (2010). Reducing racism in Aboriginal health care in Australia: Where does cultural education fit? *Australian and New Zealand Journal of Public Health*, 34, S87-S92.
- Dwyer, S.C. & J.L. Buckle. (2009). The space between: On being an Insider-Outsider in qualitative research. *The International Journal of Qualitative Methods*, 8:1.
- Eades, S.J. (2003). Bibbulung Gnarnep (Solid Kid). A longitudinal study of a population based cohort of urban Aboriginal children in Western Australia. Determinants of health outcomes during early childhood of Aboriginal children residing in an urban area. PhD thesis. University of Western Australia.

Edwards, J. & C.D. Moffat. (2014). Otitis media in remote communities. *Australian Nursing and Midwifery Journal*, 21:9, 28-

Eggins, J. (2011). Creating HIV & AIDS messages with communities: An indigenous communication for social change research approach (Masters thesis). University of Goroka, Papua New Guinea.

Fairthorne, J., Walker, R., de Klerk, N. & C. Shepherd. (2016). Early mortality from external causes in Aboriginal mothers: a retrospective cohort study. *BMC Public Health*, 16, 461-

Falster, K., Banks, E., Lujic, S., Falster, M., Lynch, J. & et al. (2016). Inequalities in pediatric avoidable hospitalizations between Aboriginal and non-Aboriginal children in Australia: a population data linkage study. *BMC Pediatrics*, 16, 169-

Fast, E. & M. Kovach. (2019). Community relationships within Indigenous methodologies (pp. 21-36). In W. Sweeney & T. San Pedro (Eds.), *Applying Indigenous research methods. Storying with peoples and communities*. New York & London: Routledge.

Finn, L.D., Pepper, A., Gregory, P. & S.C. Thompson. (2008). Improving Indigenous access to cancer screening and treatment services: descriptive findings and a preliminary report on the Midwest Indigenous Women's Cancer Support Group. *Australasian Medical Journal* 1:2, 1-21.

Fisher, M., Battams, S., McDermott, D. & F. Baum. (2019). How the social determinants of Indigenous health became policy reality for Australia's National Aboriginal and Torres Strait Islander Health Plan. *Journal of Social Policy*, 48:1, 169-189.

Freeman, T., Edwards, T., Baum, F., Lawless, A., Jolley, G. & et al. (2014). Cultural respect strategies in Australian Aboriginal primary health care services: beyond education and training of practioners. *Indigenous Health*, 38:4, 355-361.

Gibney, K.B., Morris, P.S., Carapetis, J.R., Skull, S.A. & A.J. Leach. (2003). Missed opportunities for a diagnosis of acute otitis media in Aboriginal children. *Journal of Paediatric Child Health*, 39, 540-542.

Government of South Australia. (2017). An Aboriginal ear health framework for South Australia. Adelaide: SA Health.

Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J. & et al. (2016). Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services. *BMC Health Services Research*, 16, 680-

Gribben, B., Salkeld, L. J., Hoare, S. & H.F. Jones. (2012). The incidence of acute otitis media in New Zealand children under five years of age in the primary care setting. *Journal of Primary Health Care*, 4:3.

Gunasekera, H., Morris, P.S., Daniels, J., Couzos, S. & J.C. Craig. (2009a). Management of children with otitis media: A survey of Australian Aboriginal Medical Service practitioners. *Journal of Paediatrics and Child Health*, 45, 457-463.

Gunasekera, H., Morris, P.S., Daniels, J., Couzos, S. & J.C. Craig. (2009b). Otitis media in

Aboriginal children: The discordance between burden of illness and access to services in rural/remote and urban Australia. *Journal of Paediatrics and Child Health*, 45:7-8, 425-30.

Harfield, S.G., Davy, C., McArthur, A., Munn, Z., Brown, A. & N. Brown. (2018). Characteristics of Indigenous primary health care service delivery models: a systematic scoping review. *Globalization and Health*, 14, 12-

Harrison, N. (2011). *Teaching and learning in Aboriginal education* (2nd ed.), South Melbourne: Oxford University Press.

Hayman, N.E., White, N.E., & G.K. Spurling. (2009). Improving Indigenous patients' access to mainstream health services: The Inala experience. *MJA*, 190, 604–6.

hooks, bell. (1990). Marginality as a site of resistance. In R. Ferguson, M. Gever, T.T. Minh-ha & Cornel West (Eds). *Out there: Marginalization and Contemporary Cultures* (pp 341-343). Cambridge, MA: MIT.

Hughes, P., More, A., & M. Williams. (2004). *Aboriginal ways of learning*. Adelaide, SA: Flinders Press.

Jacoby, P., Carville, K.S., Hall, G., Riley, T.V., Bowman, J. & et al. (2011). Crowding and other strong predictors of upper respiratory tract carriage of otitis media-related bacteria in Australian Aboriginal and non-Aboriginal children. *The Pediatric Infectious Disease Journal*, 30:6, 480-485.

Jeffries-Stokes, C., Lehmann, D., Johnston, J., Mason, A., Evans, J. & et al. (2004). Aboriginal perspective on middle ear disease in the arid zone of Western Australia. *J. Paediatr. Child Health*, 40, 258–264.

