“That Heart Sickness”: Exploring Aboriginal Young People’s Experiences of Rheumatic Fever Care from Childhood to Adulthood

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Abstract

The burden of rheumatic fever is almost entirely borne by young Aboriginal people in northern and remote locations in Australia while it has been nearly eradicated in other parts of the nation. Epidemiological studies are vital for highlighting disease patterns and for advocating for action. Equally important is to understand how the disease and health care dynamics are perceived by those affected by the condition in order to gain a more complete picture and to inform nuanced care, prevention and advocacy strategies. These include strategies for administering the regular painful penicillin injections that young people endure for at least one decade once they have acquired rheumatic fever, to protect their hearts.

An ethnographic study was undertaken to explore the perceptions, knowledge and understandings that young Aboriginal people and their families have of rheumatic fever and resultant rheumatic heart disease, as well as the health care they receive, including the longterm injection regimen. The ethnography was undertaken in four remote sites in the Northern Territory between 2013 and 2016 as part of a larger community-randomised trial.

No families understood these physiologically complex diseases or knew why the injections were needed, apart from to “keep their heart strong”. In addressing these diseases, it is paramount that the indelible sociocultural characteristics of the affected population, such as language and world view, are recognised and valued and that health care design takes account of these characteristics rather than simply practising biomedicine. Recognising the deep historical and political stories of the affected populations is vital for understanding the determinants driving rheumatic fever. The complexity of risk factors means that collaboration with other disciplines outside of

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biomedicine is required to work towards real change. But, crucially, improvements
must be undertaken in proper partnership with local Aboriginal people.
Statement of Authorship

This work, submitted as a thesis for the degree of Doctor of Philosophy of the Charles Darwin University, is the result of my own investigations and contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of the candidate’s knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying online via the University’s Open Access repository eSpace.

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## Authorship and Article Submission Status

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Due to my research design, I was frequently on the move and spent much time away from home and family. This would not have been possible without the unwavering interest, patience and support of my husband. Sincerest thanks to Ernie for always ‘believing in me’.
I express deep gratitude to the young Aboriginal people and their families who participated in this study. Your welcoming readiness to share your time, stories and views as I endeavoured to understand something of your lives, when our lives are so different, was a rich and privileged experience. Thank you for connecting with me and welcoming me into your spaces. My research sites were part of a de-identified set of sites in a larger study, so I am unable to name participants here.

Finally, I thank God for His provision and sustaining, wherever He leads.
This study is dedicated to

Gudjuk\(^1\),

a young Aboriginal boy I was called to help,

when he first got rheumatic fever.

His was the first heart murmur I ever detected.

In subsequent years when

I gave his painful monthly penicillin injections,

he always bounced back with his disarming smile,

as if to say,

“You didn’t get me! – I’m Gudjuk”

Tragically, at age twenty

he died from a completely preventable condition,

rheumatic heart disease.

\(^1\) Gudjuk is a ‘subsection’ title and does not identify an individual.

With permission from Gudjuk’s family.
List of Abbreviations and Glossary

ARF acute rheumatic fever
BPG benzathine penicillin G
CCM chronic care model
GAS group A streptococcus
NT Northern Territory of Australia
RF rheumatic fever
RHD rheumatic heart disease
SP secondary prophylaxis

Aboriginal language terms:
Balandanon-Aboriginal person
Baman’in past times
Napungain between
Napungawuythe entity in between

List of Appendices

A: Transcription and English gloss of study information including consent

B: Menzies study information sheets and consent form

C: Interview guides: for under 15 years and over 15 years
Preface

Connecting

There is something to cherish in human connecting. This is especially so when the connecting occurs through difference. For instance, when it happens across languages and cultures; when we are invited into others’ lives and spaces, ones very different from ours. We find opportunity to lose our narrow perspectives; it produces a kind of joy.

Figure 1. Expert shows us how to poke the sand for turtle eggs; connecting with kin, land, ‘the hunt’, and an adopted outsider

Source: A. Mitchell (photographer) 2015. Used with permission.

Throughout the following work the concept of ‘connecting’ is a woven strand tying the parts together. The present participle form is purposely chosen. This connecting
describes not only movement and practices of people but also the continual connecting between related Aboriginal groups, between Aboriginal people and governing agencies, and, for this thesis, between Aboriginal people and their health services.

The connecting is also foundational to my study design. My study is phenomenological, using the tools of ethnography. To carry out ethnography means there must be connecting; between me as a researcher investigating a human issue and the people who partnered with me for that task.

While carrying out this study I continually moved between places and people, connecting with different terrains of intense beauty as well as different human living spaces. I was connecting with those affected by an ancient (in the western world) disease, rheumatic fever, trying to understand what it means for them to experience the disease in this epoch.

This study took place among Aboriginal people in the Northern Territory of Australia. During my fieldwork I observed Aboriginal people connecting with their lands and waters, their historical song cycles and their kin. I observed people connecting with their cosmos and with their ancient law. The connecting is a continual expression and a ‘living out’ of people’s bonds with place and others, and their ancient roots.

Connecting was always at the heart of people’s movements and activities. In each location Aboriginal people moved between places to visit kin, collect food or other resources or to attend funerals and other ceremonies. At other times they travelled for health appointments, training courses or such. Even as I write, close by, Aboriginal people are greeting newly arrived family in their traditional way:
It is 9am on Sunday morning in this remote coastal homeland. This is a place of subtle beauty, with idyllic coastal scenery and a gentle sea breeze. A short time ago, a sedan car pulled up at the house across the sandy track. Quite a few people got out of the car with small bags of personal luggage. They are family arriving to attend the funeral ceremony in process here over the past four days. It must have been a bumpy journey on the road into the homeland as it is usually traversed in more robust 4-wheel drive vehicles.

The ‘arrivals’ immediately joined the residents of the house and made a group of about fifteen sitting closely on a woven plastic mat under the shade of a tree. Two men sit on chairs but are part of the group. The atmosphere is jovial and spirited; laughter and bits of their conversation (in their language) drift across to the house where I am staying. I now realise that the scraping sound of leaves being raked that woke me early this morning was in preparation for the arrival of these visitors. The tree they are sitting under has large leaves that drop in the dry, windy weather. Participating in a funeral ceremony is obligatory for certain people and respectful on the part of others. It is about maintaining the connecting.

Author’s field notes, August 2015

In my fieldwork I observed that Aboriginal people are concerned about their future and how their young people will fare in the connecting they will need to do. Interacting with the encapsulating dominant society and ensuing governments has left a legacy of concern. Good connecting has been fleeting and elusive.

Connecting is also a foundational component in public health, assumed to happen between experts and human populations. Scientists determine what practices will
address public health issues, but human interacting is required to design and convey the new messages and convince people to carry out the new practices.

As a white researcher among Aboriginal people, connecting was my greatest challenge, both practically and ethically. Historically, connecting between Aboriginal people and white researchers has not always been ethical, respectful or participatory. My efforts to engage Aboriginal co-researchers for the duration of this study fell flat and I found myself proceeding alone much of the time. One Aboriginal key informant spoke on this topic with me:

_In the past, in the old people’s day, baman’ [the time long ago], it was practice to spread a sheet on the ground and welcome your kin to sit there. This was the proper way to act. It was a time to sit and talk together. It was a way of teaching and learning. We were connected through our kinship. This is how I see Aboriginal researchers working. They can sit with their people like the old ways. They can talk from their heart. They can learn together as they discover new knowledge, for instance what rheumatic fever actually is, what causes it, what the treatment is. When people understand this new information, discovered together, then people will be well in their ŋayaŋu [innermost being], their heart._

_The best model is to have napuŋgawuy [people in the middle], yolŋu and balanda [Aboriginal person and white person]. The napuŋgawuy yolŋu is the Aboriginal researcher._

Author’s field notes: conversation with an Aboriginal Researcher 27th August 2015
In daily life, Aboriginal people try to connect with the white institutions in their communities, one of which is their health service. The degree to which they are successful in this connecting is determined by a multitude of factors; English language competency, attitudes of officials, available time within personal and community priorities, and previous experiences. People naturally see illnesses through the lens of their historical world view and for the participants in this research the view was not a biomedical one. For conditions such as rheumatic fever and rheumatic heart disease (as well as other currently predominant conditions like diabetes and kidney disease) understanding the cause and effect from their perspective can draw a blank leading people to state, “We don’t know what this sickness is or what causes it” (Study participant’s comment).

*Figure II. Symbolic juncture of two cultures: turtle tracks overlay car tracks on the beach

Source: A. Mitchell (photographer) 2015*
Real engaging sometimes happens when outsiders have a caring stance, speak with awareness of the hearer, and recognise the inter-relatedness of all parts of community life and the policies that govern it.

Essentially, the actions required to address rheumatic fever care among young Aboriginal people, and indeed to halt this condition, are only possible with effective connecting between people. To do this connecting, outsiders must understand history and themselves, how they are perceived by Aboriginal patients, the people with this condition, what the people’s experiences of rheumatic fever are, where they reside, who cares for whom and the places people are deeply attached with and are therefore moving between. This knowledge can make the difference between a healthy heart and a diseased heart in young Aboriginal people today. It can mean the difference between a healthy long life and an untimely death.

**Explanation of Thesis Structure**

This thesis has a hybrid structure with the Results section comprising three articles submitted to journals and two standard thesis chapters. In the chapters that are journal articles, each journal’s style has been retained. This explains the variation in styles within the thesis. The language of all interview quotes has been recorded verbatim to retain the authenticity and spontaneity of the text. The thesis is arranged in three parts: a background explanation of the study, the findings of the study, and an integrated discussion and conclusion.

**Part I** comprises the first three chapters: Chapter 1 explains the background for the research issue, as well as two literature reviews. Chapter 2 provides the methodology and the methods as well as the research questions. Chapter 3 concludes Part 1 with further detail of the ethnographic methods and the research sites.
Part II presents the study findings: Chapter 4 is the first journal article, entitled, “That heart sickness”: young Aboriginal people’s understanding of rheumatic fever. This article has been accepted for publication during 2018 in the Medical Anthropology journal. Chapter 5 is the second journal article, entitled, ‘Aboriginal children and penicillin injections for rheumatic fever: how much of a problem is injection pain?’ This article has been accepted for publication in the Australian & New Zealand Journal of Public Health. Chapter 6 is a standard thesis chapter providing an ethnographical description of growing up in remote northern Australia with rheumatic fever. Chapter 7 is also a standard thesis chapter focussing on young Aboriginal people who have experienced open-heart surgery due to heart failure from rheumatic heart disease. Chapter 8 is the third submitted article, entitled, ‘Transition to adult care for Aboriginal children with rheumatic fever: a review informed by a focussed ethnography in northern Australia.’ This article has been accepted for publication in the Australian Journal of Public Health.

Part III provides an integrated discussion and conclusion to the thesis as well as making recommendations arising from the findings.

The appendices conclude the thesis. They include an English back translation of an audio recording created in one Aboriginal language to assist study participants to understand informed consent. They also include the participant information sheets, the consent forms and interview guides.
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## PART 1

### CHAPTER 1

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#### CHAPTER 9

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Part 1

Chapter 1

Care for Young Aboriginal People Living with Acute Rheumatic Fever and Rheumatic Heart Disease in Northern Australia
Introduction

This chapter provides a description of the medical conditions of acute rheumatic fever (ARF) and rheumatic heart disease (RHD), and the impact they have on young Aboriginal people in the Northern Territory (NT) of Australia. It includes a description of surveillance, monitoring and ongoing management strategies. The chapter also provides a synthesis of two literature reviews. The first review collates international and national literature containing patients’ perspectives on the treatment for ARF. The second review explores self-management of chronic conditions because, although the name ARF contains the word ‘acute’ in its title, it is ostensibly a chronic condition due to the lengthy time needed to manage it in order to prevent serious complications. Self-management is a central component in a model of care named “transition to adult care for children with chronic conditions”. This second review was undertaken to consider how a transition approach may be suitable or adaptable for the NT setting.

Background

ARF and RHD in the NT

The burden of ARF and RHD remain disturbingly high in the NT, with the incidence of ARF in Aboriginal children aged five to fourteen years in non-urban areas being between approximately 150-180 per 100,000 (Parnaby & Carapetis, 2010). These incidence rates are among the highest recorded in the world. There are currently 3,355 people registered as having had ARF and/or RHD in the NT with the proportion of Aboriginal people being 95%. The 2016 census reported a total population of the NT as 228,883, with just over 58,000
identifying as Aboriginal and Torres Strait Islander peoples. The NT has a large land
mass of 1,346,200 square kilometres, with a dispersed population
data linkage in the NT confirms the severity of this condition for young Aboriginal
people (He et al., 2016). As a resource-rich nation, Australia should have the
capacity to address this urgent public health crisis that these separate, but linked,
conditions are creating. Discourse in the global literature is increasingly reporting
ARF and RHD as neglected childhood diseases in an effort to galvanise action from
governments and health policy makers to renew their efforts (Hale & Sharpe, 2011;
Remenyi, Carapetis, Wyber, Taubert & Mayosi, 2013; Mayosi, 2014). In that vein,
this doctoral thesis examines issues around managing ARF and preventing its
sequela, RHD, among young Aboriginal people in the NT.

**Acute Rheumatic Fever - Biological Determinants**

ARF is an autoimmune response which develops in some individuals a few weeks
after an untreated infection with group A streptococci (GAS) and is one of the few
autoimmune conditions triggered by a clearly identifiable pathogen (Chakravarty,
Zabriskie, & Gibofsky, 2014). Historically, the prior GAS infection was thought to
only include symptomatic or asymptomatic pharyngitis. Ongoing studies in the
Australian Indigenous context now suggest that skin infection (chiefly pyoderma) is
also likely to be making a major contribution to the development of ARF
(McDonald, Currie, & Carapetis, 2004). A systematic review of the global
population prevalence of pyoderma, published in 2015, estimated that at any one
time, 15,696 Australian Indigenous children in remote areas have pyoderma (Bowen
et al., 2015). In the studies included in the systematic review, the causative
organisms of pyoderma were both GAS and Staphylococcus aureus. While the
evidence is still incomplete, pyoderma may later be proven to have a direct link to ARF. However, while pyoderma is considered as a likely driving factor, with the high burden of ARF among young Aboriginal people, it is an important issue to manage.

A complete understanding of the mechanism of how GAS infection leads to ARF remains elusive, but headway is being made in ongoing research (de Dassel, Ralph, & Carapetis, 2014). Anti-streptococcal antibody levels are usually raised in patients with ARF, implicating GAS, and evidence of a prior GAS infection is part of the diagnostic criteria (Gewitz et al., 2015). The autoimmune mechanism may include a combination of certain GAS strains, inherited susceptibility, aberrations in the inflammatory response or particularly virulent strains (Choudhury & Exil, 2014).

Although ARF is a multi-organ condition, with fever and joint pain the most common presenting symptoms, the major concern is damage to the heart valves, which is particularly devastating for children and young people. Repeated episodes of ARF, or sometimes a single severe episode, can lead to compounded and permanent valve damage, named ‘rheumatic’ heart disease. This means that two separate, but related, conditions are involved; ARF and RHD. Although an episode of ARF is a significant acute care event, its management requires a chronic disease approach because long term prophylactic management and surveillance is required to prevent ARF recurrences and progression to RHD.

**Acute Rheumatic Fever- Social Determinants**

GAS can be transmitted through human contact or airborne droplets. Crowded living arrangements in remote community dwellings is considered a risk factor for ARF in the NT (RHDAustralia (ARF/RHD writing group), 2012). The high prevalence of
GAS skin infections coupled with frequent contact in crowded living quarters explains this raised risk. ARF was once prevalent in Australia but has now largely disappeared from the southern, most populated states, although there are still sporadic occurrences (Noonan et al., 2013). This reduction in cases is inversely proportional to the general improvements in living standards in Australia since the Second World War plus the advent of antibiotics (RHDAustralia (ARF/RHD writing group), 2012). ARF is globally understood as a marker of poverty and thus improvements in socio-environmental and socioeconomic conditions in remote Aboriginal communities is assumed to be critical to reduce the incidence of this condition (Baum et al., 2013; Parnaby & Carapetis, 2010).

Deficient housing and crowding are prevalent in remote Aboriginal communities and have been repeatedly considered strong factors in health risks; however, exactly what the links are and how to make improvements is a challenge (Bailie & Wayte, 2006). Perceptions of and preference for living in large kin groups are not universal but are culturally determined (Fu, Scott, & Laing, 2015). Aboriginal people in remote communities have a preference for connecting with extended family in close living which could be viewed as a social strength. However, shortage of public housing, inappropriate house designs, lack of maintenance of housing hardware, very low level of ownership and control of housing, hygiene behaviours as well as an array of socio-economic attributes make the issue of crowded housing in Aboriginal communities a complex one (Bailie, Stevens, McDonald, Brewster, & Guthridge, 2010). Primordial prevention of ARF involves reducing GAS infections within a community so that ARF is prevented in the first place (RHDAustralia (ARF/RHD writing group), 2012). Ways of living and housing characteristics are key components of social determinants of ARF. However, broader contextual
components such as a sense of wellbeing, power and control over one’s life, educational and employment opportunities and attainment, and communication capacities are also integral (Davidson, 2015).

**Surveillance**

Despite the overall reduction in global rates during the 20th century, ARF and subsequent RHD are increasingly recognised as significant public health problems in many global settings. In 1944, standardised diagnostic criteria were developed by Dr T. Duckett Jones, who recognised that improving our understanding and epidemiological surveillance of these two conditions would be valuable (Gordis, 1985). These diagnostic criteria were modified in 1972 and later revised in 2012 particularly for the Australian Aboriginal context (Noonan et al., 2013; Ralph & Carapetis, 2012). Surveillance systems for recording the incidence of ARF and RHD are not yet standardised or evenly distributed globally and there remains a call to improve the collation of surveillance data to complete the global picture as well as enable effective prevention and management strategies to be designed (Tibazarwa, Volmink, & Mayosi, 2008). In the NT, surveillance is supported by a Rheumatic Heart Disease Control Program and Disease Register (NT Register) that was commenced in 1997 to record new and recurrent cases of ARF as well as the delivery of treatments (Eissa, Lee, Binns, Garstone, & McDonald, 2005). This initiative was the first coordinated approach to managing ARF and RHD in Australia. ARF and RHD are now notifiable diseases in the NT and more recently in the other Australian states of Queensland, South Australia, Western Australia and New South Wales. A new and more comprehensive register design is currently being drafted in Queensland.
Disease Registers and Control Programs as Part of Surveillance

Local disease registers and control programs are recommended key surveillance tools for ARF and RHD. They are viewed as providing the service support for achieving the best outcomes for patients, and the most cost-effective way for health services to manage these conditions (McDonald, Brown, Noonan, & Carapetis, 2005; Remenyi et al., 2013). They are also recommended in locations where ARF prevalence has declined as a way to periodically review the incidence of these two conditions such as in OECD member countries (Breda, Miulli, Marzetti, Chiarelli, & Marcovecchio, 2013; Oliver, Baker, Pierse, & Carapetis, 2015). Sustained funding and support from governments for disease registers is vital to their ongoing existence; some countries such as Sudan have devised RHD registers but have not been able to implement them due to lack of funds and technical support (Ali, 2013). Registers allow long-term tracking of individual patients as well as monitoring the epidemiology (Oliver et al., 2015).

Importantly, GAS pharyngitis is easily missed in children, and pyoderma may not be acted upon, leading to the impetus for comprehensive RHD control programs rather than just disease registers (Colquhoun, Carapetis, Kado, & Steer, 2009). RHD Control Programs ideally incorporate education around ARF and RHD for communities, families and health professionals as well as case finding, prevention strategies, and the opportunity for advocacy (Colquhoun et al., 2009). Collaboration between disciplines is recommended when devising educational components of RHD Control Programs because the population group primarily affected by ARF are children and adolescents, and predominantly Indigenous, and these characteristics mean a tailored care approach is needed (Britto, 2006). In the NT, collaboration is especially called for because of linguistic diversity of the whole population and large
geographical distances over which the population is spread. This setting requires trained Aboriginal language interpreters and greater time to ensure shared understanding around ARF and RHD.

Overall, without good surveillance, it would be difficult to galvanise health services and governments into action around these two conditions and the disease burden would increase (Brown et al., 2010). An international registry is currently under development with a view to collating ARF and RHD data from a number of countries for use as an advocacy tool (Maurice, 2013).

**Ongoing Management of ARF in the NT**

Once an initial diagnosis of ARF is confirmed, management, as recommended in the 2012 Australian Guidelines, includes adhering to a difficult schedule of long-acting benzathine penicillin G injections (RHDAustralia (ARF/RHD writing group), 2012). These injections are administered every 28 days, or sometimes every 21 days, for ten years after the last ARF occurrence, or until the child reaches the age of twenty-one years, whichever is longest. The penicillin injections are painful due to the viscosity and volume of solution injected into muscle. The treatment works by slow release, and is assumed to provide a continuous therapeutic blood and tissue level of penicillin to prevent infection with GAS and thus remove the trigger for the autoimmune response, and preventing recurrence of ARF. The treatment delivers a secondary blanket covering rather than specific targeted primary protection (such as a vaccine), but it is the only current effective and achievable prevention strategy while we wait for improved primordial prevention strategies (which should reduce the circulation of GAS in communities) or a vaccine for GAS.
Availability of Penicillin Injections and Primary Health Care

Penicillin injections are generally available in the NT due to high quality medication supply and universal health care, including in remote locations. Primary health care services are situated in many NT remote locations and provide free access for most of the Aboriginal population, although some smaller communities may be dependent on fly-in/fly-out health staff or visiting clinicians. Primary health care services are either provided by the state government or by autonomous Aboriginal organisations. Remote health services are staffed by nurses, doctors and Aboriginal Health Practitioners and are visited by specialists, although there is a high turnover of all clinicians in these locations. The physical provision of health services should enable young Aboriginal people to safely receive regular injections of high quality penicillin. Sub-optimal adherence to or delivery of injections is not due to absence of health services but involves more complex factors.

Secondary Prophylaxis to Combat RHD (the Penicillin Injections)

Regular penicillin injections given to prevent recurrence of ARF, and ultimately RHD, are known as secondary prophylaxis or secondary prevention. Primary prevention entails early detection and treatment of GAS infections; pharyngitis or pyoderma (RHDAustralia (ARF/RHD writing group), 2012). For this study, the term ‘penicillin injection’ or ‘penicillin regimen’ will be retained to keep the focus on the years of injections and what they may mean to the young people who receive them. Agreement to adhere to the penicillin regimen is expected to be negotiated in dialogue between a patient/carer and their prescriber (Gasse et al., 2013). However, adherence among many young Aboriginal people is too low to prevent ARF recurrences, progression to RHD, the need for heart valve surgery and sometimes premature death (He et al., 2016; Parnaby & Carapetis, 2010).
A recent NT study in six sites revealed that, despite improvements in RHD care, there was no change in rates of injections administered at the sites during the study period (Ralph et al., 2013). Difficulties in achieving adequate rates of adherence to injections have been experienced in most situations globally since this preventative regimen was initiated in the 1950s (Gordis, Markowitz, & Lilienfeld, 1969; Walker, Human, De Moor, & Sprenger, 1987). In Australia, Aboriginal children and adolescents bear the highest burden of ARF (RHDAustralia (ARF/RHD writing group), 2012). An audit of ARF recurrences in the Aboriginal population between 1997 and 2010 revealed that recurrence rates were highest in the three to four years after initial ARF diagnosis which means that the group who require most intensive attention around adhering to the penicillin regimen are young (Lawrence, Carapetis, Griffiths, Edwards, & Condon, 2013). A further data-linkage study using NT Register data between 1997 and 2013 in the NT showed that 27.1% of patients progressed to RHD within one year of first ARF diagnosis, occurring almost 10 times faster than ARF recurrences (He et al., 2016). With the high burden of ARF and RHD among young Aboriginal people in the NT, coupled with poor adherence to treatment and subsequent poor outcomes, it is important to investigate what this group understand about the injection regimen and what their perspectives on the conditions and their management are. I undertook a literature review to explore what is known on this topic, both in Australia and internationally.

**Literature Review One: Patient’s Perspectives of ARF and RHD Care**

A narrative review of the literature was undertaken to locate and critically appraise research that reported patients’ perceptions of their condition (ARF or RHD) and the
care they receive, as well as facilitators and barriers to adhering to the penicillin regimen.

**Search Strategy**


Health care databases searched were CINHAL, Education Research Complete, ERIC, Medline, Google Scholar and PsycINFO. Alerts from the Australian Indigenous Health Bulletin were also scrutinised for relevance. Studies were included if they reported on patients’ views of the injection regimen or health staff perceptions of barriers and facilitators affecting patient adherence to the regimen.

Studies that reported on strategies that achieved sustained reduction in rates of ARF were included, as were papers that reported on adolescents with ARF or RHD. Only papers written in English language were included and papers reporting on oral penicillin were excluded. Much of the literature was obtained using a snowballing technique, drawing from references in published papers and texts. Dates for inclusion were not constrained due to the low number of papers. Therefore, any papers on the topic published between 1960 and 2015 were included. Very few papers elicited patient-reported views on ARF/RHD and adherence to the injection regimen. The initial review was carried out in 2013 with additions made in 2014 and 2015 as new studies matching the inclusion criteria were published.
Results

International Studies Reporting Patient Perspectives

Countries with high prevalence of ARF and varying success with adherence to penicillin injections include Brazil, India, Cuba, Chile, Egypt, Nepal, Iran, French Caribbean, Ethiopia, Kenya and South Africa, as well as Australia and New Zealand. These represent a range of social settings, cultures, languages and levels of economic development. While many published papers reported poor adherence to the penicillin injections, only 15 were located that met the inclusion criteria of patient-reported views. Most studies on ARF and RHD to date have been quantitative, concentrating on recording the disease incidence and prevalence, rates of adherence to injections and, more recently, the value of using portable echocardiogram to aid diagnosis and the development of a vaccine against group A streptococcus. Two international qualitative studies were located that exclusively sought patients’ views about their condition. Other studies used mixed methods, including patient interviewing; many used closed questions or questionnaires with binary choices. Such instruments have limited capacity to gain in-depth data as there is no opportunity for further probing, clarification or elaboration. The paucity of studies reporting on patients’ and their families’ perspectives of ARF and RHD in the literature constitutes a significant knowledge gap which impedes the design of effective strategies to improve adherence to the injection regimen.

Literature Reporting on Studies Outside Australia

Fifteen studies were located in the international literature that sought patients’ views, or contained components with patients’ views. They include three studies conducted in Egypt, three in India, five from African countries, and one each in Iran, Jamaica,
New Caledonia and Nepal. These studies cover 14 years from 1998 to 2012, although four do not state the year their study was undertaken. The studies are presented in the following table (Table 1.1) and are classified into four categories, A to D, for the purposes of this thesis:

**A** = qualitative study using grounded theory, open questions and on topic with ARF/RHD patients or carers (2 studies). Studies in category A have most relevance for this thesis.

**B** = mixed methods using questionnaires or surveys, statistical analysis, lists of barriers and facilitators for adherence to the injection regimen, with ARF/RHD patients or carers, (10 studies)

**C** = qualitative study using grounded theory, study not about adherence but a related ARF/RHD topic (2 studies)

**D** = quantitative study including some patient reports of adherence (1 study)
<table>
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<tr>
<th>Reference &amp; Study category</th>
<th>Year of study</th>
<th>Place</th>
<th>Setting</th>
<th>Number surveyed</th>
<th>Age in years</th>
<th>Methods used in study</th>
<th>Findings</th>
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<tr>
<td>Bassili</td>
<td>1998</td>
<td>Egypt</td>
<td>Outpatients of 5 Government Children’s Hospitals Alexandria</td>
<td>127 mothers of disadvantaged children with ARF</td>
<td>0 to 15</td>
<td>3 closed interview questions, Mixed methods</td>
<td>Poor adherence and ARF recurrences linked with parental level of education and occupation, poor parental knowledge of condition, living further from urban centres and not satisfied with health care provided. 64.6% patients compliant</td>
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<td>(Bassili, A. et al, 2000)</td>
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<tr>
<td>Category B</td>
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<tr>
<td>Kumar</td>
<td>1999</td>
<td>India</td>
<td>Northern rural</td>
<td>40 non-compliant patients with ARF</td>
<td>Not stated</td>
<td>Semi-structured interviews, Mixed methods</td>
<td>Non-adherence due to: Fear, pain or physical effect of injections Lack of awareness Belief injection not needed Fear of negative spouse response No local service Mean compliance 92% in region</td>
</tr>
<tr>
<td>(Kumar, R. et al, 2002)</td>
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<tr>
<td>Category B</td>
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<tr>
<td>Robertson</td>
<td>1999 - 2003</td>
<td>Cape Town</td>
<td>Metropolitan area</td>
<td>8 carers of children with ARF</td>
<td>3 to 12</td>
<td>Qualitative case studies, Mixed methods</td>
<td>Almost non-existent knowledge of the disease or purpose of injections or how to prevent ARF. Low community awareness Good compliance with injections</td>
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<tr>
<td>(Robertson, K. A. et al, 2005)</td>
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</tbody>
</table>
| **Petricca** (Petricca, K. et al, 2009) | **Category C** | **2006** | **Ethiopia** | **Jimma, Hospital Chronic illness follow-up clinic** | **20 patients**  
13 carers of paediatric patients with ARF | **7 to 70** | **Qualitative study**  
Semi-structured interviews  
Grounded theory  
Triangulation with medical records  
**Topic:** treatment-seeking behaviours | Patients sought follow-up if they were symptomatic and had support from teachers, colleagues and family. Adherence linked with desire for future health  
1/3 did not know cause of ARF  
Weighing the costs against personal priorities affects adherence  
Costs and distance for centralized care affects adherence and satisfaction with care  
Adherence rate not stated |
| **Kasmaei** (Kasmaei, P. et al, 2008) | **Category C** | Not stated | **Iran** | **Fifty Urban Health Care Centres** | **443 mothers**  
attending for primary health care and immunisation for children.  
No ARF or RHD | **Mean age 28** | **Qualitative study**  
Closed question questionnaire covering 5 aspects of ARF.  
Statistical analysis  
*no personal cases of ARF* | Poor to moderate knowledge of ARF symptoms  
Good knowledge of treatment for ARF  
Poor to moderate knowledge of route of infection, prevention methods or complications of ARF  
Education status significantly correlated with mothers’ knowledge |
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Country</th>
<th>Setting</th>
<th>Participants</th>
<th>Type</th>
<th>Questions</th>
<th>Statistical Analysis</th>
<th>Reasons for non-compliance</th>
</tr>
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<tbody>
<tr>
<td>Tullu</td>
<td>2006-2008</td>
<td>India</td>
<td>Paediatric Outpatients Department</td>
<td>10 patients with ARF or RHD</td>
<td>Questionnaire Completed during clinic visit</td>
<td>Some open questions</td>
<td>Statistical analysis</td>
<td>Unable to recall reason for missing injection (6/10), Trip to one’s native place, Forgetting date, Doubts that injection needed, Distance and cost of travel, Adherence average 89.6%</td>
</tr>
<tr>
<td>Elsayed</td>
<td>2010</td>
<td>Egypt</td>
<td>Paediatric Outpatient Clinic</td>
<td>100 children with ARF</td>
<td>Questionnaire</td>
<td>Statistical analysis</td>
<td></td>
<td>Fear of painful injection in 87%, Lack of confidence in treatment, Inadequate counselling, Unwilling child, Costs, Distance, Reduced adherence with greater duration of disease, Males less adherent, Irregular adherence in 53%</td>
</tr>
<tr>
<td>Thompson</td>
<td>2010</td>
<td>Jamaica</td>
<td>Three urban health centres</td>
<td>35 patients with ARF</td>
<td>Survey instrument with 5-point Likert scale re barriers, Closed questions</td>
<td>Statistical analysis</td>
<td>No relationship found between knowledge scores and adherence, 5% have good knowledge, Fear of injections a barrier, Long distance and waiting times a deterrent, Supportive clinical relationships improve adherence, Adults adherence linked with desire for future health, Adherence 48.7%</td>
<td></td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Location</td>
<td>Sample Size</td>
<td>Age Range</td>
<td>Methodology</td>
<td>Findings</td>
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<tr>
<td>Gasse</td>
<td>2013</td>
<td>New Caledonia, Lifou,</td>
<td>40 children</td>
<td>13 to 32</td>
<td>Mixed methods</td>
<td>More adherent if had symptomatic ARF episode, ≥6 members in household and had local health service</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Tropical island</td>
<td>30 adults</td>
<td></td>
<td>Standardized questionnaire with closed questions and binary choices. Multivariate analysis</td>
<td>Pain of injection not a deterrent. Mean adherence 77%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regmi</td>
<td>2012</td>
<td>Nepal</td>
<td>4712 patients</td>
<td>36.7% &lt; 18 years</td>
<td>Quantitative study Audit of RHD Register</td>
<td>Non-adherence due to needle phobia, prohibitive distance and prohibitive costs</td>
<td>Default rate 6%</td>
<td></td>
</tr>
<tr>
<td>Keoch</td>
<td>2012</td>
<td>Rural Kenya</td>
<td>10 parents</td>
<td>6 to 14</td>
<td>Separate male and female focus groups Open questions. Grounded theory</td>
<td>Poor knowledge among families and clinic staff Average 2 years to diagnose ARF/RHD Great financial and emotional costs Most children needing surgery</td>
<td></td>
<td></td>
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<tr>
<td>Musoke</td>
<td>2012</td>
<td>Uganda</td>
<td>93 patients with RHD</td>
<td>5 to 55</td>
<td>Pre-coded, standardised questionnaire</td>
<td>Reasons for missing injections: Pain of injection 29% No transport money 26.9% Distance from clinic Felt not needed 11.8%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| **Saxena**  
(Saxena, A. et al, 2015) | **Category B** | Not stated | India | Registry in Tertiary Care Centre | 167 children on penicillin injections | Mean age 11.9 | Statistical analysis  
Standard questionnaire | Other reasons: advised otherwise by friends, felt sick, injection abscess, away from home.  
Non-adherence 46%  
Lack of awareness of significance of injections - 9 patients  
Pain and fear of injection - 2 patients  
Injection not available - 3 patients  
Injection stopped by physician post valve surgery - 2 patients  
151 patients’ good adherence (>80%) |
|---|---|---|---|---|---|---|---|---|
| **Huck**  
(Huck, D. M. et al 2015) | **Category A** | Not stated | Kampala, Uganda | Attendees at Uganda Heart Institute on RHD Registry | 36 patients with RHD | 14 to 58 | Qualitative study  
Semi-structured focus groups  
Analysed for themes against pre-set variables and new variables  
Use of socioecological model  
Themes compared using statistical tests | Facilitators to adherence: Worsening symptoms associated with missing injections  
Personal motivation for future health  
Effective reminder systems  
Family and clinician support  
Living close to clinic  
Barriers to adherence:  
Travel distance and cost of medicine  
Fear of painful injections  
Lack of family support  
Poor relationship with clinicians  
Unskilled clinicians  
Long wait for injection  
No penicillin available  
Poor knowledge not linked with adherence  
58% adherent (≥ 80%) |
| Balbaa  
(Balbaa, A. et al, 2015)  
Category B | Not stated | Egypt | Aswan Heart Centre | 29 patients with ARF | 5 to 15 | Structured interviews using questionnaire including Likert scale plus some open questions. Statistical analysis of pre-set domains. Purpose was questionnaire development. | Knowledge of condition correlates with adherence. Long clinic wait times a deterrent. Conscious choice to miss injections. 65.5% of group adherent |
Narrative Summary of the Findings in International Studies

Participants in the 15 studies were either patients with ARF or RHD or parents/carers of children with ARF or RHD. Eleven of the studies were undertaken in outpatient departments attached to large hospitals or health clinics, with the remaining four taking place elsewhere (participants’ homes, or not stated). As ARF commonly emerges in childhood, the ages in the samples tended to be mostly children (youngest age 3) and adolescents or young adults but also included a small proportion of adults with RHD, up to age 70 in one study. The range of sociocultural and economic settings represented in the samples makes comparisons difficult but confirms that ARF and RHD are widely distributed public health problems affecting young people in many nations.

While a total of 600 patients and 158 parents or carers participated in the studies collectively, (with an additional 443 mothers of children with no ARF interviewed to determine their knowledge on ARF), just two studies, with 44 participants (eight parents and 36 patients) collected in-depth data using open questioning in interviews or focus groups. The two in-depth studies were conducted in African countries which narrows their applicability to other settings. This means their contribution to global public health knowledge on patients’ experiences and perceptions of ARF and RHD, although important, is limited. In view of the global burden of ARF and RHD, estimated to be at least 30 million people, the number and locations of in-depth enquiries into patients’ experiences is clearly not adequate to inform appropriate public health strategies to reduce the disease burden (Carapetis, Mayosi, & Kaplan, 2006).
The differing study designs provided a range of patients’ perspectives. Closed questions and audits with statistical analysis naturally have least ability to determine in-depth patient perspectives but are valuable for collating the types of barriers to adherence that exist for patients such as travel distances, access to treatment, costs of travel and medication as well as patients’ perspectives on the need for injections and attitudes of clinicians. Other demographic analyses such as levels of parental education and number of people per household correlated with adherence adds to the overall picture of what may be determinants of good adherence to treatment for ARF in certain sites. For instance, in New Caledonia and Ethiopia, researchers found that people were more likely to adhere to the penicillin regimen if they experienced a symptomatic ARF episode (Petricca, Mamo, Haileamlak, Seid & Parry, 2009; Gasse, Baroux, Rouchon, Meunier, Fremicourt & D’Ortenzio, 2013). Further analysis in the New Caledonian study found that having more than five people in a household is linked with more likelihood of adherence to penicillin injections in that site (Gasse et al, 2013).

Not having a health service close by was reported as a deterrent to injection adherence in four sites (Petricca et al., 2009; Elsayed & Elawany, 2012; Musoke et al., 2013; Huck, et al., 2015). This is not likely to be a direct factor in the NT as health services cover most if not all remote locations. However, if NT health services are distant from people’s residential locations, it reduces the capacity for development of good relationships between patients and clinicians. In a discussion on Australian research that follows, it will be seen that the issue of access includes more than just physical proximity.
Support and counselling were mentioned in two studies (Thompson, Brown, Edwards & Lindo, 2014; Huck et al, 2015) as important factors linked with adherence, and alluded to in a third. This support was provided by families, schoolteachers and colleagues. The quality of service in healthcare entities was found to be linked with health-seeking behaviours, with respect and continuity of carer considered important by patients and families.

While it is difficult to apply findings from the located studies to different social settings, there is increasing evidence that educational and income levels and other social demographic factors are predictive of health generally (Davidson, 2015). These are population level contextual factors. Therefore, while the determinants emerging in the 15 studies are valuable for building a picture of what influences adherence to the long-term treatment for ARF in some sites, it remains to be seen whether there are similarities in the NT Aboriginal population.

**In-depth, Qualitative Studies**

Two international studies used grounded theory designs (Huck et al., 2015; Koech & Ngeno, 2014). This design allowed researchers to construct theory from their collected data (patient interviews or focus groups) and thereby build an understanding of experiences from the affected people (Liamputtong, 2013).

In the first study Koech and Ngeno elicited rich information in focus groups in rural Kenya (Koech & Ngeno, 2014). They explored ten parents’ experiences of having a child diagnosed with RHD and found great emotional and financial distress due to the children’s conditions in this disadvantaged setting. There was poor knowledge of ARF and RHD among families, but also among local clinicians. This led to an average of two years for children to be diagnosed accurately and meant that, with the
lost opportunity to place children on the protective penicillin regimen most children in the study already needed heart valve surgery.

Lost opportunities to prescribe the penicillin regimen are not expected to apply in Australia where there is good medical care, good access to diagnostic tests and up-to-date guidelines for clinicians. However, a proportion of Aboriginal children are diagnosed with RHD at first presentation indicating that initial ARF may have been missed (He et al., 2016). There are likely to be multi-faceted reasons for a missed diagnosis in the NT, including lack of community awareness and inadequate recognition or surveillance on the part of remote health services.

The second study using grounded theory also took place in Africa, among 36 patients attending a heart clinic in the city of Kampala, Uganda (Huck et al., 2015). Identification of health behaviours, attitudes and health care system factors influencing adherence to the penicillin regimen were sought using focus groups. Facilitators of adherence were found to be personal motivation for future health; patients’ association of worsening symptoms with missing injections; family and clinician support; living close to the clinic and having an effective reminder system. Barriers to adherence were travel distance; cost of medicine; fear of painful injection; poor relationships with clinicians; unskilled clinicians; long waits for injections or no penicillin available. While the use of focus groups potentiates deeper information being illuminated than with questionnaires, further depth can be gained with the use of participant observation and serial interviewing over longer periods (Cruz & Higginbottom, 2013).

A further study, also from Africa, used a qualitative design comprising in-depth interviews using semi-structured questionnaires but focussed on treatment seeking
behaviours among ARF and RHD patients rather than their experiences of the injection regimen or having ARF (Petricca, Mamo, Haileamlak, Seid, & Parry, 2009). The authors found that one third of patients (n=20) did not know the cause of ARF and were more likely to seek treatment if they were symptomatic and had support from family, colleagues and teachers. One theme emerging from the analysis in this study is *weighing the costs* of seeking treatment against other personal priorities and this has some relevance to the NT setting where Aboriginal people’s health priorities can be quite disparate from health provider’s priorities (Senior & Chenall, 2013).

While studies using grounded theory can reveal deeper insight into patients’ views and understanding, they cannot be generalised to different social locations such as exist between rural Kenya, Ethiopia and Australia. For instance, long delays in diagnosis would not be expected in the NT. Treatments and travel expenses are also paid for by NT health services and high-quality penicillin is generally available.

**Links Between Community or Patient Awareness and Adherence**

Overall, the global literature confirms that community and patient awareness and understanding around the complex conditions of ARF and RHD is generally low (Bassili, Zaher, Zaki, Abdel-Fattah, & Tognoni, 2000; Huck et al., 2015; Koech & Ngeno, 2014; Kumar, Raizada, Aggarwal, & Ganguly, 2002; Petricca et al., 2009; Robertson, Volmink, & Mayosi, 2005; Thompson, Brown, Edwards, & Lindo, 2014). Low level of awareness curbs peoples’ ability to manage and prevent ARF and RHD. However, lack of patient knowledge on causes of ARF, reasons for the penicillin regimen and understanding of the two conditions, was not found to necessarily equate with poor adherence. Adherence to the penicillin regimen was calculated in
six of the 15 studies. Although measurement of adherence in the included studies were not consistent, the reported adherence rates ranged between 53% and 92%. Two studies found that poor knowledge was not linked with adherence as did Thompson, 2010, in a Jamaican study (Huck et al., 2015; Thompson et al., 2014). However, a study conducted in Egypt did find correlation between patients’ knowledge of their condition and adherence in Egypt (Balbaa, ElGuindy, Pericak, Yacoub, & Schwaldm, 2015). The relationship between patient knowledge and adherence remains unclear and may depend on location. In some sites patient knowledge was recorded as being almost non-existent yet adherence was good (Kumar et al., 2002; Robertson et al., 2005). To tease out the relationship between knowledge and adherence, cultural traits and histories, patients’ ages and experiences as well as methods used to disseminate educational information need to be included. The range in adherence rates within the literature means little can be currently stated about the effect of patient knowledge on adherence although it is assumed that raising patient knowledge has benefits.

**Links Between Pain of Injection and Adherence**

Pain of injections was also reported variedly in the international studies and presents an unclear picture. This was reported as pain or fear of painful injections. Seven of the fifteen studies reported pain or needle phobia as a deterrent for injections. In one study this comprised 87% of 100 children with ARF in Egypt (Elsayed & Elawany, 2012) and yet 4.9% in the register study from Nepal with 4712 patients (Regmi & Wyber, 2013). Factors such as clinician technique, age of patients, quality of penicillin, use of local anaesthetic and past experiences of the injections are related to the issue of pain of injections. Needless to say, the penicillin injections are painful, but the effect this has on adherence is not clear.
Living Conditions and ARF Development

Poor living conditions are known to be a risk factor for the development of ARF and the populations in the 15 studies represent low socio-economic groups. Interestingly, two papers, both in Egyptian sites, reported that the standard of living was ‘reasonable’ among 42% in one study (Elsayed & Elawany 2012) and 45.3% in the other (Bassili et al., 2000). The term reasonable as it relates to standard of living is not defined within the studies and is not a specific measure. A further study recorded details of housing construction while others stated that the living conditions were disadvantaged or just noted as ‘poor’ or ‘developing’ (Bassili et al., 2000; Gasse et al., 2013; Kumar et al., 2002; Regmi & Wyber, 2013). However, while poverty is linked with ARF, just which poverty-related factors lead to higher risk of ARF are not clear. Variables include the number of people per household or per bedroom, access to hygiene hardware including water, presence of scabies and nutritional status. Culturally-based ways of living are also important characteristics to keep in mind when describing poverty or standards of living in relation to ARF. In the NT Aboriginal population, this is more likely to be a foundational variable for ARF rather than poverty per se because of strong cultural practices still evident in the preferred communal ways of living.

The following section examines the literature from Australia to determine what is known about experiences of ARF and RHD among Aboriginal people.

Australian Studies Reporting Patient Perspectives

Barriers and facilitators for adherence to the injection regimen were elicited from two small studies in Aboriginal populations, one in an island community in the NT in 2006 and one in the Kimberley region of northern Western Australia in 2003. Both
sites have mission station backgrounds where institutional health care was initiated by missionaries and subsequently continued by either government or independent health services at the conclusion of the mission era. Health care of Aboriginal people by missionaries was rudimentary but stemmed from a desire to improve peoples’ physical as well as spiritual wellbeing (Wells, 1963).

The NT study used mixed methods and included interviews with 15 predominantly female adult patients and 18 of their relatives. Facilitators of adherence to the injections were mainly centred on patients having a sense of belonging to the local clinic and being supported to receive the injections (Harrington, Thomas, Currie, & Bulkanhawuy, 2006). These views are possibly historically influenced by the mission era where responsibility for health care was maintained by the mission. Recall of the mission station practices would be significant in some respondents’ memories and may remain a cause of confusion among residents about who is responsible for ‘health’ in their location. Other facilitators were having family support for the treatment and an appropriate place to receive the injections along with a belief that the injections were required for the long term.

The Kimberley research is the only study that has exclusively explored patients’ perspectives of the conditions of ARF and RHD in an Australian remote community (Mincham, Toussaint, Mak, & Plant, 2003). The study was conducted in the Kimberley region where the local population is majority Aboriginal. In-depth interviews were conducted with six Aboriginal patients and one non-Aboriginal patient over one year. This study revealed that patients value close and long-term contact with clinic staff. Remembering when the injections were due was a problem and some patients relied on nurses to inform them. Others preferred to
be independent but still lacked reminder systems or tools. Barriers to adherence were relationship problems with local health staff as well as competing personal priorities (Mincham et al., 2003). Patients’ relationships with clinicians are considered one component of access because, where relationships are strained or difficult, access is greatly reduced.

Both Australian studies reported that patients had little knowledge and understanding of ARF and RHD and could not determine what effect this had on adherence to the penicillin regimen. Poor knowledge has also been highlighted as a problem around chronic diseases in general by other authors in similar north Australian settings (Belton et al., 2016; Bryce, 2002; Cass et al., 2002).

**Health Carers’ and Others’ Perspectives on Adherence to Penicillin Injections**

In other studies, separate from the above 15, patients were not interviewed but researchers sought to understand what leads some patients to adhere to the penicillin regimen and some patients to decline. These include a New Zealand study that interviewed nine nurses delivering the injections in patients’ schools, homes, work places or nurse clinics. Nurses’ perspectives on the reasons for good adherence included having community health workers and a nurse with dedicated time for patient education (Grayson, Horsburgh, & Lennon, 2006). This study reports high adherence rates between 79.9% and 100%, depending on the clinic. The high adherence rates in this study could be posited as being due to the design of a community nurse-led flexible program.

In a retrospective study of 536 Brazilian children with ARF during the period 1985 to 2005, the authors found that most patients in whom a recurrence of ARF occurred
were male, had an average age of 14.5 years and were poor adherers to the injection regimen (Pelajo, Lopez-Benitez, J. M. Torres, & de Oliveira, 2010). Due to the retrospective design, it was not possible to determine causes of non-adherence but the authors recommended actively searching for non-adherent patients in order to initiate closer follow up, as well as including their families in care strategies and management. The difficulty of engaging adolescents is highlighted in a further study of South African children that found non-adherers were more likely to be male and over 12 years old (Walker et al., 1987).

A qualitative study undertaken in the NT explored health professionals’ views on reasons for Aboriginal patients’ non-adherence to medical treatments. This study aimed to shift the research spotlight from patients to the medical community (Humphrey, Weeramanthri, & Fitz, 2001). The researchers concluded there is a need to reconsider health service provision and purposefully examine which model of care is most appropriate in these cross-cultural settings where biomedical culture and Aboriginal culture intersect.

**Determinants of Sustained Improvement in Adherence to Penicillin Injections**

Significant improvements in adherence have been reported in two global settings via public health campaigns combined with educational support for clinicians. An educational campaign carried out in the French Caribbean islands from 1982 to 1992 had success in reducing the incidence of ARF and RHD (Bach et al., 1996). This campaign established a Register of all cases of ARF and RHD and clinically examined all new cases. An intensive educational program in the local languages via pamphlets, posters, radio and television broadcasts were carried out. The thrust of
this program was to raise understanding of the connection between benign sore throat (the source of GAS infection) and the possible serious heart damage that can be caused by ARF. Skin infections were also included in the campaign. This campaign was associated with a consistent reduction in both incidences of first ARF and recurrences over the ten-year period. The authors were not able to state which part of the intervention produced the results, and assumed it was a combination of all the elements.

Cuba also reports a similar multifaceted RHD education campaign that was successful in achieving sustained reduced rates of ARF in the one district where it was carried out (Nordet, Lopez, Duenas, & Sarmiento, 2008). The program included education of patients and health staff as well as improved service provision. Certainly, the contexts of Cuba and the French Caribbean have many differences from the Australian Aboriginal context but lessons from these educational campaigns are informative and could be translated into the Australian setting.

**Rationale for the Current Study**

Considering the high incidence and prevalence of ARF and RHD in the NT, there is not enough known about what young Aboriginal people, and especially young males, currently understand, think and feel about the disease and the long-term regimen of penicillin injections. This includes the barriers and facilitators to accessing health services, but also encompasses broader issues to do with provision of a biomedically-based health service in a cross-cultural setting. With just two previous small studies seeking Aboriginal patients’ voices in the context of a small number of similar studies in other populations, this doctoral study aims to contribute knowledge about Aboriginal peoples’ perceptions of their disease and their experiences of being on the
injection regimen in the NT. Young Aboriginal people’s perceptions will especially be sought as they bear the burden of ARF. Exploring and gaining understanding of these perceptions has the potential to inform self-care strategies for young Aboriginal people with ARF in remote settings, and enable more effective partnering of these patients with their health services. The findings may also help inform attitudes to, and hence approaches to managing, other illness of importance in Aboriginal communities.

