

Nobodies Listening:

An ecological approach to disease management may assist in reducing the rates of childhood ear infections in remote Aboriginal communities.

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Abstract

Aboriginal peoples in Australia have high levels of chronic disease including diabetes, cardio vascular, kidney and respiratory disease; all contributing to a lower life expectancy than non-Aboriginal people. In remote communities co-morbidity is common with chronic illnesses accompanied by infectious disease more usually associated with developing countries; examples include scabies, trachoma, rheumatic fever and otitis media, the latter impacting in epidemic proportions in children. Many texts refer to the health and well-being of Aboriginal peoples at the time of colonisation, and the impact of diseases introduced by the coloniser. However, the forced removal of communities off their homelands into missions and reserves resulted in severe restriction of cultural expression, with access to bush foods, medicines and language denied in the majority of cases.

Dependency developed, food provided by the missions or Aboriginal Protector was often payment for work done and limited to tea, flour, sugar and occasional meats. The disconnection from country, loss of culture, poor nutrition, associated grief and marginalisation of colonisation, is now evident in the epidemic of chronic disease.

Aboriginal children have the highest global rate of Otitis Media (OM), with 90 percent of children in remote communities suffering some form of OM. This thesis is a scoping study, from an initial literature review of Aboriginal child health, which highlighted the inadequacy of biomedical research on infection rates, particularly Otitis Media (OM).

Questions rose regarding the effectiveness of the biomedical model, the ongoing effects of colonisation and paternalism, the impacts of social and environmental determinants of health, and is anybody listening to the Aboriginal voice?

The aims of this thesis are to:

- i. Examine the biomedical model, and its effectiveness in reducing OM rates in Aboriginal children.

- ii. Describe the influence of the social and environmental determinants of health in remote Aboriginal communities.
- iii. Discuss Aboriginal Knowledge, contemporary Aboriginal research methods and debate the benefits of community participatory health research.
- iv. Outline the benefit of creating a two way collaborative approach embracing Aboriginal autonomy, knowledge and empowering communities to create healthy environments.

The framework for this study is based on critical theory highlighting the power and influence of the medical profession in controlling health research and ultimately health outcomes for Aboriginal peoples. This debate is supported by historical context, with understanding gained from social sciences and Indigenous Knowledge, to offer practical response to effect change. The conclusion discusses the benefits of an eco-health approach to chronic infections in Aboriginal children, with a focus on empowerment through community participatory action research. My aim is to write from a decolonised position as a white, female health professional and privilege Aboriginal and Indigenous researchers' voices where appropriate.

Glossary of Terms

In this thesis the words, Aboriginal peoples refer to Aboriginal and Torres Strait Islander people of Australia. The word Indigenous is used in global recognition of Indigenous people, their Knowledge systems and Indigenous estate.

ABORIGINAL	First nations peoples of Australia and Torres Strait Islands
ATSIC	Aboriginal and Torres Strait Islander Commission
ACCHO	Aboriginal Controlled Community Health Organization
AHW	Aboriginal Health Worker
AMIC	Aboriginal Maternal Infant Care
AOM	Acute Otitis Media (recent onset, short lived ear infections)
CDEP	Community Development Employment Program
CRACTH	Cooperative Research Centre for Aboriginal and Tropical Health
CSIRO	Commonwealth Scientific and Industrial Research Organization
CSOM	Chronic suppurative otitis media (ear infections with discharge present for 2 weeks or more)
ENT	Ear, nose and throat
ETS	Environmental tobacco smoke
LBW	Low birth weight, below 2,500gms
OM	Otitis Media (middle ear infections)

INDIGENOUS	First nations peoples
STUNTING	Weight for height less than 2 SD below median of international reference population
NAHA	National Aboriginal Housing Agreement
NAHS	National Aboriginal Health Strategy
NAHWP	National Aboriginal Health Strategy Working Party
NACCHO	National Aboriginal Community Controlled Health Organisation
NHMRC	National Health and Medical Research Council
NTER	Northern Territory Emergency Response
PAR	Participatory Action Research
REMOTE	As described by Australian Bureau of Statistics with accessibility/remoteness index
SIDS	Sudden infant death syndrome
SDH	Social determinants of health

I declare that:

this thesis presents work carried out by myself and does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; to the best of my knowledge it does not contain any materials previously published or written by another person except where due reference is made in the text; and all substantive contributions by others to the work presented, including jointly authored publications, is clearly acknowledged.

Chime Teob

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My thanks go to the staff at DUCIER, particularly Dr. Peter Gale for his wise words, encouragement and support.

To my friends, who have been on this journey with me, and listened with their hearts.

And to my husband who supported me throughout with his willingness to listen, sense of humour and love.

Chapter One

Aboriginal child health: the successes and failures of the medical model.

Introduction

Researching Aboriginal child health during the Master's program, it became apparent the biomedical research approach to infectious diseases, particularly Otitis Media, was having minimal impact on reducing incidence rates despite over two decades of research.

Questions rose as to the effectiveness, rational and ethics of the biomedical model in the face of serious population health issues. Medical research strives for answers whilst embedded in the colonial discourse, disregarding the impacts of social and environmental determinants of health. Who is listening to the Aboriginal voice? The aims of this thesis are to:

1. Examine the biomedical model, and its effectiveness in reducing OM rate in Aboriginal children.
2. Describe the influence of the social and environmental determinants of health in remote Aboriginal communities.
3. Discuss Aboriginal Knowledge, contemporary Aboriginal research methods and debate the benefits of community participatory health research.
4. Outline the benefit of creating a two way collaborative approach to research, embracing Aboriginal autonomy, knowledge and empowering communities.

Chapter one provides a review of the medical data of the incidence, rates and risk factors contributing to the development of Otitis Media and its treatment. The underlying contributors to infection rates including nutritional, parental and environmental health and the ineffectiveness of the biomedical model in addressing infectious disease are discussed.

Chapter two describes in greater depth the social, environmental and ecological determinants of health, how they relate to Aboriginal determinants of health and their impact on

prevalence of Otitis Media in Aboriginal children.

Chapter three considers Aboriginal Knowledge, belief systems and child rearing practices, how this influences contemporary Aboriginal research methodologies and questions the appropriateness of the biomedical model in Aboriginal communities.

Chapter four summarizes the biomedical position, effective treatment of ear infections, gaps in medical literature, new knowledge gained from community participatory action research and a research design proposal.

Chapter five concludes the thesis with a debate for an ecological approach to medical research.

Preventable Infections

According to Brewster and Morris (2015) preventable infection is the key factor to be addressed to improve the health of Aboriginal children; success depends on the provision of sanitation and water security in all health interventions. Infectious diseases include respiratory, diarrheal disease, meningitis and rheumatic fever (RF). Although rare in Australia, Aboriginal children of Northern Territory have one of the highest global rates of RF; resulting from type A Streptococci infection and causing irreversible damage to the heart's valves. In remote communities of WA, SA and NT Aboriginal children endure the highest global rates of middle ear infections, have high rates of iron deficiency and suffer rates of malnutrition comparable to a third world country; the latter two increasing the risk of preventable infections (Calder & Jackson 2000; Collins et al. 2013). Before colonisation, infectious disease with epidemic potential were largely absent from Aboriginal groups (Webb 2009). This chapter reviews the biomedical research model and the incidence, rates and risk factors contributing to the development of Otitis Media (middle ear infections), recommended treatment regimens and current child health status. Other key factors which contribute to Aboriginal children's health, include the social and environmental determinants of health, are discussed in the following chapter.

Otitis Media – it's global impact

Otitis Media is an acute inflammatory response to a bacterial or viral infection of the middle ear; it is seven times more common in Aboriginal children, occurring more frequently, at a younger age, with greater severity and more serious complications (Kong & Coates 2009). In non-Aboriginal children the acute infection has either a spontaneous resolution or is resolved by a short course of antibiotics; with occasional progression to further treatment (Couzos, Murray & Metcalf 2008). Aboriginal children's experience is more insidious with the frequent development of longstanding chronic suppurative infections commonly referred to as glue or runny ear. Ninety percent of children in remote communities have some form of Otitis Media (OM); whilst a mixed community study identified 60 percent of Aboriginal children in urban areas and 71 percent of Aboriginal children in remote areas suffering ear disease and hearing loss (Leach et al. 2014, p.200; Timms, Grauaug & Williams 2012, p.277). According to the World Health Organization (WHO), if more than four percent of children have OM it is massive public health problem, requiring urgent attention (World Health Organization 2000). In remote communities, infants are especially susceptible to bacterial colonisation of the upper airways which is directly related to OM onset (Couzos, Murray & Metcalf 2008). H Influenza, one of the bacterial agents in OM, can trigger Hib meningitis resulting in mortality rates of 14 percent for Aboriginal children compared to three percent for non- Aboriginal children (Brewster & Morris 2015, p.43).

In 2004, WHO classified populations where epidemic proportions of Chronic Suppurative Otitis Media (CSOM) existed; this included Tanzania, India, Solomon Islands, Greenland Inuit and Australian Aboriginal children. Non-Indigenous children of North America suffer infection rates at less than one percent, whilst Navajo and Apache children have rates at four to eight percent and Inuit of Alaska endure rates of 30-40 percent (Bowd 2005). This study suggested the increased prevalence for Inuit was related to the decrease in breast feeding, protein and fat intake with increased consumption of carbohydrates; the social and environmental determinants of health were excluded. Epidemiological studies in 2010 compared global rates of CSOM; rates were highest in Australian Aboriginal children, with 40 percent suffering from tympanic membrane perforation, compared to 12 percent in Bangladesh and three percent in Nigeria (Daly et al. 2010, p.232). The bacteria involved in acute OM and risk factors are identical in any population; these include Haemophilus influenza, Streptococcus pneumonia, and Micrococcus catarrhalis, environmental smoke, short term breast feeding, overcrowding and poor sanitation (Homoe 2001).

Otitis Media –the biomedical approach

Otitis Media is a complex disease with a variety of presentations, each with a different treatment regime (Vergison et al. 2010). This complexity creates a barrier to diagnosis and treatment, particularly in remote communities, as it relies on the skills of the health worker, community nurse or GP, to distinguish between each type of presentation. The initial presentation of acute OM (AOM), is redness, fever, ear pain, irritability and bulging or perforation of the membrane. If perforated, initially the hole is relatively small, and able to heal in healthy children; however re-perforation is common with subsequent infections (John et al. 2013). The use of long-term antibiotic therapy in at risk populations reduces the proportion of infants experiencing membrane perforation, but these schedules are difficult for Aboriginal families to comply with (Wiertsema & Leach 2009). Infection can be present with fluid behind the ear-drum with no acute symptoms of inflammation or pain; this may be present for three months or more and will have a detrimental effect on hearing, speech and learning (Daly et al. 2010). This variation is more difficult to assess, and may go unnoticed in both Aboriginal and non-Aboriginal children.

Chronic suppurative Otitis Media (CSOM) as defined by WHO, is persistent discharge from the ear over a 2 week period, due to perforation of tympanic membrane and tends to continue for months (Vergison et al. 2010). CSOM is rarely seen in non-Aboriginal children, as acute infections are treated and if persistent, are assessed by an ENT specialist (Daly et al. 2010). The chronic condition is distinguished by a change in pathogens change from those of the upper respiratory tract, such as *S. pneumoniae* and *H. influenza*, to those found in the external ear canal, such as *Pseudomonas aeruginosa* and *Staphylococcus aureus* (Acuin 2004). This severe form of OM occurs most often amongst Aboriginal children living in remote communities, and has recently been related to an imbalance of the intestinal bacteria (Couzos, Murray & Metcalf 2008; Vergison et al. 2010).

The high burden of bacterial infections present in young infants has been documented since 1994, with transmission influenced by hand contact, discharge from the noses of other children and the high incidence of respiratory infections of adults (Leach et al. 1994; Wiertsema & Leach 2009). Early bacterial assault of an infant's upper respiratory airways can overwhelm an immature immune system resulting in an inadequate antibody response and can predispose

infants to OM (Couzos, Murray & Metcalf 2008). Colonisation rates of the nasal passages by H. influenza and S. pneumococcal in Aboriginal children are three times the rate, and hand contamination by the same pathogens, 23 times higher of non Aboriginal children (Stubbs et al. 2005, p.427).

Clinical care guidelines for OM were updated in 2010 with antibiotics sanctioned for AOM. Notwithstanding the wealth of medical research undertaken, vaccination for children under two years of age, is the only successful intervention; for older children with CSOM, antibiotics have little impact on the antibiotic resistant bacteria (Australian Institute of Health & Welfare (AIHW) 2014a). Australia currently has one of the highest rates of antibiotic prescription; however Aboriginal communities continue to suffer high rate of infections. Recurrent infections effect hearing during the decisive years of a child's language development, the subsequent damage to the middle ear, may result in permanent hearing loss. Children under 12 months, who have early onset OM, are particularly prone to developing long term speech and language problems, with adverse implications if an underlying language or cognitive problems co-exists (Burns, J & Thomson 2013). An education inquiry identified ear disease and subsequent hearing loss as one of the most significant learning barriers faced by Aboriginal children; OM can continue into adolescence and adult life, affecting employment prospects, and increases the likelihood of contact with the criminal justice system (Vanderpoll & Howard 2012). The first national campaign for ear health was introduced in 2011, despite three decades of research.

National campaign

The Caring for Kids Ears campaign, launched July 2011, aim was to raise awareness of ear disease and highlight the importance of seeking treatment to prevent hearing loss in Aboriginal communities; the only existing program was in Queensland (Queensland Health 2009; Department of Health and Ageing 2013b). This national campaign continues with the primary audience parents and carers of infants; secondary audience for children over five years, includes early childhood educators, teachers, Aboriginal health workers (AHW) doctors and nurses. The campaign included training of AHW in ear health, hearing screenings and the provision of audiology equipment. An evaluation of the program by the Culture and Indigenous Research Centre of Australia (2013), demonstrated increased knowledge of ear disease symptoms and in help seeking behaviours. However, little had been achieved to increase awareness of the risk

factors or in the development of prevention strategies for ear infections. Paradoxically, the original developmental research with Aboriginal communities, uncovered a lack of knowledge of the major risk factors for Otitis Media. These included the nutritional impacts of bottle feeding compared to breast feeding, the effects of passive smoke on children and poor hygiene practice; none of which were integrated into the campaign. This evaluation reveals one of the common liabilities of medical research where research knowledge generated has not been transferred back to the Aboriginal communities.

The biomedical model

Biomedicine's principle tenet is that illness has a single underlying cause which is the disease or pathology, and removal of the pathology will result in a return to health (Wade & Halligan 2004). This approach emerged from the emergence of germ theory, in the 19th century, and facilitated a shift in medical practice from population health to individual health. Previous studies of the social, economic and natural environmental factors of disease were discarded in favour of behavioural and bio-chemical factors (Yadavendu 2003). The exclusion of the holistic nature of illness, its spiritual, environmental and emotional components expedited the reductionist nature of medical research. The application of natural sciences in relation to clinical medicine, including biochemistry and molecular biology led to development of the contemporary term biomedicine (Lackie, 2010). Current research analyses disease risk factors from a variety of biological sciences, reinforcing the concept of individual responsibility to health, promoting changes in lifestyle and health education for health gains.