Jersky, M., Titmuss, A., Haswell, M., Freeman, N., Osborne, P. & et al. (2016). Improving health services access and wellbeing of young Aboriginal parents in an urban setting: mixed methods evaluation of an art-based program. *Aust NZ J Public Health*, 40 (Supp. 1), S115-S121.

Jervis-Bardy, J., Sanchez, L. & A.S. Carney. (2014). Otitis media in Indigenous Australian children: review of epidemiology and risk factors. *The Journal of Laryngology & Otology*, 128(Supp S1), S16-S27.

Jervis-Bardy, J., Carney, A.S., Duguid, R. & A.J. Leach. (2017). Microbiology of otitis media in Indigenous Australian children: review. *The Journal of Laryngology & Otology*, 131(Suppl S2), S2-S11.

Jones, E., Lattof, S.R. & E. Coast. (2017). Interventions to provide culturally-appropriate maternity care services: factors affecting implementation. *BMC Pregnancy and Childbirth*, 17, 267-.

Jones, C., Sharma, M., Harkus, S., McMahon, C., Taumoepeau, M. & et al. (2018). A program to respond to otitis media in remote Australian Aboriginal communities: a qualitative investigation of parent perspectives. *BMC Pediatrics*, 18:99.

- Kanuha, V.K. (2000). "Being" Native versus "Going Native": Conducting social work research as an insider. *Social Work*, 45:5, 439-447.
- Kelaher, M., Ferdinand, A.S. & Y. Paradies. (2014). Experiencing racism in health care: the mental health impacts for Victorian Aboriginal communities. *MJA*, 201:1, 44-47.
- Kelly, J., Dwyer, J., Willis, E. & B. Pekarsky. (2014). Travelling to the city for hospital care: access factors in country Aboriginal patient journeys. *Aust J Rural Health*, 22, 109-113.
- Kenyon, G. (2017). Social otitis media: ear infection and disparity in Australia. *The Lancet*, 17, 375-376.
- Kerstetter, K. (2012). Insider, outsider, or somewhere in between: the impact of researchers' identities on the community-based research process. *Journal of Rural Social Sciences*, 27:2, 99-117
- Kildea, S., Hickey, S., Nelson, C., Currie, J., Carson, A. & et al. (2018). Birthing on Country (in Our Community): a case study of engaging stakeholders and developing a best-practice Indigenous maternity service in an urban setting. *Australian Health Review*, 42, 230-8.
- Kildea, S., Tracy, S., Sherwood, J., Magick-Dennis, F. & L. Barclay. (2016). Improving maternity services for Indigenous women in Australia: moving from policy to practice. *MJA*, 205:8, 375-379.
- Kildea, S., Stapleton, H., Murphy, R., Low, N.B. & K. Gibbons. (2012). The Murri clinic: a comparative retrospective study of an antenatal clinic developed for Aboriginal and Torres Strait Islander women. *BMC Pregnancy and Childbirth*, 12, 159-.
- Kong, K. & H.L.C. Coates (2009). Natural history, definitions, risk factors and burden of otitis media. *Medical Journal of Australia*, 191:9, S39-S43.
- Kovach, M. (2009). *Indigenous methodologies: characteristics, conversations and contexts*. Canada: University of Toronto Press.
- Krahe, K. (2016). Give Indigenous Australian women and infants a chance at life: addressing the disparity in maternal-infant health outcomes. Australian Institute of International Affairs. Accessed at: <http://www.internationalaffairs.org.au/news-item/give-indigenous-australian-women-and-infants-a-chance-at-life-addressing-the-disparity-in-maternal-infant-health-outcomes/>
- Larson, A., Gillies, M., Howard, P.J. & J. Coffin. (2007). It's enough to make you sick: the impact of racism on the health of Aboriginal Australians. *Australian and New Zealand Journal of Public Health*, 31:4, 322-329.
- Leach, A.J., Boswell, J.B., Asche, V., Nienhuys, T.G. & J.D. Mathews. (1994). Bacterial colonization of the nasopharynx predicts very early onset and persistence of otitis media in Australian Aboriginal infants. *Pediatr Infect Dis J*, 13, 983-989.
- Leach, A. & P. Morris. (2017). Otitis Media and hearing loss among Aboriginal and Torres Strait Islander Children. Australian Parliament's Standing Committee on Health, Aged Care

and Sport Public Hearing in Reference to the Inquiry into the Hearing Health and Wellbeing of Australia.

Lehmann, D., Arumugaswamy, A., Elsbury, D., Finucane, J., Stokes, A. & et al. (2008). The Kalgoorlie Otitis Media Research Project: rationale, methods, population characteristics and ethical considerations. *Paediatric and Perinatal Epidemiology*, 22, 60–71.

Loader, P. (1998). Such a shame: A consideration of shame and shaming mechanisms in families. *Child Abuse Review*, 7:1, 44-57.

Lutwak, N., Razzino, B.E. & J.R. Ferrari. (1998). Self-perceptions and moral affect: An exploratory analysis of subcultural diversity in guilt and shame emotions. *Journal of Social Behavior & Personality*, 13:2, 333-348.

