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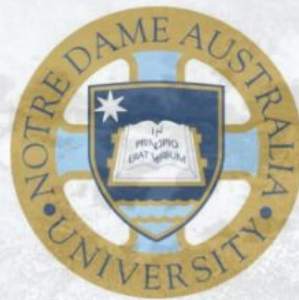
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**From Isolation to Inclusion:
Embracing Local Perspectives in Examining the Treatment Model of Care
for Aboriginal Persons Affected by Tuberculosis or Leprosy in the
Kimberley Region, North Western Australia**

Stefanie Jane Oliver

A thesis submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy



School of Medicine
Fremantle campus, Western Australia

August 2022

Note. Photograph taken by the author.

Declaration

To the best of my knowledge, this thesis contains no material previously published by another person, except where due acknowledgement has been made. This thesis is my own work and contains no material which has been accepted for the award of any other degree or diploma in any institution.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007, updated 2018). The proposed research study received human research ethics approval from the University Of Notre Dame Australia Human Research Ethics Committee (EC00418), Approval Number #017052F, the Western Australian Aboriginal Health Ethics Committee, Approval Number #777, the Western Australian Country Health Service Human Research Ethics Committee, Approval Number #RGS0000000229, and the Kimberley Aboriginal Health and Planning Forum Research sub-committee, Approval number #2017-009.

Signed:

Stefanie J Oliver

Dated: 09/08/2022

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ABSTRACT

In the remote Kimberley region of North Western Australia, tuberculosis (TB) and leprosy continue to affect a small number of Aboriginal people, despite historical efforts to eliminate either disease. Treatment, predominantly antibiotic therapy, is a principal therapeutic intervention used to cure TB and leprosy and halt infection transmission. Decisions made around treatment therefore impact not only the individual person affected, but also their families and communities. The well-worn models of Directly Observed Therapy (DOT) and case management are used nationally to assist treatment continuity and completion. Neither model has been substantiated for cultural appropriateness nor for meeting the specific needs of Aboriginal people. Given the important role of treatment, this thesis uses decolonial theory to critically examine how culturally secure and person-centred care practice could be better incorporated into the current treatment model of care used in the Kimberley region for Aboriginal persons affected by TB or leprosy. To achieve this, qualitative methods were employed to explore the lived experience of Aboriginal persons affected by either disease, as well as community members and Health Care Workers involved in care. In addition, archival research of historical documents relating to treatment was conducted. The findings of this research revealed deeper narratives about medication safety concerns, the importance of family history knowledge for early treatment intervention, and challenges relating to integrating TB and leprosy management into primary health care due to competing priorities of more prevalent chronic diseases. Health care relationships were found to play a key role in optimising treatment. However, gaps and inconsistencies were identified within these relationships in the areas of two-way trust, communicating importance and consequences of treatment, providing feedback, shared treatment decision-making, and the provision of culturally respectful support. Family relationships and connection to culture were also significant for psychosocial support. Understanding the history of TB and leprosy treatment specific to the region was found to be an integral part of understanding contemporary treatment models and in identifying ongoing colonising within the way health care services for the treatment of TB and leprosy are delivered. Using these findings, a novel treatment model of care is presented. This offers theoretical and practical strategies to re-think and apply culturally responsive approaches to optimising treatment for Aboriginal persons affected by TB or leprosy. This has the potential benefit of improved wellbeing and elimination of disease for current and future generations.

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Born and raised in Perth, Western Australia (Whadjuk Nyungar country), I come from a family with Anglo-Celtic heritage on my father's side and Anglo-European heritage on my mother's. My relationship with the Kimberley, and more particularly Broome, started early through professional working life as a newly graduated pharmacist in 1999. After leaving Broome to travel and pursue further work and study, I returned in 2012 continuing work as a pharmacist in local and regional health services. My inspiration for this thesis evolved from a combination of personal and professional experiences and from conversation with others, during my time in the Kimberley. For these people, namely Adjunct Professor Jeanette Ward, Edith Wright, Jamilah Bin Omar, Dr Kim Isaacs, Associate Professor Sandra Woollorton and Professor David Paul I am incredibly grateful for our initial conversations. This thesis has by no means been an easy journey. Learning the truth about the history of the Kimberley region related to this work has been unsettling. However, learning of the strength and resilience of Aboriginal people through the decades long leprosy epidemic has been as equally inspiring, especially relevant given the writing of this thesis took place during the COVID-19 pandemic and the impact of comparatively short periods of isolation was felt.

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LIST OF ABBREVIATIONS

AAG	Aboriginal Advisory Group
ACCHs	Aboriginal Community Controlled Health Services
ADR	Adverse Drug Reaction
AHP	Aboriginal Health Practitioner
AHW	Aboriginal Health Worker
AMS	Aboriginal Medical Service
ATC	Australian Tuberculosis Campaign
BCG	Bacille Calmette Guerin
BI	Bacillary Index
CDNA	Communicable Diseases Network Australia
CTPH	Committee on Tropical Physiology and Hygiene
DAA	Dose Administration Aid
DDS	4,4-diaminodiphenyl sulfone (dapson)
DHS	Dapsone Hypersensitivity Syndrome
DMO	District Medical Officer
DOT	Directly Observed Therapy
DOTS	Directly Observed Therapy, Short-Course
DRTB	Drug Resistant tuberculosis
ENL	Erythema Nodosum Leprosum
FDOT	Family-member DOT
FG	Focus Group
HCW	Health Care Worker
HCV	Hepatitis C Virus
HLA	Human Leukocyte Antigen
HIV	Human Immunodeficiency Virus
IGRA	Interferon Gamma Release Assay
IHW	Indigenous Health Worker
KAHPF	Kimberley Aboriginal Health Planning Forum
KAMS	Kimberley Aboriginal Medical Services

KPHU	Kimberley Population Health Unit
LCM/s	Local Case Manager/s
LPEP	Leprosy Post-Exposure Prophylaxis
LTBI	Latent Tuberculosis Infection
MB	Multibacillary
MDRTB	Multi Drug Resistant tuberculosis
MDT	Multi-Drug Therapy
NDIS	National Disability Insurance Scheme
NHMRC	National Health and Medical Research Committee
NSQHS	National Safety and Quality Health Service Standards
NTAC	National Tuberculosis Advisory Committee
PB	Paucibacillary
PCR	Polymerase Chain Reaction
PEP	Post Exposure Prophylaxis
RAN	Remote Area Nurse
RAAHS	Remote Area Aboriginal Health Services
ROM	Rifampicin, Ofloxacin, Minocycline
SDR	Single Dose Rifampicin
SG [1,2,3]	Study group [1,2,3]
STDM	Shared Treatment Decision Making
TB	Tuberculosis
TST	Tuberculin Skin Test
VDOT	Video- DOT
WACHS	Western Australian Country Health Services
WATBCP	Western Australian Tuberculosis Control Program
WHO	World Health Organization

GLOSSARY

Aboriginal	The use of the term Aboriginal in this thesis is in keeping with accepted use within Western Australia in recognition that Aboriginal people are the original inhabitants of Western Australia (AHCWA, 2019). No disrespect is intended for Torres Strait Islander peoples and community. Throughout this thesis when referring to Aboriginal and Torres Strait Islander peoples within the nation of Australia, the term First Nations peoples will be used, unless in direct quotation of another author/s. When referring to the international context, the term Indigenous peoples will be used, unless in direct quotation. Where possible, specific reference to Language group or Country will be referenced when there is no compromise to a person's privacy.
Country	The term Country gives specific reference for an Aboriginal person for the lands, waterways, and seas to which they are connected, often linked to cultural practices, family, and identity (AIATSIS, 2022b)
Cultural security	Commitment to the principle that the construct and provision of services offered by the health system will not compromise the legitimate cultural rights, values, and expectations of Aboriginal and Torres Strait Islander people (AHCWA, 2019).
Decoloniality	The dismantling of relations of power and constructed knowledge that continue to serve indoctrinated hierarchies from colonial systems and structures.
Language Group	Language group refers to a group of people who share a common language which connects people to Country and culture (AIATSIS, 2022a)
Optimised treatment	Refers to the best and most effective use of pharmaceutical medicines used for treatment, through care in the provision, access and safety of medicines, and knowledge in their optimal use through education/information and clinical application.
Person(s) affected	Throughout this thesis, the phrase "person(s) affected by (TB or leprosy)" is used in reference to individuals' who have been diagnosed with either disease, in line with international convention (Cruz, 2018)
Person-centred care	As a model of care, person-centred care involves the person receiving treatment being empowered to make informed and shared decisions about their treatment.

Shared Decision-Making	A process by which decisions are made by the person receiving care and the clinician utilising best available evidence and discussion of patients' preferences (Stacey et al., 2017, p. 264)
Treatment	Management and care to prevent, cure, ameliorate, or slow progression of a medical condition.
Treatment model	A designated model of delivering safe and effective treatment for a person.
Treatment model of care	Refers to a multifaceted concept which broadly defines a system or process of delivery of health care services to a person or population group with respect to the pharmaceutical treatment of a specific medical condition, in this case for TB or leprosy

Chapter 1

Introduction

1.1 Introduction

Tuberculosis (TB) and leprosy are considered rare diseases for Australian-born residents, unless exposed to infection through travel or familial contact in countries with a high burden of endemic disease. Despite a decrease in both diseases, endemic TB and leprosy continue to affect First Nations communities across Australia, long after they were introduced in the 19th and early 20th centuries secondary to colonisation (Bright et al., 2020; Davidson, 2016; Proust, 1991d). In 2014 in a remote Aboriginal community in the Kimberley region in North Western Australia, an Aboriginal community member presented at their local health clinic with advanced symptoms of weight loss, cough, and night sweats. The eventual diagnosis of active pulmonary TB caught local health staff by surprise and eventuated to a resource-intensive community-wide screening for TB. In the following year, three more unrelated pulmonary TB infections were identified in Aboriginal peoples across the region, prompting extensive contact tracing of household and family members to screen for TB in the event of active transmission of disease (Western Australian TB Control Program, 2015). The same year also marked the fourth diagnosis of active leprosy for an Aboriginal person within the region since 2010. Of the four people, two had presented with advanced lepromatous disease and grade 2 disabilities,¹ indicating that the infection had gone undiagnosed and untreated for several years. Both events drew political attention to the region due to concerns of local outbreaks (Parliament of Western Australia, 2016). The apparent recrudescence of leprosy—a crippling disease considered by many locals to have disappeared with the closing of the local Derby leprosarium in 1986—reinvigorated efforts to provide specialist leprosy services that had been disbanded several years earlier.

Despite historical efforts to eliminate both diseases, the scenarios above confirmed for a small number of Aboriginal people that endemic TB and leprosy continues to linger. Treatment, predominantly antibiotic therapy, is a principal intervention not just in curing TB and leprosy but also in stopping transmission of infection to others, as once a person is on the

¹ Grade 2 disability in leprosy is an indicator of advanced disease (World Health Organization, 2016)

correct treatment, both diseases lose their infectiousness (Lockwood, 2019; Migliori et al., 2019).

Given this important role of treatment in both improved wellbeing for people affected by TB or leprosy and in eliminating the burden of disease for future generations, in this thesis I sought to gain a deeper understanding of the current operationalisation of treatment, through the perspectives of local people affected by TB or leprosy who were taking treatment anytime between 2012 until September 2019 or those involved in their care, in the aim to identify improved optimisation of treatment processes and use. Central to this examination was a consideration of the intersection of a colonial history with care models and the relevance of this for current treatment.

1.2 Background

1.2.1 Health care in the Kimberley

The Kimberley region is in the northern most region of Western Australia (WA), with the majority of the region (97%) classified as very remote, and the remaining 3% classified as remote, according to the Accessibility/Remoteness Index of Australia (ARIA) (Anderson et al., 2018, p. 8). The region encompasses an area of 424,517 square kilometres (twice the size of Victoria), and is situated 2239 km from Perth, the state's capital, with a total population of 36,394, approximately 50% of this population identifies as Aboriginal (Kimberley Development Commission, 2021; Western Australian Country Health Service, 2021). In its cultural diversity, 55 Aboriginal languages belonging to five different language families are spoken within the region (McGregor, 2004). There are four Local Government Areas; the Shires of Broome, Derby/West Kimberley, Halls Creek, and Wyndham/East Kimberley, which include the respective towns, remote Aboriginal communities, and pastoral stations. Based on the 2016 census, the region has very low Socio-Economic Indexes for Areas (SEIFA) scores—particularly Halls Creek and the south western portion of the West Kimberley (Anderson et al., 2018, p. 8).

Primary health care in the Kimberley consists of non-governmental Aboriginal Community Controlled Health Organisations² (ACCHOs) located in towns and remote communities, privately-owned GP clinics in Broome and Kununurra, and government run remote area health clinics and community health centres. At the secondary and tertiary level,

² The Kimberley Aboriginal Medical Services (KAMS) is the ACCHO in the Kimberley that provides a collective voice for ACCHOs in the region. The Aboriginal Council of WA (ACHWA) is the state body for ACCHOs, and the National leadership body is the National Aboriginal Community Controlled Health Organisation (NACCHO).

the WA Country Health Services (WACHS) govern regional hospitals with the principal hospital located in Broome and smaller hospitals in Derby, Kununurra, Halls Creek, Fitzroy Crossing and Wyndham. A team of Regional Physicians provide general medical consults for inpatients and outpatients alongside District Medical Officers. The Kimberley Aboriginal Health Planning Forum (KAHPF) is the peak regional health forum that advocates for improving health outcomes for Aboriginal people in the Kimberley, consisting of sub-committees that bring together clinicians, program managers and health staff (Kimberley Aboriginal Health Planning Forum, 2018).

TB and leprosy health services are coordinated via the WA Department of Health's Anita Clayton Centre in Perth, who specialise in and coordinate the WA health response to TB and leprosy as part of the WA TB Control Program. The Anita Clayton Centre coordinate services with the support of the Kimberley Population Health Unit (KPHU) located in Broome, Regional Kimberley physicians, community health nursing staff, and primary health care. A model of case management is in operation with the use of Local Case Managers (LCMs) from these local health networks being supported by the WA TB program, due to the distance from Perth and remoteness (WATBCP and WACHS, 2017, April). Engagement with Aboriginal health services occurs at a regional level for both diseases mainly via the Kimberley Aboriginal Medical Services, including development and review of the regional KAHPF clinical guidelines that exist for leprosy (but not TB) as an addition to the state Department of Health's endorsed clinical guidelines.

1.2.2 Tuberculosis

Mycobacterium tuberculosis, tuberculosis, or 'TB' is a mycobacterium that when inhaled can lead to severe infection predominantly within the lungs (pulmonary TB) but can also be found elsewhere in the body such as in the abdominal cavity, lymph nodes or bones (Pozniak, Bernardo, & Baron, 2021). Symptoms of pulmonary TB include a productive cough, night sweats, chest pain, haemoptysis, weight loss and fever, and can be fatal if not treated. Prior to SARS-CoV-2 (COVID-19), TB was the world's leading infectious disease killer (Pozniak et al., 2021; World Health Organization, 2021c). Active infection is diagnosed by isolating bacteria from sputum samples (through mycobacterial smear and culture), bronchoscopy when no sputum is available, tissue biopsy (for extra-pulmonary TB), and TB-PCR³, in combination with clinical symptoms (Jilani, Avula, Gondal, & Siddiqui, 2018). TB

³ PCR = Polymerase Chain Reaction, used to detect the presence of bacterial DNA (Lleo et al., 2014)

can be transmitted from person to person via the air when a person sneezes, spits, or coughs and has an incubation period of a few months to 2 years. Not all people will go on to have an active infection as a result (Behr, Edelstein, & Ramakrishnan, 2018; World Health Organization, 2021c). Inactive infection, known as latent TB infection, or LTBI, occurs when a person has been exposed to TB bacteria, the immune system contains it but fails to clear it. The bacteria lie dormant within the body, it does not cause symptoms of infection, and cannot be passed onto another person (Government of Western Australia, 2019(a); World Health Organization, 2015c). TB in this state can remain dormant for a number of years and be at risk of reactivation into an active infection in the future, for example in situations of lowered immunity (Stock & the National Tuberculosis Advisory Committee (NTAC), 2017)⁴.

In Australia the majority of TB is found in migrant and refugee populations (Bright et al., 2020). In the Australian born population, the annual incidence rate of TB, while it has reduced in the last decades, continues to be 4-5 times higher for First Nations than for non-First Nations Australians, with variations from state to state (Bright et al., 2020). Specific to the Western Australian Aboriginal population, annual reports for the 4 years from 2015 to 2018 show an average annual incidence of about 4.5 times that of the non-Aboriginal Western Australian born population, with the Pilbara region and the Kimberley region representing the majority of cases in country regions during this period (Bright et al., 2020; Government of Western Australia, 2018; Western Australian Tuberculosis Control Program, 2015). Molecular genotyping confirmed an ongoing endemic transmission of multiple bacterial strains of TB within the Western Australian Aboriginal population (Forrest, Waring, & Wallace, 2018). For the remote community who were required to undergo TB screening, approximately 17% of people (adults and children) returned a positive diagnostic test, with treatment for latent TB offered (after exclusion of active infection). In addressing this disparity of TB infection nationally, the National TB Advisory Committee (NTAC) in their 2019 strategy now has as one of the priority action areas to address barriers to care for First Nations peoples through “engagement with representative Aboriginal and Torres Strait Islander groups,” with a goal of reaching zero disparity by the year 2035 (The National Tuberculosis Advisory Committee (NTAC), 2019, p. 7), in line with the World Health Organisation’s End TB Strategy Indigenous Peoples brief (World Health Organization, 2019). Treatment for active and latent TB is an essential pillar in achieving this goal.

⁴ About a quarter to a third of the global population are considered to have latent TB (Behr et al., 2018; World Health Organization, 2015c)

1.2.3 Leprosy

Leprosy, or *Mycobacterium leprae*, also known as Hansen's disease (after the Norwegian physician Gerhard Armauer Hansen who discovered the bacteria in 1873) is from the same family of bacteria, the Mycobacteriaceae, as TB (Kumar, Uprety, & Dogra, 2019, p. 1; Moraes, Silva, & Pinheiro, 2019). Leprosy bacteria cause infection in peripheral nerves, skin, and mucous membranes, with subsequent damage to the nerves resulting in visible disfigurement and disability. Leprosy is described as a chronic infectious disease with a "slow clinical progression" and is often marked by "hypersensitivity reactions" to bacterial antigens (Kumar et al., 2019). These inflammatory reactions are referred to as lepra reactions and are designated Type 1 (also called reversal reaction) or Type 2 (also called erythema nodosum leprosum, or ENL). These reactions can cause peripheral neuropathy, nerve damage, and significant pain and can appear before, during or after anti-infective treatment. Reactions are usually managed with immunosuppressant drug therapy. Leprosy can be challenging to diagnose, and the use of "slit-skin smears" and histopathology remain important diagnostic tools along with clinical signs and symptoms (Kumar et al., 2019; Walker, 2019).

While it is classified as a communicable infectious disease, leprosy is considered a disease of low contagion, transmitted via aerosols containing bacteria most commonly from the upper airways and often requiring prolonged close contact for transmission (Kumar et al., 2019; Moraes et al., 2019; World Health Organization, 2021b). Leprosy bacteria are slow-growing, and the average incubation period is 3–5 years although longer periods of 20–30 years have been reported (Keed, 2017; World Health Organization, 2021a, p. 61). The clinical presentation of leprosy is associated with a spectrum of disease usually related to the strength and type of the body's immune response. There are two formal classifications used to aid diagnosis of this spectrum: the Ridley-Jopling and the World Health Organization (WHO) classifications. The Ridley-Jopling classification follows the immune spectrum response with five designated types—tuberculoid leprosy at the less severe end of the immune spectrum and lepromatous leprosy at the other end. In-between these are borderline tuberculoid, mid-borderline, and borderline lepromatous, with each type having its own specific set of clinical and histological features. The WHO classification system has been described as more of an "operational classification system" and describes only two types of

leprosy. These are distinguished by the bacterial load, or “bacillary index (BI)”⁵, classified as either paucibacillary (PB), or multibacillary (MB) disease (Kumar et al., 2019). This system is the primary classification to guide treatment. Leprosy is still classified as a neglected tropical disease by the WHO and has a unique significance for Aboriginal people in the Kimberley region due to the history of the Derby leprosarium, known as ‘Bungarun,’ in operation from 1935 to 1986.

Leprosy occurs in Australia today in migrants travelling from endemic areas and in small numbers in First Nations peoples, particularly in the northern regions of Australia. In 2014 out of nine reported leprosy cases in Australia, two were reported as being Indigenous (state unknown), and a total of five out of these nine were from Western Australia (WA). In WA the actual annual leprosy notification rate is low at 0.1 per 100,000 population. This rate does not, however, reflect the higher pockets of infection that exist in certain areas of the state (Government of Western Australia, 2019(b), p. 14; NNDSS Annual Report Working Group, 2014, p. E128). At the time of writing this thesis, there is no current national strategy for elimination of leprosy infection within Australia for First Nations peoples. The most recent international strategy released by the World Health Organization for 2021-2030 is titled, “Towards zero leprosy,” with the interruption of transmission and elimination of disease at the core of the strategy (World Health Organization, 2021b).

1.2.4 Treatment for TB and leprosy

1.2.4.1 Treatment of active infection

While I acknowledge that treatment for TB and leprosy can extend to non-pharmaceutical means such as surgery or physiotherapy, I use the term treatment in this thesis to refer solely to pharmaceutical medications, and use this term interchangeably with medicines, drugs, or therapy, and in some cases antibiotics or anti-infectives when in specific reference to their principal action. The mainstay of treatment for both active TB and active leprosy infection is with multiple antibiotics in the aim to prevent the development of drug resistance to any one single antibiotic (Mitchison, 1998, p. 16). Antibiotic regimens used are guided internationally from the WHO and shown below in Table 2.1. Regimens used will depend on the presence of primary antibiotic resistance, severity of disease, and any known adverse drug reaction. Relapse of infection is possible from sub-optimal antibiotic therapy

⁵ Bacilli index, or bacterial index (BI), is an expression of the extent of bacterial loads (Lockwood, 2019). If the BI >4, recommended treatment extends to 24 months in WA (Government of Western Australia, 2019(b))

secondary to irregular treatment uptake (Toman, 1981). Sub-optimal therapy can also contribute to acquired antibiotic resistance and risks ongoing infection transmission (Government of Western Australia, 2019(b); Rusen et al., 2007). Treatment adherence therefore is a priority feature of TB and leprosy treatment models, especially in recognition of the associated challenges of full adherence to treatment regimens. For example, the number of tablets from the prescription of multiple antibiotics, as well as adjunctive treatment often required (for example prednisolone)⁶, means a significant pill burden for people affected, especially in the intensive phase of TB regimens, with twelve or more tablets per day. Another challenge is the long duration of treatment for both TB and leprosy, especially in multibacillary (MB) leprosy and drug resistant TB, which can be up to two years or longer. In addition to pill burden and duration, the experience of drug toxicity, stigma, and competing.

Table 1. Treatment regimens for TB and leprosy

Leprosy	Antibiotic combination
Paucibacillary (PB)	Dapsone 100mg daily + clofazimine 50mg daily PLUS Rifampicin 600mg + clofazimine 300mg Once a month for 6 months (<i>clofazimine has recently been recommended by WHO</i>)
Multibacillary (MB) leprosy	As above but for an extended duration of 12-24 months duration depending upon the ‘bacilli index’
Drug resistant leprosy	Rifampicin-resistant – switch for clarithromycin, minocycline, or a quinolone (if no quinolone resistance), <u>See Appendix A</u>
TB	
Drug sensitive TB	2 months of isoniazid (H) + rifampicin (R) + pyrazinamide (Z) + ethambutol (E) (‘intensive phase’); followed by 4 months of Isoniazid + rifampicin (‘continuous phase’) (Regimen = 2HRZE/4HR) (<i>standard regimen</i>)
Drug resistant TB	Regimens, duration, and use of intensive/continuous phases are dependent upon resistance patterns. <u>See Appendix A</u> for treatment regimen options.

(Government of Western Australia, 2019(a), 2019(b); World Health Organization, 2017b, 2018, 2020b)

social priorities for routine care (such as family or work) have been shown to impact on adherence to treatment (Fox, 1958; Girão et al., 2013; Kaona et al., 2004; Metcalfe, O'Donnell, & Bangsberg, 2015; Munro et al., 2007, p. 270; Vadher & Lalljee, 1992; van de Berg, Jansen-Aaldring, de Vries, & van den Hof, 2018; Weiland, Smith, & Muzaffarullah, 2011; Williams, 2005). Structural factors and social inequalities in some countries have led to programmatic failures, especially in association with barriers to care secondary to poverty,

⁶ Prednisolone is a corticosteroid drug with anti-inflammatory and immune-suppression properties, used to manage immune-based reactions experienced in both TB and leprosy (Australian Medicines Handbook 2020, online).

both of which have long been associated with people affected by TB and leprosy (Farmer, 1996; Farmer, Nizeye, Stulac, & Keshavjee, 2006; Greene, 2004; Heukelbach et al., 2011; Muyunda Siyoto, 2021). In order to reduce the financial burden of treatment, the WHO promotes universal free treatment for both TB and leprosy. For leprosy, this comes by the way of free Multi-Drug-Therapy (MDT) blister packs, i.e., ‘WHO packs,’ provided globally by Pharmaceutical Company Novartis (World Health Organization, 2016, 2020a, 2021a). For TB, individual countries vary in their support for the cost of treatment through public health services (Tanimura, Jaramillo, Weil, Raviglione, & Lönnroth, 2014)⁷.

1.2.4.2 Chemoprophylaxis

Chemoprophylaxis, also termed chemoprevention or preventive chemotherapy, is a term given to the use of antibiotic therapy for the purpose of preventing disease or infection (Weinstein 1955). In the case of TB and leprosy chemoprophylaxis is offered to individuals after potential or known exposure to a person with active infection and is considered an important public health strategy in TB and leprosy elimination. For TB, chemoprophylaxis (preventive therapy) is offered as a treatment course after positive identification of latent TB (LTBI), by Mantoux test (also known as tuberculin skin test, or ‘TST’)⁸, or with a blood test called the Interferon Gamma Release Assay (IGRA, also known as the QuantiFERON-TB Gold Plus test) and exclusion of active TB. Trials of treatment for latent TB started in the later 1950s (Des Prez & Muschenheim, 1962; McDermott, 1960) but it was not formally accepted into practice until 1982 as a 12-month course of the synthetic nicotinic acid derivative ‘isoniazid’ (iso-nicotinic acid hydrazide, or INH) (International Union Against Tuberculosis Committee on Prophylaxis (IUAT), 1982). Taking such a long course of INH however presented challenges for treatment completion, with further research supporting the shortening of duration to 6-9 months (Comstock, 1999). Current treatment options are listed in Table 2 below:

Table 2. Treatment options for latent TB infection (LTBI)

Option	Treatment regimen (confirmed latent TB)
a) 6H	Daily Isoniazid 300mg for 6-9 months
b) 4R	Daily Rifampicin 600mg 3-4 months
c) 3HR	Daily Isoniazid 300mg + Rifampicin 600mg 3-4 months
d) 3HP	Weekly Isoniazid 900mg + Rifapentine 900mg for 12 weeks

⁷ In Australia, TB treatment is provided for free to residents and non-residents if they are diagnosed within any state of Australia. Leprosy waivers of cost are state-dependent.

⁸ For the Mantoux test, tuberculin, a purified protein derivative from TB culture, is injected intradermally (into the skin). A positive Mantoux is if a visible reaction is seen after 48-72 hours (Nayak & Acharjya, 2012)

Note. Information sourced from Government of Western Australia (2019(a), p. 69); World Health Organization (2015b, p. 33)

Treatment of LTBI is considered important to reduce the risk of conversion to active TB, especially for people considered at higher risk due to proximity to infection such as household contacts, or due to immunosuppression such as people living with HIV or with other chronic diseases, such as diabetes or chronic kidney disease (Stock & the National Tuberculosis Advisory Committee (NTAC), 2017). The percentage reduction in incidence of culture-positive TB five years after isoniazid chemoprophylaxis treatment was shown to be 69% for a six-month course and 93% for a 12-month course (Comstock, 1999, p. 848). Treatment does not protect against any further re-infection with TB and is not a priority in countries with a high burden of TB (Dobler, Chidiac, Williamson, & Jelfs, 2016, p. 78). For countries with low endemicity such as Australia, targeting LTBI has been identified as a key strategy for eliminating TB (Degeling, Carroll, Denholm, Marais, & Dawson, 2020; Rangaka et al., 2015; The National Tuberculosis Advisory Committee, 2019).

Chemoprophylaxis for leprosy (often referred to as post-exposure prophylaxis) has only been recently endorsed by WHO in 2018, based on the contact transmission and chemoprophylaxis in leprosy (COLEP) trial which was conducted in Bangladesh a number of years earlier by Moet, Pahan, Oskam, and Richardus (2008). The trial demonstrated that a single dose of rifampicin (SDR) of 600mg (for adults) reduced the incidence of leprosy in close contacts by 57%⁹. However, criticism of the COLEP trial soon followed based on the lack of benefit in incidence reduction observed after two years and the lack of benefit for household contacts compared with more socially distant contacts (Addis, 2018). A recent feasibility trial of Leprosy Post-Exposure Prophylaxis (LPEP) by Barth-Jaeggi et al. (2019) across seven countries preceded the acceptance of the programmatic use of SDR into the WHO guidelines, despite this criticism (World Health Organization, 2018). Other variations of LPEP are currently being trialled in high burden countries such as enhanced PEP (PEP++)¹⁰ as well as using SDR with BCG¹¹ vaccination (dos Santos et al., 2018; Mieras et al., 2018). Chemoprophylaxis for leprosy was introduced into practice guidelines in 2019

⁹ Four days after a single dose of 600mg rifampicin, leprosy bacilli present are considered to be no longer viable (Lockwood, 2019).

¹⁰ The enhanced regimen for the PEP++ study comprises three standard doses of rifampicin 600 mg plus moxifloxacin 400 mg given at four weekly intervals (Mieras et al., 2018).

¹¹ BCG = Bacille-Calmette-Guerin vaccination used for TB prophylaxis in specific populations. Vaccinations are excluded from the scope of this thesis, see [Appendix B](#) for background information.

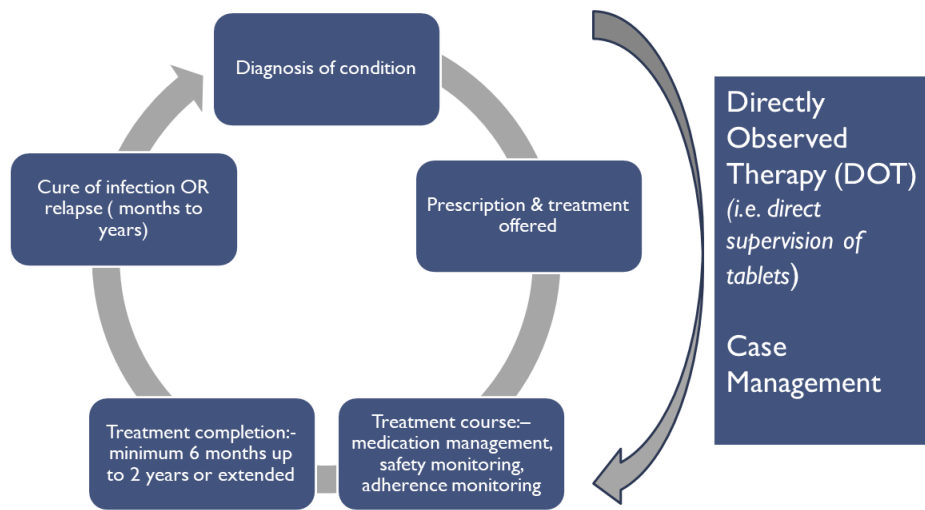
across WA (Government of Western Australia, 2019(a)), and was not in operation in the Kimberley prior to the completion of the fieldwork component for this thesis.

1.2.4.3 Treatment models

Effective treatment reduces the risk of TB and leprosy infection transmission to the public and subsequent disease development, as well as reduces the risk of disease-related disability and morbidity for the person affected (Kumar, Girdhar, & Bhavneswar Kumar, 2012; Wilder-Smith & Van Brakel, 2008). In this thesis I use ‘treatment model of care’ to refer to a multifaceted concept which broadly defines a system or process of health care service delivery to a person or population group with respect to the pharmaceutical treatment of a specific medical condition, in this case for TB or leprosy. A treatment model is a designated model of delivering safe and effective treatment for a person.

Two main treatment models are in use as part of programmatic management for the care of people affected by TB and leprosy in WA. The first is Directly Observed Therapy (DOT), where treatment is directly observed to ensure adherence, and the second is case management, where each person affected by TB or leprosy is assigned a Health Care Worker, usually a nurse with specialised training, who assists in supporting continuity of treatment and other required public health activities such as contact tracing. These models will be discussed further in Chapter 2. Facilitating access to early treatment, ensuring the continuity of safe and effective treatment, and encouraging complete treatment adherence are at the core of these treatment models for TB and leprosy control. Processes and programs put in place to ensure this are dependent upon economic and legislative practices within the respective region, state, or country. In WA, legislative and governing bodies that oversee quality medications use for public health treatment programs are the Western Australian Poisons Act and Regulations 2016; the National Safety and Quality Health Service Standards (NSQHS) (under the Australian Commission on Safety and Quality in Health Care (ACSQHC)); peak professional bodies and associated practice guidelines; individual organisational policies and practices for medicines use; and the Therapeutic Goods Administration (TGA).

Figure 1. An overview of the treatment process and treatment models used for TB and leprosy.



All aspects of treatment are therefore considered within this examination from the initial process of prescribing, dispensing, and supplying medication; equity of access; timely access to accurate information about medicines; and medication management, including the ease of adhering to treatment regimens and monitoring for side effects and drug interactions with other chronic disease medications (Australian Government, 2000; Stowasser, Allinson, & O’Leary, 2004); see Figure 1. In addition, the social aspects of disease have been considered in the design of this research. This is congruent with the notable change in both TB and leprosy policy that has seen a shift towards a more nuanced understanding of the impact of social determinants on vulnerability to disease and impact on treatment, (Craig et al., 2016; Lönnroth et al., 2009; de Assis et al., 2018), especially for Indigenous peoples (Basta & de Sousa Viana, 2019; Cormier et al., 2019; World Health Organization, 2019). There exists a complex interaction of systemic, personal, and social factors that feature as an important part of optimising treatment for both TB and leprosy and consequently a recognised need to consider a person-centred focus for treatment models (Garner et al., 2007, p.405; Getahun et al., 2016; Girao et al, 2013; Kuipers et al., 2013; O’Donnell et al, 2016; Orr, 2010a, 2010b).

