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RESPIRATORY ILLNESS IN URBAN INDIGENOUS CHILDREN: RISK AND CULTURAL CONTEXT

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ABSTRACT

Background

Respiratory Illnesses (RI) in Australia's Aboriginal and Torres Strait Islander population are predominant causes of morbidity and mortality. To date, however, although more than half of Australia's Aboriginal and Torres Strait Islander peoples reside in urban regions[1], there have been no studies focusing on young Indigenous children with RI in an urban setting.

Focusing on respiratory health in Aboriginal and Torres Strait Islander children is important as RI in Indigenous children are common and serious. Nationally, diseases of the respiratory system, although ranked fourth as the cause of death in Indigenous infants, are the most common cause of preventable deaths (Australian Institute of Health and Welfare (AIHW) 2011). They are also the most common reason for presentation to general practitioners and the second leading cause of all self-reported ill-health in this population (AIHW 2011). Chronic respiratory disease is the second most common reason for hospitalisation among Indigenous Australians, after renal dialysis (Australian Health Ministers' Advisory Council, 2008). The incidence of non-Cystic Fibrosis bronchiectasis is excessive in remote area children (Chang, Grimwood, Mulholland & Torzillo 2002) and it is associated with repeated infections in early childhood (Valery, Torzillo, Mulholland, Boyce, Purdie & Chang 2004). Aboriginal and/or Torres Strait Islander children bear a disproportionate burden of acute and chronic lower respiratory infections (O'Grady, Taylor-Thomson, Chang, Torzillo, Morris, Mackenzie, Wheaton, Bauert, De Campo, De Campo & Rubin 2010) with disease in childhood being increasingly recognised as antecedents for chronic lung disease later in life (Galobardes, McCarron, Jeffries & Smith 2008). The highest incidence of RI occurs in children aged less than 5 years, particularly in young children aged less than 2 years (AIHW 2011).

Despite the burden of disease, there are no studies that have examined risk for, and impact of, RI in Indigenous children from an Indigenous perspective. This lack of data limits the ability to plan, implement and evaluate strategies and interventions to reduce incidence and improve respiratory health outcomes.

Aim:

This study aimed to inform the development of future research and interventions by gaining an understanding of Indigenous contexts and perceptions of risk for RI in Indigenous children. Specifically, we aimed to examine the cultural context and risk factors of Aboriginal and/or Torres Strait Islander children with acute and chronic RI in an urban setting.

Primary objective:

The primary objective of this study was to explore risk for RI as perceived by the parents of young Aboriginal and/or Torres Strait Islander children from within an Indigenous context.

Secondary objective:

The secondary objective of this study was to explore the impact of RI in urban Aboriginal and Torres Strait Islander children on families and communities from within an Indigenous context

Specific Research Questions

1. What are the meanings and consequences of RI, and the associated risk factors, in urban Indigenous children within the social and cultural context of Indigenous families and their communities?

2. What is the impact of RI amongst urban Indigenous children and their families, including individual, family and community impacts

Methods

My research consisted of a study that provided a picture of the risks and impacts of RI in urban Indigenous children, their families and communities. A specific definition of respiratory illness (i.e. acute or chronic, asthma, pneumonia etc.) was not used to avoid limiting the potential scope of information gained. It employed a qualitative approach utilising Indigenous research methodology. Focus groups were conducted with members of Brisbane’s Aboriginal and Torres Strait Islander community in order to access the lived experiences of Indigenous people who have cared for children with RI. The study explored the concept of risk for RI from an Indigenous perspective and

how RI impacted upon families. Focus group discussions were digitally recorded (with prior permission of participants) and transcribed verbatim by myself. Once transcriptions were complete, I analysed the data using a thematic analysis method.

Results

We conducted a total of four focus groups, each of 6-8 members, between November 2012 and April 2013. There were 24 participants; 15 participants identified as Aboriginal, seven as Torres Strait Islander, one as both and one (a carer of Indigenous children) as neither. There were 21 females and three males. All participants stated that they (a) identified with an Indigenous community and (b) actively maintained connections with their Indigenous culture at home. The majority of participants also stated that they preferred to access Indigenous-specific or Indigenous-friendly primary health care.

In summary, participants' perceptions of risk & impact were influenced by:

- Traditional Indigenous values, culture and practices, including traditional medicine
- Connections to family, friends and community
- Beliefs handed down from elders, parents and other family members about illness and wellness
- Experiences within mainstream and Indigenous-specific health services
- Access to knowledge and information about RI
- Access to reliable support networks
- Social, emotional and spiritual wellbeing

All of these factors impacted how participants perceived health and wellbeing that in turn influenced how they and their family experienced health care and how they were impacted by RI.

Discussion

My study has identified that the perceptions of Indigenous parents/carers about RI (and health and wellbeing in general) are different to those of mainstream health care professionals; that these perceptions and beliefs have a profound effect not only on their experiences of health care but may also provide an explanation for the prevalence of RI in Indigenous children. These outcomes illustrate that medical professionals, researchers and health care providers need to acknowledge and address the concerns of Indigenous parents/carers in order to begin to address not only the prevalence of RI in Indigenous children but also the larger health disparity between Indigenous and non-Indigenous children in Australia.

Outcomes

Anticipated outcomes from this research include:

- Recommendations to build upon the information from this study and improve health outcomes for Indigenous people
- Data to inform the development of an Indigenous-specific risk assessment tool for RI that can be utilised by both clinicians and researchers

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my research higher degree candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

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I acknowledge that copyright of all material contained in my thesis resides with the copyright holder(s) of that material. Where appropriate I have obtained copyright permission from the copyright holder to reproduce material in this thesis.

Publications during candidature

Conference presentations

1. Anna M Bell, Anne B Chang, Peter Newcombe, Kerry-Ann O'Grady. Results of focus groups with Brisbane's Aboriginal and Torres Strait Islander community. Oral presentation at 2013 International Voices in Indigenous Social Work, Winnipeg, Canada

2. Anna M Bell, Anne B Chang, Peter Newcombe, Kerry-Ann O'Grady. Queensland Children's Medical Research Institute Student Expo 2013. Respiratory Illness in Urban Indigenous Children: Risk & Cultural Context. Poster presentation

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Publications included in this thesis

No publications included

Contributions by others to the thesis

Dr Kerry-Ann O'Grady is responsible for the conception of this project. Kerry Hall, Dr Jan Hammill and Dr Noritta Morseau-Diop assisted with the community focus groups. Kerry Hall and Dr Morseu-Diop also assisted with the focus group transcription. Dr Maree Toombs provided critical analysis support.

Statement of parts of the thesis submitted to qualify for the award of another degree

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List of abbreviations used in this thesis

AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health & Welfare
ARI	Acute respiratory illness
ALRI	Acute lower respiratory illness
CF	Cystic Fibrosis
NAIDOC	National Aboriginal & Islander Day of Celebration
NHMRC	National Health & Medical Research Council
QCMRI	Queensland Children's Medical Research Institute
RI	Respiratory illness
WHO	World Health Organization

CHAPTER 1. Introduction

The World Health Organisation (WHO) defines health as: "a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity" (Boddington & Räisänen 2009, p. 51). The Australian Aboriginal definition of health as determined by the National Aboriginal Health Strategy Working Party (1989) states:

> "Aboriginal health is not just the physical well-being of an individual but is the social, emotional and cultural well-being of the whole community in which each individual is able to achieve their full potential, thereby bringing about the total well-being of their community. It is a whole-of-life view and includes the cyclical concept of life-death-life. Health to Aboriginal peoples is a matter of determining all aspects of their life, including control over their physical environment, of dignity, of community self -esteem and of justice. It is not merely the matter of the provision of doctors, hospitals, medicines or the absence of disease and incapacity" (National Strategic Framework for Aboriginal and Torres Strait Islander Health Context 2003)

This definition was further expanded in the 1990s as:

> "This holistic concept does not merely refer to the 'whole body' but in fact is steeped in the harmonised interrelations which constitute cultural well-being. These inter-relating factors can be categorised as largely spiritual, environmental, ideological, political, social, economic, mental and physical. Crucially, it must be understood that when the harmony of these interrelations is disrupted, Aboriginal ill-health will persist" (Swan & Rafael, 1995)

The grave state of the health of Australian Indigenous peoples, particularly the gap in morbidity and mortality between Indigenous and non-Indigenous Australians (AIHW, 2011) has been the subject of much discussion and research. The somewhat different definitions of health quoted above are indicative of the larger differences between how Indigenous and non-Indigenous peoples perceive illness and wellbeing. It is important to be mindful of these definitions as a point of reference when discussing Indigenous health, Indigenous health research and clinical practice with Indigenous peoples in Australia.

A common, and familiar, error of logic is to confuse equality with homogeneity. 'Treating everyone the same' is an unwritten but not unusual practice in health care. On the surface, this concept sounds inoffensive and even admirable, in some ways. However, it fails to withstand close critical scrutiny. In reality, 'treating everyone the same' would mean expecting a person in a wheelchair to climb a flight of stairs unassisted. Or expecting a non-English speaking family to communicate without an interpreter To treat everyone 'the same' is to operate under the false assumption that everyone has had access to equal resources, enjoyed equal advantages in life and possessed homogenous experiences, values and perceptions. "Treating everyone the same", in other words, disadvantages some people and gives others a head start.

In the area of health, to ignore or minimise the cultural differences between Indigenous and non-Indigenous Australians not only does a disservice to both parties but perpetuates Indigenous disadvantage and masks non-Indigenous privilege. In this study, I have chosen not to do a side-by-side comparison of Indigenous and non-Indigenous beliefs and perceptions about respiratory illness (RI). A large part of that was about creating a culturally safe space for myself as an Aboriginal researcher. The lives of all Indigenous peoples are inevitably framed by the dominant non-Indigenous culture on a daily basis. It is important for Aboriginal and Torres Strait Islander people to have respite from the non-Indigenous mainstream; to have a safe space (literal and metaphorical) of nurturance and renewal. I wanted to avoid the use of dichotomisation and frame the issue of RI in a way that privileged the Indigenous voice and provided a space to capture the complexities of the lived experiences of Indigenous peoples. Therefore, this study was not a comparative study between Indigenous and non-Indigenous peoples. The research question focused on Aboriginal and Torres Strait Islander peoples because this particular area (respiratory health in Australian Indigenous peoples in an urban area) had not previously been examined from an Aboriginal perspective.

This research focused on the perceptions, beliefs and values of Aboriginal and Torres Strait Islander people who have lived experience in caring for Aboriginal and Torres Strait Islander children with RI in an urban setting. This is a group of people who experience socioeconomic disadvantage and marginalisation, racial discrimination, intergenerational loss and grief and high levels of stress. These life challenges are magnified when their children or grandchildren experience RIs.

1.1 Personal Journey as a Wakka Wakka and Batchula First Nations Australian

I have approached this research from my standpoint as an Aboriginal woman and allied health professional who has always lived and worked in urban communities, and who believes in the definition of Aboriginal health as stated above. My practice framework in social work also informs my standpoint as a researcher. This framework encompasses humanist, feminist, social justice and Indigenist frameworks and values. ‘Indigenist’ refers to the theory and practice which focuses upon the challenges faced by Indigenous people and the reinforcement of Indigenous values such as reciprocity, the importance of community and extended kinship systems, reverence for nature, social justice and so on (Keshena, 2008). Hence my specific interest in the examination of the beliefs and lived experiences of Aboriginal and Torres Strait Islander parents and caregivers of children who have had RI.

The maintenance of cultural integrity and cultural safety has been important not only in my research and professional practice but also in my personal values as a member of the Aboriginal and Torres Strait Islander community. In the context of this research project it meant the conscious decision to employ culturally appropriate and culturally safe methods of consultation and communication, not just with the individual participants involved but also with their local communities and elders, as well as the privileging of the voices and experiences of Indigenous people. As such, I will be capitalising the words Indigenous, Aboriginal and Torres Strait Islander throughout.

My methodology is built around the recognition of the value of Indigenous knowledge, Indigenous values and Indigenous ways of knowing. The accession and utilisation of Indigenous knowledge (in a respectful and appropriate manner) has the potential to successfully address the challenges that surround Indigenous health (Stephens, Porter, Nettleton & Willis, 2006). The exchange of knowledge and respectful interaction between health professionals/researchers and Indigenous people is vital in addressing health inequity (Stephens et al., 2006). As this research will show, Indigenous parents want to be actively involved in the health care of their children. An important part of that involvement is the establishment of relationships of trust, respect and knowledge sharing with health professionals.

This research involved conscious rejection of the traditional method of power relations, where the health professional or health researcher is the all-powerful source of knowledge and the Indigenous client/subject the passive receiver. In this research, I recognised the participants as the custodians of significant and valuable knowledge. I felt honoured and humbled by my interactions with participants and members of the community. Not only did these people choose to share their valuable knowledge with me and take time out of their lives to participate, they expressed great support and genuine interest for this research project. Their warmth and enthusiasm cheered me when I found my motivation flagging.

This research aimed to privilege the voices of Aboriginal and Torres Strait Islander peoples, and their lived experiences. In doing so, the aspiration was to focus on Indigenous culture and values in relation to health, particularly how these issues are viewed by Indigenous people and how they impact on each other. This research employed Indigenous methods of qualitative enquiry; specifically the creation of a culturally safe space for participants and researchers in order to form relationships of trust and share cultural knowledge via the use of traditional storytelling methods, also known as ‘yarning’ or ‘yarning up’ (Bessarab & Ng’andu, 2010) and personal narrative. In doing so, the goal was to provide an alternative narrative to the popular Indigenous health discourse that has problematised, stigmatised and marginalised Indigenous peoples and communities.

As Smith points out, social policies in health and education have been “viewed as remedies for the ‘Indigenous problem’” (Smith 1999 p. 91). Theories of cultural deprivation and/or cultural deficit which lay the blame for Indigenous marginalisation on Indigenous people are still pervasive in some quarters. Some epidemiological narratives have framed Aboriginal communities as places of chaos and chronic disease. (O’Neil, Reading & Leader, 1998) These narratives can, and have, been employed to justify extreme government interventions into the lives of Indigenous people, with one of the most recent examples being the Northern Territory Emergency Response (Stringer, 2007; Cox, 2007).

This ‘problematisation of the Indigenous’ (Smith, 1999) has several serious side effects. Foremost is the attribution of Indigenous health to Indigenous dysfunction rather than generational disadvantage, structural inequality, widespread poverty and racism (Cox, 2007) Another is that many of the solutions prescribed are imposed externally (sometimes forcefully) by the non-Indigenous, rather than created and owned by Indigenous people themselves. The ongoing strength and resilience of Indigenous people, the richness and beauty of Indigenous culture, the enduring worth of Indigenous values, are rarely recognised or celebrated as they should be.

When I was studying, I was often asked where I planned to work once I finished my undergraduate social work degree. I really had no idea, but I usually replied, “Well, I know where I *won’t* be working, in a hospital.” The fact that I did end up working in a hospital (better yet, a children’s hospital) is surely one of life’s little ironies. I believe now that I was actually meant to end up working in a hospital, that this is the path my life was meant to take. Through my work, I’ve had unforgettable experiences (good and bad), met people who have become priceless to me, and had the opportunity to start my graduate study. I’ve also had the opportunity to face down some of my fears. I’ve never liked hospitals. When I was about five years old, I was diagnosed with rheumatic fever and spent about six weeks in a children’s hospital. My father worked fulltime and my mum had many other children at home to take care of. So I was pretty much left on my own for those six weeks. I remember the loneliness and boredom. I remember all the needles. I remember spending most of my time just staring out the window at the world outside.

I remember what it was like to be that child, and this is part of the perspective I have brought to my work and study. It is always wonderful to see children get better, and become healed enough to go home. It is inspiring to see families adapt to an abrupt change in circumstance with resilience and strength. These aspects of my work have been positive and uplifting. Some of my other experiences have been confronting and heartbreaking. I have young nieces and nephews and I love them dearly. Working with gravely ill children around the same age can be difficult. Many children come into the hospital and never get to go home again. We Aboriginal and Torres Strait Islander people have such a special connection to land and country. It always made me sad when a child passed away and they were a long way away from their country, their community and their mob. This did not just seem unfair, it seemed quite wrong and I did not know if there was any way to make it right. I had to remind myself that life was not fair, and it was not within my capacity to ‘fix’ things that cannot be fixed. As an Aboriginal person working (and now studying) in the health system, I believed in the importance of my work, that it made a difference and this belief kept me going when I felt frustrated or overwhelmed.

Even though I have worked in health for a few years now and I have a degree and am working on my graduate degree in this field, I feel like the most unqualified person in the world to write an essay about health. I am probably one of the least healthy people I know. This is not uncommon among Aboriginal people, however. Aboriginal people in Australia have some of the very worst health statistics in the world. This naturally follows on to Aboriginal people working in the field of health. We fail to practice self-care. We fail to set boundaries. We work tirelessly for our community but neglect ourselves. This is not healthy. Aboriginal people in general tend to have more responsibilities and obligations. The importance placed upon caring for extended family, elders and children can mean that individuals neglect to care for themselves. We also have obligations to our community that must be fulfilled. Emotional wellbeing and physical health tend to reinforce each other. The majority of Aboriginal and Torres Strait Islander people in this country have experienced generational disadvantage and generational trauma, which takes a toll upon emotional wellbeing. In my (non-Indigenous) workplace, it never ceased to astound me that my colleagues rarely attended family funerals. During the same time period, I lost three siblings, four cousins and many friends. In the Aboriginal and Torres Strait Islander community there are so many deaths on a regular basis that the question is often not ‘Is there going to be a funeral this week?’ but ‘Whose funeral is it this week?’ And of course, the cumulative effect of so many deaths can be devastating for those left behind.

Likewise, the impact of chronic disease in our communities and our families is devastating. In my immediate family, there is a history of high blood pressure, arthritis and asthma. However, as in most cases, numbers form only part of the story. There are multiple meanings behind the shocking numbers in Indigenous health. Most Indigenous people have had some type of negative experience with health care. Hospitals are seen as places of death rather than places of healing and positive outcomes. I can empathise with these feelings. Hospitals in general are not Indigenous-friendly or safe. They can make me feel uncomfortable sometimes, and I grew up in an urban setting. I can only imagine how alien hospitals are to people from very remote communities. At the same time, it is important to recognise that hospitals *are* places of healing.

Non-Indigenous people need Indigenous education just as much as the reverse and we can learn a great deal from each other. These alliances ultimately benefit both parties and the system overall. It is never easy to step outside of our comfort zone, but it is sometimes necessary. When I see families from remote communities who have travelled to the city to access health care, leaving behind their home and all their support networks, to make their child well again, I am amazed at their bravery. These families cope admirably under the most trying of circumstances. They are the reason why I feel I was meant to work in health. Their strength inspired me and I believe that this is the type of strength that must be shown in order to remedy the flaws in the health care system and make it a place of cultural safety.

The Western medical model of health rarely fits Aboriginal and Torres Strait Islander people. In fact it can, and often does, actively oppress Indigenous patients and families. These differences are often emphasised when Aboriginal and Torres Strait Islander families, particularly those from remote communities, are forced to access tertiary health care. Under these circumstances, Indigenous families are isolated from their community, their culture, their extended family network and their home. This can be a terribly disenfranchising and dehumanising experience, and can lead to other issues, such as lack of compliance.

CHAPTER 2. Literature Review

2.1 Introduction

RIs in Indigenous Australian children present a serious and important health care challenge. RIs are the most common reason for presentation to general practitioners and the leading cause of self-reported ill health in this population (AIHW, 2008). To date, the majority of research concerning RI in Aboriginal and Torres Strait Islander children has been conducted in rural and remote areas (Chang, Redding &Everard 2008). This is despite the majority of Indigenous people residing in urban and regional areas (Australian Bureau of Statistics, 2010). In this review, I examine the current available literature and current gaps in literature in relation to the following topics in respiratory health:

- The importance of the Indigenous health perspective
- Indigenous identity and culture
- Indigenous constructs of health and well-being
- Indigenous concepts of risk
- How RI fits into these concepts
- Burden of RI in Indigenous children, including chronic RI and chronic cough
- Risk factors for RI in Indigenous children
- Impact of disease on Indigenous individuals, families and communities

A specific definition of respiratory illness (i.e. acute or chronic, asthma, pneumonia etc.) was not used in this thesis to avoid limiting the potential scope of information gained.

2.2 The importance of the Indigenous perspective

Stephens et al., (2006) pointed out the importance of Indigenous knowledge and the necessity of health professionals to access this knowledge, particularly with regards to successfully addressing the issues of Indigenous health:

> “Improved data for health and living conditions are needed to help create policies that lead to access to comprehensive, culturally appropriate health care services, health education, nutrition and housing. Listening to Indigenous peoples and responding to their priorities and ideas, is a crucial part of the policy equation” (Stephens et al., 2006 p. 2019).

Morgan, Slade & Morgan (1997) argued that the perspective of Aboriginal people - including notions of identity, what constitutes knowledge, and what constitutes health and wellbeing - is significantly different to that of non-Aboriginal Australians and this has had an important effect on the health care outcomes of Aboriginal people (Morgan et al., 1997). The Indigenous perspective in research concerning Aboriginal and Torres Strait Islander people and communities is also important. Historically, Indigenous peoples throughout the world, including Australia, have been the subject of exploitation and profound dehumanization in the name of research (Smith, 2010). This, coupled with the perception that research has had little benefit or positive impact for Indigenous people, has led to an attitude of extreme reluctance toward participation in further research (Gorman & Toombs, 2009). As such, research concerning Indigenous peoples “must address the needs of Indigenous people as they perceive them in a way that fits within their frame of reference” (Gorman & Toombs, 2009 p. 5) in order to be relevant.

There is a lack of research about the health of Aboriginal and Torres Strait Islander people living in urban areas. The limited studies on urban Indigenous people have found that their health needs are somewhat different to Indigenous people living in remote and regional areas (Eades et al., 2010). The 2000 House of Representatives enquiry into Aboriginal and Torres Strait Islander health acknowledged the importance of research in addressing Indigenous health disadvantage; (Health is Life’ Discussion Paper 2000) this included an increased emphasis on investigating the health needs of Indigenous people in urban areas. The Australian government’s stated goal is to close the gap between Indigenous and non-Indigenous health outcomes by 2020 (Eades et al., 2010). It is unlikely, given their differing health needs, that a model of healthcare that works well for Indigenous people in a remote community would be as effective for Indigenous people living in urban communities (Chang et al., 2009), which underscored the importance of further research into the health needs of urban Indigenous people. Indigenous people in urban settings largely do not have to deal with the lack of basic infrastructure (appropriate housing, access to transport, access to health services, access to employment and education) that are common in remote and rural

Indigenous communities, and which impact on the health of Indigenous people in these communities.

2.3 Indigenous identity and culture

As stated by Eckerman et al. (2006): "Identity is an individual's very being – his or her essence, self-image and awareness – based on cultural, social, economic and political traditions" (p 71). Indigenous identity in Australia was once defined by legislation and was determined according to skin colour and perceived quantum of 'native blood'. It was presumed that Aboriginal children with lighter skin were more likely to fully assimilate into the non-Indigenous community (Brown, in Chang & Singleton, 2009). The modern definition of Indigenous status has become fraught with political and social complexities, even though the definition is no longer controlled by government (Stephens et al., 2006).

The politics of identity are closely associated with the possession of power. In Australia, the non-Indigenous have historically wielded great power in defining who is considered Indigenous and who is not. A 'hierarchy of authenticity' has traditionally been employed to divide Indigenous people, and this is still evident today. Skin tone, location (rural or urban) and level of education/employment are all used to assess the 'authenticity' of Indigenous people, which many Indigenous people find offensive (Maddison, 2009). bell hooks[1] (1990) argues for a racial identity that rejects assimilation and constructs a radical black subjectivity. She states that vital to radical black subjectivity is the fundamental notion of racial identity being determined by the colonised, rather than the colonisers.

Morgan et al., (1997) argue that the holistic definition of identity for Aboriginal Australians is impossible to separate from nature and the land; forced dispossession of the land has led to alienation, identify confusion and self-destructive behaviour in Indigenous peoples (Morgan et al., 1997). Psychologist Carl Jung believed that the uprooting of groups of people from their homelands and herding them together presented a danger to the psyche which could lead to an inferiority complex and a loss of balance (Jung, 1970).

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[1] Author's spelling

Advocates of racial assimilation state that in order to successfully access employment and educational opportunities, Indigenous people need to abandon their culture and traditions and embrace Western values and beliefs (Dockery, 2010). Many Indigenous people, however, insist not only that they can retain cultural traditions and also be successful according to Western standards, but that they must retain their culture and values in order to succeed. They view their cultural values and traditions as sources of strength and sustenance in an often-hostile non-Indigenous community (Behrendt, 1994). Studies show that for Indigenous people, the maintenance of links to culture is associated with enhanced socioeconomic indicators. This indicates that, for Indigenous people, maintaining a connection to Indigenous culture, including Indigenous values, provides advantages rather than deficits (Dockery, 2010).

2.4 Indigenous constructs of health and well-being

The traditional Western biomedical model of health has conceptualised the human body as made up of many different working parts that allow the whole to function with success. Under this model, when illness or injury occurs, it is necessary to isolate and treat the appropriate part in order to ensure the effective operation of the body once more (Carson et al., 2007). This concept is at odds with Indigenous definitions of health, which usually incorporates aspects of emotional, spiritual, familial and communal wellbeing alongside the physical state (Stephens et al., 2006). All of these aspects are considered vital to the maintenance of health and wellbeing and none can be considered in isolation (van Holst Pellekaan & Clague, 2005).

The philosophy of Indigenous people (e.g. their beliefs about their knowledge and reality, their values) can have a profound effect on their relationship with health care providers, including their reluctance to utilise non-Indigenous/mainstream health services (Morgan et al., 1997). The clash between these different belief systems has had a negative impact on the experiences of Indigenous people in the mainstream health care system, which has continued. Negative experiences of mainstream health care have made Indigenous people reluctant to engage with the system, which can affect issues such as compliance (Eckerman et al, 2010). The health of Indigenous people can also be negatively impacted by isolation from any aspect of their cultural identity, such as the loss of connection to land and loss of language (Chang & Singleton, 2009); this may be particularly pertinent for Indigenous people living in urban communities. However, there has been little research in this area. Therefore, further investigation into the health beliefs of Indigenous people, particularly urban-based Indigenous people, is vital to determine how they impact upon Indigenous people's experience of health care.