However well intentioned, risk epidemiology draws attention from structural causes of ill health and the large discrepancies in society mediated by social determinants of health (Yadavendu 2003). The genome project is the definitive exemplar of health individualization, resulting in the identification of gene(s) associated with particular diseases, and tailored responses from genetic markers. This individualistic approach epitomizes neo-liberal ideals and philosophies but is of little value where basic sanitation, infrastructure, poverty, unemployment, poor housing and limited food choices exist (McMichael 2001). Due to the increase rates of ear infection in Indigenous populations, particularly the Inuit, Native Americans and Australian Aboriginal peoples, the focus has shifted to genetic research. Wiertsema and Leach (2009, p.52) suggest that "...genetic factors have a role in Otitis Media susceptibility" in the pathogenesis of OM in

Indigenous children. The most recent publication from the government's Closing the Gap (AIHW 2014) initiative on ear health in Aboriginal children provides a contemporary medical summary of what is known, what is not known and what works. From a biomedical perspective antibiotic treatments and Hib vaccines can help reduce the number of acute OM episodes. Early intervention, including ear and hearing assessments, and the fitting of hearing aids, assist in management and treatment (AIHW 2014a). The main questions raised are from a biomedical perspective; what is the epidemiology of ear disease in Aboriginal children, why are ear infections not responsive to treatment in Aboriginal children and why is the uptake of clinical guidelines slower than expected in Aboriginal communities? Disregarding the social and environmental determinants of health, these questions assume the existence of health equity in Aboriginal communities and imply the untreatable nature of ear infections as a specific Aboriginal problem.

In 1999, Cooperative Research Centre for Aboriginal and Tropical Health exposed the failings of medical research to influence health care or health behaviour with research falling into one of two categories; either mission driven to find an answer, or experimental drug and vaccine trials which fail to meet expectations (Matthews et al. 2001). In contrast, the centre observed curiosity driven research created a pool of knowledge capable of making an enormous contribution. Following are two related examples of biomedical research focused on determining the answer to the research question and the procurement of new knowledge.

Biomedical research of Otitis Media in Aboriginal children

Many Aboriginal communities have been subjected to research on OM, with considerable data collected since the first national survey, performed in the 1970s. However, very little has changed for the children and communities affected. In the mid-1990s, babies as young as six weeks were diagnosed with OM infections (Leach et al. 1994, p.985). Subsequent medical research has focused on collecting screening data on the types of infections; trialing treatment with antibiotics and assisting in the development of vaccines, with minimal improvement in infection rates (Castan Center for Human Rights 2016; Morris et al. 2011). Medical research acknowledges this is a complex disease with multiple environmental and genetic influences but continues to investigate single factors.

Over the last 15 years OM research has focused on screening, data collection and vaccine trials with little improvement for the communities studied. Morris and others (2005) published details of a 2001 OM screening study of 29 communities; the conclusion indicated one in two children had CSOM with one in four suffering from perforation of the tympanic membrane. The study's limitations include no access to treatment, inadequate employment opportunities and minimal Aboriginal community consultation or engagement. The disadvantage these communities experience with high unemployment, poverty, poor sanitation, overcrowding, poor housing conditions, morbidity and presence of environmental smoke received minimal attention. The authors acknowledged the relationship between OM and high rates of respiratory infections, however failed to investigate children's compromised immune systems or poor nutritional status. Several recommendations were offered but no community consultations occurred regarding the study's findings. Research by Leach and others (2014, p.200) determined 90 percent of children in a vaccine trial, continued to experience some form of OM regardless of vaccination, with 30 percent suffering anaemia. The research conclusion advocates additional vaccine trials and further data collection rather than debating the vaccines effectiveness, the children's comprised immune system or the social and ecological determinants of health (Leach et al. 2014)

The limitation of the biomedical model for Aboriginal communities is transparent in these two related studies, where a research question is posed and answered from a Eurocentric position. The reductionist approach serves to determine cause and effect; a simplistic approach incapable of analyzing the multiple factors which contribute to the high rates of infection. The subsequent lack of response to treatment reinforces the procurement of new

knowledge and the key underlying issues of population health are disregarded. As Brewster and Morris (2015) state, the requirements of all health interventions must include as a minimum, access to clean water and adequate sanitation.

Aboriginal population health

The basic inputs to good health are well known; clean air, safe drinking water, wholesome food, limitation of infectious agents and capacity to remove human, household and animal wastes (Gracey & King 2009). The industrial revolution and the subsequent impact of polluted air, water, overcrowding and poor sanitation created the environment for infectious agents and the development of new diseases (Baum 2008). The social determinants of health are well documented and are discussed in the next chapter; complex and multi-factorial in nature, they do not feature as part of the cause and effect bias of medical research.

Palmer and Brady (1991) report on the long history of poor nutrition in the diet of Aboriginal people of Maralinga, with minimal access to fruit and vegetables, and high intake of flour and sugar. Historically this is a common narrative with the removal of Aboriginal peoples from their land to missions and reserves. Aboriginal agricultural workers were deprived of wages and paid in tea, sugar and flour with limited supply of fruit, vegetables or bush tucker. The trans-generational impact of poor nutrition, grief and marginalisation, is evident in the increasing incidence of chronic disease, diabetes, cardiovascular disease, infections and kidney diseases. The western diet now dominates for Aboriginal peoples with consumption of high amounts of fat, refined carbohydrates, salt, sugar and inadequate intakes of vitamin E, folate, retinol and fibre (Gracey 2000). This is influenced by environmental and social factors including low income, loss of bush knowledge and dependency. In remote areas, fresh foods are expensive due to haulage and storage costs; and are often of poor quality. According to Rosier (2011, p.3) food can be 26 percent more expensive in a remote community general store compared to a Darwin supermarket. As Myers and others state (2014, p.375) "...nutrition is a key determinant of a child's health and well-being" with under-nutrition recognized as an impairment to immune function, as discussed in the following section.

Aboriginal child health

The last decade has witnessed increasing research on Aboriginal child health; these include the National Aboriginal and Torres Strait Islander Social Survey and Longitudinal Study of Indigenous Children providing authoritative information (Australian Bureau of Statistics (ABS) 2009, Department of Social Services 2012). Medical research has identified gross malnutrition with 35 percent of Northern Territory children stunted, wasted or underweight; a shocking statistic for a developed nation (Burns, J & Thomson 2008; Gracey & King 2009, p.67). Stunting, due to protein deficiency, results in atrophy of the internal organs particularly the thymus, which is a vital for the immune system. Protein enables the body to replicate cells and fight infection; its deficiency will lead to infection related morbidity. Chronic infections deplete the body's ability to develop, continuing the cycle of morbidity and poor growth (Calder & Jackson 2000).

Asher and others (2014, p.1) suggest under-nutrition and malnutrition in children of remote communities is related to Giardia infections, with 32 to 65 percent affected; rates comparable to developing nations. Giardia is associated with gastrointestinal disease, failure to thrive and developmental delay. The authors suggest repeated exposure to the parasite is due to the close relationship communities, particularly children, have with their infected dogs (Thompson 2000). Nutritional research identifies deficiencies within Aboriginal groups; however there is limited intervention based research to assist in resolving these deficits. The presence of such poor health amongst Aboriginal children is resigned to data collection, in the medical research of OM. For example, Myers and others (2014) study recognized low levels of breastfeeding, inappropriate introduction of solids, reliance on bottled formula, sweet drinks, energy-dense foods, and poor oral health without any appropriate intervention. This identification of risk factors individualizes diet and nutrition, whilst ignoring the socio-economic and environmental factors involved (Myers et al. 2014).

A successful research intervention program in NSW, introduced fruit twice a day for school children; the result was the reduction of antibiotic prescription rates after six months. The authors emphasized the importance of vitamin C as a cofactor for iron, substantially reduced in the majority of children tested, and its impact on immune function (Jones & Smith 2006). Similarly, a food subsidy program of fruit and vegetables, demonstrated a considerable reduction in oral antibiotic use in children over a 12 month period (Black et al. 2013). As mentioned, anaemia is

present in half of the children in remote communities, and combined with the deficiency in other micronutrients, has a significant impact on the performance of the immune system (Ekiz et al. 2005; Kruske, Ruben & Brewster 1999).

Due to previous devastating levels of infant mortality the collating of information on the presence of low birth weights, has been a focal point of child health research (AIHW 2014b). Thirteen percent of Aboriginal babies born in 2005 were of low birth weight (LBW) compared to six percent of non-Aboriginal babies (Burns, J & Thomson 2008, p.3). This figure had dropped marginally to 11.6 percent in 2012, but was still two and half times greater than non-Aboriginal babies at 4.6 percent (AIHW 2014b, p.7). Maternal malnutrition is also a predictor for LBW babies with a fivefold increase in risk for infants born to underweight mothers (Couzos, Murray & Metcalf 2008, p.273). Remote Aboriginal communities also suffer higher incidence of premature births, SIDS and foetal alcohol syndrome compared to non-Aboriginal infants (Brewster & Morris 2015).

Factors influencing birth weight are complex and reflect the nutritional health of the mother, duration of pregnancy, number of previous births, maternal age and socioeconomic status. A study of two cohorts of Aboriginal women from remote north Queensland concluded that the high incidence of obesity and diabetes, poor nutrition, alcohol and tobacco use, together with young maternal age, created a poor uterine environment for many Aboriginal babies. Although the authors suggested an urgent need for community level intervention to improve pre pregnancy nutrition; it was not included within the parameters of the study (McDermott et al. 2009). Identified risk factors for all pregnant women for LBW babies include substance abuse, particularly cigarette smoking and alcohol consumption.

According to Burns and Thomson (2008), breastfeeding is one of the simplest ways of improving infant nutrition, due to its anti-infective agents and immune stimulating factors. Breast fed babies have lower levels of gastroenteritis, respiratory problems and other infections, and is particularly important for low birth weight babies. The infants' immune system is reliant on breast milk to develop appropriately in the short and long term indicating bottle feeding and low levels of breast feeding are risk factors for development of OM (Turfkruyer & Verhasselt 2015). This may be related to the different type of gut bacteria found in breast fed babies compared to formula fed

infants. Human gut microbiota act to influence the growth and differentiation of the cells lining the gut with pivotal nutritive, metabolic, and immunological functions. The ecology of the gut matures over the first three years of an infant's life, before it reaches adult status and can be easily disturbed depending on the quality of nutrition received and presence of intestinal infections (Murray & Manary 2015). Infant iron stores and child's risk of anaemia are closely related to maternal iron status both during pregnancy and during childhood growth. In an adult, the majority of iron is reconstituted in the body, whereas infants and children receive a third from their diet, increasing their vulnerability to inadequate food sources (Couzos, Murray & Metcalf, 2008). A qualitative study by Helps and Barclay (2015) interviewed Aboriginal women on their attitudes to breastfeeding and discovered breast-feeding had fallen out of favour with the impact of colonisation. Young mothers trusted the knowledge passed on from extended family and women within the community, rather than the advice of health care workers, with regard to breast-feeding. This reinforces the importance for community involvement in research and intervention based studies as cultural, historical and socioeconomic factors all strongly influence the infant feeding decisions of individuals in this study (Helps & Barclay 2015).

“Nutrition is a key determinant of a child's health and well-being”, as enhanced nutrient status maintains the barriers to infection, either of the skin, epithelial layers of GI system or respiratory system by ensuring a vigorous inflammatory and immune response (Myers et al 2014, p. 375). This includes limiting the loss of nutrients from the body, especially from diarrhea in children. Calder and Jackson (2000) conclude that repeat infections will deplete the body of nutrients and limit the body's ability to mount a robust immune response when the infection reoccurs. Thus the underlying nature of chronic infectious diseases in Aboriginal children is related to their chronic nutrient depletion from repeat infections, limiting the ability of their body to fight back. These factors may help explain why babies succumb to OM as early as six weeks; their immunity reduced by the mother's nutritional status and stress response through pregnancy (Lehmann et al. 2008).

Research demonstrates the influence of the maternal uterine environment and stress on fetal development, with trans-generational studies implicating the ancestral experience (Metz et al. 2015). Parental exposure to environmental factors, including chronic emotional and nutritional stress induces changes in their offspring which can be passed down to subsequent generations through both maternal and paternal epigenetic modification (Finegersh et al. 2015). This has

profound implications for Aboriginal community health and well-being, as the health of the current generation will impact on their progeny and clarifies the decreased resilience within some Aboriginal communities and individuals to stress and disease.

Aboriginal health and well-being

Aboriginal concepts of health and well-being vary considerable from the allopathic model; National Aboriginal Health Strategy (1989) defined Aboriginal health as:

Not just the physical well-being of the individual but the social, emotional and cultural wellbeing of the whole community. This is a whole-of-life view and it also includes the cyclical concept of life-death-life (National Aboriginal Health Strategy Working Party 1989).

This definition embodies the wellbeing of the whole community and their relationship with country, ecosystem and each other. Birth and babyhood is a child-centred reality; with children recognised as capable, autonomous, in contrast to overprotective western societies who view children as helpless and dependent. Martin notes Aboriginal world views are “expansive and embracing” with cousins akin to brothers and sisters, great grandparents become grandchildren, so more than one set of people can be parent, grandparent and child (Martin 2005, p.31). Parenthood involves rites and rituals focused on maturation and empowerment of the rising spirit. This knowledge is fundamental in any child health research project, as all members of the community are involved with raising a child. Martin comments on trans-generational experiences which impact families who experience violence, erosion of family networks and a lack of healthy role models (Martin 2005). Childhood is a crucial stage of life, as it requires others to accomplish their roles and obligations for the emerging spirit and its relatedness. Western research commonly identifies single parents, with no details of the roles of extended families, or acknowledgement of influence of community life on children. The impact of the stolen generations has permeated medical literature however the loss of parents to alcohol, chronic illness, early death and current removal of children to social services for foster care are overlooked.