1.3 Aim of thesis

The aim of this thesis is to critically examine, through a decolonial lens, the current treatment model of care for Aboriginal People in the Kimberley region affected by TB or leprosy and to identify how person-centred and culturally secure care practice can be better incorporated. The rationale is that improved person centred, and culturally secure care practice assists in optimising treatment processes and use that is inclusive of social, personal,

and systemic factors that can impact treatment. This is underpinned by the rationale that treatment is one of the principal strategies in eliminating TB and leprosy.¹² Treatment can also stop TB and leprosy from spreading to family and community members, while its optimisation¹³ can assist in curing infection, preventing further disability, and assist in the prevention of antibiotic drug resistance and transmission of drug-resistant bacterial strains (Kumar et al., 2012; Rusen et al., 2007; Sardana & Khurana, 2020; van Brakel et al., 2012; World Health Organization, 2015a). The primary discussion within this thesis therefore centres around the principal phenomenon of treatment. The lens of person-centred care and cultural security throughout the research is applied to all components of the treatment model as outlined above in 1.2.4.3. The decision to incorporate care frameworks in eliciting this examination of a model of care, and not just the details of treatment provision and management is in line with the guiding principles of the WA Aboriginal Health and Wellbeing Framework 2015-2030 (Department of Health Western Australia, 2015) and the WHO's core strategies for ending TB and leprosy (World Health Organization, 2015, 2019, 2021). Within this focus is the deliberate attention of the intersection of Anglo settler-colonialism with treatment models, in the recognition that colonialism for First Nations people in Australia is "integral, continuing, and present" (Gathii, 2000; Haebich, 2015, p. 20; Moreton-Robinson, 2015, p. 10).

1.4 Why TB and leprosy?

TB and leprosy hold individual importance due to the specialised and complex treatment required and the associated challenges these diseases present within remote areas, as well as their ongoing presence in affecting next generations of Kimberley Aboriginal peoples. Furthermore, consequences of deciding to accept treatment have far-reaching implications. These reasons reflect the importance of improved understanding of TB and leprosy treatment as well as the importance of engaging people in care models that promote a culturally secure and informed decision-making approach to treatment. Due to the low incidence of endemic TB and leprosy, the experience of people affected by either condition

¹² Where TB elimination is defined as <1case per million population (The National Tuberculosis Advisory Committee (NTAC), 2019)

¹³ Optimising treatment regimens is also referred to in the context of pharmacodynamics (PD) and pharmacokinetics (PK), i.e. the integration of PK/PD for individual medications and as well as differences in things like weight and renal function across populations, that impact on optimising therapeutic efficacy for individuals in practice. While this is an important and evolving area of research for anti-mycobacterial therapy and is considered in relation to adherence of treatment, it is not the focus of this thesis.

can be lost within a myriad of other chronic diseases that garner more attention and higher resource priority, such as chronic kidney disease and rheumatic heart disease. This does not, however, negate the importance of understanding the barriers to achieving elimination of disease, how people are supported in receiving optimal treatment, and the associated complexity of care within the Kimberley health setting. Whilst there are some documented accounts of this approach for First Nations peoples in Australia (Devlin et al., 2021; Miller, Cairns, Richardson, & Lawrence, 2020; Visser et al., 2015) there is little research that has sought to determine the unique cultural and social needs of Aboriginal and Torres Strait Islander peoples regarding TB and leprosy treatment, particularly in remote areas. Consequently, there is a gap in the current literature concerning the suitability of treatment models of Directly Observed Therapy and case management for First Nations people, especially research that interrogates these models in the context of settler-colonialism (this literature will be discussed in detail in Chapter 2). As such, this research is the first academic contribution dedicated to the North West in relation to TB, and the first that examines contemporary treatment models for persons affected by leprosy inclusive of the social aspects of disease. In addition, this research provides the field with a rich and more meaningful understanding of how the context of ongoing colonising may impact and influence treatment models of case management and DOT for First Nations peoples in Australia. Implications for future modelling and policies around treatment will also be discussed.

1.5 Research question

This thesis aims to address the following: “How can the current treatment model for Kimberley Aboriginal persons affected by TB or leprosy better incorporate culturally secure and person-centred care practice?” The following research sub-questions examine the research question further:

- a) How is current treatment provided and operationalised?
- b) What are the practice challenges of operationalisation of current treatment models transculturally and in a remote setting?
- c) What are the colonial origins of treatment models and how is this influence ongoing?
- d) What are the gaps, barriers, and limitations that impact care for persons affected by TB or leprosy?

To answer these questions, decolonial theory was chosen for the theoretical framework, and person-centred care and cultural security informed the conceptual frameworks.

1.5.1 Decolonial theory

The theoretical framework of this thesis uses a decolonial lens to view, analyse and respond to the research question. Utilising decolonial theory allows for a critical analysis of the topic at hand (Mignolo, 2007, p. 493). The rationale for choosing decolonial theory for this thesis was premised on the fact that TB and leprosy were considered introduced diseases, secondary to British colonisation of Australia. Subsequently, both diseases serve as legacies of a violent disruption to Aboriginal people's lives that has left health disparities for future generations. In choosing decolonial theory, rather than post-colonial theory, I am in support of the argument that the colonisation of First Nations peoples in Australia was not just an event that occurred in the past, but rather an ongoing process embedded into Australia's political and health structures (Davis, 2016; Moreton-Robinson, 2015; I. Saunders, 2018; Sherwood, 2009). As Moreton-Robinson points out, unlike other colonised nations, "in Australia the colonials did not go home" (2015, p10). The language, laws, political and economic structures of the colonists became entrenched within Australian society and continue to exist. As Fanon writes, in his work "Wretched of the Earth" (1963), "In decolonization, there is therefore the need of a complete calling in question of the colonial situation." (p28).

Decoloniality is the dismantling of relations of power and constructed knowledge that continue to serve indoctrinated hierarchies from colonial systems and structures, expressed through the coloniality of "power, knowledge and being" (Maldonado-Torres, 2007, 2016; Mignolo, 2007, p. 450; Quijano, 2007). Latin American scholar Walter Mignolo asserts that decolonial thinking and the "enactment of the decolonial option [...] starts from epistemic de-linking; from acts of epistemic disobedience" (2009, pp. 173, 174). In the context of this work, I maintain that "epistemic de-linking" requires critically identifying and deconstructing our current health care practices and origins of treatment models for Aboriginal people affected by TB and leprosy, whether it be historical policies that persist within rigid service structures, power inequity within care provision, or hegemonic Western concepts of treatment and health care (Sherwood & Edwards, 2006). By incorporating the lived experience and perspectives of Aboriginal ways of doing, being and knowing, this thesis aims to change the "terms" of the conversation about TB and leprosy treatment, and not just the content, where new knowledge is informed from the people at the centre of care (Mignolo, 2007, p. 459; Nakata, Nakata, Keech, & Bolt, 2012).

1.5.2 Person-centred care

There is global recognition that effective person-centred care, including for preventive treatment, is a fundamental part of disease elimination strategies for both TB and leprosy (Barry & Edgman-Levitan, 2012; Chaulk & Kazandjian, 2012; Miles & Mezzich, 2011a, p. 219; van de Berg et al., 2018; World Health Organization, 2016, 2017b), and for safe and effective medication use (Payne, 2015). I have chosen person-centred care as a care framework with which to conceptualise decolonial theory in the argument that person-centred care promotes humanism and is a model of care that promotes putting people and families at the centre of their health care decisions. Person-centred care actively promotes people using health services as equal partners in planning, developing, and monitoring care to make sure it meets their needs (Australian Commission on Safety and Quality in Healthcare (ACSQHC), 2010; Kitson, Marshall, Bassett, & Zeitz, 2012; Scholl, Zill, Härter, & Dirmaier, 2014; World Health Organization, 2007). As a model of care, person-centred care involves empowering the person receiving treatment to make informed and shared decisions about their treatment. Promoting partnership and empowerment are two key aspects of a person-centred care approach that also work to reduce health-related stigma and discrimination—both of which have long been associated with TB and leprosy (Awofeso, 2005; Heijnders & Van Der Meij, 2006; Macq, Solis, & Martinez, 2006).

Within the Australian context, the terms patient and consumer are used often (Australian Commission on Safety and Quality in Healthcare (ACSQHC), 2010). My use of the term ‘person’ and not consumer throughout this thesis is a deliberate choice that recognises the person-as-human involved in care, including the person providing care (Miles & Mezzich, 2011b, p. 639) and that people do not always have a choice in consuming health care service goods, especially where a lack of social and/or economic privilege exists (Dirette, 2018; Latimer, Roscamp, & Papanikitas, 2017). The foundations of person-centred care as a model of care dates to 1927 with a publication entitled, “The Care of the Patient” by the American Physician Francis Peabody (Peabody, 1927). It was not until the work of psychologist Carl Rogers that person-centred care grew in popularity. In what he originally termed “client-centred therapy” in the 1940s and 1950s, Rogers published his landmark paper, “The Foundations of the Person-Centred Approach” in 1979. Another key person who contributed to early discourse on person-centred care was psychiatrist George Engel with his 1977 paper, “The Need for a New Medical Model: A Challenge for Biomedicine.” Three years later, Engel produced a methodology outlining a biopsychosocial model for clinical practice and its applications. In the further evolution of person-centred care, the concept of

Shared Decision Making within person-centred care models was introduced after the landmark work by Charles, Gafni, and Whelan (1997). This time, however, the model of person-centred care had become more accepted within mainstream American biomedical practice as a result of the “convergence of several evolving social and economic realities,” such as access to health information, the demand for greater transparency, and the rise of consumer expectations (Cliff, 2012).

One limitation in adopting a person-centred care framework is due to its roots in Western conceptualisation of individualism and universality. Person-centred care has historically overlooked alternative epistemologies that inform what is conceptualised as care across non-Western cultures, limiting a universal application (Charles, Gafni, Whelan, & O'Brien, 2006). As Joan Tronto (1993) reminds us, “caring is largely defined culturally, and will vary among different cultures” (p.103). The role of family and community in Aboriginal culture in WA, for example, cannot be overlooked with regard to care provision and approaching health matters and methods of shared decision making (Waterworth et al., 2015, p. 8). Due to the importance of recognising cultural worldviews and customs in care models, and at risk of adapting a universal model of person-centred care that has its roots in a Western epistemology, I have chosen to include cultural security as an additional framework to conceptualise decolonial theory.

1.5.3 Cultural security

Effective communication between person and clinician has been identified as a fundamental part of person-centred care, particularly for shared decision making (Charles et al., 2006; Dobler, Spencer-Bonilla, Gionfriddo, & Pablo Brito, 2017; Hoffmann et al., 2014; Scholl et al., 2014; Stiggelbout, Pieterse, & de Haes, 2015). It is precisely this communication breakdown and a lack of shared understanding between First Nations patients and health care providers that has been understood as a barrier to effective care (Cass et al., 2002; Hamrosi, Taylor, & Aslani, 2006; Harrington, Thomas, Currie, & Bulkanhawuy, 2006; Lin et al., 2014). The requirement for non-First Nations health practitioners to become more culturally aware and culturally competent has subsequently been realised as an essential trait in providing a nuanced understanding of how person-centred care can be adopted and adapted across cultural contexts (Epner & Baile, 2012; Nguyen, 2008; Saha, Beach, & Cooper, 2008).

There has been criticism in oversimplifying what cultural competence infers. For example, Jandt (2003) suggests that being competent in intercultural communication “is potentially unachievable [...] there is no way that you could learn all the rules [...]. You’d

always be doing something wrong; you'd always be offending someone" (Jandt, 2003, p. 74). In attempt to learn cultural norms, others have warned of the potential for cultural competency within the field of medicine to lead to "dangerous stereotyping" (Kleinman & Benson, 2006). Stereotyping, as well as oversimplifying a culture and peoples, dismisses cultural diversity among First Nations peoples. In their analyses of formal curricula in medical education, Paul, Ewen, and Jones (2014) warn that cultural competence may exacerbate health care disparity by a tendency to "reinforce unhelpful conceptualisations of the other" (p. 756). In addition, Sakamoto (2007) argues that an absence of power analyses between practitioner and recipient within cultural competence discourse renders culture "as neutral", thereby allowing "systems of oppression" that initially motivated the need to improve cross-cultural engagement to "disappear into the background" (p. 108).

It is cultural safety rather than cultural competence, according to Brascoupé and Waters (2009, pp. 11,15), that more accurately enables a two-way relationship, and the outcome of care evaluated by the Aboriginal person receiving care who decides if care is culturally safe or not. Coffin (2007) argues while cultural safety is necessary for any Aboriginal person receiving care, it is cultural security which is essential for improved health outcomes for First Nations peoples. Cultural security considers the structural elements of a health system such as institutional racism (Durey et al., 2012; Eckermann et al., 2006) and not just how safe someone feels in receiving health care in client-practitioner relationships. The onus, then, is for the structure, system, *and* the individual health care provider to act in ways that ensure that services provided do not serve to discriminate or disempower First Nations peoples and that their cultural needs are met (Dunbar, 2011; Gooda, 2011, p. 125; Northern Territory Government, 2016). Largely, these models are conceptualised and directed by First Nations peoples. The recent cultural security framework released by the Kimberley Aboriginal Health Planning Forum for Kimberley mental health/social and emotional well-being and alcohol and other drug services defines cultural security as "respect for the cultural rights, values and beliefs and expectations of Aboriginal people," and a reiteration that, "Culture fosters resilience, promotes a positive sense of community, and acts as a protective factor on physical health, and social and emotional wellbeing." (Kimberley Aboriginal Health Planning Forum, 2020). My choice to use cultural security as the second conceptual framework for this thesis, and not cultural awareness or competence, is due to the need to consider the institution and health system structure and not just the individual interactions between Aboriginal peoples and non-Aboriginal health care providers involved in TB and leprosy treatment in the Kimberley.

1.6 Overview of research design

Qualitative methods were chosen for this research project to allow for an in-depth examination of the lived experience of people involved in receiving treatment, or caring for those who receive treatment, for TB and leprosy. Mixed methods of focus groups and face-to-face in-depth open-ended and semi-structured interviews were employed. In addition, an examination of the historical and contemporary influence of, state, national and international guidelines, and policies was achieved using the sources of historical archives, grey literature, government policies, guidelines, and other relevant documents. A detailed description of the methodology and research design utilised in this research is provided in Chapter 3.

1.7 Thesis presentation

This thesis is comprised of nine chapters. In Chapter 2 I review the literature available on treatment models for TB and leprosy specific to the context of the research. Chapter 3 presents a comprehensive review of the research methodology. Chapter 4 forms the first part of the findings from the research, detailing the history of treatment for both TB and leprosy in the Kimberley and assists in providing background historical context. Chapters 5, 6 and 7 form the main body of the research findings from participant interviews and are broken into three aspects of treatment – medication management, medication adherence, and the social aspects of treatment. Within Chapter 8 I further the discussion from the research findings and what this means for dismantling ongoing colonial logic in moving towards steps for a decolonised treatment model. This is consolidated with the presentation of a new culturally responsive person-centred care treatment model and associated pragmatic recommendations. I conclude the thesis in Chapter 9.

Chapter 2

Literature Review

2.1 Introduction

In this chapter I review and discuss published literature pertaining to the context of treatment for TB and leprosy practice and the application of treatment models of care to illustrate the identified challenges and gaps in research that served as the starting point for this research. A search of literature was conducted using library electronic resources online via the databases of PubMed, OVID, Cochrane library, SpringerLink, JAMA network, Indigenous HealthInfoNet, Google Scholar and Google search engine in retrieving government and health organisation documents and other related grey literature. Citation snowballing was utilised from found articles. Search terms included “treatment,” “therapy,” “antibiotic,” “antimycobacterial,” “DOT,” “DOTS,” “Directly Observed Therapy,” “case management,” “treatment model,” “models of care,” “treatment model of care,” “person-centred care,” “cultural security/safety,” in combination with “tuberculosis,” “TB,” “latent TB,” “LTBI,” or “Hansen’s,” “leprosy,” and “Aboriginal,” “Aboriginal and Torres Strait Islander,” “First Nations,” “Indigenous” when searching for specific literature for First Nations people in Australia. Articles without direct focus on treatment were reviewed for related mentions of treatment models.

Due to the degree of literature available I present a summary of the most relevant and have utilised systematic reviews and meta-analyses where available. This is informed significantly from international work, mainly from high burden countries. Where research conducted in Australia was identified, this is included within the analysis, with a separate section dedicated solely to literature that focuses on First Nations peoples in Australia. In the first section I provide more detail to the complexity of treatment as an intended cure for TB and leprosy. I then review the treatment models of Directly Observed Therapy (DOT) and case management as they stand both internationally and within the Australian setting. I discuss how DOT has been considered as an adherence intervention and present the argument of its ability as a model to be person centred. I also highlight the nuances regarding the variation in practice that exists for DOT and case management operationally and with regard to social and or cultural context. I then provide an introduction and discussion into the impacts of stigma on influencing treatment, in consideration of the importance that social context can have on treatment. In the second section of this chapter, I outline the literature

identified specific for First Nations peoples in Australia especially in relation to DOT. I conclude this review examining First Nations peoples' experiences with stigma when accessing treatment for TB and leprosy.

2.2 A review of treatment models for TB and leprosy

2.2.1 Treatment as cure

The WHO outlines that for treatment of TB to be considered successful, treatment completion must be accompanied with a microbiological cure (that is, nil evidence of bacteria on sample smears or cultures). Treatment completion without this evidence is not synonymous with being cured (World Health Organization, 2013). While this standard holds for TB when viable microbiological samples are possible, the slow decay of leprosy bacilli means positive smears can be found months to years after treatment completion (John & Muliylil, 2001; Lazo-Porras et al., 2020, p. 2; Waters et al., 1978). In the absence of an accurate quantitative endpoint for leprosy, i.e., a “true test of cure,” the relapse rate becomes the principal method to assess treatment success. Due to relapse being identified up to ten years post-treatment completion, this translates to several years of post-treatment observation (Government of Western Australia, 2019(b), p. 55; Lazo-Porras et al., 2020). In these scenarios, early recognition of relapse and intervention with re-treatment is key to preventing further complications (Kumar et al., 2012). Even for TB, relapse is still possible after successful treatment, more so for severe infection (Cudahy, Wilson, and Cohen (2020). Relapse of infection has been attributed to the presence of bacterial persistence, or “persister” bacilli, that slowly multiplies or remains inactive (i.e., dormant) and is well adapted to a niche hypoxic environment (Comstock, 1999, p. 849; Cruz et al., 2017; Dawson, Intapa, & Jabra-Rizk, 2011; Toman, 1981). In this state¹⁴ bacteria are more successful in avoiding bactericidal¹⁵ action from antibiotics (Gold & Nathan, 2017). To adequately target persister bacilli the antibiotic duration is extended, and the antibiotic drug regimen requires at least one antibiotic with a sterilizing activity¹⁶ (Gold & Nathan, 2017; Mitchison, 1998; Toman, 1981).

¹⁴ Persister bacilli, while tolerant to antibiotics, are not classified as resistant, as once they come out of the dormant state they are susceptible to the same antibiotic (Gold & Nathan, 2017).

¹⁵ Bactericidal = the killing of bacteria by antibiotics (Pankey & Sabath, 2004)

¹⁶ The sterilizing activity of a drug is measured by its ability to kill persister bacilli, for example pyrazinamide and rifampicin (Mitchison, 1998, p. 33)

TB and leprosy treatment plans contain several unique aspects. The use of intermittent regimens, that is dosing three times a week instead of daily, has been in use for some years, but is no longer recommended for TB by the WHO. Even with full adherence, a higher risk of treatment failure, disease relapse and acquired resistance from intermittent regimens is now known to exist when compared to daily dosing¹⁷ (World Health Organization, 2017b). A degree of forgiveness in the time taken to complete the designated treatment course is also permitted for both TB and leprosy. For example, in the treatment of Multi-bacillary (MB) leprosy, as long as the designated 24 months of treatment has been completed within a 36-month period, treatment is considered complete. This translates in most scenarios to having to *add on* weeks of treatment missed. For example, if a person misses two weeks of treatment they are required to make it up by adding on two weeks to the end, pushing back the original expected treatment end date (Government of Western Australia, 2019(b), p. 62). For TB, this degree of forgiveness also depends on the phase of treatment, i.e., the intensive or continuous phase, and the accompanying microbiological evidence for infection severity. Treatment for TB is considered complete if greater than or equal to 80% of the intended treatment course is completed at the end of the planned course duration, and there is evidence of a negative smear (Government of Western Australia, 2019(a), p. 82) (see [Appendix C](#) for a list of terminology). The same degree of forgiveness also applies to treatment for latent TB infection (LTBI), (Government of Western Australia, 2019(a), p. 71). Repeat diagnostic tests for LTBI such as the Mantoux test (outlined in Chapter 1) often remain positive even after a full course of treatment. As such there is no diagnostic method to confirm success of treatment except monitoring over time (Dobler et al., 2016, p. 78).

Adherence strategies, such as reducing the number of tablets, shortening treatment duration and supervision of treatment have featured strongly in TB and leprosy control. Terminology to describe differing levels of adherence specific to TB and leprosy has varied over the decades, with such descriptors used as “completer-compliers” and “comparable to completer-compliers” (Comstock, 1999, p. 848); “irregularity in drug intake,” “non-compliance,” “non-acceptance,” or “early cessation of dosing” (Urquhart & Vrijens, 2014);

¹⁷ The WHO currently recommends daily dosing for the intensive phase of treatment, and where not possible in the continuous phase, recommend that all doses be supervised to ensure they are taken (World Health Organization, 2017b, pp. 11,12).

“poor adherence,” “interrupted treatment,”¹⁸ and “lost to follow-up”¹⁹ (World Health Organization, 2013, 2017a). Throughout this thesis, I purposely use the term adherence to relate to the agreed taking of treatment as intended and prescribed as a shift away from the terminology of compliance which implies “excessive fault/agency on the part of patients” (Porter & Ogden, 1997, p. 122; Bernard. Vrijens et al., 2012, p. 695).

2.2.2 Directly Observed Therapy (DOT)

2.2.2.1 What is DOT?

Directly Observed Therapy (DOT), also referred to as Directly Observed Treatment, is the direct observation of the patient swallowing every dose of medicine prescribed (World Health Organization, 1999). In 1993, DOT was officially made part of the DOTS (Directly Observed Therapy, Short course) global strategy to control TB (World Health Organization, 1999). DOTS consisted of five elements,²⁰ one of these being “standard short-course chemotherapy administered under standardised case-management conditions, in which patients are directly observed daily to ensure drugs are taken” (Raviglione & Pio, 2002). In recognition of both the importance and challenges of treatment adherence for TB in reducing duration of infectiousness, drug resistance, relapse or even death, DOTS was described as a policy to encourage adherence for both patient and physician adherence to standard therapy and to reduce the risk of infection transmission to the community (Volmink & Garner, 2007). By 2000 DOT, as one of the key components of the DOTS strategy, was conceptualised as the gold standard of therapy for TB (Brauer, 2015). It is still recommended as a model of treatment internationally, especially for the intensive phase of treatment (World Health Organization, 2017b). Over the years since the DOTS strategy, the use of DOT, as per Volmink and Garner (2007), has “come to mean much more than the supervised swallowing of drugs, causing considerable confusion,” (p3). This confusion is evident in the different interpretations across countries and the subsequent use of the terms DOT (i.e., the direct observation or ‘supervision’ component) and DOTS (i.e., the overall DOTS strategy by way

¹⁸ Interrupted treatment is also referred to when treatment is temporarily stopped due to Adverse Drug Reactions.

¹⁹ Lost to follow-up terminology has replaced ‘defaulter’ (World Health Organization, 2013).

²⁰ The five key components were 1) Government commitment to sustained TB control activities. 2) Case detection by sputum smear microscopy among symptomatic patients self-reporting to health services. 3) Standardized treatment regimen of six to eight months for at least all confirmed sputum smear positive cases, with directly observed treatment (DOT) for at least the initial two months. 4) A regular, uninterrupted supply of all essential anti-TB drugs. 5) A standardized recording and reporting system that allows assessment of treatment results for each patient and of the TB control programme overall (World Health Organization, 1999).

of standard short-course therapy administered with direct observation)²¹. For some the modality of DOT means the act of surveillance by direct observation of medications, for others it means the act of observation plus the incorporation of patient support via social interaction with the DOT provider, or “treatment supporter,” in the provision of informational and emotional support, working in parallel with a multi-component TB control programme (Macq, Theobald, Dick, & Dembele, 2003; Mangura et al., 2002; Stephens, 2003; Van Deun & Rieder, 2012; Volmink & Garner, 2007, p. 3). Within Australia the recommended use of DOT as part of overall TB program management varies state by state, as outlined in Table 2 and 3.

²¹ Throughout this thesis I use DOT to refer to the Directly Observed Therapy modality and DOTS as the WHO DOTS TB Strategy.

Table 3. DOT policy from WHO and available guidelines within Australia (TB, leprosy)

Guideline	Position on routine use of DOT
<i>TB</i>	
WHO-TB	DOT is recommended over unsupervised treatment. Specifically, Community- or home-based DOT is recommended over health facility-based DOT or unsupervised treatment; DOT administered by trained lay providers or health-care workers is recommended over DOT administered by family members or unsupervised treatment
CDNA*-TB	'Best practice recommendation,' 'in some cases should be mandatory'. (see selective DOT)
WA-TB	Not mandatory, however 'advocates for DOT especially in the intensive phase of treatment' (see selective DOT)
NT-TB	'Recommended method of administration' (all patients)
QLD-TB	'Strongly encouraged for patients at high risk of sub-optimal therapy' (see selective DOT)
NSW-TB	'Should be mandatory'
VIC-TB	Not mandatory (see selective DOT).
<i>Leprosy</i>	
WHO-leprosy	'As long as accessibility is not a problem, the drugs given once a month should be supervised'
WA-leprosy	Initial dose supervised, monthly doses of rifampicin and clofazimine (PB and MB) "should be" supervised. In addition, Case holding ²² is recommended, that is "supervision of treatment until compliance is established, then monthly directly observed therapy."
NT-leprosy	Monthly doses of rifampicin and clofazimine (both PB and MB) are required to be supervised via DOT

*CDNA- Communicable Diseases Network Australia (national recommendations)

Table 4. Selective DOT

Guidelines	WA (TB, leprosy)	CDNA TB)	VIC (TB)	QLD (TB)
Circumstance for DOT#1	Demonstrated consistent poor adherence	Smear positive cavitary TB	History of non-adherence	Any form of rifampicin resistance
Circumstance for DOT#2	Relapse where non-adherence considered a possible reason	Re-treatment	History of relapse	Patients on three times a week therapy
Circumstance for DOT#3	All MDRTB	Any case with drug resistance	MDRTB	Any patient who has demonstrated they do not have the capability to self-administer
Circumstance for DOT#4	All hospital inpatients		"Mental Health Problems"	Any patient who is not able to maintain compliance
Circumstance for DOT#5	All patients within correctional or detention facilities			Smear positive cavitary disease
Circumstance for DOT#6	For patients where the case manager considers there to be a high risk of non-adherence			Anyone with a history of previous TB treatment

(Centre for Disease Control, 2016, 2018; Communicable Disease Network Australia, 2015; Government of Western Australia, 2019(a), p. 53; 2019(b), pp. 52, 98; New South Wales Government, 2014; Queensland Government, 2018; State Government Victoria, 2015; World Health Organization, 2016, 2017b).

²² As defined by Slutkin (1986), case holding refers to "keeping persons on therapy until completion of a course treatment," by close supervision of their progress.

For leprosy, official terminology of DOT has never been adopted into WHO strategies. The practice of direct observation, or supervision of medication, has been utilised for the monthly rifampicin dose since 1981, when Multi Drug Therapy (MDT) was introduced at the same time as the requirement to supervise the first dose of all medications was introduced (Sansarricq, 2004; World Health Organization, 2003a). The use of supervision has not been accompanied with research that demonstrates improved treatment outcomes when used as part of treatment programs (Sansarricq, 2004). More recently, the WHO added an alternative model for people who had difficulty accessing monthly clinics for supervision, coined “Accompanied Multidrug Therapy” (Accompanied MDT). Accompanied MDT involves providing individuals the entire course of antibiotics through WHO blister packs, provided the first dose is supervised by a Health Care Worker, and there is someone who can assist the person affected with completing their treatment at home (Gelber & Grosset, 2012, p. 231) however has been questioned regarding its role in ensuring antibiotic adherence (Ji, 2002; Prasad & Kaviarasan, 2010). As outlined in Table 2 and 3, in WA and NT DOT is the adopted terminology for guidelines in regard to supervising monthly doses of leprosy therapy and there is no mention of Accompanied MDT.

2.2.2.2 To DOT or not? DOT as a person-centred treatment model

At the time of the rolling out of the DOTS strategy in the 1990s, no trial examining the actual outcomes from direct observation of TB therapy existed (Volmink & Garner (2007). Subsequent research has been accompanied by much international debate about the effectiveness of DOT as a means to improve treatment success over and above self-administered therapy on its own (Karumbi & Garner, 2015; McLaren, Milliken, Meyer, & Sharp, 2016; Volmink & Garner, 2007). Rusen et al. (2007) argue that the measure of DOT as an adherence intervention should not be limited to just the assessment of treatment completion but also the assessment of the effectiveness of DOT in reducing the risk of drug resistance. It was this measure of resistance that Garner and Volmink (2006, p.879) argue had been the justification for the continued support for the use of DOT by the WHO in the 2006 Stop TB strategy that followed on from the DOTS strategy. With the exception of two identified studies that report less acquired resistance and less transmission of drug resistant strains with universal DOT (Moonan et al., 2011; Weis et al., 1994), the majority of DOT research does not address this outcome (Volmink & Garner, 2007; Yin, Yuan, Hu, & Wei, 2016).

Accompanying the evolving practice of person-centred care (as outlined in chapter 15.2), questions have been raised about whether DOT can be person-centred, and within a package of patient-centred interventions, whether the act of direct observation is actually necessary (Bojorquez, Salazar, Garfein, Cerecer, & Rodwell, 2018; Macq, Torfoss, & Getahun, 2007; Volmink & Garner, 2007, p. 7). DOT has been criticised for its paternalistic approach and its questionable ethical standards in regarding patient autonomy and dignity, especially for socially disadvantaged groups who are often designated as more likely to be non-adherent (Brauer, 2015; Macq et al, 2007; Sagbakken, Frich, Bjune, & Porter, 2013; Volmink & Garner, 2007). The threat to civil liberty from the application of universal DOTS in the US in the 1990s became of pre-eminent importance. The primary concern in relation to this threat was the “violation of the constitutional requirement that the state uses the least restrictive alternative in pursuit of public-health goals” (Bayer & Wilkinson, 1995, p. 1547).

In a mixed-methods study in Ethiopia, DOTS was found to have limitations in its capacity to be person-centred. This was in specific relation to “treatment supporter choice” (i.e., the person who provides DOT), provision of “respect and value” to patients, and integration of allied services such as “information provision and counselling, nutritional support, mental health, and transport services” (Getahun & Nkosi, 2017). In another qualitative study that examines the health service delivery and social determinants of TB, DOTS was found more likely to increase uptake and adherence where an emphasis on person-centred support was also provided (Kelly, Morgan, Bonnefoy, Butt, & Bergman, 2007, p. 151). In answering this question of person-centredness, both studies point towards the support that accompanies the direct observation, not the actual practice of direct observation itself, that is potentially the key programmatic feature for operationalising person-centred care. This premise is supported further with evidence of the independent effect of person-centred support in a systematic review by Müller, Osório, Silva, Sbruzzi, and de Tarso Roth Dalcin (2018). In their review the authors identified that patient education and counselling was found to be as effective as DOT as an adherence intervention when measured by cure rates (16% versus 18%). Similarly, van de Berg et al. (2018) found evidence in support of improved treatment adherence with patient support, in their systematic review of individualised patient support practices. This included such measures as providing health education, reminders for medication intake and appointments either with or without DOT, and where DOT was used contextualising DOT provider and location of DOT to the person affected. The authors of the review did not find conclusive evidence that supported the

effectiveness of DOT as an intervention without these support measures (van de Berg et al., 2018, p. 17). Importantly, this review focussed on countries with low TB incidence, including one study from Australia (Wade, Karnon, Elliott, & Hiller, 2012), discussed further in 2.2.2.3. In keeping within Australia, a group of researchers in Victoria also demonstrated effectiveness from an “adherence package” without the need to use direct observation of therapy measured by low rates of infection relapse. This package focussed on the continuity of supply, communication, weekly visits, provision of dosette²³ boxes, and enablers and incentives (Dale et al., 2017).

2.2.2.3 Pragmatics of implementing DOT

Overcoming the hurdles of the operationalisation of DOT has also resulted in robust debate about its pragmatical considerations, such as who is best positioned to be the DOT provider—that is Health Care Workers versus lay community members²⁴—and at what platform DOT is provided e.g., in a health/clinic-based facility versus community-based facility such as in the home (Arshad et al., 2014; Kelly et al., 2007; McLaren et al., 2016; Zhang et al 2016). In terms of DOT providers, usually three categories are utilised—healthcare professionals, trained lay community health workers and close relative of the TB patient (Macq et al., 2003). For some Indigenous communities’ traditional healers or trained bi-lingual health workers (“health visitors”) have been used as DOT providers/treatment supporters, in keeping in line with a more culturally respectful and appropriate approach to treatment in partnerships with individual communities (Colvin, Gumede, Grimwade, Maher, & Wilkinson, 2003; Deuschle & Adair, 1960). In a qualitative review of four Pacific Island nations, traditional healers were considered a potential challenge by some participants for TB programs due to variation in modalities of TB treatment and delaying TB diagnosis (Massey et al., 2011). Nonetheless, collaboration with traditional healers and partnership with Indigenous peoples is considered an important strategy for TB programs in Indigenous communities (World Health Organization, 2019).

In the review by Massey et al, as well as the training of local health workers, it was having local people including family members involved in the implementation of DOTS, especially in more remote areas, that was seen as important to success (Massey et al., 2011, p. 44). The use of family members as DOT providers is something that has been contested. The

²³ Dosette box is a type of Dose Administration Aid for medications.