Most of the economic costs for ARF are consumed with cardiac surgery whereas the cost of the injections and their delivery is much less (RHDAustralia (ARF/RHD writing group), 2012). As RHD is mostly preventable with adherence to the injection regimen, efforts to raise adherence will be cost effective due to reducing RHD. This is the most expedient strategy while waiting for sustained improvements in the social determinants of health in Aboriginal communities, or a vaccine. The human cost of ARF and RHD also warrants consideration. The need for Aboriginal children and adolescents to endure years of repeated painful injections or to additionally undergo cardiac surgery to repair or replace their damaged heart valves must have a significant negative impact on Aboriginal individuals and families.

**Literature Review Two: Self-management and Transition to Adult Care**

As penicillin injections are given over long time periods, once a person is diagnosed with ARF, it reveals their susceptibility to recurrences of acute illness +/- development of RHD. Henceforth they are managed as having a chronic condition. As such, approaches to care of children and adolescents with chronic conditions are relevant. *Self-management* and ‘transition to adult care for children with chronic*
disease’ are two well-documented principles in the chronic care literature. Therefore, a further narrative literature search, using the same databases as previously listed, was carried out to understand how these concepts may apply in my study setting.

**Search Strategy**


**Self-Management of Chronic Conditions**

Health care moved locus during the 20th century “from the individual, family, and community to health care providers and health care institutions” (Lorig, 1993, p. 11). This move was also experienced in Australian Aboriginal societies as missions or government settlements initiated rudimentary health services thus providing a new and alternative health care entity to what was previously in existence (Hewwitt, 2013). Patients look to these new providers and institutions for their chronic conditions care. As chronic conditions increase in Australia, and worldwide, the effect on health systems has led to the concept of self-management gaining impetus among health professionals within health systems (Harris, Williams, Dennis, Zwar, & Davies, 2008). Future demand on health systems due to chronic conditions is expected to escalate, reinforcing the notion of self-management (Northern Territory Department of Health, 2012).

**Definition of Self-Management**

An increase in academic writings on self-management has led to a variety of definitions. All definitions incorporate a central principle of patients taking an active
role in the management of their chronic condition. For this study the definition in the NT Chronic Conditions Self-Management Framework will be used. The definition within the framework is, “Self-management involves the people with the chronic disease becoming participants through learning and practicing new skills to carry on an active and emotionally satisfying life in the face of a chronic condition” (Lorig, 1993, p. 11). This framework is expected to guide health services in the NT and is thus relevant to the participants in this study (Northern Territory Department of Health, 2012).

Use of the word ‘becoming’ in this definition implies a process rather than an event. Learning and practicing are ongoing processes (Lawn, McMillan, & Pulvirenti, 2011). The definition diverges from the notion of health practitioners having control on the basis of biomedical knowledge, to recognition of the patient as an expert on their own lives and how management of their chronic condition is impacted by their everyday life circumstances (Northern Territory Department of Health, 2012). Self-management is not intended to replace standard medical care but to balance that care with a new sense of partnership (Lorig, 1993). Lorig (1993) further describes self-management as having a spirit of innovation in that the processes allow patients to adapt to new problems and make informed choices as they practice new self-care skills on a day-to-day basis. The primary aim of this innovative approach among patients is to improve health and reduce deterioration by increasing patient self-efficacy or confidence in managing their own health issues.

The underlying expectation of self-management is that it “will improve wellbeing and strengthen self-determination and participation in health care, while reducing health care utilisation and health costs” (Sawyer & Aroni, 2005, p. 405). A bibliographic review of research publications on self-management between 1975 and
2012 revealed a marked increase in volume in the last decade, with these being predominantly from developed countries and most studies focussing on diabetes care (Lu, Li, & Arthur, 2014). The publications collectively provide some evidence that effective self-management improves health outcomes, although the authors note that further research is required within populations outside developed countries to determine if the same impact occurs in those populations. The main indicators or evaluations used in these publications are “quality of life, activity of daily life, patients’ compliance and satisfaction” (Lu et al., 2014, p. 4). Self-management programs based on behavioural management frameworks and including tasks such as goal setting, also demonstrate clinical indicator improvements as well as other improvements (Lorig & Holman, 2003). A study on self-management in Australian general practice highlights the cost effectiveness of this approach but states that it has not been successful with minority groups and socioeconomically disadvantaged people because of linguistic and cultural barriers (Harris et al., 2008).

**Criteria for Development of Self-Management Programs**

Implicit in the concept of self-management is that patients have information and capacity to begin to manage their condition and the degree to which they do this is a matter of individual choice or behaviour. Therefore, self-management programs tend to be based on behaviour change theories (Lorig & Holman, 2003). The Stanford and Flinders University models are such programs (Northern Territory Department of Health, 2012). However, there is evidence in the literature that NT Aboriginal residents do not have enough information about chronic conditions to begin self-management and this lack of information impedes self-management (Anderson, Devitt, Cunningham, Preece, & Cass, 2008; Cass et al., 2002). Additionally, wider impacting issues such as social determinants may not be changeable by patients and
their autonomy may be bounded in this sense (Lawn et al., 2011). It is therefore important that self-management approaches for this population take language, worldview and community development processes seriously. Once patients understand their chronic condition, then behaviour change approaches to self-management may become relevant.

Self-management requires a transformation in practice by individual practitioners, health systems and organisations as well as by patients (Lorig, 1993; Northern Territory Department of Health, 2012). The notion that health practitioners can enhance health outcomes by transforming their approach into a collaborative one with patients, including addressing power differences, is commonly articulated (Harris et al., 2008; Lawn & Schoo, 2010; Lorig, 1993). A study in one remote NT community demonstrates that health practitioners may not relinquish power easily and divergent assumptions may be held between health practitioners and patients in such culturally diverse situations (Campbell, Wunungmurra, & Nyomba, 2007). This is of interest as the thrust for the general principle of self-management originated from health practitioners looking to reduce their healthcare burdens (M. Battersby et al., 2010). This resistance shows that integrating self-management into health systems is a challenge and will take some time despite policies that promote it (Northern Territory Chronic Conditions Prevention and Management Strategy 2010-2020, 2009). One study was conducted by researchers at Flinders University on self-management support for Aboriginal adult patients with diabetes provided by Aboriginal Health Workers (Battersby et al., 2008). They demonstrated that a pilot program was acceptable, improved self-management and some clinical indicators and was useful to the community.
**Self-Management Support**

The processes of self-management require partnerships with health practitioners. This involves patient education and negotiating care plans, as well as taking a long-term view within normal clinical management. Collaborative goal setting is a self-management activity that fosters partnerships by providing discussion points to negotiate as well as aiding continuity of care (Langford, Sawyer, Gioimo, Brownson, & O'Toole, 2007). Such activities in collaborative partnerships are named self-management *support* (Harris et al., 2008). Supportive activities are dependent on respectful relationships, time to negotiate and effective communication.

**Young People and Self-Management**

Children, adolescents and emerging adults with chronic conditions such as ARF and RHD require adaptation of the self-management approach described in the NT Self-Management Framework (Northern Territory Department of Health, 2012). The literature shows that self-management for young people with chronic conditions is not well understood and the developmental changes that take place in adolescence are both a risk to their health and an opportunity to develop self-management (Kleinert, 2007). It is critical to incorporate the developmental changes of adolescence into self-management models (Lindsay, Kingsnorth, & Hamdani, 2011; Tylee, Haller, Graham, Churchill, & Sanci, 2007). Additionally, transferring of responsibility for self-management during adolescence is a key process (Sawyer, Drew, Yeo, & Britto, 2007). Self-management and self-management support are key components of the ‘transition to adult care for children with chronic disease’ model which is now well-defined in the literature.
Emergence of the ‘Transition to Adult Care for Children with Chronic Disease’ Model

The aim of ‘transition to adult care for children with chronic disease’ (henceforth called the transition model) is to support patients with chronic conditions as they move from child-focused care by paediatricians, through adolescent years with their recognised significant vulnerabilities, and safely on to adult self-management in partnership with new adult-care clinicians (Viner, 1999; Viner, 2008). The overall purpose of a governed transition is to prevent loss to follow-up as young people move to new care providers in new locations once they can no longer access their familiar paediatric care. Additionally, transition programs ideally improve young people’s wellbeing and their skills in self-managing their chronic condition.

Children with chronic conditions surviving into adulthood due to improved medical care created the impetus for emergence of the transition model of care. The transition model is also synchronous with the advent of adolescent medicine as a discipline (Hepburn et al., 2015; Jordan & McDonagh, 2006; Srivastava, Elkin, & Bilton, 2012). Adolescence is generally acknowledged as the time between the onset of puberty and adulthood, with these stages being determined by individual development rather than by age (Goodhand, Hedin, Croft, & Lindsay, 2011). Adolescence is recognised as a time of great neuroplasticity and development involving an array of cognitive, behavioural and physiological changes and may include risk taking, significant influence of peers, trialling of illicit substances and increasing independence all of which can affect how adolescents attend to their chronic condition (Klineberg & Steinbeck, 2012; Society for Adolescent Medicine, 2009).
Refinements in the transition model resulted from research on its uptake in conditions with onset in childhood such as diabetes, cystic fibrosis, juvenile arthritis and HIV. Such research has illuminated best practice for patient preparation for transition and system-level adaptations that facilitate patients’ progression to adult care (Fair, Sullivan, & Gatto, 2010). Transition clinics are either devised around specific diseases or the adolescent health paradigm (Freed & Hudson, 2006; Viner, 1999). The transition model takes a life-course view to caring for children with chronic conditions in recognition that preparation for adult self-management works best when initiated in childhood and adolescence thereby providing extensive time for learning, adjusting and developing skills and understanding (Fair et al., 2010). The model ideally facilitates relationships with new health practitioners, provides age-appropriate education on a continuum, recognises, emphasises and supports adolescent needs, prepares for transition, reduces risk of dropping out of the health system, ensures good medical record transfer between paediatric and adult services and results in emerging adults’ effective self-management of their condition. It is a managed process where transition coordinators oversee individual patient’s journeys (Srivastava et al., 2012; Viner, 1999)

** Aboriginal Children with ARF and Transition to Adult Care **

No studies were identified that examined the application of a transition model for any Australian Aboriginal setting or chronic condition. In the NT most of the Aboriginal population live in remote or very remote locations and the health services are commonly outpost type with small numbers of clinicians providing primary health care. Additionally, remote health services in the NT are working to capacity and focus their limited resources on treatment tasks such as giving the penicillin injections, rather than managing ARF as a chronic condition having significant
preventable morbidity and mortality (Lawrence et al., 2013). It is only since the year 2000 that ARF and RHD have been classified in the list of chronic conditions in the NT Chronic Disease Strategy.

There are no guiding policies for the transition model in the NT, but useful policies exist in other Australian states (Bridgett, Abrahamson, & Ho, 2015; Hepburn et al., 2015). The NT Chronic Conditions Self-Management Framework does not include transition to adult care despite self-management and self-management support being integral components of transition to adult care.

**Health Service Differences and Characteristics of Aboriginal Children in the NT**

For Aboriginal children living in remote areas, there is usually one health service in one location that governs their health care for as long as they remain in the community, which is commonly for their lifespan. Prior research has found that patients in this setting may perceive themselves as ‘belonging to’ that health service (Harrington et al., 2006). This has the benefit of health records being located in one clinic, although movement between adjacent clinics or to other locations needs to be captured and documented, especially with regard to obtaining penicillin injections in different communities.

Non-Aboriginal health staff change frequently in this setting and, while there has been an increase in numbers of non-Aboriginal staff numbers employed over the past decade, Aboriginal work force numbers have remained static (Ridoutt, Pilbeam, & Lee, 2010). This means children face an ever-cycling non-Aboriginal health staff and an increasingly overburdened Aboriginal staff. For these reasons, Aboriginal children are less likely to have strong, long term, supportive relationships with any of the
health staff, let alone one paediatrician or one physician. While the specialist attending to Aboriginal patients may change over time, Aboriginal patients likely attend the same local clinic for both paediatric and adult care.

**Aboriginal Languages and Communication Issues**

Remote-living Aboriginal children in the NT are typically English as second language speakers. Etherington (2006) describes the people in one remote NT community, typical of participants in this research, as people who, “continue to speak their own language in almost every part of life despite nearly a century of contact with the English speaking Australian population. Only a few adults claim to speak competent English” (Etherington, 2006, p. 16). This means that remote-living Aboriginal children with ARF or RHD, and their parents, need to navigate and negotiate with a health system that likely operates in a second (or possibly third or fourth) language, and frequently from within another health paradigm.

In some locations, young people are now speaking Kriol, a full language with grammatical structures based on Aboriginal languages, and with some words having an English base but with different meanings (Harris, 1993). Aboriginal English, a dialect of Standard English with grammatical rules stemming from Aboriginal languages, is also spoken (Eades, 2013). Speakers with English as a first or only language frequently have difficulty discerning the communication needs of users of these languages and erroneously believe that effective communication is occurring when it is not (Cass et al., 2002).

Qualitative studies have demonstrated that remote-living Aboriginal people experience multiple linguistic and sociocultural difficulties when endeavouring to obtain medical information about their condition from health services, often leaving
them with a sense of powerlessness and confusion (Anderson, Cunningham, Devitt, & Cass, 2013; Anderson et al., 2008; Cass et al., 2002). The consequences of unrecognised, ineffective communication caused by language and sociocultural differences can mean patients acquire very little useful information about managing their condition (Davies, Bukulatjpi, Sharma, Davis, & Johnston, 2014).

Communication and sociocultural issues are essential components for equitable national cardiovascular care for Aboriginal patients with ARF and RHD, but addressing these issues within remote health services is difficult because of time and service model constraints (Brown et al., 2015).

Additionally, remote-living Aboriginal people generally have a non-biomedical world view in their collective group history (Senior & Chenall, 2013). This aspect, along with language differences, leads to hampered communication with Western health practitioners around diseases, especially complex conditions such as ARF (Cass et al, 2002).

People express ideas via their language and language therefore provides a window for determining people’s views. However, the linguistic and communication issues go deeper than just this. Instructions to Aboriginal patients are usually delivered in English in the NT. The question arises as to how the imperative of the injection regimen is conveyed between disparate speech communities, and especially where one group are the historical colonisers and therefore start from a position of power (Saville-Troike, 2003).

**Views on Adolescence and Child Rearing**

It cannot be assumed that perspectives on adolescence and child rearing held by Aboriginal people are the same as others’ perspectives, or that non-Aboriginal health
staff know and understand these views in this cross-cultural setting (Byers, Kulitja, Lowell, & Kruske, 2012; Moisseeff, 2013). Parental status is not the same across cultures and in Aboriginal groups, other adult relatives may hold equal responsibility for children, and in some circumstances, more responsibility than parents. Research in the NT on Aboriginal ways of raising children show they are clearly disparate with non-Aboriginal ways (Kruske, Belton, Wardaguga, & Narjic, 2012; Moisseeff, 2013). These differences include value placed on development of child autonomy as they grow up within a strong kin group and the age of children not being considered related to their developmental level (Kruske et al., 2012). Who is responsible for whom and at what age, and what the general cultural perspective regarding adolescence is, needs determining in the remote NT setting for the purposes of ARF treatment. This draws on the field of anthropology where peoples’ traditions and practices are described and analysed within the context of their social structures (Podolefsky & Brown, 1997). Much of what is understood about adolescence has been gained from studying white, middle class children which does not necessarily apply in the context of Aboriginal communities (Brookins, 1993).

**Adjusting the Transition Model to the NT Setting for ARF**

There are differences between the patient populations and their health services in the transition model literature, including transition clinics in other Australian states, compared with those in the NT. While the ages of those affected by ARF and the chronicity of the condition match a transition model, other characteristics of the NT population indicate that local adaptation of the model would be required.

ARF is different from other childhood chronic diseases in that treatment (the injections) and the condition may be finite, since the autoimmune process does not in general persist into later decades. Therefore, there is not so much a need to transition...
children from paediatric to adult services, as to transition them safely through the
time where they are most at risk of recurrences of ARF. This means transitioning
them through the childhood, adolescent and emerging adult years, by identifying the
supports they require at different life stages to manage their condition. The principles
developed in the transition model are applicable in this case: appointing a transition
coordinator, monitoring children’s developmental stages, providing a continuum of
education appropriate for children’s ages, languages and culture to facilitate self-
awareness of their condition, and monitoring and addressing adolescent needs.

The wellbeing and survival of young Aboriginal people with ARF depends on RHD
Control Programs or local health services in remote locations being able to
effectively provide patient education, relevant support and medical care through the
ten years or more of the penicillin injections after the last episode of ARF. Adapting
the transition model for young Aboriginal people affected by ARF in the NT has
potential for connecting with them and improving their general wellbeing and
understanding of their condition, as well as increasing adherence to penicillin
injections and routine appointments. Therefore, in the development of this doctoral
thesis, the transition model is used as a reference point against which to appraise
current practice and propose feasible recommendations (see Chapter 8, page 271, for
review of transition model findings).

In children who require surgical repair or replacement of their heart valves, care will
go beyond early adulthood. However, common factors are shared with those with
ARF only and those with established RHD. That is, these young people in general
attend one health service, have the same language and world-view issues, and need
to go through adolescence and post adolescence and remain adherent to the injection
regimen. Good adherence is critical for their survival.
**Gap between Western Biomedical and Aboriginal Worldview**

In overviewing and synthesising findings from both the literature reviews, potential gaps between western biomedical and Aboriginal worldviews to do with the injection regimen which could affect understandings and adherence became apparent. These include people’s understanding of the time intervals between injections, their understanding of germ theory of disease, feeling ‘normal’ despite having a serious condition (i.e. not necessarily appearing sick) and the medical concept of risk.

**Time Intervals Between Injections**

Time intervals between penicillin injections are critical to the success of preventing ARF recurrences. The injections are intended to be given when blood levels of penicillin are reduced to ineffective levels and are then boosted with a subsequent injection. Once the due date for an injection passes, children are considered at risk of ARF recurrence (Edwards, 2013). This means that the ‘timing factor’ needs to be understood by parents or the young person as well as health service practitioners who provide the injections; this is imperative. The concept is made more complex by the fact that antibiotic concentrations wane during the month such that some individuals may acquire another infection (and hence an ARF recurrence) prior to 28 days, in which case, a 21-day regimen is recommended for their future safety. Aboriginal and non-Aboriginal people can have quite disparate views of ‘time’ and it cannot be assumed that the time constraint for injections is understood (Cass et al., 2002; Donovan & Spark, 1997; Janca & Bullen, 2003). Some remote health clinics have devised reminder systems such as use of moon phases for Aboriginal patients with limited success (Kearns, Schultz, McDonald, & Andrews, 2010; Mincham et al., 2003).
Health literacy is not necessarily linearly associated with adherence. In some cultural groups and for some individuals, mere instruction to follow the regimen timing may be adequate. However, this does not appear to be the case in NT settings where adherence is currently inadequate. Better knowledge about timing of injections may be associated with better adherence because the trust factor is not a given in NT settings, (in fact, no trust is often predominant).

**Germ Theory of Disease**

Germ theory of disease and the action of antibiotics are functional and foundational theories in managing ARF and RHD. The discovery and acceptance of germ theory of disease was a lengthy process in Western civilizations (Brorson, 2006). Aboriginal participant’s knowledge of germ theory of disease could have an impact on their understanding and adherence to the injection regimen.

**Appearing Sick and Risk**

The distinction between chronic and acute sickness is not generally part of Aboriginal traditional world view and a person is sick if they appear sick (Vass, Mitchell, & Dhurrkay, 2011). This could pose difficulty for Aboriginal people who are prescribed the penicillin injection regimen; if they do not yet have valve damage, they will most likely appear and feel normal, yet it is critical that they receive the offered injections to prevent valve damage. This adds to the complexity of motivating people to adhere to the injections. Related to this is the concept of risk and reducing risk, which is the main purpose for prescribing the penicillin injection regimen. In previous work I was not able to locate an Aboriginal language term for the abstract concept of risk. Risky situations are recognised and verbs describing
how to act in such situations certainly exist, but there appears to be no abstract noun for ‘risk’ (Vass et al., 2011).

**Injection Pain**

While pain from each injection is expected to be relatively short lived, it is a recurrent event; ideally this painful injection should be received 13 times per year for at least 10 years which equates to at least 130 painful episodes for children or adolescents to face. Furthermore, if there is significant damage to the heart valves, the injections are recommended until age 35, and sometimes for life. An adolescent who experiences ARF recurrences leading to moderate valve damage could be prescribed over 200 injections. While most clinical personnel expect pain to be an inhibiting issue for the injections this also needs further exploration among young Aboriginal people. In the few studies on patients’ views of the injection regimen, pain has not been a consistent theme (Harrington et al., 2006; Mincham et al., 2003). Pain could be affected by muscle bulk, which is impaired in malnutrition, as Aboriginal children in this setting are often known to be underweight (Roberts et al., 2015; Sellers, Singh, & Sayers, 2008). Pain could be affected by clinician practices and behaviours as well.

**Repeated Painful Procedures in Children**

The effect of chronic pain in children, in this instance repeated painful events over a lengthy period, warrants investigation. Green and colleagues reviewed the literature on differences in pain care received by racial and ethnic minority groups within health services and concluded there are “disparities in pain perception, assessment and treatment” (Green et al., 2003, p. 277). Children’s acceptance of pain can be altered via interventions designed to modify their experiences, and can lead to less negative
effects on the child (Weiss et al., 2013). These authors therefore recommend that health services assess acceptance of pain in paediatric patients. This makes sense in the NT setting with regards to the penicillin regimen.

A New Zealand study on actions to reduce pain and fear of penicillin injections determined these to be positive interventions, especially in children (Russell, Nicholson, & Naidu, 2013). There have apparently been no studies of Aboriginal children’s perceptions of pain, or their response to the pain of repeated injections for ARF prevention. It is important to discover to what extent Aboriginal children or their carers avoid their penicillin injections due to not wanting to face pain or other negative effects that the repeated injections have on wellbeing. Considering the duration of the injection regimen, acceptance of pain may change over time in individual children as well.

**Conclusion**

ARF and its sequela, RHD, are significant and disturbing public health problems in remote communities in the NT today. The groups most affected are Aboriginal children, adolescents and emerging adults who are subject to an injection regimen for long periods of time, including throughout their teenage years (Lawrence et al., 2013). Many have required open heart surgery to repair or replace their heart valves. While there have been many important studies describing the epidemiology of these conditions globally and nationally, there is a significant gap in qualitative literature for determining and understanding the experiences, perceptions and understandings of the people who have the conditions. Little is known about Aboriginal young people’s understanding and experiences of ARF/RHD and the injection regimen.
Self-management is a fundamental strategy for empowering patients with chronic conditions to engage and take control over the management of their condition, yet it is not known what factors impact self-management of young Aboriginal people with ARF. Finally, the transition to adult care model is a potentially useful framework to support vulnerable young patients to self-manage their chronic conditions as they journey from childhood through adolescence and into adulthood. It is not yet known what the utility of this model is in the remote Aboriginal context.

The aim of this doctoral study is to explore the experiences of remote-living young Aboriginal people with ARF who are prescribed regular penicillin injections over lengthy time frames. Gaining an understanding of these views will help inform public health strategies to address the burden of disease.

This doctoral thesis is linked with a large study that is working to enhance delivery of the injections within health services. Obtaining patients’ and families’ perspectives will provide important data to assist development of better partnerships between health service providers and Aboriginal people with ARF and RHD in order to end these conditions in Australia altogether.
Chapter 2

Research Design
**Introduction**

This chapter describes the theory and the design of my doctoral study: it is a nested qualitative study within a larger registered trial. I outline how the study was conducted by describing my fieldwork in the study sites, including how participants were recruited and how the data were collected. Ethical considerations are discussed and a description of how the study data were analysed concludes the chapter. Further detail of the ethnographic methods appears in Chapter three.

**Aims and Research Questions**

The aim of the study was to explore the experiences of remote-living young Aboriginal people with ARF or RHD, focussing on the regimen of penicillin injections they are prescribed for extensive time periods.

The research questions were:

1. What are the experiences, perceptions and understanding of remote-living young Aboriginal Australians and their families of ARF and RHD?
2. What are their experiences, perceptions and understanding of the health care they receive for ARF and RHD?
3. How do age, development and culture influence ability to self-care for ARF and RHD in Aboriginal families?
4. What community level factors facilitate self-care for ARF and RHD for remote-living Aboriginal young people?
5. What clinic level factors do young Aboriginal Australians and their families perceive as supporting their self-care for ARF and RHD?
6. What is the utility of the ‘Transition to adult care’ framework for remote Aboriginal young people with ARF/RHD?

**Contextualisation of the Study Design**

This study was nested within a larger study with a complex design. Therefore, a short description of the larger study’s design provides the context for the doctoral study design.

The larger study was funded by the Australian National Health and Medical Research Council and is titled “Improving Delivery of Secondary Prophylaxis for Rheumatic Heart Disease”. Henceforth, I will refer to the larger study by its short acronym, the “SP (Secondary Prophylaxis) Study”.

Research into health systems is promoted by the World Health Organization in recognition of the importance this has in improving public health (WHO, 2004). The SP Study aimed to enhance health systems for Aboriginal people with ARF and RHD within ten health services in the NT. Seven of these health service sites were in remote Aboriginal communities, two were in regional centres and one was an Aboriginal health service in an urban setting. The SP Study’s primary aim was clinical: to increase the number of scheduled penicillin injections received by Aboriginal patients to at least 80% in the study sites. Using a systems-based approach, a multi-faceted package of activities was instituted within each health service to improve penicillin injection delivery. Each health service was assisted to devise their own strategies to optimise the number of injections delivered. The SP Study also had a qualitative component, which focused on evaluating how the health services changed their delivery of care to align with the systems-based intervention.
The qualitative data analysis used a confirmatory deductive approach: the themes and analysis codes were pre-selected and then evaluated during analysis of the data (Gale, Heath, Cameron, Rashid, & Redwood, 2013). My doctoral study is a separate qualitative investigation which used an inductive exploratory approach (see below).

The SP Study had a multi-phase design. A three-month *baseline phase* was used to collect penicillin injection data from each health service along with staff interviews to determine what perceived barriers existed to injection delivery and to collect views on how improvements could be made. Each site then entered a 15-month *intensive phase* where an action plan was implemented by health service staff, supported by the SP Study’s project team. Following this phase, each health service entered a *maintenance phase* where the SP Study project team’s support for health service was reduced to determine the sustainability of new activities instituted to improve injection delivery.

The ten health services entered the SP Study in a stepped-wedged sequence over a period of one year and proceeded through the baseline phase, an intensive phase and a maintenance phase. By completion, the whole study proceeded for three years and all participating health services received support for the intensive phase activities for a 15-month period, see Figure 2.1 below.
Figure 2.1 Implementation of the 3 phases of the SP Study

The overall objective of the SP Study, including my nested doctoral study, was to improve outcomes for Aboriginal people affected by ARF and RHD by increasing the number of prescribed injections they received and so prevent recurrences of ARF. By using a mixed methods design, a more complete understanding of this public health issue should be gained.

The SP Study was a community-randomised registered clinical trial, Australian New Zealand Clinical Trials Registry: ACTRN12613000223730 registered 25th February 2013 (Ralph et al., 2016). It used a suite of activities developed within the ten health services. Although the study aimed to implement a comparable package at each clinic, built around the Chronic Care Model (described later), it was necessary to allow each health service to devise their own set of activities tailored to their individual settings to enhance the delivery of the penicillin injections to people with ARF and RHD in their community. Given the strict requirements outlined in the SP Study protocol, there was only moderate fidelity of implementation at the study sites. Additionally, the dose delivered at each site, in other words, the amount of support received by health services from project staff, was not completely uniform as would be ideal in a standard controlled trial but the process undertaken in each site aimed to be uniform (Hawe, Shiell, & Riley, 2004). The logic underlying this complex intervention is that the real-world context of health care provision in remote Aboriginal communities is multi-factorial and dependent on local resources. Therefore, to make improvements in outcomes for a specific medical condition, work needed to be done on multiple fronts.
Involvement in the SP Study

Initially I worked on completing the SP Study protocol and interview guides. I then worked as an interviewing project officer, collecting baseline phase data in health service staff interviews at the commencement of the SP Study. Participating in this way enabled me to obtain a good working knowledge of the complexity of the SP Study. In the maintenance phase of the SP Study I again worked as a project officer carrying out interviews to determine effects of the SP Study activities on the target population, including people living with ARF and RHD. This was deemed to be pragmatic because of the relationships that I had developed with Aboriginal participants during my doctoral research fieldwork in four of the sites, which meant I could approach these individuals most easily. Additionally, I assisted in analysis of some of the SP Study’s qualitative data towards the end of the SP Study. I remained part of the SP Study team throughout its duration, keeping abreast of activities and related issues. My study sites were four of the ten SP study sites and while working in my sites I was conscious of the local SP Study activities and aware that health service staff may not easily differentiate my role from that of SP Study project officers’ roles. This meant that I continually reflected on my activities, and took care to work within the parameters of the SP Study protocol.

Conceptual Framework for the SP Study

A description of the conceptual framework for the SP Study will further highlight how my doctoral study is embedded, but distinct. The Chronic Care Model (CCM) was used as the guiding framework for the SP Study. The CCM was developed in the 1990s at the MacColl Institute in Seattle to improve management of chronic conditions care (Wagner, 1998). The CCM has been applied in many chronic care situations globally in efforts to improve care within health systems and teams of
health workers, as well as facilitating patients to have a higher stake in self-care (S. Lee, 2011). The CCM has additional relevance in that it informs the current NT Chronic Conditions Self-Management Framework 2012-2020 (Northern Territory Department of Health, 2012).

![The Chronic Care Model](http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2)

*Figure 2.2. Chronic Care Model*


Reprinted with permission: Copyright 1996-2017 The MacColl Center. The Improving Chronic Illness Care program is supported by The Robert Wood Johnson Foundation, with direction and technical assistance provided by Kaiser Permanente Washington Health Research Institute's MacColl Centre for Health Care Innovation.

The six components of the CCM are intended to work synergistically and lead to improved outcomes for patients receiving care for chronic conditions. As a guide for health services, the model works towards patients being ‘informed’ and ‘activated’ participants in their care which is delivered through effective and satisfying interactions with a ‘prepared’ and ‘proactive’ team of practitioners (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004). The model comprises of the ‘Health System’ itself
which integrates the ‘Clinical Information Systems’ used to monitor and record patients’ episodes, ‘Decision Support’ which maximises clinician’s capacity by ensuring access to up-to-date knowledge, and ‘Delivery System Design’ which matches the operational function of the health service with the type of conditions and population for whom they provide care.

The remaining two components of the CCM require work at the community/health service interface: ‘Community Resources and Policies’ and ‘Self-Management Support.’ These two components require extension of a purely clinical and organisational focus of a health service and, while the SP Study included activities within these components, they were the primary locus of my doctoral study. My research was carried out predominantly in the community with young Aboriginal people and their families, who are affected by ARF and RHD. This group of patients and families are the people that health services endeavour to partner with for self-management support. Local community resources were also explored as potential entities or links that may enhance self-management support for young Aboriginal people affected by ARF and RHD. Thus, the two studies were concurrent and intertwined within the guiding framework of the CCM.

The following figure depicts the locus of my study. My study is part of the overall SP Study and uses the CCM as the connecting point. However, because my study intensively explored just one section of the CCM which was predominantly outside the clinic, it required an additional methodology and theoretical framework to situate and provide an operational lens.
Figure 2.3. Chronic Care Model with overlaid locus of the doctoral thesis

Study Design

Methodology

My theoretical framework provided a guide for the research process as well as a rationale for the methods I selected in order to answer the research questions (Reeves, Albert, Kuper, & Hodges, 2008). My study was situated within the qualitative research domain. Qualitative research requires an anchoring theoretical framework not only to provide direction but to maximise rigour within the research (Liampittong, 2013). Frameworks provide a lens through which to explore the issues being researched as well as for analysing the collected data (Reeves et al., 2008). Without this theoretical grounding, it would be impossible to effectively carry out a
social study of this kind because of the multiplicity of perspectives from which complex human experiences and issues can be explored.

**Conceptual Framework for the Nested Study**

I used decolonising theory and whiteness studies to situate my research within the larger SP Study. These two theories have similar sources: decolonising theory arises as a response to the negatives of colonisation, and a ‘whiteness’ stance (explained shortly) drives colonisation. These are an appropriate juxtaposing duo for my research because I conducted my research in locations strongly affected by colonisation, and the Aboriginal families affected by ARF and RHD must seek their long-term care from health services originating and continuing within the paradigm of Western medicine and where the majority of interactions within that domain are with practitioners holding power and privilege.

**Decolonising Theory**

Decolonising theory in health research is a determined response to the negative consequences of colonisation and colonialism on research practices among indigenous peoples but it also requires revisiting during studies within research in all disciplines that are preoccupied with indigenous peoples (Humphery, 2001; Smith, 1999). Colonisation describes the invasion and conquest of other people’s lands, livelihoods and identities and represents the expansion of British and European dominions from the 1500s to the 1900s (Smith, 1999). In this thesis, colonisation is signalled by the arrival of the British in the late 1700s and their appropriation of Aboriginal lands. Colonisation always leaves a negative legacy (Tesoriero, 2010).

Any assumed benefits arising from colonisation for the subjects of such conquest are neutralised by the loss of control that ensues. *Colonialism* describes the attitudes,
beliefs and values of colonising nations which are, in general, views of perceived complete superiority over ‘others’ of different cultural groups. Colonisers use their power to justify, impose and enact their interests and views, which are continually placed in the forefront of their interactions (Neill, 2012; Tesoriero, 2010). Post-colonisation describes the (theoretical) time following colonisation and assumes that colonisation is an entity of the past that has ended. Post-colonialism describes a philosophical stance upheld within the post-colonial period and is an attempt to rethink and address the discriminatory attitudes of colonialism in a more positive approach.

Postcolonial thought is emancipatory. It seeks to recognise the pervasiveness of colonialism, validate the voices of the colonised and to recognise and reverse patterns of colonialist domination. It identifies how powerful the voices of the colonisers have been, to the exclusion of others, and how this has stripped the colonised of their identity and devalued their culture (Tesoriero, 2010, p. 133).

‘Decolonisation’, moves further along this trajectory, and is a standpoint that reflects on past colonisation and its enduring effects and is a determination to shrug off old ways of knowing and working in order to forge a new stance that prevents the repetition of the harms of the past (Sherwood, 2009). Sherwood (2009) maintains that amnesic viewpoints of our colonial history, a view hard to shift in the mainstream, mean that Aboriginal peoples’ health is problematised and leads to blame being apportioned to Aboriginal people for their poor health, as well as poor statistical morbidity and mortality (Iyer, 2014; Sherwood, 2009; Smith, 1999). This is a no win approach and Sherwood argues that this is one reason why decolonising approaches in health are needed (Sherwood, 2013). If mainstream workers
interacting with Aboriginal people fail to recognise their own misinformed positions, it only adds to the turmoil of post-colonial stress experienced by Aboriginal people (Sherwood, 2009).

Within the research field, an *Indigenous standpoint* has been promulgated which upholds the rights of indigenous researchers, and for indigenous knowledge to be respected and firmly positioned within research work. This has progressed to a *decolonising* standpoint in which all researchers, whether indigenous or not, are equally responsible for decolonising all components of the research processes (MacNeil & Marsh, 2015). This means understanding and taking account of the perspectives of the previously colonised, their histories and their griefs (Wilkin & Liamputtong, 2010). It means valuing research participants’ viewpoints and the fostering and revealing of those views by the participants themselves. Researchers must deliberately adopt a critically reflexive stance to produce the heft and determination to not simply affirm the beliefs of the researcher (Smith, 1999). A decolonising standpoint also means ensuring that authentic consent to participate is obtained; a key expectation of research ethics committees which oversee research processes among Aboriginal people.

My research sites are places of colonial legacies and the choice of a decolonising lens is an attempt to enable analysis of how these legacies play out in the current families’ lives within those sites. A decolonising theory imposes research boundaries as well as a lens; the research practice is essentially governed by deliberate recognition of and respect for Aboriginal participants. Decolonising theory asserts that research methods come from such an understanding (Wilkin & Liamputtong, 2010). It surmises that research participants are not enshrined as ‘other’ but as equals.
Critical consideration of the effects of colonisation on Aboriginal people is an imperative starting place for the conduct of research with Aboriginal people. That ARF is globally labelled as a *poverty-marker*, and yet remains prevalent among a minority group within our resource-rich nation, on the whole points to enduring effects of colonisation. The majority of Australians have improved standards of living so that ARF is now almost non-existent. This indicates disparities in distribution of resources as well as power of those controlling the resources. But it could also represent a colonial stance of non-acceptance of Aboriginal difference, preference and identity.

Australian colonial history is harsh: the containment of Aboriginal peoples on reserves, policies of assimilation, the targeting of children for the teaching of new ways, removal of children from Aboriginal families (stolen generation), massacres and punitive expeditions (Sutton, 2001; Thomson, 2005). Such practices have led to Aboriginal people retaining a ‘damaged’ position; continually needing to justify their place and their programs, continually under threat from mining exploits (in rural and remote places) and ever-shifting government policies as well as new threats to cultural norms from broader society such as alcohol and illicit drugs (Moran, 2016). Contact and talk to address such threats are commonly channelled to individual ‘traditional owners’ which is in itself an example of misunderstanding and a misnomer; land ownership is not traditionally invested in individuals, but clan-based groups hold communal responsibility as custodians of certain lands. For instance, in Arnhem Land, some clans have a traditional caretaker position for a related clan’s land, and other clans may have ceremonial obligations for that same land. There are appointed spokespersons and leaders but traditionally decisions are made by consensual groups rather than individuals.
Research honesty includes understanding that research has a bad history among Aboriginal peoples as seen in past practices of phrenology and the belief in and positioning of researchers as having superiority on the basis of being European and White (Smith, 1999; Thomas, 2004). Current researchers must attempt to eschew any hints of such past practices. Use of decolonising theory recognises this new resolute position and as such, regards involving and partnering with Aboriginal participants at each stage of the research path as essential. MacNeil and Marsh (2015) argue that approaching research from a decolonising standpoint “places responsibility on all researchers involved in Indigenous research to decolonise the research process” (MacNeil & Marsh, 2015, p. 120).

The degree to which this is achieved is varied, but improvements are occurring. Further development within academic faculties is still required to achieve full and equal participation and engagement of Aboriginal people in research processes, including the leading of research,

A Decolonising Standpoint demonstrates a deep and genuine commitment to acknowledging the many negative impacts of research on Indigenous peoples and cultures, and contributes to the momentum of a shifting paradigm away from oppressive ways of thinking and working (MacNeil & Marsh, 2015, p. 122).

**Whiteness Studies**

The study of ‘whiteness’ as a cultural entity emerged in the last decades of the 20th Century in North America in response to a growing sense of inequality and bias within ethnic research that was focussing on predominantly *black* or *native* or ‘*the other*’ while whiteness remained unmarked and invisible (Kennedy, Middleton, &
Ratcliffe, 2005; E. Lee & Bhuyan, 2013). The perception of whiteness as superior, privileged and having power to study the ‘other’ extends colonialism but the new whiteness studies attempted to turn the gaze inwards. Recognition of white ethnicity as a cultural group challenged the continual view of black, and others, who were objects of study. Whiteness studies encompass all people and the way we socialise (Kennedy et al., 2005). The definition of ‘white’ used in this doctoral thesis is taken from the following author:

My use of the term ‘White’ in this ethnography draws on whiteness studies. It does not intimate that all my research participants had white skin, or even that they all identified as white. Rather, it implies that they willingly and unwillingly, knowingly and unknowingly participate in the racialised societal structure that positions them as ‘White’ and accordingly grants them the privileges associated with the dominant Australian culture (Kowal, 2015, p. 356).

Although whites can be poor, marginalised and lack power, I use Kowal’s descriptor to refer to non-Aboriginal actors in my study. This doctoral thesis requires me to identify and refer to clinicians and others who, in contrast to the Aboriginal families affected by ARF and RHD (the focus of my study), are not Aboriginal. The terms ‘non-Aboriginal’ or ‘non-indigenous’ are commonly used in such writings within this health context. Use of these terms could be construed as glossing over the divide, concealing identity. Using the term ‘white’ reveals the identity as the privileged and powerful cultural group. While this term could be deemed embarrassing or uncomfortable, in no other life space do I use the descriptor of myself as lacking Aboriginality. Using the identifier, ‘white’, as a cultural identity marker, brings attention to this group and I am content with use of this descriptor and no discourtesy
is intended. Kowal studied this group intently using ethnographic methods drawn from anthropology. I want to identify and speak of this group within the context of my study and discuss how connecting between this group and Aboriginal families has been observed, experienced and also verbalised.

My position as a white clinician enabled me access to other white clinicians in my study and the domains of their work; I could enter the inner sanctum of the health clinic, although tentatively at times - when the atmosphere was not congenial or was tense. I accessed staff tea rooms (a neutral and communal space), staff meetings (if invited), and medical records (if ethically appropriate). I want to acknowledge my white privilege, a position commonly invisible to whites. White practices can be both individual and institutional, and may perpetuate stereotypes (Gunstone, 2009). In addition to this capacity to enter white domains, I joined with Aboriginal patients in clinic waiting rooms and observed their interactions with white clinicians. Lee and Bhuyen, (2013) consider that in cross-cultural clinical encounters whiteness is Eurocentric and an unacknowledged but dominant perspective. Furthermore, I was at times welcomed into Aboriginal spaces and heard how white clinicians were talked of within those spaces.

Aboriginal Health Practitioners (AHP) are additional actors within the health service setting and they will be referred to in this study by their professional title. AHPs are positioned as ‘betwixt and between’, vested with some white powers but with deep connections to and relationships with the community. However, a further complexity occurs when the AHP does not originate from the local community where they are working and does not speak the local Aboriginal language.
Aboriginal families affected by ARF and RHD have to deal with whiteness within health services in the NT. Whites in many locations can, if they wish, live a life without encounters or interactions with Aboriginal people. But for those Aboriginal families affected by ARF and RHD, the local health service is a site of unavoidable interaction with whiteness, unless the service is completely staffed by Aboriginal workers.

**Strengths of a Qualitative Approach**

I chose a qualitative approach to understand the experiences of young Aboriginal people with ARF and RHD who receive penicillin injections over long time periods. Qualitative design is valuable in public health research due to its capacity to broaden understanding of a topic from a purely empirical one. “Qualitative research can describe the meaning of disease, poverty or caring and can help us understand how public health strategies can assist in solving the problems” (Baum, 2008, p. 142). Combining the qualitative results of my study with the results of the SP Study enabled a holistic, broader understanding of the issue at hand. Building a deeper understanding of the experiences of people affected by ARF and RHD has potential to improve health services’ and policy makers’ endeavours to optimise care for patients with these conditions in the NT context.

**Phenomenology**

This is a phenomenological study where I sought to determine, understand and describe young Aboriginal peoples’ lived experiences of a phenomenon, that is, acquiring ARF and being prescribed regular injections over long time periods, and elicit what it means for them in the context of their lives (Creswell, 2007). Phenomenology is one component in the historical development of philosophical
thought. It includes the ideas of Husserl in the early 1900s, with his emphasis on personal consciousness within experiences and capturing and building insight within consciousness (Liamputtong, 2009; Reeves et al., 2008). In a phenomenological study, a researcher attempts to eschew the prevailing and personal understandings of a social reality and endeavours to learn and understand the participants’ experiences without bias (Gray, 2014).

Phenomenology is best understood as a radical, anti-traditional style of philosophising, which emphasises the attempt to get to the truth of matters, to describe phenomena, in the broadest sense as whatever appears in the manner in which it appears, that is as it manifests itself to consciousness, to the experiencer (Moran, 2000, p. 4)

Phenomenology entails exploring an everyday activity or issue in order to understand the meaning of other’s experiences. Data are analysed inductively and tend naturally to apply only to the specific setting rather than to a broad, generalised one (Reeves et al., 2008). The subjectiveness of this knowledge construction is recognised; objectiveness is acknowledged as only ever partially possible (Hesse-Biber, 2010). This is especially so when carried out in a cross-cultural context such as in this study where qualitative methodologies are sensitive to capturing people’s lived experiences (Hesse-Biber, 2010). Within this phenomenological frame, a focussed ethnography was selected as the most appropriate methodology to address my aims and research questions.

**Focused Ethnography**

Conventional ethnography involves immersing oneself in a study population to learn directly from them about a broad range of social constructs (Liamputztong, 2009).
The method entails the researcher being immersed in the daily lives of the research participants and observing and documenting all that goes on over long time periods in attempt to gain insider understandings of that society and the manner in which it functions (Liamputtong, 2013).

However, a *focussed* ethnography explores a specific issue among a distinct group of people within a particular setting, in my case Aboriginal young people who were on the penicillin regimen and resided in remote NT Aboriginal communities (Cruz & Higginbottom, 2013). It is particularly suited to qualitative research questions around participants’ experiences of a phenomenon (Higginbottom, Pillay, & Boadu, 2013). Focussed ethnography entails pragmatically capturing data on a specific topic usually with a view to using research findings to improve an issue (Higginbottom et al., 2013). As most patients with ARF or RHD require an injection once every 28 days and reside in remote locations, opportunities for a researcher to observe the actual episodes of receiving the injection were very limited. A focussed ethnographical approach enabled the intentional raising of the topic of experiences of injections during purposeful and episodic shorter visits to participants’ locations (Higginbottom et al., 2013). It involves intense data collection around a narrower topic and thus produces copious field notes from participant observations, interviews and informal conversations, as well as review of specific relevant documents (Mitchell & Steeves, 2012). Knoblauch (2005) believes that conducting a focussed ethnography requires a prior intimate knowledge of the research setting, and while this could be contested, it is likely beneficial. As described below, I did possess prior knowledge and experience of three communities in my study and this certainly assisted in accessing and connecting with participants in the field sites (Knoblauch, 2005).
Sampling in focussed ethnography is not pre-determined but is conducted purposively to gain representativeness of the phenomenon. Sampling is bounded by saturation, that is, when no new information arises in interviews or participation in the field (Higginbottom et al., 2013). Analysis of data in focussed ethnography is iterative, cyclical and concurrent with field work, in order to inductively elicit the themes emerging within the data.

Focussed ethnography has some similarities with rapid rural appraisal (RRA), which is an approach that emerged in international community development action research in the late 1970s, primarily to replace cumbersome survey methods of data collection (Chambers, 2011). RRA is used in rural research and is restricted to gathering data over a few weeks. RRA uses similar methods as focussed ethnography but lies within the methodology of action research (Read, 2012).

**Connecting with Medical Anthropology**

This study also draws upon principles from the discipline of medical anthropology. Medical anthropologists use a holistic and interdisciplinary approach to try to understand health and illness within societies (Brown & Barrett, 2010). It is an approach “which focusses on the interrelationships of society, culture, and biology on the one hand, and sickness and healing, on the other” (Hahn, 1999, p. 6). The discipline has roots in anthropology, but the gaze is limited to the ways people make sense of their wellness or illness in their particular settings (Brown & Barrett, 2010). Such settings include not only distinct cultural groups of people but can include such entities as biomedicine and health systems within the biomedical paradigm. Critical medical anthropology extends the perspective of the local setting by critically examining the effects of broader political, economic or global issues on local health and illness (Brown & Barrett, 2010).
Medial anthropology values the contextual background of societies and places importance on local history and local people being experts on their local situations (Hahn, 1999). People’s accounts of their illness are valued as they provide key insights (Brown & Barrett, 2010). Medical anthropology positions the researcher as a neutral learner and enquirer within such local situations as exploration is undertaken into the way local people make sense of, for instance, conditions such as ARF (Shand, 2005). My study involved crossing over to a cultural group different from my own, and an endeavour to understand how people perceived and understood their ‘illness’ as part of their life.

**Study Sites**

I carried out the focussed ethnography in four field sites that were selected from the group of ten SP Study sites. A comprehensive and thorough consent process was undertaken in recruiting these ten health centres by the SP Study team. Four were government-run centres and six were Aboriginal community controlled services. SP Study sites were paired, and each pair commenced on the study at three monthly intervals. The pairs and start dates were selected using simple randomisation which was carried out by the study’s statistician. This stepped entry into the SP Study meant that a heavy schedule of travel was undertaken by project officers to support health services’ staff through the phases of the project. I initially planned to follow the random selection by taking the first four sites that commenced on the SP study. However, the complexity of travel to one of the initial sites meant that it would have been difficult to visit as often as required by my study design. As my study is qualitative and therefore not dependent on randomisation, pragmatism overruled and the ‘hard to reach’ site was substituted for a site where I resided. Therefore, my
study sites consisted of three of the first four randomly-selected SP Study sites and one site selected in the fourth pair of randomisation. My final sites included two remote Aboriginal communities (Sites A & B), a group of remote homelands (Site C), with all three (A, B & C) having majority Aboriginal populations, and one remote small supply town with a substantial Aboriginal population (Site D). The interrelationship between the SP Study sites and my study sites are represented in Figure 2.4.

Having four sites means that my findings may be more representative of the NT young Aboriginal population with ARF and RHD as a whole, but multiple sites meant the travel arrangements were complicated and reduced the time I could spend in each location. Multi-sited ethnography emerged in the 1990s in studies of migration and global systems however the multiple sites in this focussed ethnography were merely a result of the SP Study design (Marcus, 1995). While there are similarities and common backgrounds, there are also differences between the four sites. A detailed description of the four sites is presented in the following chapter.
Figure 2.4. PhD sites overlaid onto SP Study sites, including duration. Patterns represent three phases of the SP Study.
Methods

Overview of the Methods Used to Collect Data

Data were collected for this doctoral study during many field visits. The data are comprised of field notes describing the sites, the participants and activities I participated in, as well as journal entries where reflections on my experiences at the sites and the iterative meanings they stimulated were recorded. Individual participants were selected by purposive sampling from the RHD Register. Semi-structured interviewing and participant observation were carried out. Seven case studies were collated as a way of highlighting and exploring the themes that emerged in the data.

Purposive Sampling

I accessed the NT RHD Register to determine the potential number of participants residing in each of my four study sites.

Inclusion criteria were:

- Aboriginal person with a diagnosis of ARF and / or RHD, and / or their close family; and
- currently prescribed intramuscular penicillin injections for secondary prophylaxis; and
- patient aged between 5 and 35 years; and
- nominated primary clinic (usual residence) at Site A, B, C or D; or
- Aboriginal informant as appropriate or relevant key advisor inside or outside the study sites.
I was particularly interested in recruiting adolescent male participants because there are scarce qualitative data about this group in the literature and their adherence is suspected to be lower.

The NT RHD Register data provides details about all individuals with ARF and RHD residing in the four sites. After restricting this to Aboriginal individuals aged 5-35 years; a list of eligible participants was generated (table 2.1). Females are consistently over-represented in ARF rates, at a ratio of almost 2:1 (Parnaby & Carapetis, 2010). The cumulative likelihood of having RHD rises with age; although the most common age of ARF onset is 5-14 years, progression to and detection of RHD increase over time, hence most individuals in the register are in older age groups. The age and sex distribution of ARF and RHD patients in the four study sites shown in table 2.1 is generally representative of NT data apart from the unexpected male over-representation at Site B, giving an overall female: male ratio of 1.3:1.

| Table 2.1 Eligible participants from the NT RHD Register (2013 data) |
|---|---|---|---|---|---|---|---|---|---|
| Age in years | Male 5-14 | Female 5-14 | Male 15-21 | Female 15-21 | Male 22-35 | Female 22-35 | Total Male | Total Female |
| Site A | 6 | 4 | 3 | 4 | 9 | 19 | 18 | 27 |
| Site B | 8 | 2 | 1 | 0 | 4 | 7 | 13 | 9 |
| Site C | 2 | 1 | 1 | 3 | 4 | 5 | 7 | 9 |
| Site D | 5 | 2 | 4 | 6 | 5 | 14 | 14 | 22 |
| Total | 21 | 9 | 9 | 13 | 22 | 45 | 52 | 67 |
No definitive target sample size for the interviews was set; as discussed previously, sampling was guided by data saturation. Decisions on the number and category of potential participants to approach were guided by cultural appropriateness, accessibility, seeking appropriate representation, and taking iterative analysis and saturation into consideration. There were 30 child or adolescent males with experience of between 1 and 16 years on injections and a corresponding 22 females in my possible sample. People in the 22 to 35-year age bracket were included as they have the longest experience of receiving regular injections and interacting with health services.