Conclusion

This chapter has outlined the key elements involved with Otitis Media in Aboriginal children, including the standardized approach of biomedical research, focused on causality, in the pursuit of evidence based practice. Medical research is successful in identifying the key determinants of Aboriginal child health include nutrient and vitamin status, iron deficiency, importance of breast milk, impact of smoke, health of pregnant mother and fetus, and presence of parasites. Where the research fails is the lack of intervention studies which have a positive effect on the multi-factorial nature of Aboriginal child health. The two intervention food studies discussed are small scale, run by clinicians in Aboriginal Health Centres who are embedded in the communities and address the basics of good health. Unable to change the level of housing or sanitation, improving children's immune system can help fight recurrent infections. When Aboriginal people are consulted regarding the impact of research in their communities, they raise concerns about the quality and use of the data. In particular, they emphasis "...money should be spent on improving services to children, instead of spending money on researching children" (Penman 2006, p.13). A successful hygiene intervention program in Pakistan designed to educate and change behaviour, reduced pneumonia by 50 percent and diarrhea by 53 percent compared to the control group over 12 months (Luby et al. 2005, p.230). Designed as a randomised controlled trial, the objective was to compare hand washing with plain soap, antibacterial soap and a control group, who received no education on behaviour change (Luby et al. 2005). This study involved intensive field work to reinforce the practice of hand washing, with results demonstrating no difference between plain or antibacterial soap. The presence of hand infection in remote communities was identified by Stubbs in 2005, and resulted in the No Germs on Me social marketing campaign (McDonald, E et al. 2011). Without the support and education of Luby and others study, this marketing campaign has had limited success. This chapter has highlighted the inadequacy of the biomedical model in researching childhood ear infections; the standard interventions of antibiotics and vaccinations, with children who have a lowered immune response and are surrounded by vectors of disease, results in minimal improvement. The challenge for medical research is to decolonise research methodologies, collaborate with Aboriginal communities and utilize participatory action research, which with its practical design and empowerment process, can effect change. The following chapter takes an in-depth look at the social and environmental determinants of health and advocates for an ecology of health within Aboriginal communities.

Chapter Two

Social, environmental and ecological determinants of health: how they impact on Aboriginal child health, particularly Otitis Media.

Introduction

Aboriginal people's health is multi-factorial; it is not just the absence of disease, as Aboriginal health researcher Anderson highlights:

Health for us includes physical health, of course, but goes beyond it to social and emotional wellbeing, culture, spirituality, and social justice (Anderson, cited in Sylvan 2013, p.37).

For Aboriginal communities colonisation has resulted in marginalisation and social inequality within Australian society, resulting in high levels of poverty, lack of access to education and high levels of unemployment (ABS 2011b). Families face a constant struggle on low incomes, single parent benefit and the chronic stress of unemployment. Baum (2008) indicates unemployment affects health through poverty, and is associated with health damaging behaviours of smoking and drug use. For remote Aboriginal communities, who lack the structural support existing in mainstream society, these behaviours have a substantial impact on children, who exert little control over their environment. Social injustice is deeply entrenched with early childhood disadvantage, lack of life control, racism, social exclusion, poverty and lack of access to health care; as well as poor housing conditions which combined exert a powerful effect on health across Aboriginal lives (Marmot, M 2011). This chapter will discuss the social, environmental and ecological determinants of health including healthy environments, housing and sanitation, education, employment, racism and how they relate to Aboriginal determinants of health and their impact on prevalence of Otitis Media in Aboriginal children.

Historical context of social determinants of health

A brief review of Aboriginal people's experience of the laws enacted during colonisation contextualizes the discussion of the social determinants of health. In the late 19th century, legislation of Protection Laws for Aboriginal peoples by the States; subsequently dispossessed family groups from their land and placed them in "reserves" or "missions" (Broome 2009). These were controlled by government agencies and church groups; shacks were given in lieu of housing, access to bush tucker was reduced and food choices were limited to flour, salted meat, sugar and tea. Health care was limited; commonly access to bush medicine and cultural activities of song, dance, rituals and speaking language were prohibited (Broome 2009; Fredericks et al. 2014). Life was organized by the government protectors, including access to education and marital relationships; this continued until the 1970's when the majority of reserves and missions were closed (Broome 2009). Education was generally of poor quality and, for many, restricted to the early years. From age 13 or 14, girls worked as housemaids in rural homesteads, and boys worked on the sheep and cattle stations (Fredericks et al. 2014). This segregation was particularly aimed at the "half-caste" Aboriginal children, to assimilate them into white society and restrict their contact with family members through their employer or supervisor; one in ten children were taken away by authorities, becoming the Stolen Generations (Purdie, Dudgeon & Walker 2010, p. 32). In the majority of cases Aboriginal indentured labour received very little pay, the majority of which was retained by State governments, and later siphoned off for public use (Kidd 2007). Recent research by Kidd on the stolen wages catastrophe indicates that Aboriginal poverty has been governmentally constructed. This includes the state and federal governments willing subversion of Aboriginal wages into government accounts, creating the marginalisation and ill health evident in the government run communities (Kidd 2007).

Colonisation and subsequent removal of Aboriginal people from their lands resulted in widespread forest clearance for agricultural practices, with the loss of 50 percent of woodland and fragmentation of remaining vegetation (McFarlane, Sleight & McMichael 2013). After the closure of the missions and reserves the following two decades witnessed the movement onto the homelands as Aboriginal people reoccupied their country, whilst others became fringe dwellers of urban sprawl; neither groups receiving support from the States or Commonwealth (Altman & Kerins 2012). The following section will discuss the central role healthy environments play for Aboriginal people and the importance of integrating Aboriginal Knowledge to improve degraded landscapes

Healthy environments

Healthy ecosystems exert an important role in sustaining equilibrium between predators and prey, hosts, vectors and parasites in plants, animals and humans (Alves & Rosa 2007). Early forest clearance provided fuel, with large tracts of land in South Australia void of trees due to demand of steam boat trade on River Murray. During 1950's wheat production in south west Western Australia was a trigger for major forest clearance, and since 1970's, the greatest forest decline has been in northern New South Wales and south east Queensland. Agricultural and pastoral enterprises account for 61 percent of land-use plus an extensive mining sector (McFarlane, Sleight & McMichael 2013). Currently the tropical north is suffering high levels of degradation due to invasive weeds, buffalo grazing and altered fire regimes (Bradshaw 2012). The devastation wrought by agricultural and mining practices on Australia's ecosystem have resulted in the highest extinction rate, of endemic marsupials, in the developed world (International Union of Conservation of Nature 2012). Without policy and action Australia is on track to lose a large proportion of its residual, irreplaceable biodiversity. The comprehensive ways Aboriginal Knowledge influenced the environment, is now well recognized; with Ens and others commenting "the potential contribution of Indigenous Knowledge to contemporary ecosystem science and management is irrefutable" (2015, p.135).

Several studies have demonstrated the improved health gains from participation of communities in active land management, with the creation of suitable economic development resulting in both ecological and community health gains (Altman & Kerins 2012; Burgess et al. 2009; Davies et al. 2011). Aboriginal participants' response to Burgess and others study (2009) was for research to focus on workable solutions and the social determinants of health, not just more data collection. Caring for Country received federal support with the legalisation of Indigenous Protected Areas in 1998 resulting in the growth of community based programs. By 2012, 50 Indigenous groups had signed up for formal management of their country (Davies et al. 2013). Caring for Country initially was a grass roots movement developed in 1990's by Aboriginal people to take ownership of their country and endorsed by Community Development Employment Projects (Altman & Kerins 2012). This value laden, idiosyncratic phrase merged into Liberal discourse during the Howard government as Caring for Our Country; to be replaced by Working for Country, as part of Closing the Gap framework. This policy appears to be diametrically opposed to Caring for Country; encouraging the movement off homelands into

townships and the rejection of traditional culture by the “normalisation” of work patterns and behaviours (Altman & Kerins 2012).

Looking after country as a ranger or community member is fraught with many challenges including the degradation of land by farming practices, the overgrowth of noxious weeds and devastation wrought to local animal populations and plants by pigs, goats, camels, wild horses and buffalos. The impact of a million camels in central Australia is an environmental disaster with local extinction of plum bush quandong and bean tree; threatened extinction of small marsupials as animals compete for limited resources; the deposition of dung close to water holes reducing access to swimming holes for children and the accompanying flies, creating vectors for infectious diseases (Edwards et al. 2010). Dung is a food source for a variety of insects, parasites and nematodes, which compete for fluid based nutrients. The CSIRO Dung Beetle project, introduced European beetles to expedite the removal of feral animal dung, which was intolerable for native dung beetles. This project led to a decrease in buffalo and bush fly where it was trialed with complete breakdown of dung pats over a 24 hour period (Hughes et al. 1975).

A volunteer run intervention program focused on animal health in the Central desert is currently having enormous benefits for the local community. The program de-sexes and worms the camp dogs of Utopia, and has resulted in a dramatic reduction in infectious skin disease in dogs and humans, over a four year period. According to veterinarian Dr Michael Archinal:

We have reduced skin sores in people in one community by 87 per cent. ...there's no question there's a link between animal health and the human population (Allen 2015, p.1).

Camp dogs are not strays as is often portrayed, but are important for security, hunting and companionship with each having a name and an owner. Due to the absence of vet supplies and services, the dogs are allowed to breed unrestricted and rarely receive worming or parasite treatments. Since the program commenced, 1000 dogs have been de-sexed to keep the population stable, and tens of thousands have received parasite and worming medication. Camp dogs are also implicated in transmitting Giardia parasite; research indicates up to sixty per cent of children in remote communities under 10 years are infected by Giardia leading to chronic gastro-intestinal malabsorption and malnutrition (Asher et al. 2014; Thompson 2000). The discipline of public health performs through epidemiology, biostatics and health services.

Currently gaps exist in infectious disease research epidemiology and the relationship with land degradation, the presence of dust, flies and the epidemic of feral animal populations.

Known vectors of disease, including the common house fly, the presence of dust and carriage of viruses and parasites and how they are related to a healthy environment, are not researched by the medical community (Graczyk et al. 2001; Palmer & Brady 1991). The focus on reductionist science and causality in medical research has resulted in the unknown impact of this environmental degradation on Aboriginal health. Consistent with this approach, research indicates high levels of child malnutrition and its impact on immunity; however medical treatment protocols and research continues to focus on the cure as opposed to improving overall health of children.

The risk of developing OM is higher for children whose mothers smoke, with an increased risk for Aboriginal children due to the higher prevalence of smoking, and fewer smoke free environments (Jacoby et al. 2008). Smoking prevalence in pregnant Aboriginal women is quadruple that of non-Aboriginal counterparts, impacting on the health of unborn babies and children (Gould et al. 2013). Smoking is viewed as a normalised behaviour and exists at high levels in social and family groups, impeding attempts at abstinence and limiting effectiveness of cessation programs in pregnancy. High participation rates obstruct attempts to have a smoke free home and individuals feel socially isolated when trying to abstain (Passey et al. 2013).

Research demonstrates individuals are likely to change behaviour and improve their health, in relation to exercise and smoking, when they live in more favourable circumstances (Baum 2008). Hence poverty, and social determinants of health influence the cycle of substance abuse, with health promotion and education of limited value until social capital improves. Although Australia's public health strategies are concerned with prevention, early detection and acting on determinants of health, little has changed in remote Aboriginal communities to improve social capital especially with regard to housing and sanitation.

Housing issues, sanitation and successful interventions

Poor housing was one of the crucial issues that drove the public health revolution of the nineteenth century (Rosen 1958). However, in 21st century Australia, Aboriginal peoples suffer the most inadequate housing with overcrowding and poor sanitation. Almost four in ten people living in remote areas experience structural problems including cracked walls, major plumbing problems and termite damage (ABS 2009). Aboriginal peoples' kin systems are reflected in communal living with limited space available in current housing design and poor structural health hardware, to accommodate family size and visiting relatives (ABS 2009; Bailie, R & Wayte 2006). According to Black (2007, p.9) overcrowding alone contributes 30 percent to the gap in health status between Aboriginal and non-Aboriginal Australians.

Following the abolishment of ATSIC, Aboriginal affairs were immersed in Department of Health and Ageing which initiated the National Strategic Framework for Aboriginal and Torres Strait Islander Health, 2003-2013. The health gains the framework articulated are related to social determinants of health and adopted a multi-sectoral approach to improve housing, education, and employment, to support and sustain improvements in health (Department of Health and Ageing 2013a). The National Affordable Housing (NAHA) came into operation in January 2009 between Council of Australian Governments and resulted in the switch of Indigenous housing from the Department of Social Services to the responsibility of states and territories. The NAHA program's aim, to improve housing amenity for Aboriginal peoples and reduced overcrowding by 20 percent over a ten year period, will take 50 years to close the gap (Department of Prime Minister and Cabinet 2009). As of August 2012, 1,440 new houses, and 4,830 refurbishments had been delivered (O'Connor 2012). The provision of housing has passed through four different government departments in the past decade. The current housing program is delivered by an external work force with no apprenticeship, training or employment provided for Aboriginal peoples. Subsequently there exists a lack of housing maintenance, inadequate provision of sanitation services and access to clean water. These outcomes are related to the policies, inaction and inefficiencies of successive federal, state and territory governments resulting from multiple shifts in departmental responsibility.

Medical research of Otitis Media in remote communities indicate the relationship of high rates of chronic infections with the lack of access to clean water, overcrowding, bed sharing, contributing

to the easy transmission of infections (Burrow, Galloway & Weisssofner 2009; Gough et al. 2013; McDonald, E et al. 2010). From a western medical perspective, Bailie and others (2010, p.148) found limited epidemiological research to link housing with poor health outcomes due to the inability to link the "...complex web of causative and moderating factors". This single focused data research impedes policy change and of community housing improvements. In contrast, a solutions focused approach by a NSW housing program which identified local Aboriginal community priorities for improvement, successfully reduced hospitalisation for infectious diseases by 40 percent over a ten year period (Gough et al. 2013, p.95). This intervention addressed nine healthy living practices; the provision for washing people daily, especially children, ability to wash clothes and bedding, safe removal of wastes from house; improved nutrition as a result of better storage facilities and food preparation areas; reduced negative impacts of overcrowding; reduced impacts of animals, vermin and insects; reduce impact of dust; control temperature of living environment and reduce hazards that can cause trauma (Gough et al. 2013, p.95).

Housing conditions impact on sanitation with access to washing facilities a basic necessity and of primary importance in the fight against transmission of infections (Gough et al. 2013). A randomised controlled intervention involving a hand washing program in Pakistan with either antibacterial or plain soap, successfully reduced acute respiratory infections and diarrhea by 50 percent (Luby et al. 2005). This study although cited in medical literature on Aboriginal health research has not been replicated in Aboriginal communities. The historical and ongoing management of Aboriginal peoples by the States and subsequent Federal governments has resulted in the housing conditions outlined and the denial of education for many Aboriginal peoples. Currently a much lower proportion of Aboriginal children over 15 years remain in school (ABS 2015).

Access to education

Every child has the right to education regardless of location or family's employment status (United Nations 1989); education instills power and choice, allowing competition in the jobs market. Following the election of the Whitlam Labour Government in 1972, Aboriginal representation increased with the formation of the National Aboriginal Education Committee

(Broome 2009). In 1991, National Aboriginal and Torres Strait Islander Education Program outlined 21 goals and strategies to improve access, participation and outcomes for Aboriginal students; this included teacher training, Aboriginal teacher training as well as additions to the curriculum (Herbert 2012). Despite 20 years of introduced changes, little has improved school attendance or outcomes in education for Aboriginal children. In 2014, the retention rate for Aboriginal children year 8 to 12 was 59.4 percent compared with 83.6 percent non- Aboriginal children; with Aboriginal males lagging behind females by 8 percent (ABS 2015).