²⁴ The error-rate of timely medication administration of health professionals, “although not zero”, is considered to be “generally an order of magnitude or more lower” than error of administration by the patient or other lay person (B. Vrijens & Urquhart, 2005)

most recent evidence from the WHO (2017b) states that when family members were compared with Health Care Worker DOT provision, there were “higher rates of mortality, loss to follow-up and failure, and lower rates of successful treatment, cure and treatment adherence” (p. 23). As such the WHO continues to recommend against the use of family members as DOT providers. Despite this, and while acknowledging the complications that can arise due to family dynamics (Garner & Volmink, 2006), there has been evidence of success with family members providing DOT compared with community DOT from a study by Newell et al (2006) in Nepal using a cluster randomised controlled trial design. The treatment success rate was 89% and 85% respectively, demonstrating family member DOT was successful, and both methods were successful against recommended international targets. In their observation of this trial, Garner and Volmink (2006) commented that the TB officer “is engaging in a social process within the family: there is negotiation and sharing of responsibility.” More recently, in the Indigenous Peoples Brief by the WHO, evidence provided increased success when family members were involved, when provided about education of TB (World Health Organization, 2019, p. 19). Another randomised controlled trial carried out in Melbourne, Victoria, found no superior benefit of family-member DOT (FDOT) to “standard supervised but non-observed therapy” (MacIntyre et al., 2003). The authors suggested however, that FDOT may be more relevant to “cultural settings where extended family units are the norm,” which although not part of the research by MacIntyre et al, would suggest application to First Nations peoples (Lohar, Butera, & Kennedy, 2014). With the exception of the Northern Territory (Centre for Disease Control, 2016) family members are not recommended to be DOT providers in any Australian state. In Western Australia, TB and leprosy guidelines identify that the place for provision of DOT can be negotiated, i.e., arranged for any location that is “convenient and safe to the patient and the provider” but restrict DOT provider recommendations to Health Care Workers (Government of Western Australia, 2019(a), 2019(b)).

Technology, such as, Video-DOT (VDOT) and Telehealth DOT, have also been considered in some settings, such as rural or remote, to address pragmatic approaches to delivering DOT (World Health Organization, 2017b, p. 62). One study in Australia, performed by a community nursing service in South Australia, compared VDOT to in person DOT as a means of addressing barriers to the current drive-around service (Wade et al., 2012). The authors concluded that video observation is a patient-centred, resource efficient way of delivering direct observation for TB, and “is cost-effective when compared with a drive-around service.” Participants gave mixed response on the improvement in privacy but

did consider VDOT to offer more flexibility, demonstrating its potential benefit for Australian regional and remote settings.

2.2.3 Case management

The second identified model of care that relates to treatment, for both TB and leprosy, is case management. Case management is defined as an “efficient coordination of health care services to achieve specific and measurable outcomes” (Global Tuberculosis Institute, 2017, p. 12). Case management within TB care dates back to the early twentieth century, where a TB nurse also acted as a health educator for the family affected and aimed to “secure” the cooperation of the patient (Proust, 1991b, pp. 57-58). Contemporary case management is typically led by a registered public health nurse with experience and/or specialised training (Global Tuberculosis Institute, 2017, p. 12). Case managers are involved in a number of aspects of public health measures and the provision of care, such as contact tracing, ensuring the continuity of treatment, the provision of DOT, and psychosocial support (Government of Western Australia, 2019(a), pp. 49,50; 2019(b)). While case management is an historical fixture of TB care, it is less so for leprosy. In Western Australia, however, current management for people affected by leprosy adopts this model of TB case management (Government of Western Australia, 2019(b)), and as mentioned in Chapter 1, uses “Local Case Managers” (LCMs) due to the distance that would be required to travel for trained case managers from Perth to the Kimberley.

The use of case managers in TB care can enable “individualized support” that includes psychosocial and socio-economic support and is recommended as a best practice model (van de Berg et al., 2018, p. 17). Variations on standard case management models have been trialled in other settings in low incidence countries, usually with a focus on populations that experience social complexity or disadvantage. For example, in the UK, a model of case management called “enhanced case management” (ECM) was utilised for “hard to reach” people affected by TB who have identified “clinically and/or socially complex needs” (Gebril, Bell, & Woodhead, 2012). In practice, ECM did not always correlate with improved treatment outcomes but what *was* identified was that more complex situations were linked to poorer treatment outcomes (Tucker et al., 2017). TB case management usually concentrates on people with active infection. However, other variations of case management have been adapted to latent TB (LTBI) treatment. In the US, a “cultural case management” model was used for newly arrived immigrant refugees considered at high risk for active infection (Goldberg et al 2004). Within this model, cultural mediators employed by a local (non-

health) organisation that supports immigrant refugees were given specialised training and worked in partnership with the TB clinic for case management. The authors documented that overall, this model improved treatment acceptance and completion compared with the previous standard clinic-centred approach (Goldberg et al., 2004). While there was no specific literature identifying person-centeredness of case management, the variations on standard case management demonstrate the role the case manager has in providing person-centred care support, especially in situations of social and cultural complexity.

In Australia, standard case management for regional and remote areas is challenged by geography as most TB and leprosy specialist services are centralised within major urban cities. One public health nurse recounted her experience working as TB case manager based in Alice Springs, central Australia. In the challenges of providing care cross-culturally and planning travel to remote Aboriginal communities up to seven hours by road from central Alice Springs, Wales (2015) acknowledged that while TB was a disease that required “medication and monitoring,” it also required “the nurse to take on the patient’s wider world.” This insight demonstrates the importance of integration of the social into the medical especially in adapting care practice to non-urban and inter-cultural settings. Of note, there was no literature identified that considered novel and culturally safe approaches to case management of tuberculosis for First Nations peoples in Australia.

2.2.4 Treatment-related stigma

Stigma has been perceived to impact treatment for both TB and leprosy and hence is an important consideration for review (Courtwright & Turner, 2010; Sermittirong & Van Brakel, 2014). In defining stigma, I draw on the description from Goffman (1963) who describes stigma to include any “deeply discrediting attribute,” that when present within a social setting becomes an “undesired differentness” (Goffman, 1963, p. 3). This differentness is referred to by Singer, Lerman, and Ostrach (2017) as a “spoiled moral status.” In regard to infectious disease, stigma arises out of a fear of contagion within the social group and an ousting due to the marked physical signs of infection and disability they produce (Gussow & Tracy, 1970; Link & Phelan, 2001; Macq et al., 2006). In the context of TB, Link and Phelan (2001, 2006) describe a process of stigmatisation that provides detail about how this social exclusion occurs through several stages. They note that this process initially occurs through an Othering and negative stereotyping of the person affected once their status is known, followed by blame and discrimination. Consequently, normalisation of this process of status

loss occurs within the social group and is reinforced by social policy and legislative responses such as quarantine. Stigma, therefore, is uniquely a complex socially related process.

International literature on TB and leprosy related stigma has focussed on improving ways of measuring stigma to assist in the design and impact of stigma-reducing interventions (Macq, Solis, Martinez, & Martiny, 2008; Meershoek et al., 2018; Sommerland et al., 2017; Teo et al., 2020). Other authors have highlighted the need to consider the cultural context and “local sources” when understanding the way stigma is experienced, so interventions can be more tailored (Chang & Cataldo, 2014; Ebenso et al 2019). For TB, a systematic review by Courtwright and Turner (2010) identified within their emergent themes that TB stigma was “perceived to increase TB diagnostic delay and treatment noncompliance,” noting the challenges in attempts to quantify this perception. Results for the direct correlation of stigma on treatment have been variable. In a study in West Bengal, India in 2019, the results of pretested questionnaires given to people affected by TB who had been identified to “default” from the DOTS program showed that stigma had a negative influence on adherence, with the authors recommending stigma reduction as an important step in improving DOTS adherence. (Chakrabartty, Basu, Ali, & Ghosh, 2019). In contrast, a study in Nicaragua using a patient-centred intervention for people affected by TB found that a reduction in stigma after two months was not associated with any changes to treatment outcome by completion or cure measurement (Macq et al., 2008). In shifting to TB stigma in low incidence countries, a systematic review performed by Craig et al. (2016) revealed few “interventions to reduce TB stigma” and the impact on treatment adherence. Studies that existed were mainly focussed on migrant and refugee populations. Two of the studies were set in Australia (Horner, 2016; Sheikh & MacIntyre, 2009) and focussed on stigma experience in migrant and refugee populations but were not specifically related to treatment and stigma. The authors (Craig et al., 2016) report that in some settings, stigma was a consequence from the way treatment programs and practices were run, rather than a consequence of taking the actual treatment, raising what they conclude are “ethical issues about the way [migrant] communities are represented in research and in TB control programmes” (p.98).

Similarly, variable results have been found for leprosy stigma. Through an ethnographic study of social discrimination among people with leprosy in Northern India, Barrett (2005) identified that stigma resulted undertreatment due to attempts from people to conceal their diagnosis. One of the treatments for leprosy, clofazimine, due to its side effects of skin pigmentation (darkening) has been particularly problematic for this relationship between treatment and stigma, heralded as a confirmatory sign to others that treatment for

leprosy was being taken (Sardana & Khurana, 2020, p. 2). In a literature review on the concepts, causes, and determinants of leprosy stigma, Sermrittirong and Van Brakel (2014) found that the cultural context was another important aspect of stigma, but that similarities across cultures still existed. In some instances, people in advanced stages of the disease self-secluded due to the “fear and shame of being repulsive” (Sermrittirong & Van Brakel, 2014, p. 7). They also noted that in some countries it was not just community and family members socially excluding people affected by leprosy, but also from some health care providers in refusing to treat people with leprosy, subsequently impacting treatment adherence. From a different account, ‘antileprosy’ treatment was identified to be a facilitator for acceptance of social inclusion by Ebenso et al. (2019), in their qualitative ethnographic research combined with life history interviews, for Yorùbá culture in West Nigeria. Leprosy has long been associated with being ‘unclean’; in biblical times, for example, people affected by leprosy were considered to be sinners, leprosy being their punishment (Bennett, Parker, & Robson, 2008, pp. 425,426; Gussow & Tracy, 1970). A change of name in the 1970s from leprosy to Hansen’s was one measure implemented to detach any stigma associated with the disease, and while the term Hansen’s disease has been taken up by biomedicine, leprosy is still used to describe the condition (Gussow & Tracy, 1970, p. 426; World Health Organization, 2021a). In her research in Brazil, Cassandra White (2008) argues that biblical understandings of leprosy, “still exist in the public imagination.” Others however have previously departed from this view. In the US Gussow and Tracy (1970, p. 440) concluded from their qualitative research that leprosy stigma was less related to “ancient ideas and superstitions,” and more related to the fear of leprosy as highly contagious and a “potential pandemic threat” to the west. This finding was echoed by Pandya (2003) who noted the associated response to this fear was a tightening of segregation policies in this era:

The last decade of the nineteenth century saw many in the ‘civilised countries’ of the imperialist West gripped by a paranoia about an invasion of leprosy via germ-laden immigrants and returning expatriates who had acquired the infection in leprosy-endemic colonial possessions. Such alarmists clamoured for the adoption of vigorous leper segregation policies in such colonies. (p. 161)

The various accounts from the literature described above reinforce the complexity and nuance that exist for both TB and leprosy stigma in understanding any consistent causal relation between stigma on treatment. What is clear from this review however is that research in this area is challenging, and due to the social construction of stigma, there is need to consider the local and cultural context of persons affected.

2.3 Review of treatment models specific for First Nations peoples in Australia

2.3.1 Tuberculosis

2.3.1.1 *Stories behind numbers*

Research specific for treatment of TB affecting First Nation peoples in Australia is sparse, and is predominantly centred on TB incidence, comparison of incidence to non-First Nations Australians, and clinical presentation and evidence of ongoing TB transmission. Particular focus has been on epidemiological ‘hotspots’, such as in Northern Queensland and the Torres Strait Islands (due to the proximity to Papua New Guinea²⁵) as well as within the Northern Territory (Abrahams, 1975; Beilby et al., 1990; Devlin et al 2019; Devlin & Passmore, 2013; S. Forrest et al., 2018; Meumann et al., 2021; Robertus et al 2011; Simpson & Knight, 1999). The literature that does exist is focused mainly on these areas in the Northern Territory and Queensland, with some also identified for NSW. Apart from data on incidence (Aboriginal Australians having 4.1% more TB than non-Aboriginal Australians in WA from 1980-1989, (Pang, 1996, p. 16), and some minor historical discussion (Fitzgerald, 2006; Proust, 1991c), no literature was identified specific for Aboriginal people affected by TB in Western Australia

To put this focus on incidence disparity into more context, it is important to highlight the national Australian TB Campaign (ATC), which was in operation for 28 years from 1948 to 1976. With federal funding, the ATC assisted states and territories in the rollout of the campaign through state-run TB control programs (Putland, 2013). It was in the years after the campaign finished whereby it was hailed a national success and federal funding was ceased²⁶ that a higher incidence rate for First Nations peoples in comparison to non-Indigenous Australians was still evident. An increase in mortality and relapse of infection required re-invigorated programs to address ongoing active TB infections (Gruszin et al., 2012; Krause & Zweck, 2002; Putland, 2013).

My aim here is not to reflect on disparity to reify deficit (Brough, 2001), but rather to draw attention to the exclusion of First Nations peoples in the branding of the success of the national TB campaign. The focus solely on numbers fails to pay attention to the individual stories of First Nations peoples affected and the impact on families and communities. These stories include the “theft and loss of family and cultures” related to not only the disruption to

²⁵ Papua New Guinea has a more significant burden of TB, and is associated with challenges of cross-border healthcare arrangements in the Torres Strait (see Brolan, Upham, Hill, Simpson, & Vincent, 2011)

²⁶ For more information pertaining to the funding of the TB campaign and its relevance see Gruszin, Hetzel, and Glover (2012); Putland (2013); Stylianou (2009).

social lives from TB but also the impact of TB-related loss of life (Devlin et al. 2019, p. 8). The reported loss of First Nations lives has been considered by some to be an under-representation, and the true loss confounded by people passing prior to formal TB diagnosis, post-mortem investigations often being culturally inappropriate, and treating physicians not always suspecting TB (Robertus et al., 2011; Simpson & Knight, 1999, p. 1099). An example from WA of a 23 year old Aboriginal man who died in custody in 1983—his death considered by the coroner to be a result of TB meningitis confirmed only after his passing (O'Dea, 1990)—highlights this. Delayed diagnosis, in some cases due to late presentation, is thought to have contributed to this loss (Devlin et al., 2019; Devlin & Passmore, 2013; Simpson & Knight, 1999; Wallace, Williams, & Krause, 2005).

In analysing patient and health system delays in Queensland, Ward, Siskind, and Konstantinos (2001, p. 1025) found that there were shorter delays for First Nations peoples from the time of presentation to the time of diagnosis. They cautioned about the interpretation of these results suggesting First Nations people may have been less likely to report previously seeking medical care, were unable to clearly recall the onset of symptoms due to similarities with other chronic lung disease, their diagnosis may have been easier due to more advanced disease on presentation, and in not being diagnosed when triaged in remote clinics by “remote nurses or Indigenous Health Workers” (implying a perceived under-recognition or non-consideration of TB). Similar reasons were proposed for late diagnoses for First Nations people within the Top End in the Northern Territory, as well as “over-stretched health services,” and “competing priorities” (Meumann et al., 2021, p. 8). The relationship between late diagnoses, advanced clinical presentation of disease and the cultural appropriateness of services was not discussed in either study, including reasons for non-presentation up until the point of severe illness. This was discussed, however, in the results of a rapid anthropological assessment by Grace and Chenhall (2006) in the Maningrida community in the Northern Territory in the early 2000s. They found that late or non-presentation of Aboriginal people affected by TB was associated with local beliefs and values around illness, people not feeling comfortable discussing problems with non-Aboriginal clinic staff, and communication breakdown where English was not the primary spoken language of many community residents.

2.3.1.2 The use of Directly Observed Therapy

The increased loss of life and high rates of relapse of infection in the years after the end of the TB campaign prompted renewed policy responses to improve TB care both in the

Northern Territory (Krause & Zweck, 2002, p. 9) and in Northern Queensland (Simpson & Knight, 1999). In line with the WHO's new DOTS strategy, implementing DOT for First Nations peoples became front and centre of these policy responses. For example, in Northern Queensland, increased funding for Aboriginal and Torres Strait Islander Health Workers was implemented to facilitate greater capability for DOT, adjunct to other measures such as addressing relapsed infection more aggressively and with prolonged treatment (Simpson & Knight, 1999). A follow-up audit five years later revealed that the uptake of DOT practice had increased over the period of the policy intervention, and the number of deaths and relapses had reduced (Simpson, Clark, & Knight, 2006). What is unclear from this success was the actual impact of DOT as "supervision of treatment", versus the provision of improved treatment access and other measures of support that accompany DOT, such as improved information and cultural assistance from local Aboriginal or Torres Strait Islander Health Workers.

In the Northern Territory DOT has been routinely used to manage outbreaks for both active TB and latent TB. An outbreak of TB in Katherine, in the Northern Territory in 2000, resulted in the implementation of DOT for active and latent TB treatment, with a subsequent 98% (31 of 32) "compliance rate" reported (Krause, 2002). According to the authors, Registered Nurses (RNs) dispensed the medications and Aboriginal Health Workers administered, directly observed, and recorded the treatments. In addition, health information was provided with the assistance of a community barbeque, showcasing both a culturally considered and a community engagement approach. A similar model had been previously used in 1996 when the Remote Health Division of Territory Health Services began funding a fulltime, designated nurse based in Maningrida with the assistance of an Aboriginal Health Worker, to administer DOT for TB and LTBI covering small outstations and communities scattered over an area of approximately 500 square kilometres (Grace & Chenhall, 2006, p. 389). Funding however was withdrawn in 1999, and the provision of DOT became dependent upon remaining community health staff.

In recognition of the resource and time needed to provide DOT in the remote context, coupled with low levels of acceptance of and adherence to LTBI treatment, Grace and Chenhall (2006) conducted their qualitative study to gain further understanding of the situation informed by Aboriginal community members and council members. Several themes emerged related to both active and latent TB. These included descriptions of values around illness and the attribution of the presence of TB to white people. One participant noted that,

“TB is a *Balanda*²⁷ disease and they brought it—we were healthy before the *Balanda* came” (Grace & Chenhall, 2006, p. 390). The main reasons identified for poor treatment uptake were barriers to care with local health services (discussed above in 2.3.1.1) in addition to the perceived risk of latent TB and the subsequent need to take treatment. There was no discussion within the study about DOT and it appears this was not included in the research interviews or observations. Another study performed two years later in Darwin did review treatment uptake and the use of DOT for LTBI, this time in homeless Aboriginal populations in an urban NT centre, where “treatment compliance and access to medication were seen as major problems.” (Wallace et al., 2005). Out of forty-five people identified as eligible for treatment, twenty-seven agreed to go ahead with treatment. Directly Observed Preventive Therapy (DOPT) was provided for seventeen out of twenty-seven people considered less likely to be compliant due to more unstable housing arrangements, with fourteen out of these seventeen people successfully completing treatment. Of the remaining ten people who were selected based on considerations of being more compliant due to more stable housing, eight were given unsupervised daily treatment using dosette boxes, which were packed weekly by staff, who counted pills at the return of the dosette each week. Using this latter method, seven out of eight people completed treatment successfully, with the authors noting the high rates of success (87%) in comparison to DOT (82%), however the initial biased selection of groups can be seen as a limitation in this study. Despite this, and similar to international studies reported in section 2.2.2, this study does provide evidence of the impact of support for medication management without direct supervision on treatment outcomes, raising the question about the necessity of supervision even for populations with increased social complexity such as people experiencing homelessness (Story et al., 2020).

A more recent case study in Cape York (Northern Queensland), published in 2020, reported on the use of a “modified directly observed therapy approach” as an adherence intervention for an Aboriginal person affected by active TB. The authors noted that the situation was complicated by delayed diagnosis, an interference with employment status, and a process of treatment that had a “significant effect on the patient’s physical health, and social and emotional wellbeing” (Miller et al., 2020). This process included several hurdles to providing culturally appropriate care to assist in daily treatment uptake. DOT was not implemented from the start, and when initiated was done so in the community provided via a

²⁷ Balanda is the Aboriginal name for ‘white person’ in this region, as identified by the authors (Grace & Chenhall, 2006).

clinical nurse consultant with support from an ‘Indigenous health worker’ (IHW) Mondays to Fridays, and self-administered treatment on the weekend. However, locating the person for supervised treatment was found to be a barrier and the second method that proved successful was the trial of a pharmacist-packed Dose Administration Aid (DAA) and directly observing self-administration from the DAA by the IHW, with a focus on supportive care. It is not explicit within the article which part of the DOT approach the authors consider modified, given that flexibility in DOT providers and place of DOT provision, including the use of DAAs, has been utilised elsewhere. However, what could be considered from this report is a type of IHW-DOT and the demonstrated importance of the DOT provider for the person affected by TB in receiving culturally appropriate and supportive care in assisting treatment completion. Barriers in utilising an IHW-DOT approach existed due to the restrictions on medication administration within the IHW job role, meaning medications had to be pre-packed into a DAA before being observed.

In summary, the available literature signifies that the use of DOT and DOPT is considered a primary adherence intervention for First Nations people affected by TB,. What is not clear is the degree of support that is provided with direct observation, given the lack of information and the variation in practice. In building on the evidence that support for medications management appears to be as effective as just the provision of direct observation, more evidence regarding the need for supervised treatment is warranted. This is especially so in identifying the motivations, attitudes, and decisions both at an individual level and at a programmatic level of applying universal DOT in the treatment of both active and latent TB for First Nations peoples and to ensure, as per the WHO guidelines on inclusivity of Indigenous peoples, that there are active partnerships for these decisions. Repeated attention to adherence within the literature regarding First Nations peoples assist in reifying assumptions of non-adherence at a population level, that requires intervention. The cultural appropriateness of the DOT model has not been scrutinised within the context of ongoing colonising and potential for cultural harm and there is no research that has considered this from the perspective of First Nations peoples themselves. In their systematic review, Devlin et al. (2019, p. 9) suggest that the “authoritarian implementation” of DOT “reminds Indigenous Australians of invasion, systemic racism and theft of family and cultures”. By focussing this research on this colonial context and incorporating the lived experience and perspectives of Kimberley Aboriginal people, this research aims to address these gaps for care. This in turn will add to the evidence base for DOT use as a treatment model for TB among First Nations peoples affected.

2.3.1.3 First Nations-led or partnered research for TB.

In the Aboriginal and Islander Health Worker Journal in 1975, the story of a lady named Florrie, a Tiwi Islander, was published, documenting her journey to rehabilitation from TB osteomyelitis in the spine (Puautjimi, Puruntatameri, Tipiloura, Tipiloura, & Kelly, 1978). This report on lived experience was the first of its kind published and was included in the systematic review and thematic analysis by Devlin et al. (2019). The authors made particular note of the strength of “Tiwi community participation and solidarity” in Florrie’s recovery. In this review Devlin et al. (2019) also summated that the voices of First Nations peoples in Australia are scarce in the TB literature and “absent in the development of TB policies and programmes.” The authors identified several themes, that, unlike the research and reviews discussed above, also consider the colonial legacy of TB for First Nations peoples. This included the themes of “invasion,” TB contributing to “the European idea of the dying race,” “racism,” “the loss of culture,” as well as a recognition of the impact of colonisation in contributing to the construction of social sites of living and housing known to be conducive to the transmission of TB (Devlin et al., 2019, pp. 6-9). A later article by the same principal author, highlighted the utility of a multi-pronged, participatory, and family-centred approach to interrupting TB transmission within a household by providing environmental health assessment and housing “hardware” improvements, at the same time as contact tracing and treating active and latent infections present (Devlin et al., 2021).

Prior to this review, the only other research that considered First Nations perspectives was that of Grace and Chenhall (2006). While the Katherine TB outbreak in 2000 demonstrated program management that was inclusive of partnerships with the community, there was no accompanying First Nations-led or partnered research that came about, especially around treatment. In NSW, led out of a NSW Aboriginal Community Controlled Health Service, a new partnership model for “finding and preventing TB cases in Aboriginal people” has been proposed by Visser and colleagues (Visser et al 2019). As well as developing a model of care that includes latent TB treatment (Visser et al., 2019), the authors make specific recommendations for incorporating Medicare-funded Interferon Gamma Release Assay (IGRA)²⁸ into routine annual health assessments to assist the screening process. This model has the potential for application across other Aboriginal Medical Services and aligns with the national target of TB elimination and in aiding early treatment

²⁸ IGRA tests (referred to as ‘QuantiFERON gold’ tests) are currently Medicare funded only for immunosuppressed or immunocompromised patients.

intervention. However, the use of IGRA tests is not always feasible in remote locations such as the Kimberley as blood samples need to be collected and processed within a limited timeframe (Government of Western Australia, 2011).

2.3.2 First Nations-led or partnered research for leprosy.

Most leprosy research in Australia focusses on the history of leprosaria that discriminately impacted First Nations peoples. The leprosarium's that existed were Channel Island (Darwin) from 1931–1955, East Arm (Darwin) from 1955–1982 (NT), Derby 1936–1986 (WA), Peel Island (1907–1940 after which only European patients were accepted) and Fantome Island (1940–1973) (both in Queensland) (Briscoe, 2003; Davidson, 2016; Hunter, 1993; Parry, 2003; Parsons, 2010; Robson, 2016, 2018; Saunders, 1990). This history will be discussed further in Chapter 4. Of the current non-history related literature found, including grey literature, no research was identified for contemporary treatment and no literature was led by or partnered with First Nations peoples. Literature identified was clinically focussed, such as clinician-guided commentaries reminding practitioners that leprosy infections still occur within Australia (Hempenstall, Smith, & Hanson, 2019; Keed, 2017), and the presentation of clinical case studies (Barkla & Modi, 2013; Edwards et al., 2014). Of note in the case study report from Barkla and Modi (2013, p. 176) in the Northern Territory, an Aboriginal man affected by lepromatous leprosy was put on daily DOT from the time he was discharged from the hospital. No explanation accompanied the rationale of doing so within the report. It is possible that the same logic I have described that underpins decision making for DOT within TB practice, occurred in this instance. It is this lack of providing a rationale and critical reflection of this practice within publications that I argue continues to contribute to the perception that First Nations people are at risk of being non-adherent, and the normalisation of DOT as a solution for this.

No further literature was identified that investigated treatment models or programs for First Nations peoples affected by leprosy. The only exception that could be drawn is the early work by Dr James Hargrave in the Northern Territory, and the handful of published articles in relation to leprosy treatment programs and leprosy control in the 1970s and on until he left his position as a leprologist (Hargrave, 1977, 1983; Hargrave & Gamarung, 1978). In these publications, Hargrave pointedly remarks on the important involvement of Aboriginal Health Workers for treatment programs for leprosy. This is reflected in his viewpoint that, “It is the Aboriginal health worker who will ultimately hold the key to control [of] this very serious disease” (Hargrave 1983, p. 45). In Western Australia, some of the first Aboriginal Health

Workers employed in community health services also reported on leprosy control activities in 1985 (Gargita et al., 1985; Macale, 1985; Trust, 1985). Aboriginal Health Worker Allan Gore from Wyndham reported assisting Sr Olsen in the treatment and surveillance of Hansen's disease, noting that "surveillance consists of recording the weight, blood pressure and Hb, urine analysis, and checking the condition of eyes, hands, feet and skin" (Gargita et al., 1985). Aboriginal Health Worker Aimee Trust recounts the unique surveillance done in the bush, "Leprosy checks of every Aboriginal person were done yearly by Dr. Spargo, in a room made by hanging hessian bags from tree to tree" (Trust, 1985, p. 49). While these early publications demonstrate the involvement of Aboriginal Health Workers in leprosy several years ago, a more contemporary understanding of their current role cannot be identified from current literature or treatment guidelines.

2.3.3 Treatment-related stigma experiences of First Nations peoples

No literature was identified that primarily focused on First Nations peoples' experiences of stigma related to TB or leprosy treatment. There was, however, discrete amounts of information identified within other articles highlighted above. A review of TB incidence in Katherine 2011-2014 suggested that there was stigma associated with the disease, specifically a priority concern about maintaining privacy registered by some Aboriginal people in small communities around contact tracing (Gaffney, Douglas, and Krause 2014, p. 11). In Cape York, the case study reported by Miller et al. (2020) noted for this person affected by TB that a "shame factor" was a significant barrier to daily DOT, largely related to the experience of being singled out by the health service in front of their family. Despite these accounts, it cannot be assumed that all stigma or shame experience manifests the same way in differing social and cultural contexts. Shame for Aboriginal people has been described by Morgan, Slade, and Morgan (1997, p. 598) as more than an individualised awareness of guilt or a sense of disgrace and more of a "powerful emotion resulting from the loss of the extended self" that profoundly affects health and wellbeing and health care outcomes.

The reporting of shame was identified in literature for other communicable infectious affecting First Nations peoples, namely for people living with HIV and hepatitis C virus (HCV). Shame was identified to influence treatment uptake for Aboriginal peoples in WA living with HIV infection by Newman et al. (2007, p. 7), and due to fear of discrimination from disclosure to family, privacy of diagnosis became a significant factor in this experience. The link between privacy and stigma was also relevant for Aboriginal peoples living with

HCV (McNally & Latham, 2009, p. 23; Treloar et al., 2016, p. 36; Wallace et al., 2018). In Victoria, Aboriginal people living with HCV reported feeling “dirty” and the associated shame led to non-disclosure to family members, as well as feeling embarrassed about accessing care, (McNally & Latham, 2009) all of which demonstrates a link between stigma and willingness to access care (i.e., late presentation). There were similar findings in Aboriginal communities in NSW where a fear of stigma impacted disclosure of diagnosis to family, community and even health workers, and further impacting care seeking and support. When discussing their perception of HCV, participants had revealed that the sense of alienation from their family and community was “deeply significant,” disrupting social ties and needs to meet cultural obligations (Treloar et al., 2016). The authors also reported breaches in confidentiality of diagnosis by a doctor who discussed the diagnosis of HCV in front of a person’s family without their prior consent. The impact included a sense of isolation from family, associated feelings of suicide, and a reduced trust of clinic staff, and the authors warn against assumptions of family disclosure for such reasons. These accounts provide a sense of the importance of privacy in relation to stigma and impact on treatment and may have implications for people affected by TB and leprosy. This is another area where this research will assist in building the available evidence base and provide a contextualisation specific to TB and leprosy.

2.4 Chapter Summary

Treatment for TB and leprosy presents a challenging and complex dynamic of tablet burden, extended treatment duration, drug resistance, stigma, and the need for routine adherence to assist in optimising treatment outcomes and preventing infection transmission. This literature review provides an overview of this complexity confirmed by the decades of interventions, policies and research that exist for both diseases and the lack of an international consensus for the benefits of treatment models such as DOT. In the debate about the person-centeredness of DOT as surveillance versus DOT as support, the key element of difference could be seen as the “care factor” in the implementation of DOT, supporting the research approach of this thesis of care conceptualisation.. In the application of targeted or amended treatment models specific to case management there is a focus on providing increased support and targeting social groups considered to have more disadvantage. However, case management was not always related to improved treatment outcomes in socially and/or culturally complex situations and there is minimal research in Australia that considers modified case management models. A more contextualised understanding in

applying treatment, rather than a universal one, appears to be the trend of smaller successes, including the consideration of remoteness for people and communities impacted.

The lack of available TB and leprosy literature to understand the context and unique challenges for treatment for Aboriginal peoples in the Kimberley, and First Nations peoples within Australia, is likely related to the difference in the burden of disease that is experienced here in comparison to other countries who produce the bulk of the research on TB and leprosy. This however does not exclude the importance of understanding Australian social and cultural settings to enable a contextualising of care, rather than blindly adapting models evaluated elsewhere. With the literature that was identified in relation to TB, a significant degree of attention is aimed towards treatment uptake for First Nations peoples, and an often-uncritical application of DOT as an adherence strategy. The use of DOT has been subsumed into standard practice without interrogation or the assessment and acceptance by First Nations peoples in Australia., Whilst considerations for cultural appropriateness in programmatic management around treatment, such as the inclusion of Aboriginal Health Workers is notable, there is no explicit evaluation of the supervision component of DOT for its cultural security and person centredness from the perspectives of individual First Nations peoples. In addition, there was no research identified that considered cultural models of case management for First Nations people within Australian practice such as has been seen within the international context. This paucity of literature extends to treatment-related stigma for TB and leprosy. As a result, this thesis aims to provide evidence for these gaps in research.

In the international context, what is evident is the push towards more person-centred care models and an increase in focus on the social impacts on and from treatment, such as stigma within the social group—all of which support this research's aims and design. The lack of consideration of colonial context within the literature, and the impacts this has had and continues to have on the provision of optimal treatment, is also demonstrated from this review. The work from this thesis aims to address this by using a decolonial theoretical lens to contribute to the growing academic discourse on decolonised models of care. While lessons can be learnt from the experience of other countries or populations, it is critical to provide context-specific evidence for Aboriginal peoples in the Kimberley to understand place-based and socio-cultural challenges that exist, in the aim of improving models of care for treatment.

Chapter 3

Methodology

3.1 Introduction

Research continues to be a potential conduit for the perpetuation of harm through the “coloniality of knowledge, power and being” (Maldonado-Torres, 2007, p. 377). This harm is often enacted through research epistemology, process, and outcomes. Therefore, the purpose of this chapter is to provide transparency about the epistemological foundations, processes and management of outcomes used, as well as providing transparency to my relational position to the research design and this study’s participants. Historically, health research has typically examined First Nations peoples’ health from a euro-Western mindset. This has allowed the perpetuation of negative stereotypes and deficit discourse prominent in many Closing the Gap health strategies that compare First Nations peoples to non-First Nations Australians, in an ‘us and them’ manner.²⁹ This has had the effect of positioning First Nations peoples as ‘outside’ the standard health care system, unwilling to participate, or unwilling to take responsibility. Research outcomes are then constructed in the framework that Aboriginal people *are* the problem, rather than *have* a problem (Hall, 2014, p. 379; McLennan & Woods, 2018; Rigney, 2001; Taaffe, 2008). For example, health research may identify how First Nations people *should* or *could* adapt or change to meet the requirements of the dominant system, or as Wilson (2008) asserts how if “economic and environmental conditions or services were the same for Indigenous and non-Indigenous people, Indigenous people could ‘pull themselves up’ to the standards of dominant society” (p. 20). This has been the case from the earliest articles relating to First Nations Health and tropical medicine published in Australian medical journals, as recorded by Thomas, Bainbridge, and Tsey (2014), who state:

This tropical health research was not only entangled with the politics of colonialism and a white Australia, but also with broader discourses of ‘whiteness,’ race degeneracy in a ‘new’ environment, and the national Australian identity. While hookworm was the first disease among Indigenous people to receive sustained attention in the MJA³⁰, the primary focus was the protection of the health of the white population.