**Informed Consent Process**

A decolonising stance was the foundation of my approach to obtaining informed consent from Aboriginal participants. Gaining consent for participation was complex due to my inability to converse in the first language of some participants, their limited understanding or prior negative experience of research, and cultural appropriateness. In two of my sites I can speak one of the local languages. This enabled me to create a recording with a trained interpreter, explaining the research and the consent requirement. I wrote a plain English script, containing participant information as well as the consent requirement, and talked through each sentence with the interpreter who is also an experienced researcher. Each sentence held one idea or concept. The interpreter suspected that my original script included information that participants would not have the required underpinning knowledge to understand. Therefore, she simplified it and inserted what she felt were culturally appropriate points that generated a ‘tone’ of respect and passivity on my behalf. The script was interpreted and audio-recorded. I then back-translated this recording and discussed it with the interpreter to ensure that the true meanings were incorporated.
This recording was then carried on my mobile phone and played to potential participants easily and without pressure; frequently they sat undisturbed holding my mobile phone and listening to the recording while I remained at a distance. The front and back translations of this recording are included in Appendix A.

For the other two sites I was not able to create a recorded explanation or consent as I was not able to engage interpreters or language workers despite significant effort. Additionally, without a checking mechanism to ensure correct meanings, it was not ethical to proceed with an untrained language speaker. Therefore, I was restricted to operating in plain English in those locations. Plain English skills that match the linguistic constructions in Australian Aboriginal languages were developed during my prior experience in training Aboriginal language interpreters. Being honest about these research difficulties or weaknesses incorporates transparency which exemplifies a decolonising approach.

An information sheet explaining the study along with a consent form was approved by the Health Research Ethics Committee for the NT Department of Health and Menzies School of Health Research (See Appendix B). Two interview guides were approved to guide formal and informal semi-structured interviews (See Appendix C). One guide was for participants who were parents or guardians of children age five to fourteen years, the other guide was for participants aged fifteen to thirty-five years. When interviewing child/parent pairs, questions were adjusted according to individual age and maturity.

Before interviewing, all participants were asked if they were comfortable with audio-recording of the session. Where recordings of interviews occurred, these were transcribed by me and translated if required. Where sections of recordings were
unclear, they were reviewed with a qualified interpreter. However, few recordings were made. Therefore, the majority of interviews were hand written: of the fifty Aboriginal patients or family members who consented to be interviewed, nine also provided consent for their interview to be audio-recorded. Hand writing of interviews was a way of strengthening trust with research participants because people could see that I was writing down what they said. It also enabled thinking time for participants because it is a slower process. In instances where I had competence in the local language, hand written interviews were translated into English at the time of writing, with key phrases written verbatim. Probing was not carried out as to why participants were not comfortable with audio recording due to my recognition of being a white researcher, and the power this historically afforded. Participants’ preferences were taken at face value and accorded respect. Participant hesitancy was assumed to be due either to their unfamiliarity with the research process or with ‘outsider’ recordings having a negative reputation.

**Aboriginal Co-Researchers**

Co-researchers were recruited at two sites (Sites A and D) and were renumerated from my student funds. One was a clan leader and one was an adult community member, both with RHD. Tragically, the clan leader, a female in her forties, died of complications of RHD towards the end of my field work. At the remaining sites (Sites B and C) I was not able to recruit co-researchers for the duration of field work despite attempts. Two suitable co-researchers commenced but were not able to continue due to serious illness and other commitments. As these were in sites that I was familiar with, I therefore continued working alone. At this point my prior knowledge of how to approach Aboriginal people and Aboriginal dwellings was valuable and instrumental. For instance, it is considered impolite to walk up to a
front door and knock but polite to wait at an outer boundary such as a fence until you are noticed and invited to enter the property. Alternatively, while in a central location such as the community store, I asked community members as to where I might locate a particular person. Years of living in Aboriginal communities and adoption into a clan meant I was comfortable in enquiring, waiting, walking within the community, greeting strangers appropriately and making people feel at ease; in short, walking in the Aboriginal world.

**Triangulation**

Triangulation enables construction of a more complete picture and enhances credibility of the research (Houghton, Casey, Shaw, & Murphy, 2013). Triangulation was carried out by using the NT RHD Register which records care given for ARF and RHD, as well as clinical documents at local health clinics. Attention was given to the triangulation of data concerning patient mobility. White clinicians are commonly heard to lament that their Aboriginal clientele have high *random* mobility (frequently moving from community to community at whim) and consider this to be one cause of poor uptake of the penicillin injections. Young Aboriginal patients on the injection regimen were questioned about the locations they go to over a normal one-year time frame. They were asked to think back from the current time or season to the same time or season the previous year and recall the places they had resided or visited. This information was collated and then triangulated with data on the RHD Register which records the locations where injections were given. This enabled me to collate the extent of patients’ mobility within the study sites. The information included the number of places that people visited as well as their connection with those places. Twenty Aboriginal patients on the penicillin regimen (fourteen females and six males) were asked where they resided over a one-year period. Register data
received for the calendar year of 2014 and matched to the locations where participants stated they moved between.

Additionally, the data were triangulated across multiple qualitative methods employed in this study. These included, semi-structured interviewing and conversations with both patients and their families as well as with clinicians, participant observations of activities I was invited to join, including traditional activities and clinic waiting rooms, journal writings and reflections on my field work experiences and discussions with key informants and Aboriginal co-researchers.

**Recruiting Participants**

Participants were recruited within the timeframe of the SP Study and took place from December 2013 to August 2015 with serial interviews being carried out until early December 2015. My approach to recruiting participants was to obtain people’s residential locations from the local health clinics. I then attempted to find the potential participants accompanied by an Aboriginal staff member, an Aboriginal co-researcher or alone. In other instances, local health clinic staff facilitated my introduction to participants in waiting rooms in local health clinics. Participants under the age of fifteen were interviewed in the presence of an adult relative. At times I deemed it unethical practice to interview due to other circumstances (e.g. substance abuse or participant’s mental health and wellbeing issues). At other times, white clinic staff requested that I interview certain patients because of difficulties they were experiencing in connecting with them. Once again, a decolonising stance was held, and whiteness recognised by affording primacy to participants’ preferences and acting according to cultural protocols in all recruiting interactions.
Interviewing and Participant Observation

In each site I carried out a combination of semi-structured interviewing and informal conversations. In the Aboriginal cultural setting this was deemed to be more appropriate and less threatening. In a typical focus group, Aboriginal people may speak to their cultural position and roles (which may be to wait until they are asked to speak, or to sit and observe) whereas in one-to-one connecting, or family groupings, there is more personalised attention and some cultural constraints are largely removed. I also carried out participant observations and recorded extensive and detailed field notes. As much as was possible, I participated in whatever was happening in the field sites. In the homelands (Site C) this involved intimate and inclusive experiences because of my identity as an outsider in a location where there are few white visitors and control of visitors is at the discretion of the homelands leaders. I considered it respectful to participate in activities such as hunting for food and attending ceremonies. In the remote Aboriginal community sites (A and B) my participation was more closely connected with the health clinic during work hours, and with community members out of hours. In the remote town (Site D) it was not practical to participate in non-clinic activities as there was not a defined community as such and my participation consisted largely of interviewing, with some interactions at other times. This meant that my richest data originated from the homelands groups, and to a lesser extent in the remote communities, with least depth of data available from the town site.

Actual Sample

The following table and box depict the characteristics of the final sample of participants within each site. Table 2.2 shows the actual number of participants with ARF or RHD who were interviewed; some were interviewed multiple times over
serial site visits. As the patients on the penicillin injection regimen are centred within families and clans at the sites, the number of total people participating in the study is also recorded in this table. Key informants included two language interpreters, three clan elders, an experienced Aboriginal Health Practitioner now working as a community liaison worker, and two community members, one who has successfully completed ten years on the penicillin injection regimen with negligible heart damage. The selection of participants for the case studies is discussed in detail further on.

Table 2.2 Sample of all participants, ages at start of study in 2013

<table>
<thead>
<tr>
<th></th>
<th>Site A</th>
<th>Site B</th>
<th>Site C</th>
<th>Site D</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males with ARF/RHD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-14 years</td>
<td>0</td>
<td>1</td>
<td>6</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>15-21 years</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>22-35 years</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Total males with ARF/RHD</td>
<td>3</td>
<td>2</td>
<td>7</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Females with ARF/RHD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-14 years</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>15-21 years</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>22-35 years</td>
<td>5</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Total females with ARF/RHD</td>
<td>7</td>
<td>6</td>
<td>4</td>
<td>4</td>
<td>21</td>
</tr>
<tr>
<td>Adult male relatives</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Adult female relatives</td>
<td>4</td>
<td>7</td>
<td>7</td>
<td>4</td>
<td>22</td>
</tr>
<tr>
<td>Key informants</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Total participants</td>
<td>16</td>
<td>20</td>
<td>23</td>
<td>13</td>
<td>Total 72</td>
</tr>
</tbody>
</table>
The final table shows the total number of participants included in the study at the four sites.

**Table 2.3 All participants**

<table>
<thead>
<tr>
<th>Research Sites</th>
<th>All participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site A</td>
<td>16</td>
</tr>
<tr>
<td>Site B</td>
<td>20</td>
</tr>
<tr>
<td>Site C</td>
<td>23</td>
</tr>
<tr>
<td>Site D</td>
<td>13</td>
</tr>
<tr>
<td><strong>Total participants</strong></td>
<td><strong>72</strong></td>
</tr>
</tbody>
</table>

*Case Study Approach to Explore Emergent Themes*

Case studies are useful and relevant for answering questions in social research where a description of a complex social phenomenon in a natural context is required (Yin, 2014). While case study is normally considered a separate research design, in this ethnographic research it is used as a way of exploring common threads and representing convergent themes within the data. This method deliberately protects the anonymity of participants. Collating the data into a narrative allows the data to speak for itself and strengthens it (Liamputtong, 2009). This is particularly so when there is a white researcher exploring Aboriginal issues. The cases in this study are seven individuals with ARF or RHD selected from the regions of the four study sites. They were collated during the research to highlight themes around ARF and RHD experiences for young Aboriginal patients, including the health care they receive. The cases were selected because they are typical, and their existence highlights a public health problem. This means that gaining an understanding of the cases’ lives, their perspectives and possibly deeper insight into what the driving causes of ARF are in this population carries weight. Other atypical cases are represented in the final
analysis of my data. Carrying out the focussed ethnography required entry and participation into the cases’ life worlds to enable the developing of their narratives. Relationships were established and strengthened over time during multiple site visits as well as other connecting outside the sites. In collating the case studies, reflection and alternative perspectives were sought in attempt to gain understanding (Baum, 2008). Case studies are a way of collating in-depth research data that enables readers to determine if the themes are transferable to other settings (Taylor, 2013).

**Overview of the Seven Cases**

The first three cases are Aboriginal adolescent males with ARF or RHD. They were selected in response to the paucity of representation of this demographic in the literature. The first of the three cases is a deceased male whom I knew well in my previous role as a clinician in one site. This case is described in Chapter three. The second case is an adolescent male from the same site who is closely related to the first case. This boy was included in attempt to gain a longitudinal view of the family’s perspectives and responses to ARF and RHD. Additionally, I was interested to see if management of ARF and RHD in this location had improved to the extent that history would not be repeated in this site. The third case was an adolescent boy, from another site, who was selected due to multiple interactions demonstrating typical adolescent behaviour regarding the injection regimen. The remaining cases are females and consist of two girls and two young women who had all experienced RHD and open-heart surgery to repair or replace their heart valves. Open-heart surgery is the worst outcome of ARF and these cases were included to highlight the devastating impact that ARF can have today in the NT.
**Site Visits and Timelines**

The following tables indicate the amount of time spent in each of the remote sites to carry out the focussed ethnography. Considering that three of the sites are in remote areas, travel to and from the sites took up substantial time and preparation. Additionally, I found the field work experience had an emotional impact due to exposure to disturbing and unjust situations in Aboriginal communities, so I began to insert times for personal recovery between field trips.

Site A was visited four times between December 2013 and July 2015. Some community members were also contacted or visited while they were outside the site.

<table>
<thead>
<tr>
<th>Month/Year</th>
<th>Days in community</th>
</tr>
</thead>
<tbody>
<tr>
<td>December 2013</td>
<td>3</td>
</tr>
<tr>
<td>July 2014</td>
<td>15</td>
</tr>
<tr>
<td>September 2014</td>
<td>3</td>
</tr>
<tr>
<td>July 2015</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total days</strong></td>
<td><strong>29</strong></td>
</tr>
</tbody>
</table>

Site B was visited nine times between November 2013 and August 2015.

<table>
<thead>
<tr>
<th>Month/Year</th>
<th>Days in community</th>
</tr>
</thead>
<tbody>
<tr>
<td>November 2013</td>
<td>10</td>
</tr>
<tr>
<td>February 2014</td>
<td>3</td>
</tr>
<tr>
<td>March 2014</td>
<td>3</td>
</tr>
<tr>
<td>August 2014</td>
<td>2</td>
</tr>
<tr>
<td>October 2014</td>
<td>5</td>
</tr>
<tr>
<td>November 2014</td>
<td>6</td>
</tr>
<tr>
<td>March 2015</td>
<td>13</td>
</tr>
<tr>
<td>April 2015</td>
<td>2</td>
</tr>
<tr>
<td>August 2015</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total days</strong></td>
<td><strong>47</strong></td>
</tr>
</tbody>
</table>
In site C there were six visits to one of the main homelands between February 2014 and November 2015. Five other smaller homelands were visited for one or two days each. The Homeland health service office was visited on six occasions between February 2014 and November 2015. Contact occurred with some participants from this site in other locations outside these visits.

Table 2.6 Site C Visit timing and duration

<table>
<thead>
<tr>
<th>Month/Year</th>
<th>Days in community</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main homeland</td>
<td>23</td>
</tr>
<tr>
<td>Other homelands</td>
<td>8</td>
</tr>
<tr>
<td>Total days in homelands</td>
<td>31</td>
</tr>
<tr>
<td>Office visits</td>
<td>21</td>
</tr>
<tr>
<td>Total days</td>
<td>52</td>
</tr>
</tbody>
</table>

Site D was visited five times between June 2014 and March 2015. Contact occurred with some participants at times outside these visits. This site is also the site of my residence during the study allowing time for further observations.

Table 2.7 Site D Visit timing and duration

<table>
<thead>
<tr>
<th>Month/Year</th>
<th>Days in community</th>
</tr>
</thead>
<tbody>
<tr>
<td>June 2014</td>
<td>2</td>
</tr>
<tr>
<td>July 2014</td>
<td>3</td>
</tr>
<tr>
<td>September 2014</td>
<td>3</td>
</tr>
<tr>
<td>November 2014</td>
<td>4</td>
</tr>
<tr>
<td>March 2015</td>
<td>1</td>
</tr>
<tr>
<td>Total days</td>
<td>13</td>
</tr>
</tbody>
</table>
**Ethical Considerations**

As my study was part of the SP Study, ethical approval for the SP Study, provided by the Northern Territory Department of Health and Menzies School of Health Research Ethics Committee HREC-2012-1756, was utilised for my research. An amendment to the original study protocol was approved to allow interviews with key informants outside my four study sites and to permit me to specifically ask young people about pain associated with the injections. I carried out a trial interview, which highlighted the strong likelihood of participants requesting further information during the interview about ARF and RHD when this topic was raised and discussed. My expertise as a cross-cultural and bilingual health educator (in two sites) meant I was able to carry out education when requested. However, being part of a study investigating health services’ care meant that I had to be continually conscious of how requests for further information were fulfilled; either by me or with referral to the local health clinicians or the NT RHD Control Program, which is tasked with providing RHD education.

A code was assigned to participants and used to label all relevant paper and audio files. Electronic data were stored securely on password-protected computers and paper documents were stored in locked filing cabinets. Even within the SP study team, when/if my transcripts were viewed, their identifiers were not used. All data were kept confidential and interviewees’ identities were protected.

**Funding**

Travel costs to remote study sites were supported by the NHMRC Project Grant (1027040) and student funds provided by Menzies School of Health Research. An Australian Post-Graduate Award scholarship was received along with top-up support from the Menzies School of Health Research for the duration of this study.
Data Analysis

Data gathered during field visits comprised of nine audio recordings, large quantities of field notes incorporating participant observations, semi-structured interviews, informal conversations and reflexive notes as well as data from the NT RHD Register and health clinics. The recorded interviews were transcribed verbatim and hand-written interviews were typed. All data were treated the same way for analysis and integrated into the final conceptualisation.

Analysis of data commenced at the start of data collection. The continuous writing of field notes was one way of ‘holding’ what was being observed, what I was being told and my experiences in the field. Throughout the whole research period, while continually recording, I continuously reflected and considered possible emerging meanings. At times observations or experiences would be mulled over, sometimes for months. At times my understanding fell into place only at a point when my previous knowledge or opinions were able to be truly bracketed and I could ‘see’ what a situation meant.

Although my data were iteratively analysed during the field work phase of my study, when I completed field work and began to concentrate on reviewing my interviews and field notes at a deeper level, I found that the stories had a strong emotional impact on me. This was due to the sadness of the collective stories and the injustice of children experiencing a serious yet preventable condition that shortens their lifespan. I discussed this with my supervisors and others who had similar experiences. I had a break from analysing then proceeded more slowly and wrote my thoughts in a journal. After some months I was able to resume analysing full time.
QSR Nvivo 10 software was utilised to facilitate data analysis. The data were collated then scrutinised and coded. Open coding was carried out by initially applying tentative labels to chunks of data. This was followed by axial coding which brings together similar and related coding ideas. Selective coding was carried out to answer certain questions; information that was selectively coded included respondent’s statements about the pain of injections and names participants use to refer to ARF and RHD (Benaquisto & Given, 2008). Data were systematically and inductively analysed for emerging themes to answer the research questions. Use of Nvivo software enables an audit trail that illuminates my rationale for decisions and interpretive judgements about the data, both during collection and in analysis. The software also enabled queries to be run on the data so as to guard against biased emphasis, thus increasing dependability and confirmability of my findings. Member checking consisted of discussions with key informants such as clan leaders and co-researchers and with a small number of participants.

Reflexivity on my position within the research, was an integral part of the research analysis, and is captured in diary notes written throughout the study. These diary notes became part of the data and excerpts included in my findings provide a degree of transparency, allowing readers to judge the trustworthiness of the data. Similarly, excerpts from patient interviews and participant observations carry the same function.

**Limitations of the Study**

Having four sites in this focussed ethnography may have limited the depth of data able to be collected in each site because of the need to keep rotating through the sites. Essentially, there may have been a trade-off between depth of data with breadth because a wider range of participants were recruited instead of in just one site.
Additionally, lack of success in locating a co-researcher at two of the sites will have affected the data collected. This especially limited my ability to operate in participants’ first languages.

**Conclusion**

The methodological frame and methods utilised for this research were selected to appropriately provide usable data that answered both my research questions and selected aims of the SP Study. My approaches to recruitment of participants and consent in my sites as well as detail of how I conducted the study have been described. Methodological development has been closely guided by my supervisors, the qualitative literature, and approaches suitable to the specific study settings. The following chapter provides a more detailed description of my connecting with the research sites, including detailed descriptions of each site.
Chapter 3

Connecting with the Research Sites
Introduction

In this chapter I discuss how during my connecting with the research sites and participants, I continually considered their antecedent events and histories. My research required crossing cultural borders. I needed to be mindful of my identity as an outsider, as an actor in the research process. The chapter commences with positioning the first case study as a foundational narrative, highlighting issues faced by families and health clinicians around ARF and RHD. A fuller description of my study sites follows, with further conceptualisations of how research should be ethically carried out in Aboriginal communities. The chapter concludes with the topic of Aboriginal researchers because this issue increasingly arose as I connected with participants in my research journey.

Defining and Connecting with the Research Participants

Because my study aimed to understand young Aboriginal people’s experiences, perceptions and understanding of a disease and the health care they receive for it, it was important to understand and define who the people are that I was connecting with in my research endeavours. It was also important to understand the setting: for instance, where participants resided, who decides where they reside, who cares for whom and what their lives are like. Additionally, it was important to understand what connections there are between people, what freedoms or boundaries exist, what languages they speak and what is a typical day. And further, how having ARF or RHD appeared to affect them. As a researcher, I selected potential participants based on an externally determined research construct. It defined a group of participants to create a workable ambit. However, because it was created externally to people’s
reality and stemmed from the research paradigm, it is subjective. Categorising in this way has potential to limit the findings and understandings of the young people’s lives because the young people’s lives are bounded by a much larger system of clan and kin, country, culture and world view. Therefore, while characteristics that bracketed a target group of potential participants was used, my study was situated within the larger life worlds that the young people are part of and interpretation of findings depended on taking into account their whole world. Yet in saying this, there is the question of whether I could really understand an ‘other’s’ world. In a sense this is presumptuous. My demographic is so different to theirs and the inherent differences are great.

Much of my field work was comprised of observations in situations where I had opportunity to participate in the lives of the young people. Ethnographical study is constrained when carried out by a researcher from a culture so disparate from the participants’. But the aim was to understand and interpret. There were not many occasions where participants were up front with clear statements of how things are, how they see things. So, statements that did arise were considered in the broader context of the observational data. Interpretive conclusions about what is observed and heard, is of course constrained and precarious. However, there is more at stake here: young Aboriginal people are acquiring a serious and preventable disease that causes disability and can lead to an early death. Therefore, within the time frame available and using a bounded approach, I sought to connect, to understand what I was seeing and hearing, and to interpret these.

A study of this kind is also a privilege. In being permitted to join in, accepted into parts of people’s lives, experiencing the natural beauty of their landscapes as well as the cultural collegiality of Aboriginal people, I valued the privilege and richness of
such experiences. I come from another culture, language, demographic and an academic approach. The privilege also presented a challenge; how could I eschew my own identity and attempt to understand the identity of this specific, remote-living group? The only way was through acts of connecting. And to connect, I had to be aware of the local rules and mores. Living alongside the people for many years meant I did know the rules, I knew how to walk in their world.

Figure 3.1. Natural beauty of the participants' landscapes
**Reflexivity in Connecting**

Ethnographic approaches incorporate reflexivity on the part of the researcher and a recognition and an acceptance of the researcher as an actor within the study. Baum describes the bounds of research and why reflexivity is critical, “Public health research, like most others, is subject to the setting in which it is conducted and the researchers who conduct it” (Baum, 2008, p. 147).

Reflexivity is imperative for white researchers investigating Aboriginal health. My study takes place in a cultural setting (Aboriginal) that is considerably different to my background culture (White Anglo). Even in the two sites where I have local knowledge, local language skills and have been adopted into the kinship system because of my relationship with the community which spans several decades, reflexivity is still important. I wrote a journal detailing my position as a white researcher to incorporate reflexivity and improve research integrity (Rix, Barclay, & Wilson, 2014). Reflexivity in qualitative research is in general described as follows:

> Reflexivity is commonly viewed as the process of a continual internal dialogue and critical self-evaluation of a researcher’s positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome (Berger, 2015, p. 220).

A researcher’s personal position influences and impacts their research. Part way through my analysis, as I read anthropologists’ writings about Aboriginal adolescent social development, I realised that I had been profoundly influenced by the length of time spent living alongside and at times being immersed within Aboriginal society in remote locations commencing in my early twenties (Berger, 2015). On reflecting about how my research was conducted, I was struck with how I had absorbed some Aboriginal cultural norms. I had operated to a strong Aboriginal norm of holding
foremost one’s kin relationship with an interviewee or participant (Moisseeff, 2013). A different researcher, without the connections that I had accumulated over time, would likely have approached Aboriginal participants in a different way and in different spaces.

**Reflexivity and Personal Connecting with ARF in an Aboriginal Family**

The following case study reveals some of my prior experiences walking in the Aboriginal world, and connecting with ARF in that setting. Permission was gained from family leaders to tell this story, with the proviso that anonymity was preserved. It is provided here to provide background for why I was keen to pursue this study.

**Gudjuk’s Story**

While practising as a remote area nurse in a coastal community in the NT in the 1990s, I befriended an Aboriginal family living close to my house. They were a traditional family, operating in their traditional language, practising close kin living and often carrying out traditional practices such as hunting for local foods. They were accepting and inclusive, enabling me to learn about their way of life and their practices. One of their young boys, Gudjuk, became ill one weekend and they called me to assess him. Gudjuk was quite unwell with ARF, the first case I had seen, and I organised for him to attend hospital. During the subsequent three or four years I gave him the penicillin injections and recall him as a ‘compliant patient’. I left the region but returned many years later when Gudjuk was 18 years old. While I was away he had been to a distant southern city for a heart valve repair. On meeting him again he appeared to be well and assured me that he was now cured of his heart condition. The family permitted me to check his clinic records so
that I could be assured that all was indeed well. However, as I expected, Gudjuk was still prescribed the penicillin injections but was not receiving them as he and his family believed they were no longer required. I endeavoured to communicate this to Gudjuk and his family but was unable to contact them. I also connected with a young male local Aboriginal Health Practitioner and tried to set up connections between him and Gudjuk. However this also failed.

A few years later I met Gudjuk’s relatives outside the major hospital where I was working as a Patient Educator among his language group. Gudjuk was in heart failure in the intensive care unit. He was about to be medically evacuated to a southern city some thousands of kilometres away for emergency heart valve surgery. This evacuation was carried out and he was taken straight to the operating theatre on arrival at the southern city. Tragically, Gudjuk died shortly after arrival. When I interacted with his family left behind in the NT they were visibly stunned. Gudjuk was just 20 years old when he died from RHD.

Reflections on Gudjuk’s case

This experience had a profound and enduring effect on me; I reflected at length on the appalling outcome of this disease in our resource-rich nation and why a young man died at the age of 20, despite there being a health service within his reach, including tertiary level care. I reflected on the communication difficulties that were, and continue to be, prevalent and the blame that some health professionals place upon Aboriginal people for not being skilled in English, and yet the professionals remain reluctant to engage interpreters. I reflected on the weakness within our health services that result from not acknowledging or accepting that the majority of the
clientele in remote communities have an everyday, first language that is not English, and move and are motivated by different forces than in the dominant, largely urban society.

The effects of my experience with Gudjuk and his family stayed with me and were the catalyst for me taking the opportunity this research study provided. I was aware that Gudjuk was not an isolated case; there are over 3000 young Aboriginal people in the NT who have experienced ARF. Some of them have received heart valve surgery at young ages, including multiple operations. Those who have undergone surgery are marked with the central chest scars which could be viewed as scars of unrecognised miscommunication and mystification, on the part of all involved. They could also be viewed as scars of colonisation: why this disease is tolerated today within a wealthy nation and why the deaths of young Aboriginal people do not cause a public outcry, such as ebola does, and why there is such high incidence of ARF, with a continual trickle of new cases, is very disturbing.

When I viewed the NT RHD Register in March 2013, I noticed that a 12-year-old boy, Lakaram (pseudonym), who is from Gudjuk’s family, had been newly diagnosed with ARF in December 2012. According to western family relationships, Lakaram is Gudjuk’s direct cousin. At that point Lakaram had received his penicillin injections on time for three months. He is a member of the same clan as Gudjuk, has the same language and world view and has many other similar characteristics. It is imperative that history is not repeated. Lakaram and his parents became participants in my current study and additionally became one of the case stories. The following section describes the research setting: the places where participants such as Gudjuk and his 12 years old cousin, Lakaram, will likely reside for the duration of their lives.
Research Sites

Overview

As mentioned previously, my fieldwork was carried out in four research sites. A sociohistorical and ethnographic overview of my four sites provides the connecting information about the people, languages, culture and land that is important for contextualising this study about young Aboriginal peoples’ experiences of ARF. However, to preserve confidentiality, descriptions will be given without naming or indicating the location of the sites. The sociohistorical and ethnographic perspectives are applicable to all four sites, which are all situated in the Top End of the NT, (i.e. the northern coastal half of the NT). As is the case everywhere, what has gone before in these sites affects what is happening today. However, while I recognise the importance of understanding the antecedent situations when interpreting current events, my writing is confined to an overview with the purpose of setting the scene for fieldwork in public health.

ARF is a major health issue among young Aboriginal people in the four sites. This disease is recognised globally as a marker of poverty, which predicates that my research sites are sites of poverty (Hale & Sharpe, 2011; Parnaby & Carapetis, 2010). Poverty is understood to be multifactorial, arising from lack of the core dimensions of economic capacity, educational opportunity, being a valued community member, having a political voice, and experiencing security (OECD, 2001).

Three of my study sites are within an Aboriginal Land Trust held in inalienable freehold title by traditional land owners (Petheram, Zander, Campbell, High, & Stacey, 2010). The fourth site is a small remote town that Aboriginal people have...
moved towards, or have been moved into, as their lands in the surrounding district were overtaken by white mining and cattle enterprises (Merlan, 1998).

The four sites are significantly affected by settlement of foreign colonisers. This led to loss of land rights, loss of control, the imposition of mining or cattle industry onto Aboriginal lands with ensuing loss of livelihood, a history of punitive killings by powerful colonisers and ensuing significant welfare dependency.

Wherever one looks in the world, one sees that colonisation has created dependency. In every European ‘settler’ society where Indigenous people have been subjected to a colonial regime, pre-colonial autonomy has been eroded. In its place, a range of dependencies have manifested themselves in ways damaging to Indigenous peoples’ lives (Maddison, 2008, p. 41).

The dependencies resulting from colonisation of Aboriginal people in the NT show little sign of waning. While many people live on their traditional lands or the land of other Aboriginal custodians, the majority receive social welfare payments as their main source of income and reside in government-provided rented housing. Data on school attendance and education levels attained show a large gap between Aboriginal and non-Aboriginal students (Purdie & Buckley, 2010). Employment opportunities are minimal in remote areas, meaning there are high unemployment rates.

The degree of intergenerational trauma due to colonisation in the sites is hard to determine but must be acknowledged. In one of my sites it was spoken of openly. The speed of encroachment of the dominant society into Aboriginal society in the remote areas of the NT is escalating and is a cause for concern among Aboriginal adults (Etherington, 2006). Some sites have experienced loss of traditional Aboriginal languages with creole languages developing in their place, whereas other
sites have retained their languages. Despite language loss and other cultural changes, people maintain clear and strong identity as Aboriginal people, and are inseparably connected with particular geographical locations.

**Connecting with Land**

From the beginning, English colonists noted that the Indigenous inhabitants of Australia were profoundly attached to their land (Williams, 1986, p. 17). Aborigines have not voluntarily surrendered ownership of their land anywhere in Australia, and in many places, they have continued to believe the land was theirs regardless of government views (Williams, 1986, p. 19).

Aboriginal land ‘ownership’ was noted but has been poorly understood by the settling Europeans and remains difficult for the current Australian population to understand because it is so different from European land tenure. Anthropologists have done much to understand the Aboriginal land tenure system but do not claim to have complete knowledge (Williams, 1986). For Europeans, land is bordered to delineate ownership, or mapped and titled to prove ownership. Aboriginal lands are not bordered by visible fences but are delineated by natural structures and described in traditional song lines representing traditional mythological narratives. *Ownership* is not held by individuals, but by local, tribally-based groups, with connection designated based on having common language or common totemic heritage or other entities (Hiatt, 1962). In early anthropologists’ descriptions of local organisation of Aboriginal people, there is much that is different to western organisation of society. While the organisation of Aboriginal people and connection with specific land areas has been disrupted by settlers, it remains a very strong component of current identity. It is possibly the most important determinant of identity. An individual is usually
designated as belonging to the group of their father and that group is connected with
certain land, and this identity is impossible to remove (Hiatt, 1962).

Additionally, if traditional ‘land title deeds’ are brought forth by Aboriginal people,
they are not recognised as such and cannot be ‘read’ by outsiders (Trudgen, 2000).
Europeans addressed the issue of Aboriginal land ownership by trying to align it with
their own models which meant that Aboriginal models tended to be viewed as
deficient due to absence of familiar entities. This led to contestations,
misunderstanding and confusion which have added to the social trauma and loss of
power experienced by Aboriginal people. The following two figures depict some of
the contestations by Aboriginal people to explain their land situation to authorities.
Figure 3.2. Yirrkala Bark Petition 1963 to the Federal government appealing the excision of a large portion of their land for mining
Connecting with Politics

The political environment is important to understand as a background force that dominates Aboriginal lives, livelihoods, control and sense of wellbeing and security. Significant recent events continue a long line of government policies and practices that undermine and disempower Aboriginal lives in remote NT. Two such events will be briefly mentioned. The first is the so-called ‘NT intervention’:

On 21 June 2007, the (then) Prime Minister of Australia, John Howard, announced an ‘emergency intervention’ into Aboriginal communities in the Northern Territory. The intervention was justified as a crisis response to allegations of widespread child sexual abuse in Aboriginal communities, allegations contained in the Ampe Akelyerneman Meke Mekarle: ‘Little Children Are Sacred’ report. The terms of the intervention were far-ranging, including the quarantining of welfare payments, new alcohol restrictions,
compulsory health checks for children, and the acquisition of townships by the government through five-year leases (Maddison, 2008, p. 41).

This extraordinary social policy event reinforced the subjugated social position of Aboriginal people in the NT.

The second event is the attack on the existence of and support for Aboriginal homelands by the federal government. Although just one of my sites is a set of homelands, the homelands movement significantly affects remote Aboriginal communities and is thus an important background event for the community sites as well. The homelands movement is a social movement that occurred in the 1970s in response to the end of the assimilationist era and the beginning of the self-determination era (McDermott, O'Dea, Rowley, Knight, & Burgess, 1998).

‘Homeland’ is the name given to geographical areas where there are important and significant kin-based traditional and ancestral connection and custodial rights and responsibilities. Homelands are sometimes referred to as outstations. Aboriginal people moved to these custodial lands after significant periods of time living in centralised communities that were instigated by missions or governments. This movement resulted in increased opportunities for Aboriginal people to carry out traditional activities such as caring for country, living in a safer environment and pursuing local economic enterprises. It led to Aboriginal people having greater control over their circumstances. An additional benefit of the movement was the reduction in household crowding which was common in large communities (Altman, Kerins, Fogarty, & Webb, 2008; McDermott et al., 1998). Federal government policies supported the development of homelands until a turnaround in 2007 when withdrawal of support was mooted (Amnesty International, 2011). This led to unsettling and angst among Aboriginal homeland dwellers and their relatives in
Aboriginal communities who are connected to homelands. People’s sense of security was assailed. And in particular, there was the added heartfelt strain of endeavouring once again to explain how being on or having access to one’s custodial land provides a deep sense of connection and wellbeing for Aboriginal people. The economic justification behind the government policy is demonstrated in comments by the (then) Prime Minister, “What we can't do is endlessly subsidise lifestyle choices if those lifestyle choices are not conducive to full participation in Australian society that everyone should have” (Abbott, 2015).

Thus, the Aboriginal people residing in the four study sites live with knowing and experiencing political and social domination and insecurity of government support for their place. This affects how they feel and act and the decisions they make. Many communities are experiencing an encroaching and powerful permanent white presence.

**Connecting through Languages**

As NT Aboriginal communities became established, the permanent presence of white people who predominantly spoke English became a fact of life. Examination of written texts, such as language courses from each site, reveals endeavours by local Aboriginal people to connect with these new residents. At the most fundament level, there was a desire from the Aboriginal people to enable white residents and workers to understand and become competent in addressing Aboriginal people using the Aboriginal kinship system, the most polite way to address community people according to local lore, and to connect with local Aboriginal people for obtaining reliable language information and instruction (Etherington & Etherington, 1996). It was hoped that through the process of newcomers learning the language being spoken around them, new understandings of the Aboriginal world view on the part of
newcomers would emerge. However, only a minority of white workers learned
Aboriginal languages and, as time moved on, less whites stayed long enough or were
interested to learn.

**Definition of Community in This Study**

The term community is used throughout this study and requires further clarification. The term has multiple meanings and is used in a range of contexts. Tesoriero (2010) proposes that the term has such complexity that what is most important is reflection upon the concept so as to promote understanding of the entity at hand and to prevent oversimplification (Tesoriero, 2010). He contends that definitions of community are not neutral but can be value-laden in that they are used to direct social enterprises such as health services, and social policies, such as welfare (Tesoriero, 2010). For most white health practitioners, the definition of the communities where they work will likely be descriptive: geographical locations where the dominant population group is Aboriginal. For this study, a non-geographical description by Campbell and Jovchelovitch, 2000, will be used:

> When speaking of community we refer to a group of people who 1) share an identity which the community is able to articulate; 2) share a set of social representations which organises the worldviews of community members and guides interpretation of reality and their everyday practices; 3) share the conditions and constraints of access to power, both in terms of material resources and symbolic recognition (Campbell & Jovchelovitch, 2000, p. 260 authors' emphasis retained).

These three characteristics of ‘community’ appropriately describe the Aboriginal communities in this study because of their shared historical experiences of
colonialism, cultural practices, world view and languages other than English. The characteristics of ‘community’ that Tesoriero (2010) outlines also align with the communities in the study: the study communities are small in scale permitting people to know each other well; there is a strong sense of identity and belonging as a member of a group (which may be a clan), and there are obligations to participate in social functions within their specific worldview. The communities additionally participate in unique cultural traditions such as methods used for hunting for natural local foods and traditional or traditionally-based ceremonies (Tesoriero, 2010). These characteristics of ‘community’ go beyond geographical location despite the communities in this study having strong connection and thus identity with certain geographical locations (these locations not necessarily being the one where the current physical community is established). This study also explored whether there is an existing sense of community of young Aboriginal people who have ARF or RHD within the study sites. The role and influence of white residents of communities in the study also arises. In descriptions of these communities, the interactions with and the place of white residents is noted.

**Connecting with Community Development Principles**

Connecting with community development principles in this study is important because there is a continual blueprint for ongoing community development in Aboriginal communities, even though they are located within a resource-rich country and have coherent and strong Aboriginal cultural histories (D. Campbell, Wunungmurra, & Nyomba, 2007; Moran, 2016). Low socioeconomic levels, poor infrastructure, low English literacy and education levels, disempowerment and the consequential poor health, means continual externally-driven developmental processes are directed by federal and state policies in Aboriginal communities.
Participation by local communities with these developmental processes is a point of much angst among academics and community development workers alike (Eversole, 2012). Therefore, this study draws on community development principles and, in particular, the concept of ‘valuing the local’ (Tesoriero, 2010). Tesoriero (2010), proposes that valuing local knowledge, culture, resources, skills and processes is critical to facilitate changes from the ground up in community development rather than from the top down (Tesoriero, 2010). Seeking the views of Aboriginal families affected by ARF is a ‘from the ground-up’ initiative. By gaining understanding of what it is like to experience ARF and RHD, and ARF and RHD care, from the perspective of local knowledge, culture and processes, new insights will be gained into the meaningful engagement of people in the management of this condition, taking account of their priorities and communities. By seeking to understand local resources and local skills, new ARF and RHD care strategies can be embedded within local communities optimising sustainability of that care as part of community life.

**Descriptions of the Four Sites**

**Site A**

Site A is a remote Aboriginal community in the Top End of the NT. Its population was just over 1000 in the 2011 census (2013). Literature about the location, as in many similar NT sites, remarks upon antecedent contexts of custodial land ownership for multiple generations. The new type of ‘settlement living’ at Site A emerged in the early 1900s when a white farmer established a pastoral enterprise at the site. A mission was then established on the site in the 1920s thus cementing it as a permanent settlement. As is common in NT communities, the actual site is custodial land belonging to one group of Aboriginal people; other culturally-linked
groups moved in to reside at the new permanent settlement. When the current Aboriginal residents are asked, they can state who the settlement land belongs to even though other groups of Aboriginal people now live permanently on the site. English is a second language at this site, with most Aboriginal residents speaking an Aboriginal language. The health service at this site is a government controlled entity. White residents mainly live in the community because of their employment in various agencies such as a school, health service, police station, store and ‘social club’ (a source of alcohol in the community). There are also some white non-skilled workers who hold employment as cleaners and cashiers. Interactions between the white and Aboriginal residents are generally cordial and parallel rather than inclusive, although negative views towards some of the white business owners are expressed. Most of the housing for white residents is in one location with Aboriginal residents living in nearby locations delineated by clan groups.

Site B

Site B is also an Aboriginal community with a little fewer than 1000 in the 2011 census (2013). The site was founded as a mission in the early 1900s in an endeavour to reduce violent clashes between the Aboriginal people in that region and outsiders. The clans at this site have a history of a strong voice in land rights contestation but have not been successful in those endeavours. A mining enterprise has dominated the location for many years.

The site additionally is not without contestation from within certain local Aboriginal groups connected with the location via separate lines of kinship. This compounds the reduced sense of security instigated by the mining enterprise.
Today different clan groups reside in different spaces within Site B although there is nothing to obviously delineate this to an outsider. The adults in the community voice their concern about the quickening influx of new outsider entities such as illicit drugs, drinking bars and fast food in the nearby mining town that attract Aboriginal young people. English is not spoken at home and the spoken languages are connected dialects of the one language family. Management of the health service at this site transitioned from a government service to an Aboriginal Community Controlled service at the start of my study.

There are white residents at this site, with the reason for being located within the community tied to employment, mainly at the school or the air transport service. All the health clinicians reside in the nearby mining town and commute to the community daily. The mining town is the focal point for social activities of the white residents.

Site C

Site C comprises a set of homelands covering an area of 6900 square kilometres within the Aboriginal Land Trust. The Aboriginal population is recorded in the 2011 census is also around 1000, with the difference being that the population is dispersed over an area. The clans dwelling in these homelands are connected by kinship, traditional song-lines, language families and cultural practices. The clans remain aligned with and oriented to their traditional practices such as living off and caring for the land, participating in traditional ceremonies and operating via traditional mores. English is not spoken at home and a variety of connected dialects of their main language group are spoken at individual homelands.
The area became of interest to the federal government in the 1930s when an expedition was planned, but averted, to punish the local Aboriginal people for murder of white interlopers. In the social opinion of the times there was decreasing support for such expeditions and a white anthropologist was permitted entry to what was then a reserve in order to contact and establish friendly relations with the local people (Thomson, 2005). This was carried out successfully. The health service at this site is an Aboriginal Community Controlled service. I am aware of just one white person residing permanently in the set of homelands.

**Site D**

Site D is a small remote town including a regional population of 9,000 people of which approximately one quarter are Aboriginal (2013). White free settlers first took up land in the area in 1870s, drawn by a river crossing which became a hub for travellers, miners and emerging pastoral enterprises (Ogden, 1994). In texts written about the region from the stance of the colonisers, there is little information about the original Aboriginal residents of the area apart from their use as labourers and disparaging comments concerning difference. These statements typify colonial attitudes towards Aboriginal people at the time. In anthropological texts there is another story (Merlan, 1994). Those texts propose that in sites such as this, the original Aboriginal residents would have found their livelihoods seriously disrupted by competition for local resources such as water and land, severely testing of actual survival of the original local people (Merlan, 1998). As the town area grew, Aboriginal people displaced from further afield by the same competition for resources found their way into the area of Site D, or were forcibly moved there. Interactions between settlers and Aboriginal people within Site D have been chequered with domination by whites, demonstrated by prohibition of movement of
Aboriginal people into the town area; forced removals from lands when award wages for Aboriginal pastoral workers were legalised; and eventual fights for land rights by local Aboriginal traditional custodians, some of which were successful. In pastoral regions of Australia there was typically fearful and negative sentiment towards the issue of Aboriginal land rights and in Site D this resulted in formation of a protest group called “Rights for Whites” and a subsequent white protest march through the town in October 1982 (Ogden, 1994). Current interactions between Aboriginal people and others in the town are certainly still affected by this recent history.

While there are no longer restrictions on movement, Aboriginal people still reside in Aboriginal-only areas or in government rented housing distributed throughout the town’s suburban area. In both locations there is high unemployment, alcohol misuse, and obvious social disorder. Such social disorder has been the catalyst for alcohol management plans and for a new policing strategy of manning public alcohol outlets during opening times to reduce public drunkenness. These strategies are but the latest in a long line of attempts to control alcohol use with negligible evidence of effectiveness (d'Abbs, 2015). Licences to sell liquor were initially and continually applied for by local white settlers and liquor outlets are a prominent feature of the town today (Ogden, 1994). There are 21 licenses already existing in the small town. Additionally, there remains a strong presence of the local ‘white history’ as seen in road and enterprise names which are names of past white colonialists, pastoralists or residents. However, a few of the regional tourist attractions are now referred to by their Aboriginal names and this hopefully represents a positive shifting of white’s attitudes to local Aboriginal people. Aboriginal languages from the surrounding regions are still spoken by older people, with younger people predominantly
speaking a creole. The health service at this site is an Aboriginal Community Controlled service and carries a local Aboriginal language name.

**Issues in Connecting**

The following section discusses connecting as a researcher in further detail; issues covered include the challenges associated with being both an insider and an outsider in Aboriginal communities, being a white researcher in black communities, the position of power that a researcher may have in their work and in expressing views of others, and the need for continual reflexive practice.

**Connecting as an Insider/Outsider**

Culture cannot be separated from people’s practices and perceptions, therefore endeavours to gain insight must remain seated within local cultural contexts (Liamputtong, 2013). This means crossing cultural boundaries and entering Aboriginal cultural spaces to collect data and it raises the issue of whether the researcher is positioned as an ‘insider’ or an ‘outsider’ as will be explained in the following paragraphs.

While it is assumed that there are benefits in researchers having local language skills, cultural knowledge and established kin relationships with research participants, this insider/outsider status is fluid, and changes as different cultural contexts are encountered between sites and within multiple interactions within a site (Merriam et al., 2001). Certainly, in my case there is the benefit of ease of access: having been adopted into the kinship system some decades ago enables me to quickly form comfortable relationships and means I understand relationship protocols and etiquette that would not be expected from a novice outsider. I relate to and know how to walk inside the Aboriginal world. However, being an insider in this instance also means
that some relationships will be limited by cultural restrictions, for example I am required to respectfully avoid or constrain interactions with certain male ‘relatives’.

Additionally, in one site, gate-keepers have stated that they do not readily allow access to researchers, but my long-term relationships and reputation led to the gate being opened. Thus, I have access and rapport due to familiarity and trust (Merriam et al., 2001). Having worked as a primary health care clinician in one of the sites, I am perceived as a trusted outsider by residents and have insider knowledge of many of the community members’ past health narratives. This trust bestowed on me is based on my proven ability to keep information confidential and good clinical practice. As a clinician, I am also an insider within the biomedical health system that diagnoses ARF, and prescribes and provides the penicillin injections. Furthermore, I have insider biomedical knowledge from that sphere; biomedical detail of ARF and RHD in this instance.

White Researcher

Being a white researcher in an Aboriginal community is a fragile position philosophically, ethically and in real terms. The history of colonialism and of unethical white researcher practice cannot be put aside. The setting for this study is one of past colonisation and imperialism; and I am a member of the dominant colonising cultural group. I acknowledge the enduring negative impacts of colonisation in the research sites: loss of language in some sites, poverty, marginalisation and the struggle of Aboriginal peoples to gain control over their lives in a dominated political environment (Altman, 2007; Baum, 2008; Sherwood, 2009). Unequal power relations are still in play. Indeed, these enduring effects of colonisation, particularly the lack of suitable housing, may be instrumental in prolonging the existence of diseases such as ARF in the study sites (Godwin-
Thompson, 2014). White researchers working with Aboriginal populations should always be an issue of concern however my ethnic background may not have been the only factor which affected my research relationships with participants and the depth of data able to be accessed (Bissell, May, & Noyce, 2004). Factors such as language, concurrent community and political events, how someone was feeling on a day, including me as the researcher, all potentially influence research processes and outcomes. It is difficult to determine what affect my whiteness had. I could possibly have been viewed as a neutral entity or a benevolent one, and therefore someone who was safe to divulge information to.

**Researcher Power**

As a representative of the colonisers, and the dominant white culture, unequal power status is a given. However, my long-term experience living within Aboriginal communities led to a personal understanding of how outsider dominance can manifest within those communities. For instance, this dominance may appear as: a determination to use English only and refusal to learn the Aboriginal language in a location; incapacity to accept difference; perception of self as more advanced; inability to hear what is being said, or not said; inability to reflect outside one’s own world view; an unawareness of local systems of law and lore; and importance of kinship and Aboriginal people’s satisfaction with their identity.

This understanding meant that my new researcher-participant relationships in my study started from a place of historical knowing in this setting. Aside from the dominance of white society, researcher power was also heightened by the fact that the research agenda was determined before entry to the field sites. The topic of research was selected by a research institution in response to a serious public health issue, and the research design was created with little input from those affected by
ARF or RHD, or those participating in the study. This is paradoxical because Aboriginal communities will not propose a topic for research if they are not aware that an issue, such as ARF, is a public health problem in their communities. And without research, discovering the collective and serious effects of ARF and RHD is not likely.

**Connecting with Aboriginal Views and Power**

Notwithstanding my existing relationships and knowledge of the settings, care needs to be taken in collecting and expressing Aboriginal people’s views and experiences because historically research processes have compounded their disempowerment in colonised situations (Smith, 1999). The ethnographical methods in my study design are intended to facilitate the expression and interpretation of Aboriginal people’s views and experiences. But great care still needs to be taken in presenting participants’ views to outsiders, as this is also not without risks to participants (Crozier, 2003). Locating and partnering with local co-researchers in the study sites was a measure aimed at levelling researcher power and improving accuracy and depth of data. However, this was a fraught process. In some of my sites trained co-researchers existed but were not available, some sites were not familiar with research processes at all, and two willing and trained Aboriginal co-researchers experienced serious ill health during my study including one being medically evacuated interstate for a long period and another one dying.

**Aboriginal Researchers**

Indigenous researchers are making inroads into the western research paradigm, and this cannot be ignored. As I carried out my study I was increasingly conscious of this issue. These thoughts were intensified when in my interactions with research
participants, some showed an interest in research, which was new to many, and subsequently wondered how they could become involved as researchers themselves.

_I was explaining about participant observation to a middle-aged Aboriginal woman in her setting. We sat in a central location in the community. I gave an example of observing two Aboriginal boys walking along the road in front of us, apparently having just been to the local store. I demonstrated a list of observations including that they were carrying a brown paper bag. The woman offered, “I know what’s in the bag”._

(Author’s field notes).

Clearly this is a demonstration of insider information that shows the advantage of partnering with local Aboriginal researchers. I did not know what was in the bag. The woman informed me that in her community, young people commonly carried their purchases, in this case assumed to be a cold drink, in a paper bag to reduce requests from others to share the item.