Research by McInerney identified Aboriginal students as having low levels of motivation, resulting in high levels of failure, behaviour problems and truancy; they were also likely to meet indifference and bullying (McInerney 1995). In 2008, 12 percent of Aboriginal and Torres Strait Islander children aged 5–14 years reported being bullied at school because of their origin, with rates higher among children living in non-remote areas, where 13 percent of children had experienced bullying compared with 8 percent of children in remote areas (ABS 2011a).

Details of the National Assessment Program of Literacy and Numeracy, emphasizes deficiencies in English language and cognitive abilities from a western framework of reference, with reading, writing and numeracy all substantially lower for Aboriginal children; a result unchanged for more than a decade. Educational disadvantage is a significant determinant for an individual's poor health, low self-esteem, low motivation and cultural deprivation (Dodson 2010). Current Closing the Gap initiatives in education focus on the deficits of the child as opposed to the failure of the education system to maximize children's identity and self-esteem as Aboriginal people. Poor educational outcomes are related to teachers' expectations of success and strength of racial stereotypes not just individual performance (Fredericks et al. 2014). Dodson (2010) comments on the negative school experiences for many and the failure of the state to deliver an education embedded in the context of Aboriginal children's background. Schools may not be culturally appropriate, and education may not automatically lead to expected health gains (Baum 2008). Poor educational outcomes are viewed as an Aboriginal problem rather than a reflection of the institutionalism racism that exists in mainstream society. Historically, education was used to destroy Aboriginal Knowledge, cultural beliefs and lifestyles; some feel it continues to do so (Herbert 2012).

Bilingual education commenced in the Northern Territory in 1973, to reflect the 40 percent of Aboriginal people who speak another language at home (Dodson 2010). The NT government attempted to close this program in 1999, but it was retained for a brief time due to strong opposition from Aboriginal communities. This program demonstrated respect of Aboriginal language, knowledge and culture within the western based curriculum; acknowledging Aboriginal children's status, rather than being subjected to the dominant culture of the western educators and empowerment of Aboriginal teaching assistants who shared their culture and knowledge with the staff and students (Hewitt 2000). The program was retitled Two Way schooling, but was further modified following the Northern Territory Intervention 2007, which introduced compulsory English in the first four hours of school, and linked child attendance to welfare payments. As Dodson comments:

...within Indigenous families there is a living memory of education as an instrument of disempowerment, dismantling languages, cultures and traditions (Dodson 2010, p.3).

This continues for the families of Northern Territory subjugated to the punitive policies of the Intervention. Aboriginal determinants of health and well-being include annulling the effects of colonisation with self-determination; this must include a willingness of the dominant culture to understand Aboriginal world views, knowledge and culture including their holistic approach to health and wellbeing (WHO 2007). Centralising Aboriginal people's experience of colonisation in the school curriculum would affirm Aboriginal children's place in the education system instead of sidelined to the periphery (Herbert 2012). Simultaneously, it would facilitate the current generation's understanding and appreciation of Aboriginal people's struggle for social justice. Herbert (2012, p.101) states "...education should be an empowering process" for all children. Australian Indigenous Mentoring Education is a contemporary program based in urban schools and includes boarders from remote communities; improving retention rates for Aboriginal students from Year 9 to Year 12. In 2014, 93.2 percent of Year 12 program cohort completed the year; this is 6.6 percent above non-Aboriginal attainment rate and 34.7 percent higher than national Aboriginal rate (Australian Indigenous Mentoring Experience 2016). The program's success is attributed to mentoring children from Year 9, when they are most likely to drop out, through to Year 12, by young Aboriginal leaders supported by university students.

An education inquiry identified ear disease and subsequent hearing loss as one of the most significant learning barriers faced by Aboriginal and Torres Strait Islander children (Queensland Health 2013). If repeat ear infections occur during the decisive years of a child's language development, permanent hearing loss will result. According to Williams and Jacobs (2009), children who develop early onset Otitis Media, are prone to developing long term speech and language problems; with a particular negative impact if there are underlying language or cognitive problems. The effects of the disease continue into adolescence and adult life, affecting employment prospects, continuing the cycle of poverty, and increasing the chance of contact with the criminal justice system (Vanderpoll & Howard 2012)

Employment and its impact

Historical narratives both written and oral, tell of long term employment for many Aboriginal men on sheep and cattle stations; with their wives and daughters working as domestic help (Fredericks et al. 2014). Recently it has become apparent, that the reduced pay these workers were entitled to, was retained and failed to be reimbursed by the State governments (Kidd 2007). The poverty generations of Aboriginal peoples have suffered is undeniably a result of government policies and actions; as Australia was built on the sheep's back, so too was it built on what now can be called the slave labour of the Aboriginal workforce. Aboriginal unemployment continues to be related to the marginalisation and dispossession created from previous government policies, and the social exclusion and resultant disadvantage which has occurred.

Remarkable during the last two decades of growth in Australia, driven by the resources sector, the proportion of Aboriginal peoples employed has declined (Stephens 2010). According to the 2011 census the unemployment rate for Aboriginal people in the labour force is three times higher than non-Aboriginal people; and when employed, Aboriginal peoples are more likely to be engaged in manual labour and related occupations (ABS 2011b). In very remote communities the majority were employed in Community Development Employment Program (CDEP), until it was abolished through the 2007 Northern Territory Intervention. Its role was to assist Aboriginal job seekers gain skills, training and capabilities needed to find sustainable employment, aimed to improve the economic and social well-being of communities and offered significant benefits

(Osborne, Baum & Brown 2013). The closure of CDEP in an attempt to merge Aboriginal peoples into the main stream economy has been criticized as bad policy and resulted in higher unemployment (Altman & Kerins 2012). Its replacement, Working for Country, engages far fewer people, with 680 rangers employed across 95 land and sea management programs in 2013 (Ens et al. 2015, p.135).

Langton and Mazel (2008) have debated the impact of the resources boom, stating that the introduced legislation by both state and federal governments facilitated engagement between mining companies and Aboriginal communities. However, this has not resulted in "...positive, meaningful or equitable outcomes"(Langton & Mazel 2008, p.44). In the case study on the Kimberley region, Aboriginal communities living close to major life-long mines have high levels of welfare dependence with little variation between their economic status and other communities in regional and remote Australia (Langton & Mazel 2008). In this region work shifted from the pastoral industry to CDEP and community service industry, with a high proportion of young people engaged in CDEP. The trade based skills of previous generations bypassed the current generation, who find themselves unable to compete in the workforce due "to lower numeracy and literacy, lack of experience, substance abuse and low motivation" (Taylor & Scambary, cited in Langton & Mazel 2008, p.47). Restricted access to education, training and high levels of morbidity compound low levels of participation, limiting the choices and opportunities for Aboriginal communities. The mining industry instead of assisting in education and training is dependent on the influx of remote workers.

The consequences of unemployment are the multiple deficits of social exclusion over time, resulting in social isolation and deprivation. If an unemployed person's social networks are limited to others in the same situation, expectations are lowered and a downward spiral occurs, associated with socially unacceptable behaviour (McKee-Ryan et al. 2005).

Aboriginal peoples have higher rates of unemployment, with 17 percent unemployed compared to five percent non-Aboriginal unemployment rate (ABS 2011b). A study by Bartley, Ferrie and Montgomery (1999) provides evidence that chronic unemployment causes deterioration in mental health; congruently Aboriginal peoples suffer three times the rate of depression and four times rate of suicide than non- Aboriginal people (Jorm et al.2012).

Standard variables which influence employment are education, geography, health, criminal

record, housing, and for Aboriginal people, cultural attachment to language. Analysis by Stephens (2010) indicates health and education levels have a strong effect on employment for Aboriginal people in non-remote areas, whereas in remote areas human capital has a limited role in determining a place in the labour market. Communities are currently developing employment opportunities, through cultural tourism. The Yolngu community have initiated Lirriwi Tourism, creating training and job opportunities through tourism on their homelands. The aim is to develop 50 new tourism businesses employing up to 1000 Yolngu people in Arnhem Land by 2032 (Lirriwi Tourism 2014). Employment for Aboriginal people is a complex issue; for those that want to remain on country and maintain cultural ties, benefit from health gains with little structural support or opportunities (Altman & Kerins 2012).

Due to high levels of unemployment, Aboriginal peoples are more likely to have low income levels, and derive their income from social security benefits. This was confirmed in the 2012 Closing the Gap monitoring report, with average gross income for Aboriginal peoples in Northern Territory was \$269 per week compared with \$925 for non-Aboriginal people, (Department of Families Housing Community Services and Indigenous Affairs 2012a). Poverty leads to poor housing, homelessness and poor nutritional choices, generally increasing morbidity, lowering immunity and resistance to infection. This is compounded by higher food costs in lower socioeconomic areas in rural and remote areas, due to the logistical challenge of delivery, especially for perishable goods (Burns, C 2004). One pilot study indicated children were low in Vitamin C due to lack of fresh fruit, influencing iron stores and compromising their immune system and ability to fight infection (Daly et al.2010). Demonstrable health gains have been made with Maori and Native Americans, which is directly attributable to enhanced nutrition through improved standards of living, not the levels of investment in research funding (Durie 2004).Employment status and income levels directly affect child health through poverty, housing amenities, inadequate nutrition and presence of environmental tobacco smoke.

Racism is deeply engrained in Australian society, instigated in the Federation's founding document, 1901 Australian Constitution, which stated that "...aboriginal natives should not be counted" (Parliamentary Education Office 2016). It is performed through institutionalized systems, cultural biases and by individuals. To the dominant privileged white majority, it is hidden in mainstream attitudes, stereotypes and culture but the policies of racism are evident in the appalling health statistics of Aboriginal people. Consistent with evidence from adult

populations and children from other ethnic minorities, vicarious racism is associated with poor health outcomes among Aboriginal children (Priest, P et al. 2012). It could be argued that systemic racism is endemic in the treatment of Aboriginal children with OM as services and facilities accessible to non-Aboriginal children are largely unavailable, with the barriers of remote access, geography and location cited as limitations to care. In reality the barriers are the Australian health care model and lack of appropriate federal action; with too few doctors and specialists willing to travel remotely. The pioneering work of individuals, particularly Dr. Fred Hollows, demonstrated the inequities within Aboriginal child health, making national headlines in the 1970's, as the National Trachoma and Eye Health Program uncovered the high incidence of OM (Australian Indigenous healthinfo 2004).

The entrenched power of medical institutions limits any prospect of legislation to enforce doctors to work in communities; instead these positions are commonly filled by migrant doctors (Gilles, Wakerman & Durey 2008). Doctors' may experience "culture shock" in remote communities with patients who speak a different language, have different beliefs and cultural practice. This term was first used by anthropologist Oberg to describe the psychological stress felt when an individual lives in an unfamiliar cultural environment (Oberg 1960). Unfortunately, it results in high turnover rates of doctors and nurses, and harms the trust the community place in health care system (Muecke, Lenthall & Lindeman 2011).

Systemic racism is apparent in the current Liberal government's compulsory merger of small Aboriginal communities into townships, echoing the forced removal of Aboriginal peoples from their country onto reserves and missions. Connection and caring for country is a key determinant of health and well-being for Aboriginal peoples, the mandatory removal of people contradicts Aboriginal peoples' rights of independence to look after their land and will impact ominously on health (Altman & Kerins 2012). The Aboriginal social determinants of health and well-being include annulling the effects of colonisation through empowerment and self-determination whereas medical research and subsequent treatments protocols are problem rather than solution focused. This dichotomy will be discussed in the following conclusion.

Conclusion

Priest and others (2009, p.59) literature review of child health, identified 75 percent of studies focused on physical health, 27 percent on health determinants and 3 percent on mental health. The discrepancy reinforces the biomedical approach to diagnostic data collection to eliminate disease; as opposed to improving health. The “whitestream”, a term first used by sociologist Claude Denis in 1997, connotes society structured around a white western experience; Moreton-Robinson’s critique of the whiteness of academia states “...the dominant regime of knowledge is culturally and racially biased, socially situated and partial” (2004, p.88). This experience is congruent with the biomedical model; combined with reductionism, western medicine is rationalized as the solution to Aboriginal health issues. The shameful consequence is evident in the minimal reduction of chronic infections, particularly Otitis Media, in Aboriginal children. Despite commitment by successive federal governments to address social, economic and environmental determinants of health through regional partnerships and shared agreements, this has not translated into public health action or shifted the focus of medical research (Black 2007). Public health strategies are concerned with prevention, early detection and acting on individual determinants of health; with minimal consideration of social and environmental factors. According to Hunt (2010) little research is performed in evaluation of Aboriginal programs and policies, and the performance of biomedical views of health within health policies are reflective of the dominant ideology (Baum & Fisher 2014). This was demonstrated by 2014 Abbot government budget which slashed \$534 million from the Aboriginal affairs portfolio, extinguishing 150 community run programs focused on social, environmental and economic determinants of health (Coggan 2014). It was supplanted by Indigenous Advancement Strategy; a tender base government process resulting in half of available funds delivered to non-Aboriginal organisations (Henderson, A 2015).

The Aboriginal social determinants of health and wellbeing include annulling the effects of colonisation through empowerment and self-determination; facilitated by the reinstatement of funding to effective community run programs and limiting medical research to specific community determined outcomes. Through collaboration and incorporation of Aboriginal ontology into medical research and intervention strategies, an ecological and socially accountable form of healthcare would develop. It would automatically encompass the social determinants of health, including connection to country with employment and respect for Aboriginal ecological knowledge; the management of feral animals and associated dung, dust

and flies; improved housing with training and employment in building trades and maintenance; community controlled food security and access to culturally appropriate education. Within the medical clinics acknowledgement of Aboriginal cultural beliefs and healing practices would help dismantle the existing biomedical hegemony and facilitate integration of traditional healers; creating employment and affirming traditional knowledge and cultural identity (Panzironi 2013). The influence of Aboriginal Knowledge and history of Aboriginal performed health research, particularly OM in children will be the subject of the next chapter.

Chapter Three

Aboriginal Knowledge, Aboriginal research methods and their influence on Aboriginal health research.

Introduction

Current anthropological studies acknowledge the Aboriginal communities of Australia represent the oldest living culture in the world, dating back more than 60,000 years (Jebb & McGrath 2015). The discovery of the first ritualised cremation at Lake Mungo, NSW demonstrated the deeply spiritual cultural practices that have existed in Aboriginal communities for at least 40,000 years. The survival of Aboriginal peoples through two ice ages, is a testament to their deep connection and knowledge of the land orally embed in their culture. Aboriginal Knowledge, bush medicine and customary law, succeeded in creating a vibrant and healthy community impressing the first Europeans with their athletic appearance and sanguine nature. Gammage records the first impressions of Cook who wrote in his diaries they “are far more happier than we Europeans” (Gammage 2005, p.1). However, it has been argued that many views of Aboriginal culture from first contact have been idealised.