²⁹ Closing The Gap refers to the Australian health policy for Aboriginal and Torres Strait Islander peoples in aim to remedy the disparity in health and life expectancy compared to that of non-Indigenous Australians (Australian Government, 2020).

³⁰ MJA = Medical Journal of Australia

Before attempting this research, it was important for me to identify my position with the research. In transparency of my relationality with the subject, people, and place of the research, I am positioned as an ‘insider’ and ‘outsider.’ As an insider I am a Health Care Worker and pharmacist who has worked within the Kimberley region for eight years. As an outsider, I was not born or raised in the region, and do not have Aboriginal heritage or Aboriginal family relations in the Kimberley area or elsewhere. It continues to be crucial for me to listen and learn from the multitude of First Nations academics who have taken necessary steps to shift research practices and create new and decolonised research paradigms to counteract harmful research, of which I could potentially be contributing to.

Decolonisation of research asserts a research practice concerned with a “more critical understanding of the underlying assumptions, motivations and values that inform research practices” (Smith, 1999). Following this publication increasingly more First Nations academics worldwide are asserting the validity of Indigenous ways of knowing and being, such as through Indigenist research methods (Gegeo & Watson-Gegeo, 2001; Kahakalau, 2004, p. 379; Kendall et al 2011; Rigney, 1999). At the same time, a critical light has been cast on the role of non-Indigenous researchers and use of conventional research methodologies historically grounded and founded within a euro-Western epistemology and ontology (Martin & Mirraboopa, 2003; Willis & Saunders, 2007). To maintain a decolonised research approach, Kendall et al. (2011) advocates non-Indigenous researchers must build in, and be open and transparent about, collaboration with First Nations peoples. Part of this is a “relational accountability,” as a “core presupposition of the Indigenous social research paradigm” (Kahakalau, 2004; Moreton-Robinson, 2017; Wilson, 2008, p. 7). As Cree scholar Kovach (2009) describes, “Relational responsibilities exist between... non-Indigenous researchers and the Indigenous community; and between the academic community and Indigenous methodologies” (p. 178). This responsibility to relational accountability means fostering genuine, respectful, and inclusive research, that can also be flexible in times of grief (i.e., ‘sorry business’), or crisis (such as the COVID-19 pandemic) (Kovach, 2009; K. Martin & Mirraboopa, 2003, p. 212). Respecting and validating First Nations worldviews, building reciprocal and genuine relationships, assisting in the building of capacity of First Nations peoples, and maintaining humility, is part of this accountability (Dudgeon, Kelly, & Walker, 2010; Hovey et al 2017; Wilson, 2008). In addition, the responsibility to decolonised research extends to the inclusion of a critical examination of

health issues that stem from settler colonial policies. Such policies have traditionally excluded, racialised, and dismissed First Nations peoples and their customary methods of health care practice, seeking instead to control, assimilate and remove people from the very country that formed an integral component of a holistic wellbeing (Hall, 2014, p. 377).

In this chapter, I first describe my chosen methodological approach and how it fits within the goal of a decolonised research approach. I identify important aspects of this goal such as the incorporation of an Aboriginal Advisory Group to guide research process throughout the research, and the incorporation of critical reflexivity in order to acknowledge the potential for my biases and epistemological influence in data interpretation. I outline the methods used and the recruitment process, stages of analysis and the processes used to disseminate research findings and incorporate feedback.

3.2 Research design and process

3.2.1 Methodological approach

3.2.1.1 Rationale for choice of approach

With a growing trend in the use of qualitative methods for health research, methodological challenges have also surfaced. Such challenges include the ‘borrowing’ or ‘lending’ of qualitative methods from traditional social science disciplines (Tong et al., 2012) in a “breaking of the [epistemological] rules” that some researchers have argued can result in knowledge production that sits outside of foundational disciplinary structures that govern the very claim to objective knowledge production – hence the claim for reliability within the given epistemological foundation (Anderson & O'Brien, 2017; Caelli, Ray, & Mill, 2003; Elman & Kapiszewski, 2014; Freeman, 2007; Neergaard, 2009; O'Brien et al., 2014). In application to health care and clinical practice, Thorne and colleagues (Thorne, Reimer-Kirkham, & Macdonald-Emes, 1997), question this claim to knowledge production by traditional qualitative research methods, describing what they call a “methodological emancipation” to these traditional disciplinary rules in a new methodological approach labelled ‘Interpretive Description’ (Thorne, 2011; Thorne et al., 1997). Coming from a nursing background, Thorne, Reimer-Kirkham, and O’Flynn-Magee (2004) describe Interpretive Description as a “design logic” for a research approach within applied health practice to have *practical* relevance to an identified clinical problem. They argue that Interpretive Description is “more strategically grounded in epistemological orientations of the professional health disciplines,” away from historical groundings of conventional disciplinary qualitative methodological conventions, and that it is this foundation that distinguishes it

from the “method slurring”, that can occur from qualitative research that omits, or has inconsistencies in, underlying guiding philosophical assumptions (Thorne, 2011).

One of the strengths of Interpretive Description is considered to be the practical relevance the approach brings to health and medical research, asking relevant questions that have utility to practice within complex health care systems (Abdul-Razzek et al., 2014; Hunt, 2009; Thorne et al., 2004). It is this practical relevance in the posing of research questions which others have supported, stating the potential to engage “pragmatically with the multiple uncertainties involved” while offering “a flexible and emergent approach to exploring them”, resulting in the production of meaningful findings (Barbour, 1999, p. 155; Greenhalgh & Papoutsis, 2018, p. 2,3). Despite the critique that Interpretive Description is part of the movement of grounded theory (Berterö, 2015), Thorne (2016) contends it is this practical relevance that is the claim of difference for Interpretive Description to other approaches. The other claim to difference Thorne argues within their design logic is the admission of building on “a priori” experiential knowledge rather than the requirement of a “blank state” prior to inquiry, as with other traditional approaches (e.g., grounded theory). This does, however, mandate a critical reflection of disciplinary knowledge and positioning to account for any inherent biases or assumptions that serve as this a priori knowledge and experience (Thorne, 2016, p. 129; Thorne et al., 1997, p. 173). Interpretive Description is positioned as an inductive naturalistic inquiry, underpinned by a constructivist paradigm (Guba & Lincoln, 1994; Rowlands, 2005 p 81; Thorne et al., 1997). The relationship of the researcher with the research is central to naturalistic inquiry, in that the researcher is not seen as a neutral spectator in the research. The inquiry and the object of inquiry interact to influence one another and allow for participatory processes in building theory with participants (Thorne et al., 2004, p. 176).

3.2.1.2 Suitability of approach for Aboriginal Health research

My choice to use Interpretive Description was based on the strengths outlined above and the capacity for the approach to address criteria required to work within a decolonising framework: a) the positioning of the approach as an epistemic disobedience of traditional methodologies, allowing for a cross-disciplinary health perspective that is suited to both Aboriginal Health and TB and leprosy research, due to the complex interactions of social, political, and cultural components of care; b) the requirement for researcher critical reflexivity; c) a commitment to a ‘practice application’ or ‘utility’ for the research rather than theory alone, in hopes of providing benefit from the research to the community rather than to

theory building alone; d) the requirement in identifying the position and relationship of the researcher with the research and recognising the relationality of researcher with the research project; e) the iterative analysis and participatory process in building analysis³¹; and f) its suitability to health research where there are less participants, especially in respecting the privacy and confidentiality of participants.

Whilst there has been no critical evaluation of the use of the suitability of this approach within global Indigenous Health research, its use has been documented in Canadian Aboriginal Health research (see Duchcherer, 2010; Jull et al., 2015), and in Australia within health research examining social inclusion for Aboriginal people diagnosed and treated for cancer (Treloar et al., 2012). In the latter article the authors draw upon Interpretive Description in their analysis to “illuminate complexities of experience into a coherence that can inform health care policy.”

In choosing Interpretive Description I also acknowledge that it is still founded within a Western episteme and draws on concepts of social construction without consideration of colonial forces. While it may be a form of “epistemic disobedience” (Mignolo, 2013) away from traditional qualitative disciplinary rigidity, it is not an epistemic break away from Western epistemology and ontology. Questions of the ‘clinical problem’ and the aim to find solutions to the problem that forms the basis of research logic orientation (Thorne, 2011, p. 448) can still be constructed, and answered, within the same epistemic logic from which drove or still drives settler-colonial forces. In forming the research question and ‘clinical problem’ for this research, I acknowledge that it was not one directly proposed by the Kimberley Aboriginal community (despite having been discussed with individual members of the Aboriginal Advisory Group) (see ch2.2.2). Instead, questions were moulded and adapted with input from several discussion points with organisation meetings, supervisors, and Advisory Group members. In presenting my research proposal I continued to be confronted with the line of thinking that I had aimed to avoid with the structure of the question, as one clinician had asked, “*how do we get these people to take their tablets?*” in considering the potential benefit from the research. My intention was to avoid this type of logic within the construct of the clinical problem for practice application to ‘how can *we* [as Health Care Professionals] do *better* to make sure people are provided with the required care and support through treatment?’ The intention therefore was a slight shift from the research logic Thorne

³¹ While Participatory Action Research (PAR) (see Miller et al., 2015) was the other logical approach to use, the low numbers and need to maintain privacy due to the topic being researched led to the final decision to use Interpretive Description.

and colleagues put forth, that is a shift from the concept of a clinical problem to the concept of the problem with not addressing the needs of the patient within clinical practice.

The second point for the suitability of approach rests within the tensions that exist between what is considered valuable knowledge to First Nations people, and that within traditional academic discourse. According to Indigenous epistemology, the goal of research is the change that knowledge may bring about, where the knowledge produced belongs “to the cosmos,” and researchers are “only the interpreters of this knowledge” (Wilson, 2008, p. 37). This contrasts with the aim of a PhD thesis to produce “an original and substantial contribution to knowledge” (University of Notre Dame Australia, 2021), where ownership of the knowledge becomes “individual” in nature (Wilson, 2008). While the concept of naturalist enquiry in Interpretive Description necessitates understanding relationality to the knower and what can be known, the embedded culture and relational accountability of the researcher must also be considered with respect to their epistemic position—not just disciplinary—but with a sociocultural lens (Brough, 2013, p. 34). Even with critical reflexivity, there is still the possibility that the contribution to knowledge and how this is shared and owned post research, can operate without an understanding of these incongruences. Consequently, I have utilised other strategies to assist guiding the research process from start to post-conclusion.

3.2.2 Working within a decolonising framework.

3.2.2.1 *The ‘Nulungu Way’*

The experience and insights of local Kimberley Aboriginal peoples with research experience was captured in Luke Taaffe’s Masters dissertation ‘Kimberley voices’ (Taaffe, 2008). In this, we hear firsthand accounts of the need for research accountability and honouring decolonising research practices specific to the Kimberley. Such examples included the perspective of conducting research for the purpose of “self-gain” (or the “gaining of feathers”)—such as a doctoral qualification that potentially provides more immediate benefit to the researcher over the benefit experienced by the community—or for the “benefit of an institution,” rather than the community. As one participant had stated, “I get a bit annoyed with people doing research and then just getting a few more initials on their names and then you don’t hear much about it” (Taaffe, 2008, pp. 51,52). Results from Taaffe’s work were utilised in the policy development of the ‘Nulungu Way’ research process, under the Nulungu Research Institute as part of the Notre Dame University, Broome campus. The ‘Nulungu Way’ framework (Nulungu Research Institute, 2008) is a guide for working with “Right

People, Right Country, Right Way,” and is underpinned by 11 precepts that guide an ethical approach for research with Kimberley Aboriginal peoples in respecting the diversity and vastness of the Kimberley region. This includes for example, “ongoing communication, discussion and consultation, so that research activities respond to community priorities and research methods are reviewed and revised as needed,” and “understanding that cultural obligations surrounding Law, Sorry Business and other cultural responsibilities to family and community will take priority for the peoples we work with and being flexible and responsive to these needs” (Nulungu Research Institute, 2008).

This flexibility in timing, although built into the research to allow for time to fit in with participants, became an incredibly important, and unpredictable, part of the research process. Not every visit was the right time, meaning the need to re-try, or re-schedule. Coming in with ‘whitefella’ thinking about timing (i.e., arrange to stay for two days in a location and expect that all meetings and business will occur as planned), simply does not work and is also disrespectful. What worked was taking time to establish relationships, understand the community, and acknowledging what is happening and when it is best not to be there. However, there were tensions between this approach and the timing required to meet the academic curriculum. This tension has been discussed by others. For example, Anderson and O'Brien (2017) describe that “developing an ethical research relationship is more important than how the data is collected” and McLennan and Woods (2018) suggest prioritising trust and reciprocity as part of this. In honouring the commitment to the research and prioritising relationships with the community over the academic timeframe, the period of research fieldwork extended for 20 months from March 2018 to October 2019, and the presentation of results after this time was deferred due to higher priorities and restricted travel given the COVID-19 pandemic.

3.2.2.2 Establishment of an Aboriginal Advisory Group

In following the guidance from the Nulungu Way, early consultation prior to the finalised research proposal submission, and prior to ethics, an Aboriginal Advisory Group (AAG) was formed from new or previously formed collegial or non-familial relationships with local Aboriginal women and men, via myself or supervisors. Prior to initial university enrolment, early conversations were had with some (soon-to-be members) about the potential for the research project and discussion of the topic and its suitability. Once membership was formed, the group met at several stages over the process of the research before ethics/university approval and throughout the project. All members were voluntary and

worked (or had worked) within health or education. While there were no official terms of reference for the group, communication was kept open and regular updates about the research were given. Throughout the process, some members were unable to continue, and others joined at various stages to assist with advising on cultural matters. See [Appendix D](#) for an outline of meetings and advice provided. Members also assisted with data analysis and discussion about the research results. Robust dialogue and sharing experiences of the research this exchange was important for a number of reasons: a) they helped me consider perspectives outside my worldview; b) ensured I was not misinterpreting or misrepresenting cultural values and customs; and c) allowed for reflexive learning and ways of thinking that assisted a de-linking. The advice and discussions had with the AAG was significant for the direction and interpretation of this work and I gratefully acknowledge that it would not have been the same without them.

3.2.2.3 Ongoing communication with local health organisations

Early consultations for the research process prior to ethics approval and candidature, were also with local organisations. Both the Kimberley Aboriginal Medical Services (KAMS), and the Kimberley Population Health Unit (KPHU), were consulted early in the research development to gain support and feedback into the proposed research. This was done prior to formal support being provided by both organisations, and prior to the research project plan being reviewed by the Kimberley Aboriginal Health Planning Forum (KAHPF) Research Subcommittee—a required process for health research within the Kimberley region before any submission to gain ethics approval. The KAHPF subcommittee was formed in 2006 and is comprised of Aboriginal and non-Aboriginal community organisations and respective leaders within the health sector of the region, who act as stakeholders in the process of reviewing research for the Kimberley (McLoughlin, Hadgraft, Atkinson, & Marley, 2014). This process ensures the application to clinical practice is in line with the need to “keep projects locally relevant” in partnership models for ethical Indigenous research as described by de Crespigny et al (2004, p. 12). This process also assisted the testing, moulding, and approval of the research question. The commitment for ongoing communication with regular updates and feedback of results to the community was a part of this process. This commitment to the community does not end with the completion of the research or gaining of any qualification—it continues in the goals of research translation and any future publications related to the project.

3.2.2.4 Keeping research on track and ethics approvals.

In addition to addressing the six values outlined by the NHMRC ethical considerations for working with Aboriginal and Torres Strait Islander peoples required for all ethics applications—that is, keeping the relationship of the research in line with the spirit and integrity of Aboriginal peoples—I consulted a step-by-step process for ‘keeping research on track’. This involved a demonstration of reciprocity, respect, equality, and responsibility (National Health and Medical Research Committee (NHMRC), 2018). Consulting these NHMRC’s ethical considerations allowed me to take responsibility for the research and carefully consider feedback encountered. In addition, the guiding framework for good Aboriginal research was followed (see Laycock et al., p.17,18).

Ethics approvals were sought from the Western Australian Aboriginal Health Ethics Committee (WAAHEC, #777), the Kimberley Aboriginal Health Planning Forum research sub-committee (KAHPF #2017-009), the University of Notre Dame UNDA (#017052f) and the Western Australian Country Health Service (WACHS, #RGS0000000229), who also required research governance approval for site and staff visits. In recognition of potential change through the research journey, two ethics amendments were sought and approved during the research process.

3.2.3 Methods and recruitment

3.2.3.1 Methods

In order to answer the research question and aims of the research identified in Chapter 1, the methods chosen allowed me to learn the story about TB and leprosy treatment, its evolution, current applications and most importantly, what the experience was for people involved. My inquiry involved an investigation into the lived experience of people affected by TB or leprosy and Health Care Workers. Qualitative methods of face-to-face open-ended and semi-structured interviews and focus groups were chosen to allow for an in-depth examination of lived experiences. In line with Interpretive Description, the sampling was purposive, i.e., participants were purposefully selected to provide information-rich accounts of experience in relation to the given research question and phenomenon of treatment (Palinkas et al., 2013). Eligible participants across the Kimberley region were allocated to one of three ‘study’ groups. Eligible participants for ‘Study Group 1’ were individual Aboriginal persons affected by either leprosy, active TB or Latent tuberculosis (LTBI) who had been offered or taken treatment at any point from 2012; ‘Study Group 2’ were focus groups for Aboriginal family or community members who had cared for, care for currently,

or know of family or other person who has been affected by either condition, but this was not essential; ‘Study Group 3’ were individual Health Care Workers and identified as Aboriginal or non-Aboriginal. This group included medical doctors, Aboriginal health practitioners, Aboriginal health workers, registered or enrolled nurses, and pharmacists who are or had been involved in any aspect of treatment for TB or Leprosy since 2012. The study was for adults 18 years and over. The interviews were designed to be open-ended to ensure that all participants had an opportunity to tell their story and be listened to, as well as incorporating opportunity for “yarning,” an Aboriginal cultural form of conversation described as a “process and exchange” (Bessarab & Ng'andu, 2010, p. 3; Fredericks et al., 2011) (see [Appendix E](#) for interview question samples). In presentation of the findings in this thesis, quotes taken from interviews with Aboriginal participants have not been altered to fall in line with conventional grammatical understanding. The reason for this is to avoid putting further interpretation on what was said and how it was said which may have the unintended consequence of altering the intended meaning and diminishing Aboriginal voice.

Other methods used to capture the treatment story were desktop sources of grey literature and treatment guidelines and policy examination and archival research. As Mason et al (2016) point out, “how a patient’s condition is understood and treated is framed by their local historical context” (p. 224). Non-participant observation throughout fieldwork assisted formation of ideas and an understanding of the way things worked on the ground and was documented via journaling.

3.2.3.2 Recruitment

Respect for people’s privacy was at the forefront of recruiting eligible participants in Study Group 1 and 2, due to the potential for stigma from being affected by TB or leprosy. This was enacted in three separate ways. The first was for individual persons affected by TB, LTBI or leprosy, (i.e., Study Group 1), whereby eligible participants were invited to participate in the study using a pre-designed ‘preliminary information form’ (not a consent form) by a known health clinic staff member. A list of all eligible participants was first generated by the KPHU Regional TB and leprosy co-ordinator, who had access to the WA notifiable disease database, and this list provided to the relevant community health site who then coordinated contact with eligible participants to provide the preliminary information and invitation to the research project. Participants became known to me only after they indicated interest in the research project either via this form or directly via the health clinic staff member who had provided the form, on their behalf. The second, in recognition of the small

numbers and degree of privacy, was the choice to have identified communities most affected kept confidential from myself until after ethics approval. Even in the writing up of the project results, to continue to maintain this privacy, names of persons affected, language groups, place and community names have been de-identified throughout the thesis and research reports to respect individuals and communities' privacy. The third was a decision to not apply to access medical data for persons affected as other ways of confirming related medical or medicines information, in order to give priority to the lived experiences of persons affected and health care staff. After ethics approval, once communities were identified, community engagement was addressed by first going through local Aboriginal Medical Services and community health centres, then hosting small educational lunches, morning teas and larger barbeque lunches collaboratively with local services, funded by researcher funding.

Forty-one participants completed interviews. This was inclusive of six individual participants in Study Group 1, three focus groups within Study Group 2 (two groups of five participants, and one group of ten participants), and fifteen participants in Study Group 3. In some cases, participants were eligible for more than one Study Group (such as Aboriginal Health Workers) and their preference to speak as part of a focus group with other community members or colleagues was respected. Sixty-eight percent of participants identified as Aboriginal, that is thirteen percent of Health Care Workers (Study Group 3), and one hundred percent of individual persons affected and focus groups (Study Group 1 and 2 respectively). To respect confidentiality, no real names have been used in this thesis unless where explicit permission was given. For individuals in Study Group 1, I have used fictional names to humanise their story and assist with their narrative throughout the chapters. It is also important to pay attention to those who chose not to participate. While some persons showed initial interest but did not want to follow through with an interview, there were others who showed no interest from the start. There were varied reasons for this, including ill-health and an inability to locate people. Rather than view this as a limitation I see it as a representation of the challenges associated not just with research complexities within the given topic, but also with the realities of trusting non-Aboriginal researchers especially in situations constrained by privacy concerns, even where cultural liaison is present.

3.3 Analysis and dissemination of the research

3.3.1 A question of truth

3.3.1.1 *Reliability and validity in Aboriginal Health research*

Reportable standards for qualitative health research can be seen as a “set of rigid and rigorous rules to govern what might constitute quality criteria” (O'Brien et al., 2014; Tong et al., 2012). These standards assist with transparency in the methodology and methods, identifying the approach to rigor, the analytic lens used for data examination and ways of validating qualitative research as trustworthy and reliable (Caelli et al., 2003, pp. 1,5). Others argue that the success of research in providing benefits or contributing to the field becomes a separate matter that is not directly linked to meeting the checklist of quality criteria (Barnes, 2018, p. 381; Freeman, 2007, p. 30; Greenhalgh & Papoutsi, 2018; Thorne & Darbyshire, 2005). According to Patton (2002, p. 266), these issues of quality credibility and benefit intersect with the intended audience of the research and intended inquiry purpose. In the intersection of benefit from Aboriginal health research, Aboriginal scholars have also questioned concepts such as rigour and validity, and instead view research quality as “authentic and credible” and “reliable” in terms of the relational accountability and process of demonstrating this (Wilson, 2008, p. 101). This notion of relational accountability, mentioned earlier in this chapter, has been articulated by Martin and Mirraboopa (2003, p. 213), who note:

The task of interpretation is to maintain these micro- and macro- relations of research as processes for re-connecting the patterns revealed in analysis. It has less to do with capturing 'truth' or drawing general conclusions, than the re-connecting of self, family, community, and Entities that can be claimed and celebrated.

This demonstrates the tensions between, and complexity involved, in what is considered credible from traditional Western research methods and that from Aboriginal perspectives. More importantly, it also reveals who is the judge of this interpretation.

3.3.1.2 *To saturate or not? Tools used for analysis.*

Trustworthiness can be fluid when breaking the methodological rules outside of traditional disciplines. The use of saturation,³² considered by some the gold standard of tools for qualitative analysis, has contributed to significant confusion and debate among qualitative researchers in its description and application (Nelson, 2017; Saunders et al., 2018; Thorne,

³² The original concept of saturation from Glaser and Strauss in 1967, with reference to grounded theory, comes in respect of judging when to stop data collection and/or analysis in a situation where the researcher sees similar instances repeatedly. At this point, it is considered the thematic category has been saturated (B. Saunders et al., 2018)

2011). For example, according to Saunders et al. (2018), the type of saturation, that is data saturation versus thematic saturation needs to be considered, as this can alter when data collection becomes enough to *illustrate* theory or needs to continue in aim to *exhaust* theory. Others have stepped away from saturation altogether, describing alternatives such as “information power,” whereby participants hold characteristics highly specific for the study aim requiring a less extensive population sample (Malterud, Siersma, & Guassora, 2016). Greenhalgh and Papoutsi (2018) believe that data collection can never truly be complete or perfect and “decisions often need to be made in incomplete or contested data” (p. 3). Thorne (2011, p. 447) suggest that even an exhaustion of theoretical configurations becomes less logical in the application to the health field and human experience in not being able to account for every situation. This is certainly the case for this current study, especially in respect of diversity and the inability to represent people who did not participate. In knowing when to stop data collection, “information power” becomes a more reliable measure.

Analytic tools used to further assist building the final analysis were the combination of concurrent data analysis, constant comparative analysis between Study Groups, and iterative analysis, as described by Thorne et al. (2004). The initial aim was to conduct first round interviews along a similar timeframe, then to go back to ‘second round’ interviews to confirm. In practice, however, this was not possible. Not all first round interviews were concurrent, and not all people were interested, nor was it always possible to do second round interviews. In this way however, theory built from the first stages of analysis was able to be tested and further refined with other participants. Coming into this research I had considered other analytic notions of triangulation, member-checking and self-description. In practice, I found that triangulation, rather than proving trustworthiness, assisted more in understanding tensions and similarities in perspectives between study groups and member checking more as a validation exercise with participants about emergent themes or data that was proposed to be used. Self-description, through journaling, was the critical reflection element which was crucial in the consistent toing and froing between data collected, building theory and my position and biases.

3.3.2 Process of analysis

3.3.2.1 Interpretation of data

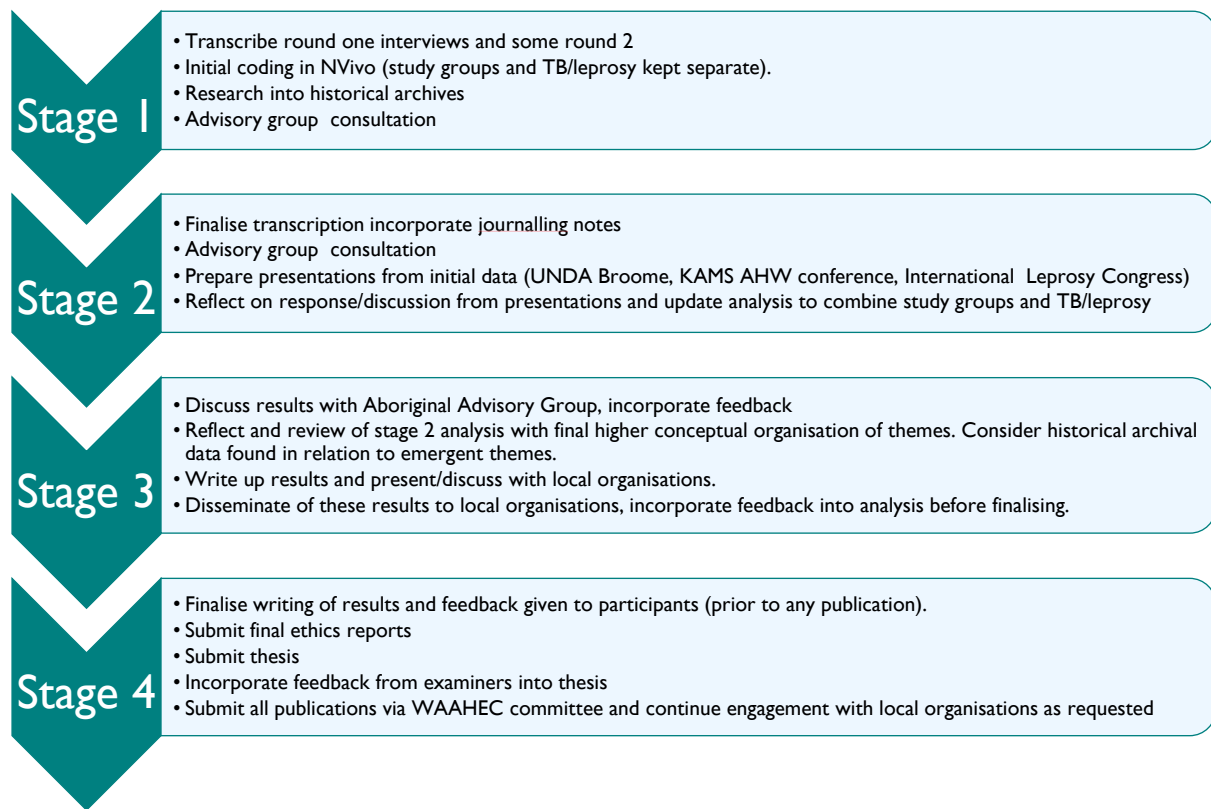
All interviews and focus-groups with participants were audio-recorded and manually transcribed verbatim. Analysis was aided by NVivo computer software to assist in sorting and coding data. While the interpretation of data for this research needed to be congruent with

‘naturalistic enquiry’, and ‘constructionism’ outlined in the Interpretive Description approach, it still needed to be purveyed through a de-colonial lens in order to dismantle aspects of the treatment model that continue colonial legacy through ways of knowing, being and doing with respect to health practice around TB and leprosy. Thorne et al. (2004) pay specific attention to the interpretation of data within the research design, stating “no matter how participatory and collaborative the method, it is the researcher who ultimately determines what constitutes data” (pp. 5–8). Interpretation, as discussed, has the potential for bias, even when approaching the research in a prescriptive way as guided for safe research involving Aboriginal participants. There is a limitation in my position as a non-Aboriginal researcher to interpret and describe cultural aspects of the research without also considering interpretations from Aboriginal perspectives, interpretations which were discussed with members of the AAG. Differing interpretations, where applicable, are discussed to substantiate analysis.

3.3.2.2 Stages of analysis

For ease of structuring the analysis, a practical approach was taken to formulate three stages used to refine generated theory in an iterative way. This has been outlined below in Figure 2. In stage 1, data was separated for study groups and for TB and leprosy relevance, using respective thematic headings that emerged. In stages 2 and 3, emergent themes from study groups across both TB and leprosy were pooled together, with ongoing re-financing of organising themes and sub-themes. In stage 3, journaling and reflections from critical reflection and non-participant observations were also merged into organising themes, headings, and sub-headings in NVivo, presented in the results chapters. All themes from Study Groups 1–3 were pooled together, and examples specific to either disease or study group were noted within this pooling. Data retrieved from historical archives was kept separate from this staged analysis in NVivo and forms its own chapter (4) to foreground the findings from the staged analysis presented in chapters 5,6,7. The purpose of the three stages of analysis was to avoid “fitting” the data to any pre-conceptions, and to “see through” the data by asking the question of “what is happening here” (Thorne et al., 2004), This approach assisted in generating new and useful conceptualisations with emergent themes throughout each stage. The final settling on results comes in the recurrence of identifying if the analysis answers the research question, how it answers the research question, how does it have application, and descriptive detail associated with application.

Figure 2. Stages of analysis



Note. While there are three stages for the analysis, a final stage is incorporated into the diagram above (Figure 2) to articulate how the findings from this research move beyond thesis submission.

3.3.3 Providing and incorporating feedback.

The original intention to disseminate findings to local health organisations was somewhat thwarted by the Covid-19 pandemic, interstate border closures, and new priority workloads related to outbreak management and vaccination rollouts. Instead, feedback and discussion were managed by remote correspondence and presentation to local health organisations. Following the submission of this thesis, I intend to continue disseminating of findings as required. Feedback to participants, while originally intended to be done in person, was achieved through emailing written summaries, or emailing/posting pre-recorded audio/video files. Feedback was incorporated through the research and formed an important part of a participatory process to ensure Aboriginal perspectives informed all stages of the research. The importance of feedback cannot be understated in honouring a respectful research process. Muller (2014) reminds us that “genuine two-way sharing of knowledge is a sign of mutual respect and understanding” (p. 100), and this knowledge exchange is explained further by Wilson (2008, p. 125) who tells us the presentation of knowledge is about continuing healthy relationships. Importantly, discussion was had among the members

of the Aboriginal Advisory Group, in raising concerns over research translation and how this could occur to make the research beneficial. Concerns were based around existing structures present that already represent a challenge for Aboriginal representation within some health services. These concerns were listened to and discussed for what actions would be possible and what would require further systemic changes. They were later incorporated into recommendations and will be discussed further in Chapter 8.

3.4 Chapter summary

With the aim of ensuring an appropriate methodological approach for this research this chapter details specific processes used in the research design. These include utilising an approach and process that is respectful and accountable for Aboriginal people in the Kimberley, maintaining a commitment to this process throughout, and using an approach that will assist in providing benefit to the community within the field of medical and social health research. I have outlined the benefits and limitations of the approach of Interpretive Description used in the suitability to work within a decolonising framework, arguing that by itself it is not a decolonising methodology. I have described other measures required that I have incorporated in the goal of working within a decolonising framework. In applying a decolonial lens, there was a need for critical self-evaluation to permit an honest examination of how any inherent Western privilege, life experience and disciplinary epistemes could influence the analysis of data. By this process I maintain that the question should not be “can a white researcher get it?” but rather “how can a non-Indigenous produce research which provides real benefit to Aboriginal peoples?” Committing to relational accountability, and not just following a prescribed process, is one answer to this question that has proved to be equal parts challenging and rewarding.

Chapter 4

A History of Tuberculosis and Leprosy Treatment in the Kimberley

4.1 Introduction

When we were taken into the Leprosarium, we were longing for our country, never to return to it. To go there was to stay forever.

Forrest (2003, p. 33)

This chapter details treatment for TB and leprosy in the 20th century and how medical decision making around treatment for Aboriginal peoples in the Kimberley region intersected with colonial policy. It is important to highlight that the main source used for compiling this history was archival research of historical documents, with incorporation of Aboriginal oral history where possible through literature found or direct from participants. I wish to be clear that I have drawn from colonists' documentation in order to explore and highlight any colonial logic that pervades care and the subsequent influence on the construction of theory and practice surrounding treatment for TB and leprosy. The re-presentation of these historical accounts however comes with the risk of further embedding colonial perspectives as "truth", if not accompanied by any critical analysis of power (Trouillot, 1995). In acknowledging this dominance and the risk of perpetuating a colonial version of 'truth,' evidence collected from these sources is presented with accompanying critical analysis in direct relation to historical management of TB and leprosy for Aboriginal people. This focus is in no way meant to disrespect or negate the experiences and stories of multiple generations of Aboriginal families that have been personally impacted by either condition and I acknowledge there are many oral histories that are not represented here.