2.5 Indigenous Concepts of Risk: social or cultural determinants of health

The Australian Institute of Health and Welfare (AIHW) defines risk as "(factors) associated with ill health, disability, disease or death". They divide risk factors into categories of: behavioural, biomedical, environmental, genetic and demographic.

The Western biomedical concept of risk has placed the individual at the centre of interventions designed to prevent and manage chronic disease (Mitchell, 2012). The concept of risk, however, has been constructed within the context of political and social power. It is constructed to privilege the beliefs and values of the dominant culture at the expense of minority groups (Sunday & Eyles, 2001). A criticism of this type of framework is that it has pathologised individuals and/or minority groups and failed to take into account structural inequalities and cultural differences (Mitchell, 2012). This is significant as studies show that Indigenous peoples often perceive their health as being adversely affected by (among other factors) racism, the effects of colonisation, chronic stress and inequality (Lui & Alameda, 2011; Purdie et al, 2010).

In their study of Canadian First Nations peoples' attribution of meaning to diabetes, Boston et al (1997) found that Indigenous Canadians linked the prevalence of diabetes in their communities to the decline of the traditional lifestyle. They concluded that it was imperative for preventative interventions for diabetes to be based around Indigenous cultural knowledge and lived experiences (Boston et al, 1997). Wexler et al (2013) argue that failure to include the perspectives of Indigenous peoples when looking at their health risk factors can lead to potentially undesirable consequences, including the formulation of interventions that are not appropriate or relevant for Indigenous people (Wexler et al, 2013).

Mitchell (2012) stated that as the ideologies of the Western biomedical system, including the concept of risk, are often incompatible with Indigenous concepts of well-being and Indigenous culture; the management of chronic disease in First Nations peoples can be more appropriately framed by the employment of a social justice framework. The social determinants of health framework are focused on the conditions of health (e.g. inequality, poverty, stressful living conditions, marginalisation etc.) rather than the behaviour of individuals (Mitchell, 2010). Thus, proposed changes are centred at a structural, rather than an individual, level. Therefore these issues are moved outside of the realm of Western biomedicine and into a social context (Mitchell, 2010). In the area of RI, Moore et al (2010) noted the high numbers of Australian Indigenous children suffering acute lower respiratory infections (ALRI) and the lack of studies specifically examining the risk factors for ALRI in Indigenous children. The authors argue that while some identified risk factors for Indigenous children with ALRI are amenable to prevention (e.g. parental smoking), some risk factors (e.g. number of mother's previous pregnancies) are not; therefore interventions need to include addressing structural factors such as education, housing and access to health services (Moore et al, 2010).

However, Brown (2013) has argued that the employment of a social determinants approach to health and wellbeing is also not appropriate for Indigenous peoples as it utilises an approach that focuses on weaknesses and disadvantages rather than strengths. She has theorised that it is more fitting to employ a cultural determinants of health perspective. An approach that focuses on the cultural determinants of health approach would include viewing health in the context of:

- Self determination
- Freedom from discrimination
- Individual and collective rights
- Freedom from assimilation and destruction of culture
- Protection from removal/relocation
- Connection to, custodianship and utilisation of country and traditional lands
- Reclamation, revitalisation, preservation and promotion of language and cultural practices
- Protection and promotion of Traditional Knowledge and Indigenous Intellectual Property
- Understanding of lore, law and traditional roles and responsibilities (Brown, 2013)

Brown has argued for a greater focus on resilience. Historically, resilience has been a positive and powerful characteristic of Indigenous people and communities (Brown, 2013). It provides evidence of the ability of Indigenous peoples to endure in the face of the most extreme adversity and the direst of circumstances. In the present context, resilience can assist encourage positivity and success, increase social capital and strengthen Indigenous communities. Therefore, the promotion, and celebration of Indigenous resilience can only benefit Indigenous peoples and communities (Brown, 2013).

However, the adoption of a cultural approach to the determinants of health must also involve an honest examination of those aspects of culture that have the potential to have a harmful effect on the health of individuals. In Australian Indigenous culture, this may involve an examination of: the widespread acceptance of tobacco use; the unquestioning acceptance of traditional narratives (e.g. the view of hospitals as places of death rather than places of healing) that may be factually untrue and unhelpful; the kinship obligations which can necessitate that individuals neglect their own health in order to maintain the health of the collective and; the perpetuation of beliefs and behaviours that may exacerbate cross-cultural misunderstanding and miscommunication.

2.6 How RI fits into this construct

There is a lack of literature exploring how RI fits into the Australian Indigenous construct of health and wellbeing. There is however some international literature on this subject. Petersen, Singleton and Leonard (2003) conducted a qualitative study of community members and health care providers in rural Alaska about chronic RI in First Nations Alaskan children. The researchers interviewed 22 participants, including eight community members (First Nations parents of children with RI), and 14 health care providers. The majority of participants agreed that acute and chronic RI in children was the most serious, common and important health issue in their communities. The majority of First Nations interviewees mentioned the move toward Western practices (e.g. bottle feeding of babies) and away from cultural traditions (e.g. breastfeeding) as a possible contributor to chronic RI in children.

> “There was a time when we were told to live like Western people. That’s when the parents stopped breastfeeding and started using bottles. Then the little kids had more earaches and more respiratory problems because they just gave them a bottle and let them lie down” (interviewee quote from Peterson et al., 2003)

Interviewees also linked the prevalence of asthma and coughing in children to exposure to other aspects of modern life, including second hand smoke from cigarettes, dust from the construction of gravel roads and mould in modern housing (Peterson et al., 2003). One participant linked the increased prevalence of allergies in the community to climate change, which they felt had made the climate warmer and caused the growth of unfamiliar types of plants.

Overall, the First Nations community members and the health care providers proposed different actions that might lower the high rates of RI in the community's children. Community members proposed improvements in the speed and accuracy of diagnosis of RI. Healthcare providers proposed improved education of the community about RI, improved compliance and increased supervision. The perception of health care providers was that the First Nation community members accepted RI in their children as normal and were slow to seek treatment.

There have also been some Australian studies that explore how Western practices/systems and Indigenous cultural traditions have impacted upon each other in the area of overall health and wellbeing for Indigenous people. Thompson, Gifford and Thorpe (2000) conducted an ethnographic mixed methods study of Aboriginal people with diabetes about their attitudes and beliefs regarding the cultural and social contexts of risk and prevention of diabetes. The study (conducted out of two Aboriginal community-controlled organisations in the urban area of Melbourne, Victoria) consisted of in-depth interviews with 38 participants, focus group and small group discussions with 19 participants and participant observation. The results illustrated that the health risks associated with diabetes in urban Aboriginal people were inseparable from the unique social and cultural risks of disconnection from family, the land and the past (Thompson et al., 2000).

In other words, health for Aboriginal people has social contexts and meanings that must be considered in the formulation of interventions and treatments for Indigenous people. For Aboriginal people residing in urban settings, culture is not considered an abstract concept but a vital component of everyday life. Culture in this context refers to (among other things) the maintenance of connections to land and the past, the extended kinship system, complex social obligations and values that emphasise the importance of the collective over the needs of the individual. The fulfilment of social and kinship obligations and the maintenance of the collective wellbeing remain vitally important to urban Aboriginal people. Aboriginal people view activity undertaken for the sole benefit of the individual as shameful and disconnecting. Participation in collective activities, on the other hand, is viewed with approval, as they are seen to benefit families and improve the collective wellbeing of the community (Thompson et al., 2000). Therefore, any health interventions which targets Aboriginal people must take into account the connection Aboriginal people have between their personal health and ties to family, community, the land and the past (Thompson et al., 2000).

2.7 Impact of disease on individuals, families and communities

There is a gap in the literature regarding the impact of chronic disease upon Australian Indigenous families, individuals and communities from an Indigenous perspective. Saggers and Gray, writing in Carson, Dunbar, Chenhall & Bailey (2007) point out how Indigenous peoples in Australia have viewed their lack of health in the context of factors such as poverty, racism, dispossession and marginalisation (Carson et al., 2007). In their study of Australian Aboriginal people with diabetes, Morgan and Morgan (1997) argue that there is a strong link between the health of individual Aboriginal people and their social and kinship obligations. Thus the Aboriginal patient is far more likely to be invested in treatment and recovery if these are shown to improve their ability to fulfil social, kinship and spiritual obligations. On the other hand, Aboriginal patients are more likely to refuse or discontinue treatments that have a negative impact upon their social, kinship and spiritual obligations (Morgan & Morgan 1997).

Walter and Saggers, cited in Carson et al. (2007) point out that while the prevalence of poverty among Indigenous people is difficult to deny, the link between Indigenous poverty and the poor health of Indigenous people has yet to be established; but that this is likely to be due to the current lack of culturally appropriate models of social determinants of health. Existing models of the social determinants of health (which are non-Indigenous) have not been adequate to accurately gauge the relationship between Indigenous poverty and Indigenous health (Carson et al., 2007) as they do not account for cultural factors. Cultural safety in Indigenous health care must, however, include evidence-based interventions and solutions, including research-based solutions such as the collection of more accurate data about the health needs of Indigenous people, and the inclusion (where possible) of an Indigenist research methodology (Horton, 2006).

Too often, particularly in the hospital setting, the impact of disease is referred to social workers to case manage. However this presents several problems for those with complex health and social circumstances that need long-term management. In a study of patient and family experiences of social work in a hospital setting, Lord and Pockett (1998) found that patients and families wanted social workers to provide support from the point of admission, and for that support to be continuous:

> "Comments from clients in this study suggest that the continuity of the relationship with the social worker was just as important as the completion of a specific range of tasks" (Lord & Pockett, 1998, p497)

The authors also noted the inconsistency of hospital social work support. While some clinical areas (e.g. oncology) received ongoing social work support, others did not. The nature of social work in a hospital setting is often crisis-driven, due to heavy caseloads and staff shortages. In their study of social work interventions in a large tertiary facility, Evans et al (1989) noted that social workers were commonly referred the patients with the most serious psychosocial and medical issues (e.g. multiple problems and risk factors). However, the role of social workers in a physician-dominated hierarchy creates tension between choosing what fits with social work values and the demands placed on their roles that are too often centred on individual problems (Rushton, 1987).

The complex medical needs of Indigenous patients with chronic disease may result in their spiritual, cultural, emotional and social needs being overlooked. A referral to a hospital social worker at the time of an acute admission may not be sufficient to address these problems and multi-disciplinary approaches and detailed post-discharge care plans are likely to be required.

2.8 Burden of Respiratory Disease in Indigenous Children

Lower respiratory diseases, acute and chronic, are predominant causes of morbidity and premature mortality across the lifespan in the Australian Indigenous population. Respiratory conditions are the most common reason for attending a general practitioner, the 2nd most common self-reported cause of ill health and reason for hospitalisation and the 4th leading cause of death (AIHW, 2011) Chronic respiratory diseases rank 4th as a cause of disease burden overall in this population (AIHW, 2011).

Disproportionately high rates of hospitalisations for ALRI occur in Indigenous Australian children, irrespective of urban or rural/remote residence (O'Grady & Chang, 2010). They account for the greatest number of hospitalisations in Indigenous children aged less than 5 years (AIHW, 2011). Indigenous children in Central Australia have the highest documented rates of hospitalisation for ALRI and radiological-confirmed pneumonia yet reported worldwide. (O'Grady, Taylor-Thompson, Chang, et al., 2010; O'Grady, Torzillo & Chang, 2010). In Western Australia an estimated 14.2% of Indigenous children present at least once to an emergency department for ALRI before 5 years of age compared to 6.5% of non-Indigenous children (Moore, 2012). In some remote Indigenous communities, ALRI is the 3rd most common reason for presentation to the local health centre in the first year of life,(Kearns, Clucas et al, 2013) equivalent to presentations for ear disease. Despite the burden there are no community-based studies that have specifically or comprehensively examined the risk factors for, and impact of, RI from an Indigenous perspective.

An acute RI may bring to medical attention for the first time those with chronic underlying disease. Chronic wet cough is important as it is the most common symptom of bronchiectasis (Chang, Bell, Byrnes et al., 2010) and earlier diagnosis and treatment improves long term outcomes. (Chang, Bell, Byrnes et al., 2010) Chronic lung disease in Australia's Indigenous children is a major public health concern. The prevalence of bronchiectasis in Central Australian Indigenous children is approximately 1500 per 100,000 (Chang et al., 2002) and associated with repeated respiratory infections in infancy (Chang et al., 2003). The incidence of first hospitalisation for bronchiectasis in the first year of life in these children is 2 per 1000 child-years and 1.2 per 1000 child years for NT infants overall (O'Grady et al, 2011). The median age at admission for the first diagnosis is 8.5 months (IQR, 4.1–10.2 months) (O'Grady et al, 2011). In Queensland Indigenous children aged less than 5 between 2005 - 2009, the average annual age-standardised hospitalisation rates for bronchiectasis were 3 times higher than non-Indigenous children (45.9 vs 14.9 per 100,000 per year) (O'Grady, Revel et al., 2011). Over that time period bronchiectasis hospitalisation rates for Indigenous Queenslanders increased from 125 to 200 per 100,000 populations per year (O'Grady, Revel et al., 2011). A major limitation of those data however is that it is unknown if the increases were due to better reporting of Indigenous status, improved access or more disease.

In their study of bronchiectasis in Indigenous children in remote Australian communities, Chang, Grimwood, Mulholland and Torzillo (2002) noted the under-reporting of cough in Indigenous children and the sometimes hidden significance of the burden of respiratory disease amongst Indigenous Australians. The true prevalence of bronchiectasis and associated RI in Indigenous children in Australia is unknown, but is likely to be disproportionately high in rural and remote communities. However, there are limited resources available to manage these patients, and the perception that RI in this population is inevitable and largely unpreventable (Chang et al, 2002). To improve outcomes for Indigenous children with bronchiectasis, Chang et al (2002) recommended the encouragement of early diagnosis of bronchiectasis; the optimisation of medical management to reduce morbidity and preserve lung function; the promotion of public health issues and healthcare delivery. Their final recommendation included the establishment of a culturally appropriate model of healthcare and a coordinated approach among health care providers that recognises the social determinants of health (Chang et al., 2002).

There are limited data regarding upper and lower RI in urban Indigenous children, which makes it difficult to make a comparison with Indigenous children in rural and remote communities. Chang, Chang, O'Grady and Torzillo (2009) theorised that the high rates of Indigenous children with chronic upper and lower RI were more likely to be due to factors associated with poverty and remoteness, including limited access to hospitals and medical resources, rather than cultural or racial identity. They pointed out that initiatives to reduce the burden of RI in Indigenous children must include addressing these socioeconomic factors (Chang et al., 2009).

2.8 Risk factors for respiratory disease in urban Indigenous children

There are limited data on the risk factors for respiratory disease in Australian Indigenous children in urban settings, particularly how they pertain to cultural factors (Chang, et al. 2009). Moore et al., examined administrative data in Western Australia and identified some risks for ARI hospitalisation in infancy, including male gender, autumnal birth, gestational age, maternal smoking during pregnancy, remote location and low socio-economic indices (Moore et al., 2012).

In their study of bronchiectasis in Indigenous children in remote communities in Australia, Chang et al., (2002) stated that the risk factors for ALRI included inadequate water supply, macro and micro malnutrition, damp housing and overcrowded housing (Chang et al., 2002). They identified a link between Indigenous health and socioeconomic factors, and stated that improvements in employment, housing, education and nutrition would assist in the prevention and management of acute lower respiratory tract infections. Their recommendations included the implementation of a model of care that was culturally appropriate and recognised the impact of socioeconomic factors (Chang et al., 2002). In their study of associations between common childhood illnesses, housing and social conditions in remote Australian Aboriginal communities, Bailie, Stevens, McDonald, Brewster & Guthridge (2010) pointed out that poor conditions and overcrowding can both increase the likelihood of infection and increase levels of stress among occupants. They also noted the psychosocial and socioeconomic factors experienced by parents/carers that can have a negative impact on the health of children, and the importance of interventions that target these areas (Bailie et al., 2010). The above data above are derived from predominantly quantitative studies that do not account for the complexities of Indigenous culture and values and how these factors can impact upon the health of Indigenous children and families. These studies did not include an examination of the perceptions of parents, caregivers or family members of Indigenous children with RI. Therefore data are dominated by a medical focus that does not account for an Indigenous perspective.

2.9 Conclusion

Indigenous constructs of health and wellbeing take a holistic approach in which the individual is viewed in the context of their family, culture, community and history. This approach has differed to the traditional Western approach to health, which has tended to treat the individual and their illness in isolation from their life circumstances. Indigenous people consider their individual health inseparable from the health of their family and community, and this philosophy has an impact on health care outcomes for Indigenous people. The health and wellbeing of Indigenous people can be negatively affected by the clash between their traditional cultural values and ideals and the traditional biomedical views and/or practices dominant in mainstream health care. There has been a lack of research into the health beliefs of Aboriginal and Torres Strait Islander people, particularly those in an urban setting. This is significant in that these beliefs can differ starkly to those held by the non-Indigenous majority. An understanding of Indigenous knowledge and beliefs around RI is of particular importance not simply because RI is such a serious illness in the Aboriginal and Torres Strait Islander population. The utilisation of Indigenous knowledge and beliefs has the potential to improve prevention, management and compliance of RI in the Indigenous population. The health beliefs of Indigenous people can impact how they access health care services and how they experience health services. These factors are vital in the successful management of illness (Purdie, Dudgeon & Walker, 2010).

2.10 Overall Aims and Objectives

Aim:

This study aimed to inform the development of future research and interventions by gaining an understanding of Indigenous contexts and perceptions of risk for RI in Indigenous children. Specifically, we aimed to examine the cultural context and risk factors of Aboriginal and/or Torres Strait Islander children with acute and chronic RI in an urban setting.

Primary objective:

The primary objective of this study was to explore risk for RI as perceived by the parents of young Aboriginal and/or Torres Strait Islander children from within an Indigenous context.

Secondary objective:

A secondary objective of this study was to explore the impact of RI in urban Aboriginal and Torres Strait Islander children on families and communities from within an Indigenous context

Specific Research Questions

1. What are the meanings and consequences of RI, and the associated risk factors, in urban Indigenous children within the social and cultural context of Indigenous families and their communities?
2. What is the impact of RI amongst urban Indigenous children and their families, including individual, family and community impacts?

CHAPTER 3. METHODS

3.1 Introduction

My research plan encompassed a qualitative study that aimed to provide a comprehensive picture of the risks and impacts of RI in urban Indigenous children, their families and communities, from within an Indigenous framework and from the point of view of an Aboriginal researcher. The qualitative approach seemed appropriate for several reasons. Firstly, it is a culturally appropriate and culturally safe research method to use with Indigenous participants, as narrative/storytelling is an integral part of Indigenous knowledge sharing. The narrative/storytelling approach is but one approach to qualitative research (Patton, 2005). From my point of view, however, this approach fostered a more equitable relationship between researcher and participant, as it allowed the participants to have a greater degree of control over their contribution to the research. The qualitative approach also provided a richness and texture of data that cannot be easily accessed by quantitative methods.

From a clinical perspective as a social worker in a tertiary health setting, I have found that privileging the lived experiences of people can be an important tool in understanding their perspective, building relationships of trust and attaining positive outcomes. Freeman (2011) in discussing the use of narrative therapy in social work practice, points out that people's narratives are shaped by their cultural, familial and community contexts and "are a mechanism for clients to manage their current life transitions and their recurring unresolved issues'' (Freeman, 2011 p. 9-10). The author suggests social work practitioners use narrative therapy in order to externalise and deconstruct client issues. Assisting marginalised members of society to articulate their experiences can subvert the narrative of the dominant culture which deliberately suppresses the voices of the marginalised and frames issues as attributable to individual dysfunction rather than ingrained social inequities (Freeman, 2011).

3.2 Insider and Outsider Perspective

My standpoint as a researcher is as both an insider and an outsider: insider due to my connections with the urban Aboriginal and Torres Strait Islander community in Brisbane and also outsider, due to my Western education and current position in research. To this I would add my sensibilities as a social worker with a reflexive, humanist, feminist, social justice and Indigenist framework. My reflexive social work perspective has included a structural analysis of social issues that rejects the attribution of disadvantage to individual dysfunction; engagement in critique of socio-political institutions; and mindfulness of the way professions (e.g. social workers, medical professionals, researchers) who work with the disadvantaged can unwittingly perpetuate inequity and function as agents of social control (Fook, 1993). Reflexivity is usually associated with radical social work practice but it can also be a highly useful concept in the context of research with Indigenous peoples. In lieu of the term 'reflexivity' some Indigenous researchers prefer to use Dadirri (a word from the language of the Ngangikurungkurr people), which refers to an Aboriginal -specific philosophy that shares many characteristics of reflexivity. Dadirri has been described as encompassing spirituality, deep listening, stillness, awareness, trust, reflection and observation of the self as well as the other (Atkinson, 2002; West, Stewart, Foster & Usher, 2012). All of these elements make Dadirri a culturally appropriate approach to use in Indigenous research methodology:

> "For the researcher, it encompasses practices that recognise the crucial role of the community; reciprocity, where both the participants and researcher share with each other something of themselves; and the trust of the people in the other person" (West et al., 2012, p 1584).

When I refer to an 'Indigenist' framework, this refers to my conscious choice to privilege the traditional culture and values gifted to me by my family, functioning in the modern urban environment in which I live/work and accessing the many opportunities available. I share the convictions expressed by Larissa Behrendt (2005) and other prominent urban Aboriginal people, in that I view the retention of Aboriginal culture, values and communities as sources of strength. Indigenous peoples have survived by our ability to adapt to change without compromising our connections to our values, culture and community. My social justice framework means that I believe in equity, social justice and equality of opportunity. My philosophy strives to respect difference and value diversity. It is this belief in social justice that drew me to social work initially and then to Aboriginal and Torres Strait Islander health. My firm conviction is that health and wellbeing – or the lack thereof - is the most important challenge facing the Aboriginal and Torres Strait Islander community. Without a reasonable degree of good health, Aboriginal and Torres Strait Islander peoples face an uphill battle to access employment, education or any other opportunities for advancement.

As stated by McCleland (2011), “Every methodology provides a lens by which the research question of the proposed study can be developed to provide answers in a distinct way” (p 365). My research methodology incorporated (as much as possible) Indigenous culture and values including reciprocity, knowledge sharing and the creation of a cultural safe space. In practical terms, this amounted to a series of tasks and actions, including (but not limited to): seeking the guidance of community Elders; networking and forging connections with other Indigenous people (not just Indigenous researchers but also community members); sharing information about the research project; and honouring community protocols while conducting the research. These actions were not completed and then ‘ticked off’ in a linear fashion. As is often the case when working with Indigenous peoples and communities, progress was often delayed as actions or tasks had to be repeated, previous plans modified or discarded completely, new approaches devised and put into action.

The employment of an Indigenous research methodology also included an exploration of the cultural context of RI and the lived experiences of Aboriginal and Torres Strait Islanders with these illnesses. Issues experienced by Indigenous peoples are complex and multifaceted but, as McCleland (2011) noted, they are unlikely to be understood, let alone successfully approached, from a mainstream or non-Indigenous standpoint.

The Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (NHMRC, 2003) provide a research paradigm that defines the responsibilities of the researcher as far as ensuring cultural integrity and respecting the values of Aboriginal and Torres Strait Islander communities (Prior, 2007). These values include reciprocity, cooperation, the establishment of mutual trust and mutual respect and the adherence to community protocols (Prior, 2007). These values guided this research.

Indigenous members of the research team had pre-existing cultural and family links to the communities where focus groups were held. Even with these pre-existing links, research in these communities still involved negotiation, consultation and observation of community protocols. Negotiation and consultation meant meeting with Elders groups and community members and communicating openly with them. It is part of protocol for the community to be kept informed regarding the nature of the research; what the research will be used for; how the research findings will be fed back to the community, and; the credentials and background of the researchers. The conduct of research in Indigenous communities is extremely important. Researchers must be open and transparent not only about the research but also about themselves. When in Indigenous communities, it is important for researchers to be of good character and demonstrate respect, with a humble attitude to everyone. Inappropriate or unethical conduct by researchers in Indigenous communities is considered a mark of disrespect not just to the individuals involved but to the community as a whole (Martin, 2006; Phillips, 2003).

My approach to this research was to not position myself as an expert or authority in this area but as a student eager to learn from the experiences of Elders and community members. The observation of community cultural protocols meant that the community set the pace of actions and negotiations. Communities often have their own internal issues to deal with and research is (understandably) not an important priority. This meant team members were often required to practice patience and gentle persistence in the attempt to arrange focus group sessions. The research team had to be flexible and patient in terms of time. Following Indigenous traditions of introduction, Indigenous members of the research team informed participants of our backgrounds, including where our families originated from and who our 'mob' or language groups are. During the focus groups, discussions were respectful, informal and good-humoured. The Indigenous cultural tradition of storytelling or 'yarning' was fully employed by participants as they related their lived experiences with RI and mainstream health services.

3.3 Methodology

3.3a Theoretical background of method used

This study was designed from a narrative discourse perspective. The concept of using personal narrative as a therapeutic method is well established in social work theory and practice (Freeman, 2011). Telling their story is vital to the process of healing for the individual concerned. Sharing stories can promote mindfulness, human connection, and caring. It can also be an expression of trust. As a research method, it is extremely useful as it allows valuable insights into people's lives and personal experiences (Reich, 2011). Narrative discourse can also provide detailed and multi-layered data on the research topic (Bird et al., 2008).

In order to achieve the aims of this research, focus groups were chosen as the method to access the lived experiences of Aboriginal and Torres Strait Islander peoples and to privilege the voices of Aboriginal and Torres Strait Islander peoples. As illustrated in the literature review about Aboriginal peoples managing diabetes (Thompson et al., 2000), Indigenous peoples tend to place a higher value upon collective and reciprocal activities that are seen to benefit the community rather than the individual. I therefore felt that focus groups, or yarning groups as they are known in the Indigenous community, were more culturally appropriate and culturally safe and that the participants were more likely to feel at ease in a group situation, considering the importance of the collective and the community in Indigenous culture. Being from the same communities, the majority of participants were already familiar with each other prior to the yarning group sessions. Yarning or (yarning up) is an Australian Aboriginal term which refers to "an informal and relaxed discussion through which both the researcher and participant journey together visiting places and topics of interest relevant to the research study" (Bessarab & Ng'andu, 2010 p 38). Yarning is the traditional Australian Indigenous way of exchanging knowledge and information. It is collaborative, reciprocal, informal and characteristically non-linear. The Indigenous oral tradition of storytelling/yarning ensured the communication of practical as well as cultural/spiritual information between the generations (Bessarab & Ng'andu, 2010).