MacDonald, C. (2012). Understanding participatory action research: A qualitative research methodology option. *Canadian Journal of Action Research*, 13:2, 34-50.

Mackenzie, I. & A. Smith. (2009). Deafness – the neglected and hidden disability. *Annals of Tropical Medicine & Parasitology*, 103:7, 565-571.

Madanes, C. (1997). Shame: How to bring a sense of right and wrong into the family. In J.K. Zeig (Ed.). *The evolution of psychotherapy: The third conference* (pp. 257-267). Brunner/Mazel.

Maguire, P. (1987). *Doing participatory action research: A feminist approach*. Massachusetts: University of Massachusetts Press.

Mahadevan, M., Navarro-Locsin, G., Tan, H.K.K., Yamanaka, N., Sonsuwan, N., Wang, P-C. & et al. (2012). A review of the burden of disease due to otitis media in the Asia-Pacific. *International Journal of Pediatric Otorhinolaryngology*, 76, 623-635.

Maher, P. 1999. A review of ‘traditional’ Aboriginal health beliefs. *Australian Journal of Rural Health*, 7:4, 229–36.

Maiter, S., Simich, L., Jacobson, N. & Wise, J. (2008). Reciprocity: An ethic for community-based participatory action research. *Action Research* 6:3, 305-325.

Martin, D.H. (2012). Two-eyed seeing: a framework for understanding Indigenous and non-Indigenous approaches to Indigenous health research. *Canadian Journal of Nursing Research*, 44:2, 20-42.

Masadeh, M.A. (2012). Focus Group: Reviews and practices. *International Journal of Applied Science and Technology*, 2:10.

McConvell, P. (1988). Mix-im-up. Aboriginal code-switching, old and new (pp. 97-124). In M. Heller (Ed.), *Codeswitching: Anthropological and sociolinguistic perspectives*. Berlin: Mouton de Gruyter.

McConvell, P. & F. Meakins. (2005). Gurindji Kriol: A mixed language emerges from code-switching. *Australian Journal of Linguistics*, 25, 9-30.

- McKnight, A., Harwood, V., McMahon, S. & A. Priestly. (2018). 'No shame at AIME': Listening to Aboriginal philosophy and methodologies to theorise shame in educational contexts. *The Australian Journal of Indigenous Education*, 49:1, 46-56.
- McNamara, B., Gubhaju, L., Jorm, L., Preen, D., Jones, J. & et al. (2018) Exploring factors impacting early childhood health among Aboriginal and Torres Strait Islander families and communities: protocol for a population-based cohort study using data linkage (the 'Defying the Odds' study). *BMJ Open*, 8(e021236): 1-12.
- Meherali, S., Campbell, A., Hartling, L. & S. Scott. (2019). Understanding parents' experiences and information needs on pediatric acute otitis media: a qualitative study. *Journal of Patient Experiences*, 6:1, 53-61.
- Monasta, L., Ronfani, L., Marchetti, F., Montico, M., Brumatti, L.V. & et al. (2012). Burden of disease caused by otitis media: systematic review and global estimates. *PLoS One*, 7:4, e36226-
- Morris, P.S. & A.J. Leach. (2009). Managing otitis media: an evidence-based approach. *Australian Prescriber*, 32:6, 155-159.
- Moreton-Robinson, A. (2000). *Talkin' up to the white woman: Indigenous women and feminism*. St Lucia, Queensland: University of Queensland Press.
- Munir, N. & R. Clarke. (2013). *Ear, nose and Throat at a Glance* (1st ed.), UK: Wiley-Blackwell.
- Nakata M. (2002). Indigenous Knowledge and the cultural interface: Underlying issues at the intersection of knowledge and information systems. *IFLA Journal*. 28(5/6), 281-91.
- NHMRC. (2013). Infant feeding guidelines. Summary. Accessed at: <https://www.nhmrc.gov.au/about-us/publications/infant-feeding-guidelines-information-health-workers#block-views-block-file-attachments-content-block-1>
- Ngo, C.C., Massa, H.M., Thornton, R.B. & A.W. Cripps. (2016). Predominant bacteria detected from the middle ear fluid of children experiencing otitis media: a systematic review. *PLoS One*. (26 pages) DOI:10.1371/journal.pone.0150949.
- Nicholls, R. (2019). Research and Indigenous participation: critical reflexive methods. *International Journal of Social Research Methodology*, 12:2, 117-126.
- Okano, K-I. (1994). Shame and social phobia: A transcultural viewpoint. *Bulletin of the Menninger Clinic*, 58:3, 323-338.
- Paradies, Y. (2006). Race, racism, stress and Indigenous health. PhD thesis, Department of Public Health, University of Melbourne. Available at: <https://minerva-access.unimelb.edu.au/handle/11343/39147>
- Paradies, Y. (2016). Colonisation, racism and indigenous health. *J Pop Research*, 33, 83-96.
- Peltier, C. (2018). An application of two-eyed seeing: Indigenous research methods with participatory action research. *International Journal of qualitative methods*, 17, 1-12.