I have purposively sectioned this chapter into pre-antibiotic, and antibiotic eras in the 20th century. In the pre-antibiotic era, isolation, or segregation were principal strategies in controlling disease. Such strategies were considered a method of prophylaxis, i.e., preventing community transmission in the absence of antibiotic treatment. In the antibiotic era, discovery of effective antibiotics (also referred to as chemotherapy) for treating TB and leprosy was pivotal in providing a cure for both conditions. The contrast in time periods between the void of effective treatment to the discovery of antibiotics provides insight into decision making for the application of the public health principles of isolation, antibiotic drug regimens, and mandatory supervision of treatment, which I argue was centred on perceived risks to the

white settler population. At the same time, Aboriginal peoples were constructed as the ‘diseased Other’ and discriminately positioned as both responsible for disease transmission, and irresponsible in disease and treatment management, despite the challenges of dosage design, treatment safety and emerging drug resistance. In this chapter I proclaim this colonial logic continued throughout the 20th century, despite the evolution of treatment knowledge and health policy, continuing to influence decision-making over isolation and treatment practices for Aboriginal people. While this section discusses this evolution of treatment for both TB and leprosy, more evidence was identified for leprosy in relation to the Kimberley and is identified within each section.

4.2 Management of TB and leprosy in the pre-antibiotic era

4.2.1 The principle of isolation

In late 19th century and early 20th century Australia, any person suspected of having TB or leprosy was compulsorily segregated from their family and community into designated and isolated sites in what was often referred to as “prophylaxis” (Pandya, 2003). This principle of isolation was “an ancient method of coping with communicable diseases” and formed part of imperialist public health policy that followed British settlement in Australia (Gussow & Tracy, 1970, p. 437). For TB, these sites of segregation were referred to as ‘sanatoriums,’ and for leprosy ‘leprosarium’s’ or ‘lazarets,’ and their use in other parts of the world predates colonisation of Australia (International Leprosy Association, 2022). Due to the “biological and etiological” similarities between the two, TB management principles were often adopted to leprosy management and vice versa. Parallels drawn between them were representative as “diseases of civilization” (see Anderson, 2003, pp. 187, 220; Worboys, 2000, p. 214). As part of the imperialist regime specific emphasis was placed on hygiene and modern sanitation as a solution to counteract TB and leprosy. The focus on hygiene was largely influenced by the British 1848 public health act, heralded as the “sanitary revolution” (Donaldson & Rutter, 2018, p. 327; Scally & Womack, 2004, p. 750). The imperialist public health approaches used by settlers in Western Australia to manage people affected by leprosy and TB hence collided with, intruded upon, and disrupted an Aboriginal way of life unaccustomed to and at odds with such practices. The focus on this section is the disruption and subsequent colonial harm and logic that occurred before the availability of antibiotics.

For the most part, the following section, discusses TB and leprosy separately. In addition, reference is given to the Kimberley region as the ‘North,’ as it was referred to

within this era, noting that often this region was combined with the ‘North West,’ which is now geographically referred to as the Pilbara region.

4.2.2 Early management of leprosy in the Kimberley

4.2.2.1 Emerging issues with isolation

There are conflicting records of the first account of leprosy identified in an Aboriginal person in the Kimberley. None of these documented accounts is direct from the knowledge of local Aboriginal people and largely from the account of settlers. The exception is the Aboriginal academic and activist Gordon Briscoe (born in Alice Springs), who in his ‘Counting Health and History’ book (Briscoe, 2003, p. 120) suggests that leprosy was first recorded among the Kimberley Aboriginal population in 1908, around Fitzroy estuary at King Sound³³. The release of a landmark publication by Dr Cecil Cook entitled “The Epidemiology of Leprosy in Australia” in 1927 that included the North of WA, suggested that the source of leprosy for Aboriginal people in the Kimberley was not through European settlers (it had been many years since leprosy was a problem in European society) but rather through “indentured labour of the pearling industry,” due to the endemicity of infection in their home countries³⁴. In other parts of the country, Chinese miners were considered responsible for the spread of leprosy³⁵ (Cook, 1927; Davis, 1939, pp. 211,212).

The principles of isolation were adopted swiftly for Aboriginal people affected by leprosy with the use of tidal islands in the North and the North-West. Initially Cygnet Bay Island was used on Bardi country, where Davidson (2016) writes, “About once in every eight months the police delivered water, firewood, flour and tea” (p. 122). This soon shifted to Bezout and Cossack islands, located in the Pilbara, north of Roebourne, until eventually the ‘old residency’ in Derby (near the main settler Derby hospital) was used and named the ‘Derby lazaret’. Due to the increasing number of Aboriginal people becoming affected by leprosy³⁶, a decision was made in 1931 to transport all people suspected or confirmed to have

³³ In his book ‘Havens of Refuge’ Davidson (2016, p. 9), alludes to the first possible cases of leprosy being at Cygnet Bay (Bardi country) and Point Torment (Warrwa country). He also raises the possibility of incidence as early as 1897 identified by Fr Nicholas, a priest in Broome, who had prior knowledge of leprosy after recently relocating from Paris (Davidson, 2016, p. 14).

³⁴ Labourers came from the Philippines, South Sea Islands, Indonesia, and other parts of south-eastern Asia.

³⁵ In his review, Cook was particularly condescending to Aboriginal women as being the source of transmission from Asian men to white men, through “conjugal relationship,” demonstrating early on his attitude towards Aboriginal people.

³⁶ Leprosy did not just affect Aboriginal people exclusively – there were reports of some settlers affected, such as nursing staff—however they were usually sent South to the Perth Wooroloo TB sanatorium. There is an account of a ship captain who refused to be sent south and chose to isolate instead at Bungarun, where he later died (Davidson, 2016).

leprosy to the Channel Island leprosarium in Darwin. The Derby lazaret, as well as an additional isolation ward set-up at the small peninsula community of Beagle Bay (looked after by the Sisters of St John of God), were used as temporary isolation sites whilst awaiting transport to Darwin (Briscoe, 2003, p. 178). Costs of transport to Darwin became insurmountable and when the Derby lazaret became overcrowded a growing discontent of the white residents in Derby town occurred. By the end of 1933 there were 30 or 40 Aboriginal people suspected or confirmed with leprosy housed at the lazaret (Davidson, 2016, p. 40; Moseley, 1935, p. 10). Members of the Derby Road Board were recorded in their outrage of how the government was handling the situation, stating that, “Six or seven years ago the road board members resigned in a body as a protest against the inactivity of the Govt towards leprosy. Very little progress has been made in dealing with leprosy in Kimberley.” (A.A.M Coverley in Moseley, 1934, p. 400). The pressure on the government from white residents in the Kimberley continued. A letter from the Broome Road Board to the Minister for Health in 1933, drew attention to a girl suffering from leprosy from the Kimberley district who had been a boarding scholar at a southern college in Perth. The members from the Road Board had persuasively argued, “should this news become public it will certainly cause much uneasiness to the parents of other scholars who were attending this particular college” (as quoted in Davidson, 2016, pp. 40,41).

In response, an allowance was approved for the first official surveys to record leprosy incidence by appointed medical doctors. After visiting the old Halls Creek, Dr. Webster recounted the isolation story of a young Aboriginal woman at Argyle who was affected by leprosy. While awaiting transport to Darwin, temporary isolation was arranged at Wyndham gaol due to the distance from the Derby lazaret, where she spent six months in solitary confinement (Davidson, 2016, p. 43). Reportedly, the Commissioner of Public Health was “quite horrified” by this incident of isolation but was re-assured that the conditions were acceptable due to the “large cell,” she was provided with “plenty of room for exercise.” Such was the blur between humane isolation practices and criminalisation for Aboriginal people that a perceived risk to the settler community justified this overt, and inhumane, practice.

4.2.2.2 The impact of the 1934 Moseley Royal Commission

The mounting pressure from Derby and Broome Road boards, as well as the increasing numbers of new leprosy infections, triggered the addition of leprosy to the Moseley Royal Commission in 1934, set up to “investigate, report and advise upon matters in

relation to the condition and treatment of Aborigines” (Moseley, 1935)³⁷. After reviewing evidence provide to the Royal Commission, Moseley presented his findings regarding leprosy in the North (Moseley, 1935, p. 10):

It is considered by the Local Health Authority that the present site of the area [Derby lazaret ‘huts’] is such that the presence of leprous natives there constitutes a grave menace. Assuming that complete isolation is necessary, and Dr. Cook, the Commonwealth Medical Officer at Darwin, considers it is, then it is obvious that the site is wholly unsuitable.

Voices of Aboriginal people in the North affected by leprosy themselves, their family members, or any of the Aboriginal community were largely missing. Moseley had spoken on their behalf, registering, “In spite of the utter discomfort and wretchedness obtaining under the present system, the only request I had from the patients was that they should not be sent to Darwin.” Although some health figures disagreed with ongoing compulsory isolation³⁸ it was the advice of Dr Cecil Cook³⁹, that influenced Moseley’s recommendation the most:

There are doubtless some medical authorities who will differ from Dr. Cook in his view on the necessity for isolation. He is, however, occupying his present position as an expert in tropical disease and I am not inclined to reject his opinion until someone of greater experience in the same branch of the medical profession satisfied me that he is in error (Moseley, 1935).

The decision therefore for ongoing mandatory isolation was settled. The final location for this “detention hospital” (as it was referred to in the report) was on Warrwa country Northeast of Derby, at the time under pastoral lease (Meeda and Point Torment) with half the cost paid for by the commonwealth and the remainder by the state (Sisters of St John of God, date unknown-b). It was this pivotal decision, influenced by Dr. Cook, which resulted in what was to become the beginning of a 50-year period of the use of the Derby leprosarium, named “Bungarun” by local Aboriginal people, from 1935, with the Sisters of St John of God

³⁷ For a detailed account of the Royal commission see Biskup (1973, pp. 167-184); Haebich (1992, pp. 326-344); Moseley (1935)

³⁸ One of the most prominent speakers against compulsory isolation was Sir Leonard Rogers, who wrote, “except under the favourable conditions existing in Norway no material reduction of the disease ever seems to have resulted from this drastic measure,” arguing that the policy of isolation deterred people in coming forward to be treated by medical practitioners, hence impacting on disease transmission (L. Rogers, 1942, p. 87). Rogers and colleagues were of the opinion from their work in India that a large proportion of people affected by leprosy had the neural type only (as opposed to the lepomatous type), describing them as “chronic un-infective nerve cases,” stating that isolation for these people did little in controlling the disease. Rogers’ arguments however had little influence on leprosy isolation practice for First Nations peoples in Australia.

³⁹ Cook was Chief Medical Officer and Chief Protector for North Australia from 1927 and for the Northern Territory from 1931

providing care from 1936. This decision would have far-reaching consequences on the social and cultural lives of Aboriginal people in the North and North-west for the current and future generations. Leprosy became known to local people as the 'Big Sick,' 'Bungarun sick,' or 'lump sick.'

The Moseley Royal Commission report was also significant for Aboriginal people in introducing new and extensive discriminatory legislative control (Paul, 2000, p. 125). This occurred via an amendment to the 1905 Aboriginal Act, to create the new Native Administration Act 1936, providing the necessary power for authorities to compel people suffering from disease to undergo compulsory medical examination and treatment, using "such means as may be necessary," including the use of force (Moseley, 1935, p. 23; Western Australia, 1891). Any Aboriginal person refusing or obstructing these regulations was punishable by law. For Aboriginal people this translated to an increase in medical policing in routine surveillance for people suspected of having leprosy, soon referred to as the "leprosy round-ups". Doctors would not be available as part of these round-ups to offer diagnosis until 1939 (Davidson, 2016, pp. 152,153; Jebb, 2002, p. 149). People under suspicion were gathered up at their camps at dawn by police with the assistance of Aboriginal trackers, suspects chained by the neck, and forced to travel by foot to a central location such as Broome or Wyndham, until formal diagnostic results were received from Perth—sometimes taking up to 2 weeks. If the tests were negative people were left to find their own way back to camps, and if positive, they were sent to Bungarun for compulsory isolation. Despite objections to the use of chains from the public (Byron, 1935, February 27; Moseley, 1935, pp. 22,23), their use was justified by means of stamping out of disease. Moseley himself had stated that he observed "[Aboriginal people] seemed perfectly comfortable in their chains..." and made reference to other reports suggesting a neck chain was the "most humane way of restraining native prisoners". The use of neck chains during this period had become accepted practice over and above the use of hand chains for Aboriginal prisoners (Commonwealth of Australia, 1937; Moseley, 1935, pp. 22,23). The normalisation of this punitive practice for people suspected of having leprosy resonated with earlier experiences of police raids and "removal of bush people" and the use of chains continued until "at least 1949" (Jebb, 2002, pp. 136, 152).

4.2.3 Early management of tuberculosis in the Kimberley

4.2.3.1 *The impact of TB on the Aboriginal community*

TB was not known to exist in Australia prior to European settlement and its introduction has been mainly attributed to the arrival of British immigrants fleeing England for Australia in the mid-late 19th century in hopes of the reported “open-air” cure of the Australian climate (Dowling, 1997, p. 152; Laylard & Proust, 1991)⁴⁰. TB became problematic in Perth and the surrounding areas of Western Australia in the early 20th century, especially due to the influx of workers to the gold mines in Coolgardie where the first Western Australian TB sanatorium was set-up in 1906. TB rates peaked in 1919, four years after the sanatorium was relocated to Perth at Wooroloo (Fitzgerald, 2006; Proust, 1991c). The impact of TB for First Nations peoples had been significant in the 19th century in the southern and eastern states of Victoria, NSW and Tasmania, and a leading cause of death (Dowling, 1997; Proust, 1991d). The impact in the Kimberley region is less clear. There is evidence that TB was present in Broome as early as 1910, via documented reports from the Japanese hospital built in Broome to care for Japanese pearl divers (Stride & Louws, 2015). As new settlers, i.e., workers and missionaries, arrived in the Kimberley, so too did the opportunity for new TB transmission. In the words of one local Aboriginal author a local Bishop (Bishop Raible) who resided in Beagle Bay became sick with TB in 1935, 12 months after returning from Germany. The article notes that “TB was incurable then” (Sisters of St John of God, date unknown). According to this same report, there was also a nun who fell ill with TB, who also worked as a nurse (Sisters of St John of God, date unknown-a, p. 23). In addition, a large proportion of Kimberley cattle had been found to be housing TB (*Mycobacterium bovis*), with concerns regarding zoonotic transmission through infected cattle occurring (More, Radunz, & Glanville, 2017)⁴¹.

Diagnosis of TB was also challenging, and often falsely attributed to other respiratory illnesses such as “catarrh, lung trouble, congestion of lungs, weak chest” or even pneumonia, with alternative descriptors such as “phthisis” or “consumption” used (Dowling, 1997, p. 14; Fitzgerald, 2006, pp. 42,43). For example, in 1893 in Broome Death registry, out of 11 deaths in 1893, seven were from male prisoners who all died in custody from “influenza,” “pneumonia” and/or “congestion of the lungs” (Gracey & Spargo, 1996, pp. 507, 508). In

⁴⁰ There is some thought that in the Northern Territory that Chinese migrants affected with TB passed this on to Aboriginal people via the close confines of prison (Kettle, 1991, p. 98)

⁴¹ *M Bovis* was not eradicated in the cattle population until 1997 (More et al., 2017)

addition, deaths for Aboriginal people in the late 19th and early 20th century were not formally recorded by settlers (Gracey & Spargo, 1996). All these factors obscured the true incidence of TB in the Kimberley.

In the years leading up to the end of World War II, and in the years following the implementation of the National TB Act and the Australian TB Campaign in 1948⁴², TB in the Kimberley began to receive more attention. In the report from the Commissioner of Native Affairs for WA in 1944, TB among Aboriginal people was documented as being “a familiar statement made by many people” (Bray, 1945, p. 7; Director Tuberculosis Branch (author unknown), 1947). The commissioner, however, argued that the proof of anything more than infrequent cases, despite a reported frequency of acute TB on post-mortem examinations and on clinical examination, was lacking. From the mid-1940s until 1950, letters from District Medical Officers (DMOs) in the North and North West supported evidence of suspected and known cases of TB, all the while pleading for improved isolation facilities (Higgin, 1947, May 17; Various authors, 1947). In stark contrast to the strict isolation of Aboriginal people affected by leprosy in the same decade, *and* despite the newly built TB sanatorium outside of Perth (Woorloo), isolation policy for Aboriginal people affected by TB in the North and North West was non-existent. Segregation was enacted in makeshift isolation wards in pre-built Native hospitals in the respective towns of Broome, Derby, and Wyndham⁴³. The condition of these Native hospitals was bad, riddled with white ants and described as “tin huts which leak freely with every rain.” When it rained, people would “crowd into the huts” among people who were sick (Jolly, 1941, October 18). The ‘isolation ward’ within these Native hospitals consisted of “two-caged in verandahs, one at each end”, with “no sanitary or

⁴² The Australian TB Campaign (ATC) was the “first comprehensive national health campaign to eradicate TB” and ran from 1948-1976. The timing of the campaign aligned with a post-World War II vision to build and strengthen the nation both “politically and economically” (Putland, 2013; Stylianou, 2009, p. 22; Taffe, 1999). The campaign oversaw the development of BCG, development of microradiography and records of mass screening (National Health and Medical Research Committee (NHMRC), 2020). Funding from the Commonwealth was provided to the states for the campaign, which aided in the introduction of mass chest x-ray screening, BCG vaccine, support for TB sanatoriums, free chemotherapy treatment, targeted health education, and a TB allowance. The TB allowance was part of social welfare policy to encourage people affected by TB who were considered “economically productive” to quarantine in designated sanatoriums without loss of income (Putland, 2013, p. 412). First Nations peoples were not eligible for the TB allowance until 15 years after its initiation (Stylianou, 2009; Taffe, 1999). As Stylianou (2009); and Taffe (1999, p. 44) have argued, this was largely due to colonists’ perceptions of fiscal irresponsibility and perceived economic contribution that discriminated against First Nations peoples at the time.

⁴³ The Broome native hospital according to Davidson (2016, p. 55) was built in response to the need to segregate people with leprosy pending transport to Bungarun in Derby.

ablution facilities” (Assistant Under Secretary Medical, 1949, May 9) going against any principles of hygiene so persistently pursued in public health practice at the time.⁴⁴

The ongoing issue of appropriate isolation continued. After a preliminary tour of the Kimberley’s in 1948 Dr Henzell wrote to Dr. Cook acknowledging this lack of appropriate isolation, stating that “there are at present in the North West no facilities for the isolation and treatment of cases of pulmonary TB in natives that could be tolerated by the department” (Henzell, 1948, December 10). Requests made from DMOs to Dr Henzell to transfer Aboriginal people to Wooroloo Sanatorium in Perth were rejected on the basis of distance, a dramatic change in climate, removal from family, and previous records of other Aboriginal people [from the South-west] “frequently absconding from Wooroloo” (Henzell, 1948, December 10). Other alternatives for isolation were considered, such as the use of Bungarun leprosarium and consideration of the use of the Moore River settlement (both ideas subsequently rejected (Henzell, 1948, February 8),⁴⁵ and discussions were also had between the Broome DMO and Commissioner of Public Health about the use of a local law ground, Fishermen’s Bend⁴⁶, for one Aboriginal man identified with TB to isolate. The Commission had written to Dr Milne stating, “if you feel that the establishment of a small isolation centre at Fishermen’s Bend is justified and can be supervised to your satisfaction, I have no objection to it” (Commissioner of Public Health, 1949, March 28). Eventually a new plan for “zoned hospital facilities,” i.e., a designated TB ward attached to the Native hospital at Port Hedland, Derby, and Carnarvon was proposed, along with the agreement to provide adequate equipment such as X-ray and laboratory facilities, and the means to carry out certain lines of treatment such as artificial pneumothorax.⁴⁷ Funding for this plan would be put on hold until the actual incidence of TB was known⁴⁸.

⁴⁴ And despite the known impact of good sanitation and isolation practice in curbing TB transmission, public health practice implemented in Australia that had been spurred by the 1845 public health sanitary revolution in England (Donaldson & Rutter, 2018).

⁴⁵ The Moore River settlement was not a designated health settlement, rather a “place of forced incarceration for many under Section 12 of the 1905 Aborigines Act” (Government of Western Australia, 2022).

⁴⁶ Fishermen’s Bend was known as “Kunin” and its history as a ceremony ground is documented (Burke, 2011, pp. 140-143; Roe & Hayes, 2018)

⁴⁷ Artificial Pneumothorax was a type of surgery used in pulmonary TB (Nicks, 1991).

⁴⁸ This was despite an initial surveillance by Dr L Musso using modified Mantoux testing, carried out in Aboriginal Australians in the Kimberley, at Beagle Bay mission, Bungarun and Moola Bulla station in 1942/43 (Henzell, 1948, December 10). Musso’s results indicated a 4.2% positive tuberculin reaction out of 646 people tested (i.e., 27 people), and that the percentage of positive reactions increased with the densities of the white population. Musso’s overall stance was that “as yet, the bulk of the native population is uninfected with TB.”

4.2.3.2 Unknown incidence

In 1947, state-wide epidemiological evidence for TB in Aboriginal people, from notifications to death rate, was requested from the Associate Director-General of Health in Canberra. The report outlined that for Aboriginal people in the state of WA, the annual number of deaths per year was 8.6, and the death rate 34 per 100,000, “which is about the same as the rest of the population of the state,” with a conservative estimation of incidence rate of two per 1000 cases of active disease at any one time (Henzell, 1947, April 2). The emphasis on identifying TB incidence in the Aboriginal population in the Kimberley, prior to altering isolation practice, was largely driven by a growing fear evident in the medical fraternity about “an immune naivety and genetic susceptibility” of Aboriginal people to TB as a new disease (Cook, 1948, December 13). This fear however was not for the welfare of the Aboriginal population but for the potential impact on the settler population - as evidenced by a letter written from Dr. Cook to justify requesting Commonwealth funds for a new TB survey for the region, stating concern about the impact on the “white population”, if indeed there was such lack of natural or acquired immunity to TB (Cook, 1948, December 13 letter to the Hon. Minister for Health). This letter, in requesting the costs of the survey to be borne by the Commonwealth, started out with words from Cook:

From time to time I am embarrassed by requests from Medical Officers along the North-West Kimberley coast intimating that they have natives suffering from Tuberculosis in their care under conditions which make adequate treatment and isolation impossible and requesting that some provision be made for the transfer or local accommodation of these cases.

The National TB Advisory Committee finally approved the survey (NTAC) and the Director-General of Health and Medical Services, in Brisbane. Although planned for the dry in 1949, due to a delay in equipment the survey was postponed until the following year.

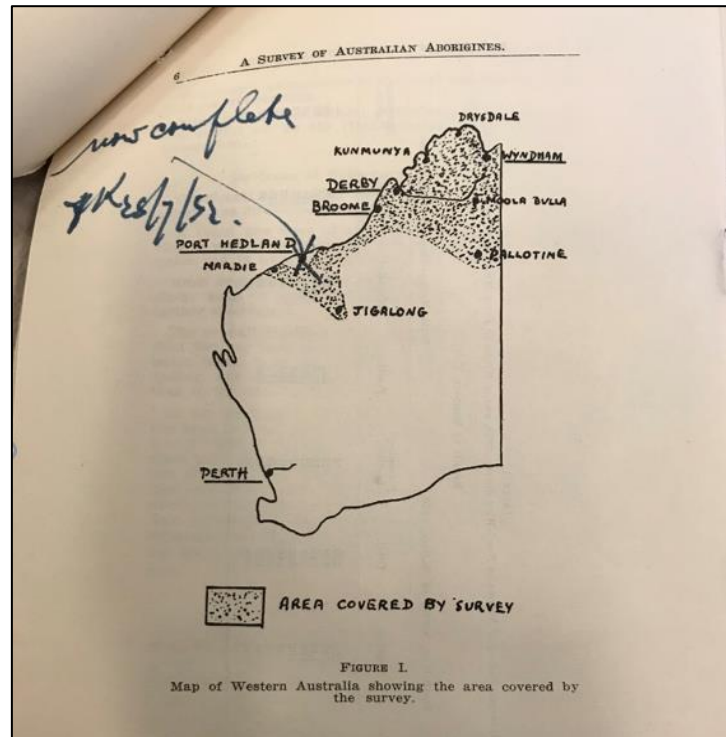
4.2.3.3 The North West TB surveys

The first major epidemiological survey for TB in the Kimberley and North West divisions was conducted over a period of just under three months, from August 7th to October 29th, in 1950 (King, Edwards, & Gibson, 1951). A total of 3,209 Aboriginal people were included in the survey, expanded across twenty-six centres: seven missions, 46 stations, and

There is no record that he followed up on positive reactions with any means to confirm actual incidence of active TB (Bray, 1945, p. 15; Fitzgerald, 2006, pp. 200, 201).

five towns including in the North—Bungarun leprosarium, Wyndham, Broome, Derby, Fitzroy Crossing towns, Moola Bulla and Drysdale stations, and Kunmunya and Pallotine (the old Balgo) missions. In the North West they included Mardie station, Jigalong mission, and Port Hedland town. See Figure 3 for a copy of the map of the survey area:

Figure 3. Map of TB survey area 1950



Note. Sourced from (King et al., 1951), [reproduced with permission from John Wiley & Sons (see [Appendix F](#))]

Nearly 50% of people surveyed tested positive for Mantoux, however most were ruled out for active disease. Fifteen people were identified to have significant evidence of active TB, with one person deemed active having miliary disease. The total incidence rate from the survey was documented at <math><5/1000</math>, considered not an “unduly significant finding” and a lower incidence rate than that in the white population (G. Edwards, 1950 letter to Deputy Commissioner of Health). Anna Plains station / mission (Mandora-Wallal) on Nyangumarta and Karajarri country was considered a pocket of higher incidence - previous reports identified four proven positive fatal TB cases in Anna Plains from 1948–1949. According to King (1951, January 12), the TB Control Branch Director, it was in this location the survey team “found a high percentage of people with significant radiological evidence of disease,” and it was from this area that and two of these people identified passed away, one week after the team left “before admissions to a native hospital could be arranged” (King, 1951, January

12). The survey clarified some of the outstanding issues that had been raised regarding incidence and risk of TB in Aboriginal people in the North and Northwest. The first and most significant finding was the outcome that the results did not show any “striking dissimilarity from those of the white population” (Edwards, 1950), and as a result no funding for isolation wards in the North West occurred. The second finding, largely driving the decision to do nothing about isolation, was the resolution of fear about a “racial lack of resistance” in Aboriginal people (King et al., 1951), hence “allaying suspicion and criticism that [Aboriginal people] [...] were a dangerous source of T.B. infection” (Edwards, 1950).

After the survey, and as a consequence of abolishing previously discussed plans to incorporate designated TB wards at native hospitals, Aboriginal people affected by pulmonary TB were approved to be transferred south to Woorloo sanatorium where treatment and surgery could be accessed more easily. In 1952, two years following the survey, and after x-raying 50 local Aboriginal men and women, Dr Fetwadjeff discovered four active cases of pulmonary TB at Port Hedland, two of whom had come from Anna Plains where the previous focus of disease had been evident (King, 1952, July 2). These four people were the first Aboriginal people from the North to be sent to Woorloo, with another 30-year-old Aboriginal man sent in 1954, issued with a leprosy precaution permit due to the restrictions of the leper line legislation at the time (see 4.2.4.4) (Assistant District Officer Northern, 1954, August 30; Deputy Commissioner of Native Affairs, 1954, September 30). From this point on, documentation in the archives was much sparser. Additional surveys were carried out in 1956, and in 1966, on the same principle as that in 1950, with additional surveillance in the Roebourne and Ashburton areas (see [Appendix G](#) for more details on both surveys). The findings were similar to the 1950 survey and did not result in any change to management. Criena Fitzgerald noted that by 1960 most adults in WA had been x-rayed and the goal of controlling and preventing TB in effect had been achieved (Fitzgerald, 2006). Archival records indicate failed attempts in recalling Aboriginal people in following-up original chest x-rays suspicious for TB in the years after (Carruthers, 1966, February 4.; Tilbrook, 1961, March 13) indicating that the records, or an absence of records, did not equate to such achievement for Aboriginal peoples in the North and North West. It is this example of absence in the historical archives that has been argued by Harkin (2021) to reveal the “epistemic violence, values and structures of feelings that sustain particular fantasies of colonialism” (p. 11). In this situation, the idea (or ‘fantasy’) presented by Fitzgerald of the achievement of the goal of the TB campaign neglected to include Aboriginal people as part of

this success. It is in this construction of success that that the imbalance in power relations in relation to TB between Aboriginal people and the settler population is made visible.

4.2.4 Isolation as an instrument of colonisation

4.2.4.1 Problem populations and the infectious Other

In considering how colonial power shaped the course of care for the Aboriginal community in response to TB and leprosy, it is necessary to consider the subjective colonial logic that undermined Western public health policy and practice that was implemented. The ideology of the colonial project with its focus on the survival of the colony and settler future corrupted any altruistic health care response for Aboriginal people, especially in the management of leprosy (Parry, 2003; Robson, 2016; Saunderson, 2008). This response was instrumental in constructing new forms of social control secondary to these introduced infectious diseases. In this section I discuss three key aspects of how this colonial logic settled into TB and leprosy health care infrastructure, the first being the discrimination of Aboriginal people as a “problem population” (Bashford, 2003).

Within imperialist thinking that centred public health practice around sanitation, hygiene, and segregation (the dirty and unclean), was the recognition of the infectious as one of the “problem populations” (along with those categorised as mad, deviant, or unfit) (Bashford & Strange, 2003). In the construction of the infectious and unclean Other who was to be segregated, Aboriginal people suffering from leprosy or suspected to have leprosy soon became categorised and treated as a population that was to be controlled and managed to protect the interests and strengths of the settler society. This suited the strategic goal of thriving in new lands and any fear of contagion thwarted plans of this goal. The response of isolation and perceived threat to the colony became the site for perceiving Aboriginal people as a problem population, evidenced by the earlier outcry from settlers in the Derby community threatening the state government, the decisions made from the Moseley Royal Commission, and the leprosy roundups. Secondary to this Othering, in agreement with the observations of Hunter (1993, p. 50), a moral foundation was laid that assigned blame and (ir)responsibility to Aboriginal people regardless of the fact that the original source of disease as external to Aboriginal people’s lives. This phenomenon would be demonstrative of the early processes of stigmatization as outlined by Link and Phelan (2001) in Chapter 2. Some medical doctors, often in positions of power, spruiked, supported, and maintained this construction. Dr. C.P. Bryan, a medical doctor who gave evidence for the Moseley Royal Commission stated, “White people do not contract it [leprosy] readily because they are much

cleaner than black people” (C.P. Bryan in Moseley, 1934, p. 378). This blame and (ir)responsibility was also reified with the words of Dr Cook in 1947 who had suggested Aboriginal people “lack knowledge of the fundamental principles of hygiene” and were “beyond civic discipline,” intimating a need for control (Cook, 1948, December 13).

Bound within this (ir)responsibility narrative, evolved a mistrust that Aboriginal people would ‘do the right thing’ regarding disease and hygiene management, from the viewpoint of what had become a normative, and hegemonic, euro-Western understanding of what the right response to infectious disease entailed. Moseley documents this mistrust in his report in, citing he did not have “sufficient confidence” that advice provided to Aboriginal people affected by leprosy of the “danger” in moving in and out of the huts at the Derby lazaret would be heeded (1934, p. 125). In her article on the role of racism in the treatment of leprosy, Peebles (1992, pp. 14,15) reports an article in the Sunday Times published by a Derby resident on June 8, 1924, which included the following letter to the Minister of Health:

It needs no debate on the fact that leprosy is an unclean thing, admitted by most modern authorities to be contagious, and the residents of this town feel that no official whitewashing or any parsimonious attitude on the part of the departments concerned will be tolerated... I should like to ask, Sir, whether the residents of Perth or any other town would for a moment tolerate ...such as awful scourge as the maintenance in their midst of a leper hospital? I think not!

This provides insight into the thinking of the settler colony at the time, and the assigned social status for people affected by leprosy that reinforced a stigmatisation process of othering, blaming and normalised discrimination (Link & Phelan, 2001). As Pandya (2003) points out, a fear of “an invasion of leprosy via germ-laden immigrants and returning expatriates” (p. 161) translated into the Australian settler context as a fear of contagion from local Aboriginal people. A report in 1936 by the then newly appointed Medical Officer to the Department for Native Affairs Dr Albert Davis, to the Commissioner of Public Health (in Davidson, 2016), confirmed this by stating, “The white people are in such a panic about the disease in these parts that in a day or two they will hunt these lepers into the bush and it will cost us pounds to recover them” (p. 52). Evidence given by the new Member of Legislative Assembly (MLA) in the Kimberley AAM Coverley to the Moseley Royal Commission (Aubrey Augustus Michael Coverley, M.L.A., in Moseley, 1934) had a similar sentiment: “Until proper medical inspection is provided, the white people are running a big risk [...] many people agree with me that the sooner this business is cleaned up, the better will it be for the white people” (p. 406).

The decision making behind the isolation practices for TB was also centralised to this perceived threat to the settler population. The director of TB, Dr Linley Hensell, used the situation with leprosy, prior to Bungarun, to build this argument of risk, “[...] our experience with leprosy has shown that the natives’ diseases can be a menace to his white associates,” and further stating:

This might be the case with a more infectious disease such as tuberculosis, which, contracted originally by the native from the white man, might traverse in the reverse direction should the disease assume epidemic proportions in a non-immune Aboriginal race (Hensell, 1948, December 10).

This blaming and shifting of responsibility from the settler population to Aboriginal people, to be a potentially “dangerous source” of TB infection, reifies this consideration of Aboriginal people as a ‘problem population’ (when it was Europeans who posed a risk to Aboriginal people). Dr. Cook utilised this fear and positioning of risk in justifying federal funding requests from the TB campaign for the TB survey “[...] it must be expected that tuberculosis will spread rapidly and extensively amongst Aboriginals, and these in turn will serve as a reservoir for its later dissemination to the population of the future” (Cook, 1948, December 13). Aboriginal peoples were never considered as the ‘population of the future’ at this time, demonstrating how public health policy and practice was inseparable from the widely held belief of the fate of Aboriginal peoples as a population that would not survive. Even Dr. Hensell had observed this disinterest and referred to it as a “negligent attitude” (. Hensell, 1948, December 10), “The lack of interest of the white population of Australia in the natives is shown in the real absence of knowledge concerning the incidence of tuberculosis in our Aboriginal race.” Taking a moral stance of Aboriginal people being attributable to fault, this *excused* any responsibility of those who brought the disease, i.e., settlers, either primarily through settlement or secondarily via indentured labour. This, in turn, allowed for the creation of this neglect. How this neglect fostered, and subsequent stigmatisation manifested within individuals or laterally within communities, may speak to a part of the more complex social impacts for Aboriginal peoples that resulted over the decades to come.