In the history of research among Indigenous peoples, predominantly in agriculture, participatory methods have become the accepted best practice for gaining in-depth, unbiased and accurate data (Chambers, 2011). For remote-living community members in my study, avenues for them to move into the conventional research field seemed limited due to the requirements of western qualifications. I felt an ethical responsibility to enquire about training possibilities for Aboriginal community members. Participatory approaches to researching in this setting would be beneficial.

There is an ethical imperative to check or confirm research findings with participants to ensure that what has been captured is accurate (Baum, 2008). I hoped to create research partnerships in this way even though the participants were not involved in
creating the original research enquiry. I endeavoured to confirm my research findings with participants; however, opportunities to do this were hampered by participants’ low levels of understanding western research processes and my inability to locate participants on subsequent site visits. Therefore, I discussed my findings with Aboriginal key informants outside my sites as a way of confirming them.

**Conclusion**

Connecting with my research sites required understanding the specific contexts and histories as well as my position as an actor in the research. My connecting commenced prior to this doctoral research as exemplified in the case study of a young boy with ARF where I was an actor. This case highlighted the kinds of issues that Aboriginal families and the local health services experience when facing ARF and RHD. Connecting with my research sites meant taking account of history, local languages, politics and lands, as well as the entity of an Aboriginal community in the current socio-political era. Involvement within the research sites also highlighted the interest that local Aboriginal people have in research.
Part 11

Chapter 4

“That Heart Sickness”: Young Aboriginal People’s Understanding of Rheumatic Fever
Table 4.1 Statement of Authorship of publication

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<tr>
<th>Authorship</th>
<th>Contribution</th>
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<tbody>
<tr>
<td>1) Alice G. Mitchell (candidate)</td>
<td>Design, data collection and validation, analysis and writing of manuscript</td>
<td>A. Mitchell</td>
<td>24/9/17</td>
</tr>
<tr>
<td>2) Suzanne Belton</td>
<td>Conceptual input, manuscript structure, editing and proofing of manuscript, primary academic supervision of associated PhD</td>
<td>B. Belton</td>
<td>24/9/17</td>
</tr>
<tr>
<td>3) Vanessa Johnston</td>
<td>Input into trial design, interpretation of findings, input and critical revision of manuscript, academic supervision of associated PhD</td>
<td>Johnston</td>
<td>24/9/17</td>
</tr>
<tr>
<td>4) Anna P. Ralph</td>
<td>Input into trial design, interpretation of findings, input and critical revision of manuscript, academic supervision of associated PhD</td>
<td>Ralph</td>
<td>24/9/17</td>
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<tr>
<td>5) Wopurrwuy Gondarra</td>
<td>Linguistic and communicative analysis</td>
<td>Wopurrwuy Gondarra</td>
<td>24/9/17</td>
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Note: This article is accepted for publication in the Medical Anthropology journal. An updated version appears in the journal, including different references.
This focussed ethnography explored perceptions that young Aboriginal people in remote Australia have of rheumatic fever, largely revealed in the names they ascribe to their condition. Semi-structured interviews were conducted with 72 Aboriginal participants of whom 35 had experienced rheumatic fever. Participants’ understanding was constrained by clinicians’ use of language rooted in biomedicine, and delivered through English, a second language for all participants. We argue that clinicians’ communicative competency is a social determinant of Aboriginal health. We recommend use of Aboriginal languages be prioritised in health services caring for Aboriginal people and that biomedical dominance in the services be relinquished.

**Key words:** Communicative competency, rheumatic fever, Aboriginal languages, social determinants

“You mean there is a reason for the injections? I thought that they were just injections.” (Rodney, father of a 7-year old with severe rheumatic heart disease, Northern Territory, October 2014)

The traditional languages currently spoken as first languages by Aboriginal people in the Northern Territory (NT) of Australia are significantly imbued as part of their deep identities as Aboriginal people, which are unalterably sedimented with specific geographical locations. That this function of languages has been little recognised by outsiders in the NT is seen in ‘bilingual education wars’ where government policies have prohibited use of Aboriginal languages as an instructional medium despite evidence to the contrary and success of this methodology previously in the NT (Devlin et al., 2017). Similarly, within NT health services there is almost no recognition or understanding of Aboriginal languages having deeper purposes than
simply for communicating while their use for health communicating is disregarded in favour of English.

Addressing social determinants of health such as housing, education and access to primary care services is currently recommended as the best approach to reducing high rates of chronic conditions among Aboriginal people such as rheumatic fever (AMA 2016; Baum, et al. 2009). However, in this racialised context there are also institutional problems embodied through “attitudes, beliefs, behaviors, norms, and practices relating to these social groups” that impact on disease rates (Paradies, 2016 p1). The most basic operational tool for clinicians in providing care explanations to their patients is communicative competency, defined as “the cluster of abilities that enable humans to convey and interpret messages and to negotiate meanings interpersonally within specific contexts” (Brown 2007 p.378). We posit that communicative incompetency among clinicians is currently having a devastating impact on Aboriginal people in northern Australia, in this instance among young Aboriginal people with rheumatic fever (Durey and Thompson 2012). This structural problem highlights that there is a need to “attend to institutional pathologies that lead to clinical pathologies” (Hansen and Metzel, 2016 p 180). Institutional attitudes and practices perpetuate health care disparities in this setting (Durey, 2010).

High rates of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) in Australia are almost entirely borne by young Aboriginal people despite Australia being “one of the world’s wealthiest countries” (AMA 2016 p.1). There are estimated more than 30 million people with RHD globally (de Dassel et al. 2015). The two conditions are described as poverty-markers due to their prevalence among poor and marginalised peoples (Hale and Sharpe 2011; Nulu 2017; Remenyi et al.
2013) and they have all but disappeared from the mainstream Australian population. They are largely preventable if people know the causes so that they can devise their own interventions, and additionally, adhere to long term protective medicine-a penicillin injection every 28 days for at least ten years- once ARF is acquired. Epidemiological surveillance reports that in northern Australia, uptake of protective injections is not adequate to prevent recurrences of ARF, worsening RHD and premature deaths among young people (He et al., 2016; Parnaby and Carapetis 2010; Ralph, et al. 2013). However, little research has explored why the uptake of the protective medicine is poor and how the people affected by these conditions perceive and understand their illness and its prescribed management. Toward this end our study focussed on young Aboriginal people with the conditions, and sought to understand their conceptualisations.

AN OVERVIEW OF ACUTE RHEUMATIC FEVER AND RHEUMATIC HEART DISEASE

This ethnography explores a complex medical condition. Due to its rarity in the mainstream Australian population the following description provides background. Compared with many medical conditions, the aetiology, variety of manifestations and clinical course of ARF and RHD are complex. This is reflected in the complex disease nomenclature, with a name for the precursor infections (tonsillitis and impetigo), a name for the autoimmune response (ARF) and a name for the permanent cardiac consequence (RHD). ARF is an autoimmune response that develops in an estimated three percent of individuals a few weeks after an untreated infection with group A streptococci (GAS). GAS infections in this instance present as tonsillitis or pharyngitis (sore throat) or as impetigo (skin sores). The ensuing ARF appears most commonly among children between ages five and fourteen, often with symptoms of
fever and painful joints (Lawrence, et al. 2013). However, ARF also causes inflammation of the valves in the heart, which may be perceived by the child as tiredness and general unwellness and may be heard by a clinician with a stethoscope as a heart murmur. In general, the effect of ARF on joints resolves without sequelae and the fever subsides, but heart valve damage may be permanent and can lead to heart failure. Once an individual acquires ARF, their susceptibility to this condition is unmasked and further infections with GAS may lead to further episodes of ARF. The most effective management is a regimen of penicillin injections prescribed to prevent the precursor GAS infections, which in turn protects the heart valves. If further ARF is not prevented, RHD may develop, which simply means valvular disease caused by the rheumatic processes. Severe RHD may require open heart surgery to repair or replace heart valves, to preserve young people’s lives. Having ARF or RHD, therefore, is serious and can, and does, limit the lifespan of young people (He et al. 2016; Lawrence, et al. 2013).

**The Penicillin Injections**

In Australia, once an initial diagnosis of ARF is confirmed, the penicillin injections are prescribed for every 28 days for ten years after the last ARF occurrence, or until the child reaches the age of 21, whichever is longest (RHDAustralia (ARF/RHD writing group) 2012). Oral penicillin has been found inadequate for this purpose (Manyemba and Mayosi 2002). The injections are painful due to the viscosity and large volume of solution injected deep into muscle. This treatment is slow release, ensuring there is a continuous therapeutic blood and tissue level of penicillin to prevent infection with GAS during the next three to four weeks. The treatment delivers a blanket covering rather than specific targeted protection, such as a vaccine, but it is the only current achievable prevention strategy while we wait for improved
living conditions, which should reduce the circulation of GAS in communities, or a vaccine for GAS.

With incidence rates among young Aboriginal people some of the highest recorded globally, health services and policy makers are pressed not only to control and reduce the number of ARF cases, but to face racial and equity issues that this disease reveals (Brown, McDonald and Calma 2007). As a resource-rich nation, Australia should be capable of solving this health crisis among young citizens, but the visibility of the crisis is constrained. ARF and RHD occur in distant locations, less-known to the mainstream population. Complexities of colonial history, worldviews, health literacy and language make the task a difficult one to approach from a purely biomedical domain.

RESEARCH METHOD AND SETTING

A focussed ethnography differs from traditional ethnography in that it explores a specific issue among a distinct group of people within a certain setting, often with a view to making improvements (Cruz and Higginbottom 2013). A focussed ethnography, conducted by the first author, was undertaken between December 2013 and December 2015 exploring young Aboriginal people’s experiences and understanding of ARF and RHD, and their longterm injections. The setting was four remote Aboriginal communities in the NT and participants were young Aboriginal people who were prescribed the penicillin regimen, and their families. The focussed ethnography was nested in a larger trial involving ten NT health services. The trial aimed to increase the number of injections received by Aboriginal people by supporting local clinicians to design activities to improve their health service systems.
around penicillin injection delivery (Ralph, et al. 2016). The secondary authors were investigators in the trial.

The focussed ethnography sites were selected from the trial sites: two remote Aboriginal communities, a group of remote Aboriginal homelands and a remote small supply town. The first three sites have majority local Aboriginal populations and the small supply town has a substantial Aboriginal population, most of whom are people, or descendants of people, forcibly relocated from their lands surrounding the town by colonising pastoralists.

Due to the larger study’s protocol requiring de-identification of all sites, the ethnographic sites were also de-identified. However, all four sites continue to be strongly affected by negative legacies of a relatively short and recent history of colonisation meaning traditional languages and practices are still in use. The negatives of colonisation are seen in Aboriginal people’s “struggle to take back control of their lives, to express and live their own identities, and to organise their communities according to their values and aspirations” (Devlin et al 2017 p2). The legacy is seen in low education and employment rates and high incidence of chronic health conditions as seen in similar racialised and post-colonial settings such as New Zealand and Canada (Harris et al. 2006; Gracey and King 2009).

Serial short visits rotating through the sites were carried out, with semi-structured interviews being conducted either in the language of the participants or in plain English. In two sites the first author has a working knowledge of the Aboriginal language and contextual knowledge after many years residing in NT Aboriginal communities, including at one time in one of the sites, and being “adopted” into an Aboriginal family. Exposure to Aboriginal practices over many years led to ability
to operate according to cultural norms in Aboriginal spaces. Confidence to function appropriately as such assisted the ethnography despite the ethnographer being representative of the Western colonial power that dominates the indigenous groups in this setting (Henze and Vanett 1993; McCoy 2009).

Interviews were carried out with 14 males and 21 females with ARF or RHD, aged between seven and thirty-five years, with some participants being interviewed multiple times. With inclusion of family members and key informants, the number of overall participants was 72. While the focussed ethnography enabled the intentional raising of the topics of ARF, RHD and injections during field visits, a substantial amount of time was also spent participating in daily activities and observing social practices, participants’ interactions with health services and general community life. Informed consent was generated either through an audio recording created by an interpreter in the Aboriginal language understood by the ethnographer, or in plain spoken English for other languages.

METHODOLOGY

Decolonising theory and whiteness studies provided an operational lens for carrying out field work and analysing data. Decolonising theory is an intentional positive researcher response to the negatives of colonisation (Humphery 2001; MacNeil and Marsh 2015; Smith 1999), while a whiteness stance, that of superiority, power and privilege simply due to race, is a recognised driver of colonisation (Kennedy, Middleton and Ratcliffe 2005). These were an appropriate juxtaposing duo for this research because the sites remain strongly affected by colonisation, and the Aboriginal families affected by ARF and RHD must seek their ongoing care from health services nested within the paradigm of biomedicine where the majority of
interactions are with practitioners holding power and privilege. Current health status and other social issues must be historically contextualised. While it is possible to frame current ill health, ARF and RHD for instance, from an epidemiological or socioeconomic standpoint, only by commencing with the recognition of how colonial history has affected and continues to play out in Aboriginal lives, will solutions based on equality and equity be possible (Bartlett 1998; Baum, et al. 2009).

‘White’ in this article is not a reference to skin colour but to the power and privilege of the dominant society (Kowal 2015). Biomedicine, although indispensable, is viewed as a dominant paradigm in the dominant Australian society (Houghton 2002). Doctors are socialised to be responsible for and in control of patient care (Hansen and Metzyl 2016) and, although this is being challenged, in rural and remote locations doctors, and primary care services, have arguably more freedom from external evaluative interrogation of their biomedical dominance (Kenny and Duckett 2004).

FINDINGS

In discussions about ARF or RHD with participants, the first author, (henceforth ‘I’), learned that the medical names acute rheumatic fever and rheumatic heart disease are not in use by people who have these conditions. To initiate discussions around participant’s ARF or RHD I found that using the above terms did not evoke the desired conversations. I found that I needed a circular approach that described the conditions and reasons for receiving the regular distinctive penicillin injections. An example of my opening sentence is, “You know you get those injections of white-coloured medicine. Can I talk with you about that sickness?” The realisation that people with ARF and RHD do not use these terms stimulated an exploration of the
etymology, and reflection on why they are not used among the participants.

Concurrent and iterative reflection and analysis during data collection, as occurred here, is practiced in ethnographic research (Grbich 2007; Liamputtong 2009).

**Language and Etymology**

Current medical terms emerged and developed through different language eras and reflect the parallel historical development of biomedicine (Fortuine 2000). The roots of most current medical terms are derived from old Latin, French, German or Greek languages and a large and precise vocabulary of such terms has grown through the centuries. An understanding of the root terms enables current clinicians to scaffold their learning in the fields of human anatomy and human ailments and to talk about them with peers. The term *rheumatic* in ARF and RHD reflects varying historical understandings along the language development trajectory. Its etymology is

The Greek rheuma (rheumat-) meant a "flow" or "stream," and even in ancient times the word commonly referred to a pathological flow of body humors. In early English the word rheum (and its adjective rheumatic) generally referred to the excess discharge of watery mucus from the nose and eyes, a use the noun form still occasionally has. The application of the adjective to joint pains seems to have originated around 1700 and probably was associated first with the notion that the painful, swollen joints had an excess of rheum (Fortuine, 2000 p.83).

With the waning of ARF and RHD in Australia among the white majority population over the past half-century, there is a corresponding reduction in understanding of the meaning of *rheumatic* among that population, although it is still somewhat familiar. For instance, a white employee in an Aboriginal student hostel stated: “You just
don’t hear the name rheumatic fever.” However, for Aboriginal people affected by these conditions there is an even greater linguistic and worldview distance due to separate histories. Therefore, this group are generally not familiar with the term *rheumatic* at all and it holds little if any meaning for them.

**Languages Spoken by Aboriginal People in Northern Australia**

Many Aboriginal people living in northern Australia communicate in their everyday lives using their Aboriginal languages. When questioned as to what their language was, participants in all four study sites responded with the names of one or two Aboriginal languages. Only one respondent, a young trainee health worker, added English at the end of her list of spoken languages, stating that it was a second language. An Aboriginal person’s language expresses their social and personal identity and additionally binds them with certain geographical locations and deeper clan identities, but even when probed, participants did not state English as a language they spoke. When a senior Aboriginal woman was questioned as to whether she also spoke English after she listed four Aboriginal languages, she stated in English, “No, that’s not my language.” When a tribal leader in a small community was asked what his language was, he stated the name and added, “All the children here speak (this language), they follow me,” demonstrating that language holds functions other than just communication. In this case, it is a clear clan and country identity marker within a localised population.

Naturally the question as to what language people speak evoked a response relating to their identity. English was not heard spoken in the participants’ everyday lives but appeared to be reserved for interactions with outsiders who commonly speak English as a first language and are frequently monolingual. English is also the operational
language of health services in the four study sites where study participants received information about and obtained health care for ARF and RHD.

**Familiarity with Etymology**

The names that participants used for ARF and RHD reflected their understandings. Considering that most explanations are provided to Aboriginal patients in English in this setting, it is no surprise that understanding of ARF and RHD was limited indicating that clinicians had failed in their explanations. However, among two of my sites, where I speak the Aboriginal language, Aboriginal people are familiar with and recognise the concept of an ancient derivative language, ‘*Gurraŋay*’, giving meanings to current significant technical terms. This is demonstrated in a discussion with a tribal leader and his son-in-law. Both these senior men have a number of close relatives with ARF or RHD. The concept of names derived from ancient language was brought up as we spoke in their language about the germ that leads to ARF. The tribal leader asked the name of the germ. I said: “Streptococcus, a Latin name. Latin is like your Gurraŋay.” He tried to pronounce streptococcus with difficulty because his language does not contain the phoneme ‘s’ or ‘e’. He and his son-in-law agreed together, “There are always our old language terms too”. I agreed. Knowledge of ancient derivative languages, such as Gurraŋay in the case above, is maintained where Aboriginal languages and cultural practices are strongly retained. Functional etymology is in play among this Aboriginal group.

**Connection Between Names and Meanings of Medical Conditions**

Participants’ knowledge of ARF and RHD was very limited in all four sites but few, if any, health educators would start with the derivative naming of these conditions, which may create a shared starting point. For instance, when teaching about diabetes
mellitus, starting with the origins and meaning of the terms *diabetes* (siphon) and *mellitus* (sweet) place the condition in an historical bodily and linguistic narrative and alludes to some of the symptoms of that condition. In contrast, if health literacy material is developed from a purely biomedical perspective, this greatly reduces scope for a foundational shared starting point as was similarly found in research on renal disease conducted with a group with Aboriginal languages with similarities to those from two of my sites (Cass, et al. 2002).

**Hearing and Pronouncing Medical Terms: The Start of (Mis)Understanding**

Aboriginal participants in the study sites are generally not familiar with a biomedical world view or its vocabulary, and use of this vocabulary by clinicians, hampers knowledge transfer (Vass, Mitchell and Dhurrkay 2011). The meaning underlying the term *rheumatic*, and possibly also *fever*, is doubly hidden for Aboriginal participants, due to unfamiliarity with the medical terms and difficulties hearing the terms within speech. Differences in sounds between English and Aboriginal languages mean that many participants have difficulty hearing and saying some terms and phrases delivered in English, as do English language speakers with Aboriginal language phonemes. This is revealed in my field notes where I was seeking a tribal leader’s approval to carry out research among his group. Despite having many close relatives with ARF and RHD, including his wife, sister, adult son, two adult daughters and two teenage grandsons, the leader was unfamiliar with the disease names and had difficulty pronouncing them: I said I was trying to find out what it was like for people living with rheumatic fever. He stumbled over the unfamiliar name and asked me to repeat it. This highlights the exclusion of
Aboriginal people, including senior elders, from participating in shared understanding and conversations about major health threats affecting their kin.

Other participants had difficulty hearing and pronouncing *acute rheumatic fever* and *rheumatic heart disease* and also demonstrated unfamiliarity with these names despite having the conditions. This is shown in an interview with the parents of a 13–year old boy who had been on the penicillin injections for two years. I stated the name rheumatic fever twice during our recorded discussion. Both times the father attempted to pronounce the English name, once as “teeba” and the second time as “mat”. This man’s first language does not contain the phonemes ‘f’ or ‘v’ (hence fever becomes ‘teeba’) and the first syllable in words is always stressed. This participant may not hear *rheum* at the start of *rheumatic* because the stress in English is on the second syllable (hence ‘mat’). Further, not only is it rare for white clinicians to speak an Aboriginal language, but it is also rare for them to understand such pronunciation differences and the hindrance that it is to their communication. In endeavouring to understand their son’s ailment, information delivered in English had greatly reduced effective communication. The possibility for comprehension can be thus stifled by clinicians at the start when they rely solely on *their* first language to explain health conditions.

A further example shows the difficulty of hearing across languages. An Aboriginal mother and daughter pair were interviewed while attending a cardiology clinic. The 12-year-old girl had been on the penicillin regimen for 15 months. This interview was carried out in the mother’s language as her English level was conversational only. Part way into the discussion about her daughter’s illness, which she described as “heart sickness”, the mother asked, “What was that name you said at the start?”
After a pause to consider her question I replied, “You mean rheumatic fever?” She affirmed this and stated that she had not heard that name before.

Clearly, the term *rheumatic fever* would have been used by clinicians over the prior 15 months, but the mother did not *hear* it within the flood of English and this was not detected by clinicians. This meant that she only picked up that her daughter had something wrong with her heart, an understanding confirmed by scheduled visits to the “heart doctor” (cardiologist). Currently the daughter has no ultrasonic evidence of RHD, and, it is possible that with complete adherence to the penicillin regimen, no valvular damage will occur. Monitoring her cardiac status annually or biannually with ultrasound is a routine part of her care but she currently does not have a ‘heart sickness’.

A man in his early twenties with severe RHD could not answer when asked what he calls his sickness. It appears that people can have ARF or RHD for many years but have no identifying name for it. Interestingly, an adolescent Aboriginal boy without ARF, attending an Aboriginal Student Hostel education session about the condition, stated that the name *rheumatic* sounded like a “*drumming word*” (rhythmic) to him. This boy placed the name outside the realm of health altogether revealing that if health educators/clinicians do not use Aboriginal languages in their teaching then understanding will be curbed.

**NAMING OF ARF AND RHD**

Many participants did not use the term rheumatic at all but in all sites, with completely different languages, I found that participants commonly referred to their condition in English as “*that heart sickness*”. A 23-year old female on the injection regimen for ten years was asked what the sickness is called in her language (not
understood by me). I then asked her to back translate this into English. She stated: “My heart is no good”. Yet her heart valve function was normal on her last ultrasound. When questioned about familiarity with the name rheumatic fever she replied, “Yes I hear that name,” indicating that although she recognised the name it is not in use among Aboriginal participants, possibly as it conveys little meaning. Similarly, I asked a mother of a 15-year-old boy about his condition. She stated that she knew he had a “heart problem.” This is also the name that the aunt of a 12-year old girl with ARF used when interviewed. This was despite the girl’s heart being normal as she had been promptly diagnosed with ARF in the preceding year and all her heart examinations remained normal. Possibly heart is the only English term that is well recognised and meaningful among the phrases and terms used by clinicians. Additionally, the heart is frequently examined in consultations for ARF, adding weight to the notion of a heart problem.

“Rheumatic Heart Fever”

Some participants did use the term rheumatic, but not with standard usage. A melding of the medical names to produce rheumatic heart fever was consistently heard across the four separate sites, whose languages are not mutually intelligible. The father of an 18-year old girl with ARF stated with concern that his daughter “is not thinking of her rheumatic heart fever.” Interestingly, a cardiologist was heard to use this name as well, and, when questioned as to his reasoning, he replied that he uses this phrase because this is how his patients refer to it. It was a small way of connecting with his patients. However, this melded phrase could hinder understanding about there being two distinct conditions, ARF and RHD, and the fact
that if people who have acquired ARF adhere to the strict regimen of injections, they may avert development of RHD and its serious consequences.

Other combination names used by isolated participants were, *heart rheumatic fever*, just *rheumatic* or *heart* alone, and *heart rheumatic*. Just one participant, a 32-year-old, well-educated teacher who has not missed an injection in ten years, used the term rheumatic heart disease. He was asked if he knew others in his community with the same condition as himself and he answered: “I know a few people here with rheumatic heart disease. There could be more that I don’t know about.”

The lay terms heard in reference to ARF and RHD may be similar to terms used in other diseases, such as diabetes being referred to as ‘sugar sickness’ (Saethre 2013). These lay terms reflect people’s conceptualizations of their health conditions and their minimal internalisation of biomedical vocabulary.

**UNDERSTANDINGS OF THE PURPOSE OF THE INJECTIONS**

Participants had uncertainties about the reason for repeated injections. Multiple interactions took place with a 33-year old male participant over the course of 18 months. Toward the end of my fieldwork, when our research relationship was well established, he addressed me in the appropriate way for his cultural group by gaining my permission to ask a question. He then asked: “The injections keep our heart good, that’s right isn’t it?” This man has been on the injection regimen for 11 years and has severe RHD. He still had uncertainties as to the purpose of the treatment and sought reassurance. In 11 years, he had not gained a full story even though he had excellent relationships with long term clinicians at his health service. He has never heard in-depth information about his condition in his first language and built on his conceptual understandings of health.
Few participants knew the long term nature of their injection regimen. I observed some clinicians refraining from informing patients of the ten-year requirement for injections. When questioned about this, they stated that, at the time of commencing the regimen, they did not want to frighten young people. While this is understandable, it also means that the majority of young people on the injection regimen have never become aware of its long term nature and some asked for my assistance to find out when the injections would stop. Additionally, some participants who had completed ten years had no sense of achievement as they had never heard that there was a ten year plan. I observed that some Aboriginal families had a perception of random intrusions by white health clinicians into their lives, and they viewed the health service’s activities as mysterious, and perhaps meaningless, as in the quote from the father: “You mean there is a reason for the injections; I thought that they were just injections.”

In contrast, a young male white hostel parent in an Aboriginal student hostel felt that knowing the reason for the injections was fundamental and is quoted verbatim as follows:

This is sort of life and death in a way. I don’t know if any would even realise that if you miss this injection, soon after you will get pretty crook (sick). I’m not too sure if they even realise it. But then when someone actually asks, ‘What’s the injection for?’ they say, ‘I don’t know’. Which is pretty bad, because you know everyone wants to know what’s wrong with them. No one wants to know just ‘Oh, I get an injection for my heart, I don’t know’.
Understandings of the Cause of ARF

Understanding the reasons for the injection regimen are naturally tied to understanding the cause of ARF. If people know that certain bacteria cause ARF, that the medication in the injection is a defence against that bacteria, and that the protective effect of the medication lasts approximately 21-28 days, then their responses as to why the injections are needed would reflect these facts. However, most participants did not know what caused their ARF, as in the following examples. A senior woman stated, “We don’t know. We only know that it is a heart sickness that people have, and they get injections. We do not know any more than that.” A 15-year-old male who was diagnosed seven months prior to an interview was asked what causes ARF. He shook his head and said, “I don’t know.” A 14-year-old male with ARF suggested that “playing in the rain” was the cause. Other patients proposed that smoking was a cause for their ARF. This could stem from anti-smoking and smoking-cessation campaigns that have been dominant in northern Australia. Smoke, either from tobacco or fires, was listed as a cause by a mother and daughter pair who took part in serial interviews. The initial interview was conducted in English as an interpreter was unavailable. The following quote is verbatim.

It is like when there is a fire and smoke, but you can’t smell it. If you are driving in a car with the windows up and there is a fire coming but you can’t smell the smoke, or if the windows in the house are closed and you can’t smell the smoke.” She then added, “People can’t smell cigarette smoke in the house. They should smoke outside.”

The constraints of explaining in a second language became clear. She was using the word *smelling* to refer to breathing and was mixing ‘could’ and ‘should’. I asked “Do
other people get sick from smelling (breathing) the smoke?” She replied in the affirmative and stated that smoke could cause heart, lung and other sicknesses.

Other participants also gave smoke as a cause of ARF including a man with RHD who was aged 30 at the start of the study. He believed that smoking tobacco caused his ARF: “Bakki (tobacco), cigarettes smoke. I used to smoke a lot, three or four packets every day in my hand. Now I have stopped. I ask people not to smoke inside my house.” When questioned how smoke causes RHD, he stated, “It goes in the lungs and makes you sick.”

A further cause of ARF proposed by a few participants was the notion of the disease having something to do with “family line” (genetic susceptibility). A belief that sorcery is the cause was admitted by one senior participant who has multiple family members with severe RHD, including deaths of young members. I heard that this was a possible belief and directly asked this participant towards the end of my fieldwork when our research relationship was well established. Another participant wondered if emotional hardship due to parental relationship difficulties were a catalyst in her son acquiring ARF. Yet another wondered if it was a mosquito borne disease. One woman suggested that the new foods brought to Aboriginal communities by outsiders may be the culprit.

These beliefs about the cause of ARF indicate that people do not understand that it is those minor sores in the skin, or that sore throat, that leads to the development of ARF, and additionally, that the reason for the injections is to destroy the bacteria in the skin or throat. This demonstrates that in this setting, clinician’s communication has been compromised.
Infusing a Biomedical View

Just four respondents provided understandings that aligned with a biomedical view of the cause of ARF. A 15-year old male was interviewed with his mother. He had been on the injection regimen for 16 months. The interview was conducted in English, but both the boy and his mother speak Kriol as their first language. Kriol is the name of a creole spoken in the cattle areas from the Gulf of Carpentaria in the NT, west to the Kimberley in Western Australia (Munro 2000). An interpreter had been engaged but was in a kinship relationship of avoidance with the son and so sat some distance away, out of earshot. The mother offered, “Because I got a young brother got a rheumatic heart fever from [pauses] I think sores isn't it? Got sores I think.” At the same time, her son stated the cause as: “Little stuff like a bug” [holds up hand with fingers together on thumb] “but you can’t see them.” When asked if he knew what the medicine in the injections does inside his body he nodded: “Kill them germs.” This mother and son pair understood that sores were implicated in the condition, a small invisible “bug” or germs were involved, and the injections killed the bug/germs, however they did not know how long the injections were needed.

A second teenager, a 14-year old girl who had experienced three open-heart surgeries for severe RHD, participated in serial interviews. In her first interview I asked what causes ARF. She replied: “A little bug.” When asked what the injection does in her body she replied: “It keeps the heart strong. Stops the bugs from infecting our bodies.” A 23-year old woman believed that: “Some people don’t eat good food or wear clean clothes or make house clean like we do.” When questioned as to why she does those things she replied, “We don’t catch sickness.” She stated that the “germ lives in skin” and believed that the purpose of the injections is: “When we get needle,
so the germs not like, we don’t get sick.” Finally, an experienced Aboriginal Health Worker stated the cause of ARF as “That small one, what’s its name, streptococcus.”

Clearly, most participants’ understanding about their condition and their treatment was generally poor, constraining their participation in the management of ARF and RHD. The fact that just four participants had absorbed a relatively biomedical view of the cause of ARF does not mean that these few have elected to align themselves with that stance. Rather it indicates that information will be filtered at an unacceptably low rate without first language explanations of this complex and serious disease.

The need therefore, is for education around these complex conditions, ARF and RHD, to be intellectually accessible and convincing by using appropriate linguistic and cultural scaffolds. It is unlikely that this approach will be appropriated in health services that continue to operate from a monolingual, English and biomedical base. This adds to complexity in managing or preventing these conditions among young Aboriginal people in northern Australia. However, when medical information is delivered in people’s language, a different situation emerges.

**Medical Information Given in Your Language**

The following interview was carried out with an Aboriginal couple whose seven-year-old son had severe RHD. I can speak this couple’s language. I asked the mother what the injection does. She said in her language: “It goes all around the body and kills germs that come in through the sores and go to the heart.” Her husband was in earshot and exclaimed (as also quoted at the start of the chapter), “I didn’t know that! You mean there is a reason for the injections; I thought that they were just injections. I didn’t know the reason.” This family had been thrust into a tumultuous ARF and
RHD episode with no prior knowledge of either condition. Their son had required open-heart surgery due to heart failure some months after a first episode of ARF, which was particularly prolonged. It took multiple consultations over 18 months, including a six month stay in hospital, for the mother to grasp what the penicillin injections were for because she had no prior knowledge of the disease, information was delivered in English, her ability to operate in English was very limited, and she was facing a health crisis for her child. Her husband, whose English proficiency was much greater, was not always present during doctor’s consultations. However, when he heard the information about the penicillin injections delivered in a few sentences in his first language, he understood the purpose of the injections immediately and was galvanised into action. I have remained in contact with this family and from that point onwards they have become vigilant in trying to keep track of the time intervals between injections for their young son. Prior to this the mother found it almost impossible to manage obtaining the regular injections around a large and busy household that included extended family, with little support.

The critical need to receive important information in one’s first language was the view of a white language worker in one site. She can speak the Aboriginal language at that site. In discussing one young participant’s journey to obtain heart surgery for RHD where she acted in a liaison role, she stated: “When information is given in English they don’t understand enough. When told why in language, then it can change your life.” At this site, a senior Aboriginal woman, a past health worker, agreed that local people need health information in their first language: “Talk to them in their own language. When I talk to them in English it’s hard. It’s clear when I talk to them in language, it’s like a picture.”
Signage at the entrance of the health service building at this site states in English that if clients need help with language, then an Aboriginal health worker can assist. However, this presumes that the sign can be comprehended, and that the health workers have training in medical interpreting, are from the local community and speak the local languages. This is not always the case.

LINGUISTIC COMPLEXITIES UNMASKED

Delivery of medical information is, however, fraught with complexities that untrained people are not aware of. A trained and experienced Aboriginal language interpreter was working on a radio announcement about ARF and RHD during my field work. I provided a plain English transcript for her to interpret. My field notes record a difficulty that arose as we started, “The interpreter says that when speakers of her language hear the word *sickness* they visualise something that comes from the ground. She said that this is why the parents ask the cardiologist to tell their kids to wear shoes.” Wearing shoes provides negligible protection against ARF.

The types of linguistic complexity were also highlighted in discussions with an Aboriginal co-researcher in one site who has aptitude in cross language communication. I provided the following phrases and asked how they would be perceived by local community members if they were stated by a clinician:

a) “You must have the injection for the next ten years.”

The co-researcher believed that this statement would be considered pushy and it would be the clinician’s *djāl* (desire) rather than the patient’s. She felt that more information would be required “an explanation, a clear story and trust.”

b) “It is important to have the injection every month,”
The co-researcher felt that some people would take the advice; some would want a deeper story while others would ignore the advice.

c) “This is a serious condition.”

The co-researcher felt it would evoke fear and would be perceived “like policeman’s behaviour.”

An additional white key informant felt that in local health services monologue is more prevalent than dialogue. This informant recommended that clinicians start a consultation with an open question such as, “What are you thinking about your condition?”

DISCUSSION

The young Aboriginal people and their families currently burdened with ARF and RHD in the NT do not conceptualise English as their language. Our research confirms that their languages, an indelible part of their identity, need to be utilised in explanations of complex health conditions. Non-use of these languages, or denial of their use, is part of a structural problem within NT health services expressed in clinicians’ communicative incompetency. Aboriginal participants in this study had little power to obtain critical information because the operational language of their health services is English and the vocabulary biomedical, thus prioritising and favouring clinicians’ functioning within their system. This is a racialised stance that may be unconscious or may be intended, in the wake of relatively recent colonisation. The non-valuing, denial and repression of colonised peoples’ languages is a known practice of colonisers; a way to exert their assumed superiority (Ka’Ai-Mahuta, 2011). Fundamental racism as such is a recognised social determinant of
health and the link between racism and poor health is well documented (Durey, 2010).

Examples in our study show that meaningful connecting with health services was fraught and the context racialised. The senior woman’s statement that her collective group only knew that young people had injections for their heart sickness and knew nothing more, and similarly, the young man’s uncertainty about the purpose of his injections despite receiving them for 11 years, points to the subduing and subordinating effects of white tutelage. An internalisation of the ‘state of unknowing’, referred to as internalised racism, is seen in the fact that participants remained unknowing about their medical conditions while concurrently knowing that there was little they could do about this (Paradies, 2005). This subdued position is further seen in participants’ filtering of *random* inputs from their health services and loose connecting with them.

Clinicians in Aboriginal health services, and the services themselves, need their conceptualisations of Aboriginal societies extended along with their understandings of how Aboriginal people perceive their illnesses and the value and symbolic functions of Aboriginal languages; in this way, the health care structures must be decolonised (Durey and Thompson, 2012).

Among Māori and Pacific peoples, in similar colonial and racialised contexts, problems of unequal access to and culturally unsafe practices such as communicative incompetency within health services, were tackled by enlisting a new health care approach, envisioned and enacted as cultural safety and cultural competence education for clinicians (DeSouza, 2008). Cultural safety education aims to produce
clinicians who regard their own and other’s broadly defined cultures as important, unique and significant to delivering good health care (Papps and Ramsden, 1996).

Communicative competency for the study setting involves using patient’s first languages and locally known concepts as referents to scaffold or assist learning (Pea 2004) while understanding cultural differences in communicating (Lowell and Devlin 1998). But of equal importance, is designing care structures and approaches that are respectful and empowering. A clue for how this is to be done is provided by the Aboriginal co-researcher in her statement that what is needed from clinicians is, “an explanation, a clear story and trust”.

We argue that communicative competency is a clinician and system-based social determinant of Aboriginal health, as illustrated in this instance of ARF. Accordingly, we recommend reflective appraisal of the biomedical dominance and preferencing of English in health services in Aboriginal communities. These services do not have competency to communicate important, and indeed lifesaving information to their clients. For competent clinicians and health services to emerge, work is needed where linguistic and cultural world views intersect, those of biomedicine and those of Aboriginal societies. This dynamic is outside the realm of biomedicine and requires a decolonising stance where white health services relinquish some power and assent to “value of the local” (Tesoriero 2010), in this case, the value of proficiency in the local languages and the value of and respect for local culture and local people. As Baum 2009 argues, different sectors need to “work collectively on the deep-rooted causes of poor and inequitable health” (Baum, et al. 2009). DeSouza 2008 recommends raising competence in health systems by, “developing bilingual outreach workers whose role is specifically education and training within the
respective community”, recognising that culturally competent organisational leadership is needed to move in this direction (DeSouza, 2008, p8).

CONCLUSION

Naming of medical conditions and treatments by those who have acquired them reveals much about their understanding as well as their social position. In this case, the naming shows just how little has been understood and how difficult it is to obtain information. Very few participants had a mental picture of germs or the real reason for the injections. Most people believed they had a heart sickness whereas many did not, or had minimal damage to their heart. That the injections are preventative of heart sickness was largely lost on participants who in general believed that their injection was for their “heart sickness, to keep their heart strong.” Clinicians’ attempts to explain ARF and RHD have not worked. The significance of miscommunication and unrecognised miscommunication has been emphasised previously in this context (Anderson, et al. 2008; Cass, et al. 2002). It is seen once more in the scars on the mid torso of young Aboriginal people who have undergone open heart surgeries. In this instance, clinician’s communication failure and health system failure, in not recognising critical traits of their clientele, carries an extraordinarily high price. Consequently, we propose here that clinician’s communicative competency be recognised as a social determinant of health in this setting, and recommend that clinicians who work in this setting receive training in cultural safety and that local Aboriginal languages, identities and cultures be given prominence in health services as a decolonising strategy.

LIMITATIONS

Some client-clinician contacts and interactions were observed, and more time spent
in observing this phenomenon, and in discourse analysis, would generate more clues and insight into the dynamics of health communication. Having four sites may have reduced the depth of data by preventing closer interactions with fewer participants.

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Chapter 5

Aboriginal Children and Penicillin
Injections for Rheumatic Fever: How
Much of a Problem is Injection Pain?
### Table 5.1 Statement of Authorship of publication

**Article Title:** Aboriginal children and penicillin injections for rheumatic fever: how much of a problem is injection pain? – article published in the Australian & New Zealand Journal of Public Health (see note below for details)

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<tr>
<td>1) Alice G. Mitchell (candidate)</td>
<td>Design, data collection and validation, analysis and writing of manuscript</td>
<td></td>
<td>2.3.2017</td>
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<tr>
<td>2) Suzanne Belton</td>
<td>Conceptual input, manuscript structure, editing and proofing of manuscript, primary academic supervision of associated PhD</td>
<td></td>
<td>14.3.2017</td>
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<tr>
<td>3) Vanessa Johnston</td>
<td>Input into trial design, interpretation of findings, input and critical revision of manuscript, academic supervision of associated PhD</td>
<td></td>
<td>27.3.2017</td>
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<tr>
<td>4) Clancy Read</td>
<td>Collation and analysis of baseline qualitative data for the ten trial sites</td>
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<tr>
<td>5) Clair Scrine</td>
<td>Collation and analysis of baseline qualitative data for the ten trial sites</td>
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<td>22.3.2017</td>
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<tr>
<td>6) Anna P. Ralph</td>
<td>Input into trial design, interpretation of findings, input and critical revision of manuscript, academic supervision of associated PhD</td>
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**Note:** see journal for final version of this article ANZJPH, 2018, volume 42(1) 46-51
Abstract:

Introduction: High rates of acute rheumatic fever persist among Aboriginal children in northern Australia. These children are prescribed monthly intramuscular penicillin injections for at least ten years to protect them from permanent heart valve damage. The injections are painful due to the viscosity and large volume needing to be injected. Methods to reduce injection pain, such as applying pressure to the site before injecting, are provided in local guidelines. Young Aboriginal people’s responses and experiences of injection pain have not been studied in Australia. Few studies have explored clinicians’ responses to administering the painful injections, including measures they use to reduce pain.

Methods: Aboriginal children in this study are defined as up to 18 years of age. Children who were prescribed the penicillin regimen, or commenced the regimen as children, were purposively recruited from four remote sites in the Northern Territory of Australia. Three males who commenced the regimen in their early twenties were included due to their long-term experience of receiving the injections. Semi-structured interviews and participant observations were carried out with patients regarding their experiences of the penicillin injections. The question on pain was one of a range of questions asked in a focussed ethnography about experiences of rheumatic fever care among young Aboriginal people. The ethnography was nested within a health services-based trial in ten health services in the Northern Territory aiming to increase the number of injections delivered. Clinicians who administer the injections were interviewed as part of the trial. Views of patients and clinicians were synthesised and thematically analysed.
Results: Twenty-nine remote-living Aboriginal children and young people between age seven and thirty-five were interviewed. Sixteen participants appeared to become accustomed to the injection pain over time, eight did not find pain an issue, and five found the pain difficult to bear. A further five believed the injections made them unwell. Patients expressed varying abilities to negotiate with clinicians about use of pain reduction measures. Fifty-nine clinicians were interviewed. Although clinicians revealed good knowledge of pain reduction measures, they were not always offered. All clinicians found administering the injections distressing.

Conclusion: Conducting repeated painful procedures on children necessitates well planned and child-focussed care. Improvement of local and jurisdictional policy and guidelines on use of pain reduction measures for children experiencing repeated painful injections for rheumatic fever is needed. Current practices are substandard and not in line with knowledge presented by the Royal Australasian College of Physicians about the known and unknown effects of repeated painful procedures on children. Initiating the injection regimen should be treated as a special event requiring expert input. Inclusion of local Aboriginal cultural experts in planning best care is recommended to improve the experiences of both children and clinicians. Aboriginal children who are currently finding the long-term injection regimen too taxing require urgent and innovative management. A newly reported finding of a subset of young people feeling unwell after receiving the injection, requires further investigation.

Keywords: rheumatic fever, Aboriginal children, penicillin injection pain, Australia
Introduction

Acute rheumatic fever (ARF) is still not controlled in Australia and occurs at disturbing rates predominantly among Aboriginal children. This necessitates long-term health care, sometimes open-heart surgery and is associated with premature deaths in this group. ARF is an autoimmune response occurring some weeks after an untreated infection with group A streptococcus (GAS). Historically the GAS infection was thought to be only in the throat, but ongoing studies now suggest skin pyoderma, a common problem among Aboriginal children, is likely making a major contribution. The significant consequence of ARF is damage to the heart valves.

Therefore, in order to protect children against further episodes of ARF, and compounding damage to their heart valves, a long-term regimen of penicillin injections is prescribed at initial diagnosis of ARF. The risk of ARF recurrence is known to be greatest in the first year after an initial diagnosis but persists up to ten years, therefore adhering to the penicillin injections during this first decade is most important. The injections are thought to provide blood and tissue levels of penicillin that prevents further GAS infection. They are given no later than every 28 days for ten years after the last ARF episode, or until the child reaches age 21, whichever is longer. For highly at-risk individuals with severe rheumatic heart disease (RHD), they are prescribed until age 35, or for life.

The penicillin injections (long-acting benzathine penicillin G) are invariably painful because of the large volume injected, the viscosity and possibly the irritant nature of the solution. It is difficult to tell what impact this repeated painful procedure has on children. Australian guidelines provide advice on six techniques to reduce the pain of the injections, such as warming the syringe and injecting slowly. Applying pressure
to the site before giving an intramuscular injection has been known as an effective 
pain reduction measure for two decades 7. This was demonstrated again more 
recently in Turkey among 51 children with ARF receiving penicillin injections 8. 
Evaluation of measures to reduce pain of the penicillin injections in New Zealand by 
using local anaesthetic and a vibrating device with an ice pack was shown to improve 
patients’ experiences, especially for children under 14 years. 9. Measures such as 
these should be used at every injection episode as intramuscular injections are known 
to cause pain and distress in children. Australian guidelines indicate that the pain of 
the injections is not the main factor preventing patient’s adherence, as does The 
World Heart Federation, who additionally admit to an incomplete understanding of 
the issue. 5,10 In contrast, African doctors advise clinicians that pain is one of the 
major problems when intramuscular BPG [penicillin] is given and they urge 
clinicians to consider using lignocaine (local anaesthetic) as a diluent 11. The 
manufacturer of the premixed formulation used in Australia does not recommend 
mixing lignocaine with their product although it has until recently been commonly 
used in Australia, and continues to be used elsewhere 5. There is global effort to 
reformulate the penicillin product largely in order to reduce pain and increase 
adherence to the regimen 12.

Fourteen studies in a variety of settings explored barriers to adherence to penicillin 
injections for ARF. In seven of these, injection pain emerged as a barrier reported by 
children, their carers, or adults on the regimen. These sites included India 13,14, Egypt 
15, Jamaica 16, Uganda 17,18, and Nepal 19. Three Australian studies among remote 
Aboriginal patients on the regimen have been conducted. In one, children were not 
included, and injection pain did not emerge as a significant issue 20. In the second 
study there were seven participants and pain did not emerge as a significant issue but
the ages are not delineated apart from one teenage male and two parents of children with ARF. A third, recently published Australian study, included 11 patients/carers but does not specify all participant ages although some children or parents of children were interviewed. The study revealed that clinicians found administering the painful injections distressing and also considered pain to be a major barrier to patients’ uptake. However, the authors state that with regard to injection pain, the evidence is not so clear from the patients'/parents'/caregivers' perspectives.

Injection pain lasting up to 48 hours was reported by caregivers in 46 out of 160 Aboriginal children who were treated with the penicillin injections for skin sores in a recent NT study.

Adherence to rheumatic fever prophylaxis among many Aboriginal children is known to be inadequate. Any missed injection is a major concern as it places children in danger of acquiring another episode of ARF. Determinants of adherence to the regimen are multi-factorial and perceptions of injection pain subjective. Expression of pain and its interpretation by caregivers may be affected by the cultural lens of children, or clinicians and where clinicians and children do not have the same primary language, care needs to be taken in assessing pain. The issue of injection pain, or fear of pain among children, has not been explored in north Australia. The aim of this qualitative study was to investigate the experiences of injection pain among Aboriginal children and young people with ARF along with clinicians’ experiences and practices of administering the painful injection.

**Theoretical Frame**

Decolonising theory, defined here as a determined response to the negatives of colonisation on research practices among indigenous peoples, along with a
determination to prevent harm, was used to frame our approach to all study participants and all study activities. Whiteness studies emerged as a push back against a focus on black or native, or ‘the other’ and we additionally used this frame to intentionally avert a white stance, that of superiority, power and privilege simply due to ethnicity, (not white skin colour) which is recognised as a strong driver of colonisation. This juxtaposing duo is appropriate for the study context because Aboriginal families of children with ARF remain strongly affected by colonisation and also must seek their care from health services where clinicians are predominantly privileged and powerful.

Methods

Clinician interviews were conducted in the qualitative component of a mixed-methods community randomised trial seeking to improve delivery of penicillin injections in ten health services providing care for Aboriginal patients in the Northern Territory (NT). Patient interviews were conducted in an ethnographical study embedded within the trial in four of the sites. Both parts were conducted concurrently but separately. Clinicians were asked about their views on injection pain including their clinic’s and their own practices to reduce pain. Questions on pain were open and were part of a series of questions about care for children with ARF. Interviews were conducted by project officers in the first phase of the trial commencing in December 2013 with clinicians who administer the injections. All relevant clinicians working in the ten sites were invited to voluntarily participate in interviews. Interviews were conducted in English which is the operational language of NT health services.
A focused ethnography was nested within the trial. A focused ethnography differs from conventional ethnography in that it explores a specific issue among a distinct group of people within a particular setting, in this case Aboriginal young people on the penicillin regimen residing in remote communities in the NT. Semi-structured interviews and participant observations were carried out with Aboriginal children who were prescribed the injection regimen, or with young Aboriginal people who had commenced the regimen as children and were now between ages of 18 and 35. Among other topics to do with their care, interviewees were asked to talk about the pain of the injections using open questioning. Children were interviewed in the company of a close relative, such as parent, if they were less than 15 years old. Interviews were carried out with an interpreter where possible, in the participants’ language where that language was spoken by the interviewer, or in English. English was not the primary language spoken by any patients. Patient interviews were conducted in four of the ten trial sites between December 2013 and November 2015. Participants between ages 5 and 35 years were purposively recruited using data from the NT RHD Register and local clinics. The number of eligible participants at the study sites was 119. Potential participants were located and invited to participate at a time that suited them. As adolescent males are least represented in the literature, interviews with this group were intentionally sought.

Consent was gained for all participants. Where possible, children were observed by the researcher after receiving their injection and were additionally interviewed at that time. Clinician’s preparation of the injection was also observed by the researcher if practicable. Practices to reduce pain, either by clinicians or patients and their family, as well as the severity and duration of pain were recorded. Some children were
interviewed or observed on multiple occasions in the ethnography and some clinicians were observed on more than one occasion.

Interviews were audio recorded and transcribed verbatim or hand written at the time, or shortly afterwards, if consent was not given for audio recording. Clinician and patient data were analysed separately by different team members: CR and CS analysed clinician data and AM conducted the nested ethnography and analysed patient data. All responses were transcribed verbatim and field notes or project officer reports related to pain were collated. All data were analysed inductively in a thematic analysis. Patient findings were reviewed with a senior Aboriginal leader from a participating community and one 16-year-old Aboriginal participant on the injection regimen while reports on clinician findings were supplied to participating health clinics and opportunity provided to comment on findings. Nvivo 10 (QSR International Pty Ltd, Victoria, Australia) software was utilised to assist with all data analysis. Collation of clinician and patient findings occurred towards the end of all analyses, with agreement on themes being reached by all the researchers.

Ethics Approval

Ethical approval was provided by the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research HREC-2012-1756. The clinical trial was registered with the Australian New Zealand Clinical Trials Registry: ACTRN12613000223730.