The initial observations of the First Australians, no longer apply, the subjugation of colonisation, dispossession of land, language and culture has resulted in increased morbidity in every stage of life and earlier mortality for Aboriginal peoples. Australian health care has failed Aboriginal peoples in its service and delivery, but also social policies for community housing, access to clean water in remote communities, employment and an end to intergenerational poverty have, as mentioned in the previous chapter, also failed. Aboriginal concepts of health and well-being vary considerable from the allopathic model, with the National Aboriginal Health Strategy Working Party (NAHSWP) defining Aboriginal health as:

Not just the physical well-being of the individual but the social, emotional and cultural wellbeing of the whole community. This is a whole-of-life view and it also includes the cyclical concept of life-death-life (National Aboriginal Health Strategy Working Party 1989).

The enduring relationships between Aboriginal peoples their land, ecosystem and each other, reinforces their mutual inclusivity; for Aboriginal peoples there is no distinction between

humanity and the environment (Kwiatkowski 2011). This chapter explores Aboriginal Knowledge, belief systems and child rearing practices, and how this influences Aboriginal research methodology; challenges the western model; and the impact this has on Aboriginal health research.

Aboriginal Knowledge

Aboriginal Knowledge and customary law sustained the local biodiversity simultaneously supporting the health of the community until the impact of colonisation (Broome 2009; Fredericks et al. 2014). This knowledge, shared trans generationally through what the Warlpiri people call Tjukurpa, and the west has labeled The Dreaming; a result of a mistranslation of an Arrente phrase (Stockton 2000). Before colonisation, 250 different language groups existed, each having their own word for Aboriginal Knowledge and law. The western use of the word “Dreaming” contradicts and degrades the complex system of beliefs which underpin Aboriginal ontology and epistemology. According to Fletcher, “...an entire epistemology had been reduced to a single word” which has completely different connotations of being remote and absent minded, reducing Aboriginal peoples' belief system to one that emphasizes mythical and magical attributes whilst negating Aboriginal reality, religion and Law (Fletcher, cited in Nicholls 2014, p.2). The remainder of this chapter will use the Warlpiri word, Tjukurpa.

What differentiates Tjukurpa ontology from western belief systems is the connection and continuity people have with the land, sea and firmament scapes. Animals, waterholes, individual mountains, geology and astral bodies are associated with an Ancestral Being; responsible for bringing each of these forms into existence. The narrative of the Ancestral Being is continually retold delivering examples for social behaviour as well as detailed knowledge of the local environment, location of water, bush tucker and survival in some of the harshest conditions (Nicholls 2014). The oral narratives, transmitted across generations, are experienced as an eternal and continuing process; not abandoned to the past but existing in the present.

Contemporary events are woven into these narratives, with experiences of the missions retold to children and grandchildren; “...we learnt by watching and listening, waiting and then acting” (Ungunmerr-Baumann 1988, p.9).

The performance of ceremonies and rituals, the narrative of sacred stories, are part of communal healing practice and reflect a sacred life. Sitting in a circle creates a revered space,

“...representing the interconnectedness of all things, the relatedness of people to land and spirit” and is well known through Indigenous cultures (Healing Foundation 2010, p.9). Ungunmerr-Baumann, an elder from Daly River community, talks of Dadirri, Aboriginal peoples’ ability to experience “...deep listening and quiet, still awareness” to nature and to each other (Ungunmerr-Baumann 1988, p. 9). She compares it to the western concept of contemplation, without over thinking; this “deep listening” has translated to profound local knowledge of Aboriginal country. This knowledge is continually adapting and changing to the variations in environment, climate and food supply (Jebb & McGrath 2015).

Contemporary ethnobotanical investigations have confirmed the benefits original custodians conferred on traditional medicinal plants; the Wilga and Lavender Bush have antimicrobial and antioxidant activity; the Emu Bush used for smoking ceremonies, has antimicrobial, anti- fungal and anti-inflammatory properties; the Black and White cypress provide both antibiotic and antiseptic therapeutic effects and the Kakadu plum has the highest level of Vitamin C of any known plant, as well as high levels of potent antioxidants and anti-carcinogens (Gorman, Griffiths & Whitehead 2006; Sadgrove & Jones 2013). Early exploitation of Aboriginal Knowledge resulted in commercialisation of the Tea Tree plant, harvested since the 1920’s; it has broad spectrum antibiotic, anti-fungal and anti-microbial properties affecting *E. coli*, *S. aureus* and *C. albican*; and is currently recommended as a replacement for the post antibiotic era (Cox et al. 2000). These are just a few of the many examples of the beneficial properties of bush medicine plants (Cox et al. 2000; Packer et al. 2012; Simpson et al. 2013).

The comprehensive knowledge of plants is applied to local animal life cycles and seasonal variation, enabling hunters to catch their prey, collect eggs, gather nuts, berries and edible plants (Gadgil, Berkes & Folke 1993). Before colonisation, Aboriginal people lived within a restricted border, adjoining other family and clan groups; this instilled motivation to protect biodiversity and manipulate the environment particularly with fire. The comprehensive representations of the ways Aboriginal Knowledge influenced biodiversity and the environment, is well recognized; as Ens and others state (2015, p. 135) the “potential contribution of Indigenous Knowledge to contemporary ecosystem science and management is irrefutable”.

As discussed in chapter two, colonisation has resulted in the loss of 50 percent of Australian woodland, with 61 percent of country occupied by agriculture and mining (McFarlane, Sleight & McMichael 2013). The resultant degradation of healthy ecosystems disrupts the equilibrium of

predators and prey, hosts, vectors and parasites, in plants, animals and humans (Alves & Rosa 2007). The land which resides under native title, the Indigenous Estate, is in sound environmental condition, however it is under threat of invasive species. Active engagement with Aboriginal Knowledge systems, local expertise and labour is essential to complement western science in engaging with these challenges (Altman & Kerins 2012). The Working for Country program has currently 775 full time equivalent jobs, employing 1612 Indigenous Rangers on sea and land management programs (Burgess et al. 2009; Department of Prime Minister and Cabinet 2016).

Aboriginal Knowledge, is collectively owned, often with an individual or group acting as custodians over certain aspects in the best interest of the group. Rose states "...rights to knowledge are graded, and the best rule is the same as the rule for country: always ask" (Rose 1996, p.32). For Aboriginal peoples knowledge is not free; a foreign concept to white non indigenous researchers. Only the group may consent to sharing knowledge through specific decision-making procedures; sharing creates a relationship between the givers and receivers with the group retaining authority to ensure knowledge is properly applied. Aboriginal worldviews of health are relational, dependent on health of country and local ecosystems, and conflicts with western concept of health as merely the absence of disease.

Aboriginal Knowledge: concepts of health

Aboriginal ontology is relational and Aboriginal wellbeing revolves around "...cultural factors including social relationships, connection to Country, kinship, traditional knowledge, reciprocity, identity, accountability and physical, social, spiritual and emotional wellbeing" (Kingsley et al. 2013, p.678). The physical body is observed through the flow of life force and its relationship with channels and containers; analogous to Traditional Chinese Medicine (TCM) and Indian Ayurvedic Medicine which reference flow of energy through the body.

Illness is the disruption of this energy flow around the body, from an external force. The Karajarri word *ngarlu*, refers to the centre of emotions and wellbeing in the stomach, home of body's inner spirit and country's spirit. According to Roe, *ngarlu* preserved Aboriginal people's health and strength, however the impact of dispossession, disempowerment, alcohol and drugs has severely weakened it (Roe, cited in Purdie, Dudgeon & Walker 2010). Correspondingly, researchers have emphasized the impact of stolen generations, transgenerational stress and

trauma on Aboriginal health and wellbeing (Purdie, Dudgeon & Walker 2010; Vicary & Westerman 2004).

Indigenous medicine, recognised by the World Health Organisation, is based on the beliefs and experiences of Indigenous people, and verbally passed down through the generations. It is:

...the sum total of knowledge, skills and practices on holistic health care, which is recognised and accepted by the community for its role in the maintenance of health and the treatment of diseases (WHO/WPR 2000, p.7).

At the core of Aboriginal healing practices are the Ngangkari or traditional healers, who utilize bush medicines, healing waters, and encourage participation in healing rituals through songs (Mayo & Tsey 2009; Tjilari & Peter 2003). Bush medicines are used for a variety of conditions including colds and flu, skin infections, fevers, stomach disorders, musculoskeletal pain, bone fractures, and snake bite; their use is reinforced with the belief they are imbued with Ancestral power (Tjilari & Peter 2003). Smoking ceremonies are performed to maintain the health of country; people utilizing the powerful vibration of Ancestral songs and dance through the communal and physical body. The strength of healing ceremonies lies in the pharmacopeia of bush medicine and the power of belief:

You can feel the jiluwa [blood vessels] working, feel the blood flowing [during a smoking treatment]. I was heavy before now I'm fresh and light. We can feel the medicine going into us. When we take gardiya [whitefella] tablets, we don't feel anything (Gija woman, cited in McDonald, H 2007, p.277).

Western science has stimulated the immune system to fight infections with fake antibiotics, and eased pain with sham analgesics; establishing the influence the mind and body has over its own healing abilities (Humphrey 2002). Healing is associated with an authority figure, both traditional and western medicine belief systems, need the power of the authority figure for health gains to transpire (Humphrey 2002). According to Williams, Guenther and Arnott:

There is a place in public policy for traditional healing—it needs to be supportive rather than dismissive. It needs to respect and value the knowledge for what it is regardless of whether it can be understood in mainstream terms (2011, p.24).

Community rituals also inform the “roles, rites and responsibilities of relatedness” and demonstrate the ontology of child and family relationships as discussed in the following section (Martin 2005, p.28).

Aboriginal Knowledge: family and child rearing practices

Children are viewed as capable and autonomous, not helpless or powerless as is often the case in overprotective western societies. Birth and babyhood is a child-centred reality with children experiencing the world through increasing levels of relatedness to others, the environment, elements and spirit. As children mature rites and rituals are observed; adulthood brings increasing responsibilities with roles for looking after country, growing up children or looking after the law; an elder being one who "...has been grown up in the law" (Martin 2005, p.30). Cousins become brothers and sisters, great grandparents become grandchildren, and people are brought closer so more than one set of people can be parent, grandparent and child. Childrearing is family centred, taking place within the relational context of the community and environment (Geia 2012). Further rites are enacted upon death, respecting the loss of the physical body and the re-emergence of the spirit. This circle of life contrasts markedly to the western binary opposition of life and death, and demonstrates Aboriginal world views as "expansive and embracing" (Martin 2005, p.31).

Tjukurpa holds the knowledge for "growing up" children; a process of emergence and development. Fundamental are the sharing of stories, rules and knowledge which describe the child's relationships and responsibilities to other people, family, animals and the land (Geia 2012). In western families, babies and children are expected to develop routines according to their parents; in contrast Anangu and Yapa children eat, sleep and play when and where they chose; if they cry they are picked up immediately, it is considered cruel to do otherwise (Byers et al. 2012). Similarly, to put babies or young children to sleep on their own is considered harsh. Children are actively encouraged to help each other, happy to give objects away with no concept of "mine"; and to help someone struggling and keep each other safe (Priest, K et al. 2008). This has been observed in classrooms where an older sibling will help a younger relative if they are having difficulty; another beneficial outcome of the responsibilities of Tjukurpa (Priest, N et al. 2009).

Knowledge of Aboriginal child rearing practices is fundamental for any research project concerning child health, as all community members are involved with raising children. Childhood is a crucial stage of life, as it requires others to accomplish their roles and obligations for the emerging spirit. The child also has responsibilities to listen and absorb imparted knowledge. Cultural belief systems form the foundation of research methodology informing us of the nature of reality and how one thinks about that reality. Aboriginal

Knowledge informs Aboriginal ontology, epistemology and methodology; according to Martin (2005) at the core of Aboriginal research methodology is relatedness, with a willingness to sit in a circle with no assertions of power or status.

Aboriginal research methods

Research methodology utilizes the way one thinks about reality to gain new knowledge (Wilson, S 2001). The dominance of the western model of research, founded on western worldviews and belief systems, frequently results in the dismissal of knowledge gained through other world views (Cochran et al. 2008). The governing western paradigms are based on positivism, post positivism, critical theory and constructionism. Positivism is founded on the existence of one reality, whilst the evolution of post positivism allows for reality to be modified; both utilize experimentation, manipulation and objectivity, and dominate medical research. Post positivism embraces contextual and emic viewpoints employing both quantitative and qualitative data collection (Roy 2014). Social science researchers apply critical theory to form an alternative reality which varies depending on gender, culture and social class allowing for exploration of power imbalances; the epistemology is subjective, predetermined and importantly ethics are central to the research methodology. Rigney (1999) adopted aspects of critical theory to inform Indigenist research, and reflects his vision of a more just world. Participatory action research is included in critical theory with active engagement in dialogue initiating social change. Health programs have utilized this method for the last decade and are starting to feature in mixed methods health research.

Constructivism determines knowledge is constructed by an individual or a group with no ontological basis, with the interaction between people and language used creating their subjective and objective reality (Roy 2014). Many argue that scientific knowledge is a construction by and for the scientific community, using scientific language to quantify and construct models of the natural world; underpinned in a belief of one reality (Foucault 1973).

Aboriginal ontology is based on relationships with self, others, the environment, and knowledge which is not individually owned but shared. Aboriginal epistemology or Aboriginal ways of being, knowing and doing, embrace relationship in talking circles, storytelling through art, song and dance, and yarning or personal narrative (Martin 2005, Rigney 2008). The development of relationships with others, the Ancestors and environment, from childhood, help inform ways of being and doing. Aboriginal diachronic observation and care of country created the ecosystem

which greeted the colonisers; “the biggest estate on earth” was the product of a multifaceted system of land management, and an intimate knowledge of the life cycle of plants and animals (Gammage 2011). This knowledge was observationally, socially constructed and passed on orally through the generations.

The detrimental effects of western research paradigm and subsequent power over Aboriginal people was challenged by Smith’s request for the decolonisation of the research process (Smith, LT 1999). Rigney's (1999) introduction of an Indigenist research methodology which involved resistance, political integrity controlled by Aboriginal researchers, and privileging Aboriginal voices sought to confront western researchers and their methods. Fundamentally Rigney asserted (2006, p. 41) "... there is no essentialized Indigenist research epistemology and ontology ". Martin has adopted a position of strength from her Aboriginal heritage; emphasizing Aboriginal world views, Knowledge and relatedness whilst viewing western frameworks as the 'other' (Martin 2005).

Aboriginal ontology demands researchers to be accountable in their relationships; the researcher is obligated to fulfill their role in their relationship to the research and to the participants, overriding the validity or reliability of the research (Martin 2008). In comparison, the singular focus of western research is answering the research question; the participants are objectified enabling the researcher to have only a relationship with the research question. Western research is an abstract pursuit to gain knowledge, obligated to the research process and dominant western worldview. Aboriginal research methodology, is focused on gathering qualitative data through developing relationships with the participants incorporating use of yarning, talking circles, storytelling, art, dance and Dadirri. Although not viewed as an essential part of Aboriginal research paradigm, quantitative data collection is considered by some to be essential, as it’s this information that influences opinion and changes policy (Roy 2014).