- Pewewardy, C. (2019). Afterword. To be an Indigenous scholar (pp. 150-153). In W. Sweeney & T. San Pedro (Eds.), *Applying Indigenous research methods. Storying with peoples and communities*. New York & London: Routledge.
- Porsanger, J. (2004). An essay about Indigenous methodology. *Nordlit*, nr.15: 105-120.
- Potter-Efron, R.P. & P. Potter-Efron. (1989). *Letting go shame. Understanding how shame affects your life*. Minnesota: Hazelden Publishing.
- Potter-Efron, Ronald. (2002). *Shame, guilt, and alcoholism. Treatment issues in clinical practice* (2nd Ed.). New York & London: Routledge.
- Priest, N., Mackean, T., Davis, E., Briggs, L. & E. Waters. (2012). Aboriginal perspectives of child health and wellbeing in an urban setting: Developing a conceptual framework. *Health Sociology Review*, 21:2, 180-195.
- Ralph, S. (1997). Working with Aboriginal families. Issues and guidelines for family and child counsellors. *Family Matters*, 46, 46-50.
- Reibel, T., Wyndow, P. & R. Walker. (2016). From consultation to application: practical solutions for improving maternal and neonatal outcomes for adolescent Aboriginal mothers at a local level. *Healthcare*, 4, 90-.
- Reid, J. & P. Trompf. (Eds.). (1991). *The health of Aboriginal Australia*. Sydney: Harcourt Brace Jovanovich.
- Richmond, H. (2019). Investigating the Prevalence and Risk Factors of Otitis Media Among Urban Aboriginal Children. Honours thesis, University of Western Australia.
- Rigney, L-I. (2006). Indigenist research and Aboriginal Australia (pp. 32-48). In J. E. Kunnie & N. I. Goduka (Eds.), *Indigenous people's wisdom and power. Affirming our knowledge through narratives*. Hampshire, England & Burlington VT: Ashgate.
- Rigney, L-I. (2001). A first perspective of Indigenous Australian participation in science: framing Indigenous research towards Indigenous Australian intellectual sovereignty. University of South Australia.
- Rigney, L-I. (1997). Internationalisation of an Indigenous anti-colonial critique of research methodologies: A guide to Indigenist research methodology and its principles. *The Journal for Native American Studies*, 14, 109-121.
- Rix, E. F., Wilson, S., Sheehan, N. & N. Tujague. (2018). Indigenist and colonizing research methodology, (pp. 1-13). In P. Liamputtong (Ed.), *Handbook of research methods in health social sciences*, Australia: Springer.
- Royal College of Physicians and Surgeons of Canada. (2012). *Defining societal health needs. Royal College definition and guide*. Canada: Royal College.
- Salmon, M., Skelton, F., Thurber, K.A., Bennetts Kneebone, L., Gosling, J. & et al. (2018). Interfenerational and early life influences on the well-being of Australian Aboriginal and Torres Strait Islander children: overview and selected findings from Footprints in Time, the

Longitudinal Study of Indigenous Children. *Journal of Developmental Origins of Health and Disease*, 10: 17-23.

Santos-Cortez, R., Chiong, C., Frank, D., Ryan, A., Giese, A. & et al. (2018). FUT2 Variants Confer Susceptibility to Familial Otitis Media. *The American Journal of Human Genetics*, 103:5, 679-690.

Saunders, V., West, R. & K. Usher. (2010). Applying Indigenist Research methodologies in health research: experiences in the borderlands. *Australian Journal of Indigenous Education*, 39, 1-7.

Scheurich, J.J. & M.D. Young. (1997). Coloring epistemologies: Are our research epistemologies racially biased? *Educational Researcher*, 26:4, 4-16.

Schilder, A.G.M., Chonmaitree, T., Cripps, A.W., Rosenfeld, R.M., Casselbrant, M.L. & et al. (2016). Otitis media. *Nature Reviews Disease Primers*, 2, Article number: 16063.

Schneider, E.C., Sarnak, D.O., Squires, D., Shah, A. & M.M. Doty. (2017). Mirror, Mirror 2017: International comparison reflects flaws and opportunities for better U.S. health care. The Commonwealth Fund; 16 August 2019.

Scott, K. & T. Janke (2002). Aboriginal and Torres Strait Islander cultural protocols. Available at: https://www.oxfam.org.au/wp-content/uploads/2015/11/2015-74-ATSI-Cultural-Protocols-update_WEB.pdf. Accessed on 27 November 2020.

Scrimgeour, M. & D. Scrimgeour. (2008). Health care access for Aboriginal and Torres Strait Islander people living in urban areas, and related research issues: a review of the literature. CRCAH discussion paper no. 5. Darwin: Cooperative Research Centre for Aboriginal Health.

Serrant-Green, L. (2002). Black on black: methodological issues for black researchers working in minority ethnic communities. *Nurse researcher*, 9:4, 30-44.

Shepherd, C.C.J., Li, J., Cooper, M.N., Hopkins, K.D. & B.M. Farrant. (2017). The impact of racial discrimination on the health of Australian Indigenous children aged 5–10 years: analysis of national longitudinal data. *International Journal for Equity in Health*, 16:116.

Sherwood, J. (2010). Do no harm: decolonising Aboriginal health research. PhD Thesis. UNSW.

Sherwood, J. (2013). Colonisation – It's bad for your health: the context of Aboriginal health. *Contemporary Nurse*, 46(1): 28-40.