Results

We interviewed the clinicians who provided the majority of penicillin injections for ARF delivered at each study site. 59 clinicians voluntarily consented to be
interviewed. Among other questions about patient care, the clinicians responded to
the question on pain of injections consisting of 13 doctors, 30 staff with ‘nurse’ in
their title, and 16 Aboriginal Health Practitioners across the ten sites. Clinicians were
predominantly female. A summary report synthesising clinicians’ interviews
conducted at baseline phase in the ten health services was generated. Clinicians’
views on injection pain within the report were collated for analysis, and original
transcripts were reviewed to confirm meanings when required.

Twenty-nine patients with ARF were specifically asked about injection pain in
interviews about their experiences of being on the regimen. This non-random sample
comprised 13 males and 16 females and participants’ ages ranged from seven to 33
years. The sample included eight adolescent males between age 11 and 15. Overall,
19 were aged ≤ 18 at the time of first interview and a further seven who had started
the injections as children (≤ 18) and at the time of first interview were between 23
and 28 years old. Three male participants started the injection in their early twenties
and were included due to their prolonged experience (≥ ten years) receiving the
regular injections. Ages of patients, sex and duration on the regimen were recorded at
the time of first interview. Duration of injections varied and included <1 year (n=4),
1-5 years (n= 9), 6-10 years (n=6) and ≥ 10 years (n=10).

There were no patterns among patient’s responses according to age group or length
of time on the regimen. The youngest participant was age seven years and clearly
experienced distress on receiving the injection; she screamed. The next youngest
were in a group aged 11-14 years and no trends were apparent. Some who had been
on the regimen for years were experiencing the most pain or dislike for the
injections. Children who were on the regimen < one year either did not express pain
as an issue or endured the pain, apart from the seven-year-old mentioned above.
Themes

Six themes relating to participants’ experiences of receiving or of giving regular penicillin injections for ARF emerged in the analysis: ‘stoic resignation’; ‘neutral response’; ‘negative encounters with the pain of the injection’; ‘impact of the injections on wellbeing’; ‘perceived control over pain reduction measures’; and ‘inconsistent use of pain reduction measures’.

Stoic Resignation to Pain

Sixteen patients described how, while the injections are painful, they had become resigned to them. Many used the phrase used to it in their responses.

“When I was 14 I just went for the injection without thinking about it. Then it got worse and worse and I couldn’t walk. But you get used to it. It’s not really a worry [24-year-old male on regimen ten years].

Similarly, a 15-year-old girl on the regimen for 7 years stated, they are painful, but you get used to it. I don’t mind getting them cos it helps me get better. One 15-year-old female, on the regimen for 7 years, described the injections as annoying but used to it and a 14-year-old male on the regimen for one year as, Mārr-gangga in his language, meaning so-so.

Four parents perceived that their children had initially found the injections painful but were now used to it. While a mother stated her 12-year-old daughter was used to it, the researcher was given permission to remain in the room while the injection was given, and the girl was observed to whimper, and tensed while receiving the injection [on regimen for 18 months].
While becoming resigned and willingly attending the clinic to receive injections, patients in this group still found the experience taxing, and their words revealed a simmering underlying stress. *Sometimes I hate it, sometimes it is okay. It hurts a lot. I just wanna find out when it stops. I feel fine now* [25-year-old male on regimen 10 years]. A 15-year-old female responded, *when I get it I don't hurt, like, but after, when I put pressure and stuff, it hurt* [On regimen for 1 year].

Some clinicians also stated that patients *got used to* the pain and that pain was not a significant issue. One nurse stated,

> We have a lot of patients who are really compliant and have been for years and years, and obviously the older ones you know they’re used to that routine of getting it and they just do it.

Another nurse felt that *a lot of those kids have had the LA Bicillin [benzathine penicillin] all their lives for other things* and suggested this led to young people’s resilience or resignation to the injection pain and additionally, their adherence to the regimen.

**Neutral Response to the Injections**

Eight patients did not use negative descriptors of the injections during interviews even after probing by the interviewer. Some were observed just after receiving their injection and showed no negative signs. In some cases the researcher met them over subsequent days and they stated that there was no ongoing pain. This group frequently used phrases such as *it’s no problem* and *they don’t really hurt* and, *it’s okay* when asked about pain. When questioned about effects on sleep or walking post injection, this group reported no ill effects.
Two patients in this group stated that they declined the offer of local anaesthetic by clinicians to help with pain. A 14-year-old female on the regimen for nine years was questioned just after receiving her injection; *did they ask you if you want lignocaine?* She replied, *Yes, I didn’t want it.* Another 15-year-old male on the regimen for <1 year stated *I don’t mind if it is given fast or slow, both ways.* There were no patterns in the pain reduction measures offered, declined or accepted in this group. In contrast to these neutral responses, while some clinicians thought patients got used to the pain, none believed that patients did not find the injections painful.

**Negative Encounters with the Pain of the Injections**

Five patients stated that the injection pain was difficult to bear.

> When I get the injection, it is painful for two to three days. I limp, and it sometimes keeps me awake at night. It leaves a lump in buttock that is painful to touch [18-year-old female on regimen 7 years].

The father of a seven-year-old child found the experience harrowing, *she screams when she gets the injection. I have to leave the room; I can’t stand to hear her scream* [on regimen 6 months]. One mother described her 12 year old son, on the regimen for four years, as *cripple next day and usually he just lies there crying.*

Most clinicians expressed degrees of anguish about the injections and used strong descriptors revealing their distress. Comments include, *that needle is horribly painful, it’s a nasty needle* [nurse]. One nurse described it as *repeatedly hurting people* and another stated that patients were *tortured* with the injection. One doctor felt that giving the injection could be viewed as *actually assaulting the child.* Clinicians’ negative experiences led to their reluctance to administer the injections. For instance, one nurse stated, *I don’t want to give the nasty needle.* Other clinicians
expressed angst at not having the time needed to give the injection well: *we don’t have that luxury of time to waste hours giving one injection.* Additionally, some clinicians expressed a lack of confidence working with adolescents as reported by a doctor, *an understanding from the health professionals about how you work with adolescents, it’s very poorly developed, and yet it’s critical in this type of scenario.*

**Perceived Impact of the Injection on Wellbeing**

Five patients reported unwellness that they believed resulted from the injections. They reported fevers, malaise and site soreness. *Two days I get like sick, like dizzy like. I feel heavy when I get it, after it* [12-year-old female on regimen for 6 years]. A relative reported about her 12 year old niece, *she has trouble walking around after the injection and stays home from school on the day*. A 13-year-old male stated, *it always paining then I feel hot and sick at night when I get the injection. I get the injection....then I go home and get sick*. When questioned about the frequency of these symptoms one year later he stated that they did not occur with each injection but, *sometimes happen*. A 25-year-old male on the regimen for ten years reported, *it makes me feel sleepy, I can’t work, I feel lazy [lethargic] while a mother reported that the injections always make her 11-year-old son sick [on regimen for 3 years].

In contrast, one young woman believed the injections made her feel well, *I feel weak and lazy without the injections. When I have the injections I feel strong and walk around* [28-year-old on regimen 10 years]. Similarly, another 29-year-old male on the regimen for 10 years stated that *I can feel when it is time for the injections. It makes me feel better*. No patient reports such as those just described were provided by clinicians.
Perceived Control over Pain Reduction Measures

Seven patients showed some ability to negotiate about the pain of their injection with clinicians, such as declining an offer of lignocaine, while thirteen demonstrated either lack of ability or opportunity to negotiate. A 23-year-old woman, on the regimen 10 years, stated that the nurses decide about pain relief, *they don’t ask me.*

**Some give it, some don’t.** One 12-year-old girl was observed asking for her penicillin to be injected fast but the nurse overrode this preference without discussion stating, *I don’t give it fast.* An 18-year-old girl stated that she did not like it when the nurses jab it in but would prefer the needle to be inserted slowly. When a 15-year-old girl was asked, *does the nurse do anything to stop it hurting? Like give you panadol or...*, she responded in the negative, *nuh* [no]. Being able to negotiate was linked with having a trusting relationship with clinicians. A 28-year-old male explained his reason for not advising a new nurse at his home clinic that he preferred pressure to the injection site, *but I don’t know this nurse* [on regimen for 11 years]. This conversation occurred just after he received his injection and was limping.

Most clinicians discussed how determining a patient’s preference for pain reduction measures is a normal part of their practice. Two different nurses spoke about use of local anaesthetic, *so I will always ask the person if they want it, some people don’t but most do,* and *everybody gets offered local anaesthetic.* One nurse expressed that having a good relationship with at least one clinician in a health service facilitated patient’s abilities to negotiate, *if they've got the one person who is kind, respectful, has a good behaviour and has that relationship... just has a nice way about them.*

Clinicians demonstrated good knowledge of measures to reduce injection pain and collectively reported twenty measures that either they used or were used in their
clinic. These included standard measures as well as others such as use of nitrous oxide gas and supervising a young patient to give their own injection.

Clinicians felt that good injection technique was an important skill to master in order to reduce pain and stress for patients as well as influencing adherence to the regimen.

*And so, the technique of giving the needle is important because when you've got staff turnover and you've got inexperienced people, someone's only got to have a really nasty experience with a needle blocking and having to have it stuck in three or four times, put in too quickly or you know, then they go 'Oh I don't think I'm going to go back there again' [doctor].*

Some clinicians were felt to be less skilled at giving the injections, such as new clinicians and midwives, who may give them less often, *so, they don't want to give it because they're, scared or they've had bad experiences or whatever. They don't feel comfortable.* Some clinicians suggested that ‘skilled injectors’ be recognised and promoted in each health service for the regular penicillin injections.

**Inconsistent Use of Pain Reduction Measures**

Patients were not consistently offered pain relief. A Buzzy Bee™ device, which uses cold and vibration to reduce needle pain, has recently been introduced in the NT. While one adolescent mentioned use of this device helped her, it was not always offered. While application of cold externally can distract from pain, the penicillin solution itself is less painful when warmed to body temperature. Only four clinicians were observed by the researcher preparing the injection. All warmed the syringe prior to administration. In two of these instances the clinicians were heard talking soothingly to the young person while the researcher remained in the room but with patient privacy maintained. Some parents reported their efforts to help their children
with the pain. The mother of an 11-year-old boy said, *I tell him, if you cry, muscles go hard. I talk to him to relax.* Other parents mentioned use of paracetamol for ‘after pain’, with one young woman stating that she would buy it from the local shop to help with her ‘after pain’. Paracetamol was commonly dispensed after administering the injection. There were varying responses to the pain relieving measure of lignocaine mixed with the injection and oral paracetamol; some patients reported it worked for them; for others, these measures did not reduce the pain substantially.

**Discussion**

There is little literature on the issue of injection pain for ARF in the Australian context. Three Australian studies containing patient views on the injection are inconclusive as they either contain few children’s comments or pain did not emerge in interviews. The injection regimen constitutes repeated episodes of procedural pain for Aboriginal children. Procedural pain management is known to be underutilised and poorly managed in children as well as for Aboriginal patients. Aboriginal patients may under-report pain leading to the erroneous assumption that they feel pain less or are more tolerant and stoic.

Stoicism and resignation to injection pain appeared to be a common patient trait and the view of some clinicians in this study. However, the Royal Australasian College of Physicians states that it is a myth that children get used to repeated painful procedures:

*Most do not get used to having them without psychological and/or pharmacological intervention.*
The College recognises stoic resignation and cooperation as an outward response to repeated painful procedures but maintains that internal responses are not necessarily obvious, and it is difficult to predict which children are the most vulnerable.

Recognising and predicting internal vulnerabilities is even more difficult when working with different cultural groups such as Aboriginal children, and even more so when the operational language of the health service is different from that of patients. The fact that it is predominantly Aboriginal children requiring the injections, and the majority of clinicians who give the injections are white, and thus represent the dominant and the privileged (non-Aboriginal), means the repeated painful episodes have potential to deepen already felt inferiority and lack of power among Aboriginal families. For these reasons, a decolonising stance would ensure that pain reduction measures are mandated for every instance. The hinted underlying stress among those who stated they were used to the injections highlights the difficulty in determining just what possible negative effects children on the regimen are experiencing. In a well-articulated patient’s story on the website of RHD Australia (the Australian national coordinating unit for RHD), a young Aboriginal man is quoted, “Now that I’m a little older, I’m quite comfortable telling my doctor how I prefer my needle”, emphasising the need to recognise children’s vulnerabilities in this regard.

Clinicians demonstrated good knowledge of the range of measures that can be used to reduce penicillin injection pain but did not always offer them. It is difficult to postulate the reasons for this omission, especially when so many clinicians stated that they always offer pain reduction measures. Time pressure is a possible explanation. This study revealed the distress that clinicians feel with having to repeatedly give the painful injections to children as seen in their use of strong descriptors such as torture.
and horrible, nasty needle. In starting from a position of distress, a flow-on effect could be overall poor management of the event. However, not providing pain reduction measures every time is substandard and unethical practice 39.

Some children and young people were not provided opportunity or did not feel able to discuss the pain of their injections with clinicians. Power to hold these discussions seemed to depend on their relationships with individual clinicians. The high turnover of clinicians in remote NT health services, who are therefore unfamiliar with the clients, may exacerbate this issue. Without power to be heard or to negotiate, Aboriginal children and young people may utilise the only power they have which is to refuse or avoid injections. The most worrying finding in this study is instances of children not being offered any pain reduction measures.

**Conclusion**

The study findings indicate that further development of supportive policy and guidelines is needed to improve the experiences of Aboriginal children and young people requiring the regular painful injections, as well as for those who deliver the injections. Substandard management of injection pain can be addressed by integrating guidelines into service delivery i.e. clinicians are prompted through their electronic medical record system every time they treat a patient with ARF 46. This can be strengthened by adoption of a philosophy reflecting high priority of pain management and the creation of specific guidelines on repeated procedural pain in children and adolescents in the NT hospitals. Children with suspected ARF are currently admitted to hospital for confirmation of diagnosis and initiation of the injection regimen. Currently, such guidelines are not in place in the guideline repositories of the regional hospitals. In recognition of Aboriginal children’s
vulnerabilities, increased multi-disciplinary and relevant cultural input at the time of initiating the injections, such as Aboriginal language interpreters, child psychologists and cultural experts, is recommended. Deeper attention at the critical time of initiating injections may foster children’s and families’ sense of control and confidence, and better prepare them for the coming years of this repeated painful procedure.

A decolonising approach to primary health care in remote services is needed in order to improve shared decision making and alleviate power imbalances between clinicians and Aboriginal patients as revealed in this and other studies. White clinicians can find the complexities of working in remote Aboriginal communities daunting and self-reflection about practice is recommended for improving health care that is acceptable to Aboriginal patients. Improved connecting with Aboriginal patients and focussing on patient-centred care may also assist with hearing patients’ voices. Valuing local Aboriginal people’s input and views will likely uncover better strategies for assisting children to cope with the years of injections.

For those young people who find injection pain a strong deterrent, seeking supportive relationships within the stable local community population in order to increase self-efficacy in their health care is recommended. These young people are at increased risk of permanent heart valve damage. Investigating local Aboriginal peoples’ views on how to find long-term local support for this group to enable them to cope with the injection pain may reduce this risk. Additionally, supportive mentors from other agencies such as schools, clubs, church groups and ranger programs could be explored on an individual basis. While injection pain was reported as being intolerable in some children in this study, every injection is a repeated painful event
for Aboriginal children and young people and needs the best and most informed care
for every child, every time.

Further research on the effect of lignocaine and other measures such as the Buzzy
Bee™ device in this population is recommended. Additionally, given the newly
reported finding here of a subset of people feeling unwell after receiving the
injection, further research into medical non-allergic adverse effects or psychological
adverse effects, and how to mitigate these, is required. Ultimately, alternative
treatments such as new penicillin formulations are needed.

**Limitations**

Aboriginal participants were interviewed in keeping with cultural protocols and
where possible in their first language. However, due to non-availability, it was not
consistently possible to utilise interpreters or Aboriginal co-researchers to assist with
interviewing as envisaged. Limitations in interpreting meaning in qualitative data
when interviews are conducted across cultures and not in participants’ first languages
are acknowledged\(^5\). In conducting research in a post-colonial setting such as the
context of this study, we acknowledge that power imbalance may hamper
participants speaking freely about perceptions and difficulties.

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Chapter 6

Growing Up in Remote Communities with “That Heart Sickness”
Acute Rheumatic Fever
“Let ‘em have a future. I got full time job now, but I would leave it for kid’s sake.”

Uncle of adolescent girl with ARF when he understood the importance of the penicillin injections for the first time.

**Introduction**

This chapter answers the research questions: how do age, development and culture influence the ability to self-care for ARF and RHD in Aboriginal families; what community level factors facilitate self-care; and what clinic level factors do Aboriginal families perceive as supporting their self-care for ARF and RHD. This chapter focusses on ARF while the following chapter focusses on RHD and heart surgery as experienced by some young Aboriginal people.

The Chronic Care Model (CCM) (Figure 6.1) that framed the SP Study trial, and therefore the focussed ethnography nested within the trial, is used as the frame for answering the research questions above. The locus of this doctoral study was the left-hand side of the CCM; exploration was undertaken in four Aboriginal communities, and in the lives of young Aboriginal people residing in those communities with ARF and RHD and who were prescribed the long-term penicillin injection regimen.

Activities were initiated in the trial within the health services in these four Aboriginal communities. Some activities were designed to work towards improving patient’s knowledge of their condition and how to manage it, i.e. work towards self-management and ‘informed, activated patients’. However, this component of the CCM proved difficult for the health services to gain traction in. Clinicians in the SP Study setting had limited knowledge of or experience in self-management and self-
management support. Gaining traction in community linkages was also difficult for clinicians; the high work load and high staff turnover in the clinics hindered them working more closely with their communities. Similar difficulties have been identified in other studies using the CCM (Coleman, Austin, Brach, & Wagner, 2009; Pearson et al., 2005).

The themes emerging from the focussed ethnography reveal some explanations around why these components of the CCM proved difficult. A strong theme was *Aboriginal adolescence*. I interacted with adolescents who had experienced ARF and who were mostly asymptomatic; they continued on their normal life courses with little understanding of their medical condition. Their (planned) monthly contact with health services was, from their perspective, somewhat mysterious. They considered that they had a ‘heart sickness’ which meant there was a requirement to ‘go to the clinic’ but health care was placed passively in others’ hands with almost no opportunity to learn about how ARF could affect them into the future. It did not
appear to be affecting them now. This chapter focusses on growing up with ARF in remote communities, not as a completed ethnographical exploration of Aboriginal adolescence per se, but rather, as catching glimpses of how adolescence appears in Aboriginal society and how having experienced at least one episode of ARF is perceived and addressed. These glimpses are provided mainly via two adolescent male case stories, with a view to revealing how little health services know of the social characteristics and social practices of this demographic. The findings show that much more research is needed to provide nuanced ARF health care that suits adolescents’ needs.

**Defining Adolescence**

The following definitions are sourced from various locations and are synthesised into a general definition for the context of this study. The World Health Organization (WHO) defines adolescence as the period between childhood and adulthood, from ages 10 to 19 years (WHO, 2014). Other definitions draw on the Latin derivation of the term, the verb *adolescere*, meaning to grow to maturity. This invokes the multiplicity of facets on the development trajectory such as physical, social, emotional and cognitive development (Rice & Dolgin, 2005). In an ethnographical series on adolescence among different cultural groups, participating anthropologists agreed on a broad definition of adolescence that they believed was sensitive to a cultural view, “the transitional period between the end of childhood and the attainment of adult social status” (Burbank, 1988, p. xii). From an anthropological perspective, physiologically-based definitions of the adolescent stage tend to be universal while socio-cultural adaptations to these physical changes are not (Burbank, 1988).
Adolescence poses a similar set of issues across cultures: looking forward to adulthood while still dependent; unmated sexual responsiveness; and greater involvement with peers—these are among the most obvious common issues (Schlegel & Hewlett, 2011, p. 287).

The definitions from the discipline of anthropology best suit my study context. While adolescence emerged as a strong theme, and this developmental stage is important for both families and clinicians to understand, or improve understanding about, the following explications are not claimed to be comprehensive.

Aboriginal language terms around adolescence were collated in two of my sites that shared the same language, and this revealed a conceptualisation of adolescence. The language terms are tabled below. However, in discussions with adults from this language group, as expected, the terms are not naturally used or perceived as a classificatory system. Rather, people perceived of themselves in general as a whole group which is clan or group centric, with certain members having social responsibility in particular areas and certain members being situated in particular stages along a developmental trajectory of the group. For instance, initiation ceremonies constituted a change in social status but not necessarily behavioural change, or change in adults’ authority, as seen in the following field notes. One father discussed social development of males with me as we talked about his adolescent son and his son’s friend.

“They had their dhapi [circumcision ceremony] on the same day”. I asked if that means the boys are adults. He said, “Yes, that is our way”. I then asked if this means they can make decisions about big things. The father replied, “No, he is still under me”.
Another father was questioned about how he perceives his adolescent son who is adult sized at 14 years of age and has had his initiation ceremony. I asked if he perceives of his son as a boy or an adult.

*He says that his son has a man’s body but, to him, he is still a boy. So, although the people don’t have a term for adolescence per se, and when boys have their circumcision their state changes to being an adult in some conceptual way, people still see that they are boys in their behaviour.*

Author’s field notes 29\(^{th}\) April 2015

The terms listed in the table below show that a conceptualisation of physical development in life stages, rather than age in years, exists in that society. Other studies, in other NT Aboriginal languages, show similar terminology that describes physical attributes (Brady, 1993; Ireland, 2015).

**Table 6.1 General terms describing physiological attributes of adolescence in one language group in the NT**

<table>
<thead>
<tr>
<th>Developmental stage</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baby</td>
<td>yothu</td>
<td>yothu</td>
</tr>
<tr>
<td>Child, but not a baby, before circumcision rite for males and before puberty in females</td>
<td>wirrkul</td>
<td>gadaku</td>
</tr>
<tr>
<td>After circumcision for males and at puberty in females, but not yet an adult</td>
<td>wirrkul</td>
<td>gurmul</td>
</tr>
<tr>
<td>Adult</td>
<td>miyalk</td>
<td>dirramu</td>
</tr>
<tr>
<td>Elderly adult</td>
<td>worrunu</td>
<td>worrunu</td>
</tr>
<tr>
<td></td>
<td>miyalk</td>
<td>dirramu</td>
</tr>
</tbody>
</table>
Adolescence emerged as a strong theme in my analysis. Many of the young people that I connected with in field work were adolescents. I purposefully sought to connect with young Aboriginal people in my study sites to explore how age and development affected their experiences of ARF and RHD. I especially sought to recruit adolescent males, but I did not intentionally seek to recruit adolescents in general. However, in recruiting young people I found that I had a group of young adolescent participants; they were at the younger end of the adolescent spectrum. There were far fewer older adolescents, for example late teens, on the RHD Register in my sites and I found it hard to engage the few that I did locate. In my search of the Register for the decade of the 1990s to determine how many males were aged in their late teens during the years of 2013 and 2014 (the time of my field work) I found there were just ten present. In site B there were none, in site C there was one (interviewed), in site A there were six (one was at a ceremony for many months, another I met briefly and a third had mental health problems limiting their ability to participate. I was not able to locate the remaining three). In site D there were three (one was interviewed but did not engage, one was not located, and I attempted to contact the third a number of times but was unsuccessful. He moved in between an interstate location and my site. Disappointingly he progressed to severe RHD and surgery since my attempts to connect with him). The reasons for low numbers of late teens on the Register are assumed to be either non-diagnosis or non-existence of males with ARF or RHD during that decade. Hence the adolescents that I connected with were young because they were more prevalent.
There is little literature on normal Aboriginal adolescence in northern Australia; most writing is in response to problems such as alcohol and other drugs abuse, sexually transmitted infections, suicide and mental illness among young people. Few anthropologists have studied Australian Aboriginal adolescence. Burbank conducted a study of female Aboriginal adolescents 25 years ago as part of a series endeavouring to improve knowledge about this life stage by conducting ethnographic studies among eight separate indigenous groups (Burbank, 1988). More recently, anthropologists motivated by the persistent paucity of knowledge about Aboriginal children and adolescents’ normal lived experiences, collated a group of anthropological essays on this topic. Thus, the editor of the volume stated, “Yet there is astonishingly little research on how Indigenous children and adolescents experience life, shape their social world and imagine the future” (Eickelkamp, 2011, p 78). Other anthropologists have noted the same underrepresentation in research about adolescence (Schlegel & Hewlett, 2011).

Aboriginal adolescence is a broad topic. However, I entered the adolescent domain in my field work and participated, observed and recorded experiences of Aboriginal adolescence in one socio-cultural context. These observations were centred upon how the entity of the chronic conditions of ARF and RHD impacted the adolescents’ lives and the supports they received for managing their conditions. Therefore, Aboriginal adolescence was significant to my study aims. Increasing the knowledge and understanding about normal Aboriginal adolescence has implications for designing appropriate health care, and in particular, how to approach self-management and self-management support (Whitbeck, Hartshorn, & Walls, 2014).

Having spent many years being immersed in three Aboriginal communities, as well as speaking an Aboriginal language in the three, I came to the current study with
familiarity of the context. My past experience as a community health educator and community resident formulated a foundation for my short and cyclical site visits. ‘I’ had a lived experience of being a health educator and both teaching and learning about ARF and RHD in this context as well as immersion in the culture of the context. I became an actor in my own study due to participants’ requests for information about “that heart sickness” which would have been inappropriate to withhold. In the analysis and discussion of Aboriginal adolescence experienced in my field work, and in particular how having a chronic condition sat within this developmental stage, I referred to and reflected upon anthropologists’ writings from similar contexts.

In general, for many adolescents, having ARF alone, without serious valve damage, did not appear to have a significant impact in their lives. The majority of these adolescents experienced a period of unwellness, a short hospitalisation, ensuing regular contact with their health service for painful monthly injections and an occasional visit with a cardiologist. As discussed in chapter five, a simmering underlying stress associated with the pain and continuance of the injections was detected among some young people on the regimen, and a few experienced a deeper stress. Much of my field data for younger adolescents with ARF provides a snapshot of aspects of normal adolescence with a small amount of information on what adolescents with ARF worry about. The data also reveal the supportive relationships that adolescents have with their families but, as understanding about ARF among these families is so limited, most are operating in an information vacuum, are mystified as to the nature of this condition and therefore are not able to offer comprehensive support to their adolescent children.
Adolescents’ Worries

Adolescents were not adept at communicating their concerns and expressing their feelings to me, or to their health service providers. This means that their experiences and deeper feelings remained largely hidden. Due to the nature of ‘growing up’ and maturing, adolescents’ feelings and experiences were likely a moving target as their feelings developed as well. However, some worries were elicited that were related to having “that heart sickness”: fear of having an operation was revealed by some but the source of the fear can only be postulated. One adolescent said she was worried about her heart, “Just don’t want to get operation”. Another Kriol-speaking adolescent had an interesting play on the word ‘heart’:

My heart tells me to just go to the clinic, make sure get my injection cos it’s important. Important than anything. Cos if I miss a day then I might get sick and start be hurtful and paining.

Warnings were possibly issued by clinicians to urge adolescents to adhere to the injection regimen or obey other medical instructions. Those young people on daily warfarin (required for those with irregular heart rhythm or prosthetic valve replacement) had much more contact with the clinic and expressed a fear of dying due to having a stroke. This group will be further discussed in the following chapter.

Adults’ Worries

Adults in the social setting openly expressed angst to do with the general managing of some adolescents in their group. This angst frequently surfaced in general dialogue. Concern was expressed around topics such as youth suicide, alcohol and marijuana use, influx of new outside cultural influences, non-attendance at school and non-attendance at traditional ceremonies. One father asked me to talk with his
adolescent daughter about her ARF expressing concern about her lifestyle, “She goes drinking and not looking after herself”. This father had experienced a valve replacement himself but was also concerned about the new drinking culture of some adolescents. But worries were aired about ARF as well. In an unquenched thirst for knowledge parents did wonder what the cause of the heart sickness was and why their child acquired it. The difficulty was in obtaining a meaningful answer, not having the question. Having just parts of the story also caused worry. Some parents knew that a swollen joint could somehow be related to the heart sickness meaning any joint injuries were a concern. Other parental worries included adolescents being taken out of school for injections, not knowing if the injections were three weekly or four weekly, wondering if it was okay to walk around or sit after the injection and wondering if smoking tobacco could affect the heart sickness. One mother expressed her worry in strong terms, “I don’t want to lose my daughter. I don’t want her to die”. Her doctor had endeavoured to explain her daughter’s ailment not recognising that her English was very limited. This had proved alarming for the mother, “There was some white cells in the heart and needs something to rub it out”.

Observing Adolescents

Despite finding adolescents easy to connect with, I found that they were in general not adept at communicating their thoughts or feelings- perhaps not unexpected among adolescents of any cultural or ethnic background. Having English as a second language may have constrained their expression or it could be a fact of their developmental stage or it may be a cultural artefact of a society that values autonomy and observation as a way of learning and additionally, perceives nodal groups being a key location for interactions and discussions (F. Morphy, 2008). This meant it was generally difficult to obtain in-depth verbal views on what young adolescents
perceived about their condition and the medical care they received. Therefore, observing and participating in their lifeworlds wherever the opportunity arose were utilised as my predominant data collecting methods along with conducting shorter conversations as opportunities arose. This meant that copious field notes were generated, as expected in a focussed ethnography (Mitchell & Steeves, 2012).

The following field notes describe an instance of participant observing in the adolescent domain. All names are pseudonyms to protect identities.

**Adolescents Hunting for Turtle Eggs**

*In a remote homeland nestled on the coast and surrounded by hundreds of kilometres of Australian native bush and ocean, a female Aboriginal ranger is taking a group of adolescents to hunt for turtle eggs after school. She*
stopped to fill a container with water for the trip. She asks me, “Nhe yurru malthun? [Would you like to join us?].

I rode in the back of the vehicle. Altogether there are 14 of us in the troop carrier including six adult women, four adolescent boys and four adolescent girls. Eleven of us are seated along the two bench seats in the back of the vehicle, with three women in the front seats. One of the boys, Wurrki, is 11 years old and had ARF three years ago. His mother told me previously that the injections make her son sick. A 13-year-old boy is Latju. He was diagnosed with ARF last year. One of the young women, Lorraine, has had severe RHD requiring two heart valve operations. She now has a prosthetic valve necessitating daily anticoagulants. I sit beside her next to the back doors.

A thin boy with shoulder-length hair seems to be the clown among the youth. As we bump along the unsealed track the kids all shout “kangaroo” excitedly when they see one in the dense scrub. They are all alert for these animals; revealing their strongly imbued hunter’s psyche. Then they spontaneously play counting games. They count by twos to see how many human eyes are in the car. Then how many noses, and so on. There is slapping and laughing; normal adolescent behaviour. I watch them quietly. All of us sit closely in the troop carrier; everyone’s skin is touching someone else’s. There will never be ‘no risk’ of streptococcal skin infections spreading among people in this sociocultural environment. Everyone has bare legs. Some of the kids have cuts and scrapes and dry sores that are expected in this outdoor environment. The penicillin regimen is crucial for Wurrki and Latju. Its protective function
comes too late to protect Lorraine from RHD, but remains critical to prevent progression.

It is time to return and the women call out to the kids who are scattered along the beach. A boy brings a bird’s nest with an egg in it. The ranger instructs him to return it to the low cliff rocks. Wurrki calls out a greeting to me when he arrives with his friend. The ranger’s son has a mock fight with the tall, long-haired boy. Energy and light heartedness. The kids eat shellfish, some turtle eggs, a banana or two, an orange, some orange juice and cold water. There is no snatching for food. A girl sucks the contents of a turtle egg. I am offered one but alas, weak stomach.

Author’s field notes 15th August 2014

Figure 6.3. Teaching children and adolescents how to find turtle eggs
Source: A Mitchell (photographer) Used with permission.
Connecting with Adolescents

Connecting, observing and participating such as this occurred both in the adolescents’ social locales and at times, in their health institutions. I found the adolescents surprisingly easy to connect with. This was unforeseen with regard to adolescent boys in particular because of my demographic of being an older white female. This contrasts Burbank’s ethnographical experience with adolescent males in a study on Aboriginal adolescence in a similar location. Burbank had trouble connecting with males in her site due to segregation of males and females at that time which prevented opportunities to meet and talk with males (Burbank, 1988).

I developed a rapport with some of the adolescent participants in my field work. Cases of two adolescent males with ARF will be presented. The males, Lakaram and Latju, were aged 13 years at the start of the study. Contact and interactions were always in public spaces and often in a group of other adolescents and /or family. Similarly, I had regular contact with two older adolescent girls with ARF and one of them is referred to further on. Gapulil was 17 years at the start of the study. Interactions with the two girls also took place in family settings or public spaces, with only a few conversations in private. These adolescents resided in two of my sites and I was able to communicate with them in their Aboriginal language.

As seen in the following cases, if the first ARF episode in early adolescence left participants with no residual heart valve damage or negligible damage, then growing up with this condition appeared to have minimal impact in their lives. It predominantly meant that health services periodically tracked, or endeavoured to locate the adolescents for regular injections over many years, with the health service holding responsibility for this repeated task. In between injections, life continued
normally. As one young woman with ARF who had been on the injection regimen for six months stated, “I just feel normal, I don’t think about that sickness”.

**Connecting with Two Adolescent Males with ARF**

The following case stories provide descriptions of ARF in normal adolescent life in the study settings. The adolescent boy Lakaram (pseudonym) was noticed incidentally on the Register at the start of my study and I purposely sought to include him because he is Gudjuk’s cousin (deceased) who was described as a case in chapter three. Including Lakaram provided an opportunity to gain a longitudinal perspective on his clan group’s understandings of ARF as well as how things may have changed in their health care experiences for ARF over the years since Gudjuk had passed away. Discussion points stimulated by both case stories are used to enable a deeper analysis; some points are discussed after the first story and others after the second story. This is then followed by a general discussion section which includes analysis of the different community and clinic factors that affect care of adolescents.

**Lakaram’s Story**

Lakaram was aged 13 when he and his family first became participants in the study. His clan group was well known to me from prior experiences, but I had not met Lakaram or his parents prior to my field work. We met seven times over 20 months and, at our first meeting, I interviewed his parents outside their home in their community.

*Lakaram’s small sister, his parents and I sat cross-legged on the concrete veranda talking. I could see Lakaram through the open front door lying on a couch inside the house, apparently unwell. He had received his injection the previous day.*
During our conversation, which was conducted with all of us code switching between English and their language, Lakaram’s parents demonstrated that they had little information about his illness. Lakaram had been diagnosed with ARF 18 months prior when he had presented to his local clinic with a sore ankle and unwellness. He thought he could recall a sore throat some time before this.

We discussed the injections. His father thought that the injections had been stopped and re-started. He asked Lakaram’s mother if she knew why he was getting the injections. She just stated the injections were for Lakaram’s heart. At that time, the RHD Register reported that Lakaram had moderate valve damage. When questioned, Lakaram’s parents said they did not know any other children with this condition although I knew there were some in their community according to the clinic lists.

Lakaram’s mother stated that he had woken her last night and had asked her for Panadol. He was clearly still feeling unwell and they stated that he had been to the clinic during the afternoon. Lakaram believed that the injections usually made him unwell for one day after receiving them.

As Lakaram’s parents demonstrated little knowledge of ARF, I spent some time in an education session with them after the interview at their request. At the end of this, Lakaram’s father stated, “Health staff give lying story.” He had not heard the information about his son’s illness in a way that made sense prior to this.

The next time I met Lakaram he was 14-year-old. I was walking through his community at dusk when his mother hailed me and invited me to sit on their mat on the veranda with their extended family. This was a newly constructed brick house and through the open door I could see white tiled floors and a sturdy looking new kitchen. The veranda was small compared with previous house designs and clothes
pegged onto the line between the veranda posts flapped just above our heads in the breeze. Lakaram approached from a narrow pathway between the houses and his mother called him to join us. It became dark and the veranda was lit with a fluorescent tube. Lakaram grabbed a chair and sat looking down on us. He had visibly grown and was tall and slim. He was wearing a baseball cap backwards over long hair, a hooded jacket and long shorts. He had bare feet. His expression was bright and attentive, and he smiled as he greeted me. He said to his mother that he was hungry, and she told him in their language that there was some damper in a top cupboard inside the house. He went inside and returned to join us a short time afterwards.

The family started to talk about kinship and where I slotted into their system through ‘adoption’. Everyone joined in this conversation and they worked out how I related to each person present. Lakaram conversed with me easily and confidently. I asked him what causes ARF, where it starts. He began telling me about when he first got ARF. He was about 11-year-old and had a painful ankle. He rubbed his ankle while telling this story. He then talked about being sent to hospital.

The difficulties of dialogue in two languages became apparent; he was telling me about when ARF started ‘for him’ rather than giving a generic answer about the cause of ARF that I thought I was asking. I asked again what causes ARF in young people, but he did not know. He knew he needed the injections until aged 21 years, but he could not say what would happen if he missed an injection. I asked when the next injection was due, and he nodded in the direction of the clinic stating, “They let me know”. Then he offered that he was going interstate the following week to play football. I asked if he would get the injection prior to going and he replied concerning the clinic again, “Yes, they will tell me”.

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Lakaram’s parents sat quietly listening to this talk. More people arrived and were sitting in a group nearby. After a while, Lakaram’s father asked if we were finished and I said yes. He hopped into the driver’s seat of the four-wheel drive car and a small child began fussing and crying to go in the car as well. Lakaram’s mother asked the child’s mother if the child could accompany them, and on her agreeance, Lakaram’s father told the child to hop in the car. Lakaram, his parents and others drove off; there were at least three generations of relatives in the car.

I remained at the invitation of a young woman, who I called ‘sister’ and we conversed for some time. Other people came and went. A tall and thin young person in a black hooded jacket and shorts walked in from the dark and entered the house but I couldn’t tell what sex they were. Clap sticks and didgeridoo were heard nearby, and the young woman said they were waiting for a deceased person’s body to arrive in order to begin a funeral ceremony. She told me, “Everyone is starving for cigarettes”. People were coming and going, free to walk in and out of the house.

Sister advised me that they had moved into the house that day.
Figure 6.4. A typical remote homeland site where some young people with ARF reside
Source: A Mitchell (photographer) 2015

Boundaries of Young Adolescents’ World

The following section describes social, environmental and domestic boundaries of adolescents in Aboriginal communities. Understanding these boundaries has implications for ARF care. Firstly, increasing health clinicians’ general knowledge about an adolescent’s world, such as who cares for and is responsible for whom, is beneficial for those designing health care for them. Additionally, understanding the significance of the kinship system as a foundational tenet for all relationships within Aboriginal society is essential for knowing who to talk with about an adolescent’s care and realising that the ‘right’ people may not be readily apparent to outsiders. Understanding the environmental boundaries is useful for locating adolescents and for assisting health carers to recognise any aberrations that may warrant intervention. Understanding the domestic boundaries is useful for knowing how to enter those
spaces respectfully and for raising appreciation about the fluidity of sleeping locations and how this can impact the transmission of *group A streptococcus* as evident from molecular typing studies, showing that infection transmission is not confined to individual households (Bowen et al., 2016). This understanding is also critical when undertaking contact tracing for group A streptococcus infection as in an outbreak investigation for acute post streptococcal kidney infection or ARF itself. Overall, understanding the social, within-community and domestic boundaries is important knowledge for clinicians as it increases the possibility of connecting with adolescents who have ARF and their families.

**Social Boundaries**

Lakaram’s story revealed how connecting in an Aboriginal world view remains centred on kinship and the system is inclusive of outsiders. In conversations with all my participants, including adolescents, how I related to them, how I fitted into their kinship system by adoption was consistently the starting point. This kinship system has been stressed but remains central, as described by Morphy and Morphy 2016, below, about one group of Aboriginal people, the Yolngu:

> While systems of alliance have changed over time, genealogical data confirm the Yolngu perception of the existence of enduring regional systems of marriage and affinity that link sets of clans together in connubial relationships. The establishment of government settlements and mission stations in the 1920s and 1930s created an externally imposed spatial framework for the relocation of the Yolngu population that was shaped by the pragmatics of the time (F. Morphy & H. Morphy, 2016, p. 303).
The kinship system places every individual within the social domain. It determines the specific or generalised behaviour that is acceptable across the domain for everyone. Thus, if it emerged that I was in an avoidance kin relationship with a potential participant, I adhered to the protocols and respectfully avoided them. All adolescents were knowledgeable of the kinship system, with some showing more proficiency with breadth of the system; some adolescent participants were confident masters, and a few were more hesitant. The kin system provided a boundary for the adolescent’s social worlds which meant that, by the very nature of the system, their world was intergenerational. Intergenerational close living was observed in each site. Additionally, all the adolescent participant’s friends were also their relatives; either close relatives or more distant kin. For instance, one adolescent male enjoyed spending time with his aunt, who was of similar age to him. Improving health clinicians’ knowledge of just how sedimented the kinship system is for their clientele may reveal how kin relationships can be a resource for assisting adolescents to navigate interactions with the health system.

**Environmental Boundaries**

I observed where adolescents went within the bounds of their communities. I was not free to engage with the adolescent participants without parental consent, as of course research practice designates, but I observed a generalised and natural watching, or a loose guarding of these adolescents by the adults in their group. However, this watching or holding was not the same as occurs in western society. Young people were not asked to report their whereabouts always or to provide the exact time they would return to their family dwelling. Thus, Lakaram returned to his parents just on dusk and another adolescent returned a short time afterwards. Theirs was a more generally bounded domain rather than a specifically bounded one. The borders were
the community or homeland boundaries, or in the instance of the small remote
township site, the borders were locations within the town where their clan groups
congregated or resided. There was a strong sense of adolescents being both part of
the extended family group, and of being under the care of adults within the group, yet
with autonomy being granted. This included all children within the extended family
groups.

_I observe that the community here keep an eye on each other’s whereabouts._

_There is often small talk about where someone is. It is not necessarily
accurate, but it is a talking point. Collective society. People have a general
idea of where everyone is. I see adults watching where their adolescent kids
are. “Don’t go into the jungle! (referring to coastal rain forest)” was yelled
to Wurrki by his mother as we drove off to get shellfish yesterday._

Author’s field notes 17th August 2014

Children and adolescents commonly left their community boundary only in the
company of adults or in a group in daylight hours. In the following field notes I
observed Aboriginal children playing in a park next to my elevated house in the
remote township. The group included adolescents. It was 5pm and I could view them
unobserved. They were all speaking Kriol, most were barefoot, and they were
throwing basket balls around, bouncing and throwing them at each other. The bounds
of their play area were the section of the town where their kin group were housed.

_Loud laughter. Running, playing the game called ‘British bulldog’ with the
balls but it is not highly organised. Girls and boys play together. All dressed
in baggy shorts and singlets or T-shirts, a couple of boys without shirts. One_
boy is wearing two pairs of shorts and no shirt. All appear well nourished and energetic. One boy looks overweight.

One girl stands on my driveway not wanting to join in the game. She plays with her hair while watching the game. If the ball comes near she retreats, but later joins in more. They look to be around age 12. Some get sticks to use in the game. These are broken off plants growing in the park. It turns into a sort of hockey game with the sticks. Some sticks are quite long, up to 2 meters, and mock stick fighting starts. One boy erupts into Aboriginal dance moves with his stick. There is raucous laughter at times. One or two start practising loud whistling. One boy yells coarsely something starting with, “You gottim stick...”. He seems to be a warning or telling the others off about a big stick. I think I hear some swearing at one point, but it soon dissipates. The kids are competent throwers.

One older teen girl has some of her hair dyed blond. Others have bits of hair that have been dyed and are an orange shade. There is no obvious carer or supervisor. The dangers are a busy road nearby and stick or feet injuries. But none occur. A black and white dog arrives and wanders through the game unperturbed. The kids ignore the dog. It wanders off again. After 45 minutes the kids wander off along the footpath in a straggly group. There is still plenty of sunlight.

Author’s field notes 29th April 2014

Adolescents’ interest in the opposite sex may lead to liaisons after dark (Ireland, Narjic, Belton, Saggers, & McGrath, 2015; Senior & Chenhall, 2008), but it
appeared that these liaisons occurred either within locations in their community or on its perimeters under the cover of the vegetation or sand dunes.

**Domestic Boundaries**

The domestic bounds of the adolescents were commonly not one dwelling but rather an area consisting of two or three houses and the spaces in between them, where connected groups of people lived. Narrow walking tracks connected the houses in the community and homeland settings. This was not possible in the town location where the streets were paved and houses were separated by fences. The boundaries of a *group of houses* as such were not physically marked but are marked in the minds of the residents of this *space*. Knowing the boundaries of a group’s space was obvious to members of the community but not to outsiders. This meant that outsiders, including clinic staff, frequently entered the *space* in inappropriate ways, for instance walking to the front door of a house and knocking. This was akin to entering right into a white person’s house and knocking on their bedroom door. I often felt embarrassed when I observed this inappropriate approach by outsiders; I knew where the boundaries of the spaces were. However, it was not easy to verbalise about their exact location, I just knew, or felt it, as the residents of the spaces would have.

Familiarity with the domestic boundaries meant I just knew where to wait until noticed if I wanted to visit a person in their *group space*. Over the years, wear and tear on the houses meant some were refurbished or replaced but the same family groups remained in the same locations within a community or homeland. This was also a boundary based on clan associations that is not likely apparent to outsiders.

Sleeping locations were multilocal within the group’s social network with changes observed during my cyclical visits; sometimes Lakaram and his parents were sleeping in one house in their clan location and sometimes in another on my next
visit, or sometimes he slept at his aunt’s house. Other adolescent males with ARF changed houses during my field work; sometimes they slept at their grandmother’s house, which at times was in another community, and at other times they slept at their parent’s house.

Although I did not collect quantitative data on household occupancy or suitability of public housing, my observations confirmed high numbers of individuals utilising a dwelling. Inadequate housing for Aboriginal people is currently understood as a public health problem and a social determinant of health affecting the development of ARF among young Aboriginal people (Bailie & Wayte, 2006).

During field work I observed and heard lament from residents about the reduced outdoor shade in newly built houses provided for a group of people who prefer to congregate out of doors. I observed foam sleeping mattresses in all the spaces of some dwellings, including the lounge room and kitchen, as well as on verandas. This was especially so during ceremonial events that led to a large influx of kin visitors congregating throughout and around one or two dwellings. Houses appeared to be hubs where kin-based groups were free to access, congregate and share resources such as food. I heard laments about the low number of bathrooms to service household groups and in particular the difficulties that a centrally-located bathroom caused because of the cultural more of not being able to observe when adult relatives of the opposite sex use the bathroom.

**Latju’s Story**

Latju’s family were part of a large group of connected clans living on their lands in small dispersed homelands that are all marked with a slash of unsealed airstrip in expansive bushland. All names are pseudonyms.
Latju was a 13-year-old Aboriginal boy living with his parents and siblings in a remote homeland on the coast. He is named after his father’s father. This means he is sometimes referred to as Latju number two, with his grandfather being called Latju number one. His grandfather proudly stated to me that, “Latju has my name; he is my future.” Latju has multiple names derived from historical cyclical clan connections with people and locations; Gadayka is another one of those names and Dharpa is his clan name and is used as a surname within the western naming system. Latju also has an English name, Simon.

One year prior to our first meeting, one of Latju’s aunts had noticed that he had strange movements while he sat in an evening fireside circle with his family group. He kept changing from slouching on one side to the other, and repeatedly moved to different places around the fire.

The aunt advised Latju’s mother to take him to the health service because of his strange movements. Latju was sent by plane to the only tertiary hospital in the region, some hundreds of kilometres away, accompanied by his grandmother. When asked what happened in the hospital, Latju’s grandmother, who has little English and is quiet by nature, could not give any detail. Her role seemed to be to provide a comforting presence to her grandson and not to receive or relay medical information to Latju’s family. This role was later confirmed by a key informant. In a conversation about his own echocardiogram later in that year, Latju’s father quietly asked me if people had a right to get their results.

Latju returned to his homeland with a prescription for penicillin injections. Life continued normally after his diagnosis. His strange movements and fidgetiness (symptoms of Sydenham’s chorea, a manifestation of ARF) dissipated; he attended
school and often played volleyball with the other adolescents in the afternoons. Sometimes I saw him absorbed in shooting at small creatures on the ground with his sling shot. He gave much attention to his grooming. He stated that the injections did not bother him, but neither he nor his parents knew what caused his ARF, how long the injections were needed or what function they performed. This was despite both his parents having had ARF when they were young and being on the injection regimen themselves years ago.

On one of my visits to his homeland, I saw Latju walking along with a sling shot. He was looking intently at something on the ground. I greeted him and asked when his next penicillin injection was due. He said he didn’t know so we went to the small clinic where the nurse was visiting for the day. I asked her to see if his name was on the injection list. She could not locate it. I asked her if I could assist and I quickly recognised one of his names, Gadayka, on the list. I checked with Latju if this was indeed one of his names and he confirmed that it was. He was subsequently given the injection.

Latju was large for his age and clearly took an interest in his appearance. He combed his thick hair into various styles, frequently topped with a Reggae-coloured knitted cap. Despite being a long way from any shopping facilities, his clothing and accessories were frequently bright and interesting; sometimes as well as the cap, he wore a football club’s vest, sunglasses, and red plastic slip-on shoes. Latju attended school in his small homeland along with around 30 other Aboriginal children of varying ages.

Both of Latju’s parents experienced ARF in their youth but they still had little information about it other than it was a ‘heart sickness’. The family began living
permanently in the homeland some years ago and were offered a two-roomed small, transportable dwelling. The dwelling was air-conditioned, had an indoor bathroom with hot running water, and the family had created a neat garden around the perimeter. Latju’s father stated to me that he felt fortunate to have this provision even though it meant that he and his wife slept in a tent outside much of the time. It was not culturally appropriate for his teenage sons and daughter to sleep in the same room so they each slept in one of the bedrooms leaving no space for the parents. For a period Latju dwelled in his maternal grandmother’s small house that had no inside running water or toilet facilities. When I asked others about why he lived there I was told that Latju was a comfort to his grandmother who had recently lost her adult son.

**Adolescents’ Expression of Identity through Grooming**

Trends in grooming reveal some aspects of adolescence in Aboriginal societies, particularly that of expressing their identity. Trends were evident in self-presentation of adolescents across the four sites and were expressed openly in the dying of their ubiquitously-dark hair and females wearing short legged shorts plus the common accessory of current electronic devices with ear plugs. Schlegel (2011) points out that these expressions may develop into youth cultures, “These styles of self-presentation can coalesce in youth cultures, with their codified behaviors and preferences” (Schlegel & Hewlett, 2011). This expression of agency and individuality as well as separateness from adults through attention to appearance is common in any adolescent cultural group. However, it seemed to remain just that, an expression of agency but not resistance to authority. I found Latju’s attention to his appearance a source of interest as he cut a stunning figure at times; sometimes a bright white shirt in an out of doors environment was a surprise, as was his reggae hat and sunglasses that he wore without any hint of self-consciousness. In all sites I
found a trend of adolescents and sometimes younger children colouring their hair with dyes and use of other accessories. The following field notes were written in a hospital waiting room where adolescents with ARF had appointments with a cardiologist.

*Mulmu was quite confident in speaking with the hospital receptionist, giving correct phone number and allergy information. He is about as tall as me, aged 14, wearing sun glasses, one silver ear ring, perfect clear skin, a black glove on one hand and short white socks and runners. He is easy to talk with. He is accompanied by his grandmother.*

Author’s field notes 27th October 2014

A further interaction with adolescents that shows their open attention to grooming, unhindered in the presence of adult relatives, is presented in the following interview notes. The notes describe preparation for an interview with a woman about her adolescent son with ARF.