Yarning is an informal, relaxed discussion; it can be intimate, one on one, or in a group situation and identifies significance from individual and collective experiences (Healing Foundation 2010). During the research process it can be broken down into four components; social, research topic, collaborative and therapeutic. Identifying different types of yarning are crucial for successfully in data collection, necessitating ability to elicit information from the participants (Bessarab & Ng'andu 2010). Oral histories are dependent on the ability to listen; for Aboriginal people this takes the form of Dadirri, a term introduced by Ungunmerr- Baumann (1988) which

embraces deep listening. Atkinson (1994) identified it as an effective methodology in her research on transgenerational healing; and Geia (2012) utilized Dadirri as an underlying principle of her research framework on child rearing practices (Atkinson 1994; Geia 2012).

Dadirri provides a space for awareness, connection, balance between logic of mind and feelings of the heart which incorporates listening and observing the self and acknowledging that the researcher brings to the research his or her subjective story as well as their relationship to others (Geia 2012, p.70).

Aboriginal research methods have developed from cultural practices and may be incorporated with western models that align with the ethics and values of Aboriginal people, for example Participatory Action Research (PAR). It is essentially a democratic process of participation, inquiry, reflection and action, embedded in social relationships and influenced by local context, culture and history. Central to PAR is community empowerment, with the facilitation of practical solutions (Baum, MacDougall & Smith 2006).

Over the past decade the incorporation of PAR with Aboriginal communities has emerged, as the recognition of relationship development and alignment with the ethics and values of Aboriginal people, becomes central to the research process (Martin 2005; Wilson, S 2001). Tokenistic attempts of PAR in western research are not uncommon, with limited involvement of steering committees and lack of true negotiated community participation (Kendall et al. 2011). PAR is grounded in shared knowledge construction and understanding, and can mobilize collaborative action for change; the researchers acting as facilitators for participation, learning and empowerment. According to Wallerstein and Duran (2010), PAR can be effective for improving health equity, through its process and the effects it generates. A common framework for Aboriginal researchers includes ethnographic methodology, the integration of symbolic imagery and the process of reflexivity; assisting in the decolonisation of the research processes which is the challenge for non-Aboriginal researchers (Smith, LT 1999). The following section discusses how Aboriginal research methodologies have been utilized in health research to the benefit of the communities they worked with.

Aboriginal health research: improving health

Ethical guidelines for health research in Aboriginal communities were introduced in 2003 by NHMRC. These include multifaceted concepts which are related to each other and intrinsic to Aboriginal communities; spirit and integrity, respect, responsibility, reciprocity, equality and survival and protection (National Health and Medical Research Council 2003). The first component, spirit and integrity bind the core values emphasising the permanence of the past, present and future generations. Respect helps to build and promote individual and community self-respect and recognition. Acknowledgement of responsibilities is fundamental to ATSI communities and comprises kinship bonds, caring for others and country, and the preservation of balance within and between the physical and spiritual realms. Reciprocity is the mutual obligation for a balanced allocation of resources, and responsibilities for survival of the group; this continues and extends to food, money, property, housing, cars and land. In a research setting this guideline reinforces the need for reciprocal beneficial outcomes for the communities in the present or near future; not just to the research institutions. Despite the impacts of colonisation and marginalisation Aboriginal peoples continue to survive, protect their culture and individuality by drawing strength through a communal identity.

The NACCHO ear trial, was an early community initiated research study where the community chose to partner with James Cook University (Couzos et al. 2005). The project is embedded in the western medical model, however embraces core ethical guidelines to the community's benefit. Aboriginal health workers (AHW) were employed as part of the research process, both treatments trialed were effective so no child was comprised, risk factors and community education on OM were included. Before publication, the results were shared with AHWs and community members on information days. This particularly study resulted in improvement in ear infections by 47 percent after a single course of twice-daily ear drops (Couzos et al. 2005). Unfortunately, no follow up data is available to determine the current rates of ear infections; if guidelines were changed to adopt the successful treatment, whether community awareness has maintained or if other risk factors were addressed.

Bainbridge and others (2011) constructed an Empowerment Research Framework, with an Indigenist foundation, to create a pragmatic alliance of Aboriginal and western knowledge relevant to Aboriginal people. It embraced the PAR process and reflexivity, continually asking questions of relevance and benefit to the individuals, communities and researchers.

Inherent in PAR processes is community engagement, collaboration and strengthening of capacity by empowerment. According to Bainbridge and others (2011), Aboriginal people who have participated in the Empowerment Research Program over the past decade understand empowerment as a social action process in the context of their lived experiences; coming to terms with their past and present situations; dealing with pain; gaining control; becoming strong; finding their voice; participating in change; and working together for a strong community (Bainbridge et al. 2011). Empowerment is a step in the process towards improved health and well-being in socially excluded communities. Over the ten year research period outcomes for individual/family, community and organisations, demonstrate that concepts of empowerment and control are critical in effective management of health, education and employment. This study reinforces the need for community involvement in any research project, health or social promotion in communities; as Tsey (2008) concluded, having no control is a neglected social determinate of health. The era of self-determination rhetoric may be over in the Northern Territory and replaced by “Stronger Futures”, but strength comes from empowerment and resilience (Department of Families Housing Community Services and Indigenous Affairs 2012b).

Walker and others (2012) identified yarning, as a successful research framework for community based health research with Aboriginal women, despite cultural and language protocols. The benefits included empowerment as people talk freely with their contributions validated; it establishes relationships between people influencing accountability; it allows for the acquisition of new knowledge and reinforces self-determination. Eight Aboriginal Community Controlled Health Services took part in Queensland and WA with yarning used in the initial stages with the community elders; enabling the elders to sign off on the project, before it was given the status of women's business. This is particularly important for a child health project, to seek contributions from elders, and their involvement with children and mothers (Walker et al. 2014). It may also help illicit Aboriginal Knowledge of childhood infections, and encourage development of a community project in the use of bush medicine for children's ear health.

The authors discuss the nature of cross- cultural yarning normally underpinned by white privilege, and the necessity of non-Aboriginal researchers to align with Aboriginal protocols, demonstrating cultural respect. They reinforced that no individual had all the knowledge, with all participants able to contribute to improved outcomes; this was assisted by talking in lay terms about the project, enforcing intellectual property rights and research guidelines. This project demonstrates how using an Aboriginal framework can assist in the development of a

research project and how the principles can be applied to collate information once the project has commenced (Walker et al. 2014).

Women Elders from an Aboriginal community in regional south-west Western Australia collaborated with researchers to develop a health intervention programme focused on nutritional education and cooking skills (Nilson et al. 2015). The project's aims were to facilitate a healthy life style change in the women and their families, provide a supportive environment for women, and encourage community ownership leading to program sustainability. Methodologies used were ethnography, participatory techniques and action research guided by the Making Two Worlds Work framework; with empowerment as its core principle. Over a twelve month period 24 cooking classes were held, qualitative data was obtained during and on completion; this included group or individual yarning, participant observation and art projects. The study assisted in new skills acquisition for healthy inexpensive cooking, increased self-esteem and empowered the participants to negotiate and advocate for healthy family food choices. By providing an opportunity for participants to voice their experiences, challenges, interests and aspirations it has encouraged change in community behaviour and developed a framework for the community's health needs. Yarning created a safe space for the participants to talk through feelings of shame about of what is healthy food and loss of old knowledge; how they feel crippled by a lack of resources, lack of purpose and acknowledging that change is hard. Major themes that emerged from the yarning, demonstrated that having access to resources, particularly good food, will not automatically lead to improvements in nutrition, as so many other factors come in to play. The outcomes from this type of research are focused on the participants; they include empowerment through increasing knowledge base, and generation of new knowledge concerning participants' sense of well-being. These two studies utilize different approaches both aimed at empowering the participants to enhance the research process and contribute to communities' welfare. The incorporation of PAR may help illicit Aboriginal ways of knowing with respect to childhood infections, and assist in developing a community project to assist in improving child/ear health.

Conclusion

‘Aboriginal health’ in medical discourse, is embedded in the western paradigm of health; it is not embraced for its holistic nature nor translated into current health practices (Phillips 2015). Attempting research from a singular western perspective, without integrating and respecting Aboriginal ontology will continue to deliver western outcomes; which are less likely to be embraced by communities (Wiertsema & Leach 2009). Henderson (1993), discussing the epidemic of OM, confirmed there were no experts, as neither the Aboriginal or medical communities had experienced this type of epidemic. Henderson questioned who defined the problem; is it the medical research into infections or the Aboriginal families experience of OM and its impact on the child and community (Henderson, I 1993).

This chapter has advocated for acknowledgement and respect of Aboriginal Knowledge and law, and its inclusion in land and sea management practice; the power of Aboriginal traditional medicine, and its addition to contemporary health practice; the recognition of Aboriginal child autonomy, community relationships and the importance of this knowledge in research design. With the aim of decolonising the research process, Aboriginal research methodologies have been compared to the tenets of western research. For some Aboriginal researchers an Indigenist methodology is favored, for others combining the science of western research whilst embracing Aboriginal methodologies is preferred.

The chapter concludes with an exploration of two research studies; the first employs an Aboriginal framework to assist in the development of a research project and how the principles can be applied to collate information. The second’s aim was to facilitate a healthy life style change in women and their families, by utilizing PAR design. This method empowers the participants with increased knowledge and skills, whilst encouraging community ownership and action. The following chapter summarises current strategies to improve childhood ear infections, identify gaps in literature and introduce a PAR research design.

Chapter Four

Nobodies listening - why ear infections remain a high burden for Aboriginal children.

Introduction

According to Sherwood medical research is funded through western mechanisms of research power and is “authorised to speak of and for Aboriginal peoples about what is best for them” (2010 p. 151). The ontology of biomedical research is focused on the cause of illness in individuals rather than searching for patterns of disease in populations. This single focus ignores public health initiatives that may lead to more effective prevention (Baum 2010). The combined effect of this power and belief system is reflected in the high burden of morbidity in Aboriginal communities, with Aboriginal children suffering the highest rates of ear infections worldwide (Daly et al. 2010, p.232).

The high prevalence of middle ear disease in Aboriginal children has been systematically researched since the 1970’s; a decade later it was recognized as a major health concern by the National Aboriginal Health Strategy (Hudson & Rockett 1984; National Aboriginal Health Strategy Working Party 1989). By late 1990’s, National Aboriginal and Torres Strait Islander Hearing Strategy was developed, focused on ear disease prevention in children 0-5 years (Department of Health and Aged Care 2001). This was followed in 2001, by the House of Representatives inquiry into Indigenous health; it recommended addressing social determinants of health including improving housing, provision of clean safe drinking water and implementation of a child nutrition program (Department of Health and Aged Care 2001).

The increased funding from the 2001 inquiry produced a proliferation of data collection related to middle ear disease and its consequences including hearing loss, educational impairment and increased chance of contact with criminal justice system (Burns, J & Thomson 2013). Further policy development for children at educational risk from hearing loss ensued with the formation of the National Strategic Framework for Aboriginal and Torres Strait Islander Health, 2003-2013. A subsequent Senate inquiry report tabled in 2010, Hear us: Inquiry into Hearing Health in Australia, prioritized hearing screenings and follow-up for all Aboriginal children from remote

communities once schooling had commenced (Commonwealth of Australia 2010). Despite the development of policies and contribution of medical research over the past 15 years, ear health in Aboriginal children has not improved (Castan Centre for Human Rights 2016). According to Paul (2007), the rewriting of frames of reference are a form of paternalism, continually doing but not fostering change. This chapter will summarise the biomedical position and treatment of ear infections, discuss why this approach is not working, describe new knowledge gained through Aboriginal community collaboration and a community participatory research design proposal.

What we know

The biomedical model is effective for diagnostic research on Otitis Media however, the knowledge gained serves to increase disease complexity by identifying multiple variations and pathogens. This complexity creates a barrier to treatment, particularly in remote communities as it relies on the skills of the Aboriginal health worker, community nurse or GP, to distinguish between each type of presentation and treat according to prescribed guidelines. These variations have been detailed in chapter one; key aspects include early infection of babies, re-perforation of ear membrane, asymptomatic infection, hearing loss, delayed language development and progression to the severest form, Chronic Suppurative Otitis Media (CSOM) (Daly et al. 2010; Leach et al. 1994). This latter condition occurs most commonly in Aboriginal children in remote communities where current treatment protocols of vaccinations or long term antibiotic therapy have minimal benefit (Leach et al. 2014; Wiertsema & Leach 2009).

Aboriginal children are severely impacted by the progression of acute OM into CSOM, particularly their future learning and employment prospects. The Stronger Futures legislation, a re-badging of the NT Intervention, introduced in Northern Territory in 2011, increased access to primary health care services. However, the latest Closing the Gap report indicates demonstrates minimal change with a minor reduction in incidence of OM by four percent (Castan Center for Human Rights 2016). The development of a mobile children's ear clinic in WA is proving to be a more effective intervention. Included in the mobile service is initial screening of ear and hearing health, followed by regular access to services throughout the year. Children at risk are seen at least four times a year, allowing for ear health status to be monitored and appropriate treatment given (Higginbotham & Shur 2015). Additionally, the Ear Bus Team provide preventative education and information for families, children, schools, child care centres and

professional development sessions at ACCHOs. Children are assessed for a wide range of conditions as the service recognises ear disease may be symptomatic of a weakened immune system (Higginbotham & Shur 2015). The bus is identifiable to communities and assists in raising ear health awareness, with over 5000 consultations provided to 1566 at risk children in 2014 (Higginbotham & Shur 2015). To date no results are available in the reduction of ear infections, however the program expects with early assessment, treatment and three month reviews, the progression to CSOM, language delay and loss of hearing will decline. A similar service has commenced in Cherbourg and Cape York communities in Queensland (Smith, AC et al. 2012). This model recognises the difficulty ACCHO providers face with the complexity of OM and provides experienced ear health professionals to diagnose and treat the disease; the failure to deliver suitable services is a silent risk factor in the progression of the disease (Vergison et al. 2010). The following section will outline medically determined risk factors for OM and how they have been addressed in collaborative approaches to public health intervention.

Collaborative intervention approaches to risk factors of Otitis Media

The core risk factors for OM are exposure to environmental tobacco smoke, bottle feeding, malnutrition and overcrowding; however, the development of intervention strategies to reduce their impact is very slow. The first report concerning the adverse effects of environmental tobacco smoke (ETS) on children's health was published in 1967 (Cameron 1967). The impacts of ETS on ear disease have been documented since 1993; maternal smoking also doubles the risk of SIDs and contributes to low birth weight infants (Anderson & Cook 1997, p.356; Stenstrom, Bernard & Ben-Simhon 1993). Both conditions exist at higher prevalence rates in Aboriginal births compared to non-Aboriginal (Stamp et al. 2008). Jacoby and others (2008) undertook the first Australian based research into Otitis Media, from 1999 to 2003, comparing smoking and ear infections in Aboriginal peoples and non-Aboriginal people. The conclusion stated:

...although Australia has been a world leader in reducing ETS exposure in public places and reducing smoking rates in the general population, public health campaigns have not been as successful in Indigenous populations (Jacoby et al. 2008, p.602).