Sibthorpe, B., Agostino, J., Coates, H., Week, S., Lehmann, D. & et al. (2017). Indicators for continuous quality improvement for otitis media in primary health care for Aboriginal and Torres Strait Islander children. *Australian Journal of Primary Health*, 23, 1-9.

Sikes, P. (2013). Working together for critical research ethics. *Compare*, 43:4, 516-536.

Smith, D. & E.F. Boss, (2010). Racial/ethnic and socioeconomic disparities in the prevalence and treatment of otitis media in children in the United States. *The Laryngoscope*, 120:11, 2306-2312.

Sofaer, N. (2014). Reciprocity-based reasons for benefiting research participants: most fail, the most plausible is problematic. *Bioethics*, 28:9, 456-471.

Streubert, H.J. & D.R. Carpenter. (1995). *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia: J.B. Lippincott Company.

Stringer, E.T. (2014). *Action research*. Perth: Curtin University of Technology.

Su, J-Y, He, V.Y., Guthridge, S., Howard, D., Leach, A. & S. Silburn. (2019). The impact of hearing impairment on Aboriginal children's school attendance in remote Northern Territory: a data linkage study. *Australian and New Zealand Journal of Public Health*, 43:6, 544-550.

Swift, V.M., Doyle, J.E., Richmond, H.J., Morrison, N.R., Weeks, S.A. & et al. (2020). *Djaalinj Waakinj* (listening talking): rationale, cultural governance, methods, population characteristics – an urban Aboriginal birth cohort study of otitis media. *Deafness & Education International*, (online), <https://doi.org/10.1080/14643154.2020.1826101>

Thomson, M. (1994). Otitis media. How are First Nations children affected? *Canadian Family Physician*, 40.

Thorne, P.R., Holt, E.A.L., Nosa, V., Oh, C., Lopati, S. & et al. (2019). Provision of hearing care in Pacific Island countries and territories. *Bulletin of the World Health Organization*, 97, 719-721.

Thornton, R.B., Kirkham, L.S., Corscadden, K.J., Wiertsema, S.P., Fuery, A. & et al. (2017). Australian Aboriginal children with otitis media have reduced antibody titers to specific nontypeable *Haemophilus influenzae* vaccine antigens. *Clinical and Vaccine Immunology*, 24:4.

Threlfall, K.D. (1999). Using focus groups as a consumer research tool. *Journal of Marketing Practice: Applied Marketing Science*, 5:4, 102-105.

Tuhiwai-Smith, L. (2003). *Decolonizing methodologies: research and Indigenous people*. Dunedin, NZ: University of Otago Press.

Tuhiwai Smith, L. (1999). *Decolonizing methodologies: Research and Indigenous peoples*. London and New York: Zed Books.

To the Senate - Community Affairs References Committee Hear Us: Inquiry into Hearing Health in Australia 2010. Commonwealth of Australia.

Vallesi, S., Wood, L., Dimer, L. & M. Zada. (2018). "In their own voice"—Incorporating underlying social determinants into Aboriginal health promotion programs. *International Journal of Environmental Research and Public Health*, 15, 1514-

- Vergison, A., Dagan, R., Arguedas, A., Bonhoeffer, J., Cohen, R. & et al. (2010). Otitis media and its consequences: beyond the earache. *Lancet Infect Dis*, 10, 195-203.
- WA Department of Health. (2013). Otitis Media: Model of Care. Perth: Government of Western Australia.
- Walker, M., Fredericks, B., Mills, K. & D. Anderson. (2014). "Yarning" as a method for community-based health research with Indigenous women: the Indigenous Women's Wellness Research Program. *Health Care for Women International*, 35:10, 1216-1226.
- Ware, V-A. (2013). Improving the accessibility of health services in urban and regional settings for Indigenous people. Resource sheet no. 27 produced for the Closing the Gap Clearinghouse. Canberra: AIHW.
- Wax, M.L. (1982). Research reciprocity rather than informed consent in fieldwork. In J.E. Sieber (Ed). *The Ethics of Social Research*, (pp 33-48). New York, Heidelberg, Berlin: Springer-Verlag.
- Westphal, D.W., Lehmann, D., Williams, S.A., Richmond, P.C., Lannigan, F.J., Fathima, P. & et al. (2019). Australian Aboriginal children have higher hospitalization rates for otitis media but lower surgical procedures than non-Aboriginal children: A record linkage population-based cohort study. *PloS One*, April 23, 1-15.
- Whitman, G.P., Pain, R. & D.G. Milledge. (2015). Going with the flow? Using participatory action research in physical geography. *Progress in Physical Geography*, 39:5, 622-639.
- WHO. (1998). Prevention of hearing impairment from chronic otitis media. Report of a WHO/CIBA Foundation Workshop.
- WHO. (2020). Social determinants of health. Accessed at: https://www.who.int/social_determinants/sdh_definition/en/
- Wiertsema, S.P. & A.J. Leach. (2009). Theories of otitis media pathogenesis, with a focus on Indigenous children. Supplement. *MJA*, 191:9, S50-S54.
- Williams, R. (1999). Cultural safety – what does it mean for our work practice? *Australian and New Zealand Journal of Public Health*, 23:2, 213-214.
- Williams, C.J. & A.M. Jacobs. (2009). The impact of otitis media on cognitive and education outcomes. *MJA*, 191, S69–S72
- Williams, C.J., Coates, H.L. & E.M. Pascoe. (2009). Middle Ear Disease in Aboriginal Children in Perth: Analysis of Hearing Screening Data, 1998–2004. *MJA*, 190:10, 598-600.
- Wilson, S. (2001). What is an Indigenous research methodology? *Canadian Journal of Native Education*, 25:2, 175-179.
- Wright, M. (2011). Research as intervention: engaging silenced voices. *ALARJ* 17:2, 25-46.