Prior to the beginning of the focus group sessions, it was necessary for the researchers and participants to engage in social yarning:

> "Social yarning...is about establishing a connection by sharing information about you as the researcher. In identifying who you are in the research process the relationship shifts from expert to person to person, enabling a more real and honest engagement as researcher and participant" (Bessarab & Ng'andu, 2010).

Social yarning in this instance incorporated the Indigenous tradition of introduction, which consisted of the exchange of cultural information, such as the identification of one's family and extended kinship group, traditional lands and home community. Social yarning is valuable not only for the purposes of introduction but also for the establishment of boundaries and trust (Bessarab & Ng'andu, 2010).

Some of the limitations of focus groups include the possible suppression of more detailed stories and the potential for suppression of participant's personal/sensitive information in a group situation (Stewart, 2007). Other challenges include managing the yarning session effectively without offending individuals, breaching cultural protocols or disrupting the flow of conversation. This includes knowing when and how to close the yarn in a respectful and appropriate way. Similarly, in a yarning session, the storyteller, not the listener, controls the content and pace of the yarn. The challenge for the researcher is to ensure that the yarn remains relevant to the research question (Bessarab & Ng'andu, 2010). Yarning, particularly group yarning sessions, can often produce large amounts of data that is time consuming for the researcher to transcribe and analyse (Bessarab & Ng'andu, 2010). Another negative aspect of focus groups as a data collection method is that participants may inadvertently move away from discussing the topic at hand and onto subjects that have little relevance to the research questions and it is the responsibility of the facilitator to ensure that the discussion remains somewhat focused (Bessarab & Ng'angu, 2010). I remained mindful about reflecting on my own performance as a facilitator. Following each focus group, I checked my perceptions by discussing with the other researchers how they thought the session had gone. These debrief sessions were useful not only in putting past focus groups in context but in planning for subsequent groups.

In support of the use of focus groups, I was very grateful to have my social work background, particularly my training and experience in counselling and active listening. Active listening appears simple but is quite difficult and takes considerable time to master. It involves (a) listening to what the other person is saying (b) assessing the underlying message by examining tone, content, body language and (c) formulating and voicing a non-judgemental response which encourages the other person to openly express their thoughts/emotions and explore the topic in more detail. Part of this is checking that you have correctly understood what the participant is saying by reframing their message and repeating it back to them. All of this has to be done simultaneously and without disrupting the flow of the conversation (Freeman, 2011). Trigger questions were used as prompts and points of reference. Participants were interrupted as little as possible. My rationale was that if a participant was telling a story, that story must be extremely important to them, even if it appeared to have little relevance to the research topic/question. Listening without interruption is a sign of respect, not just for the individual but for their stories, and it assists with the establishment of mutual trust. I wanted participants to feel free to tell their stories at their own pace and feel in control of the process. Interruptions, when required, were undertaken in a respectful and culturally appropriate way (e.g., sincerely thanking the speaker for their contribution).

From my clinical experiences working with Aboriginal and Torres Strait Islander families I was aware that conversations rarely follow a conventional narrative. Conversations with Indigenous peoples often go in many different directions and cover different topics. People usually prefer to take their time and not rush. Interactions with Indigenous peoples require sensitivity, patience, respect, tolerance, good humour and flexibility. In my clinical practice, my goal is to make Indigenous families as comfortable as possible. The interior setting of the hospital can be intimidating and sterile and make Indigenous people uncomfortable. Therefore, when yarning, I engaged with families outside in the open as much as possible. Interactions always involved an informal exchange of information. I endeavoured to be as transparent as possible about my research project. I examined non-verbal cues and body language. It involved noting not just what people said but how they said it. I took my cues from participants. Trigger questions were open-ended (rather than closed) in order to encourage discussion of the topic.

The offering and sharing of food and drink is an integral part of yarning and Indigenous protocol, as is the acceptance of the presence of children and support persons. Again, this is part of making people as comfortable as possible and fostering a relaxed and informal atmosphere. When employed as a research method, yarning is informal and interactive yet semi-structured, with set questions used to encourage the discussion and 'start' and 'end' points for the sessions (Roe, Zeitz & Fredericks, 2012). It involves the establishment of a relaxed interaction between researchers and participants where information is exchanged in an informal manner (Bessarab & Ng'angu, 2010). The interaction between the facilitators and participants was a conversational exchange of information but as the facilitator I was responsible for asking the questions and leading the interaction.

3.3b Setting and overall approach

I conducted four focus groups with members of Aboriginal and Torres Strait Islander communities. The communities chosen for the focus groups were all large urban Brisbane communities (Table 1) with strong elements of multiculturalism. I chose these communities because: (a) Indigenous members of the research team had pre-existing links to the communities; and, (b) the communities all have a vibrant and visible Aboriginal and Torres Strait Islander population. As such, these groups are good examples of urban Indigenous communities.

Table 1: Indigenous population of Brisbane communities selected for focus groups

SUBURB	TOTAL INDIGENOUS POPULATION*	% of TOTAL POPULATION	MEDIAN AGE NON-INDIGENOUS	MEDIAN AGE INDIGENOUS
South Brisbane	5,416	0.8%	38 years	30 years
Woodridge	12,787	5.1%	30 years	18 years
Deception Bay	19,672	4.2%	34 years	17 years
Redcliffe	9,201	2.0%	44 years	21years

Source: Australian Bureau of Statistics - (2011 Census)

3.3c Study participants

These were parents/ guardians/carers of Indigenous children and other adult members of the Aboriginal and Torres Strait Islander urban community in the greater Brisbane area who have had experience of caring for children with RI. In accordance with Aboriginal and Torres Strait Islander cultural traditions, other members of the community (i.e. Elders) participated as support people for the yarning sessions. A specific definition of respiratory illness (ie acute or chronic, asthma, pneumonia etc) was not used to avoid limiting the potential scope of information gained.

Inclusion Criteria

All participants must have:

- identified as Aboriginal and/or Torres Strait Islander
- had experience in caring for children with RI
- been aged over 18 years
- provided written and informed consent

Exclusion Criteria

No exclusion criteria applied

3.3d Recruitment Processes

Participants were recruited via personal and community contacts, networking with local Indigenous community groups and individuals, distribution of flyers promoting the focus groups, and word of mouth in communities. An important part of the recruitment process consisted of community consultation with groups and individuals. This involved going out into the communities, liaising with Elders and other community members, having formal and informal meetings with Elders groups in the community, attending interagency meetings in the communities, disseminating information about the study to individuals and groups in the community, and meeting with Indigenous-specific medical services in the communities. This was a time consuming but necessary process, as it was vital to have community clearance prior to commencing focus groups. It was also necessary to be transparent about the research project, the process and about ourselves as researchers.

The research team established an Indigenous Research Reference Group (IRRG) comprising of Aboriginal and Torres Strait Islander Elders and community members. The IRRG provided advice and guidance about cultural matters, including community protocol and disseminated study information to the rest of the Indigenous community. Members of the research team also had ongoing and direct contact with Indigenous community organisations, including Elders groups, other service providers in the community and individual community members.

3.3e Ethical Clearance and Informed Consent

The study was conducted according to the NHMRC criteria for the ethical conduct of research in humans and the NHMRC Statement on Values and Ethics in Aboriginal and Torres Strait Islander Research (2003). The study protocol, information statements, consent forms, advertising materials and all other required documents were submitted to and approved by the Queensland Children's Health Services Human Research Ethics Committee (HREC/12/QRCH/169) and the University of Queensland Behavioural & Social Sciences Ethical Review Committee (2012001237). .

Informed consent processes were consistent with the principles of the Declaration of Helsinki (1964 – amended in 2013) and the NHMRC requirements. Informed consent was obtained from every participant. Information about the study was provided in written formats in language fully comprehensible to the potential participant. The study was explained to the participants face-to-face and they were provided with sufficient time to ask questions, discuss participation with relevant others and obtain further study details prior to signing and dating the informed consent form. Copies of the information statement and informed consent form were provided to the participants. Copies of these documents have also been kept on file at the Queensland Children's Medical Research Institute (QCMRI).

3.3f Data Collection

Focus groups were held in locations across Brisbane that were accessible and culturally safe for participants. Locations for focus group meetings were either Indigenous-specific venues (i.e., cultural centres) or venues familiar and accessible to Indigenous people in the area. Groups were held during school hours to accommodate the needs of parents/carers of school-aged children. Following completion of the community-based focus groups and preliminary thematic analysis, a further focus group was held with members of the IRRG to discuss the themes so that members could offer their thoughts and opinions on the validity of the data already gathered.

Each participant was provided with a folder containing an information statement about the study, a consent form and a short questionnaire. The questionnaire collected information about participants such as age, employment status, educational level, if participant maintained ongoing connections with traditional lands and/or Indigenous communities, cultural connections, number of children cared for, how many children had RI, and whether the family preferred to utilise Indigenous-friendly or mainstream health services. These were collected in order to ascertain participants' cultural connections, extent of caring responsibilities and the importance or otherwise of access to Indigenous-specific health care. Having this information enabled critical assessment of focus group responses in the context of their environment/situation. I was interested in the degree to which participant responses supported the literature review findings of the importance of maintaining cultural connections to Aboriginal and Torres Strait Islander peoples living in urban areas.

Following informed consent, participants filled out the questionnaire with assistance from the research team if required. The focus groups were co facilitated by a senior Aboriginal researcher and observed by an Aboriginal research officer. My roles included co facilitating the focus group sessions and transcribing the digital recordings. Each focus group lasted from 90 to 120 minutes and was digitally recorded.

In accordance with Indigenous cultural traditions, researchers introduced themselves by the exchange of identifying knowledge (e.g., where our families are from and our 'mob', language group). Icebreaking involved informal discussions of people's cultural ties. During the focus groups, discussions were respectful, informal and good-humoured. The Indigenous cultural tradition of storytelling or 'yarning' was fully employed by participants as they related their lived experiences with RI. The focus group or 'yarning' sessions were semi-structured, with the following questions employed to guide discussions:

- What does being healthy mean to you?
- What does 'well-being' mean to you?
- What do you know about chronic cough in children?
- What do you think may be the causes of children getting a cough that lasts a long time?
- What do you know about respiratory/lung illnesses?
- What do you think may be the cause of children getting lung illnesses?
- What sort of things (e.g. lifestyle factors) do you think increase the chances of children getting lung illnesses?
- Why do you think RI/cough may be more common in Indigenous children than non-Indigenous children?
- How do RIs/chronic cough affect the family?

These questions were chosen following much discussion and consultation among Indigenous members of the research team and were also driven by the aims and goals stated in my research questions. The literature review, my own professional background in social work and my interest in the psychosocial and cultural side of health care also informed the topics that I wanted to explore. The data collected (both digital recordings and paper based questionnaires) were kept in a locked filing cabinet at QCMRI to maintain the confidentiality of the participants involved in the study. Questionnaire data were entered into a Filemaker Pro v12 (Filemaker, Santa Clara, CA, USA) password protected database prior to analysis.

The data gathered from the initial four focus groups were analysed and sorted into themes and subthemes. These themes were then utilised to inform questions presented to the IRRG. The main aim of the IRRG focus group was to discuss and examine the findings from the previous focus groups. I wanted to get the perspectives of the IRRG members, not only to see if they would be similar or not to the perspectives of the other focus group participants; but also to see if they brought forth themes that had not previously emerged in the other focus groups or in the literature.

The focus group was conducted during an IRRG meeting in the setting of a tertiary paediatric hospital. The demographics of the IRRG focus group were markedly different to the previous focus groups. All participants identified as Aboriginal and there were no Torres Strait Islander participants. The majority of participants were Elders. Only one participant was the parent of a young child and no participants identified that they had cared for a child with RI. The majority of participants were originally from a remote or rural location, rather than an urban setting. Furthermore, as the focus group was held during an IRRG meeting, some participants had difficulty distinguishing between topics previously discussed during the meeting proper and the focus group topics. Taking these factors into account, it was not surprising that this focus group discussion had a different perspective to previous focus group discussions and participant perceptions were somewhat dissimilar to those expressed by participants in the previous focus groups.

The following questions were used to prompt discussions:

- Where do you get your health information?
- How do you think the health of Indigenous people has been affected by modern lifestyle?
- How important is keeping connected to Indigenous culture and values?
- Have you experienced racism or discrimination in a health care setting?
- Describe your ideal health care experience
- How important is cultural safety in health care to you?
- How do you maintain health and wellbeing (for self and family)?
- How important is it for you to be kept informed/have information about you/your family's health issues?
- Do you have trust in doctors/health professionals? Why or why not?
- What is the role of a parent with a sick child? What should they be doing?
- Do you think financial issues can affect health? How?
- Why are smoking rates so high in our community?
- Do you ever use traditional Indigenous medicine/healing? Holistic or alternative medicine?
- How important is staying connected to community, friends, extended family?
- How do you think diet affects health?

- How do you think stress can affect health?
- What do you think would improve Indigenous health overall?

As a facilitator, this last focus group was by far the most challenging possibly because I felt less in control of this group compared to the others. The majority of participants were my elders, and I was keenly aware of the necessity to balance maintaining control of the group discussion alongside maintaining Indigenous cultural protocols with regards to respect and deference to elders. The stark differences of their perceptions (compared to previous focus groups) threw me off-balance, as did the tendency of some participants to break off into off-topic smaller group discussions. I found the process of transcribing the digital recording from this focus group to be time consuming and frustrating. It took much longer than I initially estimated, as I had great difficulty understanding some of the discussions.

3.3g Data Analysis

Descriptive analyses were performed on the questionnaire data using Excel and Stata V12 (StataCorp, Texas, USA) and presented by group. I transcribed the data gathered from the focus groups verbatim into a Word document; an Indigenous colleague similarly completed a second transcript. One of the focus group recordings required the assistance of a Torres Strait Islander researcher to translate the Kriol language used by Torres Strait Islander participants. It is not uncommon in conversations amongst Indigenous peoples for participants to have more than one conversation going simultaneously (Eckermann et al, 2006). Therefore, the process of transcribing the focus group recordings was difficult, time-consuming and occasionally frustrating.

To understand the data, I adopted a thematic analysis method that is widely used to analyse qualitative data collected via the use of open questioning (Toombs, 2010). Adopting a top-down process, the prompting questions used in the focus group sessions and the themes in the literature review were initially used to categorise the data collected (e.g., information contained in the transcripts). In a bottom-up process, subsequent themes and subthemes also emerged independently of these sources. Themes were identified by finding similar words, phrases, commonalities and/or disparities in the data. I examined these patterns in the context of previous and/or similar research found in the literature review. An analysis of data must include consideration and understanding of the philosophy, values and culture of the participants in order to fully capture the richness of the data (McCleland, 2011), including the context of participants' lived experiences (Prior, 2007).

3.3h Feedback

In keeping with Indigenous research methodology and Indigenous protocols; community consultation was an ongoing process. Members of the research team have engaged in ongoing and regular consultation to ensure that the community is kept informed about the progress of the research and the results. Once data analysis was complete and written up, participants were contacted to ensure that their views have been recorded accurately, and if there was anything they wish to change.

Follow-up with participants proved to be more challenging than I had anticipated, due to their transient lifestyles. Indigenous peoples of my parent's generation tended to settle in one urban community and remain there for a long time. However, Aboriginal and Torres Strait Islander peoples now are far more likely to move around and live in many different communities, changing addresses and contact details. As noted by Thompson et al (2000) as urban Indigenous communities comprise Aboriginal and Torres Strait Islander people from many different clan groups, there is a high degree of mobility, which often led to a sense of fragmentation and a lack of unity. Mobile phones are seen as disposable accessories and numbers are changed on a frequent basis. The fieldwork base was located on the campus of a tertiary paediatric hospital rather than in an Indigenous-specific or Indigenous-controlled community setting, which also made the process of following up with participants more challenging.

One participant did not provide any contact details at all and was therefore follow up contact was not possible. I followed up via email and sent copies of their focus group transcript to the 12 participants who had provided email addresses. The 11 participants who had not provided email addresses were followed up by phone and asked if they wanted copies of their focus groups transcript. All but one participant declined. This participant was mailed a copy of the transcript. I presented the results from the IRRG focus group during an IRRG bimonthly meeting. Participants were also provided with hard copies of the transcript.

CHAPTER 4. RESULTS

In this chapter, I explore the themes that were defined by participants as of the greatest importance. The themes were categorised according to whether participants considered them to be protective factors for RI or risk factors for RI as well as the main themes surrounding the impact of illness.

4.1 Study participants

We conducted a total of four focus groups comprised of 6-8 members each between November 2012 and April 2013. In total, there were 24 participants and their characteristics are described in Table 2. Fifteen participants identified as Aboriginal, seven as Torres Strait Islander, one as both and one (a carer of Indigenous children) as neither. There were 21 females and three males. All participants stated that they (a) identified with an Indigenous community and (b) actively maintained connections with their Indigenous culture at home. The majority of participants also stated that they preferred to access Indigenous-specific or Indigenous-friendly primary health care. Group 2 was the most distinctive of all the focus groups. This group had:

- the highest median age,
- the highest percentage of Torres Strait Islander participants
- the highest percentage of participants who were currently health workers or had formerly worked in health
- the highest percentage of female participants

Table 2. Characteristics of study participants

	Group 1 **N = 5**	**Group 2** **N = 7**	**Group 3** **N = 7**	**Group 4** **N = 5**
Median Age (IQR)	41.3 (28.5-46.9)	55.6 (44.7-61.4)	44.9 (16.8-47.5)	52.7 (24.3-60.2)
Gender				
Female	80%	100%	86%	80%
Male	20%	0	14%	20%
Employment status				
Casual	0	0	29%	20%
Part-time	0	14%	29%	40%
Fulltime	0	29%	0	20%
Not in paid employment	100%	57%	43%	20%
Worked as health professional				
Yes	20%	57%	0	20%
No	60%	43%	86%	80%
Not answered	20%	0	14%	0
Identify with Indigenous community				
Yes	100%	100%	100%	100%
No	0	0	0	0
Maintain cultural connections				
Yes	100%	100%	100%	100%
No	0	0	0	0
Connection with traditional lands				
Yes	20%	57%	71%	80%
No	40%	0	0	0
Unknown	20%	0	29%	20%
Not answered	20%	43%	0	0
Any family members Stolen Generation				
Yes	40%	14%	29%	0
No	40%	14%	29%	20%
Unknown	20%	14%	43%	40%
Not answered	0	57%	0	40%
Indigenous status				
Aboriginal	60%	14%	100%	60%
Torres Strait Islander	0	71%	0	0
Both	0	14%	0	0
Non Indigenous	40%	0	0	40%
Highest education level of participant				
Post graduate degree	0	0	0	20%
Bachelor degree	20%	29%	0	40%
Certificate/Diploma	0	43%	0	0
Currently studying	20%	0	29%	0
High School	40%	29%	43%	40%
Did not finish high school	20%	0	14%	0
Not answered	0	0	14%	0

4.2 Overview of the narratives

Participants built their own unique narratives around health, wellbeing and illness. Narratives were drawn from family stories and shaped by personal experiences and beliefs. These narratives influenced peoples' current perceptions, how they experienced and reacted to situations. These formed part of the preconceptions that people brought with them when placed in highly stressful situations like the hospitalisation or sudden acute illness of a child. Participants' beliefs and perceptions about illness were often markedly different from the non-Indigenous medical professionals they encountered in the mainstream health system; this frequently resulted in communication issues, and clashes around management of their child's illness. Participants mentioned specific incidents when they had disagreements with doctors about their child's illness and pointed out when their concerns were justified. Parents stated that they were often insistent and outspoken with medical professionals during these encounters; they expressed anger and dismay when medical professionals dismissed their beliefs and perceptions.

Participants expressed dissatisfaction and a lack of trust in mainstream health care; in contrast, they spoke well of Indigenous-specific, culturally safe health care (e.g. health care that recognised the importance of traditional Indigenous values, culture and practices). The lack of trust in mainstream health care, particularly in a tertiary health care setting, resulted in parents and carers taking on a great deal of responsibility for the management of their child's illness, in addition to all their other caring responsibilities, having a heightened sense of vigilance and relying more upon their extended family and support networks. These factors resulted in an exacerbation of stress for parents, carers, siblings and extended family when the child suffered episodes of acute illness.

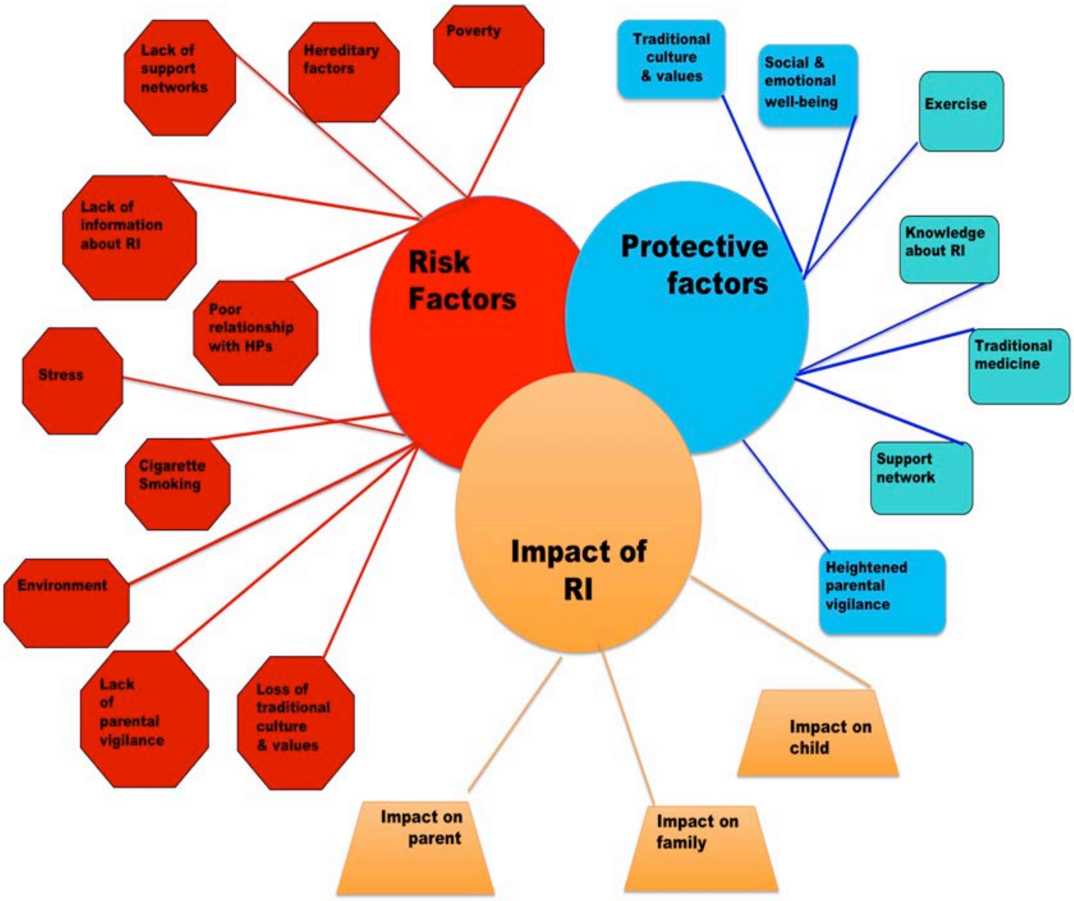
Participants expressed a strong moral code. This included expressing, sometimes, harsh judgements regarding what they perceived to be poor parenting (their own parenting as well as the parenting of others), inadequate health care, and lack of motivation and compliance in some Indigenous children. Participants prided themselves on being good parents and expressed great guilt and shame when they perceived that their parenting skills had been less than adequate. Micromanagement of their child's illness (and taking on the roles of carer and protector) appeared to positively reinforce parents' sense of self and identity. Parents and carers juggled multiple identities (Aboriginal or Torres Strait Islander, sole parent, female etc) as well as complex and often competing responsibilities. The result was that participants experienced ongoing and consistently high levels of stress and an associated lack of self-care. On the positive side, this ability to 'juggle' multiple identities and responsibilities affirmed participants' strength, resilience and sense of self. In summary, participants' perceptions of risk and impact were influenced by:

- Traditional Indigenous values, culture and practices
- Connections to family, friends and community
- Beliefs handed down from elders, parents and other family members about illness and wellness
- Experiences within mainstream and Indigenous-specific health services
- Access to knowledge and information about RI
- Access to reliable support networks

All of these factors profoundly impacted how participants perceived health and wellbeing, which in turn influenced how they and their family experienced health care and how they are impacted by illness. This inter-relationship between risk, protection and impact is illustrated in Figure 4.1.

The results presented in this chapter are grouped into protective factors (section 4.4), risk factors (section 4.5) and impact factors (section 4.6), in accordance to the three objectives of my thesis. This is followed then by the results from the IRRG (section 4.7).