Lack of community consultation, either prior or on completion, combined with a lack of smoking cessation programs during the four year study severely restricts the outcomes this

study provided for the communities involved. In contrast a public health study carried out by Gilchrist and others concluded that “targeted antenatal smoking cessation programs are needed for Aboriginal mothers” due to risk of low birth weight and other health problems, has influenced intervention strategies (Gilchrist et al. 2004, p.228).

Services offered at ante and postnatal clinics are designed to track health problems, educate women on breast feeding and nutrition, and in Aboriginal communities, run smoking cessation programs. Minniecon, Parker & Cadet -James (2003) acknowledged barriers to attendance at antenatal clinics for Aboriginal women as shame factor, family obligations, caring for other siblings and transportation. This was supported by Wilson (2009) who identified Aboriginal women failing to attend antenatal clinics due to shame of pregnancy if they are young, fear of machines e.g. ultrasound, and shame at not understanding information given by the doctor or nurse. The Northern Territory’s Department of Health and Community Services developed a community based intervention program, Strong Women, Strong Babies, Strong Culture Program, to address nonattendance at antenatal clinics. Senior Aboriginal women were employed to mentor younger pregnant women and encourage early attendance at clinics. They advised on nutrition, the benefits of bush foods, safe behaviours including cessation of smoking and alcohol during pregnancy, to seek medical help and to take prescribed medicines. The outcome of the program demonstrated the beneficial role of women elders in health care, with increased weight gain of new born compared to pre-existing data and recognised women elders’ knowledge and their status in the community (Tursan d’Espaignet et al.2003).

Following consultations with senior Aboriginal women in 2003, an Aboriginal Birthing Program was created for regional South Australia. The program initiated the creation of a new role, Aboriginal Maternal Infant Care (AMIC) worker, and having a leadership role within maternity services. The AMIC workers are trained in antenatal, intrapartum and postnatal care, creating partnership with midwives and providing continuity of care for Aboriginal women and families (Stamp et al. 2008). This program has expanded from two to six regional areas in South Australia and from servicing 20 women in 2004, to 90 women in 2014; an evaluation is currently underway (Brock 2015, p.1). Anecdotal evidence from an AMIC worker proposes clinical benefits: ‘breastfeeding, how important that is... I think a lot of our girls never had that information ’ (Stamp et al. 2008, p.6). The strength of these two programs lie in the empowerment of women elders to reclaim their previous role, acknowledgement of elder women’s role in women’s health issues by the dominant culture and education by women for

women in their own language. Correspondingly Moort Boodjari Mia, an Aboriginal led midwifery service in Western Australia, commenced in 2010 as a funded National Partnership agreement on Closing the Gap in Indigenous Health outcomes. Despite its success, increasing the attendance of women to ante and postnatal check-ups, the clinic is under threat of closure due to 2014 budget funding cuts (Stewart 2016).

Overcrowding as a risk factor for infectious diseases is commonly used; it signifies congestion, over peopled and overrun, denoting an ongoing Aboriginal problem. A more appropriate and effective debate on communal living and how this impacts on the size, configuration and suitability of housing in remote communities is required (Fien & Charlesworth 2012). High usage puts severe pressure on kitchen, bathroom and laundry facilities, often leading to blocked sewers and drains with a lack of skilled labour, to repair or replace. Poor maintenance of housing reinforces the lack of community trade skills, within no current government apprentice training or employment schemes in communities for builders, carpenters, plumbers or electricians. Due to the harsh environment and high usage, the robustness of materials and quality of construction are vital factors documented in the National Indigenous Housing Guide (Department of Family and Community Services 2007). The houses must be sufficient to cater for real family sizes and compositions, as distinct from the western nuclear family, with considerations of culturally distinct behaviours (Memmott & Moran 2001). Fien & Charlesworth suggest “one house can serve the needs of what may be seen as up to three families, thereby effecting net savings in housing costs” (Fien & Charlesworth 2012, p.21).

A NSW housing program identified nine healthy living practices as part of a solutions focused approach with local Aboriginal community groups. This intervention addressed; the provision for daily washing especially of children, ability to wash clothes and bedding, safe removal of wastes from house; improved nutrition as a result of better storage facilities and food preparation areas; reduced negative impacts of overcrowding; reduced impacts of animals, vermin and insects; reduce impact of dust; control temperature of living environment and reduce hazards that can cause trauma. It successfully reduced hospitalisation for infectious diseases by 40 percent over a ten year period (Gough et al. 2013, p.95).

High bacterial load in communities is a secondary risk factor, with transmission of pathogens through hand contact, discharge from the noses of other children and the high incidence of respiratory infections of adults (Wiertsema & Leach 2009). Paradoxically the high load of environmental vectors for disease including the common house-fly, high volumes of dust, camp dogs and impact of feral animals are not recognised by the biomedical model (Graczyk et al. 2001; Palmer & Brady 1991). As mentioned in chapter two, colonial impact has denuded the landscape through its agriculture practice and presence of hoofed animals; disturbing the existing ecosystems, decimating native animal populations and creating severe dust storms. Poor health infrastructure and inadequate sanitation facilities, the presence of domestic waste, feral and camp animal dung combine to increase the transmission rates of infectious diseases requiring a public health intervention from state, territory and federal governments. The first two chapters outlined the narrow focus of medical research in relation to Aboriginal health, with little impact on the high incidence of infections, particularly OM. To continue the same biomedical approach will perpetuate the same outcome; as it has for the last 30 years (Wiertsema & Leach 2009). Clinical factors alone are not sufficient to improve individual or population health as social and environmental inclusion is essential. Biomedical research requires a social ecological approach for effective intervention. According to social ecological theory, projects that intervene at many levels offer greater potential for promoting health effectively than do those with a single focus (Stokols 1992). Johnston and others (2013 p.35) state "...effective interventions to improve population and individual outcomes require environmental change as well as strategies that target individual behaviours and clinical factors".

What's missing?

Endeavouring to find a cure for Otitis Media, without involving Aboriginal communities, reinforces the concept that biomedical "research is a tool of colonisation and remains so because it is critical that the power remain in the hands of the superior Western researcher" (Sherwood 2010, p.206). The major risk factors associated with OM include environmental tobacco smoke, bottle feeding, poor nutrition and overcrowding, and are discussed in medical discourse as the individual's responsibility. In reality, they are derivatives of the social determinates of health. Correspondingly the associated environmental risk factors of land degradation, biodiversity loss, dust and flies are omitted (AIHW 2014). As Wilke states "it is the responsibility of government

departments to do their job to address the wider determinants of health” (Wilke, cited in Paul 2007, p.218). Despite the identification of safe housing and clean water in 2001 House of Representative’s inquiry, limited intervention has occurred with the conditions for the majority of remote communities not addressed. The most drastic solution of current legislation is the closure of up to 150 smaller remote communities in WA, likely to impact 2000 people (Toussaint 2015).

Johnston and others reviewed programs that targeted environmental determinants of health and their impact on Aboriginal health, they concluded: “...the most complex programs with multiple environmental targets achieved measurable improvements in health” (2013, p.42). In relation to the rates of childhood infections and poor hygiene, the review recommended an ecological approach to health promotion including “...community housing construction, repair and maintenance programs; environmental health programs including garbage collection and disposal; animal control; and maintenance of public places/sewage treatment” (Johnston et al. 2013, p.36). Current gaps in biomedical health research are evident in the lack of environmental interventions to reduce vector borne disease and public health initiatives.

According to Knibbs and Sly (2014, p 2):

...there is scarce information on the association between environmental risk factors and Indigenous peoples’ health in Australia. Most of the very limited work has quantified environmental exposures without linking these to health outcomes .

Considering the high burden of communicable diseases Aboriginal people endure related to environmental factors, this gap is of grave concern. In a recent study by McDonald, Bailie and Morris (2014, p.6) on children’s health, the community participants from NT reported “the dust, dogs, rats, cockroaches, litter and overturned rubbish bins, poor housing and crowded and dirty houses were making their children sick”. If the communities understand the impact of the environment on the children’s health, government inaction adds further grief to the most marginalised communities. Wiertsema and Leach (2009) described the difficulties of delivering prescribing long term antibiotic therapy for Aboriginal families; perhaps if concurrent public intervention strategies occurred, compliance might improve.

As discussed in chapter three involving participants in community participatory action research, delivers a methodology to empower the community, facilitates new knowledge, instills ownership of the research process and intervention developed. It has the opportunity to validate

Aboriginal Knowledge whilst current research practice negates Aboriginal ontology (Trudgen 2010). The biomedical identification of individual risk factors of OM, particularly bottle feeding, smoking, and poor nutrition focuses attention on individual responsibility for behaviour change and improvement in outcomes. The failure to acknowledge and address the environmental and social determinants of health maintains the health inequity and disempowers communities. This is well illustrated in the recent analysis of the Stronger Futures policy in progress in NT, which has achieved a minimal four percent decrease in number of Aboriginal children with ear infections, and in number of pregnant women who smoke (Castan Center for Human Rights 2016). In the current era of antibiotic resistance, the appropriate use of bush medicines with antibacterial and antimicrobial properties, developed through a community participatory research model, could have profound effects on early prevention of ear infections. The following section gives examples of effective community participatory action research (PAR) studies and a proposal for a community PAR study to address ear infections.

Community participatory action research and new knowledge

Examples of community research in hygiene practice and smoking demonstrate that this type of research can be effective in addressing some of the risk factors of Otitis Media. McDonald and Bailie (2010) consulted with Aboriginal community members, to determine attitudes to infections and hygiene behaviours. The key findings were limited knowledge of hygiene benefits of hand washing, no knowledge of the infectious nature of discharge or toilet training in young children nor the health risks associated with a contaminated living environment.

However, the research findings remained undisclosed until the social media campaign, No Germs on Me, was unveiled four years later. This campaign incorporated local television, media adverts, posters and give-away materials promoting the purchase of soap. The post intervention survey demonstrated message retention was high, with increased awareness of hand washing and self-reported behaviour change (McDonald, E et al. 2011). Couzos and others (2015) undertook a collaborative PAR project, with the aim of building partnerships and through impartial conditions, create knowledge production to challenge smoking behaviours..Thirty four ACCHO were involved with benefits including employment and training of 95Aboriginal research assistants, awareness raising within health services and support to develop local quit programs for workplace and the community.

Both of these studies are controlled approaches to individual risk factors; with limited direct influence on ear infection rates. As discussed in chapter three, the prerequisite for biomedical research is the integration of Aboriginal concept of health and well-being into its framework; enabling the model to address all attributable risk factors of Otitis Media, including social and environmental determinants. This requires a multifaceted approach, with the research question focused on the outcomes for the community; how can we improve the health indicators of the community? Successful interventions studies discussed in chapter two with a positive impact on the social and environmental determinants of health include; NSW house maintenance program for a rural community which reduced infection related admission to hospitals by 40 percent over a ten year period (Gough et al. 2013, p.95), improved access to fresh food for children resulted in decrease antibiotic prescriptions (Jones & Smith 2006), women elders supporting pregnant mums improves the weight of newborns (Tursan d'Espaignet et al. 2003) and decreasing rates of infectious skin disease by improving health of camp dogs (Allen 2015).

Several studies have demonstrated the improved health gains from participation of communities in active land management, with the creation of suitable economic development resulting in both ecological and community health gains (Altman & Kerins 2012; Burgess et al. 2009; Davies et al. 2011). Djelk environmental rangers of Northern Territory, work in three main areas; weeds, feral animals and use of fire and have decreased incidence of diabetes and heart disease. The health improvements are attributed to increased exercise, improved nutrition through bush foods, and empowerment through mutual respect for Aboriginal Knowledge (Burgess et al. 2009).

The majority of remote communities are under severe stress from lack of control, with communities reliant on diesel generated power, expensive processed food and vegetables, minimal employment opportunities and are welfare dependent (Tsey 2008). This manifest in ill health, malnutrition, chronic substance abuse, violence, suicide, disinterest in education and high levels of morbidity and mortality (Trudgen 2010). Indigenous research methodologies are based on community empowerment; giving back control. Research of health inequalities in British civil service, identified those at the bottom of a hierarchy suffered heart disease at four times the rate of those at the top (Marmot, M et al. 1991). In this case, all employees would have access to medical care, good nutrition, education and receive appropriate income. Marmot and others concluded exerting control at work is linked to good health, reinforcing the difficulties

faced by Aboriginal people who have suffered loss of control in all areas of their lives (Marmot, M et al. 1991; Tsey 2008)

A recent innovation of an integrated green house, incorporates solar power to provide energy, food and clean water and is specifically designed for remote communities. The greenhouse's innovation is its ability to deflect heat from its shell to heat water through steam power generation, eliminating the need for diesel generators and able to operate in extreme temperatures (Tribal Technologies 2016). The simple design of the generator requires only basic mechanical skills for maintenance. A prototype model is currently proposed for Cape York communities, included in set up costs are training programs for subsequent employment. The green house incorporates fish farming with nutrient enriched water, recycled from the fish tank through the garden bed. This system allows communities to grow their own food, create employment and generate their own power. Community gardens have been attempted in many regions but fail due to extreme temperatures and water supply; this integrated greenhouse solves these problems. As food interventions have shown providing a daily source of Vitamin C from fruit and vegetables can decrease the rate of infections (Black et al.2013).

A progression of McDonald and Bailie (2010) hygiene intervention study involving community PAR, and designed to facilitate Aboriginal Knowledge in the solutions is discussed. The first steps involve relationship building, initially sharing the proposal of improving child health, with Aboriginal Health Council of SA and Council of Elders. Progression would be dependent on permission granted by the Elders and approval from the Human Research Ethics Committee. The research would initially take the form of discussion groups or yarning, the Malparara way, involving two or more Aboriginal health workers, researcher and elders.

... "malparara" means "a person going along with a friend or companion". Malparara is used to describe the process of two people, one Indigenous and one non-Indigenous worker, working together (Collard & Palmer 2006, p.28).

Yarning with the community elders in the initial stages, would facilitate the project's development. This is particularly important to generate new knowledge and empower community from the initial stages. The preliminary dialogue could take several meetings, before approval was gained; meetings would be inclusive allowing community members to raise issues they feel contribute to children's health. Meetings would be recorded with permission, information collated and key issues raised shared with the community.

Visual information, in form of culturally appropriate posters, anatomical models, and animated videos to demonstrate the pathology of ear infections, how early they start and how bacteria are transmitted. According to Trudgen (2010) Yolngu people have little knowledge or understanding of bacteria, infections or the immune system; the assumption is this type of disease process was unknown to Aboriginal communities. The outcome of the project is dependent on integrating community's current knowledge of ear infections, bacteria and immune system with new knowledge. It is likely few adults had educational opportunities and contemporary knowledge will need to be combined with local Aboriginal Knowledge. Through this process advice on women only consultations would be followed.