Wright, M., O'Connell, M., & T. Jones. (2013). Open Hearts, Open Hands: A Spiritual Journey of Change Handbook. The Looking Forward Project. Telethon Kids Institute: Subiaco WA.

Wright, M., O'Connell, M., Jones, T., Walley, R. & L. Roarty. (2015). Looking Forward Aboriginal Mental Health Project. Final Report. December 2015. Telethon Kids Institute, Subiaco, WA.

Wuest, J. (1991). Harmonizing: a North American Indian approach to management of middle ear disease with transcultural nursing implications. *Journal of Transcultural Nursing*, 3:1, 5-14.

Young, C., Tong, A., Gunasekera, H., Sherriff, S., Kalucy, D. & et al. (2016). Health professional and community perspectives on reducing barriers to accessing specialist health care in metropolitan Aboriginal communities: a semi-structured interview study. *Journal of Paediatrics and Child Health*, 53, 277-282.

APPENDICES

APPENDIX A – WAAHEC APPROVAL



30th September, 2016

Dear Rose,

WAAHEC HREC Project Reference: 737

Project Title: Kadadjiny Dwank Project Otitis Media from an urban Aboriginal perspective

Thank you for submitting the above research project which was considered by the WAAHEC at the out of session meeting held on 20th September, 2016. I am pleased to advise that the WAAHEC has reviewed and approved the following documents for use in this project:

Document(s):

- WAAHEC Application Form
- Research Proposal
- Response to Ethics committee, August 2016
- Full Scientific Protocol
- Consent Form
- Consent Form, photographs
- Information Sheet
- Community project flyer
- Community focus group questions
- Questionnaire community focus group
- Individual questionnaires
- Individual questionnaire sheet
- Letter of support, Moorditj Koort

The WAAHEC has granted approval of this research project from date of the meeting held, pending your agreement of the following conditions:

1. Conditions

The WAAHEC will be notified, giving reasons, if the project is discontinued before the expected date of completion.

- The coordinating Investigator will provide a Progress Report every 30th June each year in the specified format. This form can be found on the AHCWA website (www.ahcwa.org).

450 Beaufort Street, Highgate WA 6003 / PO BOX 8493, Stirling Street, Perth WA 6849
Phone: (08) 9227 1631 **Fax:** (08) 9228 1088 **Email:** ethics@ahcwa.org **Web:** www.ahcwa.org
ABN: 48 114 220 478 ACN: 114 220 478

APPENDIX B – CURTIN UNIVERSITY HREC APPROVAL



07-Jun-2017

Name:
Department/School: Curtin University
Email: rosemary.walley@student.curtin.edu.au

Dear Rosemary Walley

RE: Reciprocal ethics approval Approval number: HRE2017-0339

Rosemary Walley

Thank you for your application submitted to the Human Research Ethics Office for the project Kadadjiny Dwank (listening, thinking and learning with your ears) Otitis Media from an urban Aboriginal perspective..

Your application has been approved by the Curtin University Human Research Ethics Committee (HREC) through a reciprocal approval process with the lead HREC.

The lead HREC for this project has been identified as Western Australian Aboriginal Health Ethics Committee (WAAHEC).

Approval number from the lead HREC is noted as WAAHEC HREC Project Reference: 737.

The Curtin University Human Research Ethics Office approval number for this project is **HRE2017-0339**. Please use this number in all correspondence with the Curtin University Ethics Office regarding this project.

Approval is granted for a period of one year from **07-Jun-2017** to **06-Jun-2018**. Continuation of approval will be granted on an annual basis following submission of an annual report.

Personnel authorised to work on this project: Name Role
Walley, Rosemary Student

You must comply with the lead HREC's reporting requirements and conditions of approval. You must also:

Keep the Curtin University Ethics Office informed of submissions to the lead HREC, and of the review outcomes for those submissions Conduct your research according to the approved proposal

Report to the lead HREC anything that might warrant review of the ethics approval for the project

Submit an annual progress report to the Curtin University Ethics Office on or before the anniversary of approval, and a completion report on completion of the project. These can be the same reports submitted to the lead HREC.

Personnel working on this project must be adequately qualified by education, training and experience for their role, or supervised

Office of Research and Development

GPO Box U1987
Perth Western Australia 6845

Telephone +61 8 9266 7863 **Facsimile** +61 8 9266 3793 **Web** research.curtin.edu.au

Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, that bears on this project

Data and primary materials must be managed in accordance with the [Western Australian University Sector Disposal Authority \(WAUSDA\)](#) and the [Curtin University Research Data and Primary Materials policy](#)

Where practicable, results of the research should be made available to the research participants in a timely and clear manner. The Curtin University Ethics Office may conduct audits on a portion of approved projects.