Figure 4.1. Inter-relationship of main themes and examples of subthemes



4.3 Risk Themes Identified by Participants

Themes were classified into two major categories, protective factors and risk factors. Dominant themes within these categories were then identified. These dominant themes are as follows:

4.3a Protective Factors

1. Heightened parental vigilance
2. Access to support networks
3. Traditional Indigenous culture and values
4. Knowledge about RI
5. Traditional Indigenous medicine

6. Social and emotional wellbeing
7. Exercise

4.3b Risk Factors

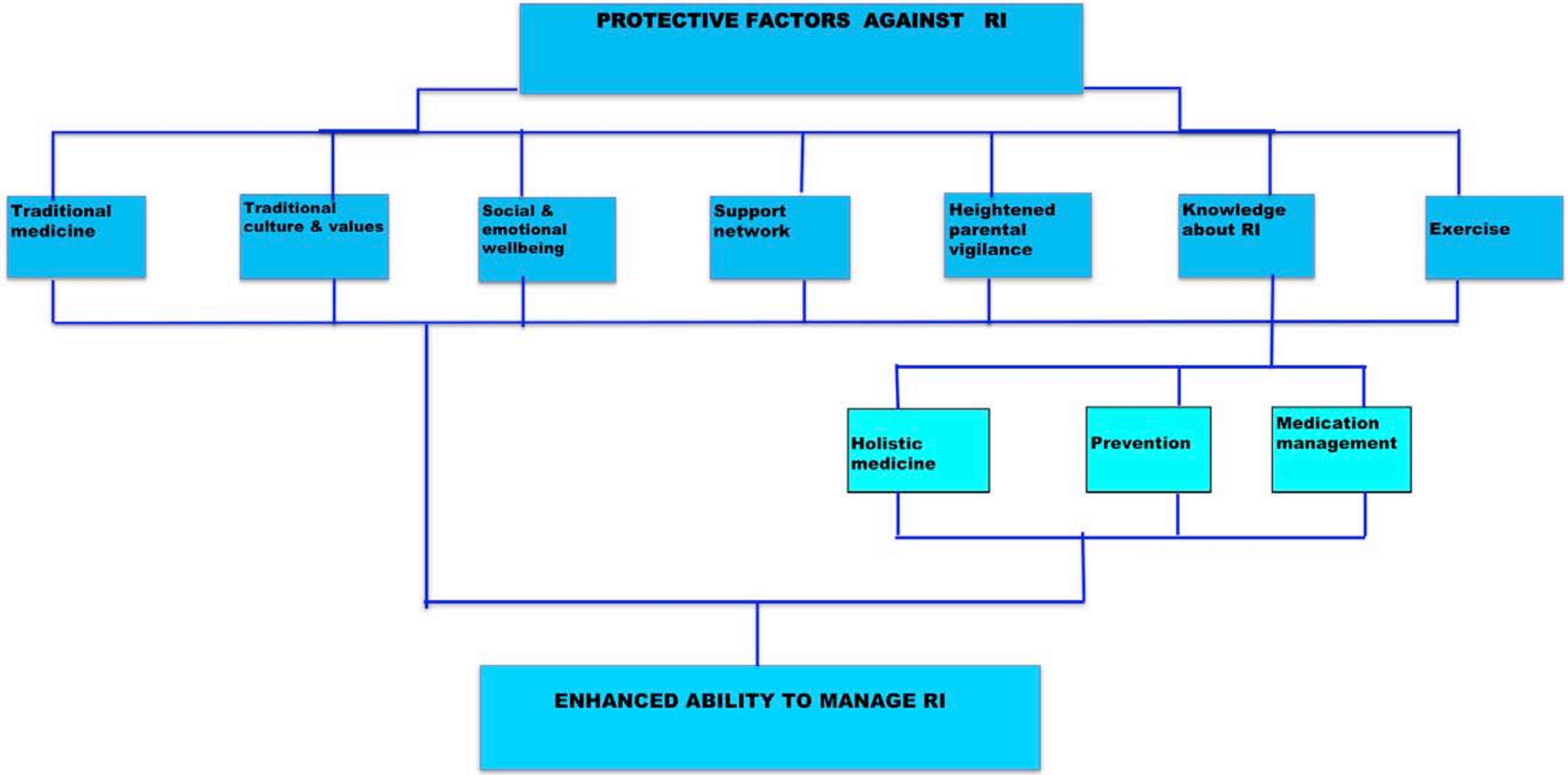
1. Parental neglect
2. Lack of support networks
3. Poor communication with and lack of trust in medical professionals
4. Lack of information about RI
5. Stress
6. Loss of traditional Indigenous culture and values
7. Environment
8. Tobacco smoking
9. Hereditary factors
10. Poverty

Each of these dominant themes and the subthemes within are described in further detail below.

4.4. Protective factors

Figure 4.2 represents the protective factors against RI identified by participants. The diagram illustrates how each protective factor can be linked to: culture; connection to family and community; empowerment and proactivity. Analyses of the data provided by participants illustrated how these themes and subthemes enhanced the ability of participants to manage RI in their children.

Figure 4.2 Overview of predominant themes of protective factors against RI



4.4a Heightened parental vigilance

Parents and carers of children with RI stated that they were extremely vigilant and proactive in managing their RI. This included remaining alert for symptoms of RI, managing the child's medication (e.g. ensuring the child had easy access to medication and took medication when required) and closely monitoring the child when they were sick. Participants associated being overly vigilant with being an effective and caring parent. However, it is possible that heightened vigilance was employed also as a coping mechanism for parents to manage their own anxiety and distress. Participants admitted that they experienced extreme anxiety and distress when their child/children became ill, particularly when the child was distressed by breathing difficulties or painful medical procedures.

> 'For my daughter her (asthma) signs are really clear for us, we know what her triggers are and we generally know the distance between start and when it's gonna hit. We know when to go to hospital and when to wait it out or whatever…we pretty much know her signs. We do have an asthma action plan; we know when to kick it in to avoid a big attack. She's very precious to us; we need to be on top of it'
>
> 'I don't sleep. My son's in bed with me or any of the kids when they have asthma, they're in bed with me, I prop them up so they're right next to me so I just monitor them' (Torres Strait Islander mother of children with chronic asthma)
>
> 'The grandson now, you watch him so closely, as soon as he starts coughing, we don't let him go out and get wet. You sort of have to lay down the law' (female Aboriginal elder)
>
> 'I've lost two first cousins actually, when I was young, with asthma. And that's terrified me so when I see my kids, I think that's sort of in the back of my mind so I'm just a little edgy. Just the first sign they start puffing, I say 'take the puffer, manage it now', you know'

Heightened parental vigilance also extended to parents taking on the role of advocate and protector for their child within the hospital system. This included (but was not limited to): being acutely aware of the immediate environment experienced by the child and how it impacted upon the child;

monitoring how and when medication was administered to the child; being assertive and outspoken with medical staff; actively seeking information and feedback from the medical team.

> 'We will say something if we see like the nurses administering wrong…or if they're late coming to administer the next round of medication, we'll go and find them.' (Aboriginal mother of child with chronic asthma)
>
> 'I've ordered nurses out of (child's) room because they've come back from a lunch break with cigarette smoke on them.' (Aboriginal mother of child with Cystic Fibrosis)
>
> 'We've had doctors whisk (child) away. So we tell em, give em feedback, we ask for lots of information'
>
> 'We sat at A & E for nearly four hours with my son's fingers and lips going blue, that was not long ago. I spacked it big time and end up throwing a big tantrum'
>
> 'They (doctors) went 'he doesn't have a cough'. I said 'I'm telling you, he's got something going on'…getting the doctors and hospital to listen and say something's wrong…'

4.4b Support networks

Participants emphasised the importance of having a reliable support network for managing caring responsibilities when their child became ill. Managing the care and needs of one or more children was a daily balancing act in itself, particularly if the parent was single. Caring responsibilities had to be temporarily reorganised when a child or children experienced acute bouts of illness as the situation demanded that their focus was on the ill child.

> 'I have back up or I'm screwed. We've got a girlfriend that lives with us and if I didn't have her…. I've actually been at hospital with the entourage and I say 'please get us in' cos you can't do it, you just can't do it'

4.4c Knowledge about RI

Historically, Indigenous people in Australia have been disempowered with regards to their health, including management of their health (Cox, 2008), which may partially account for Indigenous peoples current beliefs around health knowledge. Participants associated knowledge with empowerment, self-determination, sense of self (identity) and good parenting. All the parents/carers of children with RI communicated that it was imperative for them to be empowered with information and education in order to have better outcomes for their children when they became ill. Increased knowledge was associated with a greater capacity to manage their child's illness and better health outcomes for the child, which enhanced participants' self-image as good parents.

4.4d Prevention of RI

Participants discussed the prevention of RI as an important protective factor. Prevention was associated with increased knowledge and education about RI, including medication and alternative medicine. Prevention and the protective factors in general were seen by participants as something that they as parents had a degree of control over, as opposed to when the child became sick and entered into the tertiary health system, an environment that was largely beyond their control.

> "I'm just kind of interested in what's happening, the different medications or treatments. But yeah, I just do a lot of reading myself" (Aboriginal mother of asthmatic child)

> "They don't have access to the right medication, the right puffer, the right preventer, actually using a spacer instead of using the puffer. I think its education in that sort of sense."

> "Education plays a big role in it. So we do things like changing our mattress every so often. Buy new mattresses often and put pillow protectors and mattress protectors. We just have a better night's sleep."

> "If it's about retraining your breathing and cleaning up your environments at home, that would go a long way, it would stop us going to hospital. Cos that's the point, isn't it? I prefer to stop being sick or getting sick"

4.4e Holistic medicine

One of the participants mentioned that she was interested in pursuing holistic treatments as well as mainstream medical treatment for her child but that this was something that doctors were unwilling to support. This stance tended to (a) reinforce the negative beliefs already held about doctors in the mainstream health system and (b) re-emphasise the cultural divide between Indigenous people and the mainstream health system. Participants also mentioned traditional medicine and healing practices as part of preventative measures and holistic treatments for RI.

> “A lot of doctors, I don’t find them holistic. So they prefer to recommend something where drugs are involved. If it’s a drug that you can buy over the counter or get a prescription for, they’ll give it to me. I wish they were holistic and looked at other things” (mother of chronic asthmatic)

4.4f Medication management

As with all other aspects of managing their child’s illness, parents and carers were vigilant and proactive about the use of medication, including ensuring that their children had proper access to medication and used medication appropriately.

> ‘I think some of these kids need to be better, like with these parents, with our medication, how to treat it, to know how to use it better’’

> ‘The hardest part is when you send them to school. Like, you can manage it at home but then you send them to school. And I’ve actually had to have letters written so my son could carry his inhaler with him at all times otherwise the school wouldn’t let us’

> ‘For him to go to camp the other week, I went to the extent that I bought a portable nebuliser with batteries. Cos I thought, if they take him somewhere and they can’t get him back to town, the kids dead.’

> ‘My son has that bag that he carries everywhere. That’s the best way. I’ve had to put it into him, as you walk out the door, you put on your shoes, where’s your bag. And he’s got that packed with all his gear.’

> ‘I noticed with treatment of asthmatics, people don’t know how to take their medication properly. Like the blue puffers, I think that they’re the worst, they’re the worst relievers cos

> people don't know the right technique'
>
> 'People don't get shown it or need to. They need refreshers all the time'
>
> 'Cos you may as well not use it sometimes if you don't use it properly'
>
> 'My daughter, she's only eight, she's not dumb, she knows what she needs to do, she knows how many puffs she needs when she needs it. Sometimes I've got to fight with her to have it'

4.4g Traditional diet

Participants discussed food choices as being either a risk or a protective factor, depending on whether the food was fresh ('traditional') or processed ('junk'). A balanced diet was seen as a protector against RI. Certain foods were perceived to be triggers for bouts of acute asthma in some children. Interestingly, when discussing specific incidents of bad reactions to food, the food triggers described by parents included processed, unhealthy food and fresh, healthy food. The consumption of junk food was associated with an urban, fast-paced lifestyle dominated by a reliance on technology.

> 'I put some of it (asthma) down to; we found a few food triggers. He was a bit allergic, that made him scratchy, wheezy and then it exacerbated.'
>
> 'The amount of times that we'd gone to the hospital and she was at death's doorway and given stuff to keep her breathing. I'm glad I haven't had one of them days for a long time.'
>
> 'My daughter, its bananas. She was just running around playing, then she had a banana and within twenty minutes...'
>
> 'I don't know why. Mine have a very balanced diet.'
>
> 'All the foods that are modified and prepared a certain way…I think it weakens our system.'

> 'Another factor would be the way we eat cos when I was little, we had lots of fresh food and now a lot of stuff is processed, everybody just goes and gets junk food, only on special occasion you cook something traditional.'

4.4h Traditional medicine

Participants discussed how they employed traditional medicine and traditional healing methods alongside Western medicine to manage RI. Traditional medicine and healing were discussed in matter-of-fact way as part of everyday family life. In other words, these were aspects of culture that were implicit rather than explicit. Participants associated traditional smoking (e.g. the deliberate burning of specific plant matter) with healing and/or illness prevention and these were viewed as a positive, protective factor.

> 'One of the best things is, there's a whole range of plants, that lemon scented Teatree is my favourite, and if you get cold or if you've got a wheeze, you get the leaves and crush em up and breathe in and it just clears everything' (male Aboriginal elder)

> 'I know when I was growing up, there was a lot of traditional stuff happening, a lot of the preventative stuff. Heating the chest, that's what they used to do to us, our grandmothers, do all those stuff for us to clear our airways. Mostly used a lot of island medicine as well as preventative and also that was a knowledge that was passed down.' (Torres Strait Islander mother)

> 'Those plants were used traditionally to clean, to clean the air and to keep the air nice and to keep the insects away. It's a powerful part of healing, is those scented smokes' (male Aboriginal elder)

4.4i Social and emotional well-being

Participants discussed the importance of maintaining wellbeing, which they defined as: related to themselves or their children or both; a way of preventing illness and; vital to maintaining good physical health. Wellbeing was described as a holistic concept including physical, mental, emotional and spiritual components: ensuring that all aspects of life were balanced and stable. Some participants related it to emotional happiness, while others associated it with a state of cleanliness and abundant nourishment, or physical exercise and self-care. Those with particularly stressful lives associated wellbeing with survival.

> ‘It’s like a mental state’
>
> ‘They eating good food, good nourishment…being clean, washed’ (Torres Strait Islander elder)
>
> ‘A good indicator for my kids are if they are happy or not…when they’re grumpy or whatever, it’s not a good sign…That’s a good sign for that they’re not well is if they’re not happy’
>
> ‘If I get through the day, well, I’ve survived. 95% of my days at home, like when I’m at home with my little ones…there’s no let-up’ (Aboriginal grandmother caring for grandchildren)
>
> ‘When you’re eating right, you’re exercising, regular check ups just for, you know, a check rather than going to the doctor when you’re sick’ (young female Aboriginal participant)
>
> ‘To me it’s extends beyond your physical wellbeing…it’s also mental and emotional and spiritual. That’s how I look at it. So it’s not just about eating right and exercising or going to the doctors to get regular health checks but it’s also taking care of yourself…other things like making sure that you’re okay with your emotions, it’s also taking care of that part’ (female Torres Strait Islander participant)
>
> ‘It’s about balance…a holistic approach’
>
> ‘It’s all about your eating…getting proper sleep. I’m no doctor but I think it keeps you moving and alive’ (Aboriginal elder)

4.4j Exercise

Participants did not see RI as a barrier to regular exercise or participation in sporting activities. On the contrary, they stated that they considered exercise to be a strong protector against RI. For those that discussed exercise, they mentioned running as a good way of maintaining fitness and preventing illness. Running was perceived to improve lung function and breathing for children with RI, particularly asthma. Exercise was also seen as a positive and proactive way of managing RI that the child had control over.

> ‘I try to tell my kids, get up and move around cos otherwise you can get sick. You got to get your kids into sport, get them running’

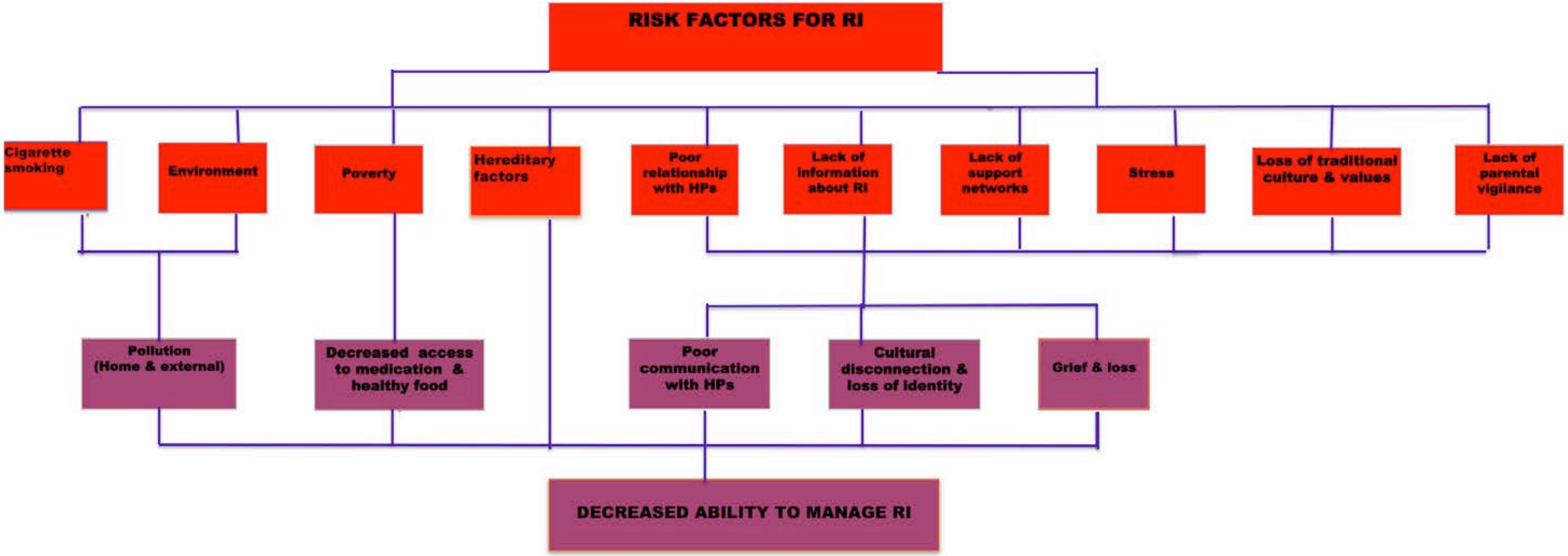
> ‘I think the exercise is good for her, straighten the lungs out, to get more exerted’ (Torres Strait Islander mother of asthmatic child)

> ‘He’s found that if he gets up and goes for a run of a morning, he says it feels like he can breathe a bit better’ (Aboriginal mother of child with chronic asthma)

4.5 Risk factors

Figure 4.3 illustrates the major themes associated with risk factors and the subthemes emanating from these. The diagram also shows how the risk factors ultimately decrease the ability of families to successfully manage RI in their children.

Figure 4.3 Overview of predominant themes for risk factors for RI



4.5a Lack of parental vigilance

Participants attributed childhood illness and family dysfunction to a lack of parental vigilance that was implicitly linked to a loss of traditional Indigenous values such as reciprocity, caring for each other and respect for elders. Neglect was also associated with parental alcohol and drug misuse and lack of parenting skills, which could be attributed to a loss of connection to family/kin networks, which would usually act as role models and educate parents about how to care for their children properly. Some participants were grandparents who were caring for their grandchildren because they perceived the parents as being unfit and incompetent. One participant, a Torres Strait Islander Elder, mentioned that she had taken on a caring role (providing food and shelter) with her neighbours children, who she perceived as being neglected:

> 'The home environment, the love and care I think is not there. Before in close knit families you always take care of everyone, maybe things are just drifting apart' (Torres Strait Islander mother)
>
> 'Them parents don't look after them kids, they still run there, no clothes on and runny nose…the mother doesn't bother. They drinking, drinking or smoking and then no money to buy nutritional food. Mother not looking there, he run with no shirt on…cause sickness' (Torres Strait Islander Elder)
>
> 'Before (grandchildren) come to live with us, they was forever…sore ears, snotty green noses, coughing like no one's business. They'd have boils; they'd have all sorts of things.' (Aboriginal grandmother caring for grandchildren)
>
> 'I tried to get this one's mum to come and visit to see why I'm so pedantic about the four year old having a cough and she just went 'no, you do it'. Cos the kid has a shocking cough and she doesn't need antibiotics, she needs to see someone about her lungs'
>
> 'I've got my granddaughter now. And I kept saying 'she's got a cough'. For 12 months I battled with mum, saying 'she's got asthma, get her up there'. Well, I've taken the kids now. But it's been a battle of wills'
>
> 'We were brought up by a village; everybody could tell you what to do. But that's broken down now'

> 'I became like the mother. The kids would come over and eat with me, the mother and father doesn't care, sometimes they would sleep at my place, they get up and go to school and come back to my place' (female Torres Strait Islander elder)

4.5b Lack of reliable support networks

A side effect of the increasing urbanisation and transient lifestyle of Aboriginal and Torres Strait Islander peoples is that their immediate connection with their family and kin networks can be weakened. This effect was exacerbated if the parent lacked a partner or spouse. Participants who were geographically distant from their family and extended kin discussed how difficult it was for them to manage their child's RI without that informal support.

> 'I do miss my extended family. Like at home, if we're sick at home we'd share those caring duties' (Torres Strait Islander participant now living in Brisbane)

> 'When there's no support, it's like being by yourself'

> 'The extended family are really good for that but you've got to have them close by. If you don't have that support, family support, you struggling' (Torres Strait Islander elder)

> 'Being in the sole parent situation that just adds to the burden'

4.5c Poor relationships with medical professionals

Participants discussed how they often had challenging relationships with the mainstream medical professionals they encountered, characterised by poor communication. Parents felt misunderstood and marginalised by medical professionals. They felt their beliefs and opinions (particularly regarding their child's RI) were not respected or taken into account. The poor communication and perceived lack of respect from medical professionals resulted in parents becoming overly vigilant and taking on the role of advocate/protector for their child as they perceived that medical professionals were not doing their job adequately.

> 'They (doctors) went 'he doesn't have a cough'. I said 'I'm telling you, he's got

> something going on'…getting the doctors and hospital to listen and say something's wrong, it's not til they put him on the machine that they go, oh jeez. I go 'His fingernails are blue, his lips are blue, and that's not good'

> 'My grandson's got a wheeze and every time you take him to the doctors he says to me 'it can't be whooping cough. They're too old to have croup'. But they keep getting it.'

4.5d Lack of information about RI

Participants expressed a desire to be informed and educated about RI. They wanted access to information and education about RI in order to manage their child's RI and also to be able to pass the knowledge on. Participants stated that they felt information about RI was only provided after the illness was diagnosed and there was not enough access to preventative education. They also felt that there were not enough visible public health campaigns about asthma and other forms of RI and that this needed to be remedied.

> 'How do we educate them when we don't know what to do?'

> 'That's the place for medical centre; (they) should be running workshops like that for our people to make sure that we are aware of it. If something like that happens to our child, then we know how to deal with it.'

> 'There's not much information, education about that. Asthma is one of those areas you don't see much of.'

> 'Does anybody know what an asthma attack is? Cos how do you know when a person is having an asthma attack, and what do you do? Cos I wouldn't know what to do'.

4.5e Stress

Stress was an important and recurring theme amongst participants, who emphasised that stress, was not limited to the sick child but was experienced by all members of the family. Participants also pointed out that the nature of asthma attacks (and the accompanying difficulty in breathing) increased feelings of fear for all concerned and heightened feelings of anxiety.

Stress experienced by siblings

Participants appeared to have an acute awareness of how their child's illness impacted on the rest of the family, especially siblings, who often exhibited feelings of jealousy and resentment about the parent's focus being on the sick child.

> 'It really affects the family. Cos I concentrate so much on her. Our whole house revolves around my daughter and how well she is. When she gets sick, that's it, I'm not going to the shops, doing grocery shopping or anything like that. It affects the boys, my son gets cranky 'how come you're spending so much time with her?' and I'm like 'because she's sick'. (He says) 'Why are you sleeping with her for?' 'So I can hear her breathing during the night in case she needs a puffer' so things just stop in our household until she gets better. ' (Mother of chronic asthmatic)
>
> 'I kick everybody out. Thank goodness I haven't had the experience of having two or three of them sick at the same time with asthma or it would get really bad.'

Stress experienced by parents

Participants were open and frank about the stress they experienced. Their stress was multi-faceted and complex, and included: the stress of managing their child's illness; the stress of dealing with the health care system; the vicarious trauma of witnessing their child in acute and sometimes life threatening respiratory distress and managing their own reactions and anxiety; the stress of managing competing responsibilities. Participants displayed a remarkably stoic and resilient attitude to the high levels of stress in their daily lives. One participant spoke in depth about the stress she experienced with her unsupportive workplace when her daughter, a chronic asthmatic, experienced bouts of illness.

> 'Oh, it's really scary. Like, what can you do? You just got to have faith in the doctors eh?'
>
> 'But they can be right as rain one minute; come that night, (coughing) like that…it's scary.'
>
> 'It didn't go very well with my work. Because she gets sick a lot and it wasn't nice ringing up all the time saying 'I can't come in, my daughter's sick'. If she's showing those signs I can't take her to day care. And even if I could, I wouldn't. If we see those signs, we'll do everything we can to stop an attack coming and if that means keeping her at home then that's what we do. You don't like ringing up saying 'I've got to stay home, she's sick', you always have to hear some snide remark on the other end of the phone and that's not nice. In the end I just said 'no, no more of that'.

Nature of asthma attacks as distressing for sufferers and family members

Participants discussed how the nature of asthma attacks (e.g. difficulty breathing) was distressing for patients and family members and exacerbated anxiety in the asthma patient:

> ‘I never realised what a frightening thing it was, asthma. I see my sister she coughs and chokes.’
>
> ‘When someone’s got a breathing problem, you can patch someone who’s bleeding but when they can’t breathe, they can’t breathe. And it’s very annoying, especially when it’s a child. Cos adults can control ourselves and do the slow breathing but when the kids are that hyped up and they’re panicky, they should be in straight away but no they make you sit down and wait.’
>
> ‘Nebuliser is the only thing we can use. Once he gets into panic mode…’
>
> ‘Sometimes you can’t use a spacer. I know with the young kids, you can’t. They’re gasping for air and I know myself when I’m like that, there’s no way I could use my spacer.’
>
> ‘You know when you have an asthma attack, you panic, you know you just feel really short of breath, you start panicking and you know sometimes people just go really silly, eh.’
>
> ‘And the more you paranoid about breathing, the more anxiety comes on.’

Loss and grief

The different types of stress discussed by participants included not only the stress associated with illness and other factors but also how illness can be prompted by issues of loss and grief. Aboriginal and Torres Strait Islander people can be affected by generational, long-term grief and loss as well as the daily stresses of life.

> ‘We tend to forget that a lot of illness that we have are affected by our lifestyle and stress is such a big thing especially in today’s society. If you’re worried about something, you’re not gonna get cured easily. It keeps going round and round or it’ll manifest in other ways. And it affects our young children as well, it’s not just adults, kids take on a lot of pressures too’
>
> ‘For me it was (associated with) loss and grief because I lost a whole lot in one year. Ill health is a pattern, so over the years when these major things happen, the physical

> illness goes along with the trauma' (male Aboriginal elder with history of RI & childhood institutionalization)

4.5f Loss of traditional Indigenous culture

Participants discussed the differences between their own upbringings, which they viewed as active, healthy and balanced, and the lifestyle of Aboriginal and Torres Strait Islander children today, whom they categorised as unfit, unmotivated and reliant on technology.