4.2.4.2 The power of white settlers in influencing the course of care.

History is the fruit of power, but power itself is never so transparent that its analysis becomes superfluous. The ultimate mark of power may be its invisibility, the ultimate challenge, the exposition of its roots.

(Trouillot, 1995, p. foreward xi)

The fear of economic loss and associated stigma for pastoralists employing Aboriginal workers suspected of having leprosy was real, both in the loss of employment due to the removal of ‘lepers’ and the downturn in trade associated with the stigma to pastoralists of housing Aboriginal workers affected by leprosy (Davidson, 2016, p. 136). In 1936 the owner of the Roebuck Plains station wrote a letter to the minister for the North, Mr Wise, in response to a visit from the Chief Medical Officer at the time, Dr Davis, who had identified three Aboriginal workers on the Roebuck Plains station to be infected with leprosy, and who had asked Mr Male’s son to “keep them about the place so they don’t disappear.” In his letter Mr Male threatens public notification of criminal neglect for allowing this to happen, stating that these workers cannot stay there as it was hindering engagement or retention of white employees on the station, further noting, “it is a menace to my son and his wife.”⁴⁹ Within the use of power was also the purposeful withholding of information accompanied by doctors making decisions for Aboriginal people, for their own good, or to control their actions. This is exemplified by a letter from CL McBeath, who was travelling with Dr Davis, to the Commissioner of Native Affairs with respect to non-disclosure to five Aboriginal people identified to have leprosy of their condition. McBeath’s letter notes: “The above natives were not told of their condition as both Dr. Davis and myself were of the opinion that if they had any idea that they were affected they may run away bush” (McBeath, 1937, August 17).

The power of medical doctors often extended beyond medical jurisdiction and into political strategy, undermining medical decision-making in response to improved health for Aboriginal people affected by either condition. This was particularly the case for Dr. Cook, whose role as an expert in public health was extensive across both leprosy and TB control in WA and the Northern Territory (NT), whilst also fulfilling the role of Chief Protector of Aborigines in the Northern Territory from 1931—all of which demonstrated a blurring of

⁴⁹ The Male family were influential in Broome, Arthur Male being a previous MLA for the Kimberley and then on the Broome Road Board until his retirement in 1930, showing not only pastoral power but political power. His eldest son Anthony Male took over his interests in 1930 (Bain, 1986)

political and medical responsibilities. Cook, after establishing a TB clinic in the NT, moved to the Chief Public Health Officer position for WA from 1947–1950. This position of power placed him in a primary decision-making capacity for the health and wellbeing of Aboriginal peoples in these two states. What is disturbing about this is Cook’s reputation for holding extreme eugenic views and being one of the main contributors to so-called progressive eugenicist policies (Austin, 1990, p. 113). These policies followed on from the unanimous passing of the Policy of Absorption⁵⁰ from the 1937 Conference in Canberra on Aboriginal Welfare, moved by AO Neville (then Chief Protector of Aborigines in WA) (Commonwealth of Australia, 1937, p. 125; Paul, 2000). The subsequent influence on medical decision-making resulted in a re-focus on Aboriginal people with any degree of non-Aboriginal heritage—at that time referred to as “half-castes”—as a potential source of infection (Austin, 1990, p. 113). Cook’s influence soon spread to the media, evidenced by an article published in the *West Australian* on October 8, 1949, with the title “Points to Danger Spot in Leprosy,” and reading “[...] in the north the danger now is that the half-caste can be the possible port of entry for leprosy between white and native” (*The West Australian*, 1949, October 8).

The concept of Aboriginal people of mixed descent being the source of infection for settlers was also promulgated within TB discourse. In his letter to Cook in 1948, Dr Linley Henzell had written that the “half caste domestic workers infected with intestinal disease or tuberculosis are a menace to the people they serve: their health needs must be studied in order to preserve the health of their white associate.” The eugenics movement of social engineering and building national strength was fundamental to the decisions made around both isolation and treatment of TB and leprosy in labelling Aboriginal people as problem populations, akin to non-Aboriginal “illiterates and criminals” (Stylianou, 2009, p. 33). A fear of contagion promulgated by the mixing of “race” drove an ongoing perceived threat to the strategy of social survival for a middle class with “desirable traits” (Austin, 1990, p. 108). This fear further prompted an acceptance of segregation as a consequence of disease, demonstrating the insidiousness and subjectivity of medical decision-making for Aboriginal people affected by leprosy and TB during this period. It also highlights the juxtaposition of the different approaches taken to control leprosy as opposed to TB that pivoted on the proximity of this

⁵⁰ The resolution at the conference of the Policy of Absorption heralded the formal adoption of a national policy of assimilation which led to both “biological absorption” (the desired removal of physical Aboriginal characteristics), and “social integration” (whereby Aboriginal customs and culture would yield to those of settlers (Chesterman & Douglas, 2004; Paul, 2000, p. 125). The belief of biological absorption, i.e., the “breeding out” of Aboriginality, “miscegenation,” or “racial mixing,” became firmly rooted in the “white Australian psyche” (Haebich, 1992, p. 318).

threat and reinforces how isolation became a colonising tool—the overwhelming response to isolation of people affected by leprosy, and the underwhelming (or neglectful) response in isolation of people affected by TB.

4.2.4.3 Criminalising disease

The final method of enacting isolation as a colonising tool was the criminalisation of disease and punitive responses in the treatment of disease, enabled by legislative control by way of the 1936 Native Administration Act. A. Haebich (1992) describes the WA Aborigines Act 1905, where this legislation was created, as the beginning of an “unprecedented outburst of racism and discriminating behaviour towards Aborigines during the pre-war years and in demands for their total segregation” (p. 127). Criminalisation of Aboriginal people affected by leprosy was particularly evident throughout this pre-antibiotic era. Examples of this can be seen during the early leprosy isolation period on tidal islands, the evidence of the Aboriginal girl isolated for six months in a Wyndham gaol cell and the use of neck chains to transport people to isolation institutions. Once the leprosarium was built, the use of police to chase down people who had absconded the leprosarium was enabled by the enforcement under section 23 of the Health Act, with a detention order signed off by the then Commissioner of Public Health (Kingsbury, 1946, December 20). The treatment of Aboriginal people affected by leprosy as criminals became normalised through punitive medical legislation and enforcement.

This use of the law to control and punish the behaviour of Aboriginal people was not new. A history of policing and control had been evident in response to cattle killing and formed part of the rationale for the development of the Moola Bulla station (Rumley & Toussaint, 1990, pp. 82,83). As Moreton-Robinson (2015) reminds us Australia (and New Zealand, the U.S., and Canada), “have a long history of detaining Indigenous people, denying their rights, and controlling behaviour through and beyond the law” (p. 153). Leprosy infection was the tool and justification through which this control of behaviour was made possible and did not just stop at the legislative changes made in 1935. In 1941, a further amendment to the Native Administration Act prohibited any Aboriginal person, regardless of being suspected to have or diagnosed with leprosy, from travelling south of the 20th parallel unless specifically medically excluded from having leprosy (Author unknown, 1950)⁵¹. The exception to this legislation was when travelling south of the boundary line “as the employee

⁵¹ Located on Nyangumarta country between Pardoo and Wallal in the East Pilbara.

of or in company with any person driving stock,” the theory being this border would control the spread of leprosy further south. There was good reason to believe that this addition of a new regional border to an already existing border (of Bungarun leprosarium), was an economic tool to preserve a labour force for the pastoral industry by preventing Aboriginal stockmen around the isolated cattle stations moving south where wages were much higher (Scrimgeour, 2012)⁵². The ‘leper line’ as it was referred to, is an early example of invisible border control in the wider segregation of a population used to justify overt discrimination towards Aboriginal people in the name of health and halting of infectious disease. Even though it was objected to by the Commissioner of Health some years later, the legislation was not repealed until 1963.

4.2.5 Summary for the pre-antibiotic era

The period of history from the first signs of leprosy or TB, up until antibiotics were discovered in the late 1940s, was an incredibly disruptive period for Aboriginal people affected by these introduced diseases. I have argued that the principle of isolation for public health was applied subjectively for Aboriginal people affected by leprosy and TB. The degree of and forcefulness of isolation was proportionate to the degree of fear or concern for the wellbeing of the settler population and disproportionate to the ability to hamper the spread of disease. This was in line with the current colonial thinking of the time, that is, to strengthen prosperity and future for the white race influenced by the intention of the colony and the belief that Aboriginal people would not survive. The public health policies problematized and blamed Aboriginal people for disease and created an irresponsibility and mistrust narrative apropos the ability to do the ‘right thing,’ thus disseminating hegemonic hygienic health practices introduced by settlers. This resulted in public health campaigns that were oppressive, controlling, and punitive towards Aboriginal persons affected by leprosy, and neglectful for Aboriginal persons affected by TB. Medical care was dispensed with clear economic and political motives and the Public Health Act became a tool for colonisation and the historical exercise of state power. Despite this, and despite the belief of the settlers,

⁵² Scrimgeour (2012, pp. 43-46) details of a ‘walk off’ of workers at Wallal Downs Station travelling south across the 20th parallel – and although in breach of this legislation, noted that Aboriginal men and women travelled back and forth across this line. This was an example of activism that challenged restrictive legislation in hopes of achieving equal rights for Aboriginal people. Members were of an organisation named Pindan, or ‘McLeod’s group’ and made up from several different language groups – Ngarla, Nyamal, Warnman, and Western Desert speaking people. Scrimgeour also comments on the restriction on movement across the leper line prevented people from maintaining family and cultural links.

Aboriginal people resisted, rejected, and survived this early colonial legislation, oppression, and institutionalisation. As Patrick Dodson writes (in Haebich, 1992) “Aboriginal people were able to adapt to and transcend colonial society..., but the legacy of the trauma suffered still impacts generations today” (p. pxv).

4.3 The arrival of chemotherapeutics into the Kimberley—the antibiotic era

4.3.1 Trial and error: Establishing safe and effective treatment.

4.3.1.1 Experimental treatments in the pre-antibiotic era

It is important to note that prior to antibiotics being discovered, the search for effective treatment had been ongoing. For example, the use of Chaulmoogra oil, a botanically derived treatment that had gained traction internationally for its supposed effect in leprosy management. Chaulmoogra oil traditionally used for skin diseases, extracted from the seeds of the chaulmoogra plants belonging to the genus *Hydnocarpus* (dos Santos, Souza, & Siani, 2008, pp. 31,32), and made into commercially available products. As Chaulmoogra gained popularity internationally, so too did the complications with sourcing available botanical species and manufacturing it into the least expensive and most effective pharmaceutical formulation. The use of poorly tolerated oral capsules was soon replaced by the hypodermic needle, via the intramuscular or subcutaneous route (the extract was mixed with camphorated olive oil and resorcin) and was notably painful for patients (Bercovitz, 1917; F. S. D. dos Santos et al., 2008; Read, 1924). The oil was by far the most popular remedy trialled at Bungarun, using the injectable form. In documenting her time providing care at Bungarun, Sr Daly (Daly, 1986), described the use of Chaulmoogra oil, or “needle poke,” as it was referred to, “A kerosene stove graced the ‘needle room’ as the patient named the place. The oil was heated over the flame and 10c.c. of heated oil were given by intramuscular injection into the arm or leg of the patient.” In his book Ernest Hunter (1993) recounts the experience of one Aboriginal man in Bungarun in receiving Chaulmoogra oil:

The injection, I’ll never forget, I’ve got lots of scars from it. Twice a week, they’d give you a needle and you’d wake up all swollen up. Real painful. When they gave it on your buttocks you couldn’t sit down (p. 67).

Local people also continued to utilise traditional therapies. Bush medicines and traditional healing approaches were incorporated into care by Aboriginal people isolated within Bungarun (Briscoe, 2003), and even adopted by the nuns, as informed by one participant who recounted this knowledge in one of the focus groups, “[...] and the sisters were using our bush medicine before we have... [new medicine]” [P2-FG3, SG2]. One of these methods was

referred to as the “burn ‘im method”, according to Sr Gertrude, documented in Daly (1986). Bush gum was also collected “to immobilise parts needing such treatment.”

4.3.1.2 A New Cure

The discovery of injectable streptomycin in 1941 marked the beginning of a new era for the treatment of TB⁵³, with evidence for its effectiveness from a largescale clinical trial (the first of its kind) following shortly there afterwards in 1948, conducted by The British Medical Research Council (Keshavjee & Farmer, 2012, p. 931; Radhakrishna, 1998). Streptomycin became available to use at Perth’s Wooroloo Sanitorium towards the end of this decade as confirmed by a report from the Wooroloo Medical superintendent Dr HR Elphick and was soon followed by the addition of oral para-amino salicylic acid (PAS) (in Henzell, 1949, p. 22). New treatment and accessibility to surgical therapies was only accessible at Wooroloo – treatment at the Native hospitals in the North was available only on advice or request and needed to be transported from Perth. The earliest identified account of a request for the North was for a three-year-old Aboriginal girl who was suffering from miliary TB and was being treated in the Broome Native Hospital. Dr Milne, on writing to the public Health Department with his concerns about her situation and arguing for transport to Wooroloo, was told that transport could not occur for one month and the suggestion was made to communicate with Dr Linley Henzell about streptomycin for her treatment. Sadly, the child became too sick to be transferred, even after streptomycin treatment was finally arranged, and she died (Milne, 1949, Feburary 22).

From 1952 onwards the third medicine isolated effective against *Mycobacterium tuberculosis* to become available was isoniazid (iso-nicotinic acid hydrazide), and like PAS available in oral form. The triple therapy combination of PAS, isoniazid and streptomycin was soon o include a fourth newly derived antibiotic pyrazinamide (Keshavjee & Farmer, 2012, p. 932). One of the most important anti-TB medicines discovered (and eventually anti-leprosy) was Rifampin (also known as rifampicin), developed in 1957. This allowed for an all oral four medicine combination, i.e., PAS, isoniazid, pyrazinamide, and rifampicin, removing the need for streptomycin injections. The next antibiotic discovery ethambutol, also available in oral form, would soon replace PAS by the 1970s to provide standard four-antibiotic regimen for all people affected by TB (Keshavjee & Farmer, 2012). As discussed in 4.2.3

⁵³ The British Medical Research Council conducted the first largescale clinical trial of streptomycin in 1948. This study, was said to be the world’s first published drug trial that involved the randomization of participants and assisted in setting the methodologic standard for the modern randomized controlled trial (RCT) (Keshavjee & Farmer, 2012; Mitchison, 1998, p. 15)

above, it was not until 1952 that the first Aboriginal people from the North or Northwest diagnosed with active pulmonary TB were transferred to Wooroloo and would have had improved access to this evolving treatment.

The excitement around antibiotic discovery was much more pronounced in the North with respect to leprosy, the words “Lepers⁵⁴ cured by new drugs” hitting the headlines of the Daily News (Daily News, 1950, August 1). The discovery of the sulphone antibiotic group was the most noteworthy for the effective treatment of leprosy. The injectable sulphone ‘Promin’ was the first onto the market, trialled in people affected by leprosy in 1941 in Carville leprosarium in the United States⁵⁵ (dos Santos et al., 2008; Huikeshoven, 1981, pp. 230,231). A number of sulphone derivatives were trialled in populations in Trinidad and Madras (oral diasone and sulphetrone (the latter also used parenterally), and intradermal 4,4-diaminodiphenyl sulfone (DDS). It was, however, the re-purposing of the oral form of DDS in 1946 (originally synthesized in 1908) that proved to have effective bacteriostatic action against the leprosy bacilli and become the breakthrough treatment needed.⁵⁶ DDS, commonly known as dapson, had a history of toxicity and required a much-reduced oral dose than earlier trials had used (dos Santos et al., 2008; Huikeshoven, 1981). Dapsone use as a single agent soon became the choice of therapy as it was inexpensive, well-tolerated and was able to reach greater therapeutic levels in the body than other substituted sulphones (Gelber & Grosset, 2012, p. 221). Settling on dosing regimens was complicated as, unlike the tubercle bacilli, leprosy bacilli could not be cultured *in vitro*. It was not until 1960 that the mouse foot pad system was adapted to assist in identifying bacteriological and pharmacological properties of anti-leprosy medications and assisted in rationalising chemotherapy and standard dosing (Huikeshoven, 1981, p. 235; Rees, 1967; 1978, p. 98).⁵⁷

Experimentation with chemotherapy and posology also occurred for Aboriginal peoples affected by leprosy in Australia. Treatment first became available in Bungarun from 1948. As identified from the records of Dr L. Henzell (1949, p. 70) trials with sulphetrone gave “the best results” and, although there were a small number of resistant cases, it was

⁵⁴ Considered a derogatory term.

⁵⁵ Coincidentally, it was the preliminary work of Promin on TB that led to the use of sulfones in leprosy (Huikeshoven, 1981)

⁵⁶ An antibiotic with bacteriostatic action inhibits the growth of bacteria but does not kill them like bactericidal agents (Mitchison, 1998)

⁵⁷ The mouse foot pad technique is a method of cultivating bacteria in the foot pad of mice to reproduce leprosy infection, and hence test potential therapeutic agents, due to its inability to be cultured using standard microbiological techniques (Levy & Ji, 2006)

considered better than that of Promin® [an injection] or diasone [tablets] (it was unclear from the report if the injectable or the oral form of sulphetone was used). For Aboriginal people affected by leprosy at the Channel Island leprosarium in Darwin, a trial by Humphry (1953), compared the effectiveness of ‘TB-1/698’ (thiosemicarbazone) to an oral form of substituted DDS (avlosulphone). While Humphry had reported that the results were “disappointing” and much more response was had from DDS, what was concerning within this experimentation was the downplaying of toxicity from TB-1/698 by Humphry who surmised, “with the possible exception of the patient on thiosemicarbazone who died, there was no evidence of toxicity from either drug” (Humphry, 1953). This kind of experimentation with treatment was incidental to the time, occurring in a period before ethical practice for medical trials was commonplace (Bhatt, 2010)⁵⁸. In the same year the WHO had stated that TB-1/698 was “considered unsuitable for large-scale or mass treatment” and was only to be used as an alternative for people intolerant to sulphones, due to a greater possibility of toxicity (World Health Organization, 1953, pp. 16,17). The temporal link to Humphrey’s trial and the WHO publication was unclear.

Despite ongoing uncertainties and confusion around the choice and dosing of the various therapies (Huikeshoven, 1981), new treatment was having an impact. One man who was resident at Bungarun in the early 1950s had spoken about the new hope and possibility of going home to Country that treatment had brought: “[...] we were very happy. The faces of men and women alike began to look normal again... they began sending us back” Forrest (2003, p. 34) (translated from Walmajarri by O. Knight). Treatment had been brought in from India (likely DDS), from Dr Lawson Holman who had arrived in Derby in 1956 (Holman, 2004, p. 11). Prior to Dr. Holman facilitating this new treatment, leprosy related illness had caused significant loss of life:

People died. They were people from everywhere, from the north, from the west, from the south, from the east, from all over the place. Day after day and through the night people died. We saw them die. We took them east, to the cemetery, four, five bodies in one day. That’s the way we were (Forrest, 2003).

4.3.1.3 Emerging considerations for treatment safety and ‘racial tolerance’

The 1940s and 1950s marked a global period of rapid pharmaceutical development, and changing pharmaceutical regulation catalysed by unfortunate safety events as a consequence (McEwan, 2007; Rågo & Santoso, 2008, pp. 65,66). In her doctoral work on

⁵⁸ An examination of early medical trials for different populations is out of the scope of this thesis.

leprosy, Robson (2018) reported of the experimentation on persons affected by leprosy in Queensland with a drug called 'CIBA1906' (thiambutosine) that had led to such events. In this case, a person had such extreme side effects of weight loss and "crippling muscles" that they were reported to have to "crawl on [their] hands and knees to move around." Another report of an unfortunate outcome of the loss of a 12-year-old girl at Channel Island was highlighted by Robson (2018, p. 65) whereby the young girl developed a severe blood disorder to DDS, a known toxicity from earlier DDS trials. This type of adverse reaction to sulphetrone was reported by the DMO at Bungarun, Dr Herz, after several cases of severe anaemia had occurred with one person dying of, "a very severe exfoliative dermatitis" (Davis, 1939, p. 175). Another account of what appeared as fatal DDS toxicity in Bungarun after dapsone became the prominent treatment was located in the memoirs of Sr Alphonse Daly's 'Healing Hands' (Daly, 1986). In this account, Sr Daly describes a male who was discharged from Bungarun in the early fifties but was soon brought back due to a relapse of infection. After being restarted on drug therapy within 1–2 days he began to show signs of jaundice, and soon passed away.

It was not too long that these examples of safety, primarily from observational surveillance and anecdotal accounts (rather than drug trials), led to discussions about the potential for a "racial intolerance" to leprosy therapy. The newly formed national Committee on Tropical Physiology and Hygiene, CTPH, (with Dr. Cook now having taken up the position as the Commonwealth Chairman of this committee), having met at a National Health and Medical Research Council (NHMRC) conference on leprosy, had reported this concern of racial intolerance. The CTPH had stated at the conference the observation of "marked variations in the tolerance of sulphone therapy particularly in native patients from different areas" (Public Health Department, 1956). The concept that intolerance was primarily due to a "racial" character was soon negated in favour of the theory that concurrent hookworm infection influenced sulphone tolerance. Consequently, routine treatment for hookworm to supplement sulphone therapy was recommended, but not without also altering the dosing schedule "for the coloured patient," by reducing the sulphone dose. The conference reported: "It can be taken as a rule that the Australian Aboriginal can only tolerate between 1/2 and 2/3 of the dose for a white patient and that results with these dosages will be just as good,"

although there was no scientific evidence to support this shift away from trialled therapeutics⁵⁹.

4.3.1.4 Growing concerns of antibiotic resistance

The concept of antibiotic resistance was identified early on for TB after the introduction of streptomycin. Early trial results from the 1948 trial by the British Medical Research Council had indicated that greater than 60% of people developed resistance to streptomycin during the study (Venkat, 2016, p. 486). The use of combinations of antibiotics to avoid this became standard practice in the late 1950s for TB (Poole & Stradling, 1960). However, for leprosy, the identification of drug resistance, and the use of multiple drug therapy for treatment, was much slower. The first proven cases of dapsone resistance were reported in 1964, but it was not until 1973 at the tenth international leprosy conference held in Bergen, where dapsone-resistant leprosy was considered significant enough to review monotherapy with dapsone, and that inadequate dosage and irregular treatment contributed to resistance (Huikeshoven, 1981; Pearson, 1981, p. 245; Waters et al., 1978). Part of the delay was the prolonged time of relapse of infection suspected to be from dapsone resistance, as well as the months to test and successfully detect resistance (Pearson, 1981, p. 417). The seriousness of newfound primary and secondary resistance to dapsone propelled the decision to use MDT for leprosy globally.⁶⁰ By 1982 standard MDT of daily dapsone, clofazimine (a bacteriostatic antibiotic with action against mycobacteria) and a once-a-month ‘pulse’ of high dose clofazimine and rifampicin,⁶¹ became the first line of treatment for multibacillary leprosy. While the WHO have since trialled other treatment regimens, standard MDT from 1982 is still mandated as the most effective first-line treatment for leprosy (Lazo-Porrás et al., 2020).

In reviewing dapsone-resistance history in Bungarun, no documented accounts of secondary or primary resistance were identified, unlike that reported at the Darwin leprosarium in the Northern Territory from 1971 where resistance was reported on at least

⁵⁹ See [Appendix H](#) for further discussion on pharmacogenomic considerations.

⁶⁰ Secondary resistance is acquired drug resistance during treatment, primary resistance is initial infection with a drug resistant bacterial strain (Pearson 1981).

⁶¹ The WHO MDT dosing regimen of once-a-month rifampicin was primarily influenced from a trial demonstrating equal effectiveness of 1200mg once a month dosing compared with 450mg daily rifampicin. The once-a-month pulse dose, later revised to 600mg, provided an economic solution to what was at the time an expensive drug, and was more conducive to supervision (Gelber & Grosset, 2012, p. 224; Languillon, Yawalkar, & McDougall, 1978).

three occasions (Lush, Hargrave, & Merianos, 1998, p. 711). In the memoir of Sr Daly, anecdotal accounts of failed treatment and worsening of clinical condition were reported for two people whose situations potentially resonated with that of possible drug resistance. The first was a female patient, who was not responding well to “usual treatment.” Sr Daly writes that this person “failed to become [smear] negative” even after “all the potent drugs were available in her time and were tried ... [she] appeared to have no immunity at all.” A second report from Sr Daly was of another patient, “heavily infected,” with leprosy and “confined to bed on admission” to Bungarun. Sr Daly reported that “although modern drugs were available, [the patient] made no response to therapy” (Daly, 1986). Sr Daly (Daly, 1986) had reported the impact of MDT at Bungarun stating that “we no longer had wards full of very sick patients with reactions, high temperatures and severe nerve pain leading on to nerve damage, muscle wastage, mutilation and deformity.”

4.3.2 Impact of antibiotic therapy on institutional isolation

4.3.2.1 Changes to isolation policy and special legislation

The availability of new treatment in the 1950s started to have some impact in shifting policy for compulsory segregation, more noticeably for TB. A landmark study in Madras, India in 1956 compared home-based versus sanatorium based treatment for pulmonary TB, for twelve months, with the authors concluding from the results that the majority of patients could now be treated at home (TB Chemotherapy Centre, 1959, p. 128)⁶². Consideration was given to the advantages and disadvantages seen with both sanatoria and home settings, but noticeably the authors paid due attention to the social disruption in family life that segregations in sanatoriums entailed. The trial led to the eventual close of TB sanatoria, with the Wooroloo sanatorium in Perth to follow suit in 1969 (Uziel, 1969).

Prior to the study on TB care in Madras the WHO expert leprosy committee’s first report in 1953 (World Health Organization, 1953) had denounced strict leprosy isolation policies stating, “institutional isolation alone has not given the results expected of it and has failed as a control measure” (p. 9). The caveat to this was maintaining isolation for the most “infectious cases,” i.e., people with the more severe forms of disease (lepromatous leprosy). In the ensuing years, the WHO strengthened their position to abandon compulsory

⁶² The Centre was set up in 1956 under the joint auspices of the Indian Council of Medical Research (ICMR), the Madras State Government, the World Health Organization (WHO) and the Medical Research Council of Great Britain (MRC) (TB Chemotherapy Centre, 1959).

segregation altogether for *all* people affected, regardless of infection severity, noting the significant social consequences of isolation to family relationships and financial welfare of patients' dependants. The shift in focus was towards case-finding, case-holding, and the eventual integration into general community health services, as well as recovery of institutionalised patients and their adjustment to life outside the institution. This included recommendations for abandoning special legislation that discriminated against people affected by leprosy (World Health Organization, 1960, 1966). This shift did not translate into Australian policy however, and the National Committee on Tropical Physiology and Hygiene (CTPH) concluded at their 1956 conference that, "the management of Leprosy in Australia should [...] not be misdirected by what appears to be a careless and erroneous interpretation of overseas experience," further recommending that, "the time is not ripe in Australia for abandoning the present prophylactic system" (Committee on Tropical Physiology and Hygiene, 1956). People were continually admitted into Bungarun, some with the experience of being wrongly diagnosed, as expressed by one participant "yeh, they got it wrong, sometimes. Some people was there for nothing, some people was there because of leprosy." [P10, FG3-SG2]. Any hope of a quick discharge back to Country was soon diminished and framed by racially discriminated discharge criteria, reproducing earlier colonial logic of perceived risk and mistrust of Aboriginal peoples and the practice of tightened control via medical surveillance:

For coloured patients [who will be more difficult to keep under surveillance] I recommend that in addition to the twelve consecutive negative bacteriological reports a biopsy be taken from any suspicious skin area and that this biopsy be negative before discharge is allowed...and that patients discharged be put on 'parole' for 5 years or more, under surveillance. (Committee on Tropical Physiology and Hygiene, 1956).

What was additionally disturbing about the CTPH decision-making was the special legislation that was *introduced* in 1956, as impacts of social traumas from discriminatory legislation were being realised internationally. This legislation persisted despite calls for abandonment by the WHO in 1960 and further in 1966. The CTPH had recommended the removal of newborns to mothers affected by leprosy who had given birth in the leprosarium to be sent to "a special institution or private home approved by the Central Health Authority," (Committee on Tropical Physiology and Hygiene, 1956; Farrer & Simpson, 2013) creating an emotional trauma for mothers and children alike, akin to the Stolen Generations⁶³

4.3.2.2 *Supervised treatment and the origins of Directly Observed Therapy*

The issue to be settled is whether patients will take any form of medicine by self-administration regularly for a period of many months or possibly even years, and, if not, how regularity may be achieved.

(Fox, 1958, p. 269)

Accompanied with the novel discovery of antibiotic therapy was the ideology of treatment compliance, that is, the “basic and reasonable assumption...that the patient will take the prescribed medicine” (Fox, 1958, p. 269). This assumption, however, proved to not hold for all patients. In re-visiting the landmark Madras Study published in 1959, Wallace Fox had documented his observations regarding the irregularity to which some patients were self-administering treatment at home compared to patients who were taking medicines regularly under direct observation at the sanatorium (Fox, 1958, p. 273). His solution was supervision of treatment, or in Fox’s words, “regimes given daily or intermittently under direct observation” (Fox, 1958, p. 274). The Medical Research Council in Britain at the time were also reviewing the issue of drug resistance. In an examination of clinical records from the Hammersmith Chest Clinic, they identified the chief cause of acquired resistance was from unintended monotherapy secondary to the failure of patients to take adequate PAS when prescribed as part of dual therapy, regardless of whether the patient was at the sanatorium or at home⁶⁴. Consequently, direct observation was implemented into practice on the hospital wards at Hammersmith, and recommendations for “domiciliary” treatment regimes were amended to streptomycin plus isoniazid instead of PAS, with daily supervision (Poole & Stradling, 1960).

Subsequent trials for supervised therapy were conducted over the coming years. In 1962, a trial of six-times-a-week clinic-based supervised therapy for 6 months (followed by self-administered oral therapy at home), was conducted by (Moodie, 1966) at a clinic in Hong Kong. As per the author, the trial demonstrated a “practicable economic solution to a serious and complex tuberculosis problem.” In continuing this line of rationale of practicability in developing countries (Lotte, Hatton, Perdrizet, & Rouillon, 1964), Fox began trials for increased dose twice-weekly intermittent supervised therapy in comparison to daily home-based therapy—intermittent to reduce the burden of clinic attendance. The success of this

⁶⁴ The authors also raised concerns of “faulty prescriptions” contributing to drug resistance, although this occurred less often than that of the failure of patients to take PAS (Poole & Stradling, 1960, p. 164).

trial led to additional trials conducted and by 1974, the WHO had endorsed intermittent supervised regimens (Fox, 1983, p. 101; Lotte et al., 1964). Both of these lineages of supervision (Madras and Hong Kong) have been argued to be the genesis for the models of short course directly observed therapy treatment that eventually led to the WHO DOTS strategy, in company with additional work performed by Fox in reducing the duration of therapy from 9 to 6 months (in the East Africa trials), and Karel Styblo in model programmes of case-finding and treatment (Brauer, 2015, p. 3; Fox, 1983; Fox & Mitchison, 1975; Radhakrishna, 2010, p. 8; World Health Organization, 1999). Bayer and Wilkinson (1995) in their review of the history of DOT, make due note of the setting of these supervised trials being conducted in nations “emerging from, or still characterised by, colonialism, poverty, and illiteracy” (p.1545). In such colonial or recent post-colonial settings, the impact of the model of supervised therapy at the clinic (or other designated health setting), instead of self-administration at the home—as per the original Madras study for sanatorium vs home-based care—re-locates the “sovereignty of the gaze” back to the associated medical clinic and its “many powers” (Foucault, 1989, p. 108). It is within this power analysis that further consideration is warranted in not only the development of this practice of supervision in settings where social inequities existed, but also how this practice was adopted and adapted within developed countries, prior to implementation of the official DOTS strategy. As Bourdieu (1977) states:

The practical privilege in which all scientific activity arises never more subtly governs that activity...than when, unrecognised as privilege, it leads to an implicit theory of practice which is the corollary of neglect of the social conditions in which science is possible. (p1)

Supervised therapy for TB was soon considered as part of an approach to treatment both in London and in the US, however differed in the application as a universal versus a selective approach. Bayer and Wilkinson (1995) outline how in the US, supervision of therapy was considered necessary for patients deemed unreliable, for example in San Francisco, “problem patients,” who came from the “lowest socio-economic groups of all races” (p. 1545). Prolonged hospitalisation was justified by Sbarbaro and Johnson (1967) in addressing such “recalcitrant” patients, differentiating the “usually reliable ‘middle-class’ patient” to the “unreliable, uncooperative or alcoholic patient” (p.895). What was not clear was how people were selected as unreliable—by judgement of individuals by physicians, or from associated social markers considered related to non-adherence such as alcoholism and homelessness (Slutkin, 1986). Universal DOT (UDOT) eventually became a standard of therapy in the early

1990s, due to the increased emergence of HIV/AIDS and multi-drug-resistant tuberculosis (Bayer & Wilkinson, 1995). However, Mangura et al. (2002, p. 660) observed deficiencies in universal DOT alone as a strategy and instead demonstrated the success of combining UDOT with comprehensive case management approaches.

Similar to the US, the use of supervised therapy for TB in Australia was not universally applied, in 1968 the National Tuberculosis Advisory Council (NTAC) advising a similar consideration to the need of, “closely supervised intermittent treatment” for unreliable patients (National Tuberculosis Advisory Committee, 1968). Proust (1991a) explicated that supervision designated for such people were “easily recognisable”, including “refugees with problems of communication, Aborigines in the more remote parts of Northern Australia, and in urban areas the alcoholic or drug-dependent” patient (p195). It is unclear why Aboriginal people in the remote areas of Northern Australia were considered unreliable. In a tuberculosis conference held in Darwin in 1978, a TB nurse working in the Northern Territory painted such a picture. Whilst explaining the need for developing close relationships with Aboriginal people affected by TB by having some knowledge of cultural concepts of health and sickness, she had also commented on problems with follow-up due to the “increasing independence” of Aboriginal people, and the cessation of the TB allowance in gaining their co-operation. Also noted were “community concerns about the alcohol problem among the Aboriginal people,” and travel for example back to remote areas and leaving medications behind (Summerton, 1978). Another speaker at the conference, in discussing the potential for supervised chemoprophylaxis, had also made reference to Aboriginal peoples living in the rural/remote areas of New South Wales, stating, “We all know that the results of unsupervised chemotherapy, particularly among rural Aboriginals in Australia, are appalling.” He went on to describe the reason for this being “cultural deprivation,” shown as a “combination of extreme apathy, anxiety often quelled only by excessive alcohol intake, hostility and resentment towards whites, and, in particular, those whites they see as authority figures” (Thompson, 1978). There was no hint that these sequelae of “cultural deprivation” were all related to colonisation, suggesting instead a conditioned “passive resistance” over an “active refusal” to the offer of chemoprophylaxis, separating Aboriginal people who lived in urban centres as different to those who lived in rural and remote areas. Even though this conference took place six years after the introduction of the self-determination policy in 1972, no viewpoints from Aboriginal people themselves were evident. Instead, colonially constructed stereotypes were enabled to be re-produced, sustaining the status quo within the TB medical community.