*The mother welcomed me, and we sat on a woven mat under the shade of the veranda. Another woman came along as well as a man and they sat and joined in our talk. When I arrived, there were two teenage girls near us. One was sitting on a chair in the sun and the other was doing something to the seated girl’s hair. I noticed they had lipstick on and had some streaks of red in their black hair. They showed no embarrassment at all about their teenage grooming experiments in front of the other adults. I think it was lunch break from school.*

Author’s interview notes April 2015
Further field notes provide a view of one adult about adolescent’s grooming and hair
dying that showed acceptance of young people’s grooming experiments:

*I asked the community worker what adults think of the dyed hair that is
currently so popular. She said, “Some of the older people think they are crazy
and others say the dye will eat their hair”. Personally, she does not mind it
though. “If that’s what they want to do it is okay”.*

Author’s field notes 30th July 2015

In contrast to some adults’ acceptance of new popular trends such as hair dying, an
older Aboriginal man was asked about young people. His negative comments reveal
the tension that can occur between some adults and adolescents as adults face new
outsider influences on young people in their group:

*I sat with the Aboriginal man outside the store while waiting for others. He is
thin, aged 57, with good English. At one point we look at girls just leaving the
store and going across the road to the park. I ask him about their dyed hair.
He states, “Youth look like monkeys with coloured hair”. He then added,
“We say they are half men-half women when they dress like that” (young
women wearing the long baggy shorts).*

Author’s field notes 31st July 2015

The attention to grooming, following new trends as a social act, and the issue of
adult’s acceptance and understanding of new outside influences into their offspring’s
world is both normal and a common topic in many societies (Crockett & Silbereisen,
All participants appeared to or were observed to pay attention to their personal hygiene as part of grooming. However, lack of hardware such as hot running water in some dwellings or having just a garden tap to wash under, curtailed their hygiene practices at times (McDonald, Bailie, Brewster, & Morris, 2008; McDonald, Bailie, Grace, & Brewster, 2009). Poor hygiene hardware is assumed to be one driver for high rates of ARF but among my participants, ARF appeared in both those with good hygiene hardware and those without suggesting that the drivers are more complex.

**Discussion**

**Community Level Factors Affecting Self-Care for ARF**

*Adolescent Males and Their Grandmother*

A community level factor with potential to facilitate self-care for ARF in younger adolescents, and especially males, was the relationship that existed between them and their grandmother. In my sites it emerged that adolescent boys lived in close relationship with their grandmother and often resided with her, sometimes periodically, and sometimes for longer, even when parents lived close by. Key informants verified that this was a culturally embedded relationship of mutual general care and wellbeing, but with natural restrictions around certain topics such as of a sexual nature. It took me some time to bracket my preconception that an Aboriginal male adolescent’s most significant relationship was with their uncle or other male adults and to ‘see’ what I was observing; that grandmothers were a significant carer in the adolescent male’s lives. This contrasts with descriptions of Aboriginal male relationships in Central Australia, where young males have strict behaviour codes preventing interactions with females post circumcision rites (Watson, 2005). As most of the adolescents participating in my study were male, it is
hard to comment on whether the same relationship with grandmothers applies to girls. The point here is that it was an unexpected finding that the grandmother-grandson relationship was so strong in this setting.

Towards the end of my field work, when community participants were most familiar with my role and topic of research, grandmothers spontaneously offered information to me about the whereabouts of their grandsons with ARF who were on the injections. On walking back in the dark from a traditional ceremony, a grandmother of two adolescent males on the injections (not siblings) veered to walk with me. She began talking about them and advised me that one was in a community linked with their clan and that he was getting his injection in that community. She had started to track her grandson’s injections. She knew where he was located and where he got his injections.

At times grandmothers accompanied grandsons to hospital when they first acquired ARF. A 15-year-old male recounted his admission to hospital with his grandmother, stating, “Boys live with their grandmother because she looks after them, takes them to hospital. It is good.”

However, this role of accompaniment did not necessarily include responsibility to obtain and pass on medical information about the boy’s condition. Rather, it was a role of comforter to sustain emotional equilibrium. One reason that adolescent males were easy to connect with in my study may be that they are enculturated into a relationship with an older female. A mother’s mother (grandmother) and her siblings hold social responsibility for her grandsons. These responsibilities may be above and beyond the responsibility that a father holds for his son. This fact holds implications for adolescent males who are prescribed the injection regimen; their grandmother is a
key social carer and likely knows their location at any time point. She has a keen interest in and responsibility for her grandson’s wellbeing, including his physical wellbeing. This was confirmed in the following quote from a young mother of boy with ARF.

Märi is like ŋändi [grandmother is like mother]. My son’s märi [grandmother] knows everything about him, what he’s up to; they support the ŋändi [mother]. Märi is mother’s mother. When I did my Aboriginal Health Worker training I left my kids with my mother, she’s like me, she knows the due date (for injections).

Interview transcript: mother of 10 year-old-boy with ARF 31st March 2015

Further investigation is needed to determine if this special relationship also applies to the paternal grandmother.

‘Holding’ Adolescents

With encapsulation by the colonising outsiders and the enduring impact on Aboriginal people’s lives, adults expressed their hope that young people would retain receptivity to traditional instructional processes such as learning through ceremonies and holding to traditional values. However, with the social impacts of change, adults at times also expressed their perceived fragility concerning control and wellbeing of their young people. The following notes describe a ceremony where young men and adolescent boys participated and were watched by a ring of other adults.

I watched a group of 15 young men and boys dancing. A group of eight men were singing and playing the yiḏaki [didgeridoo] in song cycles; butterfly, pigeon and magpie goose were some of the songs. There was a jovial spirit. I
could not understand the jokes but there was lots of good humour. It seemed to be directed at certain singers (Were they making mistakes?) and to certain dancers (Were they out of step in the dance moves?).

The dancers all had their eyes fixed on the singers and danced in a row moving forwards during the song. I watched some of the adolescent boys carefully look to the older ones for confirmation of their dance moves. It struck me that this has been occurring for a very long time; generations and generations. Perhaps even in this same spot on the sand under casuarina trees. I have seen old film footage of this location when it was a tin hut or two. One of the boys does the steps correctly but doesn’t seem as smooth as all the others. He looks like he is trying too hard and would do better to ‘feel’ the music and the beat.

Author’s field notes 19th August 2015

However, not all the young people from the clan were at the ceremony despite being present in the small community. An old man lamented at this and stated to me that they should be there because they would be “teaching them in the bungul [ceremony]”. Attendance was not mandated but highly valued by adults and hoped for. The adolescents chose whether to attend or not. Similar instructions for life-skills and appropriate behaviour through attendance at ceremonies and traditional stories were described on signage for tourists in an NT National Park near one of my sites, confirming these traditional teaching methods.

I noticed that the adolescent girls changed their attire when they were at the ceremony; shorts were exchanged for skirts to dance. They knew there were separate dress codes; one suitable for daily life which needed to be swapped in recognition of
the importance that traditional cultural events held. Cloth and fabric clothes were introduced by early traders and missionaries, and fashions for adult females in the study setting have morphed from ‘shift styles’ to mini length dresses in the 1970s to the current long rayon skirts produced in Indonesia. The trend for younger females to wear shorts now has increasing acceptability with clan groups for daily life.

The Aboriginal societies in the remote communities faced strain. During my field work an adolescent male from one site suicided and I observed another young female in another of my sites threatening to do so. In the case of the first male, his distressed grandmother stated that it was not right that young people were losing their lives.

The following notes describe the second case:

On our way to this camp we came across an impending scene of self-harm. A teenage girl was clinging high up on a steel power pole and the ambulance and another health car were nearby. A lone woman was standing at the base of the pole- the girl’s mother? It took me a moment to realise the situation at hand and I thought that they did not need any more cars or onlookers. As we drove on, I noticed that many nearby residents were looking on. Later on, we heard snippets of the care for this girl who was now sedated at the clinic.

Author’s field notes August 30th 2014

In a society that was previously relatively secluded from outside influences, new influences are strong. Some social stability of the society remains threatened due to changes from outside. It appeared that children and adolescents were not molded as such by adults but adults waited for children’s personalities and preferences to emerge on a background of traditional instruction and observing. Children and adolescents, both male and female, were observed to be adept and comfortable with
certain roles, such as *mothering* and caring for smaller children and babies. But radical influences from outside meant that the prior roles and status of adolescents had undergone evolution, such as the attendance at school. Burbank describes a culturally unprecedented period of what she terms maidenhood, the time between menarche and motherhood, in a similar setting to that of this study (Burbank, 1988). For instance, attendance at school now occupies much of the adolescents’ time as well as placing them closely with members of the opposite sex. In these new scenarios, social rules are not culturally established, thus causing social strain. In 1988, Burbank described male and female adolescents forming distinct groups but my observations indicate that this has changed; male and female adolescents now mix, but kin relationship rules are known and mostly enacted, and additionally, the kin system constitutes their friends as also their relatives (Burbank, 1988).

Yet teaching still occurred. I observed a card game during the heat of the day in one community. A large group of adults were seated in shade of a house playing cards with money. Close by, a group of three children were modelling what their adult relatives were doing by sitting on a sheet in the shade and using stones for money in their card game.

*Receiving Information about Your Health Condition*

It emerged that families in general received insufficient information from their health services to enable them to participate meaningfully in their children’s ARF care. Both Lakaram’s and Laju’s parents had scarce explanatory information about their sons’ ARF and its management and this was a typical finding in my discussions with other participants. It appeared that, with regard to gaining medical information and understanding ARF, little had changed in the years since Lakaram’s group had experienced Gudjuk’s illness, his heart valve surgery and his tragic death. In
Gudjuk’s case, the group believed that his heart operation was a cure for his heart sickness. In Lakaram’s case, the same group still had paucity of understanding. This placed him and the adults in his circle in a fragile position of unawareness; just as Gudjuk had been. Lakaram was still young and compliant with his injections but was moving towards a ‘young adult’ phase without a good understanding of the purpose of his injections and the critical time intervals between injections. In both instances, the families had cordial relationships with their health service, but vital information was missing. They were living in an informational vacuum, all the more ironic in the light of the finding that there was a strong sense of the adults holding the adolescents in their group.

My field notes describe some interactions with Lakaram’s wider family group that depict this vacuum as well as the lack of power they experienced within the health system. A young woman in Gudjuk and Lakaram’s family had recently been started on the penicillin regimen and became one of my participants:

I ask if she has ARF. She said, “Yes”. She struggles to recall which month she got it and counts various months. She says she got a swollen left ankle and she is waiting for an echo [echocardiogram]. When she has the echo, they will tell her if she can stop the injections or not. She is not on the RHD Register. She has been having the penicillin injections since May 2014. How long does a person need to wait for an echo and cardiology appointment? It’s been five months already. I wonder if a white person would accept the injections and the wait. Possibly the clinic is being cautious due to the number of family members with ARF. But who knows if the clinic has a ‘family view’ or if they even know who her family are because there are no local Aboriginal people working there? There is little traction in
Author’s field notes 29th October 2014

Returning to Lakaram, I had time, familiarity with the context, understanding of his language and worldview as well as training in cross-cultural community development. This enabled us to sit together and discuss the explanations and some of the critical ARF information that was missing. As previously discussed, younger adolescents were still under the care of their parents and other adult relatives. Many demonstrated immature mannerisms that extended to their health care. It may have been possible for them to start to become involved in their own care but, no one was expecting this or asking them to do this. Culturally, there was a sense of waiting to see what emerged in the young people on a background of autonomy, and clinically, health services were holding responsibility for the management and prevention of ARF. Therefore, it was the Aboriginal adults who were recipients of health information about younger adolescents.

Lakaram’s father’s response that the clinic had “lied to him” is not unusual, depicting a sense of lost integrity that sometimes occurs between the health service and the Aboriginal people it cares for (Anderson, Devitt, Cunningham, Preece, & Cass, 2008; Cass et al., 2002). The father of an adolescent girl with ARF asked me if the doctor had been lying to him when he was informed that his rheumatic valve needed replacing at 50 years of age. He wondered why this information was only being revealed now (previously undiagnosed RHD). Another similar aged Aboriginal man stated that he was thinking of suing the doctor because his condition was not
picked up earlier and the clinic was “keeping his data” and not providing him the true information (Authors field notes 25th November 2013).

A further response was received from the uncle who was caring for an adolescent girl with ARF. At the beginning of a similar educational session after an interview, which included the girl and her aunt, he stated,

\[
I \text{ wanna know where this thing came from? How do kids pick it up? Is it house, cigarettes, smoking, when the mother has a baby inside? We thought we were gonna lose her.}
\]

This uncle linked the issue of being privy to enough key information as paramount to the children’s futures. After receiving information in the education session at the end of an interview he went on to state,

\[
This \text{ is the first time I heard this, I didn’t think it was serious. I got a shock. No-one tell us. Clinic mob should tell people, should talk with family’s who got heart problem, so they know” .}
\]

Thus, he offered to give up his employment to spread the information to his group himself, as presented in the quote at the beginning of this chapter, “‘Let ‘em have a future. I got full time job now, but I would leave it for kid’s sake” (Interview transcript 18th October 2014).

**The Right Story in the Right Way**

The repeated responses on hearing information about ARF for the first time in a way they could understand raises the question of what is required for Aboriginal patients in the context of this study to receive this information. It also raises the question of why Aboriginal parents do not question their health care providers. In the first
instance, understanding ARF is difficult due to its complexity as an autoimmune response to a prior bacterial infection. Information complexity requires that learning be scaffolded onto a learner’s worldview and tailored to individuals or individual groups. The story that is told needs to be fashioned collaboratively between Aboriginal language speakers and clinicians so that it contains meaningful themes and analogies. It also needs to be delivered in a language that the hearer is proficient in and with adequate time for dialogue. The best location for receiving information and facilitating dialogue was clearly not within the clinic but rather within community spaces. Clinicians are not currently well placed to provide such information in this context, due to having English as their operational language, being time poor and untrained in delivering information cross-culturally.

In the second instance, it is difficult to know and ask about what you do not know. Apart from powerlessness due to an ongoing legacy of colonisation, if the information you are provided with leads you to think that the condition is not serious, then it is logical that people will not pursue further information by asking questions. For instance, one father of a young girl with severe RHD did not question her need for injections. He assumed that her heart surgery had remedied the problem. When he heard the information in his language on why the injections were needed, he revealed his prior assumption that the injections were just injections and did not have any particular relevance to his daughter’s heart health.

For Aboriginal adolescents who had experienced ARF without valve damage and were prescribed the longterm penicillin injections, much in their life remained the same. The aim of the regimen was to prevent further attacks of ARF and if they adhered to the strict regimen, they likely felt normal. Even if the adolescents had experienced valve repair surgery (not replacement), once they had recovered from
the operation, most felt normal. None of the adolescent participants completely understood the purpose of the ongoing injections and their regular contact with their health services was passive as described below.

**Trained and Learned Passivity**

A trained and learned passivity to do with health care was apparent in Lakaram’s case as it was in many others. Without enough information to generate ownership of the injection regimen the only available position was one of dependence on the local clinic to organise and follow up all his health care needs. His nod towards the health clinic and statement about the next injection, that “They will let me know”, is telling. The onus is on the health service to locate patients. Some participants stated that their clinics rang or texted them when the injection was due. Participants expressed an expectation that this was their clinic’s role: “They always come and let me know and get me for the injection” and, “I always waiting for the nurses to come” and, “They got it (the injection), the doctors visit, they tell me”. A 23-year-old woman knew that her injection was overdue but stated that she was waiting for the clinic to come and get her. This young woman had a better understanding of the injection regimen than most, likely due to having a close relative who was an Aboriginal Health Worker. She stated referring to this relative that “She knows my disease”. However, the following verbatim transcript demonstrates passivity in obtaining the injection;

*Young woman:* I’m still waiting for them to pick me up. I’m overdue. If I get bit late, maybe end of month I always get needle. Cos I know that I don’t wanna get germs again, get sick.

*Author:* Do you always wait for the clinic to pick you up for your injection? Can you go by yourself sometimes or do you have to wait for the clinic?
Young woman: Sometimes I go by myself, I go there, and they tell me to come back after lunch. I come back myself there after lunch. I can go myself.

Interview Transcript 27th July 2015.

I argue that, combined with paucity of information about purpose of the treatment, there is an historical component to this position of passivity. In Lakaram’s and Latju’s case, their community was a prior Christian mission, with the missionaries instituting a new health care system, overlaying extant traditional health care. The main role of the new service was caring for the Aboriginal people. A paternalistic, parent-to-child relationship was the prevalent approach and attitude of the missionaries to the Aboriginal people on their mission. The people were, at that time, ‘wards’ of the state, as described in a report to the Welfare Department on the Mission in one of my sites in 1957-8:

A roll is maintained by the sister (nurse) showing the names of the wards attracting maintenance (funds from government) and those show all details necessary to check the Welfare Returns (Bradford, 1959, p. 15).

The new health care was also ad hoc and not always provided by health professionals:

The superintendent flew to [name] Bay on the Saturday afternoon to distribute a few rations, tobacco, sweets for the children, and medical supplies, and to conduct a short religious service. About forty natives came to the strip where the Superintendent administered eye drops to natives with sore eyes and issued tablets to those suffering with yaws (Bradford, 1959, p. 15).
The following extract from the report reveals the power and cultural incapacity of those administering the new health system:

Pre and post-natal: this group are usually loathe to come up to the sister and reveal their condition, but when it becomes apparent to the sister that the ward is pregnant, the sister tells the ward concerned to report to the dispensary for treatment and from then on the ward usually reports regularly for the special issue diet provided at the hospital. Some difficulty is experienced if the sister feels that the expectant ward should be seen by the doctor. There is a natural shyness about these people, and if not watched, the ward will go into the bush on the doctor’s arrival at the Mission (Bradford, 1959, p. 2).

**Origins of Passivity**

The transfer of health services from mission to government typically occurred in NT Aboriginal communities in the last decades of the 1900s. Two elderly key informants provided their views on this *progressive* development of the local health services. One older male was asked what stood out to him about the early health services. He replied that,

*The main thing was care. We knew each other. Missionaries lived here and stayed here for long periods of time. We had a good number of Aboriginal health staff. They did training, both here and outside. They helped the nurses a lot. We thought we were going to have our own [Aboriginal] nurses and doctors.*

When asked what had happened to prevent this occurring he stated, *“Changes in staff, they had different vision. Then new sicknesses came in”*. 

Page 227
An older female was also asked to talk about the original mission health service and her expression lit up as she started talking:

_We were learning all the chores to do in a house so we could look after our own homes. I was a midwife and used to stay up all night helping women to have their babies. We used to earn good money._

When questioned about what was different then compared to now she stated, “Care. They did good care”. When asked what had happened she stated, “They took over. They wanted all the money”.

During my field work, management of Lakaram’s government-run health service was transferred to a local Aboriginal corporation but organisation of work remained much the same and the historical paternalistic approaches continued within the now strong, biomedical dominance in the health system. This was played out in trained and learned passivity regarding health care by the community members. In locations of colonial legacies, the position of dominance is not easily changed. With new health philosophies of self-management, stemming from societies that value individualism, the position of passivity of Aboriginal people, who value the group, is a cause of tension between them and current clinicians.

**Perceived Roles of the Clinic**

Tension between Aboriginal health clients and clinicians was felt on both sides. Analysis of clinician interviews in the SP study demonstrated the tension among clinicians. Statements revealing the tension were also heard quite frequently when I was in clinic waiting rooms, and, at times, they were aired strongly. As one clinic staff member stated in the SP study interviews, “in the last 40 years we have taken that responsibility away from them. And now we have got to find some way to give it
The tension can be summed up in the statement, “They (patients) should take responsibility for their health”. This responsible behaviour was to be demonstrated in patients arriving for appointments under their own initiative or readily taking the opportunity of health vehicles sent to pick them up, in following treatment advice and in adhering to medication prescriptions. Instead clinicians felt that they had to chase patients and were reluctantly resigned to the burden of this chase.

One young woman with RHD was in a regional city when her injection was due. On contacting the woman’s local clinic for advice, one of the SP project officers was told in a deprecating tone by a local clinician, “[patient named] will need to get in touch with one of the city clinics and get herself there”. The young woman had no idea how to do this. A father of a child with RHD complained to me that he couldn’t walk in the hot sun to take his daughter to the clinic because he was a sick man and did not own a car. In an enlightening experience, I accompanied a clinic driver to pick patients up for a cardiology clinic in one site. The driver expected that when she arrived at people’s houses that they would immediately get into the vehicle. I observed one patient with a spoon half way to his mouth as he ate his breakfast out of doors being asked to come in the vehicle, and another with wet paint on his brush while doing a traditional painting seated on the ground. Both declined to come at that time. In a worrying incident, I observed a mother being reported to Welfare for not acquiescing when the driver arrived to transport her daughter with ARF for her injection. Yet, in discussion with the mother, who had very little English, she said that the driver did not tell her what she was being picked up for (he did not know) and she had prior plans to go elsewhere. Clinicians in general approached patients as having a deficit in this area of taking responsibility for their health while many patients believed the clinicians had a deficit in providing responsible care.
In addition to Aboriginal patient’s passivity concerning their clinic’s role, many also used the term ‘responsible’ in their views about local clinics. Their statements included that the clinic staff should do their work responsibly. The father of a young girl on the injections stated, “It’s their responsibility, they should come (to pick us up)”. A further young adult with RHD stated about local health staff, “They lazy, not doing their job properly on call”.

The issue of taking responsibility, or acting responsibly, appeared as a no-win situation from my perspective of hearing from both sides. However, to improve uptake of injections, dialogue and understanding needed development.

**Spontaneous Perception of Self-Responsibility for Injection Timing**

On asking participants about the cause of ARF, many turned this question back to me, stating they did not know the cause and did I know it. Although my study was nested in the SP study and it was agreed that I would inform the clinics of participants’ needs for further education about ARF, the time to answer a question was the time it was asked, and I was a trained community health educator. In this way, I became an actor in my research. In contrast to trained and learned passivity, a spontaneous sense of adults’ responsibility for the injections emerged when critical information about the purpose of the regimen of injections was received during educational dialogue. Participants spontaneously viewed remembering the due dates for injections as their responsibility. No one mentioned that this was the role of the clinic despite previous interviews revealing that patients were passive in relying on the clinic to inform them when injections were due. I found the strength of the responses surprising. This suggests that, at least for some participants in this context, behaviour may change when a critical amount of information is understood. I have been able to track one family over the time since they realised the importance of the
injections and they have continued to get the timing of the injections right and have close to 100 percent adherence.

In educational sessions with adult patients and parents I found spontaneous and consistent responses as to their responsibility to recall the injection dates. When adult patients and parents received and understood information that was provided away from the clinic setting, in a language they understood, with unrestricted time and to a depth that provided meaning, they came to a different conclusion; the protective effect of the injections for a limited time meant that the timing had to be accurate and, in the first instance, this was something they viewed as their own task.

*Calendars to Track Your Own Injections*

Many adults asked for calendars to help them know when injections were due. The uncle described previously showed angst on hearing of the purpose of the 28-day interval between injections,

> At one point he holds his head in his hands and states, “I can’t keep every 28 days in my memory. We need warning; we need a bell to ring to tell us. Can you do that on the mobile phone? We need something that counts the days; a thing that will go off on 28 days” He is describing a phone application and struggles to explain it as does not know the term ‘app’ but has the idea in his mind.

Interview notes 18th October 2014.

This led to the development of a mobile phone application funded by one site’s health service to do just as this man envisaged (Take Heart Smartphone app, http://www.takeheart.tv/take-heart-app/). In a focussed ethnography, the researcher is alert for changes or actions that will lead to improvements and my involvement in
developing the mobile phone application (providing advice to the production company and testing iterations with my study participants) was one way of doing this. The application uses alerts and internet connection is not required for function. Users enter their own injection dates.

Figure 6.5. Screen shots of phone application developed during my field work

Prior to this however, requests for calendars kept coming in education sessions. One father asked me for a large calendar so he could cross off each day to keep track of his son’s injections. Another grandmother stated, “I want a calendar so I can mark it”. Another mother asked for a small calendar that she could keep in her handbag to track injections for her son. These responses were spontaneous and not in any way suggested during education sessions.

Calendar Literacy

Further explorations included determining the ‘calendar literacy’ among Aboriginal adults and adolescents on the injection regimen. This was often a simple request for
the day’s date upon meeting and in general people had a conceptual understanding of calendars. At times adolescents used recall of their school day to work out the date. Others used their mobile phones adeptly to find the date. In my connecting with Amelia (pseudonym), a young woman with RHD, we worked on using her mobile phone to keep track of injections over consecutive visits. Field notes written on the 6th March 2014 are as follows:

Working out when next injection is due Amelia asks, “Do I count from that number [last injection], one, two, three, four….up to 28 and then that is the next one?” “Yes”. I did this with her on my phone calendar. She put the date for the next due injection into her phone, April 1st.

A phone conversation transcript recorded after the above session shows Amelia’s progress in tracking her dates for the injections although she does not rely on the phone at this point.

Phone text Author to Amelia: Hi Amelia did you get your Bicillin injection on April 1st?

Reply text Amelia to Author: Yea I have on the 8 off April.

Reply text Author to Amelia: Great. But it means that you could have got rheumatic fever again between the 1st and the 8th. Do you know when next injection is due?

Phone call Amelia to Author shortly after last text: “I had it on 8th. I am at [community named] for funeral. I couldn’t get it on the 1st. I went to the [community] clinic and I saw a nurse who used to work at [my usual health service]. She looked it up and found that I was due.
Author: Can you work out when the next one is due by adding 28 days from last one?

Amelia: Yes I add up 28 days, and they will let me know anyway.

Author: What is that date next one due? Will you put it in your phone?

Amelia: Yes I can add 28 days.

On the 22nd of April Amelia rang me and we arranged to meet. I asked her about getting her last injection at the community that she was visiting for the funeral.

Author: “How did you know it was time for your injection?

Amelia: “I thought it was close to 28 days, in my head [points to head]. Then I looked on my phone, thought oh no – I missed that injection!”

Author: So you didn’t look at your phone first?

Amelia: No, I keep it in my head.

Author: Do you know when the next injection is?

Amelia: Yes, I can count 28 days.

Author: And did you put it in your phone?

Amelia: Yes. (Out of respect, I did not ask where in her phone and she did not offer to show me).

Determining adolescents’ calendar literacy and ability to calculate the injection intervals on a calendar revealed a good general knowledge but practice was needed by some to count on from the end of one month to the next because the first day of a
new month did not always start on a Monday (the first box on the top left side of the calendar grid).

Project officers in the SP Study began to provide calendars to clinics when the interest in calendars and patients tracking their own injections was revealed. One 17-year-old girl on the injection regimen, named Gapuli (pseudonym), was visited three times during my field work. She was prescribed the injection at the usual 28-day interval, but the clinic used a recall at 21 days to allow people 7 days to attend before their dose ran out. She was provided with a calendar by her clinic and both she and her grandmother stated at different times to me that they had the calendar on their wall although I did not ask to see it. I accompanied Gapuli to the clinic on one occasion and asked the nurse if she had an appointment card that Gapuli could use. She provided one.

*I showed Gapuli how to count 28 days from today and asked her to write the day and date of her next injection on her own appointment card. She wrote this on the card. In the card section where it was printed ‘For’ I asked her what she would write. She said ‘LAB’ and I waited for her to write it. She wrote ‘LIB’ as this must have been what she was hearing me say. I then wrote ‘long-acting bicillin’ so she could see where the abbreviation originated (She is in year 12 at school). I explained how the bicillin stays in the body but after 21 days it is used up.*

*To practice, I asked her to count forward a further 28 days from the next due date on a calendar and she did this correctly. The nurse did something else at her desk while this was going on and did not take any interest. She seemed to think it was my job to teach about the dates.*
In partnership with the SP Study project officers, we devised some different graphical designs that depicted how people were tracking with their injections. However, while the graphs provided information about how people were going with their regimen, and participants were interested to see them, no one wanted to keep the graphs.

In observing what community-level factors may enhance self-care for ARF, it emerged that historical factors remained influential on participants’ positioning with regards to their health services. However, language, and time to connect to provide information were revealed as strengths. Additionally, social strengths such as the caring role of grandmothers and the holding of younger adolescents emerged as potential relationships that could be drawn upon for moving towards self-care. The spontaneous sense of self-responsibility for injection timing is certainly a social strength.

**Clinic Level Factors Affecting Self-Care for ARF**

**The Contact Zone**

The contact zone is a way of describing the ‘spaces’ where contact and interactions occur between different cultural groups and was first described by Pratt (1992) as “social spaces where disparate cultures meet, clash and grapple with each other, often in highly asymmetrical relations of domination and subordination” (Pratt, 1992, p 4).

The contact zone can be theoretical, such as in the meeting between different cultural groups (Sonn, 2011). It can also be a physical spatial zone. I argue that it is both a theoretical intercultural space and a physical zone for my study participants in remote NT health services and that this zone tends to be characterised by dominance.
and subjugation because of colonial history and biomedicine. ‘Border work’ within the zone is required for improvements in health care services. I spent time in the physical contact zone within clinics; the waiting room. As well as observing participants I assisted some with their difficulties, thus once again becoming an actor in my study by carrying out ‘border work’ in the contact zone. This border work attempts “to find a system of communication where the greatest differences can be expressed simultaneously and, instead of cancelling each other out, be instantaneously transferred from one side to the other” (Carter, 1992, p 180).

This border work is ambiguous and labile. It is a risky work, and the labelling of patients by clinicians as having a deficit in responsibility for their own health care, exemplifies this riskiness. Aboriginal Health Practitioners are always operating within the contact zone and this could possibly be one reason why it is such a difficult role (Mercer, Byrth, & Jordan, 2014).

The ‘Problem’ of Aboriginal Names

Latju’s story demonstrates how having multiple Aboriginal names caused confusion in the contact zone, as it does in other institutions. However Aboriginal names are clear and enduring clan-based identity markers in contrast to mere personal identification markers. At times these name markers are unintentionally erased by white clinicians by insisting on one first name and surname, such as whites have, with other names being aliases. Teenagers on the penicillin regimen do not necessarily have confidence to discuss the difficulties that institutions experience with their names. If I had not been aware of Latju’s other names, he may not have received his injection on time because the visiting nurse was not familiar with his multiple names or the reasons why he was imbued with many.
A similar demonstration of difficulties with institutional names was experienced in one clinic’s waiting room. A nurse came through the code-locked door into the waiting room and called out an Aboriginal patient’s English name. No-one in the room recognised this English name as belonging to anyone present and, in their language, they asked each other if they had this English name. This was somewhat comical because each person knew the others’ multiple Aboriginal names; many of them were relatives, and all likely knew each other their whole lives. This also demonstrates that English names sit loosely with Aboriginal participants; they have been issued for the benefit of outsiders but are not a strong part of their identity. The nurse returned from the contact zone to the inner clinic without finding her patient.

As well as name difficulties, Aboriginal parents and adolescents were observed to lack power in the clinic. To enter the clinic was to cross a border from one’s community into the realm of the ‘other’ for many participants in my sites. Some clinic contact zones were more comfortable, especially older clinics. Newer constructions had an intensified demarcation between clinician and patient zones. Where the inner and outer zones of the clinic were strongly demarcated, there was less comfort in the patient zones. One mother asked me to find out if her daughter’s injections were three weekly or four weekly. I did so and asked her why she was not able to find this information. Her local clinic had strongly defined clinician and patient zones. She told me “I forgot” which I expected was code for ‘I don’t have that confidence or power’. Additionally, the patient may not be believed in the contact zone. One young woman received her injection just one week after the last one because the local clinic did not believe that she had received one in the prior week while hospitalised. She stated, “I told them, but they didn’t believe me”. Key informants, who were community members, were asked for their views about what
was important to them about their current health service. One woman from Site A stated, “They should do mobile clinics, then people feel comfortable as they are in their own space and can find out about their condition” (Field notes 14/7/14).

**Patient Mobility**

A further *deficit* was perceived by clinicians regarding the cohort of patients who are on the penicillin regimen: seemingly random patient mobility between variable locations meant it was hard to find patients for their injections. Mobility of patients caused angst among clinicians, but this angst was unbeknownst to participants. However, mobility was not random or frivolous. For homelands residents, “Short term, localised mobility, is fuelled by both social and purely logistical considerations” (F. Morphy, 2008, p.127). Movement of people in this context always has a good reason, but it may not be visible to outsiders. Additionally, there is a predictability of these people movements, “Patterns of movement between communities are highly predictable on the basis of both clan organization and individual kin relationships” (F. Morphy & H. Morphy, 2013, p.179).

**Triangulating for Mobility**

Nineteen study participants were asked where they stayed or moved to in any one-year period. The period of one year was framed as being from the current season to the same season past. This information was then triangulated with the RHD Register for the year 2014 to determine levels of mobility and correlation between where participants received their injections and the locations that they said they moved to or between. Almost complete corroboration was scored in this exercise. Two injections were received in hospital which is not perceived as a place one ‘resided’, and two
further injections were received in a homeland that was not verbalised as a location the person visited but is a socially-linked predictable location.

The majority of the 19 participants received their injections in one location, just under one third received injections in two locations and one received their injection in three locations. This suggests that participants are not as mobile as clinicians perceive. It also reveals that for those participants who move between two sites, that just two health services need to articulate to facilitate participants receiving their injections. In the SP study clinician interviews it emerged that when clinicians contacted other clinics where their patient was visiting, a positive response was not always received. There seemed to be a sense of patients being perceived as the responsibility of just the one sole clinic, the one where they normally or mostly resided. However, as one clinic manager from one site stated, “If they are standing in front of you then they are your patient”.

Additionally, the locations that participants moved between were socially linked, and thus predictable. Two young males were absent from their designated community for extended months and missed their injections. This was due to attending important ceremonies that were a cultural legal requirement. Special attention is needed in order to address this circumstance; these young males were at high risk of ARF recurrence, but organisers of the ceremonies were not likely aware of this and were thus not likely asked to make an arrangement for injections. They just ‘disappeared’ from their clinic’s radar. Interestingly, it was not difficult to find out where these young men were; several people in the community knew and readily told me when I asked if they knew where the males had been over the recent months. This highlights the importance of connecting with local communities that a clinic provides care for, and especially the role of local AHPs.
An additional entity arose in my interviews with participants to do with mobility. Although participants knew the places they were likely to visit or stay in for some time during any given year, they were not generally asked by their health services to advise them of their travel. When questioned if this was a possibility, many adults stated that they could let their clinic know, and were not averse to doing so. They just did not detect that this is something that their clinic would want to know. Further, however, some participants did not want to receive their injections in other clinics as the following transcript of a conversation with a 30-year-old male with RHD shows:

*Author: Can you get your injection at those places if it is due?*

*Participant: No, only here. I don’t trust them at other places.*

*Author: You can get it at other places you know.*

*Participant: No, I only trust these people (points in direction of local clinic)*

Interview transcript 19th August 2014

Care and nurturing on the part of clinicians that generated trust among participants was determined in a similar setting in a study on the penicillin injections (Harrington, Thomas, Currie, & Bulkanhawuy, 2006). Having opportunity to develop positive relationships with clinicians was similarly found to be a key factor in patients trusting clinicians in similar Australian studies (Chamberlain-Salaun, Mills, Kevat, Rémond, & Maguire, 2016; Rémond, Coyle, Mills, & Maguire, 2016).

**Invisibility of ARF and RHD**

Adolescents and their families were asked if they knew of others in their communities with ARF or RHD. Some knew one or two others in their family who were on the injections and others did not know of any. There was no sense of a ‘community’ of people with ARF or RHD and this was likely because most young
people with ARF appeared normal after an initial hospital admission. The unique features of Sydenham’s chorea can be subtle and easy to miss for an untrained eye and this manifestation of ARF is quite rare. Worsening RHD would only be noticeable if a young person became breathless which may be perceived as a lung problem. Some people knew of other young people who had had heart operations. Understandably there was no collective sense of a group suffering from conditions that all had one cause; streptococcal infection. Thus, ARF was an invisible disease.

**Conclusion**

ARF frequently occurs during adolescence. However, Aboriginal adolescents with ARF, and some with RHD, commonly feel normal, yet are obliged to receive regular penicillin injections for at least ten years meaning there is continuing need for them to interact with clinicians in local health services. However, paucity of information and understanding among young people and their families creates a fragile situation. There is a need for emphasis on the ‘adolescence’ of this group, a need for improved understanding about how Aboriginal adolescence appears and how they are ‘held’ in their sociocultural groups.

Younger adolescents were found to be easy to connect with and held in the care of adults in their kin groups. The finding that grandmothers play a significant part in the care of adolescents has implications for connecting with them. Older adolescents were harder to engage or were missing in the group of young people on the injections in my sites. Their grandmothers may or may not still hold sway over them, as one woman said, “When they become older and start to look after their own lives, we don’t know how they will turn out”. The valuing of autonomy in Aboriginal society,
and their strength of identity, can lead to confusion and frustration among white clinicians who may simply desire adherence to their medical instructions.

The historically-based learned passivity to do with health care can be circumvented when critical levels of information are understood by families. This can occur when there is adequate time allowed, an understanding of scaffolding for learning (due to complexity of ARF), use of the participant’s language and carried out in the right location. This then entails providing support for adults to recall when injections are due, such as providing calendars or other devices.

Mobility of patients on the penicillin regimen needs to be understood. Two clinics in places where there are known social links between certain Aboriginal groups would do well to articulate their work. An additional response would be to legitimise each person attending a clinic as having a valid reason for being there due to deep seated socio-cultural links with that location.

The strain and unequal power relationships in the intercultural space of the clinic is argued to be why participants do not take a more active role in self-managing in their health care; it is an encounter with the ‘other’ system. Participants maintain their own sense of identity and autonomy as Aboriginal people who live in a very different space from the white clinicians. Clinicians exist in the other system. Participants held their ground and did not get subsumed into the clinic system when they entered this contact zone.

Clinicians expect (or hope) that patients will be relatively subservient in their system. But this assumes that there is no legitimate ‘other’ knowledge or practice. In a more effective approach there is no belittling of either knowledge or system, but a valuing of each other and finding the commonalities that can be built upon. However, this
implies more time than clinicians have available. It also produces the rationale for 
including people from other disciplines outside biomedicine such as social scientists, 
ethnographers, community development workers and applied linguists (where 
English is not the first language).

There is an increasing shrinkage of the contact zone in clinics in the NT, with 
security barriers such as locked swipe-card doors, windows between insider 
receptionists and outsider patients and big gates with big locks. Additionally, there is 
a focus on acute care training among white clinicians in a setting where chronic 
conditions, such as ARF, are paramount and increasing.

A greater awareness and understanding of the social characteristics of the sub-group 
of the population who are acquiring ARF may lead to better connecting between 
health services and adolescents. A critical awareness around just what is required for 
this connecting has potential to improve health care relationships and thus self- 
management support.
Chapter 7

RHD as a Manifestation of Structural Violence
Introduction

This chapter focusses on RHD and in particular the resultant open-heart surgery as experiences of some young Aboriginal people in this focussed ethnography. It illuminates RHD as a social responsibility implicating a wider audience; the public health of RHD in Australia. If ARF is a sentinel disease for poverty (Parnaby & Carapetis, 2010) then RHD is a sentinel disease for much deeper problems. The presence of RHD among young Aboriginal people in Australia points to a structural violence against a vulnerable minority group, in this instance, within a well-resourced nation (Hale & Sharpe, 2011). On a molecular level, there is a fairly good but as yet incomplete knowledge of the causal pathways for the two conditions ARF and RHD. Group A streptococcus is understood as the catalyst and reducing the circulation of this bacterium in a community of people is understood as being a key requirement for prevention, while other foundational health building blocks such as good nutrition and growth are receiving increasing attention. But the pathophysiology of the course and outcome of RHD are only part of the picture; the course and outcome of RHD are also determined by social forces. These conditions, ARF and RHD, are almost eliminated within most of Australia’s population which is a public health success. This has been achieved during a steady developmental trajectory including an increasing standard of living that reflects a good economy, social freedoms and opportunities. However, even a cursory look at such development in Aboriginal communities in northern and central Australia reveals
another story. Therefore, socioeconomic and equity issues must be examined as part of the course of RHD (Baum, Bégin, Houweling, & Taylor, 2009).

Young people may get through ARF somewhat unscathed in one sense, especially if they adhere to the ten-year penicillin injection regimen after diagnosis, or they have someone to help them persist with it and they do not develop RHD. However, some go on to acquire RHD through failure to receive enough protective penicillin injections to prevent recurrences and the compounding heart valve damage, which is RHD. Or their sore throats and ensuing ARF recurrences may be subtle and therefore missed. Or their repeated skin infections may not be viewed as warranting attention, with the same outcome. In the worst presentation, some children develop severe RHD as part of their first episode of ARF and may need open heart surgery at that point to keep them alive. It is not fully understood why this occurs in those individuals.

**Young People’s Experiences of RHD**

Of the 35 participants with ARF or RHD in my study, eight young females had experienced open heart surgery at young ages to repair or replace one or more of their damaged heart valves. Some of them had required multiple open-heart surgeries. Their ages at the start of the study and number of open heart surgeries are tabled below. Five of the females were of child-bearing age during my field work and all will face dangers in pregnancy due to their damaged hearts. For some, a pregnancy journey will carry extreme risks for them and their unborn baby. The case stories that follow outline the experiences of four of these females. Their cases are then analysed through the lens of decolonisation and whiteness and the component of structural violence. All names are pseudonyms to protect identities.
Table 7.1 Female study participants with experiences of cardiac surgery

<table>
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<th>Age at start of study</th>
<th>Age at first open heart surgery</th>
<th>Number of valve surgeries</th>
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<tr>
<td>6</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>13*</td>
<td>6</td>
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<td>24*</td>
<td>13</td>
<td>4</td>
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<tr>
<td>26</td>
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<td>4</td>
</tr>
<tr>
<td>27*</td>
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<td>29</td>
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<td>1</td>
</tr>
<tr>
<td>33</td>
<td>32</td>
<td>1</td>
</tr>
</tbody>
</table>

*Case stories collated in this chapter

Alaisen’s Story

I met with Alaisen and her family five times during fieldwork. Alaisen appeared to me as a young 13-year-old with childish mannerisms and she let her mother do the talking during our interviews. Sometime later I realised that Alaisen had a hearing loss which may have accounted for her continual smiling but non-verbal participation. Her mother recounted the story of Alaisen’s heart problems:

Alaisen was around nine or ten years old and was swimming in a billabong containing a large rock. At this location, Alaisen first became unwell with a painful knee. She described going to hospital where “they put a pipe in her knee”. Nothing was revealed by the ‘pipe’ so they returned to their homeland. However, Alaisen became very unwell, “she had pneumonia and she was very weak”. Her mother described Alaisen being placed on a breathing machine and then going to a city almost 4000 kilometres away with an aunt as her accompanying escort. The aunt had
no children and Alaisen’s mother had other younger children to care for. When asked what happened during that hospital admission Alaisen’s mother stated, “She had an operation. Her heart was up-side-down”. She showed me the upper part of the scar on her daughter’s chest by pulling her shirt down a little at the top edge. In our continuing discussion Alaisen’s mother explained that her daughter’s up-side-down heart was caused by environmental smoke, largely from the seasonal burning of local dry grasses near their community. The information of her daughter’s heart problems and the smoke were obtained from doctors in the city hospital. Alaisen did not offer any explanations regarding her condition.

Throughout my interactions with Alaisen’s family, her mother showed a caring attitude and warm relationship with her daughter. However, Alaisen’s mother was limited in her understanding of her daughter’s condition; seemingly, all explanations had been provided to her and the family in English. She also had to explain to me what had happened in English, since we did not share her primary language and no interpreter was available. English is not her first language and she showed limited English proficiency.

Alaisen is recorded on the RHD Register as having severe RHD on her first presentation at six and a half years of age. Her initial presentation was so severe that she required a valve repair at that time. Due to the severity she is now on lifelong penicillin injections. She also has a lung condition and has had at least six hospitalisations since her valve repair with lung problems. Despite her mother not understanding what the heart problem was or what the surgeon did to fix it, in the ensuing years, she has followed all clinical instructions and Alaisen has only received less than 80 percent of her prescribed penicillin injections in one of the ten years of her prescription since her cardiac surgery. The RHD Register recorded that
Alaisen was out of the community in the year with lower adherence. Up to this point, she has received 120 penicillin injections and has not had any ARF recurrences. Interestingly, in one of my visits to Alaisen’s local health centre, I asked the clinician who was co-ordinating the penicillin injections to check Alaisen’s medical records for other pathology that may have led her mother to conclude that her daughter’s heart was up-side-down. The clinician, who had worked at the health centre for several years, advised me that Alaisen had not had any cardiac surgery. On examining the electronic medical records however, the clinician was surprised to find the entry for the previous valve repair six years prior.

According to a local key informant, Alaisen’s mother, who is estimated to be in her 30s-40s, grew up in a traditional Aboriginal setting and lifestyle some distance from the current community under the care of a much older father in an extended clan group on their clan lands. During field visits I observed her keenness to hunt for traditional foods such as file snakes in the local billabong and her retention of traditional ceremonial and cultural practices. She had a husband and five children and now lived in the large but remote community in a newly built concrete block house with a conventional ‘three bedrooms’ design. There appeared to be more people residing in this house than just the nuclear family and the building seemed to be used mainly for sleeping. As seen with other families, the new houses had reduced outside shade for outdoor living that was preferred by local residents and we usually huddled outside in the small amount of shade provided by the house to talk when I visited.

**Makemmi’s Story**

In a separate site, Makemmi was 14-years-old when we first met, and she had already experienced four open heart surgeries for severe RHD. As with Alaisen,
Makemmi developed severe RHD at a young age, just seven years old, and had required open-heart valve repair surgery at that time. However, unlike Alaisen, Makemmi did not receive enough penicillin injections in the year post-surgery and her cardiac state worsened; according to the RHD register, in the first year she experienced 111 days at risk (days calculated without adequate penicillin coverage to prevent risk of recurrence of ARF) and in the following year, 85 days at risk.

Makemmi described being taken to hospital by her parents when she was younger and the emotional impact of this experience, “*It was like scaring me when I heard that I had rheumatic fever. And my mum, she was also scared of that, and my dad. They were sad*”. Makemmi became critically ill several times due to ensuing heart failure. She experienced incapacity to live normally, “*Well, before the operation, when I play sports or ran around, it was like hard because I always get puffed*”. As well as these physical limitations, she also experienced deaths of others in her close family from RHD, and for her most recent open-heart surgery, she was hospitalised thousands of kilometres away from home without an accompanying family member because they were in mourning. Needing to cope with serious and life-threatening events with limited support, Makemmi developed an acceptance and fatalism,

*Well, I bin in hospital for a long time and mostly when I was a little girl and I think. especially for my operations which last year I bin in hospital for Christmas, New Years and my birthday. That was a long time. Before, I was scared but now it’s ok I think, I’m okay, used to hospitals.*

Makemmi’s father displayed an understandable emotional impact of the many deaths of close relatives from RHD. Makemmi showed concern for her father’s emotional predicament, “*Well he was, he had trouble like coming to [the city] and he had trouble with everything, I think, and having trouble telling someone to come with me,*
to come and stay with me at [the distant city]”. Overall, she felt that it was unfair and stated, “It’s really hard having rheumatic heart disease”.

Makemmi showed a reasonable understanding about caring for her new mechanical valve and the anticoagulants that she needed to take daily. She stated that the ‘ticking’ noise of her artificial valve reassured her that it was working well. Her biggest need, which she stated clearly several times, was for transport to her health clinic. She knew that she needed regular anticoagulant monitoring as well as the penicillin injections, which she thought were likely required until the age of 18 years. Living some distance from her health service meant that transport was required; however, the health service was not able to provide transport that Makemmi needed and her family only had private transport sometimes. She undertook her own anticoagulant medication responsibilities alone at the age of 14 years. Makemmi was too young to be fully responsible for her medications and still experienced days at risk and unsatisfactory anticoagulation during my field work. Insufficient social and structural support has been Makemmi’s experience since first acquiring ARF and this has clearly impacted her adverse disease course and outcomes.

**Tilly’s story**

In the same site as Alaisen, Tilly presented with ARF at age 11 years and in the following year experienced a recurrence. One year after that she had her first open heart surgery at age 13 years, and had a further two surgeries at ages 15 and 18 years. She had her most recent valve replacement at age 20 years. During her experiences of RHD Tilly became critically unwell a number of times including having renal failure and hepatic failure both stemming from her failing heart. Although Tilly received at least 80 per cent of her scheduled injections each year since her first
presentation, there were still days at risk of recurrence in the injection intervals and the prophylactic injection regimen failed to protect her.

When I first met Tilly, she was 24 years old and we met three times during my field work. She stated that her aunt had brought her up as her mother was not able to. She lived in a newly built concrete block house with her father and other relatives. She had an elderly grandmother who joined our initial interview, as did another aunt. I sensed that although I had been warmly invited into their premises that Tilly’s relatives were concerned about her condition and somewhat cautious about interactions with me. I also found Tilly’s demeanour flat and expressionless. She brought up the issue of compensation for her many heart operations, “I see lots of people with heart operations who get money”, and stated that she wanted to speak with a lawyer about this. Knowing that compensation is poorly understood by remote-living Aboriginal people, and sensing that not all was well, I offered to help her with this and connected her to Indigenous legal aid.

**Louisa’s Story**

I met with Louisa five times during the study. She was aged 27 and was a single mother of a small child and lived in her father’s house with other relatives in a remote community. Louisa had experienced undiagnosed RHD that was dramatically revealed late in her first pregnancy when she developed pulmonary oedema (excess fluid in the lungs due to an incompetent heart valve). She recounted going to her clinic because “I was vomiting gulaŋ [blood]”. Louisa described an emergency evacuation to [city 600kms distant] and then to southern city some thousands of kilometres distant for a caesarean section and a heart valve procedure. Unfortunately, the heart procedure failed, and she needed a repeat heart operation.
shortly after the first where a mechanical valve was inserted. When I asked her about her emergency journey she replied, “It was hard, big”.

The notable and uncommon feature of Louisa’s care during my field work was having a primary care nurse with a strong self-management support approach and wholistic care for some of that period. As Louisa was on daily anticoagulants due to having a mechanical heart valve, the nurse organised the purchase of a blood monitoring (INR) machine so that Louisa could monitor her own blood levels. She stated this would enhance Louisa’s sense of control. The nurse expressed that some of the local clinicians did not support her way of working which included home visiting and treating other family members for various ailments if they were apparent. When Louisa presented to the clinic with symptoms of a stroke during my field work, some local clinicians voiced this as evidence of failure of self-management whereas her primary care nurse viewed it as success because Louisa had learned the significance of her symptoms, knew they may indicate a stroke and had presented early to the clinic. The nurse described a long-term perspective in chronic care where mistakes or underachievement such as this were to be expected as well as useful for further education and self-motivation.

Louisa had a flat affect in our early discussions, but this improved over the course of my field work. Improvement in her mental state seemed to be related to having a new boyfriend who was a health worker, named Baru. For a short while Louisa moved to Baru’s community but Baru stated, “It was hard for her there. She didn’t know the staff at the clinic”. So, they both returned to live in Louisa’s father’s house.
Analysis

Four themes emerged in the analysis of RHD among Aboriginal girls who had experienced open heart surgery; structural violence; needing structural help; missed diagnosis; gender, pregnancy and ARF.