> 'We always played some sort of games but you don't see kids do that anymore, you have to force them out the door to go. They refuse to do work or anything physical, that's dying out as well.' (Torres Strait Islander mother)

> 'People were really strong back in those times, they used to row the boats and they'd walk places. When you look at the old photos, they were all thin and fit. You look at our boys these days that age; they're unfit, out of shape. I suppose with the changes, technology, nobody walks anymore, hop in the car just to go
> down the road.' (Aboriginal grandmother)

> 'The kids don't even have to walk to go and see their friends, they just text.'

> 'They're not very active, the majority of kids, they don't want to participate.'

4.5h Environmental factors

A number of participants stated that they believed that the environment (including outdoor pollution, structural/home environment and weather) to be risk factors for RI.

Pollution

Participants categorised outdoor pollution as both part of the natural environment and the result of industrialisation. Both types of outdoor pollution were viewed as inevitable, unavoidable and largely out of participant's control. A female Aboriginal elder originally from Gladstone discussed how the town had been transformed for the worse following the heavy industrialisation of the area. She described how the variety of fruit trees in her family's yard had perished after mining was established. Other participants discussed pollution in terms of heavy dust in dry and remote areas.

> 'Yeah, where I grew up, it's very dusty; it's like red dust, iron dust and everywhere. It's just

> natural, just the ground, the ground is red, and the wind, the dust is just everywhere.'
>
> 'That pollution has caused a lot of chest complaints in Gladstone area. It has to be affecting the children' (female Aboriginal elder originally from Gladstone)
>
> 'I think it's the environment, the flowers, it triggers her hay fever, hay fever triggers her asthma and then it just goes downhill from there and then she gets really sick.'

Weather

Several participants stated that they had relocated to Queensland for the climate, as they believed the warmer weather would be beneficial for the health of their children. They believed that exposure to cooler weather had worsened their child's RI and moving out of that environment would have a positive effect. Of the participants who had relocated, some believed that the move had been beneficial while others believed there had been little or no change in the health of their child.

> 'We lived in Canberra and one of her biggest triggers was the cold. And being in Canberra was the worst place we could have been.'
>
> 'See, we got told it was where we were living too. But we did the rounds and it hasn't made any difference to us' (mother of chronic asthmatic)
>
> 'It did when we first came here, from Tassie, did for the first 4 months we were here but after that we got acclimatised'
>
> 'When I moved from Canberra, the doctor said Queensland would probably be better for my daughter, just the warmth. And he said 'oh but you realise it's got one of the highest rates with asthma in the country'. But her main trigger is the cold. We had to get away from the cold'

Structural (home) environment:

Participants perceived the home environment as one they could control in order to better manage their child's RI. Often this meant removing carpets, changing bedding on a regular basis and maintaining a high standard of cleanliness. One parent stated that she felt she lacked the time and resources to clean her home thoroughly enough. Spending too much time indoors, particularly in air-conditioning, was viewed as detrimental to the health of children. An air-conditioned environment was perceived as a risk factor for RI and ill health in general.

> ‘I think it’s also environmental. We don’t clean well enough, we don’t have time to do our walls, get all the mildew, we don’t do our cupboards often enough, all the dust gathers. So I think it’s very much environmental’
>
> ‘I had a lovely housing commission home and they even came in and pulled the carpets out, gave me a wood fire cos we had a gas heater and they reckon that was contributing as well. ’
>
> ‘See I think that’s what triggered - we moved and we’ve now got a wood heater out there and we think that’s what set (child) off this year’
>
> ‘Well, we had a gas heater and the department of housing pulled the gas heater out. They said they found that people with asthmatic kids have got these heaters, point up to a high rate. And they ripped the carpets out’
>
> ‘We went to the extent of, the house we’re living in, there’s no carpet, the carpets gone’
>
> ‘Children are spending more and more time indoors rather than outdoors. The TV becomes their babysitter and just not being exposed to that air outside. You’re not letting fresh air in, you’re having the aircon on all the time and you’re picking up all kinds of stuff’

4.5i Cigarette Smoking

Cigarette smoking rates are much higher in the Indigenous than non-Indigenous community, particularly among young people. Participants consistently associated parental smoking with RI in children. One participant stated that she had smoked throughout her pregnancy and attributed her daughter’s subsequent RI to this, for which she expressed guilt and regret. Cigarette smoking was also associated with social bonding and stress relief but was generally mentioned in a negative way, and was the subject of harsh judgements and parental feelings of guilt.

> ‘I used to smoke and that’s the thing I put her asthma and stuff down to me smoking

> through my whole pregnancy with her. I never smoked while pregnant with my 2 boys, and they've got nothing. But my daughter has it all and I put it down to me smoking when I was pregnant'
>
> 'That's what I was trying to say early part…that's why we try stop the mothers from smoking from being pregnant at the early age, or cut down'
>
> 'A lot of young teenage women smoke and they say 'oh yeah we give up smoking when we pregnant then we take it up again after the baby's born' so it's like they know the danger but only for that period of time then they back on it again'
>
> 'Well, that's what my daughter tried to tell me, she didn't do any kinds of things. It wasn't alcohol so much it was more the marijuana.' (Aboriginal grandmother caring for grandchildren)

4.5j Hereditary factors

Several participants described RI as hereditary or as a 'family disease' that they believed was passed down from generation to generation. Many participants had witnessed members of their immediate or extended family struggle with RI. Two participants talked about how they had experienced family members passing away from severe asthma attacks, and how this had a profound effect on how they managed RI in their children. When there was no or little history of RI in their own family, participants speculated that their child's RI had probably originated from their partner's side of the family.

> 'Cos you always have that when somebody's sick, they'll say 'yeah it's a family sickness', it's connected or it's happened to family members'
>
> 'I've always thought it was hereditary'
>
> 'Predisposed genetically, I think. Or hereditary. I think so, anyway.'
>
> 'I often think of my grandson now, I wonder where that comes from, it must be his other family. We have to look at all those things that come down through generations' (Aboriginal elder).

4.5.k Poverty

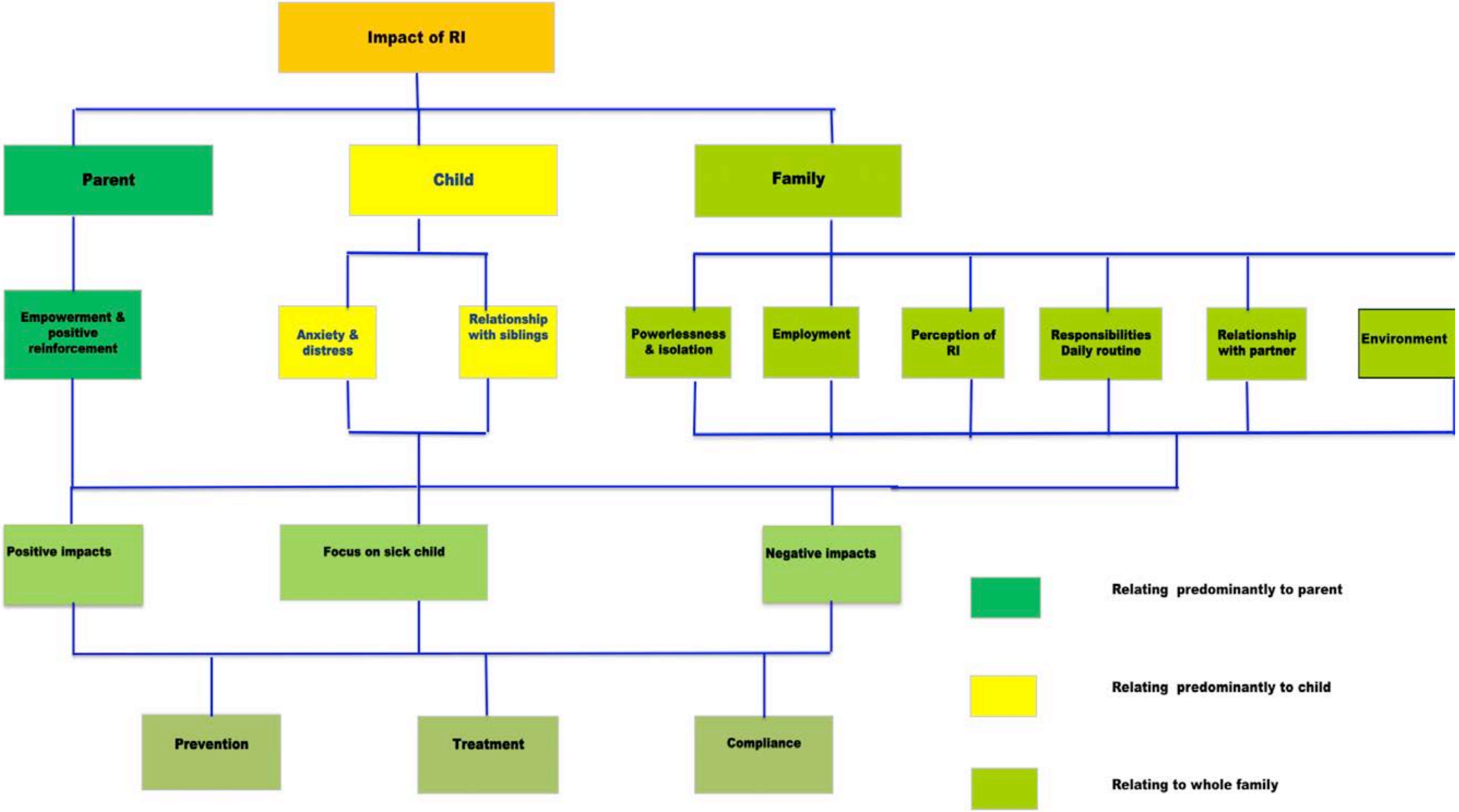
As stated by Marmot (2005) the social determinants of health inequality are complex in that the allocation of resources is determined by social factors. In other words, economic and social policies have profound effects on the health outcomes of the disadvantaged. Participants discussed how poverty made the management and prevention of RI more difficult. Limited resources meant that the purchase of medications was viewed as non-essential and had to be weighed up against other financial priorities. Torres Strait Islander participants also discussed how much more expensive food, particularly fresh food, was to purchase on Thursday Island, which made it more problematic for residents to maintain a healthy diet. This is somewhat ironic considering that traditionally Torres Strait Islanders have grown their own food. The anecdotal evidence about scarcity of fresh food on the islands could be seen as indicative that some Torres Strait Islanders have abandoned this tradition to some extent and become reliant on store-bought fresh food.

> ‘Thursday Island, Torres Strait, very expensive stores up there, so you’re not getting a good nourishing. It is very expensive’
>
> ‘Because we’re all asthmatics, one of my things is about $35. Sometimes I have to buy some here and some there’
>
> ‘Like last week, I had to go out and buy my son all his medication because how he’s slipped through the net and apparently he’s not on CTG (Closing the Gap). I never thought to check…til I had to pay for all the medication’ (Aboriginal mother)

4.6 Impact of RI

My third objective was to explore the impact of RI on Aboriginal and Torres Strait Islander families. In this section, I present the themes that were identified and the relationship to the parent, the child and the family. Many themes impacted on all three. Dominant and subdominant themes are discussed in relation to each other. Figure 4.4 illustrates these themes and the relationship between them. They were many overlapping themes and relationships between them and these are explored in the relevant sections.

Figure 4.4 Major themes relating to impact of RI



There were both positive and negative impacts on parents, with a large component of that being the parental role in caring for a child with RI. Despite the many apparently negative aspects of RI, there were also some positive impacts that RI had on parents. Successful management of RI led parents to feel more empowered and more capable of controlling their own anxiety and fear. It also led to parents cultivating a positive self-image of themselves as good parents.

Successfully advocating for their child within the health system led parents to feel that their beliefs and perceptions were positively reinforced. Illness prevention via close management of physical environment (e.g. home environment) assisted parents to feel more in control of the illness. Participants associated all of these factors with better health outcomes for their children. In contrast, parents had extremely negative emotions associated with parts of the illness that they felt they had little or no control over; and situations (e.g. when dealing with the health care system) where they felt their beliefs and opinions were ignored or discounted.

Many participants had a long history of RI in their family. Hence, they tended to view RI in their children in the context of their previous experiences. They viewed RI as a ‘family disease’ that was passed down from generation to generation. When discussing RI in their children, they constantly referred to how their other family members had experienced RI. Other participants had had extremely traumatic past experiences with RI and this heavily influenced their reactions when their children or grandchildren had RI. For these participants, part of managing RI in their children included managing their own fear and anxiety.

A male Aboriginal participant discussed his own history of RI and how he associated it with the loss, trauma and grief he had experienced at a young age. As a result, he experienced fear and anxiety whenever he contracted RI as an adult, as he always associated these negative feelings with physical illness. These feelings were revisited when his children and grandchildren had experienced RI.

A female participant with children with chronic asthma discussed how her past traumatic experiences with RI influenced how she reacted when her children had asthma. This participant had had two young cousins die from asthma attacks. As a result, she felt terrified and edgy whenever her children experienced asthma attacks. She admitted to being extremely vigilant about ensuring her children took their inhaler at the first sign of symptoms and that she refused to leave their side when they were hospitalised.

> ‘I’ve lost two first cousins actually, when I was young, with asthma. And that’s terrified me so when I see my kids, I think that’s sort of in the back of my mind so I’m just a little edgy. Just the first sign they start puffing, I say ‘take the puffer, manage it now’, you know’

Overall the predominant theme was that of stress related to the management of illness in the child. This stress was both precipitated and worsened by the factors influencing their ability to manage illness. Participants discussed the issues of managing illness under themes of: recognising and dealing with triggers of illness; managing the symptoms when the child was ill; access to medications and managing the side of effects of those medications, and; the need to maintain constant awareness and vigilance when the child was both well and ill. Participants discussed the need to maintain constant vigilance and awareness with children regarding the symptoms and triggers for RI. Most parents of children with chronic RI stated that they were aware of the triggers for RI; capable of determining whether an attack could be treated at home or should be treated in hospital; had an action plan in case of an acute attack. Parents noticed an exacerbation of respiratory symptoms when their children had certain types of food or were exposed to certain types of plants or a change in the weather. Some reactions were mild and others were serious enough to require hospitalisation. Parents described these life-threatening reactions in their children as extremely distressing for them to witness and vicariously experience.

> ‘The amount of times that we’d gone to the hospital and she was at death’s doorway. I wouldn’t wish it upon me enemy, let alone me best friend; it’s not the kind of thing you’d want any kid to suffer’

Some participants who were grandparents discussed how they were vigilant with their grandchildren. They felt strongly that the parent was often not being vigilant or mindful enough about the health of the child and this had led to disagreements or conflict with the child’s parent. In at least two cases, this had led to the grandmother taking custody of the grandchildren. These grandparents stated that they believed the parent’s early lack of vigilance had led to the children now suffering chronic RI or other chronic health issues.

Participants touched on the link between stress and chronic illness. Stress in this case was categorised as being experienced by both the parent/carer and the child. Participants believed that stress provoked illness as well as vice versa. In many cases it was viewed not as a temporary effect but a constant and ongoing part of life.

The major subthemes of this dominant theme are outlined below and then discussed in further detail:

1. Frustration/powerlessness/helplessness
2. Poverty and lack of resources
3. Physical relocation
4. Change of home environment
5. Impact on family relationships
6. Interruption of daily routines
7. Balancing caring responsibilities
8. Balancing employment
9. Parental guilt
10. Issues with use of medications

4.6a Frustration and powerlessness/helplessness

Participants expressed frustration and a sense of helplessness about several matters: trying to ensure that children used their medication properly; having to monitor children who were unable or unwilling to recognise their RI symptoms; dealing with an unsympathetic health care system; trying to manage competing responsibilities and their own feelings of anxiety. Grandparents caring for grandchildren discussed how they also had to manage conflict and disagreements with parents. Often the parents and grandparents had very different perceptions about the health status of the children involved.

Some participants expressed frustration about what they viewed as the reluctance of doctors to try any treatments for RI that did not involve mainstream medication. These participants were keen to explore holistic or alternative treatments for RI but were frustrated by the unwillingness of their doctors to participate in any way. This attitude had led parents to conclude that the doctors were not open to alternative or holistic medicine and not receptive to the parent's input. This added to the overall perception of parents that the doctors tended to dismiss parental beliefs and opinions.

Educating and informing themselves about RI was considered by participants to be a strong protective factor against RI. Not coincidentally, it also had the positive effect of assisting the parents to feel more empowered, as this was an element of RI that was within their control.

> 'I'm just interested in what's happening, you know, the different medications or treatments. So what they've done is they've developed courses where people can go, workshops, and just learn to retrain your breathing. I did it for a short time many years ago; it was very, very helpful.'

4.6b Poverty

Participants discussed how lack of economic resources impacted on how they managed RI. One parent of a child with chronic asthma discussed how lack of money prevented her from pursuing an alternative treatment that she was interested in and joked about having to win the lottery to be able to afford it. Another parent stated that lack of funds prevented the family from moving interstate, where they believed the treatment and support options for their child were superior. Participants acknowledged that the Closing The Gap program had made medication more affordable than previously. However for participants who were not currently using the program, there was some confusion about how to access it. Participants from the Torres Strait Islands discussed how fresh food was much more expensive to purchase in the islands and that this made maintaining a healthy diet more difficult, which could potentially increase the chances of people getting ill.

4.6c Physical relocation

Parents of children with chronic RI discussed how they often had to move to a warmer climate for the sake of their children. Cold weather was viewed as a significant trigger for RI, therefore relocating to a warmer climate was seen as an effective preventative measure and a way of improving children's health outcomes. Some parents stated that relocation had helped their child's RI while others were adamant that there had been little or no health improvements. One mother who had moved to Queensland stated that she now regretted the move as she felt the health care system and her own support networks were better in her previous location. She stated that since moving, she had been ringing her support person in her former location on a regular basis.

4.6d Change of home environment

Parents of children with chronic RI discussed how they had modified their home environment in order to prevent illnesses. Participants removed carpets, heaters and changed bedding often in order to minimise the chances of illness. Changing the home environment was viewed as a positive, proactive action that they could take, as the home environment was largely under their control. They stated that they felt these home modifications had improved their child's health and was a strong protective factor against illness.

Managing the home environment included maintaining cleanliness and hygiene, which participants believed created a 'safe environment' for their children or grandchildren. Participants originally from interstate said that they believed that the weather in Queensland caused increased mould, mildew and dust in the home that required constant cleaning. Other participants spoke of the importance of children having access to 'fresh air'. These participants associated children constantly being indoors with an increased risk of RI. On the other hand, being outdoors also meant being exposed to pollution, which was believed to be a strong risk factor for RI. Parents felt that the outdoor environment (unlike the home environment) was largely out of their control; exposure to pollution was seen as unavoidable in urban areas.

As discussed in the risk factor section participants viewed parental smoking – both prenatal and postnatal - as a strong risk factor for RI in children. It was acknowledged that smoking was an important issue in the Aboriginal and Torres Strait Islander community, particularly among young people. An Aboriginal grandmother caring for her grandchildren discussed how she believed her daughter's cannabis smoking had impacted negatively on the health of the grandchildren. She believed that her daughter was in denial about both the extent of her cannabis use and the effect it had on the children.

A parent of a child with chronic RI discussed being extremely watchful of her child, to the extent of not letting any smokers, or anyone smelling of smoke, to come near her son.

> 'And so my husband's a smoker and I don't allow him near my child when he's been out smoking, he basically goes and has a shower before I let him touch the kid.'

One parent described how their asthmatic child had become a heavy smoker as an adult and blamed peer pressure:

> ‘My kids, one older one, he’s still smoking and he’d get asthma really bad and go into hospital and had infections…had pneumonia all that…and yet he’s a heavy smoker. It just doesn’t help and then peer pressure as well, it makes kids do things. I’m very healthy and sporty and I tried to encourage that with my kids, it’s a shame they picked up that’

4.6e Impact on family relationships

Participants discussed how an important part of managing acute bouts of RI was concentrating completely on the ill child and their illness. For parents/carers, this often meant: changing or delaying household duties; rearranging caring duties; changing daily routines; staying with the ill child to monitor their condition; segregating him or her from siblings.

> ‘I don’t sleep…any of the kids when they have asthma, they’re in bed with me, I prop them up so…they’re right next to me so I just monitor them cos they have to take their puffer, at times I’ve had to stay there just to listen to them cos all of their chest is really congested’

> You just don’t come out, there’s stuff when she goes ‘I can’t come out, my daughter’s sick’

The parent’s insistence on being overly vigilant and constant monitoring had a profound effect on siblings. Participants discussed how some siblings were openly resentful of the time and attention paid to the sick child.

> ‘It affects the boys, my son gets cranky, ‘how come you’re spending so much time with T?’ and I’m like ‘because she’s sick’; ‘why are you sleeping with T for?’ So I can hear her breathing during the night just in case she needs a puffer or something’

> ‘Or the big one in our house ‘why have they got to get in your bed, why can’t we?’ Because they’re missing out. It does affect the whole family.’

The mother of a child with cystic fibrosis (CF) discussed the need to keep her child segregated from other CF sufferers and also from siblings and schoolmates when they were ill. She stated that her other children and extended family members were aware of the necessity to stay away from her child when they were unwell. She discussed how, apart from the times of segregation, her other children were involved in the care of their sibling and remained close to him.

> ‘They know not to go near him…it’s like segregation I suppose.’
>
> ‘They (siblings) are totally involved with everything. My 11 year old would give him physio. The hardest thing when they’re sick, because they’re like 2 peas in a pod, always with each other, so if he gets sick it’s okay for her to go in cos what he’s got is usually not contagious to her. But if she gets sick, he wants to go lay with her and make sure she’s ok.’

Several participants discussed how hospitalisation of their child disrupted their daily routines and responsibilities. Participants preferred to access informal support (e.g. family and friends) rather than formal supports (e.g. childcare). Those with a spouse or partner had access to the extra support of their partner but this in turn, placed a strain upon that relationship.

4.6f Interruption of daily routines and juggling responsibilities

Some participants, particularly single parents, viewed their daily lives as so filled with stress; life was a matter of ‘survival’ and thinking in the short term. When their child became ill, routines were thrown into disarray and they were forced to ‘juggle’ complex and often competing responsibilities. For parents and carers of children with RI, managing the illness involved a complicated ‘juggling’ act of simultaneously managing not only the practical aspects of illness (e.g. medication and treatment, arranging care for other children when the child suffered acute episodes) but the emotional aspects, such as guilt, frustration and a sense of powerlessness

> ‘It’s harder when he was younger, trying to juggle six kids at home. When he’s in hospital it’s sort of an upheaval to the house cos you’ve got to fiddle about with the other kids… it’s a bit of a struggle’
>
> ‘You just juggle your family, however. I honestly cannot tell you how I juggled that.’

Some of these parents coped with the help of extended family or friends while others stated that they had family nearby but that their family was not supportive. One mother of a child with chronic

RI stated that she had moved to Queensland in order to be closer to family but that she now regretted her choice to move as she believed she had better support networks where she was previously.

> ‘Well that’s why I moved back to Brisbane, I thought I’d have my family support here. I would have been better off staying in NSW with my friend’s support.’

People without partners had to manage responsibilities differently to those with partners. A married mother of a child with chronic asthma spoke of how the child’s illness had caused tension in her marriage:

> ‘It was very stressful, caused a lot of arguments cos my husband, he had to work and we didn’t have no family to back us up’

> ‘Being in the sole parent situation that just adds to the burden’

> ‘I’ve been a single mum for a while and it’s annoying to have to take all the kids to hospital. You sit there for four hours, five hours before seeing anyone’

4.6g Impact on employment

Employed parents of children with chronic RI discussed how difficult it was to juggle caring for their child and doing their job. One mother of a chronic asthmatic detailed a negative experience she had with her former employer. She stated that when her daughter was ill and had to be kept home, which was often, she felt that her workplace was less than supportive and not ‘family friendly’ at all. The mother talked about how upsetting and stressful it was for her to have to deal with an unsupportive employer alongside the stress of managing her child’s illness. This mother eventually resigned from her job due to: having to take so much time off to care for her daughter; feeling unsupported by her workplace and; feeling increasingly stressed about being unable to balance her roles as parent and worker.

4.6h Parental guilt

Some mothers of children with chronic asthma who had smoked during pregnancy expressed great guilt and regret. They blamed themselves as they attributed their child's current health issues to their past actions. Other participants expressed guilt and frustration when they felt that they had failed in some way to care for or protect their children.

> 'I'm finding it very frustrating cos I feel like I'm not helping him enough. I feel I'm failing him, I feel like I'm not doing enough. Like is there something more I should be doing.' (Grandmother caring for grandchild with RI)

> 'That's what I see with my son, he was born premmie and with a gift bag of health issues attached to him but if I had done anything, I don't think I would have forgiven myself. Please girls, don't do it cos if you're smoking, how can you look at what you've done?

4.6i Issues with use of medications

Participants discussed the appropriate management of medication and the speedy recognition of RI symptoms as important but potentially complicated parts of managing RI. While some children were vigilant about managing their symptoms and medication, other children sometimes failed to self-administer their medication properly; therefore the medication was not as effective. Some children were also slow to recognise their own symptoms of RI. Participants reported that this slowness of symptom recognition often delayed the seeking of treatment and produced some alarming side effects. It also required parents to be more vigilant of recognising symptoms in their children and monitoring their children to ensure that medication was used properly and effectively. One parent reported that she frequently had to chastise her daughter to make sure she used her asthma inhaler properly and that she believed that asthmatics should have regular 'refresher courses' on how to properly use their inhalers.

Due to the chronic nature of asthma, sufferers are required to carry their medication with them at all times in case of an unexpected attack (see also managing medication at school/away from home). This caused parents to feel increased stress; increased concern for the child's wellbeing (and their own lack of control over symptom recognition and medication) when they were required to be away from their home base, e.g. at school or camp etc. Medication in this case included inhalers and a nebuliser machine to improve breathing. Parents of children with chronic asthma discussed buying portable nebulisers for their children to use when away from home. Others discussed how they continually emphasised to their children the importance of having asthma inhalers on them whenever they left the house so that it became part of the child's daily routine. They discussed how they had to use their own judgment regarding the seriousness of an asthma attack; when to continue with medication and when to take the child to hospital for treatment.