In 1980, NTAC continued to advocate for “fully supervised intermittent chemotherapy” for patients whose reliability was “doubtful,” as well as prolonged hospitalisation—the issues experienced by the US of drug-resistant TB were not apparent in Australia (National Tuberculosis Advisory Council, 1980). This advice continues today, albeit with the terminology of “reliability” dropped from recommendations of supervision, as illustrated in Table 2 and 3 in chapter 2.2.

4.3.2.3 The “Big Sick”: Prolonged isolation and rigid supervision

Many Kimberley families were broken up by the big sick.

(Helen Yubu in Sr Brigida Nailon, 1950)

One of the early British leprologists (Robert Cochrane, who introduced sulphone therapy in 1945 while working in Madras), like that of Fox and colleagues for TB, also had concerns about the effectiveness of sulphones due to what he considered “disadvantages” to be overcome, specifically related to mass treatment. One of the main concerns was the method of administration of daily pill taking for masses of people, who were “not used to taking large numbers of tablets every day,” and considered it impossible to expect success without close supervision of patients (Huikeshoven, 1981, p. 232). Supervision of treatment soon became standard practice, with physicians tasked with identifying which patients could be “trusted” in using tablets according to the instructions provided (Huikeshoven, 1981, p. 251), similar to what was occurring in TB and the “unreliable” patient. Supervision of treatment became a running item for the WHO Expert Committee on Leprosy, especially given the availability of long-acting injectable medications seen to solve some of the problems encountered with the daily administration of tablets. In their second meeting in 1960 the WHO leprosy expert committee had refrained from recommending first line choice of therapy and left the choice of the formulation of medication (i.e. injection or tablet), and consequently treatment regimen, open to the local circumstances for each region or country (World Health Organization, 1960). If tablets were decided upon, the WHO advised they were to be swallowed under supervision. By the time their third meeting had occurred in 1966, the WHO altered their recommendation to a first line preference for oral treatment over parenteral but stopped short of changing the recommendation to countries to adapt to their “local circumstances” (World Health Organization, 1966).

In the adaptation to “local circumstances” in the Kimberley, the perceived need to survey Aboriginal people influenced the form and supervision of treatment - mistrust in Aboriginal people as responsible citizens evidently become embedded into the health infrastructure, demonstrated in a handbook given to nursing staff set to be working in remote communities. ‘Nursing in the outback’, from 1959, had a specific section on leprosy stating, “Do not for a moment think that the sulpha tablets you give with instructions to take them at stated times with a large glass of water will be actually swallowed as you direct.. You must see each one swallowed” (The Department of Public Health, 1959, pp. 2,3). The practice of maintaining supervision over the self-administration of tablets for people cleared for discharge from Bungarun to community was not a question of should, but rather a question of how. The trial of oral therapy for supervised community-based treatment using “such non-medical people as station managers’ wives” was considered a failure and the decision to switch to the six weekly acedapsona depot injection was made (Spargo, 2003). Dr Randy Spargo, the principal medical officer for leprosy in the region⁶⁵, revealed the rationale behind the decision in an interview conducted with a student investigating the history of leprosy in 1982 (Spargo, 1982, p. 4):

You could not achieve compliance at all once you lose control of them and we sure in WA that we never lose control because we’ve removed all responsibility for compliance with treatment schedules, i.e., we no longer rely (because I do not trust people) on people to take their treatment themselves, so we’ve removed that responsibility and the health team administers this treatment—a depot preparation of DDS.

One participant recalled these depot injections from their time nursing in the 1980s, stating they were “horrible injections” [RAN5, SG3]. However, despite this, as well as new recommendations for oral treatment over injections due to evidence of this pain (World Health Organization, 1966), DDS injections replaced the use of tablets once people were discharged from Bungarun to community, managed through the community public health nurses. The need for supervision in the community was relinquished, the concept of self-administration refuted, and the normalised colonial positioning of Aboriginal people as irresponsible and not to be trusted, continued. The rationale for the need of prolonged supervision of oral therapy, prior to discharge home on depot injections, also underpinned Spargo’s bid to keep the leprosarium open. The injection itself did not have the same

⁶⁵ Like Holman, Spargo was reported by Briscoe (2003, p. 68) as having no prior experience or knowledge of leprosy, stating that “I was not aware on coming to Derby [1968] that there was leprosy in Australia.”

therapeutic reliability as did dapsone tablets⁶⁶ (Zuidema et al., 1986), meaning daily oral therapy was needed for the initial months of treatment. Self-administration or community-health management of this oral therapy was not considered a reliable option. Spargo had argued that Bungarun was “the only facility where the necessary encouragement and support can be given” for this prolonged supervision (1982). This was despite national and international recognition that institutionalised care had not been recommended for years, except for the severely ill. And decisions that were made with the absence and omission of Aboriginal people themselves.

4.3.3 Closing Bungarun and community integration

4.3.3.1 Justifying extended use of Bungarun.

The justification from Spargo for the use of Bungarun for prolonged supervision of daily oral therapy, (in addition to his mistrust in Aboriginal people), appeared to be compounded by his lack of confidence in local health services to manage leprosy, citing that the hospital ward system “would not cope” with the recommended prolonged treatment supervision (Spargo, 1984). The ongoing use of the leprosarium created a dependency on an institution for specialist services. Significant financial investment was made in 1968 to upgrade the buildings at the leprosarium and remove the “security” section for “people who tried to abscond” (Sunday Times, 1968, June 2), rather than investment into community health infrastructure that would adequately support people affected by leprosy, at the time when Community Health was developing (see Briscoe, 2003, p. 68)⁶⁷. Additionally, investment had been made for a new hospital on the grounds of Bungarun that was built as late as 1976 (Heritage Council of WA, 2000). The lack of capacity of external health services to Bungarun to support those required for leprosy, including disability, has been posed as the main reason behind Spargo’s insistence on maintaining the use of the leprosarium (Robson, 2016). This seemingly caring position and intention to provide adequate health care services for people affected by leprosy, is juxtaposed by his overt mistrust in Aboriginal people regarding treatment and his perceived need for prolonged treatment supervision that he

⁶⁶ Acedapsone is a prodrug, needing conversion in the body. Reports indicated that low concentrations of oral dapsone levels, even though above the MIC, favoured resistance hence higher dosing was indicated. Acedapsone levels when tested were identified to sit just above the MIC and hence less reliable for initial therapy (Spargo, 1982, p. 4; Zuidema, Hilbers-Modderman, & Merkus, 1986, p. 10)

⁶⁷ According to Briscoe (2003, pp. 68,69) after successful trial of community nursing in Derby from 1968, the formation of the Community Health model was extended to Broome, Fitzroy Crossing, Halls Creek, and Kununurra. It was also in the late 1960s when Native hospitals were disbanded and care for Aboriginal patients absorbed by District Hospitals.

argued could only be done in an institution. It is this type of exclusive decision-making (i.e., without the input of Aboriginal people themselves), and protective paternalism (i.e., decisions made for Aboriginal people in what is considered for their own good) that reflects the type of colonial care discourse that had become enmeshed into Aboriginal health and demonstrates a persistence of an ongoing colonising mindset, despite evolution in Aboriginal health policy. Other officials outside the region did not share Spargo's position on maintaining Bungarun, arguing isolation was no longer necessary and even "illogical" (Beresford, 1984; Hargrave & Gamarung, 1978). Even Dr JC McNulty, the then executive director of public health, wrote in October of 1984 "Only Dr. Spargo seems determined to retain it as a centre for treating leprosy" (McNulty, 1984, October 12). Sr Germanus Kent, one of the sisters of St John of God, who had been working at Bungarun, addressed a letter to Spargo on the topic, part of this letter reading:

In the past leprosy has made havoc and destruction for the aborigines. The disease has broken many stable homes and left children abandoned...The future should hold a brighter outlook for these people, not a further disruption to family life. These people who have been afflicted with the disease have not been compensated in any way whatsoever. (Sr Germanus Kent, 1982)

Finally, nearly 20 years after the national recommendation to cease mandatory isolation for leprosy, and even longer after international recommendations, Bungarun was finally closed in 1986. The reason stated for its closure was due to the advances of treatment enabling "short stay treatment to be carried out in hospitals" meaning such a facility was no longer required (Director of Community Health Services, 1987, July 31; McNulty, 1984, October 12). In 1952 there were three hundred in-patients at the leprosarium, and by its close in 1986 there were only four in-patients, who were relocated to the aged care home in Derby, Numbala Nunga.⁶⁸ For those who survived leprosy and its complications,⁶⁹ the average stay in Bungarun was 3.5 years, with a range of one month to several years (Director of Community Health Services, 1987, July 31; Robson, 2016, p. 80). Mandatory isolation, including for children, continued through shifts in legislation and Aboriginal policy such as the 1967 referendum and self-determination in 1972 (Rademaker & Rowse, 2020), and even

⁶⁸ Numbala Nunga has cultural heritage importance for leprosy as it was the site of the original Derby lazaret in the 1920s (Heritage Council of WA, 2019).

⁶⁹ A recently constructed memorial board at the old Bungarun cemetery site lists the names of 357 inpatients who died during the course of its operation and is open for public viewing.

after the introduction of MDT in 1982.⁷⁰ The Public Health Act of 1911 with its special legislation for leprosy, was not repealed until 2016, long after Bungarun, the largest and last leprosarium in Australia, closed its doors.

Despite the significant social disruptions and harms for Aboriginal people over the 50 years since Bungarun opened, the one thing that is clear is the strength and resilience of Aboriginal people that continued through these times in continuing culture and livelihoods where possible within the institution. Aboriginal people did not allow the stigmatisation that had been constructed to stand in the way of routine weekend trips to visit family (although at a distance) at Bungarun (Wright, 2001, p. 209). Culture was maintained, with regular performance of corroboree as well as other strategies to maintain ceremonial and social obligations. Residents had created their own community, including a bakery and a dedicated orchestra (Jebb, 2002, pp. 148, 190; Knowles, 2019; Wright, 2001, p. 211).⁷¹

4.3.3.2 Post Bungarun

After the closure of Bungarun, the Kimberley Public Health Unit in Derby oversaw community-based care and surveillance with the assistance of the Sisters of St John of God until the mid- 1990s and Dr. Spargo who remained on as the main leprologist. Government-employed Aboriginal Health Workers had become involved in care as early as 1975 in assisting screening for Hansen's and the supervising of treatment after discharge from Bungarun (Gargita et al., 1985; Macale, 1985; Trust, 1985).⁷² In 1985, Allan Gore, an Aboriginal Health Worker in Wyndham reported on the treatment used, confirming the continued use of the acedapsone injection Hansolar® (DDS) and Lamprene® (Clofazimine) 1200mg (12 capsules) every eight weeks (made possible due to its long half-life) (Gargita et al., 1985) as the new community-based treatment regimen, continuing this avoidance of relying on people to self-administer daily standard MDT that was recommended by the WHO. Other regimens that were used were a six-week regimen (225mg of acedapsone and 600mg of clofazimine) and an intermittent regimen of dapson 50 to 100mg thrice weekly (Ilett, Chiswell, Spargo, Platt, & Minchin, 1993). A 'leprosy bus' (a caravan towed by a

⁷⁰ The referendum saw a change in power from the state to Commonwealth to make laws for Aboriginal people, meaning inclusion in the census and being counted as Australian citizens for the first time (Education Services Australia, 2021).

⁷¹ The orchestra, using donated instruments of the banjo, guitar, was led by one of the Sisters of St John of God and was excellent physiotherapy to assist with fingers and hands (Australian Broadcasting Corporation, 1999).

⁷² The first Kimberley Aboriginal Medical Service, BRAMS, opened in 1979 (see Briscoe, 2003, p. 71; Sisters of St John of God, date unknown-a)

Toyota 4WD) provided a mobile service for the region for leprosy surveillance by a Derby nurse (Trust, 1985, p. 49). New guidelines for Health Care Workers in the management and treatment of leprosy were published in 1997 (Kimberley Public Health Unit, 1997), altering the treatment regimen to daily rifampicin, dapsone and clofazimine with recommendations for treatment supervision, due to “growing concerns worldwide about bacterial resistance.” These efforts were maintained until 2002/2003, when specialist leprosy services in the Kimberley were gradually disbanded, specialist staff relocated, routine surveillance ceased, and the Kimberley Population Health Unit (KPHU) in Derby transferred to Broome. This was largely based on the declaration of the WHO that leprosy was no longer considered a public health problem at the 54th World Health Assembly in May 2001 (World Health Organization, 2003b). Prior to this disbandment, some medical practitioners were advocating for the maintenance of leprosy services to continue, as there had been several recent cases identified where the diagnosis of leprosy was delayed, despite multiple presentations to primary health care staff and medical specialists (Mak, Platt, & Heath (2003, p. 452).

4.3.4 Summary for the antibiotic era

I have described in this section the evolution of treatment with antibiotics for TB and leprosy and the genesis of respective treatment models. What started as a spark of hope from the potential cure of disease from antibiotics became laden with new challenges of the identifying the most appropriate combination and dosage of antibiotics, challenges with their tolerance and safety, acquired drug resistance and a surveillance of treatment due to a growing recognition of the challenges of regularity with prescribed treatment courses. I have detailed how this recognition was closely associated with the perceived reliability of the patient in the global leprosy and TB health communities in regard to treatment, and how this became interpreted in different settings largely implicating people living with social disadvantage. In Australia, for First Nations peoples, such practice collided with a colonial setting at a time where Aboriginal people, especially in remote areas of the country, continued to be marked as a people who were irresponsible in complying to the dominant biomedical model of care, requiring oversight. What is also apparent in these models of direct observation is the not only the power difference between recipients of supervision and those providing the direction or actually doing the supervision but also the absence inclusion of decision-making at both an individual level and at a higher policy level, i.e., ‘a seat at the table’ in determining associated public health policy in relation to treatment of both TB and

leprosy. As Boulton & Branelly (2015) remind us, "people who inhabit positions of power, conventionally gendered and at the expense of marginalised groups, enable their power to continue" (p77). The need to critically reflect on these power differentials and omission of active participation is something that contemporary debate on surveillance and supervision of therapy addresses (as outlined in Ch2) along with the concerns infection transmission and antibiotic resistance due to non-adherence—by patient to treatment or by physician to prescribing recommended standard therapy.

Within this discussion, I have also outlined the influence of antibiotics on ongoing isolation practices and the different applications of this practice globally, nationally, and locally for TB and leprosy, despite TB being known to be more contagious. More crucially, for the management of leprosy, these policies have been applied remarkably differently for First Nations peoples than for the non-Indigenous Australia public, reflecting colonial logic in public health practice management during the era. Discriminatory medical decision-making in regard to leprosy treatment shortly after the arrival of antibiotics was tainted by notions of racial intolerance to treatment and assumed behavioural risk to taking treatment, resulting in unevidenced alteration to treatment regimens. Prolonged opening of the Bungarun leprosarium was attributed to the lack of appropriate health facilities in the community to care for patients affected by leprosy as well as to enable supervision of treatment prior to outpatient management due to a mistrust of Aboriginal people. Despite these hardships, what is apparent is the continued strength and survival of Aboriginal people and culture through this era, and the willingness of newly trained Aboriginal health workers to care for their people affected by leprosy following the closure of Bungarun.

4.4 Chapter summary

This chapter provides readers with the foundation for a deeper understanding of the introduction of tuberculosis and leprosy disease in the Kimberley and the early roots of harm from colonial influences on public health management and response, including before and after the discovery of antibiotics. While I have highlighted similarities in the principles of management and treatment for leprosy and TB, a notable difference between the isolation practice between the two conditions was enmeshed within a logic at the time in regard to the influence of medical decision-makers on public health policy that has been central primarily to the survival of the settler population ('the future population') over and above that for Aboriginal communities. Instead, the health system structure and the influencing colonial

forces on this structure sustained the focus on the fate of the ‘future population,’ and the strength of the colony’s survival, influenced from colonial policies legislated for Aboriginal people throughout the 20th century, particularly with respect to policies concerning the absorption and assimilation of Aboriginal peoples. As a result, TB and leprosy infection have had different socially constructed trajectories in the interaction with Aboriginal communities. The focus and reaction of isolation policy for leprosy in the Kimberley, despite it being less contagious than TB, has had more far-reaching consequences of social disruption for Aboriginal communities in the North and North West.

I have demonstrated the importance of antibiotics as the main defence in controlling infection accompanied by the subsequent challenges that arose regarding drug and dosage experimentation, safety concerns, acquired resistance and direct observation of therapy, prior to the implementation of the WHO DOTS strategy for tuberculosis. The origins of this supervision draw attention to the colonial and post-colonial settings of Hong Kong and Madras, and the burden of disease in populations experiencing poverty and social inequities. Such populations were continued to be considered in need for supervision that developed into biomedical practice in regard to the modalities of treatment, until the late 20th century when supportive models of case management and building in flexible options for programmatic management became recommended. The subsequent impact that supervised therapy had on Aboriginal peoples was apparent for TB across the country, and more specifically for leprosy in the Kimberley.

During this era, in regard to both isolation and treatment health policies, I have argued how medical decision-making of those in power was influenced by the colonial gaze and bound up in the settler imagination of the destiny of Aboriginal peoples⁷³ and how this impacted the course of TB and leprosy care for Aboriginal people. Whilst there is a limitation from examination of historical archival documents in fully capturing the complexities that may have existed for practice at this time, I maintain it is important to learn from this history and the way such values became embedded into current practice and maintain a critical

⁷³ In 1958 William Stanner in his essay “Continuity and Change among the Aborigines” writes about the future of Aboriginal peoples, the ‘destiny of the race’ and the European ‘mystique’ about the future, in relation to the policy of assimilation: “we deal with the present and future on the basis of what we believe the past to have been. And from the first days of settlement, right down to the present time, our understanding of the Aborigines has been blinkered as well as spectaclled. The blinkers have been emotional general ideas formed by some kind of social philosophy. The spectacles have been the facts we had in our possession and the interpretations we placed on them.” (Stanner, 2010, pp. 155-156).

reflection on medical decision-making practices from those in power during this time as bound up with the settler state.

Most importantly, the absence of Aboriginal accounts in the archive constitutes a failure and a neglect to represent the considerable influence Aboriginal people have had in shaping colonial lives and Australian history and tells us of the notable absence of their seat at the table in decisions about health of their people. The resilience, resistance, and refusal of colonial values and colonial control from multiple generations of Aboriginal families through these epidemics is tantamount to how wrong early settlers were, including distinguished medical thinkers, in their predication of the future of Aboriginal Australia. Understanding the history of TB and leprosy treatment for Aboriginal people in the Kimberley region therefore becomes an integral and essential part of understanding contemporary treatment models as well as identifying ongoing colonising within the way health care services for the treatment of TB and leprosy are delivered today.

Chapter 5

The Treatment Model and Medication Management

5.1 Introduction

This chapter is the first of three that presents the research findings from the thematic analysis as described in the methodology chapter (Chapter 3). In Chapters 1 and 2, I introduced the concept of the treatment model and described two core components that feature in treatment programs for TB and leprosy, that is the use of DOT and the role of case management (discussed further in Chapters 6 and 7 respectively). Within this chapter I draw attention to the operational aspects of the treatment model, that is medication management as it applies to treatment for TB and leprosy. Medication management is described as “a system of processes and behaviours that determines how medicines are used by the health system and patients” (Stowasser et al., 2004) encompassing the prescription and provision of medications, related information about their use and safety, associated regulatory and legislative documentation, and the logistical and practical aspects of taking medications safely and effectively. I break this chapter into three sections that focuses specifically on the processes of supply of and access to medications, knowledge about treatment, and medication safety. These constitute foundational and practical elements of the overall treatment model.

In the first section I detail how the supply of treatment is coordinated and how this interacts with timely access to treatment, highlighting features unique to the Kimberley setting. I define supply as the availability and provision of a medication, and access as the opportunity of a person to receive or procure this medication. Having an effective supply of and access to medicines is a fundamental component of any treatment program for TB and leprosy (Australian Government, 2000, p. 2). In the second section I discuss the knowledge of medications used for treating TB and leprosy and review how this knowledge connects to other areas of the treatment process, extending to Health Care Workers as well as persons affected by TB and leprosy. In the third section I discuss key findings in relation to medication safety and highlight how the lived experience of Aboriginal people interacts with the history of treatment for TB and leprosy. Medication related problems have the potential to interfere with the achievement of optimal treatment outcomes (Geeson, Wei, & Franklin, 2017, p. 2) and the WHO considers that “patients and the public are not always medication-wise” and are too often “passive recipients of medicines,” not informed and empowered to play their part in making the process of medication safer (World Health Organization, 2017c,

p. 7). In this section, and in support of the last section, I identify that the provision of medication information and systems to support medication safety form key aspects of optimising treatment processes and use. In discussing medication safety, I also present the specific safety challenges for implementing TB and leprosy treatments within remote health care settings. I conclude with why addressing medication management is critical in providing optimal care for TB and leprosy.

5.2 Supply and access

5.2.1 Responsibility and control of supply

In the Memorandum Of Understanding Between the Perth based WA Tuberculosis Control Program (WATBCP), and the Western Australia Country Health Services (WACHS), the responsibility of ensuring adequate and continual supplies of medication for persons affected by TB or leprosy in the Kimberley falls to a specialist nurse case manager employed under the Anita Clayton Centre in Perth (Government of Western Australia, 2019(a), p. 97; 2019(b); WATBCP and WACHS, 2017, April). Supplies of TB and leprosy medications on reaching the Kimberley are then required to be distributed through “existing regional pharmacy processes to ensure governance and medication safety processes” (WATBCP and WACHS, 2017, April).⁷⁴ In practice, this medication supply goes through several steps and different people before reaching the intended person. To start, medications are prescribed by the relevant specialist, then dispensed at a Perth tertiary public hospital pharmacy (Royal Perth or Sir Charles Gairdner).⁷⁵ The Case manager then arranges these medications to be couriered to Broome, which takes three days by road. The TB/leprosy medications, or WHO leprosy blister packs,⁷⁶ are re-packaged into new Dose Administration Aids⁷⁷ (DAAs) and further distributed to a primary health care site where the assigned Local Case Manager

⁷⁴ All services associated with notifiable infectious disease management, including treatment for TB and leprosy, are provided free of charge by the WA Department of Health (WA Health, 2021, p. 27)

⁷⁵ Dispensed means to “supply in accordance with a prescription” (Western Australian Government, 2017). Certain TB and leprosy medications require additional approval and associated documentation to be procured through the ‘Special Access Scheme,’ a scheme to allow for the use of imported drugs not registered with the Australian Therapeutic Goods Association.

⁷⁶ For leprosy, Swiss pharmaceutical company Novartis in combination with the WHO, provides free first-line medications for leprosy (that includes daily Dapsone and Clofazimine with once-a-month Rifampicin and extra Clofazimine) in a one-month pre-packaged blister pack, referred to as the ‘WHO-pack’, ‘WHO-blister pack’, or ‘BCP’ (World Health Organization, 2021a).

⁷⁷ Dose Administration Aid are aids used to re-package medicines to assist in medicines management, such as Dosette boxes, Webster-Paks or Dose-Aid Sachets. The latter are tampered sealed DAAs, packed and sealed by pharmacists (Pharmaceutical Society of Australia (PSA), 2017, p. 84). (See [Appendix I](#))

(LCM) is employed. The LCM will then supply and administer the prescribed medication to the person affected, often utilising DOT.

The coordination of TB and leprosy medications for people within the region has historically had different pathways for each. TB medication has historically been managed from the Perth Chest clinic (prior to being renamed as the Anita Clayton Centre) and coordinated in the Kimberley via regional community health staff and the central regional hospitals. Medications for leprosy, after the close of Bungarun, were supplied out of Derby hospital and included the direct sourcing of WHO blister packs when they became available in the 2000s. It was difficult to pinpoint when a change in this supply process occurred that saw it relocated to being managed from the Anita Clayton Centre in Perth. The timing does align, however, with the WA TB Control Program becoming more involved in working together with the Kimberley Population Health Unit in leprosy control in the region in 2013. As the visiting Infectious Diseases Physician [SG3] had realised at that time, “there were patients who were not getting any drugs,” prompting questions of who had oversight of treatment. For reasons unidentified during this research, the change in supply process resulted in all medications being sent directly from Perth to a private community pharmacy within Broome, to be re-packed into DAAs and further distributed, rather than through the public hospital system. The Regional Chief Pharmacist in Broome commented that this supply system was odd and that, “it sits outside everything else [we do] [...] it almost entirely bypasses us.” The impact of this current system was not having ready access to treatment when people affected by leprosy were admitted into any of the regional hospitals:

We’d really only find out about [the person affected by leprosy] when they came to hospital because that’s when supply of their treatment became an issue for us, trying to track down where to get that supply and then getting our hands on a WHO pack.

[Regional Chief Pharmacist Broome, SG3]

What also became evident from this supply re-alignment, was that the WHO blister packs, once they reached the Kimberley, were no longer provided to people affected, replacing them with DAAs used within the region in other routine medication management processes. Although there is a lack of robust evidence, DAAs are used to assist medication management where a person has a complex medication regimen, is forgetful, or uses it to aid the management of their medications (Elliott, 2014). Once re-packaged into a DAA, medications have a reduced shelf-life due to changes in their stability, evidence suggesting that expiry dates on Webster Paks and Medi-sachets (forms of DAAs) in tropical conditions have a shelf-

life of 2-3 months or less (Raman, 2017). The decision to use standard DAAs over WHO blister packs for leprosy supply, which are stable for two years and purpose-built, hold up to one month's supply (instead of one week), and fit into a shirt pocket, is puzzling. More so was the finding that even at the beginning of the treatment process for supply and access, people were excluded from decision-making related to choices for where to access their medications and if they preferred to use the WHO blister pack over standard DAAs (when standard MDT for leprosy was prescribed). One Remote Area Nurse suggested this was due to the WHO packs looking different from standard DAAs, therefore potentially stigmatising people—although this was not confirmed during the research. What was confirmed is that few participants knew about or had seen the WHO blister pack in use. The other suggestion by this nurse was that using standard DAAs may have been easier when people were on other regular medications so they could be put into the same pack. Either way, people were often excluded from the choice of making these decisions for themselves.

This was evident even for latent TB medication for those who had to take treatment after testing positive to the Mantoux test for LTBI in the community wide TB screen (identified in Chapter 1). A participant explained about this addition of isoniazid in peoples pre-packed DAA:

Interviewer: So it was combined with other medications?

Participant1: Yeh with other medications, it wasn't sort of ok we're going to this house in the morning you need to take this medication and tick them off⁷⁸. It was just added to other medication.

Interviewer: Could you recognise which tablet it was?

Participant1: I would but I don't think community members would.

Interviewer: Was that a decision that people made – were they involved in that decision to have their medicine that way...?

Participant1: No.

[P1-FG1, SG2]

The decision to use DAAs for latent TB treatment was even applied to people who had no other regular medications and were capable of managing a regimen of three tablets once a day. The only exception identified to this routine decision-making was the separation of prednisolone from DAAs, largely when dosing was variable and to be titrated, i.e., reducing over a period. For optimal person-centred care, the decision to use DAAs is recommended to be made in partnership with the person affected due to variation in motivation, needs and willingness (Elliott, 2014; Pharmaceutical Society of Australia, 2017, pp. 8,13). For persons

⁷⁸ In reference to providing Directly Observed Therapy and adherence monitoring, discussed in Chapter 6

affected by leprosy, the decisions for DAAs are also relevant due to physical disability in people's hands and fingers that can restrict the opening of DAAs or tablet packaging. There is also a cost for the packing of DAAs. All these factors need to be taken into account as part of this decision-making. From the findings from this research, decisions were more likely to be made for persons affected rather than with them.

5.2.2 Delays in access

The current arrangement of medications coming from Perth as the central supply point translated to increased challenges in timely access to treatment, affecting the ability to implement treatment at the time of diagnosis and maintain a continuity of supply for people in community and in transitions of care. While a supply of most of the first line medications used to treat TB were stocked at the local regional hospital, there was not a supply of medications kept for leprosy. One of the local regional physicians explained the consequences of this:

The fact that we don't stock clofazimine, in any form, so we can't just make up a pack, and that we don't have a supply of the [WHO] blister packs and they all have to be sent up from Perth, which limits our supply. I understand that it might make it easier for reconciliation down in Perth, but there are times where it directly impacted on the ability to dose a patient where there's been an opportunity to help them access their medications.

[Regional Physician1, SG3]

An example of these challenges to providing timely access to medications also occurred for people wishing to restart therapy after interruptions. One person who had previously stopped taking treatment in discussion with the health care staff had agreed to re-start treatment, but efforts to coordinate treatment were met with an inability to supply them on three separate occasions. The Regional Physician reflected on this lost "window of opportunity" not just in terms of being able to re-engage this person back into treatment, but also in terms of jeopardising future confidence in the system, and the Health Care team, as a result, "I sort of think [...] did it affect their faith in what we were talking about, that we knew what we were talking about, when we couldn't produce that for them on three separate occasions?"

[Regional physician1, SG3]. An inability to get a timely supply of medications had additional unintended consequences identified during the research. One Health Care Worker, being unable to access supply of medication for a person wishing to restart leprosy therapy, decided to use another person's medication held at an alternative health site, as it was identical. While the intention to provide a timely supply of medication cannot be faulted, in using another

person's medication supply it bypassed standard medication management policy and protocols put in place for safety and legislative purposes. The original patient's name labels were removed, and the medication was transported via a health staff member travelling back to Broome. On further questioning, I was assured that the medication was still in date, and it did not leave the original person short on supply.

Further examples of delayed access to treatment due to this central supply arrangement were identified and largely logistical. The first example of this delay was secondary to the weather during cyclone season, where heavy rains caused road closures between Perth and Broome, further delaying the road transport of medications. The second example of a delay was identified when a person who was irregular in therapy wished to restart therapy. Due to the short-shelf life of re-packaged DAAs, and needing to renew expired prescriptions, a delay in supply occurred. This was made worse when coinciding with delays induced by the weather:

Unfortunately, we promised to...give the tablet on that week, but because of the cyclone and organising the tablet it wasn't available. And that's the other thing at that time [their] tablet is not available at the pharmacy, the script is [expired].

[Regional Chronic Disease Co-ordinator, SG3]

The third identified barrier to access was proper planning in ensuring the timely arrival of medications into Broome from Perth before the end of the week, to ensure continuity of supply to remote communities relying on transport services that do not operate during weekends.

5.2.3 Equitable access

Due to the remoteness of the Kimberley region, challenges are already present in ensuring equitable access to medications for persons in remote communities. As a result of the WATBP memorandum of agreement with WACHS (mentioned in 5.2.1), a decision was made at the executive level to introduce long-term weekly compliance reporting (WATBCP and WACHS, 2017, April, p. 7). This contrasts with the current WA guidelines that suggest weekly supply to start therapy, and after one month, supplying it monthly (Government of Western Australia, 2019(b), p. 54). This research revealed that all Aboriginal people affected by leprosy in the Kimberley were required to have weekly compliance reporting unless on monthly only treatment such as a monthly dose of Rifampicin, Ofloxacin and Minocycline (ROM). This weekly reporting also restricted supply of DAA's to weekly. This restriction made continuity of the supply of medication challenging in remote areas, especially in

situations of temporary mobility such as travel to other communities or towns to visit family, for cultural reasons, or health appointments. Such an arrangement in the context of a geographically vast and remote region such as the Kimberley, is at odds with any goal of equitable access to health care. Having only one- or two-weeks supply of medications limited the individuals' freedom to travel. For those who did, access had to be arranged at a new site. Instead of providing extra supply directly to the person affected, supply would be arranged to be sent directly to the clinic at this new site, thereby increasing the number of people involved. This impacted not only a person's privacy but also the potential for error due to challenges in having correct medication records. Maintaining continuity of supply and the necessary documentation during periods of mobility also resulted in an increased workload for health staff. One participant noted:

There is one person being treated and they have actually been away a lot of the time that I've been here, but there's been a lot of communication by email about where this person is and who might be able to approach them to give medication. And then there was a whole lot of confusion about whether they were given two weeks or one week or what they'd actually been given across the services, so that was a bit of a trick as well.

[RAN3, SG3]

The decision to implement restrictions on the duration of medication supply reflects not only a lack of trust in people adhering to treatment but also in being competent to manage their own medications. On only one occasion during the course of this research was a supply of greater than one month of medication provided, and this was for a person who was about to travel interstate.

Transitions of care such as from community clinics into local hospitals, or to different regional clinics also raised similar issues as those identified to temporary mobility and access. For example, the choice to relocate to another community for one person on treatment for latent TB came with a shift in the responsibility to a different primary care service. Unbeknown to this service, the new supply arranged was not connected to the previous supplying pharmacy, nor to the WA TB program who were providing free treatment and overseeing management and treatment progress. Other examples of transitions of care were when persons were flown from remote communities into Broome hospital by the Royal Flying Doctor Services, without their leprosy medications, and as identified above, no supply

was kept at the local hospital.⁷⁹ In other situations, persons brought into hospital had pre-packed DAAs that mixed regular medications with leprosy medications which were unable to be administered on the ward. This was due to hospital medication administration policies and prescribed changes in regular medications on admission into hospital, leading to a temporary interruption of leprosy treatment and urgent need to source medications. The current dependence on a central, Perth-based, control in the supply of TB and leprosy medications has impacted equitable access for persons affected by leprosy and similarly the same issues, and while not specifically identified, are likely present for those affected by TB. As Regional Physician1 [SG3] noted, Perth is “not central to the lives of any of our patients,” and, as the Regional Chief Pharmacist in Broome commented, precedents often set operational process without challenge:

I try and make things equitable and try and ensure people have access to medicines [...] in a manner that’s equitable because that’s how it should be. And yet we just accept that this is the way it’s always been done, so that’s the way it will always be done.