This letter constitutes ethical approval only. This project may not proceed until you have met all of the Curtin University research governance requirements.

Should you have any queries regarding consideration of your project, please contact the Ethics Support Officer for your faculty or the Ethics Office at hrec@curtin.edu.au or on 9266 2784.

Yours sincerely

Dr Karen Heslop
Deputy Chair, Human Research Ethics Committee

A handwritten signature in black ink, appearing to read 'KHeslop'.

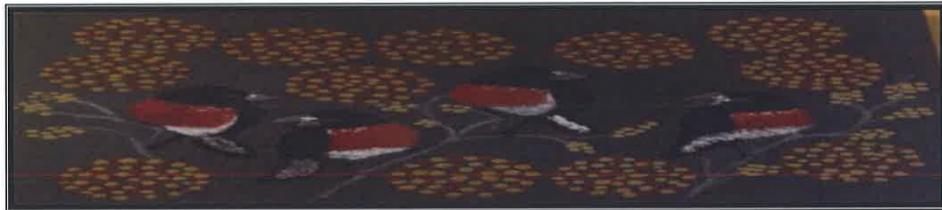


Kadadjiny Dwank

(Listening, Thinking, Learning)

Otitis Media from an urban Aboriginal perspective

Information Sheet



What is the research project about?

Poor ear health is a major issue for Aboriginal children. It sometimes begins within weeks of birth and can persist into adolescence and adulthood. Otitis media (OM), or middle ear disease can have profound implications on a child's learning potential, which can lead to social and learning difficulties as well as behavioral problems at home and later at school. This in turn will impact on life as an adult in terms of having relationships, connection to culture, and employment prospects.

A great deal of research has been undertaken regarding OM. However most of the research has focused on remote communities despite the fact that most Aboriginal Australians live in urban settings. This research project will look at OM in urban areas.

Through community forums, focus groups, and semi structured questionnaires with individual families, the research aims to address three broad questions:

- ✚ What do people know and do about ear infections?
- ✚ What are the barriers to accessing care?
- ✚ How does OM impact on the child and family?

Who will be involved in the project?

Rosemary Walley, Chief Investigator
Dr. Deborah Lehmann Clinical Assoc. Prof. Principal Researcher Fellow
Dr. Michael Wright from the Looking Forward Research Project
Ms Victoria Stroud from the Telethon Kids Institute
Mr Danny Ford community consultant and facilitator
Families (young children with ear problems).
Aboriginal community organisations and members
Eight key community members from the Research Focus Group
Aboriginal Health Worker to provide an understanding of Otitis Media.

What will be the possible outcomes of the research?

It is intended for this research project to contribute to helping prevent ear disease in small children. The research will consider possible interventions and strategies that could reduce the impact of poor ear health for children, and their families living in an urban environment. It will inform of more culturally appropriate delivery of ear health services that will provide effective and long-term outcomes from an Aboriginal urban perspective.

Where to from here?

The Kadadjiny Dwank research project will commence from 2016 to 2019 and focus on two regions: Rockingham/Kwinana and Armadale. Ten families from each region will be involved in the project.

In each region there will be an information forum and workshop at the start of the project and all community members will be invited to attend and participate. These will be held to explain to the community what the project is about, what OM is and its consequences, and why the research is being undertaken.

The workshops will provide the opportunity for community members to voice their opinions and concerns around OM and service provision in an informal manner, which could then be incorporated into focus group discussions. It is intended to gain the support of the community, identify those who will participate in focus groups as well as begin to identify some of the families that may like to be involved in the research.

Role of families

Role of Focus Group

Participate in an average of 6 – 8 meetings per year over.
Compensated for their expertise and time.
Work together to guide the setting of the project's research priorities

The project will commence in mid 2016 and continue until 2019.

Contact details

Researcher Rosemary Walley

Mobile: 0455271332

Email: rosemary.walley@telethonkids.org.au



APPENDIX D – KADADJINY DWANK CONSENT FORMS



Kadadjiny Dwank

(Listening, Thinking, Learning)

Otitis Media from an urban Aboriginal perspective

Consent Form

I
(First name) (Last name)

agree to participate in the focus group for the Kadadjiny Dwank research project conducted in Southwest Metro area of Perth.

I have read the information sheet explaining what the 'Kadadjiny Dwank' research project is about what it is aiming to do.

I understand the information given to me. I was able to ask any questions I have about the research and state that these questions have been answered to my satisfaction.

I understand that information collected from this research may be published in reports, publications and documents. I have been informed that there will be no identifying information of myself in the reports, publications and documents that may be prepared from the research without my consent.

By signing this consent form I am agreeing to participate in focus groups as part of the 'Kadadjiny Dwank' research project on Otitis Media from an urban Aboriginal perspective.

Please indicate Yes / No

I agree to participate in a face-to-face interview

I agree to participate in the focus group

I agree to have the focus group discussions recorded

Dated day of 2016

Signature(as appropriate)

I, have explained the above to the
(Investigator's full name)

signatories who stated that he/she understood the same

Signature





Kadadjiny Dwank

(Listening, Thinking, Learning)

Otitis Media from an urban Aboriginal perspective

Consent Form - Photographs

I
(First name) (Last name)

agree to participate in the focus group for the Kadadjiny Dwank research project conducted in Southwest Metro area of Perth.