Parents stated that they had to remain mindful of always keeping medication nearby due to the potentially fatal consequences of a severe asthma attack. Parents also discussed the difficulty of finding the correct medication for their child, and that when medication did not work, the consequences were often serious. Parents associated better knowledge about how to manage RI with better health outcomes, increased confidence and a more positive self-image. While some parents were extremely vigilant about managing all aspects of their child's RI, others were relatively confident about their child's ability to manage things like their medication.

Another part of managing RI involved dealing with the unwanted side effects of medication. For older or teenage children, some medications produced physical side effects that affected their body image in what they viewed as a negative way. Parents expressed concern about the side effects of medication. One parent of an adolescent daughter with chronic asthma detailed how medication had changed her daughter's voice and body shape. This parent expressed ambivalence about using this medication due to the negative side effects but was told that the only other choice was to place her child's life in danger. Another parent reported that her adolescent son was distressed at the weight gain that had accompanied his use of medication. The son attempted to manage this by increasing his exercise.

> 'He's only tiny but we found the new medication has bunged the weight on him and he's upset – he's really upset about it at the moment cos he plays a lot of sport and he runs 6 kms every morning'

Other children with chronic asthma also managed their condition by engaging in regular exercise. They felt that exercising on a regular basis led to better health outcomes and increased their wellbeing. It is possible that they saw exercise as a positive thing as it was a preventative measure within their control; whereas a large part of asthma management was beyond their control.

Traditional or bush medicine was viewed by participants not only as a cultural practice but a body of knowledge that has been handed down from generation to generation in Aboriginal and Torres

Strait Islander families. Our participants confirmed that it is still in widespread use in urban Indigenous communities. Participants discussed using traditional or bush medicine alongside mainstream medicine to prevent and treat RI in their children. One parent stated doctors had wanted to prescribe steroids to her children but that she had refused, preferring to use traditional medicine instead to treat their RI. Traditional medicine had extremely positive connotations for participants. They associated it with remaining connected to culture, family and history. It was also viewed as both more accessible and more holistic than mainstream medicine.

4.6j Relationship with health system

Families experienced stress and frustration when dealing with the mainstream health care system, particularly within hospitals. One parent of a son with chronic asthma recounted how she and her son had waited for four hours in a hospital emergency room before being seen. She admitted to ‘throwing a big tantrum’. She stated that the doctors wanted to admit her son but the son was so upset by the experience that he insisted on going home instead after obtaining a prescription. Another parent of a chronic asthmatic stated that her daughter became reliant on the nebuliser machine as it relaxed her and put her to sleep. When they relocated to Queensland, doctors told them that the daughter should only use the machine in the case of a severe asthma attack. Other parents of chronic asthmatics discussed different types of medication and how the nebuliser was sometimes the only thing their child could use when in ‘panic mode’ (e.g. extremely distressed at being short of breath).

Parents described the unpredictability of RI and the severity of symptoms, particularly asthma attacks, as frightening for all concerned. They also described how this, along with disagreements with doctors about correct diagnosis and treatment for their child, exacerbated stress. One mother of a chronic asthmatic mentioned how she dealt with her anxiety re witnessing her child struggling to breathe by trying to be as involved as possible in the child’s care and seeking lots of information from the doctors. When their child experienced bouts of acute illness, parents/carers appeared more comfortable accessing informal support, like extended family and friends, rather than formal support like childcare. However, it also appeared that some types of formal support were often unavailable even when participants were willing and eager to access them. One participant mentioned that she and her family had been attending the same hospital for years but had never met the Indigenous Liaison Officer at that hospital. Under these circumstances, it is possible that Indigenous people are utilising extended family and friends for support because supports within the health care system are unavailable, inadequate or unreliable.

4.6k Cultural safety in health care

Participants articulated a tangible difference in the quality of care they had experienced between Indigenous-specific health care and mainstream health care. The majority of participants accessed Indigenous-specific health care at the primary level and had positive things to say about the quality of care and cultural safety of these health care services. However, health care at the tertiary level, which was mainstream (e.g. non-Indigenous specific) and focused on the biomedical perspective, was the target of sharp criticism from participants, who recounted negative experiences they had had. Participants' statements indicated that cultural safety and cultural respect in health care were important to them.

> 'They are really nice out there at Murri Medical'
>
> 'When I went out there in so much pain, they couldn't do enough for me'
>
> '(Doctor) is lovely…he would have to be the most culturally aware and respectful man towards Aboriginals that I've ever come across'

4.6l Parental assertiveness within health care

Within mainstream health care, parents felt entitled to openly challenge the actions of the health care professionals caring for their children. This assertion of power by parents was associated with good parenting and better health results for children. Increased assertiveness of parents was also associated with high levels of parental vigilance, mistrust of the mainstream health care system and a sceptical attitude toward doctors. Assertiveness could be viewed as a potential defence mechanism against being negatively judged and disempowered within the health care system. However, there were also negative effects associated with parental assertiveness including: a greater workload of responsibility; increased stress for parents; exacerbation of parental guilt and frustration, particularly when parents perceived themselves to be inadequate in caring for or protecting their children and; greater reliance on extended family and friends for emotional and practical support.

4.7 Summary of focus groups with parents/guardians

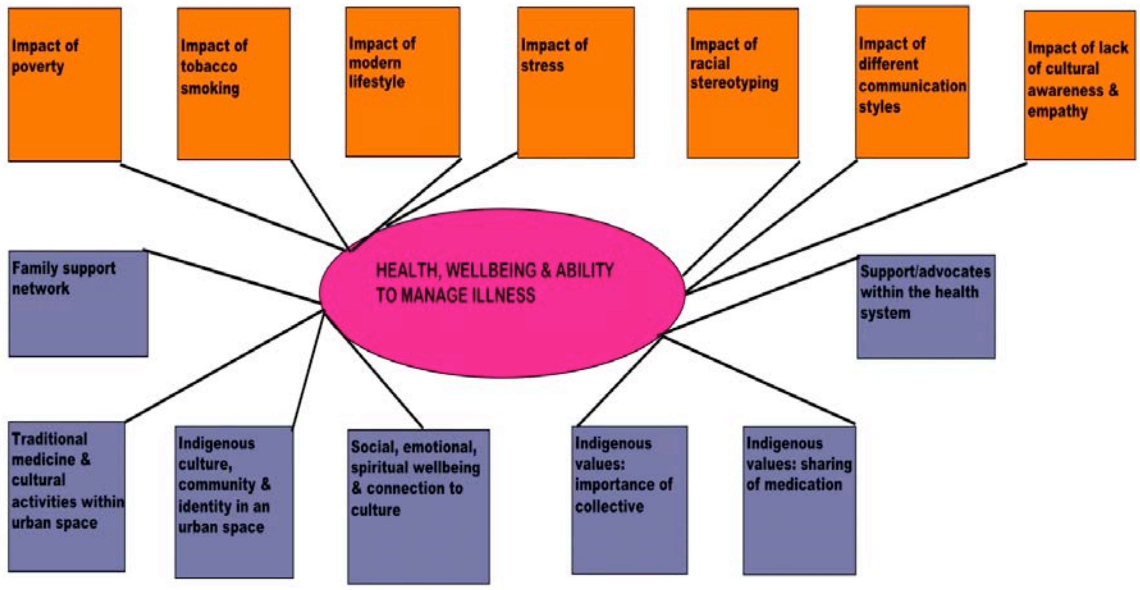
In summary, participants brought forth themes and subthemes from the original researcher questions employed to prompt discussion. Participants were frank and open about expressing themselves. Some of the focus groups veered off into discussions that were not specifically about RI but were valuable in providing a bigger picture about the type of daily stresses experienced by participants, their concerns, their lived experiences with racism and generational disadvantage, and their struggles in raising their children and grandchildren.

The majority of protective factors identified by participants were associated with traditional Indigenous culture and values. This indicated that these urban participants viewed the maintenance of links to their traditional culture and values as vital to the good health and wellbeing of their families. Participants viewed the health issues of their children in the context of Indigenous cultural values, specifically the values of caring, reciprocity and collectivism. Participants spoke of how they managed their child's illness with the help and support of others (family members and friends) and the difficulties they encountered when this support was unavailable. They spoke of how the management of their child's illness impacted upon their other carer responsibilities and relationships (with their partner, other children, and elders). Participants identified their health issues (and those of their children) as located in the context of their history. This included family, personal and community history as well as the general history of Indigenous people.

4.8 Indigenous Research Reference Group (IRRG) Yarning

As discussed in the methods, the IRRG Yarning took place during a scheduled meeting of the group at QCMRI and was a challenging session to facilitate, transcribe and interpret. The major themes identified by the group are illustrated in Figure 4.5 and discussed in detail below.

Figure 4.5. Predominant themes identified in IRRG Yarning



4.8a Social, emotional, spiritual wellbeing and connection to culture

Participants spoke of how important it was to their emotional and spiritual wellbeing to remain connected to country (their traditional land) even when they lived and worked in an urban setting. This often involved taking time out from their daily lives, travelling long distances and enduring discomfort and inconvenience. However participants felt that the healing benefits gained outweighed the negatives. Participants expressed concern about young Indigenous people in urban areas, who they felt were becoming disconnected from their traditional culture. The disconnect from culture was associated with a lack of social, emotional and spiritual wellbeing. Participants stated that this was an issue of concern that needed to be addressed but were unclear about possible strategies.

> ‘Since going back home it felt like I was being held, I was being hugged, I was being caressed. I need to go home, that’s something that is so strong, even though I’m living in an urban setting I still have to go back home, I still have that strong link and my children are starting to show that as well’

> ‘As a healer, you look at the spiritual reasons around why there’s a physical manifestation and fundamentally at the bottom of all our chronic diseases is that disconnect from culture, country and spirit, and ritual and ceremony, it’s a fundamental need’

> ‘People are so…especially the young ones, getting so separated from their culture and, and spirituality’

4.8b Traditional medicine and cultural activities in an urban space

Participants agreed that the majority of Indigenous people in urban areas still practiced traditional or ‘bush’ medicine; sometimes alongside conventional western medicine and sometimes in isolation. They added that they believed the mainstream health system and non-Indigenous health professionals often demonstrated a lack of respect or regard for traditional Indigenous medicine, which forced Indigenous peoples to practise their traditional medicine covertly. This often meant that people were taking conventional medication and traditional medication simultaneously, without the knowledge of their health practitioner. As participants pointed out, this practices often led to patient confusion about the effectiveness or otherwise of both types of medication. It also had the potential for dangerous health consequences for those who were accessing both types of medicine simultaneously. A participant pointed out that the popularity of traditional medicine amongst Indigenous peoples was understandable as it appeared that Western medicine was not having a discernable impact on the health issues of Indigenous peoples.

> ‘I would say 99 to 95% percent of all (Indigenous) people do their bush medicines secretly from their western medicines. There are stories, anecdotal evidence of somebody taking western medicine and then doing their bush medicine, they were getting worse. Are we killing our people with these two mixtures? Because our chronic diseases aren’t getting any better yet western medicine is supposed to have the answers’

> ‘Within health we’re still pushin the cart uphill especially about traditional medicine, because (mainstream) don’t understand it, they won’t listen to the Elders that know all about it and because it’s not written, it’s only oral, they don’t want to know’

> ‘It’s not (seen to be) evidence based’

> ‘Some of the communities, they’re definitely proudly showing and sharing their stories about their traditional medicine but what they’re also saying is that our mob are taking the western medicine first then coming back to traditional medicine when the other one isn’t working and therefore leaving it too late’

Participants discussed how traditional Indigenous cultural activities, including food gathering, can be practiced in an urban setting. They also discussed the importance of maintaining these cultural activities within an urban setting.

> 'Yeah, so that's the sort of thing I think would be really good if we had somewhere close to Brisbane that we could have bush tucker too, some of the stuff down near the bay, the walkways and stuff'

> 'Maybe there's space somewhere for an Aboriginal medicine garden or bush'

> 'They've got a bush garden up there. The community that lives there has created it…It's not a large garden but it's important what they've got there'

4.8c Maintaining Indigenous culture, community and identity within an urban space

Participants discussed the difficulties of maintaining their Indigenous identity, culture and communities within an urban, largely non-Indigenous space. They stated they felt there was fragmentation, clashes of interests and a lack of unity within the larger urban Indigenous community. They also felt that there was a general negative perception of urban Indigenous people by non-Indigenous people; they pointed out the irony of various non-English speaking background groups in Brisbane having their own community centres while the gathering of Indigenous peoples in urban spaces was perceived (by the non-Indigenous) to be anti-social, deviant and threatening.

> 'There are a number of little community groups now that are springing up but we just need to make better use of them'

> 'But it's all fragmented'

> 'In one suburb, in urban centres, there could be ten different community groups within that one suburb. Caboolture's got a diverse Aboriginal population out there, Redcliffe…there's a huge Aboriginal population'

> ‘I mean, you look at the non-English speaking background, you know, they have their clubs’

> ‘We have one, it’s called Musgrave Park (laughter) and the police move us on (laughter)…’

> ‘Again it’s about the perception of the gathering of Aboriginal people, there’s gonna be drunks and fights’

> ‘I mean the fact is we sit under trees…try sitting under a tree down there and see how long you last…and you know just doing your usual thing, which is sit under a tree, you’ll find yourself locked up’

> ‘It’s more than NAIDOC isn’t it, it’s more than just having that celebration one day of the year, okay we’re Aboriginal, raise the flag, forget about us for the rest of the year, we’re still there, we’re still celebrating our culture’

> ‘From then on you know there’s one day of the year when Musgrave Park is a safe haven and then for the rest of the year it’s the Gaza strip’

> ‘What do you have to do to turn Musgrave Place into a safe place? The Elders are saying the cultural centre down there, nobody wants to give the money for it or when they have consultation there’s so many different desires expressed there’s a clash, the groups that meet can’t come to a common solution so… Musgrave Park remains one of those no-go areas which is such a dreadful shame’

The majority of IRRG participants were originally from remote or regional areas, therefore their perspectives were quite different to the previous focus groups (comprising Indigenous people from urban communities) who had discussed the importance of maintaining their connections within an urban Indigenous community. Participants discussed the many challenges of living in an urban space as an Indigenous person including the risk of invisibility e.g. their mere presence challenged the widely held notion that ‘genuine’ Indigenous people only lived in remote areas and that there are no ‘real’ Indigenous people in urban areas.

> ‘You become an invisible blackfella in an urban setting, really’

> ‘People don’t even know what race you are, they’re like ‘what kind of background are you’ and I’m like, well I’m Indigenous’

> ‘Coming down to Brisbane, it’s really isolating. It’s like you do lose identity as well and there’s no family support and it’s hard trying to reach out to services…I don’t really know any’

4.8d Modern lifestyle and effect on health

Participants stated that they believed the modern lifestyle; (including diet, technology, social media and advertising) had a negative effect on the health of Indigenous people, particularly young Indigenous people. They also stated that they believe modern lifestyles, including the widespread use of technology and social media had caused young Indigenous people to become disconnected from their traditional culture and caused social and emotional dysfunction in the Indigenous community.

Indigenous peoples, particularly young Indigenous people, and their culture are becomingly increasingly affected by the inevitable collision with modern consumerist culture. The advocating of a temperate, healthy lifestyle for young Indigenous peoples is at odds with the mainstream media promotion of materialism, excessive consumption and Eurocentric ideals of beauty (Chaturvedi, Arora, Dasgupta and Parwari, 2011). While the older Indigenous participants in the IRRG focus group exhibited a cynical attitude to the media, they believed that young Indigenous people were vulnerable to the unhealthy narrative offered by mainstream media and advertising.

> ‘Technology is very detrimental to our social and emotional wellbeing’

> ‘With the youth, it makes you sedentary, they don’t get out and move around, they don’t eat right foods, you know they see TV ads, and they eat processed foods. Particularly with our young uns, their lifestyles changed, they’re not so much interested in culture, and they go toward the American way of living’

> ‘They’re on (social media) they’re not so much playing sport, sitting down, glued to that computer’

> ‘I am an absolute believer that no Aboriginal person should have gluten. We should not touch wheat. It has a shocking effect on us. Dairy and gluten are really detrimental to Aboriginal people as a whole’

Participants stated that they believed mainstream media, social media and advertising had an extremely negative effect on the physical and emotional health and self-image of young Indigenous people. They believed that the healthy traditional Indigenous narratives were being replaced by unhealthy modern Western (or international) narratives produced by mainstream social media and advertising. One participant pointed out the irony of sporting events being used to promote ‘junk food’ products:

> ‘What they see on TV… our young people are listening to that garbage and getting sick from it’ (male Aboriginal elder)

> ‘And the effect on our girls are wanting to be slim and barbie looking…its bullshit…women aren’t meant to be built like that’

Participants associated the widespread use of social media by young Indigenous people with negative consequences like bullying and self-harm.

> ‘That’s a big problem that I can see, the bullying on (social media)’

> ‘And the bullying that happens, it’s huge, it’s resulted in suicides.’

4.8e Impact of poverty on health

As stated by Altman (2000), “As a group, Indigenous people have the lowest economic status of all Australians, without any qualification”. Altman adds that Indigenous economic disadvantage is so deeply entrenched that it appears “intractable”. Focus group participants agreed that poverty was widespread in the Aboriginal and Torres Strait Islander community and had a profound effect on the health of Indigenous peoples, particularly when resources are scarce and people have to choose between paying for medication and buying daily essentials. Two participants associated poverty amongst single parents with a lack of social or family connections as factors that impacted negatively on children’s health. This reinforced the findings of previous focus groups where single parent participants discussed how difficult it was for them to manage their child's health without the practical and emotional support of extended family/friends.

> 'It impacts upon every hour of every day, in what you do, how far you can go out and see friends, how you can meet with family, how you can participate in things. You've got to get there, you've got to get back, if you've got a car you've still got to get petrol. So your income impacts upon every day of your life'

> 'Access to transport in emergencies, I think that's so important, when you've got a mum out in the suburbs. This is happening more and more as we get our families, the single parent families, mums living by themselves' (Female Aboriginal elder)

> 'Yes, income has a huge impact when a person and often they're single parents, looks at, do I pay rent, electricity, water and food or that medicine. It's gonna go down the list of priority'

> 'With the medication they're not buying the medications cos all the other factors such as your rent and electricity and there's the gambling, there's the alcohol, the cigarettes, cigarettes are seen as far more vital to their life than medication'

4.8f Family support network

Participants emphasised the importance of having a strong support network of extended family and kin during times of crisis (e.g. when a child suffers an episode of acute illness). They also pointed out that it is part of the Indigenous cultural tradition for caring arrangements to be flexible and not focused on the nuclear family (e.g., grandparents being the carers of the child rather than the biological parents). They also discussed how family members or family friends can act as advocates and assist in navigating the complexities of the health care system.

> 'There are a lot of grandparents that are actually the carer of the child, not the mother itself'

> ‘My experience is that educating the young mother is through the grandparent, whatever mum says, the mother does. Mother knows best. They play a really traditional Indigenous role’ (male Aboriginal elder)

> ‘But even someone in their own family…who may have more education or may understand the English better, who is a strong person…we have em all in our family.’

> ‘I think that’s about mum’s education too. Education and knowledge about the illnesses and when to panic. Sometimes young mums do miss those cues that something’s happening here’ (Female Aboriginal elder)

4.8g Connection to culture and community

Participants stated the importance of urban Indigenous people remaining connected to their community, family and culture. Some participants with children emphasised that they made an effort to ensure that their children remained connected to Aboriginal culture and country (traditional lands). Lack of an ongoing connection to land, culture and community was considered extremely detrimental to health and well-being, particularly amongst young people, and was associated with increased levels of stress.

> ‘It’s critically important. It’s culture’

> ‘It’s the number one priority, staying connected to your community’

> ‘When they become isolated, they then suffer stress, emotional. Just having people around that can help you does make a huge difference’

> ‘It’s the time when you actually relax, when you’ve got family around you’

> ‘That’s a community thing…whether you’re in a traditional situation out in the bush or whether you’re in Inala……you get to know the community and you go to the health centre because your cousins there or somebody and you connect. It’s important, to keep in touch with your community, it’s vital’

> ‘Not with the younger ones. Modern life and technology is eroding all that’

> ‘I try to take (my children) back, go hunting and camping So I try to keep them connected by taking them back. When they’re there, they have a ball, they love it. They appreciate just not having technology and it’s all the simple stuff. They really appreciate their lifestyle. I think it’s important to take em back’ (Aboriginal mother of three)

A male Elder discussed his experiences acting as a mentor and cultural educator to young Indigenous males, who found it difficult to access their culture in other ways.

> ‘They got a majority of kids that are looking for their culture. And they’re not getting it. So they’re drop outs, and they’re walking the street, so we give em, that cultural thing for em, I go in as the Elder and I do stories and bush medicine and bush tucker. They’re tying into their culture cos they’re not getting that where they are’

4.8g The impact of stress

Participants discussed the prevalence of stress in the Indigenous community and the profound effect it can have on the health and wellbeing of Indigenous peoples, particularly young Indigenous peoples. Stress was associated with experiencing racism, bullying, substance abuse, mental health issues, lack of physical exercise, lack of self-care and wellbeing. All these factors were considered to be inter-related. Stress was also considered to be hereditary.

> ‘It’s all inter-related…you know, racism causes stress…yeah so they’re all very influential and they’re things you end up passing down to your children’

> ‘So much illness is stress related. Not just mental health problems but worrying, they’re not eating properly, they’re not exercising. If you’re sitting there and you’re brooding over things that have happened, like racism and then you’re getting stressed. Don’t ever underestimate the stress on anybody’

> ‘They get bullied all the way through school, up to high school…the stress they got to go through. And when they stressed out as young people, what do they go to? They go to alcohol’

4.8h Cigarette Smoking

Participants discussed the prevalence of smoking (including passive smoking) among Indigenous people, what they thought were the reasons behind this and the health consequences. Stress was mentioned as a reason for smoking, as were hereditary factors and the historical media promotion of tobacco smoking as a fashionable activity. There was an acknowledgement that the QUIT campaign (anti-tobacco) campaign had had some positive effects on the smoking habits of Indigenous people but that this could be misleading as some of the effects seemed to be superficial. Participants also acknowledged the highly addictive nature of smoking and the trans-generational effects on families and children.

> ‘They smoke cos they’re stressed’
>
> ‘And because they’re born addicted too, they’re born into it, born into families that smoked’
>
> ‘Then there was the media, up until recently it was deadly to be smoking a cigarette, very sophisticated…’
>
> ‘You know it’s a combination…maybe if you have a cigarette it’ll deaden the hunger pains’
>
> ‘But it’s just so addictive. And of course that’s affecting IQ of the kids
>
> ‘The flow on effect is huge’
>
> ‘Yes, yes, it’s trans generational’
>
> ‘Grandmothers too can often be the biggest smokers, you see the grandmother with the newborn over here ’
>
> ‘Smoking at the same time, as she’s got the little one on her shoulder’
>
> ‘Passive smoking is a huge issue’

> 'They're ticking the box saying 'yes, I'm doing the right thing' but it's the other things, that really need to be addressed as well and people need to be educated in'.

4.8i Indigenous values: the importance of collectivism

As pointed out by Thompson, Gifford & Thorpe (2000) in their study of urban Aboriginal people with diabetes, the family and community obligations of Aboriginal people often take precedence over self-care and the health of the individual:

> "Aborigines stress how taking care of family relationships, both within the household and outside of it, is of greater importance than one's own individual physical health needs. Aborigines give priority to maintaining and nourishing the social health of the family unit over the physical health of any one individual. The risk or outcome that is worse than (illness) is the risk of being disconnected from one's family" (p 9, p11)

One participant specifically discussed how Indigenous parents prioritise the needs of children or grandchildren over their own, and how this lack of self-care can lead to further health complications for the parent. This participant advocated education as a way of improving health outcomes for Indigenous parents:

> 'The mother won't think about her own health but she'll put her children's health first or the grandmother will put grandkids health first and it's about their own awareness, okay they'll buy medication for their kids rather than for themselves. You know, we're not looking after ourselves as well'

4.8j Indigenous values: sharing of medication

Participants discussed the trend of medication sharing between Aboriginal and Torres Strait Islander peoples with health issues. This was a theme that was not brought up in any of the previous focus groups; therefore it may be a trend associated with adult, rather than paediatric patients. Some participants attributed medication sharing to: poverty in the Indigenous community and the perception of medication as being a non-essential item; a lack of knowledge about the correct use of medication, and; the Indigenous cultural tradition of sharing resources. Medication sharing, like the practice of traditional medicine, was seen as a covert activity that medical professionals were kept uninformed about.

> ‘We say to doctors, and pharmacy ‘don’t give our mob medication to be taken three times a day with a meal, our mob eat one meal a day’. And the other thing is, just cos you got a heart condition; don’t go giving it to your cousin cos they think they got the same symptom’

> ‘They don’t understand that that’s…yes it’s a community education problem but it’s an education problem within the health system. It’s really important. The doctors got to be aware of all these factors’

> ‘We get our mob, and I see this frequently, they share the puffer or they get an extra puffer for brother over there cos he needs it more than me or I won’t take all my antibiotics because cousin there might need it so they’re not taking the full amount of medication’

> ‘I found a group of women where one of them was supplying insulin to everyone…no testing; they assumed that they were diabetic so they were injecting themselves with insulin. I nearly died…there’s no way they were going to the doctor’

A study of the perceptions of Aboriginal Health Workers confirmed that the sharing of medication is a significant issue amongst Aboriginal people: “(medication) sharing had a two pronged effect: the person prescribed the medication had less available to take, and the person provided with the medication may not seek medical assistance.” (Hamrosi, Taylor & Aslani, 2006). The authors theorise that medication sharing may be a ‘cultural phenomenon’ amongst Aboriginal people due to the importance of collectivism and reciprocity in Aboriginal culture and values.

4.8k The impact of different communication styles

Participants discussed the difference in communication styles between non-Indigenous health professionals and Indigenous people, and how this often led to misunderstandings and gratuitous concurrence, which is a cultural tradition of Indigenous people (regardless of their true feelings) agreeing with authority figures in order to avoid being offensive. It was also attributed to non-Indigenous health professionals not communicating effectively enough with Indigenous patients/families and failing to provide the appropriate information about treatment, medication etc.