Structural Violence

The strongest theme emerging in the cases of young females with poor cardiac outcomes of ARF and RHD is that of structural violence. Living in a context of reduced power and capacity, stemming from past colonisation and its ongoing outplay, the structural violence evident in the setting emphasises a harsh reality of RHD among young Aboriginal people today (Zambas & Wright, 2016). Structural violence is a concept initially used by Johan Galtung (Galtung, 1969) as a descriptor for the structures in society that prevent “individuals, groups and societies from reaching their full potential” (Farmer, Nizeye, Stulac, & Keshavjee, 2006, p. 1686). Structural violence occurs when “the violence is built into the structure and shows up as unequal power and consequently as unequal life chances” (Galtung, 1969, p. 171). It refers to unintended harm done to individuals or groups of people (Grewal, 2003). Structural violence in this instance speaks of the structures within the health systems, primary care health services and other institutions in remote communities, which are subtle and unintended, and which indirectly caused harm to young people with RHD.

In the remote NT milieu, which are locations of past colonisation, and in the health services located there in particular, which are dominated by white people with (relatively) privileged backgrounds and power to maintain a biomedically-based service design, the harm done to Aboriginal patients is built into the structure. It is apparent in the refusal to legitimise or operate in the Aboriginal languages that their
clientele speaks, in the disinclination to use interpreters, in the clinic-centric biomedical focus, in the disconnection between Aboriginal elders or leaders and providers of those primary health services and in the incapacity to hire and hold adequate numbers of proficiently-trained staff, including Aboriginal staff. It is also apparent in the designs of newly built public housing which do not match the cultural ways of living of those who the houses are built for and that may fuel stress in those living spaces and the spread of group A streptococcus (Fien, Charlesworth, Lee, Morris, Baker & Grice 2008). There are improvements emerging in some locations where the health service design and power are starting to be shared with local Aboriginal elders. However, there is still work to be done for health service providers to understand and connect with the real needs of the remote Aboriginal population they serve.

Unmet needs

The structural violence apparent in the described cases was the inability of the health service providers to understand and meet the critical needs of this group in order to prevent harm. The needs of the families were not understood by health service providers. Outcomes such as no further recurrences and no need for further heart surgeries are indeed possible, as seen in the case of Alaisen. In her case, structural violence was ameliorated, even though she lived in the same community as Tilly and received care from the same clinic, because her personal social situation had a robustness that protected her whereas Tilly’s social situation was a picture of brokenness. Despite not having knowledge about what she was dealing with, how to prevent it, or why injections were needed, Alaisen’s mother did understand that injections were required and did whatever clinicians instructed her to do. She had self-efficacy to follow clinical instructions because of her own sense of identity as an
Aboriginal clan member, woman and mother, and her stable social situation (Bandura, 1977).

In the other three cases, knowledge of the condition was not obtained by adult family members, some of whom had the disease themselves, who were responsible to care for children with the disease. They did not have capacity to follow clinical instructions because of turmoil and stress in their social world. If the need for understanding via communication in a language and world view that the participants could understand were met, it is possible this may have produced more thrust on the families’ side. But it is unlikely to have had complete success. The stressed social issues were too pervasive and entrenched, and some families experienced brokenness that unknowingly prevented them from protecting their children. In this sense, the children were victims of a structural violence because health services did not find ways to deliver the injections within this stressed social context or at the time did not realise the medical significance of missing injections and days at risk and so declined to press the issue (Edwards, 2013). As Makemmi stated about her father at that time, “He had trouble with everything”, and of her parent’s response to her condition, “They were sad”.

**Risks of Acquiring ARF and RHD**

Merely residing in a remote Aboriginal community today means that risks for ARF and RHD are high if you are a susceptible person but this is not solely determined by individual biochemistry or individual or group behaviour (Farmer et al., 2006). Socio-economic risks are equally high, or possibly higher, and these are part of the rubric of structural violence for this group of people who live in a legacy of post-colonialism in the NT; insufficient housing and lower standards of housing, infrastructure, education, employment opportunities and health mean that Aboriginal
people are constrained from reaching their full potential in remote Australia (Jain & Swasthya, 2012; Zambas & Wright, 2016). In the cases of RHD described here, this also includes not reaching their full potential lifespan; those with severe RHD and multiple surgeries statistically have an expected median lifespan of 35.7 years (Carapetis & Currie, 1999). This means that at this point in time, at least one of the young women described here statistically has just five more years to live. This can only be viewed as an embodiment of structural violence; of deprivation and unmet needs leading to premature deaths in distant locations within a wealthy nation.

Concentrating only on the biochemical factors risks missing the social and human side of these conditions; young Aboriginal people are still newly acquiring ARF each month which immediately enlists them into at least ten years of regular engagement with their health services. There is a continual small group of patients travelling massive distances to receive live-saving open heart surgery, bringing major emotional upheaval, but also social upheaval as a guardian figure needs to take time away from community to support the young patient. There is recent interest in good monitoring of ARF and RHD in the Aboriginal population, and globally (Zühlke, 2013), in creating a vaccine and studying the as yet incompletely solved pathological course of the disease (Moreland, Waddington, Williamson, Sriskandan et al, 2014), but scarce research interest about the social determinants that make people vulnerable to ARF; the nutritional status or socioeconomic and political status that drives these conditions. “Illnesses are, in fact, reflections of local deprivation rather than mere biological events with universally common appearances” (Jain & Swasthya, 2012, p. 7).
Galtung argues that the slowness of history in colonisation and post (official) colonisation, despite good intentions, means the dominant and encapsulating group can be dulled or become apathetic to seeing the reality of what occurs ‘on the ground’ (Galtung, 1990). The participants on the ground in this instance, both white and Aboriginal, are ‘remote’, meaning remote from the majority Australian population and from deeper scrutiny. Inadequate provision of resources, such as appropriate housing in remote locations, is needs deprivation. Inadequate provision of structures, such as culturally skilled clinicians and enough health practitioners to staff health services is needs deprivation. These social forces are beyond the control of the Aboriginal community members.

The concept of structural violence enables a deeper picture of the implications of ARF and RHD. The effects of social determinants of disease on young Aboriginal people (inadequate housing, education, and economic opportunities) can be named and analysed but there is a slowness to act and a perception that these are difficult and cumbersome to address. They remain named and theoretical while being perceived as very difficult to improve, as well as outside the realm of clinical practice. Farmer contends that “it is possible to address structural violence through structural interventions” (Farmer et al., 2006, p. 1687). In addressing HIV care in Baltimore, he stated, “The goal was to make sure that nothing within the medical system or the surrounding community prevented poor and otherwise marginalized patients from receiving the standard of care” (Farmer et al., 2006, p. 1688). A similar manifesto could be written for the setting described in this study, such as:

The goal is to make sure that nothing within the health care system or the surrounding community prevents marginalised young Aboriginal patients from being
efficiently treated for GAS infections; efficiently diagnosed with ARF; receiving treatment on time and with skill, respect and compassion; receiving correct medical information in a language they understand; and receiving all care in a spirit of self-management support.

Farmer contends that while addressing the social determinants of disease is outside the realm of medicine, the fact that these things cause disease means that they are central to public health (Farmer 2005). He also states that it is an error to think that nothing can be done and contends that a multidisciplinary approach is needed otherwise only part solutions will be attained (Farmer, 2005). A newly published World Health Organization report also states inaction on the social determinants of the disease and inequities in health are barriers to progress on RHD (World Health Organization, 2017).

At times the structural violence was overt and concerning. Although the following observations did not involve the four girls in the case studies, they occurred during my field work. Clinicians in one site were observed to abdicate their clinical care by reporting their patients to the welfare department for not receiving the prescribed penicillin injections. This threat of, or actual reporting, was conducted based on health clinician’s power over a subordinate, in an effort to force an Aboriginal patient to behave in a certain way. This measure may be enacted out of frustration and possibly concern or even lack of time, but is inappropriate because enlisting punitive measures without prior dialogue in a person’s first language, as I observed, is unjust. This is structural violence as a continuance of colonisation. It shows that some remote health services and some clinicians are removed from the scrutiny of peers or policy makers, creating a harmful and unacceptable situation. It increases marginalisation of those without power and deepens colonisation (Bird Rose, 1996).
It shows that decolonisation, previously described as a standpoint that reflects on past colonisation and its enduring effects and is determined to ameliorate old ways of working, is required. It shows that decolonising work is still required in the white and power-holding institutions situated within remote NT communities.

**Needing Structural Help**

It follows that if the problems are those of structural violence then the solutions will be structural (Farmer et al., 2006). Figure 7.1 depicts reasons that some patients need structural help to prevent poor RHD outcomes.

*Figure 7.1. Entities indicating that structural help is needed*

Both Alaisen and Makemmi experienced severe RHD at their first presentation and at very young ages which is a worrisome presentation of ARF. The sense of holding children that was discussed in the previous chapter is evoked here again. Children are held in the circle of traditional life with its rules, mores, teaching processes and care. Yet, with the encapsulating effect of colonisation and removal of power and with overwhelming, new, outside influences Aboriginal society has been strained to say
the least. The holding of young people slips into brokeness in some cases in this social context.

**Relationship of Knowledge to Adherence**

For Alaisen, the holding withstood social changes meaning she experienced the best outcome in her situation; her mother had capacity to follow instructions despite not understanding why and having almost no opportunity to learn, so that Alaisen received enough penicillin injections to prevent recurrences of ARF. No further ARF episodes were acquired and no further surgeries have been needed. This capacity was not reliant on understanding biomedical concepts of her daughter’s condition, as clearly, she had erroneous information (believing the heart to have been up-side-down), but her capacity is purported to be based in her own observed self-efficacy and secure sense of identity likely born out of her traditional upbringing, as well as her ongoing stable family situation. Alaisen’s family group was able to hold her which included family help and availability to travel the large distance with Alaisen for surgery while her mother remained at home to care for younger children.

The question of the relationship between patient knowledge or health literacy and adherence is evoked here. It seems intuitive that if patient knowledge is good it will have a positive effect on adherence and in my work experience as a health educator in this marginalised setting, this is so, and can be life changing in many instances. It is especially so among marginalised populations that do not have means or general literacy to obtain information for themselves. However, while patient knowledge is important, it is insufficient in some social contexts and for some individuals. While Alaisen’s mother operated successfully without information, the other three girls’ families did not. Even if they had heard the full story it may still not have been enough to enable them to act. Their stressed social situations prevented this.
While Alaisen had a good outcome, Makemmi had a poor one; further ARF episodes and compounded valve damage necessitating open heart surgery to preserve her life. And not just once, it kept occuring. Makemmi was, and still is, immersed in a weakened and difficult social situation that has a major impact on her health and now her future. Similarly, Tilly also was immersed in a social setting without the supports needed to enable her to obtain her penicillin injections. Something was and is very wrong in this situation. It is argued here that Tilly and Makemmi needed different structural help because of their increased social vulnerability and this was not perceived or understood by their health providers or the providers did not have the capacity to provide the help needed. The approach of blaming Aboriginal people for their poor health is a known phenomenon (Durey and Thompson, 2012) and was also found in this study, seen in the white practitioners’ beliefs that Aboriginal people had a social or personal deficiency and just needed to “take responsibility for their own health”.

Makemmi’s health service was not located in her residential community which is situated on her group’s traditional lands. She stated that being on that land provided her with comfort. Her designated service could not and still cannot meet her broad socially-based developmental and medical needs. Similarly, Louisa, Makemmi and Tilly have not been able to access services or entities that could consistently connect well with them and assist and guide them in their mental and emotional needs; in each case they showed signs of depression observed in their expressions of fatalism and flat affect during our conversations. This is not surprising considering the number of life-threatening scenarios they have experienced at young ages. In this regard, they are somewhat invisible to their primary health services and this position,
combined with their families’ reduced capacity to ‘hold’ them is argued to be a strong factor in their poor health and social outcomes.

**Biomedical Dominance in Primary Care**

It is possible that some of the structural help required, such as provision of regular transport and health service flexibility to deliver injections in people’s homes, could be provided via local health services but this was not observed to be forthcoming during my fieldwork. In Louisa’s case, the nurse clinician’s adept capacity for self-management support and ability to go against the pessimism of other local clinicians was notable because it was uncommon. Yet it was some of the help that Louisa needed. Having her own INR machine afforded her some independence as well as a sense of achievement and partnership with her primary care nurse. As a 14-year-old, Makemmi knew one of her structural needs was for transport to her health service. Tilly, Louisa and Makemmi all needed ongoing appropriate and supportive counselling which could have been arranged by local health services.

The constraints of the primary care services in this regard were mostly bound up in the bureaucracy of their biomedically-focussed systems that insisted that their workers remain inside the clinic, created strong boundaries around their work spaces, were unable to staff their clinics adequately and unknowingly utilised biomedically-based programs that could not meet the needs of their Aboriginal patients. While clinical care was delivered, it was inadequate. If the structural help required fell out of the biomedical clinical system and system structures then it was not available.

The penicillin regimen only works if it is strictly adhered to. For this to happen multiple entities have to be in synchronisation: a flexible health service able to deliver injections in a number of patient-tailored approaches; an understanding of the
regimen and its purpose on the part of both families and clinicians, including the strict timing of injections, and social functioning and capacity within families at a level where the injections can be negotiated with clinicians in daily life routines and stresses. Where any one of these structural components is missing or reduced, the regimen can, and does, fail. And the outcomes can be catastrophic in young people’s lives.

The young women on the injection regimen who were not adequately held by their family for deep social reasons needed more help with understanding and coping with their chronic condition and the multiplicity of things this entails. The reasons they did not receive adequate injections are socially-based as well as based in the lack of power and control that is demonstrative in colonised peoples and is expressed in the stress within families such as alcoholism, lack of ability to cope, strained identities and lack of self-efficacy. Where this social circumstance exists, the children and young people on the injections need more structural help to prevent the poor outcomes exhibited in the lives of Makemmi, Louisa and Tilly.

**Missed Diagnosis**

Missed diagnosis is a signal that, either clinicians had incapacity to recognise ARF, or children were not recognised as being unwell enough by adults to warrant a visit to the local clinic. In the setting of this study as well as in other settings, there are a proportion of people who are diagnosed with RHD without a preceding diagnosis of ARF. Some of these are young and others are middle aged when their RHD is first revealed. For some, such as Louisa, their ARF was missed, presumably either because the episodes were mild meaning no health care was sought at the time of experiencing ARF, or because clinicians did not detect it on presentation. It is not
known if ARF can be subclinical. Either way, missing an episode of ARF has serious consequences.

At times RHD is unmasked incidentally in critical situations as a result of injuries or when there is increase load on the heart in pregnancy. Two other young adult males participating in the study had similarly missed diagnoses of ARF and RHD. One was first diagnosed with RHD incidentally when he was treated for a fractured jaw in hospital from a sporting injury and the other when he was treated for critical injuries obtained during an assault. Both these young men expressed surprise at their diagnosis as, prior to that point, they had felt normal. They have both remained on the penicillin regimen since their diagnoses of RHD were unmasked.

Clearly Louisa’s case in pregnancy was a traumatic experience; any positive expectations of having a first baby were shattered as she was thrust into a life-threatening scenario in a distant city where her heart and existence as well as the survival of her baby became priorities. The capacity to provide the comprehensive support needed on return to Louisa’s small and remote community after the birth of her baby and her open-heart surgery would have been a challenge and in the four to five years after these events Louisa had to come to terms with her suddenly-revealed, serious chronic illness and the now the daily management of the ever-shifting target of correct anticoagulation.

Missing the diagnosis of ARF and/or RHD among young people in Aboriginal communities strongly affects their future wellbeing and their length of life and is an important challenge for primary health services. It calls for improved and continuous clinical education on ARF and RHD considering the high staff turnover, continual surveillance and monitoring along with primordial measures to prevent ARF in the
first place. It also calls for linguistically-appropriate campaigns to raise public awareness of ARF symptoms and the danger of those symptoms.

**Gender, Pregnancy and ARF**

It is well-documented that females present with RHD more than males as was found in this study and this is stated in the following recent report:

Rheumatic heart disease disproportionately affects girls and women. The risk of developing rheumatic heart disease is up to two times higher for females than males, and females accounted for two thirds of patients with rheumatic heart disease admitted to selected hospitals in 12 countries in the African Region, India and Yemen. Where rheumatic fever and rheumatic heart disease are endemic, rheumatic heart disease is the principal heart disease seen in pregnant women, causing significant maternal and perinatal morbidity and mortality (World Health Organization, 2017).

Females are more likely to develop ARF and other immune-mediate diseases such as autoimmune thyroid disease and lupus, and additionally and more likely to progress to RHD, hypothesised to be related to hormonal factors or physiological demands causing cardiac strain, especially those associated with pregnancy. A study from Zambia on self-reported recall of sore throats found that girls recalled more sore throats than boys in a one-year period (Musuku, Lungu, Machila et al, 2017). Some genetic research projects are currently underway which may uncover biological attributes of RHD linked with female sex that may assist in future management of females with ARF (Arain, Kuniyoshi, Abdalrhim, & Miller, 2009). Most research reports on the physical problems with pregnancy for women with RHD and prior heart valve surgery, mostly due to the teratogenic effects of anticoagulants and the
risks incurred in undiagnosed RHD in pregnancy (Sethuraman, Ramachandran, Noorjahan, & Kanna, 2014; Sharma, 2016). The Australian RHD guidelines include a section on managing pregnancy in a woman with a known prosthetic or tissue valve to facilitate a well-planned pregnancy (RHDAustralia (ARF/RHD writing group), 2012). An Australian RHD in pregnancy surveillance study included the social effects of RHD in pregnancy (Belton, Sherwood, Peek, Vaughan, & Sullivan, 2016).

For the young female cases discussed in this study, pregnancy is a known medical challenge. This is concerning on a background of them receiving little information and ineffective adherence to treatments due to social strains and unmet needs that meant they acquired RHD in the first place. Further research on ARF and RHD must include the socioemotional impacts of RHD in pregnancy among socially disadvantaged young women to improve their holistic care.

**Conclusion**

In this focussed ethnography I attempted to understand the experiences and lives of young Aboriginal females with RHD who had required open heart surgery. In carrying out this part of my study I detected a fragility of the situation in all four case stories that demanded a sensitivity to know when to cease asking questions, just sit with people and to reciprocate with offers to assist. Additionally, some information has not been recorded here out of respect for and sensitivity to the case’s situations. Yet it must be considered why these young people are having the experiences in the first place. Their experiences pointed to a larger problem. It originated in colonisation and has persisted as unintended structural violence in that these young females now have curtailed life expectancies. To decolonise this situation is to urge
the primary health care services to stop and reflect, to try to gain insight and to alter their approaches.

Aboriginal girls with severe RHD requiring open heart surgery are bearing the full weight of this ‘preventable’ condition. The question needs to be asked why this burden exists in Australia in 2017. As a resource-rich nation Australia can afford to pay for expensive surgeries via our health system funded via the nation’s taxation. Yet new cases of ARF continue to emerge each month with clinicians and data entry staff faithfully recording them to monitor the situation. New cases of severe RHD requiring open heart surgery to save young Aboriginal lives are still occurring. The gravity of this situation, new cases of a preventable condition, with a preventable outcome in young people, requires strenuous and strategic boosting of advocacy and strong public attention. While this research illuminates the structural violence manifesting as RHD in this setting, action is what is needed to address it. One discipline will not fix this problem. Neither will a poor attempt at multidisciplinary networking. The problem is too big and the power of those with the conditions too small.

Structural interventions can be instrumental while concurrently working to improve the social determinants that are driving these two conditions. This can include improved transport for people on the injection regimen, greater flexibility in health care design, fostering a no-blame attitude to young people and their families on the injection regimen, including cultural, social and linguistic support for families and better care models such as a modified transition to adult care approach for young Aboriginal people. However, a caveat is needed; structural improvements need to be inclusive, beneficial and planned in collaboration with those on the ground to prevent unintended deepening of the marginalisation of Aboriginal people. These are
structural issues that can be addressed if institutions holding power have a good understanding of the local social context and good connecting with local Aboriginal people.

(Since writing this chapter, one of the participants has passed away from RHD.)
Chapter 8

Transition to adult care for Aboriginal children with rheumatic fever: a review informed by a focussed ethnography in northern Australia
Table 8.1 Statement of Authorship of publication

Article Title: *Transition to adult care for Aboriginal children with rheumatic fever: a review informed by a focussed ethnography in northern Australia* - article published in the Australian Journal of Public Health. (See note below)

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<th>Authorship</th>
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<tr>
<td>1) Alice G. Mitchell (candidate)</td>
<td>Design, data collection and validation, analysis and writing of manuscript</td>
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<td>24/9/17</td>
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<tr>
<td>2) Suzanne Belton</td>
<td>Conceptual input, manuscript structure, editing and proofing of manuscript, primary academic supervision of associated PhD</td>
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<td>3) Vanessa Johnston</td>
<td>Input into trial design, interpretation of findings, input and critical revision of manuscript, academic supervision of associated PhD</td>
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<tr>
<td>4) Anna P. Ralph</td>
<td>Input into trial design, interpretation of findings, input and critical revision of manuscript, academic supervision of associated PhD</td>
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**Note:** see journal for final version of this article: Australian Journal of Public Health, 2018, 24(1) 9-13, https://doi.org/10.1071/PY17069
Abstract

Aboriginal children in northern Australia have high rates of rheumatic fever and rheumatic heart disease which are chronic conditions due to the need for long term treatment and monitoring. This article critically reviews the literature on transition to adult care for children with chronic conditions and considers applicability to the care of these children. The review was merged with findings from a focused ethnography conducted in four remote Aboriginal communities with young people who have these conditions. Transition care aims to support adolescents on a health care trajectory to facilitate best long-term health and personal outcomes. Characteristics of the two medical conditions, the children, and their local health services in northern Australia were generalized and merged with principles from the transition care literature including policies governing transition clinics in urban locations. In this setting, the challenge is to transition Aboriginal children safely through to adulthood without rheumatic heart damage rather than to a separate health service on reaching adulthood. Recommended tailoring of transition care involves engaging and valuing local navigators who can address language and cultural barriers to provide a sustainable alternative to transition coordinators in mainstream programs. This has potential to improve care without further burdening overstretched clinical resources.

Introduction

Primary health services in northern Australia manage care for Aboriginal children with rheumatic fever (RF) and rheumatic heart disease (RHD) which still occur at disturbing rates in this setting (Parnaby and Carapetis, 2010). This article critically reviews the literature on transition to adult care for children with chronic conditions (henceforth transition care) and considers its applicability to the care of the above
children. The review was additionally informed by a focussed ethnography conducted in four remote Aboriginal communities from December 2013 to November 2015 with young people who have the conditions. Decolonising theory, defined as a determined response to negative legacies of colonisation on research practices among indigenous peoples, was used to frame all parts of the ethnography (Sherwood, 2009; Smith, 1999). In addition, Whiteness studies were used as a frame to intentionally avert a white stance, that of superiority, power and privilege simply due to ethnicity (not skin colour). These theories were appropriate because Aboriginal families in the NT remain strongly affected by colonisation and must seek health care from services where clinicians are predominantly privileged and powerful (Kennedy et al, 2005; Lee & Bhuyan, 2013).

The ethnography sought to determine patients’ and families’ experiences of the conditions and the care they receive. The transition care model’s fit with existing services, potential advantages, challenges, need for adjustment and overall benefit for improving the care of Aboriginal young people with these conditions was appraised. Adolescence is defined by the World Health Organization as people aged 10 to 19 years (World Health Organization, 2014). The definition of adolescence applied in this research was “the transitional period between the end of childhood and the attainment of adult social status” (Burbank, 1988, p xii). This broad concept, believed to be sensitive to diverse cultural views, was agreed upon by anthropologists in an ethnographical study on adolescence among different cultural groups.
Background Explanation of RF and RHD

RF is an autoimmune condition, and, although the exact mechanism is still uncertain, it occurs some weeks after an untreated group A streptococcus (GAS) infection of the throat, or possibly skin. Children between the ages of five and fourteen are most susceptible (Parnaby and Carapetis, 2010). In the past RF and RHD were common conditions in mainstream Australia but currently Aboriginal children almost entirely bear the burden of these conditions and the rates in the Northern Territory (NT) remain high (Lawrence et al., 2013; Parnaby and Carapetis, 2010). RF most commonly presents as a fever and arthralgia with carditis. It sometimes presents as Sydenham’s chorea, which causes unusual and uncontrollable limb movements and sometimes has an accompanying emotional lability that may last for some years. Permanent damage to the heart valves, RHD, is the biggest risk with RF, and repeated RF episodes can cause compounding valve damage. This can lead to heart failure and the need for surgical valve repair or replacement, as well as premature death (He et al., 2016).

RF is a Chronic Condition

RF is addressed as a chronic condition due to the requirement for longterm treatment and monitoring. To prevent further episodes, children are prescribed long-acting penicillin injections to deter further GAS infections. These injections are given no later than every 28 days for ten years after the last episode of RF, and sometimes longer, and are the only effective management strategy currently available (RHD Australia (ARF/RHD writing group), 2012). Care plans for children include heart reviews during regular visits to a paediatric cardiologist or paediatrician. The intervals between these visits depend on the severity of valve damage and vary
between three-monthly and bi-annually. Children, who have had RF but have no
heart damage, or mild damage, may be entirely asymptomatic and may feel normal
between episodes but still need to vigilantly remain on regular injections and be
regularly monitored by primary care services. This is a challenge for children and
families to appreciate as, even if an injection is missed, there may appear to be no
immediate consequences, since RF may be asymptomatic or minimally symptomatic,
and only occurs if infection with a ‘rheumatogenic’ streptococcus occurs in the
window when penicillin protection is lacking (RHDAustralia, 2012).

Children with moderate to severe valve damage may experience symptoms of
ensuing heart failure (increasing breathlessness and tiredness) and may require open-
heart valve surgery in a distant city, combining the strain of a life-threatening event
plus post-operative recovery (RHDAustralia, 2012). If they have required an
artificial valve, their care will thereafter include daily anticoagulant (blood-thinning)
medication to prevent strokes. Management complexity for children with prosthetic
valves is on a par with Type One diabetes and HIV which similarly require daily
medications, or regular injections and frequent monitoring (RHDAustralia, 2012). As
can be seen, RF and RHD are complex chronic conditions.

The Transition Care Model

Transition care for children with chronic conditions is now a globally-established
model for improving children’s care and has been implemented, including in
Australia, for conditions such as diabetes, cystic fibrosis, juvenile rheumatoid
arthritis, HIV and epilepsy (Camfiel et al., 2011; Fair et al., 2010; McDonagh, 2007;
R. M. Viner, 2008). This model emerged to address poor social and health outcomes
when children with chronic conditions moved from paediatric to adult care services
and it aims to achieve and maximise adult patient’s quality of life, well-being and self-management, with support from their clinicians. Preparation for adult self-management works best when initiated in adolescence as this provides time for learning about one’s condition, and from mistakes, and for developing knowledge and skills (Fair et al., 2010; Reider-Demer et al., 2008). An increasing understanding of adolescent brain development has led to better understanding of adolescent behaviours and best ways to approach transition care for adolescents (Colver and Longwell, 2013). Accordingly, in the transition care trajectory, adolescence is a strong focus due to increased vulnerabilities, and opportunities, in this developmental stage (Campbell et al., 2016; Sawyer and Aroni, 2005; Sawyer et al., 2007).

Transition care takes a longterm perspective, ideally with coordinators monitoring and overseeing children’s developmental stages and age-appropriate education needs about their condition, self-management skills, and plans for transfer to adult care once children can no longer access their familiar paediatric care provider. Transition care is a managed process tailored to individual patient’s journeys (Srivastava et al., 2012; R. Viner, 1999).

In recent years, process evaluations and outcome measures for transition care programs have been undertaken (Chu et al., 2015; Sequeira et al., 2015), including in Australia (Steinbeck et al, 2015). These have concentrated on retention of young people in adult services and biometric markers after transfer. Concurrently, advocacy for Adolescent Medicine to be recognised as a clinical specialty in Australia has been undertaken, along with the development of new training programs to that end (Sawyer et al., 2016).
Ethnographic Report on Aboriginal Children and Adolescents with RF

In two sites, Aboriginal language terms describing adolescence were collected, confirming an existing cultural conceptualisation of this developmental stage. However, the terms were not naturally perceived as classificatory but rather, a sense of the whole group (clan or tribe) was prevalent, with members being situated in certain stages within the collective group’s identity. Adolescents with RF commonly felt “normal” yet frequently stated that they had a “heart sickness”. Despite sometimes many years of RF or RHD, few adolescents or their families have learned what causes RF, know when their next injection or doctor’s appointment is due, or know how long the injections are required (Mitchell et al., under review). Similarly, young people on daily anticoagulants have incomplete knowledge about this medication. The operational language of health services in the NT is English whereas few Aboriginal families in remote locations speak English at home or claim to be competent speakers of English (Etherington, 2006). Communication difficulties are a pervasive barrier to families and children gaining knowledge, and to clinicians teaching about the conditions (Cass et al., 2002). The children live in widely dispersed communities with a range of sizes over a large land mass in the NT. Close communal living is preferred with housing infrastructure often insufficient to prevent transmission of infections (McDonald et al., 2009). Strong connection to clan lands and kin means some Aboriginal children and families regularly move between culturally-linked locations but these are generally limited to two sites and are (to them) predictable (Morphy, 2010). A few children board in student hostels away from home in order to attend secondary school.
Characteristic of Primary Health Services and Clinicians

Few clinicians in remote Aboriginal health services are trained in adolescent health care. Trained child health nurses are more likely to be employed but in general their care focus is on children aged up to five years. Adolescence is not categorised as a group for targeted care in NT primary care services reflecting an invisibility of adolescence that, according to the World Health Organization, is a critical predictor of adult health and an opportune time to invest in (World Health Organization, 2014). Most remote primary health services experience high staff turnover which constrains development of relationships and consistent support for children with chronic conditions (Rickard et al., 2012; Russell et al, 2017). Patients are the more stable entity in this regard, with many remaining in their community and receiving care from the one health service for their life. More non-Aboriginal clinicians tend to be employed in remote health services than Aboriginal clinicians and all health care is free (Australian Indigenous HealthInfoNet, 2016). Medical records for patients are retained in local health services and with increasing use of electronic records they are sometimes able to be accessed by primary health services in separate communities or hospitals.

Adaptation of Transition Care for Aboriginal Children with RF and RHD in the NT

Policy documents available from Australian children’s hospitals and urban jurisdictions on transition to adult care reiterate foundational principles found in the literature (Bridgett et al., 2015; Klineberg and Steinbeck, 2012; Royal Australasian College of Physicians, 2007). These principles, when merged with ethnography-
based information from the NT, inform an adaptation of the transition care model for this setting:

1. Transition children safely through adolescence to adulthood with no valve damage within one primary care service, or two primary care service locations that are linked according to traditional Aboriginal connections
2. Focus on adolescence as the time when most RF is acquired, and opportunity exists to teach and learn so as to optimise health outcomes
3. Value local knowledge, cultural processes, languages, resources, and skills as critical to adapting transition care for this setting (Tesoriero, 2010)

**Utilising Local Lay People**

Relevant Australian and international examples exist where local lay people are utilised for addressing chronic health care needs such as those of children with RF and RHD in the NT. These include a Personal Helpers and Mentors program for mental health care and Patient Navigators services to support primary care for other chronic conditions (Doolan-Noble et al., 2013; Dunstan et al., 2014; Overholser et al., 2014). Importantly, representative community members have been successfully engaged as navigators to address health disparities associated with language and culture in cancer care for marginalised groups (Natale-Pereira et al., 2011).

Engaging and training local Aboriginal navigators who speak local languages and understand local cultural and community issues is an alternative to mainstream transition coordinators. Looking outside clinical roles and resources as such provides basis for an adapted and sustainable transition care strategy for remote contexts. Local navigators have potential to provide the longterm supportive relationships needed for self-management and, more importantly, are likely a more stable entity
than outsider clinicians. Local navigators may be linked into the health system at the local primary health services level and/or at the level of the NT RHD Control Program which has jurisdictional oversight of care for RF and RHD. With appropriate consent, navigators may access certain primary care data such as schedules for medical reviews and injection dates for an adolescent patient or small cohort. This approach reduces burdening of local health services although research shows that navigators need to feel connected to local health services (Kemp and Henderson, 2012). See Table 8.2.

An equal partnership between affected Aboriginal families and primary health care services, connected by navigators, is recommended for transition care in this setting. This should be applied within, and be informed by, existing local kinship networks and traditional social structures. Adapting transition care in a locally-relevant and tailored approach has promise for improving safety and wellbeing of Aboriginal children and adolescents with RF and RHD.

Table 8.2 Characteristics of potential local Aboriginal navigators

| Understand patients’ perspectives and can act as patient advocates for connecting with health services; |
| Speak local languages and can be trained in interpreting; |
| Have local cultural knowledge to do with adolescence, age of independence and consent; |
| Know culturally linked locations and local people movements; |
| Can learn to teach about RF and RHD in locally meaningful ways; |
| Can be trained in self-management support; |
| Have potential to increase adherence to treatments and appointments and |
| Are not constrained by clinical work |
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Viner R M (2008).Transition of care from paediatric to adult services: one part of improved health services for adolescents. *Archives of Disease in Childhood*, 93(2), 160-163.

Part III

Chapter 9

Integrated Discussion and Conclusion
Part III

Part One of this thesis, consisting of the first three chapters, explained the background and why the study was conducted. It reviewed the pertinent literature, listed the research questions, described the research sites and explained how the study was conducted. Part Two provided the findings of the study in five chapters. In this final chapter the research findings are summarised in relation to the research questions and an integrated discussion is presented. The implications and contribution to the field of public health as well as recommendations arising from the research are provided. They are constructed around the concept of ‘connecting’ as a critical component required in application of the Chronic Care Model.

The research questions for this study are reiterated here once more as follows:

- What are the experiences, perceptions and understanding of remote-living young Aboriginal Australians and their families of ARF and RHD?
- What are the experiences, perceptions and understanding of the health care they receive for ARF and RHD?
- How do age, development and culture influence ability to self-care for ARF and RHD in Aboriginal families?
- What community level factors facilitate self-care for ARF and RHD for remote-living Aboriginal young people?
- What clinic level factors do young Aboriginal Australians and their families perceive as supporting their self-care for ARF and RHD?
- What is the utility of the ‘Transition to adult care’ model for remote Aboriginal young people with ARF/RHD?
Summation of Objectives and Aims

This focussed ethnography was undertaken during a three-year period (2013-2016) in four remote locations in the northern region of the Northern Territory in Australia. Three of the locations were Aboriginal communities and one was a small town with a substantial Aboriginal population. During fieldwork, time was designated to develop relationships with young Aboriginal people and their families, within their spaces, enabling me to fulfil the research objectives of determining remote-living young people’s perceptions and experiences of ARF and RHD and the ways these conditions are managed, from their point of view. These findings outlined in the five results chapters, are summarised in the next section titled Summary of Results.

Unexpected impacts and issues arose through carrying out this research. In connecting with young Aboriginal people and their families, I found the impact and the embodied vulnerability that ARF and, in particular RHD, caused in Aboriginal children’s lives disturbing. I also determined that as a white researcher, working alone in research among Aboriginal people, without the consistent presence of an Aboriginal co-researcher, although not intended, was a troubling practice and instilled a determination to improve this practice.

An unexpected occurrence was the sudden resolve of one Aboriginal leader to address the issue of ARF among his group’s young people once he developed a critical awareness of the impact of this disease on the group’s future, which he intrinsically tied with the future of their land. This has eventuated in a new research project on the ‘lived experience of RHD’ dove-tailing with my research, using community-based participatory action research methods, and which includes training Aboriginal researchers. I am an investigator in this new research.
Additionally, the opportunity to develop a culturally appropriate phone application, to assist families to keep track of their children’s penicillin injections, was unexpectedly funded by a health service in one of my research sites (http://takeheart.tv/take-heart-app/). A catalyst for the development of this application was my research finding that Aboriginal families were not aware of the collation of their longterm injection data by the NT RHD Register; were interested in and perceived this keeping of their data by the NT Register as an act of caring; lacked knowledge of when their injections were due; and requested calendars to assist them to keep track of their penicillin injections once they understood the importance of injection timing. My experience as a community health educator among this language group meant I was well placed to govern the iterations of this application development. The application is currently being evaluated and the funding health service has given approval for an African group with high rates of ARF to adapt it to their cultural setting.

**Summary of Results**

Findings of the study are summarised as follows:

**Connecting with the Conditions of ARF and RHD: Understandings, Perceptions and Experiences**

Aboriginal young people in the NT have a high prevalence of ARF and RHD yet their family groups have only superficial and sparse understandings of these conditions such as what the causes are, what the management is, when prophylactic injections are required, the duration of the injection regimen and likely disease outcomes. This is reflected in their glossed naming of both conditions into one entity, “that heart sickness”. There was essentially no sense of how to prevent the
conditions occurring in the first place because beliefs about the causes were not correct, but were nonetheless attempts to make meaning with available information. Without a sense of how these conditions were affecting their group, largely due to the variable presentations of ARF (such as chorea, or joint pain and fever), the complexity of the disease pathogenesis and the usually short hospitalisations and short duration of the presenting symptoms, there was no perception of a ‘group problem’ despite having such high rates. This meant that no catalyst existed for communities or groups to address the problem themselves and people remained embedded in their normal life activities without understanding how the conditions were affecting their children’s futures. An exception was the community leader mentioned above. When a level of critical awareness was reached, after many research interactions, this became a catalyst for change. When patient education was delivered in community spaces, with adequate time and using Aboriginal language and worldview constructs, along with an attitude of respect, families spontaneously viewed the timing of the injections as their responsibility and were self-motivated to work on this.

**Connecting with Clinic Care for ARF and RHD**

The health care that young Aboriginal people and their families receive for ARF and RHD was variably perceived across the four remote sites but with some common factors. All health services operate in English, the national language, and there was ubiquitous non-recognition of the difficulties this caused for Aboriginal patients without English as a first language, as well as for clinicians and other health centre employees in communicating their health messages. Aboriginal languages represent Aboriginal people’s identities. Clinicians’ communicative incompetency, based on a lack of awareness, is argued to be an unrecognised social and structural determinant.
of ARF and RHD in this setting. Insistence on a predominantly biomedical frame for health service design in Aboriginal communities negatively impacted on Aboriginal patients.

In some health clinics, patient spaces have become increasingly separated from clinician spaces which constitutes a contact zone and a border to be negotiated and in which Aboriginal patients find difficulty. In other clinics, ironically with older buildings, there is more fluidity and mingling of these spaces, reducing this barrier for patients while making it more difficult for clinicians to operate from a purely biomedical stance. There is passivity on the part of patients connecting with health services deemed to be due to facts of history where health services had transitioned from mission to government management with seemingly little collaboration or corroboration with local community leaders and therefore with control being retained by outsider clinicians. For those with positive experiences of the mission era, there is an accompanying sense of loss of some beneficial characteristics such as longevity of staff and a focus on caring and working together. Overall, there is general disconnection between community people and their increasingly busy health services which tend to maintain a clinical focus in their work. The effects of this on patients with ARF and RHD are limited opportunities to learn about their conditions or to take an active or meaningful part in their care. This is demonstrated in children who are prescribed long term injections not being able to negotiate the location or the way they receive their injections, especially regarding reasonable pain relief.

The effect of high staff turnover, combined with recruitment of short term staff without local knowledge or experience in chronic conditions care, as found in the SP Study results (Ralph et al, under review), is that relationships developed between
Aboriginal families and clinicians are ever shifting, and opportunities for continuity of care are negligible. This also means there is a corresponding lack of opportunity for clinicians to gain more than superficial knowledge about cultural characteristics of their clientele that could enhance their clinical practice. For these reasons, clinics were observed to often be locations of employee stress, leading at times to decreased standards of care.

**Self-Care and Health Service Design**

The concept of self-care as promoted in current chronic conditions care, including the Chronic Care Model, did not exist among families with ARF and RHD. Health care delivered in local clinics was an entity initiated and provided by *outsider* others, and the learned expectation was that it was others’ role to provide it. Thus, passivity towards clinic care was observed. Self-management and self-management support for chronic conditions as construed in the Chronic Care Model is determined in this setting to currently be a poor cultural fit. The option of partnering in a health care relationship with clinicians was not apparent to Aboriginal families with ARF and RHD attending local health services, and considering the colonial historical background, this is not surprising. Additionally, if there was any sense of partnering, it was thwarted by continual turnover of clinicians and other employees. In the one site where self-management support was provided by one clinician, it was not looked upon favourably by local colleagues. The apparent power that is held by white clinicians in this setting, and internalised by Aboriginal families, means that relationships are unequal, further inhibiting care partnerships.

Adaptation of ‘transition to adult care for children with chronic conditions’ for this setting holds high potential for providing the supportive relationships that children with ARF or RHD need in order to navigate their adolescent and emerging adult
years safely with regards to their medical conditions. Engaging local people in this model as navigators and mentors, linked with their health clinic, was deemed to be a requirement for this model to be effective. Additionally, the focus on adolescence in the transition care model and the continuum of individual coordinated learning are prime factors giving it relevance to the study setting where childhood and adolescence are the predominant times when ARF is acquired.

**Community Level Factors for Care**

Traditionally, Aboriginal cultural stance and practices held their young people, and this holding remains, although it is recognised that cultures are dynamic. Grandmothers were found to be a key relationship for grandchildren’s wellbeing, particularly for adolescent grandsons. With intrusions of the now-dominant white society into Aboriginal lives, remote-living groups were observed to experience increasing stress. Some families had personal capacity to ameliorate the impacts of white dominance by bracketing their own lives, maintaining traditional practices and filtering the outside, ever-changing influences and intrusions. Others fell into dysfunctional despondency and cultural hopelessness. This impacted the potential resilience of young people who acquired ARF in those families. Highly stressed families needed service flexibility and increased awareness and understanding of their social situations by clinicians. Health services delivering care in remote communities did not recognise these and other social characteristics of their target clientele to enable health care design to match the social situation. All families experiencing ARF and RHD were keen for their children’s wellbeing to be maximised. Children and young people needing to have open-heart surgery for their failing hearts because of poorly managed ARF and RHD is viewed as a toxic embodiment of structural violence in this setting. This means that structural help is
required while waiting for improvements in their social situations that may lead to a reduction in incidence of ARF.

**Integrated Discussion**

**Unravelling Gudjuk’s Early Death**

Gudjuk was the first case study presented early in chapter three where I was an actor, firstly as a remote area clinician and family friend, then as a visiting patient educator. The following discussion has implications for young Aboriginal people such as Gudjuk who, although he lived in a resource-rich nation, passed away at the age of twenty years from a preventable condition despite being part of a caring and close-knit family who, it is believed, held hopes for him to become a future leader. It is critical that health services and public health systems understand the intricate web of occurrences and perceptions that caused Gudjuk’s death, both from the clinical and the family views, because addressing these issues is where public health solutions to the conditions of ARF and RHD lie. Even if a vaccine against group A streptococcus is developed within the next decade, there are still many young Aboriginal people living with ARF and RHD, and a trickle of new ARF cases continues. Current endeavours to stem ARF are not yet working. These young people with a new diagnosis of ARF are now on a path that urgently requires health services to make adjustments, find new ways of approaching their work and new directions for solutions; in essence, to decolonise their work. The following discussion begins with reviewing the model underpinning remote public health care for chronic conditions in recognition of its impact on the ground. This leads into recommendations for new approaches, with better understanding of the contextual issues. New understandings
may strengthen health care and ultimately, go towards preventing the occurrence of ARF in remote Aboriginal communities.

**The Chronic Care Model: Connecting with the Public in Public Health Care for ARF**

The Chronic Care Model (CCM) (Figure 2.2) is a widely used framework employed to improve chronic conditions care and was the framework for the SP Study where my study was nested (Coleman, Austin, Brach, & Wagner, 2009). It is discussed here in relation to my findings, with a preamble on the SP Study. The CCM was selected for the SP Study due to its wide use and because it currently underpins the Chronic Conditions Strategy for the NT. Results of the SP Study were overall disappointing in that the expected increase in the number of injections delivered for ARF was not achieved (Ralph et al., under review). One conclusion is that the length of time needed to achieve change in health service delivery and patient behaviour was longer than the fifteen months provided, and this is confirmed in other research using the CCM, for instance to improve diabetes care in a low-resource setting in North America (Chin et al., 2007). Research in North America among 42 health organisations, agreed that it is difficult to see benefits from implementing CCM interventions in just one year (Pearson et al., 2005). To address cardiac care for remote communities in Queensland, researchers deemed that a 10-year approach at a minimum was vital to effect change (Tibby, Corpus, & Walters, 2010). The qualitative component of the SP Study (Read et al., under review) highlights nuanced reasons within the health services for failure of the CCM to impact the number of injections delivered in the study sites, recognising that there could still be some delayed positive impacts of the study.
Ethnographic Study: Connecting with Community Linkages and Self-Management

The CCM contains six components shown to improve quality of care and patient outcomes, especially where more of the model’s components targeted for improvements work synergistically (Coleman et al., 2009; Pan American Health Organization, 2013). The challenge is to devise interventions with uniformity across the scope of the CCM and previous findings illustrate this is often challenging. Pearson et al reported that it is difficult to deliver interventions across all six components (Pearson et al., 2005). The two components of the CCM where my ethnographical study focussed were ‘community linkages’ and ‘self-management support’. These are repeatedly reported as the most difficult components for health services to work on (discussed below) and I endeavoured to understand what is required from the communities’ perspectives for these components of health care for ARF and RHD to be effective.

Community Linkages

Exploration of the CCM literature reveals inconsistency in the way that the ‘community’ component of the CCM is conceptualised and described. This is considered important for my study context where small residential settlements on Aboriginal land are the communities in question and primary health care services are placed within those communities. The ‘community’ in this context, is both a location and a tight social milieu. For the community component in the CCM, many authors use the text ‘community linkages’ although this term does not appear in explanations of the original model (Coleman et al., 2009; Pearson et al., 2005; Si et al., 2005). Other authors use the term ‘community based resources’ (Cramm, Strating, Tsiachristas, & Nieboer, 2011; Glasgow, Tracy Orleans, Wagner, Curry, & Solberg,
2001) and yet others just the ‘community’ (Barnes, 2009). In one study the community component was left out altogether in a seemingly permissible discussion of the health service elements for chronic care with no reference to the community (Cramm, Strating, & Nieboer, 2014). No matter what it is named, the spirit of this element, as intended by the model’s designers, was to urge the health system to look outside itself.

In this discussion the term community linkages is intentionally used to evoke the differences between Aboriginal community milieu and the health institution therein. I characterised ‘community’ in reference to my study sites in Chapter three as being small in scale permitting people to know each other well; having a strong sense of identity and belonging as a member of a group (which may be a clan), and having obligations to participate in social functions within their specific worldview. Additionally, the communities participate in unique cultural traditions such as methods used for hunting for natural local foods and traditional or traditionally-based ceremonies (Tesoriero, 2010).

While health practitioners could be described as also belonging to a community with certain characterisations, the point here is that these two entities—health services and Aboriginal communities—are socially and ecologically very different meaning that linking will not occur easily or naturally. This is the crux for community linkages in this study setting. Gilchrist refers to community linking in the domain of community development as occurring “between people or organisations beyond peer boundaries, cutting across status and similarity and enabling people to gain influence and resources outside their normal circles” (Gilchrist, 2009, p. 12). This describes the linking required for the study context and embodies the health system ‘looking
outside itself’ that is critical for health care partnerships to form. As Chambers states referring to viewing the world from the position of one’s learned professional training, or ‘community of practitioners’, that training “may also be disabling because it gives you pre-set frames, concepts and words into which you fit reality, and defined boundaries, and these affect what you see and what you do not see” (Biekert & Gasper, 2013, p. 170). Thus, clinicians in remote community health services may have little insight into the deep and historical entities of the communities where they work, compounding the difficulties in creating and maintaining linkages.

Si et al conducted a systematic review on the effectiveness of the CCM in general, as well as analysing its effectiveness in supporting chronic illness care in Indigenous communities in the NT and found that studies consistently reported that community linkages as the hardest element for health services to devise interventions for, and therefore improve (Si, Bailie, Cunningham, et al., 2008; Si, Bailie, & Weeramanthri, 2008). They concluded that there is less certainty around the benefit of the community linkages component of the CCM because it is harder to implement with intensity. Pearson et al agree with this summation (Pearson et al., 2005). Findings in this thesis add to understandings as to why it is difficult to instigate interventions in this component of the CCM in this setting, including for ARF care. That is, primary health services had high clinic-centred workloads, did not recognise the value of a foundational connecting with their communities to design appropriate and relevant health care or how to go about this, and lacked broad based insight into the history and current effects of history in the Aboriginal communities.
Community Linkages and the Contact Zone

The only available western health care for Aboriginal people in remote communities is in small local health services (Si, Bailie, Cunningham, et al., 2008). Yet these health services are overwhelmed with the high needs of Aboriginal clientele due to high rates of all chronic conditions as well as acute ailments, as seen in the following statement from the NT context, “all health service staff reported that acute care demands often prevented the development of community relationships that may have improved chronic care” and, “under-recognition of the worth and benefit of staff working out in the community, lack of effective communication networks and support arrangements with other organisations” reduced the effectiveness of the CCM (Si et al., 2005; Si, Bailie, Cunningham, et al., 2008, p. 7). The authors concluded that interactions between health care providers and patients needed to be enhanced to improve chronic conditions care.

My study findings support this position: the health centre contact zone was increasingly difficult for Aboriginal patients to negotiate for their ARF care. This was apparent in the increasing physical barriers such as locked gates, swipe-card locked doors, perspex windows in reception areas and even at times in the nature of questioning that patients faced in the first instance before getting access to a clinician. Some patients found this questioning affronting as it conflicts with their social mores which dictate that a barrage of open questioning is impolite. This operational approach at the point of first contact between the health service and Aboriginal patients often revealed that the ‘questioner’ lacked local knowledge, such as the impoliteness of this act. Difficulties hearing and saying Aboriginal names, or the erasure of those names in favour of an English substitute, meant that patients were disempowered ‘at the front door’.
The health centre is not currently a location conducive to expressing community linkages for improving chronic conditions care. In carrying out my field work I had capacity to spend time in the communities with young patients and their families, sometimes attending the clinic with them and developing relationships. This relating included carrying out education sessions on request, which led to increased family knowledge around ARF and spontaneous motivation around injection timing.

Aboriginal people frequently commented that their preferred location for connecting as described in this discussion is in their community spaces. Expression of poor connecting with their health centre was heard in the notions of the clinic lying to them and information being purposely hidden.

It is argued here that there is enough background literature, social theory, (for instance decolonisation, fundamental cause theory and anti-racism), and local reasoning to conclude that improved health service linking with Aboriginal communities is beneficial and desirable for improving chronic conditions care (Castro & Farmer, 2005; Blue, Shove, Carmona & Kelly, 2016; Farmer, 1999; Moran, 2016; Paradies, 2016; Reich, Hansen & Link, 2016).