I have read the information sheet explaining what the 'Kadadjiny Dwank' research project is about what it is aiming to do.

I understand the information given to me. I was able to ask any questions I have about the research and state that these questions have been answered to my satisfaction.

I understand that information collected from this research may be published in reports, publications and documents. I have been informed that there will be no identifying information of myself in the reports, publications and documents that may be prepared from the research without my consent.

By signing this consent form I am agreeing to participate in focus groups as part of the 'Kadadjiny Dwank' research project on Otitis Media from an urban Aboriginal perspective.

Please indicate Yes / No

I agree to have my photograph taken

I agree to have my children's photograph taken

Dated day of 2016

Signature (as appropriate)

I, have explained the above to the
(Investigator's full name)
signatories who stated that he/she understood the same

Signature



 Curtin University

 Centre of Research in Ear and Hearing Health

 Research Excellence in Global Health

Kadadjiny Dwank
(Listening, Thinking, Learning)
Otitis Media from an urban Aboriginal perspective

Have your children got ear problems?

Would you like to be a part of a research project to look at why and what can be done about it?

The Dwank Kadadjiny Ear Research Project is seeking families to participate in the research about common ears problems that affect Aboriginal children in your community.

Come and share your stories and experiences with us so we can hear your solutions or ideas to enable change.

When

Date:
Time:
Venue:

Lunch provided

RSVP To Rosemary Walley by (date) on 0416998665
If you wish to find out more about this important research please call Researcher Rosemary Walley on the number above.



APPENDIX F – COMMUNITY FOCUS GROUP QUESTIONS



Kadadjiny Dwank

(Thinking, Listening, Learning & Ears)

Otitis Media from an urban Aboriginal perspective

DRAFT for CAG review

Community Focus Group Questions

Focus group Id. No. _____ Date of meeting: _____

Location of meeting: _____ Suburb/Address of meeting: _____

No/Names of participants: _____

Name of facilitator: _____

Name of Aboriginal Health Worker: _____

Name of scribe: _____

Audio recorded: Yes No

Introduction

Welcome / Acknowledgement

Thank you for joining. The information you provide will be used to assist us identify issues and solutions around ear health services in your community as part of the Kadadjiny Dwank study (*refer info sheet*). This is voluntary, if at any stage you are uncomfortable with the questions you do not have to answer. (*Explain other housekeeping matters & format of the focus group*)

Going around the room, would you state:

- Your name
- Where you are from
- How long have you lived in community?
- What would you like to get out of today?

DRAFT FOR CAG REVIEW- Questionnaire community focus group 1

Demographics

1. Age range of participants: _____

2. Gender: Female _____/Male _____

3. Where are members from:

What do you know and do about ear infection or OM?

Let's talk about ear infections - your understanding about them, what do you know about them? And issues you may have around them.

4. How do you recognise ear infections in children?
(Aboriginal Health Worker to help explain ear infections & OM using flip chart)

5. What do you do when a child has an ear infection?

6. What has worked / not worked for you?

Worked: (Prompts: prevention, treatment, who to go to (particular ear health providers))

Not worked: (Prompts: barriers to accessing care or what stops you/family from going to the doctor or health care centre; transport; cost; wait lists; cultural/respect)

7. How does ear infections/OM impact on child and family?

(Prompts: impacts on our children, this may include difficulty hearing and bad behaviour. These can also affect families)

DRAFT FOR CAG REVIEW- Questionnaire community focus group 3

Where to next

8. What do you think needs to happen to enable change? / How would you like to see ear health services in community change?

Thanks

Signature of scribe: _____ Date: _____

Checked by CI: _____ Date: _____

Entered t _____ Date: _____



DRAFT FOR CAG REVIEW- Questionnaire community focus group 4

APPENDIX G – LETTER OF SUPPORT



moorditj koort

Aboriginal Health and Wellness Centre
Kwinana and Rockingham

To WAAHEC

Dear Sir/Madam

I write this support letter to confirm that Moorditj Koort Health and Wellbeing Centre will support the research to be undertaken by Rosemary Walley of the Telethon Kids Institute on otitis media as a part of her Masters Research studies.

Otitis media and ear health is a very important issue in the Aboriginal community and the research that will be undertaken will play an important role in addressing the problems this causes for affected children and their families.

Moorditj Koort will assist as much as possible including helping identify families, encouraging the families to participate, supporting the families during the research, providing a venue for interviews and group sessions, and assisting with any focus groups as well as any data required.

Moorditj Koort will ensure the research meets standards and cultural protocols, which will help the building of trust and integrity of the research within the local Aboriginal community. This will protect the families and the community as well as the research.

Should you have any queries please contact me as per below.



Jonathan Ford
CEO

Moorditj Koort
Contact details.

08 6174 7000

150 Gilmore Ave, Medina WA 6167

Tel: (08) 6174 7000

Fax: (08) 9439 6268

Email: info@moorditjkoort.com.au