> ‘That would be 99% percent of our mob, they wouldn’t have a clue what the hell was going on’

> ‘No there’s no educational stuff. Practitioners like you say in that age group, when you walk in their surgery…they see colour…there’s no question about it. And there’s no education or understanding about the client or explaining about medication and what’s going to go on. (Indigenous patients) don’t understand one iota, they don’t have a clue’

> ‘(Indigenous patients) say yes cos they don’t want to offend anyone’

> ‘But doctors need to say that to our young people that don’t understand the medical condition that they’ve got and need to give em a proper educational information of what diseases they’ve got and how it’s going to go when they take this medication’

4.8l Racial stereotyping and assumptions

Participants discussed at length what they described as negative racial stereotyping, e.g. non-Indigenous health care workers automatic classification (prior to any type of assessment) of Indigenous patients as unhealthy or as substance abusers merely due to their racial/cultural identity. Racial stereotyping was associated with lack of cultural safety, poor cross cultural communication and racism within the health care system. Participants cited specific incidents concerning Indigenous patients and non-Indigenous health workers that they had witnessed or experienced, and expressed anger that these incidents were still occurring.

> ‘They make all these assumptions just cos you’re Aboriginal. I think it’s the health care professionals that need to do some cultural safety training in the way that they communicate, the way they make incorrect assumptions all the time’

> ‘They make assumptions, you know, I’m an Aboriginal woman, 64, I must have diabetes, cholesterol, blood pressure. I haven’t got any of them’

> ‘We’re all put into one basket and targeted…’

> ‘Its racism, ignorance…cos of stereotypes’

Participants also discussed the negative impact that racial stereotyping and lack of cultural safety had on Indigenous people’s experiences in health care, including miscommunication, misdiagnosis and non-compliance. They stated that they believed that the lack of cultural safety in health care was highly detrimental to and for Aboriginal and Torres Strait Islander peoples and their health outcomes. Lack of cultural safety in mainstream health care was attributed to poor training which failed to equip health care workers/professionals with the tools to provide a culturally safe space in the health care system for Indigenous peoples; also to a general lack of interest amongst health professionals in cultural safety. One participant acknowledged that lack of cultural safety could also be attributed to health professionals having a large caseload and not having enough time to ensure effective cross cultural communication or create culturally safe space for Indigenous patients.

> ‘It stops people from accessing health care’
>
> ‘If you’re going to go across and get treated like that, why would you go near the place?’
>
> ‘It’s a combination of racism, lack of understanding. But the medical professional trains health professionals to look at body parts and not individuals. They’re overworked, therefore they’re time poor and they have a lack of actual interest in cultural awareness. They carry a lot of stereotypes and we’ve proven that culturally insensitive communication not only definitely results in poor diagnosis, it ends up with then through the lack of communication, Aboriginal people just shutting down, they don’t follow through with their medical regimes. So they don’t take their medication, they don’t do the exercises or the diet…so you have a break down both in figuring out what’s wrong, and they miss so many things, so misdiagnosis and then noncompliance with their health, medical regime’

Participants gave anecdotal evidence about when they had witnessed Indigenous people in the health care system be incorrectly stereotyped (by non-Indigenous health professionals) as homeless or alcoholic.

> ‘The doctors are bad but I reckon, worst of all are the nurses…they are a shocker…the rough treatment they give to our people. And okay so a man comes in as a repeat offender for alcoholism. So what, it’s a human being that needs care’

> ‘Cultural empathy, that’s very important’

4.8m Advocates within the health system

Participants stressed the importance of Indigenous people having access to supports within the health system (e.g. Indigenous liaison officers or health workers) as well as informal advocates and extended support networks to help negotiate the complexities of the health system, particularly when the patient or family felt intimidated or less confident.

> ‘One way to try and circumvent people being shy, is that’s one of the reasons we pushed so heavily to have hospital liaison officers who then be advocates or you encourage the patient to have somebody from the family that be there that will speak up’

> ‘But if you’ve got a patient that you can see is really withdrawn and shy, maybe they’ve got a history with the Aboriginal medical centre back where home is, you ring to speak to one of the workers there who can advocate and be the communication liaison for that patient’

Participants also discussed how budget cuts were having a negative impact on the delivery of culturally appropriate health services to Indigenous peoples. Participants who had worked in community health pointed out that teams had been drastically cut and they believed this had a negative impact on the capacity of some health services to deliver culturally appropriate services.

> ‘Of course things are not getting better with the load on the doctors these days cos there’s more patients, less doctors and we’re in a crisis situation with medical staffing, so that’s impacting, they don’t have the time to listen’

Participants stated that they believed in the effectiveness of advocacy on a macro as well as micro level e.g. high profile or more powerful Indigenous people advocating for the rights of the less powerful, could help provide positive changes in health service delivery for Indigenous people in general:

> ‘You’ve got to fight and you’ve got to agitate and it’s gotta come from the community.’

‘Also empowering some of our younger Elders…generations coming through’

‘And you got a lot of Aboriginal doctors around, harness them’

4.8m Summary of IRRG findings and relationship to the yarnings

Participants in the IRRG focus group discussed the unique issues that Indigenous people face when living in an urban setting. They discussed the fragmentation and lack of unity in urban Indigenous communities. Indigenous people were viewed as ‘invisible’ if they failed to fit the mainstream stereotype of Aboriginal people. If visible (e.g. on National Aboriginal & Islander Day of Celebration (NAIDOC) day or at public gatherings) they were viewed as a threat to the larger mainstream community and in need of authoritarian regulation/control. They noted the lack of safe Indigenous spaces in urban settings, particularly when compared to spaces set aside for other types of minority groups.

The IRRG participants analysed the issues of Aboriginal and Torres Strait Islander health in the wider context of society, public policy and human rights advocacy, as opposed to other participants, who viewed health issues in the immediate context of themselves and their family. In the IRRG group, there was an acknowledgement of (and empathy expressed toward) the struggles experienced by non-Indigenous health professionals who work with Indigenous families. There were explicit (as opposed to implicit) discussions of racism and racial stereotyping in health care and the importance of culture for Indigenous people in urban settings. The IRRG focus group participants discussed the covert use of traditional medicine in tandem with mainstream medicine, including the phenomenon of medication sharing and medication hoarding. Health behaviours and concepts of wellbeing were linked with Indigenous cultural traditions and values. They also discussed some of the negative aspects of Indigenous cultural mores and the negative impact that mainstream/social media and modern technology has had on young Indigenous people. Like the other participants, they discussed the importance of cultural safety in health care, good communication between Indigenous families and health professionals, support network, the links between stress, poverty and ill-health. They also stressed the importance of Indigenous people in urban areas remaining connected to their culture, extended family, community, values and land.

4.8n IRRG focus group recommendations

At the end of the yarning, the group discussed what they considered would be key recommendations for improving the health of Aboriginal and Torres Strait Islander peoples. The key recommendations are listed below:

- Improved cultural awareness/cultural empathy training for health professionals, including examining the effect of Indigenous culture and values on Indigenous peoples health (e.g. compliance, sharing of medication)
- Education for health professionals about the use of traditional medicine by Indigenous people
- Two way educational system that targets health professionals and Indigenous people who utilise the health system, in order to: improve communication, enhance understanding, circumvent treatment/compliance issues and improve health outcomes
- Increase the use of health promotion for better Indigenous health outcomes
- Improve sobriety in the Indigenous community via an anti alcohol promotion strategy similar to the anti-smoking strategy

CHAPTER 5. Discussion

This study aimed to inform the development of future research and interventions by gaining an understanding of Indigenous contexts and perceptions of risks for, and impact of, RI in Indigenous children. Specifically, I aimed to examine the cultural context of these issues as they relate to Aboriginal and/or Torres Strait Islander children with acute and chronic RI in an urban setting.

The study's two main objectives were a) to explore risk for RI as perceived by the parents of young urban Aboriginal and/or Torres Strait Islander children from within an Indigenous context, and; b) to explore the impact of these illnesses in urban Aboriginal and Torres Strait Islander children, their families and communities from within an Indigenous context. Although the sample size of participants was relatively small, the information provided about their experiences with RI was rich in texture and detail.

As stated by Thompson et al (2000), "risk factors relating to health outcomes can only be understood in terms of their social meanings and consequences, recognising the important role that social identity, connections, and sense of coherence and control play in the physical configuration of risk". The information from the participants demonstrates how deeply their beliefs and past experiences impact upon how they perceive RI. This in turn, heavily influences how they manage RI in their children. Thus, it is important for health care professionals involved in the care of Indigenous children to be aware of the health beliefs and perceptions of the parents and other carers.

In this chapter, I discuss the study's findings with respect to the major themes identified and how they relate to existing literature. As indicated in Chapter 4, many of the themes overlapped in many ways and recurred throughout the major categories of risk, protection and impact. Further in this chapter, I discuss the strengths and limitations of the project and the implications they have for the validity of my research.

5.1 Common Themes

Stress

Stress was a theme that consistently recurred in discussions about the risk factors for RI and the impact of RI. In other words, stress was seen both as a risk factor **for** and a by-product **of** RI (e.g. stress was perceived to cause RI and RI was perceived to cause stress). Stress was a factor with wide-ranging impacts, affecting the entire family as a whole. Studies have shown that chronic stress has profoundly negative effects, particularly on the growing brain of adolescents and children. For Indigenous peoples, the consequences of intergenerational trauma can be experienced by entire communities and affect current and future generations. This can present in increased risk-taking behaviour as well as learned helplessness and disempowerment (Lui and Alameda, 2011).

Participants recounted their feelings of anxiety and distress when their child became ill. The parent's reactions are not uncommon, as the link between stress and asthma has been well established by the literature. The distressing nature of asthma attacks often provoked emotional responses from the child and their family which included fear and anxiety. In a 1996 study of paediatric asthma patients and their parents, the children with asthma had a higher rate of anxiety disorders than a comparison group of healthy children. The asthma patients and their parents also displayed higher rates of stress (Bussing, Burket and Kelleher, 1996). The study of Callery et al (2003) into the beliefs of parents and young people around childhood asthma found that the parents experienced great fear and anxiety around acute asthma attacks in their children (Callery et al., 2003) and that this anxiety influenced how parents perceived the child's illness. The Bussing et al study discussed the common issue of anxiety symptoms being misinterpreted as asthma symptoms and vice versa. Our participants also discussed their confusion when attempting to distinguish anxiety attacks and acute asthma attacks.

Participants expressed feelings of powerlessness, frustration, isolation and alienation in relation to their child's RI, particularly when it came to dealing with the mainstream health care system and health professionals. For some participants, stress was an intrinsic part of their lives and they viewed just getting through each day as an accomplishment. Those without a reliable support system spoke of how they felt isolated and alone in trying to manage their child's illness. Yet all participants, regardless of how disadvantaged or unsupported, expressed an extremely stoic and resilient attitude.

Resilience

In their study of Canadian First Nations children in care, Flynn, Dudding and Barber (2006) discuss the concept of resilience as it applies to Indigenous peoples and communities. They begin by rejecting the common notion of resilience as a personal trait and define it as a process that involves interactions between individuals, families and communities.

The authors link resilience to the ability of Indigenous peoples, communities and cultures to adapt without losing identity. They argue that Indigenous peoples have sought to preserve continuity and identity through time by emphasising sameness in those aspects that have endured. Similarly, our participants have preserved their cultural and collective identity by viewing RI through the lens of their family history; they understand their child's RI by linking it to the RIs experienced by their elders and other family members. This narrative created a sense of continuity and meaning by the connection off present day events and children to past occurrences and long-departed relatives. This is the framework that people employed when attempting to manage their child's RI and negotiate with the mainstream health system (Flynn et al 2006).

Social and emotional wellbeing

RI was perceived as detrimental to emotional and social wellbeing. Stress was lessened when the parent had: access to a reliable support network to manage their child's illness; access to culturally safe healthcare; access to information and education about RI; a degree of control over the management of the child's RI. Numerous studies have noted the benefits of parents becoming more involved in the care of their hospitalised child. Apart from relieving parental boredom and anxiety, it was shown to improve the relationship between parents and health care professionals (Palmer 1992). The literature also illustrates that the social and emotional wellbeing of the carer has a profound impact on the health outcomes for the child. A study of Spanish-speaking children with asthma and their caretakers in an urban area by Weil et al (1999) found that ineffective parenting associated with parent/carer mental health issues can impact negatively on the management of their child's RI (e.g. compliance with medication regimes). The researchers also highlight the reciprocal nature of psychosocial issues and chronic illness. In other words, chronic illness negatively impacts on social and emotional wellbeing; while psychological issues negatively impact on chronic illness (Weil et al 1999). Similarly, our results found that parents found managing RI in their child provoked their own anxiety, fear and stress; in turn, these psychological effects had a negative impact on the parent's ability to manage their child's RI.

Heightened Parental Vigilance and Parental Quality of Life

In their study of 40 African-American parents of asthmatic children, Mansour et al (2000) categorised the heightened sense of vigilance parents felt as 'parental quality of life issues'. Their participants described caring for their sick child as having a negative impact on their own quality of life. In particular, they described the vigilance with which they had to keep watch over their children as emotionally and psychologically draining. Like our participants, these parents described experiencing feelings of fear and anxiety around their child's RI. They also expressed a desire to have more control over the management of their child's RI (Mansour et al., 2000). Studies done in Great Britain of mothers' beliefs and perceptions about illness have found that mothers wanted to have their parental competence recognised; have their concerns taken seriously by health professionals; have their knowledge recognised (Mayall 1986; Cunningham-Burley & Maclean, 1991). The researchers speculated that these concerns could be related to the possible perception of mothers that the illness of their child meant that their parenting skills were called into question.

The study of Callery et al (2003) into the beliefs of parents and young people about childhood asthma, the parents sought to balance often complex conflicting concerns (e.g. between managing the child's symptoms and managing the quality of life of the family as a whole) by attempting to minimise the impact of their child's asthma on themselves and other family members. Parents made subjective judgements about what they considered to be a 'tolerable' level of asthma symptoms in their children. Parents did not follow the advice of health professionals to the letter but modified asthma management plans according to their own beliefs and concerns. Like our participants, the perceptions and beliefs of these participants regarding asthma were influenced by their past experiences with asthma. Thus the beliefs and perceptions of parents had an important impact on how they managed their child's asthma (Callery et al., 2003).

Aboriginal and Torres Strait Islander Culture

Participants discussed the importance of remaining connected to their culture and values. These included: reciprocal & communitarian values; traditional medicine; food and activities; fulfilling familial and kinship obligations. The loss of Indigenous culture and values was associated with risk factors like parental neglect.

In their study of Australian Aboriginal people's experience of social capital as it related to health, Browne-Yeung et al (2013) found that maintaining links to culture had both positive and negative effects. Retaining connections to family and friends was viewed as extremely positive for participants. However, fulfilling cultural obligations also had some unwanted negative effects, such as the, often unbalanced, nature of reciprocal arrangements, which placed excessive stress and demand on individuals. Connection to culture was maintained by identity and participation and both were linked to increased social capital (Browne-Yeung et al., 2013).

Hereditary or genetic predisposition was perceived both as a risk factor for RI and an impact factor. Participants associated RI with other family members in the past (including those who had passed away from RI). Hence RI was located as a part of familial history and used as a point of reference. RI was also associated with other forms of cultural knowledge. Traditional healing/bush medicine rituals were associated with RI and certain locations were perceived as 'worse' for Indigenous people with RI. As noted by Chaturvedi et al (2011), "Cultural constructs…continue to influence communities even after acculturation and rural-urban migration. They need to be factored while designing health programs that facilitate integration of traditional and modern practices"

Cultural safety in health care

Participants emphasised the importance of cultural safety in health care. The majority of participants stated a preference for accessing primary health care that was either Indigenous-specific or Indigenous-friendly. However, when it came to accessing tertiary health care, they were forced to use mainstream systems, which they found culturally unsafe and inappropriate. Participants noted with disapproval the lack of holism and biomedical focus of mainstream tertiary health care. Sunday and Eyles (2001) examined the differences between the biomedical narrative and the narrative of Canadian First Nations peoples around diabetes and concluded that while both narratives linked the improvement of health to a moral intervention, the biomedical perspective targeted individual lifestyle changes while the Aboriginal perspective advocated utilizing traditional forms of knowledge to restore health (Sunday et al, 2001).

The different values of Indigenous and non-Indigenous peoples regarding health can be linked with: their different definitions of health and; different views regarding the agency of the individual in relation to health. For patients and families, the experience of illness (e.g. the stress and disruption it caused to daily life) caused a crisis. To re-establish order from the disruptions created by the illness, they must come to an understanding of the direct impacts of the illness and the subtle implications. In this situation, the core beliefs and perceptions of parents regarding health and sickness come to the foreground (Sunday, et al 2001).

As stated by Lui and Alameda (2011), the biomedical model of health "could be seen to constitute a colonial enterprise to neutralise health inequities as genetic or cultural". Of course, this is not accidental; a vital part of colonisation involves the implicit perpetuation of inequities between colonisers and the colonised by framing them as natural, neutral or inevitable. Western institutions are designed to function in ways that reinforce existing power structures, strengthen the dominant paradigm and perpetuate inequality.

In their study of urban Aboriginal people living with diabetes, Thompson and Gifford (2000) point out that the biomedical approach has not served Indigenous people well. Health interventions that target the risk behaviour of individuals have been largely unsuccessful with the Indigenous population. They advocate for the use of an ethnographical, ecological paradigm that focuses upon the connections of Indigenous people, including the level of connectedness they have to family, community and society (Thompson and Gifford, 2000).

In their qualitative study of the aetiology of chronic respiratory disease in Alaskan Indigenous children, Peterson, Singleton and Leonard (2003) identified the most commonly discussed contributors to chronic RI by their interviewees. These include: smoke and steam, dust, nutrition and feeding practices, socioeconomic conditions, mould, genetic/familial factors, allergy and inhalant abuse. Interviewees, who were the parents and carers of the children, associated certain aspects of a modern lifestyle and Western practices, such as bottle feeding of infants and exposure to construction dust, as contributing to the incidence of RI in their children (Peterson et al., 2003). Interestingly, these interviewees expressed concern that daily steam baths (an Alaskan First Nation cultural tradition) put children at increased risk of RI. This was in stark contrast to the Indigenous participants in our study, who viewed the use of steam as a traditional healing method and a powerful protector against RI in children.

Like the participants in our study, the Alaskan First Nation interviewees also perceived second hand smoke, poor nutrition, socioeconomic factors, hereditary factors, allergies, overcrowded living conditions and household mould as risk factors for RI. Unlike our participants, the Alaskans included the abuse of inhalants and the use of steam as risk factors. The Alaskans interpretation of 'poor nutrition' was also different; they associated the term with bottle-feeding of infants as opposed to our participants, who associated the term with the consumption of junk/fast food. The Alaskans, who resided in rural communities, were more concerned with access to basic infrastructure like clean water and appropriate sewerage systems. The same could not be said for our participants, who resided in urban areas.

Traditional medicine

The majority of our participants admitted to using traditional Indigenous medicine and healing methods alongside mainstream medicine. Research completed in remote and rural Aboriginal communities (McCoy 2008) confirm that Aboriginal people often choose to access both types of medicine in an effort to manage their health. Traditional medicine reflects the holistic definition of Indigenous health, where good health is linked to social, emotional, physical and spiritual wellbeing. This definition also includes connections to land, family, culture, community and the past (Oliver, 2013).

There has been little research on the practice of traditional medicine by Aboriginal and Torres Strait Islander peoples living in an urban setting. As such, there is currently little understanding of the possible implications and consequences of the interaction between the use of traditional medicine and mainstream medicine in this space. However, our participants also admitted that their use of traditional medicine was not a matter that they discussed with mainstream health professionals. This may be attributed to several reasons: the perception that mainstream health professionals were reluctant to investigate or even acknowledge the possible benefits of alternative medicines; the fact that traditional medicine is shared orally and by practice, rather than by written communication; the fact that traditional medicine is viewed by Indigenous peoples as secret business, e.g. important cultural knowledge which should not be shared with non-Indigenous peoples; that the breaking of this cultural taboo could have potentially dire consequences for the Indigenous person involved, regardless of the intent behind it; and the fear that this cultural knowledge may be misused (Oliver, 2013).

Support Networks

Lack of reliable support networks was perceived as a strong risk factor for RI. It was also seen as a significant handicap in the parents' efforts to effectively manage RI, and a source of stress, isolation and alienation. Unfortunately, some parents appeared to view some of the medical professionals they encountered, particularly those in mainstream health services, as adversaries rather than allies. Thus their support networks were weakened further. Due to the often-transient nature of their lifestyles, many parents found themselves living at a distance from their family of origin and friends. Lack of a support network meant that parents took on a great deal of responsibility for managing their child's RI. A few parents mentioned that, in the absence of other support, they enlisted the help of their other children to help care for their child with RI.

Few studies have specifically examined how lack of social support impacts family's ability to manage RI in their children. Kaugars et al (2004) suggest that family dysfunction, which has been strongly associated with more severe types of asthma in children, could be adversely affected by a lack of parental access to friends/family that could provide practical and emotional support. The research of Oakley (1994) found that children experienced improved health when their mothers had access to social support networks.

In their study of Aboriginal Australian's experience of social capital in urban settings, Browne-Yeung et al (2013) found that for Aboriginal people in an urban setting, social support networks were vital to the maintenance of health and wellbeing.

Knowledge about RI

Participants associated knowledge about RI with empowerment and a degree of control (e.g. by employing daily routines and medication) over illness. Lack of knowledge was perceived as a risk factor for RI. Increased knowledge/education about RI was perceived as a protective factor against illness. It was also associated with increased level of vigilance and micromanagement of RI. Participants complained about medical professionals failing to share information with them about RI, including alternative treatments. Melnyk (1994) found that in the tertiary paediatric context, parental anxiety decreased when parents were kept informed about how to assist their child and actively participated in the child's care.

In their study of the perspectives of urban African-American parents of children with asthma, Mansour et al (2013) reported that parents expressed a lack of knowledge about asthma, which they often attributed to the asthma education provided by doctors/medical professionals as difficult to comprehend or not adequate. This lack of knowledge had concrete effects as it often led parents to unnecessarily limit the physical activities of their children and fail to follow the asthma action plans provided by doctors. Parents were more aware of factors relating to environment but felt they had a minimum of control over their structural environment, as changes were deemed to be cost prohibitive. They also expressed concern about the stress placed on them by having a child with asthma. These parents preferred to follow their own beliefs rather than rigidly adhere to prescribed asthma management plans. In most cases, they preferred to restrict their child's physical activities. They preferred not to use preventative medication, as they feared their child would become addicted or become immune to it. They preferred to use more holistic alternative for both treatment and prevention (e.g. breathing exercises, changing the child's diet). The researchers attributed the parent's actions to a lack of knowledge about RI or misinterpretation of the information provided to them. However it is entirely possible that the parents had been given the medical information and comprehended it but had decided instead to follow their own beliefs.

As stated by Bird et al (2014) in their study of Indigenous people with diabetes, their participants identified that having knowledge and gaining understanding about their illness played a large part in accepting the illness and "taking ownership of (their) health". They considered the sharing of knowledge about their illness to be a form of social and emotional support, not just for themselves individually but for their family; deepening the understanding of family members allowed the family to be more supportive. Having more information about the illness also allowed them to more easily manage the stress associated with the illness. The authors concluded that Indigenous narratives about health can be used to enhance cross cultural understanding and communication between Indigenous patients and non-Indigenous health professionals (Bird et al, 2014).

Our participants communicated that they wanted to be kept as informed and as involved as possible in the management of their child's RI. They associated more involvement and education with better health outcomes for their child and increased levels of empowerment for themselves. Accessing the knowledge, beliefs and experiences of Indigenous families will increase the level of family involvement in management of the child's RI, which can increase parental feelings of ownership, empowerment and positivity.

Exercise

Regular exercise was perceived by participants to be a strong protective factor for RI. Importantly, it is a method of managing RI that is also associated with self-care. It was seen as an activity that children suffering RI had control over – and it was simultaneously seen as a method that children could employ to gain some degree of control over their RI.

In contrast, the parents in Mansour et al (2000) study of urban African American children with asthma expressed confusion regarding the usefulness of exercise as a physical therapy. Some parents restricted their child's physical activities as they (incorrectly) equated an asthma diagnosis with the child being too unwell to exercise at all. Other parents allowed their child to exercise but expressed concern about the physical and emotional impact on the child. Mansour et al (2000) concluded that these parents had either lacked information about asthma and exercise or had misinterpreted information provided to them on the topic.

In their study of children with asthma living in an urban area, Lang et al (2004) found that parental beliefs strongly influenced whether the children engaged in regular physical activity. However, one fifth of the parents in the study believed that physical activity was 'dangerous' for their asthmatic children. These parents expressed fears that the child would become ill or upset when they exercised (Lang et al., 2004). The researchers, however, noted that the literature illustrated that in children with asthma, regular exercise was found to produce positive outcomes like decreased severity of asthma symptoms and better health in general. More importantly, these effects lasted into adulthood (Lang et al., 2004). Similarly, our participants firmly believed that regular physical activity lessened the symptoms of asthma in their children. Lang et al (2004) recommended further exploration of parental beliefs in order to appropriately address parent's concerns and correct any incorrect perceptions that may possibly be causing parents to restrict their children's physical activities unnecessarily.

Poor relationship with health professionals

Participant's poor relationships with some mainstream non-Indigenous health professionals had significant implications. It led to issues with communication and trust between participants and medical professionals. Participants perceived that medical professionals were unwilling to share information about RI or provided information that participants found confusing or conflicting. This in turn resulted in disagreements between parents and medical professionals regarding diagnosis, medication and treatment of their child's RI. As noted by Kaugers et al (2004) the consequences of parent-medical professional conflict are potentially dire:

> “There is emerging evidence that conflict in (parental) relationships with health care providers may lead to poorer asthma adherence outcomes. Difficulties communicating effectively with a child’s treating physician and with other medical personnel have been associated with ineffective asthma management behaviours, including failure to provide appropriate intervention for children’s asthma symptoms.” (Kaugers, Klinnnert and Bender, 2004)

In their study examining the beliefs of parents of African-American children with asthma living in urban areas, Mansour et al (2000) found that the majority of parents considered having trust in their health care provider to be of paramount importance, and equated this with high quality health care. Like the participants in our study, these parents reported feeling distrustful of health professionals. They felt that health professionals were:

- unwilling to take a holistic perspective
- judgemental of parent’s lower socioeconomic status
- prone to delay diagnosis unnecessarily
- prone to discharge children from hospital prematurely
- unwilling to listen to parent’s beliefs or acknowledge their perceptions

As mentioned in the section regarding social supports, the poor relationship some parents had with health professionals meant that these parents were missing out on the potential benefits of having the health professional as an ally and support person within the health system.