**Self-Management**

Self-management is a recent concept tied to the escalation of chronic conditions globally, and in realisation that old ways of doing health care were not going to be sufficient for big increases in demand. Some authors additionally argue that self-management reflects current reductionist philosophy of individualism and economic imperative (Blue et al, 2016; Cohn, 2014). Thus, self-managing is good for the economy and society.
Self-care or self-management of a chronic condition was not a construct that was familiar, understood or accepted by Aboriginal community members in this study. My findings echo those of Senior and Chenall among a similar population group. There was no “perceived ideal that involved using the clinic as a resource to actively manage an individual’s health care” (Senior & Chenall, 2013, p. 159). Senior and Chenall tie this to Aboriginal people’s health beliefs that the clinics had responsibility for the community’s health which led to passivity on the part of Aboriginal attendees. As found in this study, Senior and Chenall determined that the structure of the clinics and differences in expectations between clinicians and community members made it difficult for self-management to emerge as an acceptable concept.

On the other hand, my study found that culturally-based social structures existed that could be engaged to enhance ‘activities’ of self-management such as grandmothers’ position of carer for adolescent grandsons. Additionally, people’s requests for calendars once they gained critical awareness of the penicillin injection timing indicates that self-management has potential in this setting if it is approached in participatory ways and based on critical patient awareness. The crucial point in discussing self-management for ARF and RHD is that it is predominantly children who acquire ARF, necessitating self-management to be applied to primary carers and children, as well as across cultures and languages. Compounding these challenges is the fact that ARF is not viewed as a serious condition by many Aboriginal patients largely because it is asymptomatic between acute episodes, and even acute episodes may have mild symptoms only, so it does not appear serious, meaning no out of the ordinary care is called for (Senior & Chenall, 2013; Vass, Mitchell, & Dhurrkay, 2011). As one father stated, he thought the penicillin injections for his son were just
another of the usual unexplained activities of health services which did not require special parental concern or involvement.

**Connecting for Self-Management Support**

The definition of self-management support as presented in Chapter one was that it is a process that requires partnerships between health practitioners and patients. It involves patient education, negotiating care plans, collaborative goal setting and continuity of care in respectful relationships with time to effectively communicate (Harris et al., 2008; Langford, Sawyer, Gioimo, Brownson, & O'Toole, 2007). Self-management support “involves the people with the chronic disease becoming participants through learning and practicing new skills to carry on an active and emotionally satisfying life in the face of a chronic condition” (Lorig, 1993; Northern Territory Department of Health, 2012).

Si et al (2008) reported that the CCM component of self-management support has been effective in producing improved patient outcomes whereas my findings, and those of the SP Study, revealed that self-management support was not well understood by NT remote area clinicians, and, as just discussed, self-management was not a construct that Aboriginal patients in the setting were comfortable with, thus implicating contextual factors as important moderators of this component of the CCM.

Factors that increase the challenge of providing effective self-management support in the NT remote setting are that the setting is 1) cross cultural, 2) bi-lingual, and 3) relatively recently post-colonial, and the target group for self-management development, as mentioned above, are young; children, adolescents and emerging adults. Additionally, many young people with ARF and RHD felt normal and
therefore did not perceive a need for deeper relationships with health service providers.

Several studies have shown that self-management support has not yet been internalised as a care construct among clinicians in general, despite many tools and policy documents being available. Battersby et al state that “chronic conditions programs in Australia are at an early stage of evolution” and feels that their inclusion in Aboriginal communities is enormously challenging (Battersby et al., 2008, p 72). A pilot study among remote Aboriginal communities in South Australia showed that self-management support was acceptable to community members, but the social needs were so pressing and hard for clinicians to address that this precluded success (Battersby et al., 2008). This indicates that self-management support requires in-depth understanding of historical, social, political and cultural factors in remote Aboriginal communities.

**Culture and Self-Management Support**

The CCM is a construct of western health care and to be successful, especially in the elements of self-management support and community linkages, an equal power relationship is the basis for clinical interactions to develop into partnerships. I argue that for such relationships of equal power to form, much more needs to be understood by clinicians about Aboriginal people, their histories and their social practices.

For instance, Aboriginal cultural social constructs value group identity which at the same time respects and values individual autonomy. Therefore, group-based chronic conditions care rather than self-management may be a more culturally-aligned approach. In this instance, culture, as expressed in people’s languages, their kinship
networks, social practices and their world view, is an unrecognised, underutilised and an undervalued resource. In contrast, Kowal argued that the act of categorising culture and indigeneity may be better left alone and replaced with a less seemingly separatist approach (Kowal, 2015). However, on a background of various political ideations such as assimilation and self-determination, in vogue at various times in recent Australian political history, I contend that Aboriginal culture has not been understood well enough to leave it alone. It remains poorly understood by white people in general, and by white institutions working within Aboriginal communities. Valuing Aboriginal cultural constructs as a resource and a starting place, has not, if ever, been fully achieved among white institutions working in remote communities. Overlooking this resource as a starting place is described as a deficit by Moran in case studies of such institutions working in Aboriginal communities (Moran, 2016). In the realm of health services in the NT, understanding of the current expressions of culture of the Aboriginal people they serve is also poor. Some of the reasons behind this are explained in the following paragraphs.

**Conventional Biomedical Approaches in the Setting**

Results of this study reveal that today, in remote Australia, ARF and RHD among young Aboriginal people are pressing public health problems. Clinicians and health services in the ARF-affected locations tend to approach their work from a conventional biomedical stance which is fundamentally clinical and focussed upon individuals. Clinicians use their skills to solve individuals’ health puzzles, with the aim that those individuals are either healed or their condition is controlled. For instance, clinician’s expertise is needed to diagnose ARF and their qualification is needed to prescribe penicillin and to administer it. The elements of the CCM that generated most activity in the SP Study were based within this clinical domain. For
instance, making the change in computerised recalls for patients’ penicillin injections from monthly to 21-day intervals was an attempt to better follow the medicine prescription and keep patients’ blood levels of penicillin at adequate levels.

Thompson describes biomedicine as a “community of practice ‘welded’ together around shared ideas, principles and values” which are cemented over a long training trajectory and which also provide strong social identity (Thompson, 2015, p 91).

Public health work on the other hand is not primarily clinical or based on individuals, but also values social justice and equity and works at the population level (Thompson, 2015).

With escalation of chronic conditions among the remote Aboriginal population, primary health care services are now finding increasing difficulty in providing for changing population health needs. There is a need for public health expertise and a shift to prevention to curb the escalation of chronic conditions such as ARF. Yet there is a struggle in this. Brassolotto et al describe this struggle as due to tensions arising from the use of a “framework of individualism” in trying to address a population context (Brassolotto, Raphael, & Baldeo, 2014). Discourse in this framework talks of targeting risk factors, which in the instance of ARF includes being Aboriginal, young, residing in a remote community in a crowded house and having a continual exposure to group A streptococcus (Nutbeam, 2000). To reduce the risk of ARF, the circulation of the bacteria must be curtailed. This is a biomedical view which invokes individual behavioural changes such as treating skin sores in children, recognising and treating sore throats and scabies, plus improving hygiene.
Social Determinants of Health and Health Equity

Social determinants of health are well described in a multiplicity of international health and government documents, and the literature, as being root causes of Aboriginal poor health and a key locus for prevention work (Baba, Brolan & Hill, 2014; Donato & Segal, 2013; Marmot, Friel, Bell, Houweling & Taylor, 2008). It is difficult to achieve risk reduction as described in the previous paragraph without addressing structural issues such as adequate supply of public housing, economic advancement, reduction of institutional racism and the like. This automatically places prevention work into the political domain, evoking broad factors such as new policy and funding provision in order to change the conditions in which people live (Baum & Fisher, 2014). Brassolotto et al explain that those working on the social determinants of health still tend to take the view that social determinants are primarily risk factors, “more or less decontextualized from broader public policy approaches and structural inequalities” (Brassolotto, Raphael & Baldeo, 2014, p 327). This approach aims at individual behaviour change to improve health by imagining that, for ARF prevention for example, an individual can alter their risk of streptococcal exposure on their own, within a new house which may still retain high occupant density and non-functioning hardware.

In effect, work on both individual and political fronts is required; work among individuals or family groups, and among those political structures that impact “environmental, social, cultural, economic and political settings in which people live” (Baum & Fisher, 2014, p. 219). This author recommends that community development strategies are best placed to address social determinants of health in Aboriginal communities which places it outside the current scope of primary health services.
Other recent investigation of health policies in Australia found that “strategies to address health inequities predominantly consisted of health care or individualised promotion/prevention strategies (Fisher, Baum, Macdougall, Newman, & McDermott, 2016, p. 557) thus revealing that there is still some way to go on shifting the policy front from an individual lens to a population and equity-based lens.

**Moving on from Individualism and the Social Determinants of Health**

In progressing and deepening the discussion on how to address public health problems such as ARF in Aboriginal communities, an emergent approach moves on from either attempting to change individual behaviour or focussing on the structural social determinants of health. Blue et al argue that a more accurate conceptualisation of social in such settings is required and they propose investigating social practices of people as more pertinent to finding solutions. In order to find solutions to ARF, especially how to prevent it, unpacking the bundle of shared social practices that are driving it holds strong potential for devising solutions. This unpacking will likely include the structural social determinants of health, such as housing, but will provide deeper and more nuanced social understandings that will point to solutions. Nutbeam promotes a similar more sophisticated and comprehensive approach to community education for public health issues (Nutbeam, 2000). The value of investigating the social practices involved in housing and crowding are described in the following section by way of example and in response to my observations on the domestic boundaries of houses for young people growing up with ARF in Chapter six. At times, large numbers of people ‘used’ one dwelling and the designs of new public housing appeared less appropriate than older designs.
The Example of Housing

Taking a ‘social practices’ approach, just how people live in a house is what needs to be understood by public health workers, that is, house dwellers’ relationship-based values, conceptualisations and social practices to do with how they reside in their dwellings and the nature of their households. As the above authors point out, social practices are entwined with other practices and are not static. Environmental architectural studies reveal that sleeping locations in Aboriginal houses can be fluid and founded on the social kin status of who is currently present at any one time (Memmott, Greenop, Clarke et al, 2012). I observed this fluidity among participants in my field work. The above study also revealed that this practice is at times a strained one due to a (general) lack of enough sleeping places for the number of people needing to sleep, indicating a house supply and design problem. Musharbash found that household patterns for sleeping locations are dynamic and dependent on the sociospatial availability as well as peoples’ dislike of being alone (Musharbash, 2003).

Unpacking some of the social practices of ‘living in a house’ has revealed that housing policy and Aboriginal kinship norms are entwined in the social practice of living in public housing in an Aboriginal community, and this is where greater understanding is required to facilitate public health improvements for diseases such as ARF (Memmott, Greenop, Clarke et al, 2012).

The Example of Crowding

Crowding and overcrowding are common descriptors applied to current public housing in Aboriginal communities and are closely tied with the social practice of how people live in a house (Bailie & Wayte, 2006; Bailie, McDonald, Stevens et al,
2011; Brown, McDonald & Calma, 2007). Use of the term *overcrowding*, a tautological construct, is likely aimed at emphasising inadequacy of housing provision in Aboriginal communities and frustration that improving this situation is so slow (Brown et al, 2007). Memmott and others have analysed household crowding in relation to the stress which it may or may not cause for Aboriginal residents. Perceptions of crowding and impacts of crowding in Aboriginal dwellings is an intricate subject, including starting with the definition. This topic has been demonstrated as not being well understood by either public health researchers or housing policy makers (Memmott, Birdsall-Jones, & Greenop, 2012).

In measuring household crowding and density, Memmott et al 2012 argue that foundational measuring instruments for Aboriginal housing occupancy are flawed due to reliance on the Canadian National Occupancy Standards which are based on Anglo ways of living that are known to differ from Aboriginal ways (Memmott, Greenop, Clark et al, 2012). Additionally, it was found that stress on residents of houses is not related to the number of occupants but rather to control over who stays and their behaviour (Memmott, Greenop & Birdsall-Jones, 2014). Fien et al state regarding family visitors to households that, “most visitation was unplanned and unannounced and, hence, unable to be planned for within daily family routines” (Fien et al., 2008, p. 31). While this may be true, Peterson concludes that what is termed ‘demand sharing’, meaning that relatives who are visiting will not be refused sleeping space, “is a deeply sedimented social practice often well removed from self-conscious calculation” (Peterson, 1997, p. 189).
Potential to Understand Social Practices Driving ARF

In a similar vein, social practices of living and crowding could be analysed with a view to understanding the ways that group A streptococcus is likely to be passed from person to person and how this can be realistically alleviated. This is important for three reasons. Firstly, because substandard housing and crowding are so frequently named as drivers of ARF by researchers, insight and explanations of just how they drive it is required. A more deeply nuanced understanding is needed beyond the statement that poor housing and crowding lead to greater exposure to group A streptococcus. Secondly because instruments currently used to measure housing density and occupancy in Aboriginal communities are argued to be flawed, the true levels of crowding are likely higher than reported thus reducing ability of housing authorities to plan accurately to alleviate supply problems (Memmott, Greenop, Clarke et al 2012). Thirdly, on the background of reduced power and control among Aboriginal people, sensitivity is required in measuring and discussing Aboriginal people’s personal spaces and personal hygiene practices, and this provides an opportunity to enlist Aboriginal researchers with the aim of gaining accurate insight into social practices and operating in culturally respectful ways. Bailie and Wayte argue for stronger local research on this topic (Bailie & Wayte, 2006).

Understanding the Social Context

Critical and accurate understanding of current social contexts and related social practices in Aboriginal communities is vital for all service providers. Without this social understanding, effectiveness of their work is greatly curtailed. In the pilot study mentioned previously, where Aboriginal Health Workers (AHW) interviewed Aboriginal community members about diabetes, AHWs were overwhelmed by social
needs, “AHWs were confronted with the problems of overcrowding, inadequate housing, finances, drug and alcohol misuse, domestic violence and unemployment” and the “inability to provide solutions also caused some patients to lose confidence in the system” (Battersby et al., 2008, p. 71). This indicates that analysis of social contexts may be confronting. However, in a positive example, researchers investigated the social practices of active living among Aboriginal community people and discovered key information leading to solutions for directing exercise programs for Aboriginal people (Thompson, Chenall & Brimblecombe, 2013).

**Community Development Principles and Partnerships**

Given the difficulty identified in this and the overall SP Study in fostering genuine healthcare and community connecting, clear strategies for managers and employees of health services are needed to achieve this. Corpus argues that the required starting position for connecting between a health service and remote community Aboriginal people is “to empathise with those marginalised or disadvantaged communities along with acknowledgement and understanding of the history and grievance suffered” (Corpus, 2014, p. e35). In collaboration with colleagues, Corpus established an innovative cardiac care outreach program in remote locations in Queensland by using community development principles that, based on firstly understanding the historical position of Aboriginal people and their traditional cultural values, was then able to weave those values into their service design (Tibby et al., 2010). RHD is one of the conditions they address. They concluded that “traditional values can work harmoniously with an inclusive medical approach in a relationship” but this was only possible by partnering with a community development practitioner and using community development principles (Tibby et al., 2010, p. 366). Other authors have found that a sticking point in attempting similar strategies was clinicians’
unfamiliarity with participatory processes, unwillingness to share control and devaluing of local knowledge (Campbell, Wunungmurra, & Nyomba, 2007). These authors believe that, although community development principles are mentioned as intentions, those delivering primary health services in Aboriginal communities pay lip service to the notion of community development and partnerships where local knowledge, culture, resources skills and processes are valued (Tesoriero, 2010).

While only a fraction of Australia’s overall population has ARF and RHD, our attention must be turned to the remote Aboriginal populations with these conditions because the conditions are preventable and could be argued to be a product of inequality and poor infrastructure (Onen, 2004). While Australia is not a developing nation, the conditions in Aboriginal communities remain akin to those of the developing world, adding weight to a community development approach (Brown, McDonald & Calma, 2007).

**Health Literacy around ARF Needs to Reach Critical Awareness**

Young patients and their families in this study had minimal knowledge or understanding of their health conditions, ARF or RHD, which impacted their adherence to the injection regimen and thus their outcomes. While the penicillin injection regimen, prescribed after a diagnosis of ARF, has been shown to be effective in preventing recurrences, adherence to the regimen is well-documented as being troublesome in many locations globally (Bassili et al, 2000; Kumar et al, 1999; Gasse et al, 2013; Musoke et al 2013). These included elements that are not applicable to the NT setting such as needing to pay for transport to clinics and for medicines. Reasons for poor adherence in other settings are claimed to be only partly due to low patient knowledge and understanding of the purpose for the regimen. In
this current research, few, if any, participants understood ARF or the purpose of the injections other than them being “for their heart- to keep their heart strong”. If people did not know the purpose of the injection and the critical timing factor for injections, then it was given low priority in many families. For some this led to experiencing recurrences of ARF and compounded heart valve damage. It additionally placed the onus on health services to locate patients for their injections. Thus, adherence was impacted by health services’ abilities to locate patients as well as patient’s availability to receive injections once located.

It is argued here that, in general, patients developed a laissez-faire attitude to the injections due to a combination of poor knowledge and understanding about the medication and its critical timing, and learned passivity towards health clinician’s activities based on historical experiences. At times patients used refusal or deferring injections as one way to express control over their lives from the intrusion of white clinicians which is not unexpected in a situation of post-colonisation, unequal power and competing world views.

The finding of low levels of patient knowledge is supported by other studies in the setting, with other chronic diseases, and demonstrates the slowness in affecting change within this domain in the NT (Anderson, Devitt, Cunningham, Preece, & Cass, 2008; Cass et al., 2002). This could be an effect of white power and biomedical dominance in the health services caring for Aboriginal people, or it could be that the health needs caused by escalation of chronic conditions are increasing too rapidly for design of health care services to keep pace with changes.

The act of complying with prescribed treatments is multifactorial and in cross cultural and cross language settings, such as in this study, the added complexity
requires deeper understanding on the part of clinicians (Harrington, Thomas, Currie, & Bulkanhawuy, 2006; Humphrey, Weeramanthri, & Fitz, 2001). I argue that patient education for community members in this setting, and similar settings, is outside the usual range of clinician’s skills and requires the expertise of other disciplines. Currently it remains difficult to state what place patient knowledge and understanding of their condition has on the outcomes for ARF and RHD in this setting because currently the only situation is that of low health literacy. Nutbeam contends that the role of patient education has been underestimated due to concentration on risk factors and individual behaviour change (Nutbeam, 2000). Battersby et al argue that information alone is insufficient to improve health outcomes and shared decision making should be aimed for (Battersby et al 2010). However, shared decision making is contingent on a certain level of patient understanding of their condition.

A new finding in this study is that Aboriginal adults consistently showed spontaneous perception of the responsibility for the timing of the injection as theirs, and not their health services’, upon reaching critical awareness. This flies in the face of clinician’s laments that Aboriginal patients do not take responsibility for their health and adds weight to the notion that patient education has a positive effect on adherence when it includes certain attributes. In this instance the attributes were: unpressured time to conduct information sharing; information sharing conducted away from the health service; having a facilitator who is adept at cross-cultural community education in the local context; use of methodology which raises learner’s critical awareness including the use of relevant tools and empowerment through dialogue in patient’s first languages.
Study Limitations and Methodological Challenges

The SP Study research was undertaken in health centres in remote communities and employed a health system strengthening approach using the CCM. The aim was to increase the number of penicillin injections received by Aboriginal patients with ARF or RHD. The SP Study, along with its qualitative evaluation component, and this focussed ethnography, were designed without input from local Aboriginal communities or local Aboriginal researchers. This was a fraught situation because Aboriginal communities were not likely to request research into ARF without sense of a collective problem. This collective sense arose during my fieldwork and led to a new participatory research project being started. Although I was able to design the focussed ethnography as a component of the SP Study, I was constrained to working within the SP Study protocol.

A limitation of this study was that the NT has a large land mass and distances between small Aboriginal settlements are vast. Having four sites in this focussed ethnography meant increased travel and logistical work which reduced the time I was able to spend in each of the four locations. Having four sites and the geographical restrictions meant the depth of data was constrained due to the need to keep cycling through the sites. Additionally, my inability to recruit Aboriginal co-researchers due to serious illness, lack of availability and the death (from RHD) of one co-researcher part way through my fieldwork, limited the depth of data able to be obtained. It meant that I was restricted to operating in plain English in two of the sites where I did not have capacity to speak and understand the local language. However, where I could speak the local language, gaining in-depth understanding in a different world
view is difficult and working with an Aboriginal co-researcher for the duration of my field work would have enabled greater understanding.

**Study Implications**

*Expansion of the CCM to Suit the NT Setting*

As previously mentioned, the concepts of the CCM underpin the NT Chronic Conditions and Self-Management Strategies (Northern Territory Department of Health, 2009 & 2012). Findings in this research imply that refinement of the CCM would be beneficial in the NT setting to improve connecting between health services and the populations they serve. Refinements have been undertaken in other locations. For instance, Barr et al expanded the CCM in order to de-emphasise clinical work by adding more elements to the community section of the model. Population health promotion and self-managing were integrated in an emphasis on the community and Barr and colleagues state that the population health promotion field has a “strong emphasis on ensuring that community members are involved in planning for new or revised services” (Barr et al., 2003, p. 76). This holds relevance for the NT where involvement in planning and control of local health care services has not always involved Aboriginal leaders although the advent of Aboriginal corporations has been welcomed and good outcomes of Aboriginal community controlled health organisations are becoming evident (Australian Institute of Aboriginal and Torres Strait Islander Studies & the Lowitja Institute, 2017).
An additional expansion of the CCM also shifted the focus from clinical care to increase its applicability to the global setting, and developing countries in particular. This expanded version, named the Innovative Care for Chronic Conditions framework (ICCC), may be better suited to Aboriginal communities because of the emphasis on primary care settings (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004). The adaptation was intended to become a framework for policy development and system redesign in developing countries. However, it has applicability for policy improvement related to the remote NT setting in developing and strengthening partnerships with communities as well as enhancing the design of health systems in those locations.
The Innovative Care for Chronic Conditions (ICCC) Framework

The ICCC framework adds community partners to the central tenet, so that the health team, patients and families, and community partners work together. This frame better enables the placement of group management for chronic conditions that likely fits with Aboriginal social structures.

In what the authors describe as the meso level in their model, prominence is given to the community for involvement in chronic conditions care. It describes the echoing of essential messages about prevention and management to the community.

However, it is more important in the NT context, where world views of community members and western health services are so different, that the essential messages are
created in collaboration (Epping-Jordan et al., 2004). Otherwise nothing will alter; the same instructions that are devoid of intellectually convincing background will continue to be repeated (Vass et al., 2011). A key point in the meso level is that support given to communities to manage their health conditions i.e. self-management support is delivered outside the clinic.

A promising strategy embodied in the ICCC for the NT setting is leadership and advocacy in the policy environment. Changes are sustainable if they are supported by high level policy. More integrated and connected policy would protect against some of the isolated poor practices observed in my field work such as reporting families to welfare when injections were missed. This is important and also a challenge due to northern areas of Australia where remote health services are situated being fragmented by state boundaries and having large regions with both dispersed populations and health services. Examples of inclusively integrating policies for chronic conditions are provided by Epping-Jordan et al. (2004) with the main point being integration at all levels, for instance, with other governmental programmes and community based organisations.

The CCM and both the expanded models of the CCM discussed here can only be effective if there is a real partnership; connecting as equals. Weaknesses in connecting that were observed in my study impeded the SP Study achieving its aim of increasing the number of injections received for ARF. Health centre managers need to promote and actively facilitate meaningful community partnerships. The transient health staff themselves have no means of knowing how to connect with the community; structural change to enable connection is required.
It is critical in unravelling this situation that history is understood, and in particular the short duration of western health services within Aboriginal societies in the NT.

**Contribution to the Field of Public Health**

This thesis attempts to determine the experiences of those affected by ARF and RHD with a view to improving the situation. Current activities to improve management of these conditions among young Aboriginal people in Australia are focussed on improving the measuring of the disease burden, itemising the range of variables that are assumed to drive the conditions such as crowding, hygiene hardware and rates of streptococcal infections, development of a vaccine, portable echocardiographic heart valve screening and producing comprehensive guidelines for clinicians to manage the conditions. Understanding the socially-based variables is much harder and requires cooperation with other disciplines and local Aboriginal people. Patient education in a language people understand and from their world view is an important emphasis that needs to be implemented in this situation. This will enable the effect of patient knowledge on adherence to be more accurately determined in the setting.

**Recommendations**

Recommendations arising from this research are divided into two themes: improving care for children in the NT with ARF and RHD and prevention of ARF in the NT population.

**Improving Care for Children in the NT with ARF and RHD**

*Transition to Adult Care Clinic*

ARF usually starts in childhood or adolescence. To address adolescent health needs and take advantage of opportunities that adolescence presents for learning about a
chronic condition, an adaptation of the transition to adult care model for Aboriginal adolescents with ARF and RHD should be trialled in the NT. Design of the transition clinic should ensure it meets the needs of Aboriginal young people affected by ARF and RHD and ensure it is feasible within the setting of remote Aboriginal communities.

The design of this ‘clinic’ should be based on knowledge of the transition model in the literature, from other existing transition clinics and with cultural advice from relevant local Aboriginal leaders and those affected by ARF and RHD in the trial site. Patient Navigators or Mentors should be selected and provided with comprehensive training on ARF and RHD in their first language so that they can provide ongoing education to local patients in their first language. Patient Navigators or Mentors should be speakers of local languages, have insider understanding and knowledge of local cultural perspectives including understanding of the developmental stage of adolescence, know culturally-linked locations that local people move between and be accepted in the role by local people. Navigators should be linked with the local health service or the RHD Control Program and have access to certain patient data such as injection schedules and appointment dates. Monitoring and evaluation should be built into the design of the transition clinic to ensure it is meeting adolescent needs.

Peer Support Groups

Knowledge and understanding of ARF and RHD and related management is poor among the young population in the NT who have these conditions. Improvement in patient health literacy on these conditions is expected to have a positive influence on adherence to penicillin injections and anticoagulants, care in general among this
Local peer support groups, based on groupings occurring naturally according to local Aboriginal custom, should be created in the NT for young Aboriginal people and families with ARF and RHD. Exploration of the ‘group care’ concept in place of self-management and self-management support should be undertaken in the peer support groups. Local Aboriginal mentors or navigators should have oversight of and facilitate support groups. Such mentors require remuneration, integration with local health clinics and/or the RHD Control Program, as well as access to certain patient data relevant to the patients in their group, such as injection and appointment dates. Comprehensive education on ARF and RHD should be provided to the mentors in their languages to enable them to undertake this work proficiently. Educational resources should be provided to mentors. Regular outsider support and oversight of mentors should be provided to sustain the support group entity by quickly addressing needs that arise.

In recognition of the widely dispersed nature of Aboriginal communities in the NT, support groups should be expected to be small and numerous and to have differing characteristics. Due to the web of difficult socioenvironmental issues currently existing in Aboriginal communities, mentors’ roles should be projected as being to support young people and families to adhere to the injection regimen, learn about their condition and be supported in linking with local clinics. Instituting peer support groups may assist with improvements in connecting between remote health clinics and their local communities as families begin to perceive their health care needs with more understanding. Groups would also foster a sense of ‘community of people’ with ARF and RHD, which may lead to further advocacy and actions to address prevention. Such groups may also lead to links with other organisations in communities such as schools and sports clubs.
Hospital Program

Young Aboriginal people are admitted to either of two major NT hospitals when first presenting with ARF symptoms. This enables specialist management, testing to ensure timely and accurate diagnosis, and commencement of the penicillin regimen. The hospitals, in conjunction with the RHD Control Program, should devise a program specifically catering for new young Aboriginal patients with ARF. Instigating a new penicillin injection prescription in children and adolescents should trigger a program of priority care from the widest range of disciplines available in the hospital such as cultural advisors, adolescent health experts, paediatricians and pain management specialists. Electronic communication media, such as Skype, could be utilised to strengthen inclusion of appropriate disciplines and advisors.

Cultural and linguistic support should be provided as part of the program, including a set of specific ARF education messages deemed critical for ongoing wellbeing at that point in the illness. These messages should be created in collaboration with cultural experts and may include facts such as the need for at least ten years of injections, introduction to a community mentor, tools to help remember when injections are due and an explanation of the overall aim of care such as no recurrences of ARF and no valve damage needing valve surgery. The specific messages should be selected with the understanding that ARF is a complex condition and ongoing patient education is essential for best outcomes.

Overcoming structural barriers for disadvantaged families

Some Aboriginal families are vulnerable to suboptimal care for their child with newly diagnosed ARF or RHD due to difficult and complex social circumstances. Such patients should be actively identified as soon as possible after diagnosis. This identification should activate a special care plan in local health services. Flexibility,
cultural sensitivity and a ‘no blame approach’ should be hallmarks of such an approach. This means that local knowledge and cultural expertise is required to support such families. Support to overcome structural barriers, such as providing reminders, providing transport, locating local support people and giving injections outside the clinic environment is required to prevent toxic outcomes of ARF such as recurrences and ongoing cardiac damage leading to heart surgery in young people.

**Health Service Linkages**

It is quite common for Aboriginal young people to travel between culturally-connected locations. Collection of information on which clinics are connected in this way should be commissioned by the RHD Control Program and collated by cultural experts. Remote health services with such cultural linkages should create formal partnerships so that patients from linked clinics are considered part of each clinic’s ‘usual’ clientele no matter which location they are present in. Collaboration around delivering penicillin injections should be strong between connected clinics.

**Update of Guidelines on Pain Management**

The Australian guidelines governing care for people with ARF and RHD in the NT should be updated to include more comprehensive information on the effects of repeated painful procedures in children, reducing injection pain and the reasons for ensuring every injection is delivered with the best pain reduction method and emotional support possible. The updated version of the guidelines, or amendments, should be disseminated widely.

**Family Data on the RHD Register**

An RHD Register was commenced in 2007 in the NT which allows epidemiological measuring of status and outcomes of ARF for the NT. To strengthen the data, the
RHD Control Program should collate data describing immediate family relationships between patients with ARF or RHD. This data could serve two purposes: firstly, it would identify the appropriate next of kin/main carers for a young person (such as grandmother) to be contacted regarding medical care such as injections due dates. Use of such family data on the Register may enhance the well-being of adolescents by raising clinicians’ awareness of who to contact and who to engage with over substantial lengths of time. Secondly, it would allow high-risk families to be flagged, to ensure that primordial and primary prevention activities are offered to children in the family not yet diagnosed with ARF but at heightened risk. The data could also be useful for clinical appointments with specialists where families could be given grouped appointments. This data should be collated by Aboriginal adults with local knowledge in each location. As an exercise in respect for Aboriginal people, correcting errors in spellings of Aboriginal names, and collating correct names and addresses of patients should be collected concurrently.

**Prevention of ARF in the NT**

*Future research*

Insight is required to prevent ARF in young Aboriginal people in the NT. ARF is assumed to be driven by multiple strains and high circulation of GAS that lead to untreated pharyngitis and skin infections in Aboriginal children. Crowded, sub-standard and poorly maintained houses and fluidity in dwelling and sleeping locations are assumed to be a catalyst of these infections.

Mixed methods participatory research should be conducted into the complexity of social practices of Aboriginal families that may be driving ARF. This may or may not be critically linked with living practices in public housing, which is the most
common type of housing in Aboriginal communities (Christie, 2013). Research needs to uncover how to prevent spread of the bacteria. Due to the highly sensitive nature of this topic (people’s personal spaces, and possibly their hygiene and health practices), research should be designed and conducted with Aboriginal co-researchers from the outset and should be participatory in nature, with respect for Indigenous knowledge. It may be useful to include a history of Aboriginal housing and obtain Aboriginal people’s perceptions of their public housing as well as measuring true occupancy levels and fluidity of occupancy.

Rapid antigen testing for GAS is now available and may assist in determining the level of skin and throat infections in certain households or cohorts. Participatory action research is an opportunity for research participants to gain knowledge (for instance about harmful bacteria) and the possible links between public housing, social practices and GAS infections in children that are driving ARF. It also allows for development of ‘local insight’ into ways to prevent ARF and opens the possibility of advocacy to governing bodies based on findings, as well as to Aboriginal leaders and customary law custodians.

Public health campaign

Despite high rates of ARF and RHD among young people, Aboriginal communities have low levels of knowledge about these conditions and no sense of a collective problem. This situation makes it difficult for families and communities to work on preventing ARF and significantly reduces effectiveness of clinicians’ explanations. Attempts to carry out community education on ARF are currently fragmentary and often designed by health professionals working outside their area of expertise.
An integrated public health campaign on ARF should be conducted to raise awareness to critical levels among the dispersed Aboriginal population. Population language characteristics must be taken account of in the campaign. Although many Aboriginal languages are currently in use in the NT, certain languages have become the lingua franca within a region, thus reducing the number of languages for a campaign to approximately eight. Specialists in cross-cultural and cross-language communication, both Aboriginal and other, should be enlisted to work together to create pertinent educational messages around ARF and RHD in plain English with reference to the known structures of Aboriginal languages. The plain English versions should then be tested with local people, modified accordingly and worked into the predominant Aboriginal languages. These messages should then be used by media specialists, partnering with local Aboriginal people with a range of ages, to create campaign resources. Such resources may include radio broadcast messages, television messages, short films, smart phone applications and other culturally relevant media. Dissemination of local resources should be carried out in each language region, and coordinated by a central body such as the RHD Control Program or RHDAustralia. Although the costs in reaching a dispersed population are increased, this expenditure will be offset in the preservation of good health among Aboriginal children.


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Appendices
Appendix A

Participant information recording

Recording carried on my mobile phone for participant pre-consent and study information. Transcription and English gloss provided by Alison Mitchell. This language was applicable in two of my research sites.

- Ngarrany dhuwal [interpreter named]
- I am [interpreter named]
- Ga Bulanydjan dhulu narrany dhuwal nagnun
- and Bulanydjan asked me [Bulanydjan is the author’s subsection name and is a polite way to be addressed]
- naru dhu rirrakay dapmarranhamirr nhumalaŋ
- to make this recording for you.
- Bulanydjan'thun nguli gänha warkthunna wayjtjil
- Bulanydjan used to work in the hospital [to place researcher into time and known location]
- Ga dhuwal rirrakay dapmarranhamirr ga marr ga nhuma dhu náma
- and this recording is so you can hear
- nhä nayi ga dhuwal Bulanydjan'thu yuṯa djäma
- about Bulanydjan’s new work
- Bulanydjan’thu nhumalanydhu nän’thun dhiyak wark’gu
- marr ga nhuma dhu rrambaŋi warkthun dhuwal yuṯa djäma
- Bulanydjan would like to ask you if you can work together in this new work.
- Dhuwal wark núnhi yuṯa researchdja, mayali nayi larrum ga malŋ'marram
- This new work is research which means searching and finding.
- [Two health services named,] walal Bulanydjan’gala mam’thun marr ga walal dhu rrambaŋi djäma dhiyali dhi researchŋur
- [Two local health services named] are working together with Bulanydjan on this research.
- Ga researchdja dhuwal maltjanawuy rerripuy rheumatic fever ga rheumatic heart diseasepuy
- The research is about two diseases, rheumatic fever and rheumatic heart disease.
- Nhaltjana limurr dhu dhuwali mal'maramany gulmaramany dhuwali märrma rerri
- It’s about how we can find ways to stop these two sicknesses.
- Bulanydjan’da ga djälthirr nayi dhu waŋa yolŋuwal
- walalaŋgal nünün yolṯu ga dhuwalidhi rerri maltjana nayatham
- Bulanydjan would like to talk with people who have these conditions.
- nayindja Bulanydjan’da djälthirr nayi dhu náma nhumalangu yol’ŋupuy nhaltjana nhuma ga birrk’yun ga nayajuy mal'marlam
- nühidhi rerri marr ga nhuma dhu gunŋgayunnirmirra bala-räliyunmirr
- Bulanydjan would like to discuss with you, to hear what you think and feel about these conditions
- Ga nayiny ga dhuwal Bulanydjan’da djälthirr nayi dhu waŋa yolŋuwal
- walalaŋgal ga djamarrkuļiwal ga gurrutumirriwal
And she would like to talk to people, their children and families.

Yolŋuny dhu waŋa nhanukal luŋmarranhamirr wo gānhathu
waŋa nhanukal Bulanydjan'gal

People can speak in groups or by themselves with Bulanydjan

ŋayiny ga Bulanydjan'dja djālthirr ŋayi dhu mārrram riirrkay nhumalany
yorranhawuy mārr ga nhuma dhu waŋanhamirr bala-rāliyunmirr
gunga-yunnirrnga dhāрук dhunupayan ga rightyan gurrupan

Bulanydjan would like to record your story if you agree, so she can get your story correctly.

Ga junhi ŋayi dhu Bulanydjan' dhumbalyundja yākuy wānganydhu,
ŋunhi ŋayi dhu buku-roŋjiyirr ga do'yun nhunu ga mal'maram ŋuniyi yāku nhā
ŋayi mayali

And if she is not sure about something you say (in your language) she will return and ask you in order to get the right meaning you intended.

Ga dhuwandja junhi djamarriŋunjy nhumalaŋ ga rirrikthun ŋurrunjdi rērr

And if your child has this disease

Bulanydjan'dja djāl walal dhu ŋayi dhu djorra walalany gurrupan mārr ga
walal dhu drawing ōturrk

Bulanydjan would like to give them paper to draw their heart,

walal nhawaynha walal

how it appears to them.

Ga dhuwandja warkwuy researchpuydja Bulanydjan
ga djālthirr nhumalanydhu ŋāŋthun ŋayi nhuma nhauŋ dhu yorrar
ŋayi dhu nhumalany yāku warkthun ga bulu nhuma dhu djorra

signing

And for this research work, Bulanydjan would like to ask you to consent and to write your agreement on a consent form

yurr yaka ŋayiny dhu junhidhi yākuny gurrupan yoljuwaldja
walalangal bukmakkaldja, ŋunhiny dharrpalnha hnanju

researchkun

but she will not give your name to anyone else because it is confidential, for her research only

bili ŋayi ga malthun romgu researchgu ga dharrpalnha ŋayiny ŋunhi yāku

ga nhā ŋayi dhu mārr-maram nhumalangal dhāwu

because she is following research law that means your name and information must be kept confidential.

Bulanydjan'dhuny ga dhuwal djāma Charles Darwin University

ga Menziesngur

Bulanydjan is doing this work through Charles Darwin University and Menzies

Yalala ŋunhi dhā-dhawarryunamirri djāma hnanju ŋunhidhi research

ŋayiny dhu djorra mārrram yāku PhD

Later on when the research is finished, she will gain a qualification called PhD.

Nhuniyinyŋayi mayali ŋayi dhu dokta’thirrhna.

This means she will use the title ‘doctor’.

Yalalangumirriyi ŋayi dhu dhawarryuna dhuwal hnanju work

yāku research dhiyak Bulanydjan’gu ga ŋayiny dhu nhā ŋayi ga mal’maram
nhumalangal dhuwalagu rerripuy
• Later, when the work is complete, she will return to you to tell you what she has found
• Ga buku-djulŋimirri, nhinany ɲayi ga dhuwal galkun nhumalaŋ
• ɲuli nhuma dhu ɲunhany ɲāŋ’thundja nhā nhuma ga ɲayatham questions malany
• She is very thankful to you and is happy for you to ask any questions
• Galkun ɲayi gan nhuma marrtjin nhuma dhu bunha nhanukal
• ga wanj ɲanyany ga ɲāŋ’thun ɲanyany mala lakaram dhāwu
• and she will give you more information that you would like
• Yo thankyou
Appendix B-1

Consent Form: ARF/RHD clients 15 years and over

Rheumatic heart disease project - Improving delivery of secondary prophylaxis

This means you can say NO

- I have read and understood the ARF/RHD client information sheet for the above research study.
- I have had the opportunity to ask questions of the research team and these have been answered to my satisfaction.
- I understand that I do not have to take part in this research study and I can stop at any time.
- I understand that my information will only be used for this research study and will be kept confidential. My name and details will not be made public and nothing written in the reports will link me to this research study.
- I understand that my information will be stored in a secure place at Menzies School of Health Research and can only be accessed by members of the research team.

I consent to be interviewed and/or be part of a group interview for this research study.

<table>
<thead>
<tr>
<th>□ Yes</th>
<th>□ No</th>
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I consent to have my interview and/or group interviews tape recorded.

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<tr>
<th>□ Yes</th>
<th>□ No</th>
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I consent to participate in drawing.

<table>
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<th>□ Yes</th>
<th>□ No</th>
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</table>

I agree that some of my words or my drawings (but not my name) can be used in reports and publications.

<table>
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<th>□ Yes</th>
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Participant Sign: ...........................................

Interpreter/Witness Sign: ...... ...............

Name (please print): .................................

Name (please print): .................................

Date: ........................................................

Date: ......................................................

Research team only:

I have explained the nature and purpose of the research to the above participant and have answered their questions.

Researcher's name: ......................................

Signed: .................................................... Date: .............................................

Menzies understands that the ownership of Aboriginal knowledge and cultural heritage is retained by the informant and this will be acknowledged in research findings and in the dissemination of the research.

For more information about the project, contact:

Kerstin Bycroft– phone: 08 8922 8196 or email: kerstin.bycroft@menzies.edu.au
Appendix B-2

Consent Form: ARF/RHD client under 15yrs - parent/guardian consent
Rheumatic heart disease project - Improving delivery of secondary prophylaxis

This means you can say NO

My name is ____________________________, I am the parent/guardian of ____________________________, and

Print your name

Print your child’s name

- I have read and understood the ARF/RHD client information sheet for the above research study.
- I have had the opportunity to ask questions of the research team and these have been answered to my satisfaction.
- I understand that my child does not have to take part in this research study and my child can stop at any time.
- I understand that my child’s information will only be used for this research study and related research projects and will be kept confidential. My child’s name and details will not be made public and nothing written in the reports will link my child to this research study.
- I understand that my child’s information will be stored in a secure place at Menzies School of Health Research and can only be accessed by members of the research team.

I consent to be interviewed and/or be part of a group interview for this research study. □ Yes □ No

I consent to have my interview and/or group interviews tape recorded. □ Yes □ No

I consent to participate in drawing. □ Yes □ No

I agree that some of my words or my drawings (but not my name) can be used in reports and publications. □ Yes □ No

Parent/guardian Sign: ____________________________ Interpreter/Witness Sign: ____________________________
Date: _________________ Name (please print): ____________________________ Date: ____________________________

Research team only:
I have explained the nature and purpose of the research to the above participant and have answered their questions.
Researcher’s name: ____________________________
Signed: ____________________________ Date: ____________________________

Menzies understands that the ownership of Aboriginal knowledge and cultural heritage is retained by the informant and this will be acknowledged in research findings and in the dissemination of the research.

For more information about the project, contact:
Kerstin Bycroft– phone: 08 8922 8196 or email: kerstin.bycroft@menzies.edu.au

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Appendix B-3

Preventing rheumatic heart disease - Improving delivery of secondary prophylaxis

This is for you to keep

We would like to invite you to be part of our project – we want to find ways to better prevent and treat acute rheumatic fever (ARF) and rheumatic heart disease (RHD).

What is this project about?

This project wants to improve the way that doctors, nurses, health workers and other people in your health centre and in the Health Department care for people with RHD. We especially want to see if improving the ways that your health centre delivers care can increase the number of people with RHD who get most of their regular penicillin injections (which are given to make sure RHD doesn’t get worse). If this project works, it would mean fewer people getting acute rheumatic fever again and hopefully fewer people developing and dying from RHD. Your health centre is participating in the project and we would like to talk to you to find out more about what you think about the care you receive.

What will I be expected to do?

If you take part, we will ask you to talk to us, either on your own or in a group about your thoughts and feelings on how the health centre looks after you and what things would help you to receive your regular injections on time. If you agree, this conversation will be audio recorded and written down. This is so we can get your words right. You can say no to having your words recorded. If you want, you will have a chance to read the notes to make sure you are OK with the information we collected. This interview will take place in your community.
Can I choose not to participate?
YES. If at any point you do not want to answer questions or want to stop the interview you can do so. You can also ask later that the information you have provided be taken out from the project.

How long will it take?
The individual and group interviews may take between 45 to 60 minutes.

What are the benefits of me participating?
As a person with ARF/RHD, we hope that this project will improve the health systems that help you get your penicillin injections. We hope that through these activities your heart will remain strong and this will benefit you, your family, and your community.

The activities being tested in your health centre may also improve the health of people with other diseases by improving the overall way the health centre works. The findings of this project will also benefit other communities, both here in Australia and in other countries where ARF and RHD are major issues.

Who else is being invited to participate?
The project staff will be talking to ARF and RHD clients from all over the NT. Health centre staff and RHD programme staff will also be invited to participate.

Are there any risks for me in participating?
There is little risk from taking part. We do not think any questions we ask will cause you distress. If you do get upset or talk to us about something else that is upsetting you, we can organise extra help and support for you.

All the information you give us will be kept private. No names will be used in project or other reports. We understand that the Indigenous knowledge of Indigenous lives (stories around RHD care) collected during interviews and group discussions will remain in the ownership of the Indigenous participants.

How will my information be stored?
We keep all of your information in protected and locked files at the Menzies School of Health Research and it is only available to the researchers involved in the Project. We would only give it to someone else if you gave us permission to do so beforehand.

How can I find out the findings of the project?
Communication of results will be tailored for each community and health centre. We may use newsletters, media or other methods for communicating.
project results, depending on the needs and preferences of health centres and clients. Talk to the person who interviews you or to your health centre for more information.

**Where can I find out more information?**

If you have any questions or comments about the project, please contact Jess Singleton on 08 8922 6969 or jess.singleton@menzies.edu.au.

**Concerns and complaints**

If you have any concerns or complaints regarding the ethical conduct of the project, you are invited to contact the Ethics Administrator of the Human Research Ethics Committee of the NT Department of Health and Menzies School of Health Research on 08 8922 8196 or email ethics@menzies.edu.au, or the Secretary of the Central Australian Human Research Ethics Committee on 08 8951 5844.

*Thank you for considering taking part in our project.*
Appendix C-1

Interview guide: Improving delivery of secondary prophylaxis for rheumatic heart disease: focussed ethnography

Participants: Parent with children 5 to 14 years- questions adjusted for maturity of child if child participating

Your story, your perceptions and experiences of rheumatic fever:

1. Can you remember when you/your child first got sick? Can you tell me about it?
2. What causes rheumatic fever? How do people get it?
3. What is it like getting the injections? How does it make you feel?
4. How long do you/your child need to have the injections?
5. What does the medicine in the injection do? How does it do this?
6. How often do you/your child need the injections?
7. What happens if you miss an injection?
8. If they have had surgery: what did the surgeon do in your/your child’s heart operation?

Exploring dynamics around RF/RHD

9. What is your language word for ‘heart’
10. What is the job of the heart?
11. Can you draw on paper what you understand rheumatic fever does in your body?
12. What did the clinic/hospital staff tell you about rheumatic heart disease? Do those things make sense to you?
13. Have you heard these English words: mild, moderate or severe RHD? What do they mean to you? Do you know which one you/your child has?
14. If someone at the clinic said this sentence to you, how would it come across to you? : “You must/should/need to have this injection every month for ten years” (if negative response, ask how it should be said - in language if feasible)
15. In your language, can we record how you would talk about or explain rheumatic fever to your friends? (Only where translations are feasible)
16. What language words describe young people in your culture? What age are these groups?

Self-care during development
17. Who looks after/organises your /your child’s injections?
18. Who goes with you/your child when you get injections?
19. When will you/your child go by yourself for your injections?
20. What language words describe young people in your culture? What action or behaviours do people in those groups have? (What factors determine the groupings?)
21. How do you know when it is time for the injections?
22. How can you remember the time of 28 days? (If deflected to the clinic, ask them to imagine how to do this without the clinic, explore for calendar or other reminders in use)
23. What things make it hard to get your injection on time? What things make it easier to get them on time?
24. Has anyone at your clinic talked about you and them working together to organise your injections? What plans have you made together?
25. Do you get help/support from others in the community to manage your condition? Could you/do you work with someone else outside the clinic to organise or plan your injections? What do you do?
26. What does it feel like when you get the injections? What do clinic staff do to try to reduce the pain? How would you describe the pain in your language (if feasible for translation)

Perceptions of health service role to do with RF care

27. What are the most important things about your health service to you? Why?
28. What areas do you understand your health clinic provides services for? (Geographical locations)
29. Can you talk about the history of your health service? How did it start? (Older people only).

Getting injections in other locations

30. Sometimes people need to go to other communities/homelands during the year. Where do you usually go? If you think back from this season to the same season last year, where do you remember going?
31. Can you get your injection when you go to other places? If yes, how do you organise that? If no, why not?
32. Do you let your clinic know if you are going to another community for a short or long visit? Do they ask you to let them know?
33. Can visitors to your community get their injections there?
Appendix C-2

Study title: Improving delivery of secondary prophylaxis for rheumatic heart disease: focussed ethnography

Participants: ages 15 to 35 years - questions adjusted according to individual age and maturity

Your story, your knowledge and perceptions of rheumatic fever

1. Can you remember when you first got rheumatic fever? Can you tell me about it?
2. What causes rheumatic fever? How do people get it?
3. What is it like getting the injections? How does it make you feel?
4. How long do you need to have the injections?
5. What does the medicine in the injection do? How does it do this?
6. Why do you need to get the injection every 28 days?
7. What happens if you miss an injection?
8. If they have had surgery: what do you understand the surgeon did in your heart operation?

Exploring dynamics around RF/RHD

9. What is your language word for ‘heart’?
10. What is the job of the heart?
11. Can you draw what you understand rheumatic fever does to your body?
12. What did the clinic/hospital staff tell you about rheumatic heart disease? Do those things make sense to you?
13. Have you heard these English words: mild, moderate or severe RHD? What do they mean to you? Do you know which one you have?
14. How would you say in your language that you wanted a person to do something every 28 days, such as have the injection? (if feasible and translation possible then ask for this in their language)
15. If someone at the clinic said this sentence to you, how would it come across to you? “You must/should/need to have this injection every month for ten years” (if negative response, ask how this would be better phrased by health practitioners - in language if feasible)
16. In your language, can we record how you would talk about or explain rheumatic fever to your friends? (Only where translations are feasible)
Self-care during development

17. Who looks after/organises your injections?
18. Who goes with you when you get injections?
19. What language words describe young people in your culture? What action or behaviours do people in those groups have? *(What factors determine the groupings?)*
20. When did you (or will you) start going by yourself for injections?
21. How do you know when it is time for your injections?
22. How can you remember the time of 28 days? *(if deflected to the clinic, ask them to imagine how to do this without the clinic, explore for calendar or other reminders in use)*
23. What things make it hard to get your injection on time? What things make it easier to get them on time?
24. Has anyone at your clinic talked about you and them working together to organise your injections? What plans have you made together?
25. What things could the clinic do to make it easier to get your injection on time?
26. Do you get help/support from others in the community to manage your condition? Could you/do you work with someone else outside the clinic to organise or plan your injections? What do you do?
27. What does it feel like when you get the injections? What does the clinic staff do to try to reduce the pain? How would you describe the pain in your language *(if feasible for translation)*

Perceptions of health service role to do with care of RF

28. What are the most important things about your health service to you? Why?
29. What areas do you understand your health clinic provides services for? *(geographical location)*
30. Can you talk about the history of your health service? How did it start? *(older people only)*

Getting injections in other locations

31. Sometimes people need to go to other communities/homelands during the year. Where do you usually go?
32. Can you get your injection when you go to other places? If yes, how do you organise that? If no, why not?
33. Do you let your clinic know if you are going to another community for a short or long visit? Do they ask you to let them know?
34. Can visitors to your community get their injections here?