Discussions would include the medical risk factors including smoking around babies, bottle feeding, maternal and child nutrition as well as environmental factors. This may facilitate a debate of various issues including health hardware, house maintenance, community dogs, presence of flies, dust, employment, access to fresh food and difficulty in giving children medication. The challenges for the project are many, initially gaining trust of the community, empowering and validating community knowledge and facilitating prevention of ear infections through use of bush medicine. Endorsement of community contributions would be vital through all stages to facilitate a supportive environment for members to share ideas.

Following identification of issues and to facilitate informal yarning, an all-inclusive soap-making workshop would be available; soap is often viewed as a luxury item. The workshop would create an informal, relaxed atmosphere to discuss the benefits of hand washing, as demonstrated in the No Germs on Me Program (McDonald, E et al. 2011). Care would be taken to inform and not embarrass participants of their lack of understanding. Utilization of the resources from the No Germs on Me Program, in the health clinic and local school, would help to reinforce behaviour change. As the relationship develops, follow up workshops utilizing local plants for aromatherapy and medicinal properties, could be incorporated in the soap making process. Depending on the response of the community, the integration of bush medicine could initiate a preventative strategy for new mums and carers to practice from birth. The community may want to trial using suitable local plants to assist in children's ear health as antibiotic agents. This could also lead to a discussion on local plants high in Vitamin C, which children could be encouraged to collect and consume.

The use of bush medicine could follow the model created by Simpson et al (2013) working in partnership with the Chuulangun Aboriginal Corporation, where the community retained intellectual property rights. Following recurrent workshops over a six month period, the participants would have learnt new skills to make soap and where to source the ingredients. Involvement of children in the soap making process, could assist in their behaviour change. Evaluation of the project may include clinic records of antibiotic prescriptions for workshop participants, prior to commencement, at one year and two year period. Ongoing support would be vital to facilitate behaviour change with return visits for soap making, education workshops and where feasible to address environmental issues the community has concerns with. This approach is restricted to only addressing one area of prevention, with limited potential for employment and no direct impact on the available sanitation facilities, housing status or environmental health. However, as demonstrated appropriate hygiene practice can have a substantial impact on reducing infection rates in children (Luby et al. 2005).

Conclusion

A researcher's obligations do not end with simply conducting methodologically-sound research. Researchers have an obligation to ensure that their research is conducted in an ethical manner, and that it will bring benefit to the community (Wilson, cited in Roy 2014, p.125).

This chapter has identified the limits of medical research methodology to decrease rates of infection and improve health in Aboriginal children. Otitis Media is a complex disease which can be reiterative in non-Aboriginal children; however due to availability of primary health care, including GP's and ENT specialists, and uncompromised living conditions it does not create generations of families with hearing loss. The training and employment of AHW in ear health and the provision of mobile services in some remote areas is helping to manage this insidious disease, but this is a long way from reducing the epidemic rates to an acceptable level or preventing the progression to chronic status. The latest Closing the Gap report indicates a minor reduction in incidence of OM by four percent (Castan Center for Human Rights 2016).

Medical risk factors for OM have assisted in establishing a variety of public health programs focused on individualised responses. These include ante and postnatal clinics, designed to track health problems, educate women on breast feeding and nutrition, and in Aboriginal communities run smoking cessation programs. Despite the success of these services increasing attendance and

improving infant birth weight, many are losing their funding following budget cuts of \$524 million from Indigenous affairs, in 2014 (Coggan 2014). Funding has reduced to ACCHOs, already underfunded, despite independent evaluation demonstrating they are the most effective way to deliver health services in remote communities (Mohamed 2014).

A review of environmental determinates by Johnston and others (2013, p.36) recommended an ecological approach to health to decrease rates of childhood infections including “community housing construction, repair and maintenance programs...garbage collection and disposal; animal control and sewage treatment”. This knowledge is not new. The National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013, articulated the relationship between health and the social determinants of health adopting a multi-sectoral approach to improve housing, education, and employment to support and sustain improvements in health (Department of Health and Ageing 2013a). Currently Aboriginal housing is included in the National Affordable Housing Agreement (NAHA) 2009; the proposed outcome to improve housing amenity is marginal, with a target to reduce overcrowding by 20 percent over a ten year period (Department of Prime Minister and Cabinet 2009). The houses are provided by an external workforce with no training, apprenticeships, or employment provided for Aboriginal peoples. Despite the success of NSW housing program reducing hospitalization for infectious diseases by 40 percent over a ten year period, the limited construction of houses, failed response to sanitation management and lack of apprenticeships or employment reinforces the dominance of health care model of treatment intervention (Gough et al. 2013, p.95). To continue the same biomedical approach will perpetuate the same outcome; as demonstrated in the persistent high rates of ear infections (Wiertsema & Leach 2009). The current gaps in medical research include a lack of environmental interventions for vector borne disease, addressing sanitation and access to health hardware concurrent with medical research, and involving community in Participatory Action Research to stimulate employment, new knowledge and empowerment.

It could be argued that funding for health research continues to be wasted particularly with the unchanging burden of morbidity in communities. For research to be effective, it requires the medical research body to decolonise the research process with Aboriginal communities; develop community participatory action research to empower participants and facilitate knowledge transference between both groups without power relations of expert and client; and incorporate environmental health research with Aboriginal Knowledge of land care, and biodiversity

management. Education becomes a dual experience with white health professionals discovering the existing knowledge base of communities, from which to scaffold new information for the community and for the researcher. The failure of multiple education and health campaigns created and delivered by white educators is related to lack of understanding of Aboriginal world views (Trudgen2010).

Collaboration entails expanding the biomedical lens, accepting and incorporating Indigenous and social science methodologies; and most importantly refraining from judging research as unempirical or value laden (Baum 2010). Participatory action research with Aboriginal communities will assist in facilitating solutions for health issues by respecting local knowledge and empowering community to deliver the solutions; as demonstrated by the NSW housing project (Gough et al. 2013). In the era of antibiotic resistance, utilizing a community's knowledge of local bush medicine may assist in decreasing infection rates whilst waiting for governments to address the social and environmental determinants of health.

Chapter Five

Conclusion: an ecological approach to medical research.

We need good research that doesn't just describe the problem, but actually comes up workable solutions that can be transferred into practical change for our people (Gooda, cited in Tarquinio 2016, p.40)

This thesis aim is to debate the biomedical research approach and its lack of influence on the unchanging rates of Otitis Media infection rates in Aboriginal children from remote communities. Biomedical research identifies OM as a complex disease with a variety of presentations and treatment approaches. However, due to the medical model's single focus of health being the absence of disease; a multitude of affiliated factors are ignored (Wade & Halligan 2004). Chapter one examined the disease process of OM, its risk factors and the exceptionally high rates in Aboriginal children. Secondary risk factors identified include anaemia, low iodine levels, poor nutrition in mothers and the presence of gastro-intestinal parasites; resulting in malnourished and immune compromised children (Asher et al. 2014; Gracey & King 2009). The medical model fails to incorporate these secondary factors which predispose Aboriginal children to infections, paradoxically limiting the effectiveness of current treatment regimes.

Consistent with disregarding the holistic approach to child health, medical research neglects the impacts of the social and environmental determinants on health; as discussed in chapter two. Communities have stated "dust, dogs, rats, cockroaches, litter and overturned rubbish bins, poor housing and crowded and dirty houses were making their children sick" (McDonald, E , Bailie & Morris 2014, p.6). Despite the drastic changes to remote living environments since colonisation, the social determinants and environmental degradation are rarely mentioned in medical research. The resultant impacts of colonisation, inadequate housing and sanitation, unemployment, poverty and limited education opportunities, continue to be neglected. Nevertheless, improved outcomes do occur; a NSW housing intervention focused on community raised issues, demonstrated a reduction in hospitalisation from infections by 40 percent over a ten year period (Gough et al. 2013, p.95).

Priest and others identified a lack of research in social and environmental factors in relation to Aboriginal child, with the majority of research, 75 percent, focused on physical health (Priest, N et al. 2009, p.59). Medical research embraces reductionism, with disease diagnosis dependent on a specific pathology and associated with a definitive treatment. Resources are primarily allocated for the treatment of the diagnostic label; with minimal attention given to understanding other contributing factors to illness. Reductionism and the biomedical model, fosters the belief that medical science is the only solution to the Aboriginal health issues identified. McDonald and Bailie (2010, p.491) state "...it is widely understood that poor living conditions and poor hygiene are major factors underlying the high burden of infection experienced by children living in these communities". Despite this acknowledgment, the medical focus to reduce the high burden of childhood infections experienced by Aboriginal children is through vaccines and antibiotics.

Farming practices continue to degrade land; feral hoofed animals proliferate, creating wind borne dust and obliterate local biodiversity. The impact of wild pigs, buffalos and a million camels roaming central Australia has resulted in biodiversity loss; unable to compete for limited resources. Water holes are destroyed by the sheer physical impact and the presence of dung attracts flies; vectors for infectious diseases. Examination of the relationship between infection rates, the presence of feral animals and dung, the proliferation of the common house fly, and transference of disease to the immune compromised child is absent in environmental or biomedical health research.

The thesis demonstrates the inadequacy of biomedical research to provide space for a multifaceted approach to health. However, the fundamental negligence lies with successive government agencies who have failed to fund and implement basic infrastructure and support systems, within remote communities. In the last 40 years, multiple reports and inquiries have been undertaken, the most significant of which, National Aboriginal Health Strategy (NAHS) in 1989, was written by members of Aboriginal Community Controlled Health Organisations (ACCHO). Major recommendations from NAHS were neither implemented nor evaluated; paradoxically an alternate version was created by Minister for Health and Aged Care in 2001, without Aboriginal consultation (Paul 2007). Following the abolishment of Aboriginal and Torres Strait Islander Commission, Aboriginal affairs have transferred through numerous departments and have fallen victim to political ideology (Baum & Fisher 2014). Aboriginal

housing policy is an exemplar of this lack of long term future planning and commitment. The Department of Health and Ageing initiated the National Strategic Framework for ATSI Health 2003-2013; before completion housing switched to Department of Social Services, under the banner of Australian Remote Indigenous Accommodation program. In 2009 the National Affordable Housing Agreement (NAHA) was introduced by Department of Prime Minister and Cabinet, discarding Indigenous housing responsibility to the states and territories. NAHA target is to reduce overcrowding by 20 percent by 2019; a rate that will see overcrowding extinguished in 50 years (Department of Prime Minister and Cabinet 2009). As of August 2012, 1,440 new houses, and 4,830 refurbishments had been delivered (O'Connor 2012, p.1). Housing development is provided by an external workforce with no apprenticeship, training or employment provided for Aboriginal peoples.

The continual development of policies has been labeled paternalism, continually doing but not fostering real change (Paul 2007). This is demonstrated in the current 'Closing the Gap' report, which assesses the national targets set by COAG in 2008 and endorsed by the incumbent PM, Kevin Rudd. The targets have failed in every area except child mortality and high school attendance, with worsening levels of incarceration and unemployment (Castan Center for Human Rights 2016). Despite poor trends since the initiative began, the 2014 Liberal federal budget reduced funding to ATSI programs by \$534 million dollars (Coggan 2014, p.1). In the budget review of 2015, Treasurer Hockey claimed money was wasted in Aboriginal affairs, but failed to mention that "...areas of health, housing, education, employment and community infrastructure are all underfunded" (Behrendt 2015, p.1). Despite an independent evaluation demonstrating the effectiveness of ACCHOs in delivering health services in remote communities, finance was reduced (Mohamed 2014). It could be argued funding for medical research continues to be wasted particularly with the unchanging burden of morbidity in communities.

In medical discourse the term 'Aboriginal health' is used as a reference for Aboriginal people's health and is embedded in the western health paradigm; it is not embraced for its holistic nature nor translated into current health practices (Phillips 2015). Chapter three highlighted key areas of Aboriginal Knowledge and how they influence child health, including the Aboriginal views on child rearing which are contradictory to the western model. Recognition by the medical profession that "...health care belief systems are critical to the patient's healing process",

however there is limited acknowledgement of traditional healers; whose advice is often valued more highly than medical practitioners (Williams, E, Guenther & Arnott 2011, p.18). Attempting medical research from a singular western perspective will only deliver western outcomes; which as demonstrated are unlikely to be effective or embraced by communities (Wiertsema & Leach 2009). Land currently under native title, the Indigenous estate, is in sound environmental condition but is faced with the threat of invasive species. Active engagement with Aboriginal knowledge systems, local expertise and labour is recognised as essential to complement western science in engaging with these challenges (Altman & Kerins 2012).

Cultural belief systems are the foundation of research methodology, informing us of the nature of reality and how one thinks about that reality. The dominance of the western model of research, founded on western worldviews and belief systems, frequently results in the dismissal of knowledge gained through other world views (Cochran et al. 2008). Aboriginal ontology is based on relationships with self, others, the environment as well as a relationship with knowledge. Aboriginal epistemology embraces relationship in the form of talking circles, storytelling through art, song and dance, and yarning or personal narrative. Utilizing community Participatory Action Research methods to embrace Aboriginal ontology and epistemology encourage participation, and reflection will empower communities into action and facilitate practical solutions (Baum, MacDougall & Smith 2006).

The final chapter identified the limits of current medical research methodology to decrease infection rates and improve Aboriginal child health. Otitis Media is a complex disease which can be reiterative in non-Aboriginal children however due to availability of primary health care, including GP's and ENT specialists, and adequate living conditions it does not create generations of families with hearing loss. The training of AHW in ear health and the provision of mobile services in some remote areas is helping to manage this insidious disease; however, this is a long way from prevention. The biomedical identification of risk factors of OM, particularly bottle feeding, smoking, and poor nutrition focuses attention on the individual; with individual responsible for changing behaviour to improve outcomes. The failure to acknowledge and address the environmental and social determinants of health maintains the health inequity and disempowers communities. The prerequisite for biomedical research, is the integration of Aboriginal concept of health and wellbeing into its framework; enabling the model to address all the attributable risk factors of Otitis Media, including the social and environmental determinants

of health. This requires a multifaceted approach with the research question focused on the outcomes for the community as opposed to new knowledge for researchers. Collaboration with Aboriginal communities will facilitate solutions for health issues if Aboriginal Knowledge is respected, and the community participates to deliver solutions; as demonstrated by the NSW housing project (Gough et al. 2013). Collaboration entails expanding the biomedical lens, accepting and incorporating Aboriginal and social science methodologies; and most importantly refraining from judging research as unscientific and value laden (Baum 2010). New terminology could be incorporated in form of an ecological approach to health or eco health which “recognizes the fundamentally interdependent nature of health and other societal, developmental and ecosystem related factors in human communities” (Asakura et al. 2015, p.1).

Biomedical research rationalizes “the cure” will be discovered with sufficient funding. Conversely, based on this research, if governments appropriately funded communities to remain on their homelands with access to appropriate education and employment, adequate sanitation facilities, affordable fresh food, suitable housing for large family groups and maintenance services, environmental policies to address feral animal control utilizing Aboriginal knowledge of land care; and critically self-determination, rates of morbidity including ear infections would improve.

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