Poverty

Poverty was categorised as a risk factor and a strong stressor in itself. Thus poverty in addition to RI magnified stress. In their study of African-American parents of children with asthma living in urban areas, Mansour et al (2000) found that their participants reported ‘financial barriers’ as one of the barriers to properly managing their child’s asthma. Parents reported that a lack of financial resources prevented them from purchasing medication and modifying their home environment (e.g. installing carpet). In the absence of a socialised health care system, parents also expressed great concern about the costs of health care insurance. This was not a consideration for the parents in our study, who benefited from the socialised health care system in Australia. Research in Great Britain has shown that children of lower socioeconomic status have worse health outcomes in general than children living in affluent circumstances (Reading 1997). They are also ill more often and present with more serious types of illnesses (Mayall 1986; Reading 1997; Clarke & Hewison 1991; Wyke et al 1990).

The importance of incorporating parental beliefs and perceptions

The participants in our study largely felt that their beliefs and perceptions about RI were ignored or discounted by non-Indigenous health professionals. This was a source of parental irritation/indignation and symptomatic of the poor relationship that some parents had with mainstream health professionals.

Mansour et al (2013) acknowledge the importance of addressing the health beliefs and perceptions of parents in order to provide the best health care for their children and if this fails to occur, there will be no improvement in health care outcomes.

> "The barriers most frequently reported by parents were intrinsic to the parents own health beliefs. This study reinforces the need to expand asthma management beyond a strictly biomedical approach to one that incorporates patient and family health beliefs. Parental attitudes and beliefs as well as their environment modify how parents respond to caring for their child with asthma." (Mansour et al 2013 p 516-517)

> "Addressing patient and family's health beliefs and concepts of disease and evaluation the cultural competence of health care system practices may be particularly important for improving asthma outcomes" (Kaugers et al 2004)

Kamrosi et al (2206) recommend the recognition of the different health values and beliefs held by Aboriginal people in order to improve treatment and compliance among Aboriginal peoples.

> "It is imperative that HCPs (health care professionals) increase their understanding of the different cultural needs of their patients and provide adequate counselling to

> ensure a thorough understanding of the reasons for, and the nature of the treatment but also actively include the patient in the consultation" (Kamrosi et al 2006)

Callery et al (2003) found that the parental beliefs and perceptions around asthma had an important influence on how they managed their child's illness. This had significant implications as some of the parent's beliefs were not factually correct or accurate. The reliance of the parents on their own subjective beliefs and judgements meant that they (like the participants in the study of Mansour et al.) often ignored or only partially implemented the recommendations of health professionals regarding the management of their child's asthma. This in turn had consequences for the health and quality of life of their child (Callery et al 2003).

5.2 Strengths and limitations of this study

The predominant strength of this study is that it was conducted by an Aboriginal person with Aboriginal and Torres Strait Islander communities and was founded in Indigenous methodologies and ways of knowing. This allowed the free and open expression of opinions, beliefs and perceptions of Aboriginal and Torres Strait Islander parents/carers about RI, employing the Indigenous cultural traditional form of communication known as 'yarning' or 'yarning up'. This occurred in a culturally safe, culturally appropriate environment with Indigenous researchers.

I wanted to use open-ended questions and informal language in order to encourage discussion. I intended to use the questions in a flexible way; as initial prompting tools and as points of reference for myself. My aim was to let the discussion flow as freely as possible with minimal input from myself. Utilising my social work training, I employed non-judgemental active listening and appropriate body language to facilitate open and frank discussions. The detail discussed in focus groups, reflected in the results section, strongly suggest my goal was achieved. Although the number of participants was small, participants in the groups were from four large Indigenous communities in Brisbane and their lived experiences were similar to that reported in the limited studies that have been conducted elsewhere. Further, many of the themes raised in the initial four groups were reiterated by members of the IRRG. This suggests many of the themes identified were not uncommon experiences. In hindsight, I would have slightly changed the questions to include an exploration of peoples lived experiences as Indigenous peoples in an urban setting given the many comments that were raised about this experience by the participants.

There were some limitations of the focus groups that consequently necessitate consideration when interpreting the study's results. I discussed some of the challenges of conducting the yarnings in my methods chapter (Chapter 3) and those are not repeated here.

A common issue raised with respect to qualitative methods is the representativeness of the study participants and hence the generalisability of the findings and much of this criticism stems from a quantitative perspective (Patton, 2005). The focus groups only captured participants who had the time and means to attend and who were interested in the research and motivated to take part. The views of those who did participate may not reflect those of the broader Aboriginal and Torres Strait Islander population, particularly given the diversity both within and between communities across Australia. This research was not intended to be broadly generalisable and was not designed for that purpose. However, like the Australian Aboriginal and Torres Strait Islander population, our groups were considerably heterogenic and sourced from four very different Aboriginal and Torres Strait Islander communities in the greater Brisbane region. Notably, there were several issues raised, particularly factors such as racism, dissatisfaction with mainstream health services, the impacts of poverty and intergenerational trauma, that have been reported by Indigenous peoples elsewhere, both in Australia and overseas. This suggests that the experiences of our participants were not unique and can be further explored in future larger studies designed to address risk for and impact of RI in the Australian Aboriginal and Torres Strait Islander population.

There were a limited number of male participants and also of Torres Strait Islander participants. That there were more females may reflect the methods for recruiting participants and that both recruitment and the yarnings were conducted by Aboriginal women. Cultural issues may have played a role however it may also reflect different caring and/or family responsibilities in these communities. With respect to the number of Torres Strait Islander participants, this again likely a reflection of the sources for recruitment. Further research is needed that is more inclusive of both of these groups is needed to determine whether there are important differences to my findings.

Finally, the experience of the majority of the participants in my research centred on chronic childhood respiratory illnesses such as asthma. There was limited discussion of issues such as hospitalisations for pneumonia and recurrent acute respiratory infections. Given the burden of these acute illnesses are excessive in Aboriginal and/or Torres Strait Islander children (O'Grady, 2010) my findings may not entirely reflect perceptions of risk and impact for these conditions. Future research should consider targeting either chronic or acute, or provide clear delineation between the two if they are addressed in the one study.

5.3 Implications of this research

More Aboriginal and Torres Strait Islander workers are needed in the health care system and in health research. With more Indigenous workers, the health care system can become a culturally safe space for Indigenous people. By that, I am referring to a space where Indigenous people can be healed while maintaining, as much as possible, a connection to culture and identity. For Aboriginal and Torres Strait Islander people, culture and identity are sources of strength and comfort. As such, the health system should be encouraging Aboriginal and Torres Strait Islander clients to tap into their culture and identity. However it is also necessary for Aboriginal and Torres Strait Islander workers and families to engage with the health care system to help create a culturally safe space. This means establishing alliances, nurturing connections and sharing knowledge with non-Indigenous workers (doctors, nurses, social workers) in the health care system.

The Western medical model tends to treat 'the problem', rather than the person as a whole. Indigenous health must be looked at in the wider social context that recognises the important role of identity, connection, community, land, family and social obligations in the everyday lives of Aboriginal people. Any health intervention targeted toward Aboriginal and Torres Strait Islander people must take into account all of these factors. At the same time, it is important for Aboriginal and Torres Strait Islander people (communities, families and workers) to actively engage with the health care system and ally with non-Indigenous people within the system in order to enact the changes that need to occur. Cultural safety within the health care system – for families and workers – is imperative. For this to occur, Indigenous and non-Indigenous people have to work together with this common goal in mind. It is also important for those working in Aboriginal health to focus on self-care, as well as community care. There are no simple or easy solutions to the many challenges associated with Indigenous health. There are many solutions and they must be put together one piece at a time, with patience, compassion and cooperation.

CHAPTER 6. Conclusion

In conclusion, the literature review confirmed the high incidence of RI prevalent in Australian Indigenous children in rural and remote communities. There have been few similar studies conducted in Indigenous children in urban communities. There is a lack of data regarding the health views of urban-based Indigenous people in the area of child RIs. This includes how RIs in Indigenous children impacts upon families and communities. This type of research is vital as the health views of Indigenous people can affect how they access and experience health services, which in turn can affect treatment issues such as medical compliance and prevention. There is great value in this type of research being conducted by Indigenous researchers who are cognisant of the cultural and historical issues surrounding Indigenous people and research (Gorman & Toombs, 2009).

Any research with Indigenous peoples must be conducted in a culturally appropriate and culturally safe manner in order to ensure integrity (Smith, 1999). This means engaging in ongoing consultation and information exchange with Indigenous communities and Elders, as well as creating a culturally safe space for participants and employing culturally appropriate methods of communication. The focus groups were conducted with a set of questions designed to prompt discussions about respiratory health and participants brought forth their own themes and subthemes from their articulated concerns. Participants were extremely frank and open about expressing themselves. Some of the focus groups veered off into discussions that were not specifically about RI but were valuable in providing a bigger picture about the type of daily stresses experienced by participants, their concerns, their lived experiences with racism, intersectional and generational disadvantage and raising their children/grandchildren. Participants did not view RI as something separate from their daily lives but as part of a larger narrative of that included their daily struggle to maintain a sense of balance, wellbeing and control under often very trying circumstances.

This study has brought forth important information about the perspectives of Indigenous parents regarding their lived experiences with RI in their children and grandchildren, and the impact that RI has had on their family. It uncovered that: the perceptions of Indigenous parents/carers about RI (and health and wellbeing in general) are different to those of mainstream health care professionals; that these perceptions and beliefs have a profound effect not only on their experiences of health care but may also provide an explanation for the prevalence of RI in Indigenous children. These outcomes illustrate that medical professionals, researchers and health care providers need to acknowledge and address the concerns of Indigenous parents/carers in order to begin to address not only the prevalence of RI in Indigenous children but also the larger health disparity between Indigenous and non-Indigenous children in Australia.

6.1 Significance of the research

This research is significant. It addresses Indigenous concepts of health and wellbeing and the unique challenges that confront urban Indigenous children and their families. The results will be directly relevant to health service policy, planning and delivery and will be critical to informing evidence-based strategies to reduce the social and economic impact of respiratory infections on the Indigenous community. This is the first study in Australia and one of the few worldwide, of respiratory infections, their associated risk factors and the social and cultural impact of these diseases on Indigenous families and their communities in an urban setting **from an Indigenous perspective**.

The importance of this study is that it provides critical data to inform the development and implementation of tailored interventions at the primary, secondary and tertiary levels to reduce the impact of these diseases on Indigenous children, their families/communities and on health services. The results of the research will have direct relevance to health service providers, policy makers and funding bodies. It will contribute to informing, and developing evidence-based guidelines and best practice standards of care that are culturally sensitive, competent and applicable to the unique nature of urban Indigenous communities in Australia and potentially applicable to similar populations internationally.

This research project directly addresses the National Research Priority are of Promoting and Maintaining Good Health with a specific goal of a Healthy Start to Life (National Research Priorities & Their Associated Priority Goals 2012). RIs during childhood in Indigenous children are important contributors to poor adult lung and cardiac health. Investigating the impact of these diseases on Indigenous children and their families and communities fills an important gap in knowledge that limits evidence based policy and service delivery. The results of this research will contribute to not only the development of clinical pathways for Aboriginal and/or Torres Strait

Islander children with RIs but provide a solid foundation for the development, implementation and evaluation of interventions to reduce the social, economic and health burden of disease.

6.2 Recommendations

- Further research is required into the implications and effects of Aboriginal and Torres Strait Islander people's utilisation of both traditional and mainstream medicines.
- Further research is required into how the health beliefs and perceptions of parents and carers are impacting the health of their children.
- Honest and open dialogue is required between health care professionals and parents regarding the health beliefs of parents and how these impact the health outcomes for their child
- Health care professionals need to not only acknowledge the stress parents experience while caring for their child with RI but help parents to link in with appropriate support systems (formal and informal) and respite options.
- The psychological distress, fear and anxiety commonly experienced by parents and children with RI need to be addressed as part of a care plan in order to prevent major crises from developing. A flaw of the hospital social work system is that intervention is crisis-driven and does not necessarily cater to the everyday stresses experienced by parents of chronically ill children. This means that stress, left unchecked, can build over time until a crisis situation occurs.
- Cultural safety and cultural competency are essential for the delivery of inclusive and effective health services. Programs that achieve these outcomes in our health system need ongoing support and consideration should be given to mandating this training for all employees engaged in services that have Aboriginal and Torres Strait Islander clients.

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Appendix A: Plain Language Statement & Consent Form

Queensland Children's Medical Research Institute

Queensland Government
Queensland Health

LUNG SICKNESS IN MURRI KIDS STUDY (Part A)

Participant Information Sheet – Focus Groups

Project name (short): **LUNG SICKNESS IN MURRI KIDS STUDY (LSIM Kids)**
Project name (long): Perceptions of risk of respiratory illness in Indigenous children.
Ethics Committee Project Number:
Researchers' names: Professor Anne Chang, , Kerry Hall, Anna Bell, Dr Janet Hammill Dr Kerry-Ann O'Grady

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Thank you for taking the time to go through this Information Statement. This Information Statement is **3** pages long. Please make sure you have all the pages. These pages tell you about the research project. The information is to help you to decide whether or not you would like your child to take part in the research. Please read this Information Statement, or listen to the researcher read it to you, carefully. You can ask us questions about anything in it. You may want to talk about the project with your family, friends or health care worker.

You are invited to participate in a research project that is explained below. Participation in this research project is voluntary. If you don't want to take part, you don't have to. You can withdraw from the project at any time without explanation. Once you have understood what the project is about, if you would like to take part please sign the consent form at the end of this information statement. You will be given a copy of this information and consent form to keep.

What is this project about?

Respiratory infections (coughs, colds, lung sicknesses such as pneumonia) are the most common causes of sickness and poor health in Aboriginal and Torres Strait Islander children. They cause many problems for children, their families and communities. However, all of the information we have about respiratory illnesses in Aboriginal and Torres Strait Islander children comes from people living in remote areas. This information is very unlikely to apply to Aboriginal and Torres Strait Islander people living in urban areas.

This study is about getting better information on respiratory illnesses in Aboriginal and Torres Strait Islander children who live in and around Brisbane. We want to look at how common they are, what may be causing the illness, how they are treated, and, most importantly, what is the impact of these illnesses in Aboriginal and Torres Strait Islander communities. This information will then help us work out better ways to treat and prevent these problems in ways that respect culture and Aboriginal and Torres Strait Islander views on health and wellbeing.

Who are the Researchers?

Professor Anne Chang is a specialist doctor in children's respiratory health at the Royal Children's Hospital with a long history of working with Indigenous communities. Dr Kerry-Ann O'Grady is a researcher at the QCMRI with lots of experience as a nurse and researcher in lung sickness in Aboriginal and Torres Strait Islander children in several areas of Australia. Kerry Hall is Kuku Yalanji woman an enrolled nurse and Aboriginal Health Worker with family and cultural connections across Brisbane and far north Queensland. Anna Bell is a Social worker who is doing a PhD on this project; she is of Waka Waka and Badjula descent with family and cultural connections in South East QLD. Dr Janet Hammill is an Aboriginal woman and Senior Researcher at the University of Queensland

What does the Aboriginal and Torres Strait Islander community think about this study?

This study has the support of the Pamanyungan Elders Alliance in the northern region of Brisbane. We have also set up a steering committee of Aboriginal and Torres Strait Islander Elders, Traditional Owners, community members, researchers and health professionals to make sure the study remains culturally safe and culture is respected.

Who is allowed to be in this study?

We are asking parents/guardians of young children in the community and other interested community members to be in this study. Participants must identify as being Aboriginal and/or Torres Strait Islander and provide written consent. We are asking about 6 – 8 people from the Northern and Southern Brisbane regions to participate in one of 4 groups:
Group 1: Yarning session in northern Brisbane with parents/guardians of young children
Group 2: Yarning session in southern Brisbane with parents/guardians of young children
Group 3: Yarning session in northern Brisbane with other adults in the community
Group 4: Yarning session in southern Brisbane with other adults in the community

What do I need to do in this study?

A researcher will explain the study to you and if you would like to be involved, we will ask you to sign a consent form.

If you agree to be in the yarning sessions, we will arrange the meetings at a time and place that is convenient. The meetings will most likely be held over morning tea or lunch and we will provide that for the group. The meetings will be led by a senior Aboriginal person to ensure that everyone is comfortable and that cultural protocols are adhered to. An Aboriginal Research Officer and an Aboriginal Social Worker who is doing a research degree as part of this study will be in the room listening to the discussions, recording them on a digital recording device, taking notes and contributing to the discussions.

The yarning sessions will be based around a set of 3 – 4 questions that focus on respiratory illnesses in children in the Aboriginal and Torres Strait Islander communities in Brisbane. We will be asking about what people think about these illnesses, what things people think may cause these illnesses and what things people think may make these illnesses worse. We want to find out about how these illnesses are perceived from an Aboriginal and/or Torres Strait Islander perspective. You can say as little or as much as you feel comfortable with. We will also collect a small amount of information about you and your family and your connection to the Indigenous community in your area.

The discussions are not a test. They are yarning sessions about what you think about respiratory illnesses in children and what the community thinks needs to be looked at more closely by health service providers and researchers. We are recording the discussions on a digital recorder so that we do not miss any important information and the discussions will also typed up. We will then look at all the information we get from the yarning sessions and summarise the findings. The information will be used to help us in other studies and also to help health service providers better understand the problems respiratory illnesses cause in Aboriginal and Torres Strait Islander communities.

Will being in this study lead to good things for me or other children?

The information we collect from you will help us work out the best way to treat and prevent Lung Sickness in Murri Kids. It will also help us work out how to do this in ways that are culturally appropriate to Aboriginal and Torres Strait Islander families and communities. The study will also help us improve how health services for Aboriginal and Torres Strait Islander people are funded.

Can I be harmed by being in the study?

No. There are no bad consequences for you if you participate in the study

Will I get paid to be in the study?

No. There is no payment for being in this study. We will provide lunch or morning tea for you at the meetings and parking vouchers for the Royal Children’s Hospital if the yarning sessions are held in the meeting rooms there.

If I take part in the study, will I be treated differently by my doctor?

No. Your treatment by your doctor or medical clinic will not be affected if you agree to take part or not.

Can I pull out of the study at any time?

Yes. Your decision whether or not to participate will not cause problems for any future relations with the QLD Children’s Health Services (RCH). You are free to withdraw (pull out of the study) at any time.

What will happen with the results of the study?

We will summarise all the information we collect and have another meeting with you to give you feedback about what we found. The information will be used to help in other research studies by making sure those studies are collecting the right information, and the information that the Aboriginal and Torres Strait Islander want to know about respiratory illnesses in their community. The results will be published in a medical journal that will tell other doctors and researchers about the study. None of your personal details will be revealed at any time.

What will happen with my information?

The personal information the researchers collect about you in this study will be kept secret unless we are asked to provide that information by the ethics committee. All of the information collected in this study will be kept in a locked cabinet and on a password protected computer at the Queensland Children's Medical Research Institute for a minimum of 7 years. You can ask to see your information at any time and ask for it to be destroyed.

We will send you regular newsletters letting you know how the study is going. We will also send you a letter at the end of the study telling you about the study's results. We will also talk about the study at community meetings and events.

What if I have other questions?

You can and should ask your parents/guardians and the researchers questions at any time. If you want to talk to the researchers, you should call **Ms Anna Bell** at the Queensland Children's Medical Research Institute on **(07) 3636 1296.**

How can I make a complaint about the study or its organisers?

The QLD Children's Health Services (RCH) Human Research Ethics Committee (HREC) has approved this study. Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning policies, information about the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, at any time, you may contact the Co-ordinator of the Ethics Committee on 3636 9167. If this phone is unattended, please leave a message and your call will be answered as soon as possible.

Queensland Children's
Medical Research Institute

Queensland
Government
Queensland Health

"LSIM KIDS" STUDY YARNING SESSIONS
Participant Consent Form (Part A)

I, ____(name of participant)

Subject ID number: |__|__|__|__|, have had the purpose and nature of the LSIMKids Study Yarning Sessions

explained to me by (Researcher Name)____

I understand the purpose of the study is to get better information on what Aboriginal people think about respiratory illnesses, and I understand that my participation is voluntary.	Yes	No
I understand that I can say "NO" to taking part in the study.	Yes	No
I understand that being in the study, or saying no, will have no bad consequences for me, my family or community.	Yes	No
I understand that I will be asked for information what I think about respiratory illnesses during the yarning sessions	Yes	No
I understand that the yarning sessions will be recorded and also that notes will be taken during the interviews	Yes	No
I understand that all personal information that I provide to the researchers will be kept confidential and that my personal information will kept in locked cabinets at the Queensland Children's Medical Research Institute for 7 years.	Yes	No
I understand that I can withdraw my consent for the study at any time prior to the completion of the study with no bad consequences to me or my child.	Yes	No
I have been given the contact details of the study organisers.	Yes	No
I have been given the opportunity to ask questions.	Yes	No

I hereby give my consent for participation in the study.

Signed___________________________ Name__________________________ Date: ________________

Witness signature__________________ Witness name__________________ Date: ________________

Translator signature________________ Translator name__________________ Date: ________________

Appendix B: Baseline questionnaire

Queensland Children's
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Lung Sickness in Murri Kids Part A

Participant Questionnaire Focus Groups

Study ID: **LSIMKS|__|__|_/_|__|__|__|__|**

Date Enrolled in Focus Group |__|__|_/_|__|__|_/_|__|__|__|__|

Group Location **Redcliffe** ☐ **Deception Bay** ☐ **Inala** ☐ **Acacia Ridge** ☐

Participant Consent Signed **Yes** ☐ **No** ☐ **Date signed** |__|__|_/_|__|__|_/_|__|__|__|__|

DEMOGRAPHIC

Surname: ________________________________ **First name:** ________________________

Skin name: _______________________________

Date of Birth: |__|__|_/_|__|__|_/_|__|__|__|__| **Gender:** **M** ☐ **F** ☐ **I** ☐

Indigenous status of person participating in the focus group:

☐ Aboriginal ☐ Torres Strait Islander ☐ Both ☐ NI ☐ Declined ☐ Unknown

Contact Details

Address: ____

Phone: ___________________________ **Mobile:** ___________________________________

Email: ____

Employment Status ☐ Full time ☐ Part Time ☐ Casual ☐ Not in Paid Employment

Do you work, or have you ever worked as a Health Professional ☐ **No** ☐ **Yes**

Relationship to Indigenous child of participant in focus group:

☐ Mother ☐ Father ☐ Other family member ☐ Guardian

Who is your mob/tribe? 1. ____________________________ ☐ Unknown ☐ Declined

2. ____________________________

3. ____________________________

Do you identify with an Indigenous community? ☐ Yes ☐ No ☐ Unknown ☐ Declined

Which Indigenous community do you identify with? ____

☐ None ☐ Unknown ☐ Declined

Do you maintain cultural connections at home? ☐ Yes ☐ No ☐ Unknown ☐ Declined

(eg Art Music/Dance Storytelling Food Traditional medicine)

Do you have a connection with traditional lands? ☐ Yes ☐ No ☐ Unknown ☐ Declined

Did the child spend any time in the past 12 months living in an Indigenous community outside of Brisbane? ☐ Yes ☐ No ☐ Unknown ☐ Declined

If yes, community name: ___________________ ☐ Inner Regional ☐ Rural ☐ Remote ☐ Unk

If yes, how many months I__I__I ☐ Unk

Are any members of your family from the stolen generation? ☐ Yes ☐ No ☐ Unk ☐ Declined

Indigenous Status of the Indigenous child/children you usually care for:

Child: ☐ *Aboriginal* ☐ *Torres Strait Islander* ☐ *Both*

Mother: ☐ *Aboriginal* ☐ *Torres Strait Islander* ☐ *Both* ☐ *NI* ☐ *Declined* ☐ *Unknown*

Father: ☐ *Aboriginal* ☐ *Torres Strait Islander* ☐ *Both* ☐ *NI* ☐ *Declined* ☐ *Unknown*

Primary carer: ☐ Mother ☐ Father ☐ Grandparent: *Legal Guardian* ☐ *Yes* ☐ *No* ☐ *Unk*

☐ Other Relative: ____________________ *Legal Guardian* ☐ *Yes* ☐ *No* ☐ *Unk*

(specify)

☐ Other non-family:____________________ *Legal Guardian* ☐ *Yes* ☐ *No* ☐ *Unk*

(specify)

Care type at home: ☐ Both parents at home

☐ Single parent at home

☐ Shared care (i.e. moves between homes)

☐ Other relative: *Legal guardian* ☐ *Yes* ☐ *No* ☐ *Unknown*

☐ Other non-family: *Legal guardian* ☐ *Yes* ☐ *No* ☐ *Unknown*

How many children do you have /care for? ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6

If your child is less than 1 year please write age in months

Age of child 1 ___________years/ months

Age of child 2 ___________years /months

Age of child 3 ___________years/months

Age of child 4 ___________years/months

Age of child 5___________years/months

Age of child 6___________years/months

Have any of the Indigenous children you regularly care for been diagnosed with a chronic Lung disease?
☐ No ☐ Yes ☐ Unknown

If yes please list

Child 1 ☐ No ☐ Yes ____

Child 2 ☐ No ☐ Yes ____

Child 3 ☐ No ☐ Yes ____

Child 4 ☐ No ☐ Yes ____

Child 5 ☐ No ☐ Yes ____

What health professionals/ services do the children in your care attend when they are ill?

☐ Aboriginal Medical Service

☐ Indigenous friendly private practice

☐ Pharmacist

☐ Mainstream GP

☐ ED/Hospital

☐ Indigenous Health Worker in community

☐ Other

Comments____

____

Highest level of education of focus group participant:

Did not finish high school ☐
High School ☐
Currently studying ☐
Certificate ☐
Diploma ☐
Bachelor degree ☐
Post graduate degree ☐
Not applicable ☐
Unknown ☐
Declined to answer ☐

General comments:

____