[Regional Chief Pharmacist, Broome, SG3]

5.2.4 Summary for supply and access

I have demonstrated within this section that arrangements for the supply of and access to medications for TB and leprosy have presented additional and unnecessary logistical barriers to early treatment intervention and continuity of treatment. Specifically, these are a centralised control of supply of medications in Perth rather than the Kimberley region, i.e., a supply pathway for TB and leprosy medications that sits outside already existing regional supply structures for accessing medications; exclusion of persons affected in shared decision making over places of access and choices around DAAs; and the restrictions on supply specific to Aboriginal people that are at odds with the goals of equitable access to health care. I have detailed the implications of these factors in this chapter as the exclusion of persons affected in their own care; increased challenges to access medications in situations of temporary or permanent travel; an increased number of health care staff and health sites involved in a person’s medication supply; reduced capacity to provide treatment on time or continuously; and a bypassing of adequate medication supply processes.

⁷⁹ The Royal Flying Doctor Service is ‘one of the largest and most comprehensive aeromedical organisations in the world’ (Royal Flying Doctor Service, 2020)

In contemplating a supply process from Perth, it would be easy to believe that getting a medication from point A to point B is all that is required. In practice, medication supply for TB and leprosy is more like point A to F. Once supply reaches the Kimberley, it becomes entangled in the existing, and sometimes unchallenged, public-private mix of supply and access processes. This can be complicated by the vast distances between communities and towns and the mobility that occurs because of social, cultural and health reasons, and during the wet season when roads block transport back to communities. Co-ordinating the logistics of the fundamental aspects of supply and access needs excellent inter-organisational and inter-disciplinary communication to re-position the person at the centre of care. Decisions to improve this model should not come at the cost of the persons affected.

5.3 Medication knowledge

5.3.1 Missing information

Well, they're not telling me anything. That's why I'm just sitting here you know?

[‘Remy’ (P1, SG1-L)]

Ways of learning about TB and leprosy medications were identified to be primarily from personal or familial experience, verbal information provided from Health Care Workers, and on the rare occasion, from the internet. However, a general lack of resources on specific medications, such as medication leaflets, and treatment were unavailable. One Health Care Worker noted this lack of information provision:

Interviewer: Do you have any available resources to assist a client – any written or audio-visual or... Hansen’s booklets? Is there anything official that’s been made available to people?

Participant: You know I’ve been really quite shocked myself, because when I was looking for medication information there was none. I rang up Anita Clayton because they’re the ones who establish all these [guidelines] and rules [and] they don’t even have one either [...] I think this could be why the patients are not taking it because they’ve never been handed out the information about the medication. All they’ve been handed out is the medication and that you have to take them and why you have to take them.

[Regional Chronic Disease Coordinator, SG3]

To help address this lack of information, a one-page informational sheet was compiled rapidly by this co-ordinator to be able to provide medicines information. Brochures about active and latent TB are available on the WA Department of health website (Healthy WA, Yr unknown), however, these brochures provide readers with general information on the disease

but not on treatment. For leprosy, there are no available informational brochures to help people understand their condition or available treatment. More importantly, there was no information related to treatment that is culturally tailored. This seems surprising given the significant history of leprosy in the region. However, Aboriginal Advisory Group members commented that written information was identified as not always the most appropriate form of passing on knowledge and this was also affirmed from my own experience as a pharmacist in the Kimberley. Preference is usually given to the verbal and the visual, and some Aboriginal elders still have English as a second, third or fourth language after traditional languages and may not be able to read or write in English.

The lack of any information provided about medicines was also noted by another Health Care Worker. Of importance, this person cited the lack of information provided about medication side effects as a troubling omission:

And I think from the few cases where people haven't taken medications because of the side effects I don't think they were given all of the information about the side effects and what they mean, how they could be managed. Some people just felt really sick.

[HCW12, SG3]

'Missing' information emerged as a theme that tied together this paucity of culturally tailored medicines information with the lived experience by those who felt that they didn't have all the information, they didn't have all the story. As Remy explained further:

Remy: They said they gotta find more medication [...]there's some things that they're not really telling me.

Interviewer: Is there information missing?

Remy: Mmm. But it's really about the medication, you know?

['Remy' (P1, SG1-L)].

The experience of missing information was also raised in relation to treatment for latent TB, as articulated by the following participants:

Well in regard to the treatment, there were some of us, even myself, that sort of wasn't—it wasn't explained properly what the treatment was for and what would be the outcome of the treatment. So, most of us were just sort of told that we had to have it done [...] we only just knew that some of us had TB but it wasn't active, it was asleep, and we were told that we had to take this medication for six months, and no other information.

[P1-FG1, SG2]

All I was told was I was exposed to TB. No one said you were latent or active or whatever—they just said you was, and that was because of that test being positive. All I was told is that I was exposed to TB, nothing other than that [...] you was exposed to TB and it's recommended that you start taking this medication.

[‘Charlie,’ SG1-LTBI]

For these participants, it was clear that information was missing not just about medication side effects, but also about the diagnosis and expected outcomes of taking treatment.

5.3.2 Having the background.

5.3.2.1 ...for community members

In addressing this missing information, learning about treatment was not just about learning about the medications, what they are for, how they work and/or potential medication side effects. The information about medications also connected their importance to the bigger picture of treatment, and the role and place of treatment in managing TB or leprosy, i.e., the ‘what for’, including the expected outcomes. Having background information about the condition helped in understanding the story behind the need for and importance of treatment, as this Aboriginal Remote Area Nurse pointed out:

That's also the knowledge base [of] how much understanding do they have of that disease and how it works, why it's really important to have that medicine, sometimes I think that's the key as well.

[RAN4, SG3]

Oral histories of TB or leprosy passed on or observed through family and community were an important source of understanding the place of treatment. Leprosy, and the place of Bungarun, was more prominent than TB in this regard (discussed further down). Few participants had knowledge of what TB was or had “never heard of it” (P5-SG1).

Recollection of TB knowledge for some participants was related to the presence of TB in the cattle:⁸⁰

Participant5: That bullock, that cattle I remember they had TB. That's all I know.

Interviewer: Had you ever heard of anyone getting—

Participant5: Nah, first time here.

Participant4: Well I've heard that before, from bullock, get it from bullock. You get it from eating beef or something, contaminated beef, or something, that's what I think, I don't know for sure, back in the day.

[FG1-SG2].

⁸⁰ As discussed in Chapter 4, *M bovis* in cattle was not eradicated until 1997 (More et al., 2017).

A limited knowledge about TB impacted participants' understanding of treatment for latent TB. Charlie was one participant who was diagnosed and was aware TB being a "terrible disease" through an earlier experience. In recounting his personal story of having witnessed active pulmonary TB in the late 1960s, he noted:

Charlie: Well, the first time I become aware of TB was when I was a young boy working at De Grey Station⁸¹. I was a young bloke then, and that was the first time. I never knew what tuberculosis and thing was, like what it was until I was a young bloke. I was a jackaroo, a ringer—that's what they called it—and we had a guy there, a middle-aged bloke, and he had tuberculosis.

Interviewer: A local fella?

Charlie: From Pilbara, yeh. And I asked the other guys "what's wrong with ..." I won't say his name. And they would say "oh he's got TB" and I said, "what's that"? Well not many people then didn't know what tuberculosis was, "suffer from TB," "he's got TB." Well at night we'd be long way from him. Because all night he'd be [makes coughing noise] really bad, really, really bad - when we were sleeping, and we were on the cattle station, and we were all working in the one place. But we were never in a confined place, we was always in an open—But we never used to, we didn't know about sharing, we never shared things at that time. We always used to have our own cups and all that. And um, I thought it was a terrible disease then, when I seen it as a young boy and seen what he went through and how he had to—Because in those days I mean the problem really was medicine was not like it is now.

Interviewer: What year was that?

Charlie: Oh, about 1969-70, yeh.

Interviewer: So, did he stop working, get medicine?

Charlie: Nah he was working... no medicine...just living with it already killed him. Because he died, he wasn't really that old. He would have only been, might be lucky to be 40. I was only a young bloke then, I was only 16, 16,17, and he was about lucky to be 39, 40. But he smoked as well. But he never had any medication or went to the doctors or anything. And I always thought it was a terrible thing to have because I could see what he put up with and when he goes to sleep, I don't think he slept a full night, just waking up coughing. And I don't think there was treatment, proper treatment, for people in those days. Especially for Aboriginal people those days out in the remote places they weren't aware of, you know you might be able to go over there and get treatment or [...] But that was when I became aware of tuberculosis, yeh.

[‘Charlie,’ SG1-LTBI]

In connecting this story from Charlie to the history of TB, 1969-1970 marked a time where treatment *was* available, the sanatorium in Perth had closed, and there was a sense of TB being controlled due to the public health measures put in place supported by the TB campaign in combination with effective treatment. The story of this man affected by TB

⁸¹ De Grey Station was in the Anna Plains region, identified to be hotspot for TB 15-20 years prior to this time (See [Chapter 4.2](#))

dying without seeking medical care or receiving treatment provides further evidence of how the outcomes for Aboriginal people, especially in remote areas, fared differently from non-Aboriginal Western Australians during this campaign.

In contrast to knowledge about TB, the wider social impact of leprosy and isolation into the Bungarun leprosarium in Derby, meant most Aboriginal people interviewed had some recollection of the background, and that there was treatment available. Connecting to this through personal or familial experience made earlier treatment intervention possible through self-presentation. One General Practitioner (GP) recounted the situation of a person who self-presented at a remote clinic, concerned that they had “Bungarun disease,” after a patch had appeared that the person was suspicious about. Another person affected by leprosy conducted regular checks on their children and extended family’s children to look for early signs of the disease. This practice of checking others and self-presentation, according to one Remote Area Nurse who had been working in the region since the 1990s, used to occur often—but not so much in the current day:

We had people referred to us by people who have been on treatment or have had family members on treatment, who [would] say “sister come and have a look, I think this person might have it” ...yeh we just don’t have that any more.

[RAN5, SG3]

One line of reasoning for this change in practice was identified to be the belief that leprosy was a thing of the past, that it had finished up with the closure of Bungarun. There was knowledge about “that old place in Derby—that leprosy place”, but also a belief that it had gone: “Because we thought only them old people, like that was the last of them mob you know?” [FG2- SG2]. Another Aboriginal Health Worker remembers hearing about it from their grandmother, “I didn’t really grow up with that understanding of it, just hearing about that leprosy hospital in Derby” [HCW15, SG3], connecting knowledge of the disease and treatment to place and institution, but not aware that it was still present until starting their work in health. There was also a belief that knowledge had been lost as it had not been passed down to younger generations or lost with the passing of older generations. One participant in Focus Group 2 described memories of growing up seeing an elder with visible signs of disability in his hands being “all clawed up,” but not knowing it was leprosy, “we didn’t know, we just thought ‘oh because he’s getting old now, and he doesn’t do much.’” Another participant described the disconnect for younger generations not having grown up during the time of Bungarun:

I don't think it's been as talked about. My generation were well, you know...that [Bungarun] was talked about when I was growing up, so that's how I was aware of it. Whereas the generation of now, you know I'm even talking about 20's and the teens and that, they wouldn't have had anyone.

[RAN4, SG3].

Even though it was considered a thing of the past, knowledge of the understanding of leprosy and the familial linkage was explained to me in one focus groups with elders. The way leprosy 'skipped' through family was described by one participant, who recalled how leprosy didn't affect them but affected their sister, brother, and eldest son who "had that thing as well, yeh, fall back to brother one" [P3-FG3-SG2], explaining how this familial linkage played out. There was a consensus among this group who had personal experience with leprosy that it also started out as a burn, "from a fire, like when you're sitting next to a fire", with another participant recalling being "burnt with hot ashes" while asleep, "it's like we get burn and we have that thing⁸² you know?" Another person recounted the numbness in the feet that occurred, "you can't feel him [sic]—stick, poke—you been walking around with that thing in your foot, you got no feeling." Another participant linked this concept of burns to her top which she recalled had been "sung": "and I was looking for my top one night, and I been get that top and I put him on, and I was real hot then, someone been singing my top—In Aboriginal way they was" [P1-10, FG3, SG2]. While this thesis is not about the cultural understandings of disease causation, the knowledge presented by this group of elders is salient for connecting cultural knowledge of leprosy infection with first signs of infection, important for self-presentation and therefore early treatment intervention, potentially providing richer understanding of the role and place of treatment in relation to disease severity.

Harnessing knowledge of social and cultural history for both family connection and general disease-treatment understanding I argue becomes a needed part of preventing any further loss of knowledge that ties in with the importance of treatment. 'Having the background' assists younger generations in understanding this importance for both TB and leprosy and constitutes an area of information for inclusion within future development of culturally tailored medication resources.

⁸² Where 'thing' meant leprosy and was referred to as 'him'.

5.3.2.2 ...for Health Care Workers

Knowledge of social and cultural history, not just epidemiology, also impacted Health Care Workers ability to consider leprosy or TB as a possibility. A lack of knowledge contributed to missed opportunities for early (or earlier) treatment intervention. This was evident in two main ways— the first being misdiagnosis, and the second from *missed* diagnoses, due to a low index of suspicion of both TB and leprosy. For TB this became an issue for one person who had delayed seeking care (for reasons unidentified), presenting late in the stage of their infection at the local remote Aboriginal Medical Service and whose initial diagnosis, with input from a respiratory specialist from Perth, was lung cancer. It was not until this person was flown to Perth and reviewed with the aid of further diagnostics that the diagnosis of active pulmonary TB was made. As informed by one participant the source for the TB was not identified:

We had a patient who was identified as having active pulmonary TB and had probably had it for a number of years. And when this person was eventually diagnosed and the typing was done this person was not matched to any of the main cases in the Kimberley, so it was really unclear who this person had contracted the TB from, because they weren't connected to any other known case⁸³.

[HCW9, SG3]

The lack of suspicion for TB was apparent for another person in a different location, who was “diagnosed [with TB] on a trip to Perth for a health reason” [Regional Physician2, SG3]. The presentation of visible loss of weight was a common feature identified in these presentations. Loss of weight featured again as a key sign of TB in a different community from those already discussed, as relayed by a Remote Area Nurse:

I think one person we picked up; they kept coming in, they came in one day and said, “I’m losing all this weight...all this weights just falling off me,” and I was like, “oh, are you trying to lose that?” and they said, “nup.” Where they had TB.

[RAN2, SG3]

Importantly it was the Aboriginal Health Workers who recognised and confirmed the visible loss of weight, as RAN2 continues, “In fact one of our Health Workers, they said, ‘that so and so, look at her,’ and I was like ‘why?’ And they said ‘well they’ve lost all this weight. They used to be big and look at them now.’” As identified from a discussion with Aboriginal Health Worker participants, there was no formal training for TB (or leprosy) provided within their training course—anything they had learnt was through workshops or other education

⁸³ Suggesting reactivation of an old latent TB infection, as this person had not travelled out of the community.

forums, or from information sessions provided as part of this project. In relation to the community impacted by the subsequent community wide TB screening described in Chapter 1's introduction, one visiting Health Care Worker stated they did not think the clinic staff "were given enough education" [HCW10, SG3]. The recognition of the need to build up more capacity among Aboriginal Health Workers (AHWs) for this setting, particularly in a leadership role, was articulated by another Health Care Worker stating they, "would like to see more capacity, whether it happens before, or, well, ideally before an outbreak, in Aboriginal Health Workers, so they're sort of the lead team in community" [HCW12, SG3].

Like TB, a lack of any index of suspicion in leprosy diagnosis also led to delayed diagnosis in some situations. Even more significant, was that blame was placed with the person affected for their symptoms:

I think this person started presenting in 2008 or earlier—I shouldn't say facts off the top of my head, but for quite a long time. And there were notes there saying "presents with paraesthesia, told not to sit on their feet." That sort of stuff. And they had a neuropathy.

[HCW12, SG3]

The diagnosis took at least two years after this person had presented on numerous occasions to their local hospital and was finally recognised by a nurse who had had some previous experience with leprosy. A late diagnosis meant missed opportunities for early treatment intervention, which equates to a missed opportunity to prevent further disability and potential transmission.

On the flipside, Health Care Workers who did have the background knowledge aided early treatment intervention. The first example was from a participant who recounts the story of their diagnosis where the doctors were aware of the family history:

It was after a-while they thought that I had leprosy because of my family history. My uncle had it, two of my uncles had it as far as I remember, my cousin he had it. They were all at the leprosarium. So, the doctor thought oh, because of family history, maybe you've got it.

['Sam' (P3, SG1-L)]

Here, the doctor connected the history of the presenting complaint with the knowledge of history of place, people, and family, and not just the timeline of symptoms. The same connection was made for the GP above who was able to listen to the person presenting with what they called 'Bungarun disease,' and have awareness of what this was and not dismiss the person. By then going through the correct referral pathways, the diagnosis was not

missed. As one of the regional physicians pointed out, in the intersection of this knowledge in the remote context of providing health care in the Kimberley, that:

Leprosy kind of hits the Achilles heel of the Kimberley health service in particular...you need to understand its history in the region, and you need to understand the care pathways and accessing care across all organisations, and often you need a longitudinal assessment of the patient.

[Regional Physician1, SG3].

5.3.2.3 *Who's the expert?*

I tell 'em 'how you gonna fix my thing? Because you mob only just learning.'

['Remy' (P1, SG1-L)]

For some participants who had been affected by leprosy, there was a recognition of a lack of the knowledge about the history of leprosy in the region from local Health Care Workers:

This mob here didn't know what Hansen's disease was. What it bin really mean. They didn't know 'til I told them. These doctors and nurses. They didn't know about all these things before, what was really happening. They didn't know about this thing before, like back in the day. Everybody asks what it really means. I had to tell 'em 'you heard about leprosy?' I mean only know about that because people went through that [sic].

['Remy' (P1, SG1-L)]

This lack of knowledge affected the confidence and trust in the local staff, as compared to the visiting specialist. One Remote Area Nurse noticed this lack of confidence, explaining that one person affected by leprosy already had a "real dislike for medical services," and that the specialist team in Perth, "were the only ones who could visit and talk to them about their condition, they were the only ones this person trusted." [RAN3, SG3]. One of the regional physicians also recounted another example of trust in lack of specialist knowledge for another person, "they know that doctors today don't have the same knowledge as Dr Spargo⁸⁴, there's probably not any extra info they are going to get from the clinic." Remy also expressed being blocked from talking with the specialist at times, "They [the local health staff] just tell me [the specialist] is flat out too and they're busy, like [they] got another patient and all that." At times tensions between health staff and local primary health care staff were reported, in relation to this expertise. Local staff had described the experience of being undermined, contributing to this lack of trust in knowledge from them. This was considered by one GP not

⁸⁴ As detailed in chapter 4, Dr Randy Spargo was the principal leprologist at the time of the Bungarun closure.

only in providing clarity when prescribing roles and responsibilities but in being kept involved in a person's care. This GP noted that it was "not appropriate for primary care to be making treatment decisions. That's not our role. But primary care also has to be kept informed because we are the people that they're going to see when anything happens" [HCW10, SG3]. The discernment of who is the expert in providing disease and treatment advice comes from the person affected – that is determining which health staff they can have confidence in. It also comes from the lived experience of people affected themselves, as they both connect to family history and gain knowledge through personal experience and as such should be considered as 'lay' experts.

5.3.3 Ways of communicating

5.3.3.1 *Communicating importance and consequence.*

Doctors, they just look at you and say, "you'll be right, here take your Panadol" [they all laugh] [...] "and you'll be right."

[P5-FG3, SG2]

Another key theme identified from the interviews for this research was in relation to communicating knowledge about medications in culturally appropriate ways. Themes such as communication exchange, that is taking the time to explain, imparting the knowledge face-to-face. One of the key examples of how *not* to communicate about medications was not being told what to do. The 'telling thing,' was brought up by several participants. I often heard or was told that, "some people don't like being told what to do," [FG1, SG2], and "you can't tell people what to do," [FG3, SG2], and that others will just do as they are told [FG1, SG2]. One Aboriginal Remote Area Nurse explained:

It's not about "you've got to do this," the telling thing, it's about the way you put the picture together. So then there's an understanding of why you have to have this treatment. Taking time, and not rushing it, you know not looking at, and not telling you know, that telling, "you gotta do this and you gotta do that."

[RAN4, SG3]

This RAN further explained, "it's got to happen from that empowerment and that passing on of knowledge, not 'we're the professionals and I'm going to do this to you, I'm going to do this.'" As part of not telling people what to do, explaining the *importance* of treatment was identified to be key. The other aspect of communication raised was avoiding the use of 'high' words, such as medical jargon, and using language at the right level, "you need to explain as basic as you can especially in a community environment because not everybody is highly

educated, so you got to speak at their level” [P1-FG2-SG2]. In recognition of the need of this, another HCW was critical of how it occurred in practice:

We actually don’t simplify it. We strip it bare and give the most minimal amount of information, rather than giving the full amount but in a way that’s easily understood. We do that with skin infections, “you’ve got to take this because its infectious,” “you’ve got to wash your hands.” But we don’t actually talk to people about germ theory and how soap works.

[HCW12, SG3]

For the treatment of for latent TB, and less severe forms of leprosy, communicating importance became even more challenging when people did not feel unwell with their condition, as explained by one of the Regional Physicians:

Latent TB and Hansen’s—often the patients don’t feel that unwell, if at all. So, one of the really big challenges, and it’s the same with diabetes, is explaining to people we’re treating you now to keep you well in two years’ time, five years’ time, 10 years’ time, because this is what might happen to you, and it might not, so that’s challenging as well. I think, I don’t think we do this as well as we could do because we’re always too busy in some ways, but I think it really does require a lot of time spent talking to the patient and developing trust and understanding of what you’re doing and why.

[Regional Physician2, SG3]

As well as ways of communicating, and taking the time to explain, the need to communicate the importance of treatment extended to involving family (when there were no issues of privacy), specifically in relation to leprosy:

That’s the thing about it is how much is communicated to family, how much that education to families about you’ve had this in your family, you’re at risk, we really have to monitor you if you’ve got a suspicious patch.

[RAN4, SG3].

Communicating importance was also intricately linked with communicating *consequence*—being explicit and clear about what happens if treatment is *not* taken and identifying options. This ‘cycle’ of communication linked in with missing information and as identified in 5.3.2, included information on treatment outcomes. For some people who took treatment for latent TB, there was a distinct experience of not getting feedback after treatment had been finished and understanding if it had worked:

Well, there’s one thing that hasn’t been done—follow-up—well anybody, doesn’t matter who it is, if something happened, they’d like you to tell them, where we are at now, what’s happening, every-body wants feedback. That’s the most important thing

that people look forward to. It's no good saying "well oh, but its ok now," and they sit here thinking, "well what's happening"? And that hasn't happened to me, not at all.

[‘Charlie’ (P6, SG1-LTBI)]

Um, I can't remember if there was feedback or anything throughout that—I think it was just given to us and we had to take it and that was it.

[‘Andy’ (P4, SG1-LTBI)].

Yeh, like they was all for it, I mean they came full force, everybody in the community got tested, screened whatever. And for that whole course some people took it, some didn't, and we was just left—no follow up, no nothing.

[P2-FG1, SG2]

Feedback also related to medication changes made during treatment courses of leprosy. Not communicating, or not communicating in ways that people understood about changes, caused much confusion and frustration. In reference to prednisolone dosing being consistently changed often, Remy [P1 (SG1)], had asked me, “[...] I mean, what do I gotta still stay on the same dose, or what they gotta change me another?” and further expressed their frustration concerning the lack of communication exchange: “All this medication that you mob changing, decreasing, or increasing it or whatever, it's not changing anything. So they're not listening to me” [P1, SG1-L].

In reflection on the earlier words of Remy in 5.3.2., “that's why I'm just sitting here”, and Charlie in 5.3.4.2, “and they sit here thinking ‘well what's happening,’” and, in discussing this with one of the Advisory group members, it was identified that the onus of providing information rests on the Health Care Worker. This expectation, often accompanied without specific questions from patients, forms a key part of intercultural misunderstandings around the provision of treatment information. That is, it is not up to the person affected to ask questions when they don't understand, rather the Health Care Worker to provide this information regardless of any perception that people don't want information. One of the non-Aboriginal Health Care Workers acknowledged this intercultural misunderstanding:

But a lot of the times people presume Aboriginal people don't want all that information, but a lot of the time it's that cultural language barrier and Aboriginal people sit down and don't look at you and look away, and they think “oh they don't want to know all of this.” So it's our cultural understanding. But certainly, when we've asked Aboriginal people, they say they want more information, tell us, but we don't. We tell white service providers.

[HCW12, SG3]

This was confirmed in a separate conversation in an all-Aboriginal participant focus group, where the want for ongoing education was communicated, “Education...pictures, [we] need something more. Keep coming back and reminding us—doctors don’t have much [time], we need something more” [P5-FG3-SG2]. In relaying their experience to me of miscommunication, one participant considered it was due to underlying discrimination, “I think discrimination is a part as well, I dunno—makes you wonder” [P5-FG1, SG2]. This feeling of being discriminated against was also discussed in the context of not making efforts to use language that could be understood. As well as communicating importance, consequence, and providing feedback, effective communication is about making the effort to ensure language used to provide information is clear. This is relevant to all stages of the treatment process and is reflective of communication exchange where Health Care Workers explain and listen, rather than tell people what to do.

5.3.3.2 Mixed messages

The last theme presented within this section identifies mixed messages from communication, where information provided by different Health Care Workers became conflicting. One of the key examples of this was relayed by Charlie, [P6, SG1-LTBI] who prior to their diagnosis of latent TB, had raised a concern with one of the clinic nurses of having been exposed to TB (due to their proximity with the person diagnosed with active TB). The clinic nurse had told Charlie that he “wouldn’t be affected in any way,” and “had no worries.” This information was in conflict however with information provided by an emergency department (ED) nurse at a local hospital. Charlie was accompanying the person affected by TB into ED, when the ED nurse had had told this person affected by TB that they needed to be wearing a mask.. This caused Charlie confusion: “and then it hit me, and I said to her [the ED nurse] ‘well what about me?’ And I said then, ‘who’s telling—who’s advice was the right one?’” After the tests came back positive for latent TB, Charlie explained how he felt about this conflicting advice:

So, the professional advice you take it from there. You take it like that’s the right advice. But then deep inside I was feeling I was let down by the clinic. I feel like I was really, really let down by the clinic. I blame the clinic myself for me being exposed to TB.

[‘Charlie’ (P6, SG1-LTBI)]

Conflicting messages from health staff working in different organisations also occurred with leprosy, as observed by one of the regional physicians, who explained:

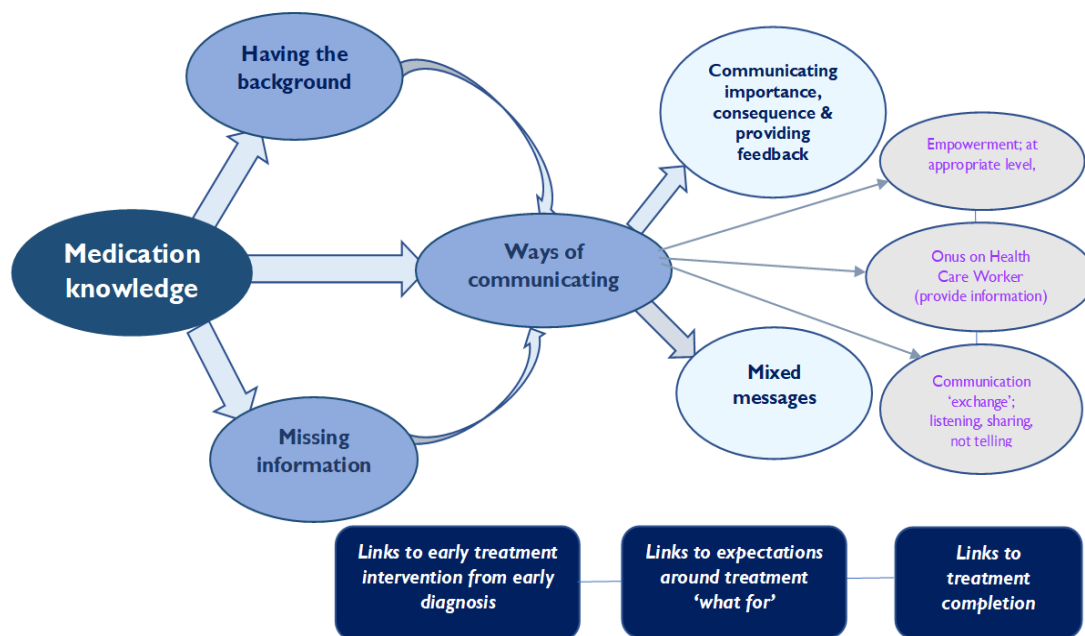
I think it is fraught with danger in terms of working across different organisations and what gets presented to the patient, the patient can get mixed messages even if we are all trying to deliver the same message. Sometimes if it's not, sometimes it can make the message more uncertain, and certainly I think patients lose trust when they start to think we're not all talking to each other.

[Regional Physician1, SG3]

These inter-organisational relationships and inter and intra-disciplinary relationships between and within organisations, impacted people's confidence in health staff, as experienced by Charlie. The consequence of conflicting messages for Charlie was on the relationship of Charlie with their local clinic staff, particularly the nurse who had provided the original assurances, rather than with the hospital staff.

In linking the themes identified for medication knowledge together, I contend that there are many layers to providing information that include a connection to history and relationships, in assisting people affected by TB or leprosy to gain meaningful information about treatment. The following diagram assists in the visualisation of these layers and connections:

Figure 4. Medication knowledge: Summary of themes



5.3.4 Summary for medication knowledge

In this section I have discussed several interconnected themes related to medication knowledge for TB and leprosy. An intimate relationship was identified to exist between

knowledge of condition with knowledge of treatment that links in social histories for the treatment of the condition. For some persons affected by leprosy, this knowledge assisted self-presentation and earlier treatment intervention but was reliant upon the Health Care Worker also being aware of this history. For Health Care Workers, while having clinical knowledge is important to recognise symptoms of disease, having knowledge of the history of disease in the region assists with a higher index of suspicion, which further assists in earlier treatment intervention. The absence of this knowledge for both TB and leprosy has led to missed opportunities for early treatment intervention from misdiagnosis and missed diagnoses. The identification of this absence of clinical and historical knowledge in health staff by persons affected subsequently impacted their confidence in health staff capabilities. By the same token, persons affected become ‘lay’ experts in their treatment and condition. This challenges traditional hierarchies of knowledge, namely, superiority of knowledge from health professional versus inferior knowledge of ‘lay’ person.

5.4 Medication safety

5.4.1 Safety concerns of community members

5.4.1.1 *Pharmaceutical histories: Experimentation, forced treatment and trust.*

Back in the days, our people lived out of the bush. They didn’t worry about medicine what to take, or everyday medicine, like what we have now.

[‘Remy’ (P1-SG1-L)].

Social histories were identified to be interwoven with modern understanding of treatment also in relation to medication safety. Even though regulation of medicines to improve their ethical use and safety (as outlined in Chapter 4.3.1) has improved significantly over the past decades, participant’s stories revealed that the history of forced treatment and experimentation, particularly for leprosy, is not just a distant memory but remains as a real and present suspicion. For example, one Health Care Worker relayed how one of the people they had been seeing who was affected by leprosy had observed the way their family had been treated in Bungarun, “where they just forced them to take medications.” Having to take treatment for leprosy reminded them of this time, and according to this Health Care Worker made them feel like they were, “one of them, like a guineapig, telling me to take the medications.” [Regional Chronic Disease Coordinator, SG3]. This suspicion extended to treatment for latent TB as well as that for leprosy, with some participants voicing their concerns regarding a feeling of being experimented on with current treatment, resulting in a

lack of confidence in the safety of medications used. In this situation, the feeling of being experimented upon was triggered by a lack of feedback and explanation about the latent TB medication, as noted by one participant:

Interviewer: So no-ones explained what can happen, what you need to look out for? How does that make you guys feel?

Participant4: Pissed off.

Participant1: We feel like guinea pigs. Like test rats, lab rats or whatever they call them.

Participant4: Does this sort of, neglect happen all around or just communities?

[FG1, SG2]

These concerns around safety also link with missing information, as identified in medication knowledge. The consequences of this were significant for the trust and confidence of health staff, expressed through feelings of anger, being let down, and feeling neglected by these services as a result.

While the two quotes above display a concern for medications being forced upon the individual and not explained, what also emerged was the extension of this suspicion or mistrust to the person administering the medications. With respect to general medicines use, one Aboriginal Health Worker noted:

All about trust—old people they think too much medication killing them and making them more sick. And a fear and feeling of not trusting the doctor thinking they're trying to poison them. Same thing with generics if they change shape or anything. If someone sits down properly, it takes a lot of convincing, [and] can be dependent on who's talking to them.

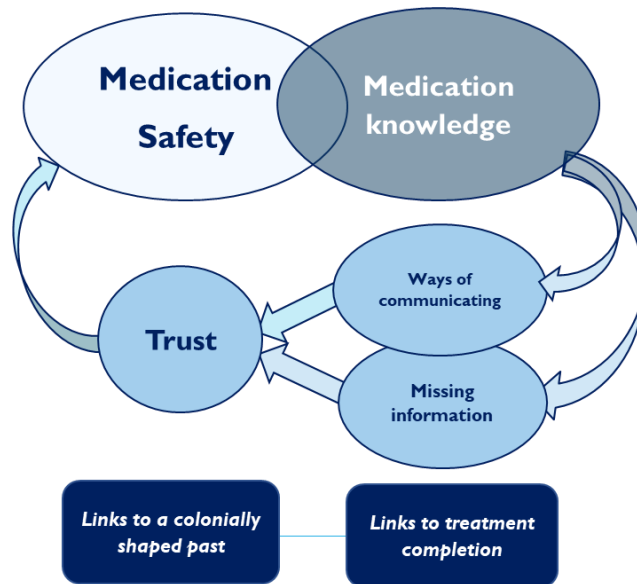
[P3-FG2, SG2]

Such mistrust reflects on a colonial past that includes oral histories of poisoning by settlers (see for example Duncan, 1996, p. 103), a past that remains present in the minds of people that influence their modern-day experience of medications. This concept of being poisoned had also been raised in conversation by some Aboriginal patients during my time working professionally as a pharmacist in the Kimberley.

The other link to safety is knowledge, and how people gained this knowledge and information about medicines, as detailed in 5.3. As the participant in the above focus group further explained, “there's medications that can bugger other organs up. And some of them understand that. They understand the whole body.” Consequently, addressing medication safety means addressing these concerns with information provision and transparency, as well as establishing trust relations. Having open and honest conversations about medication safety

is in line with communicating importance and consequence and filling in any ‘missing information,’ visualised in Figure 5.

Figure 5. Relationship between medication safety and knowledge



5.4.1.2 “Too much”: Pills, safety, and stress

Well now, we on all this medication every day, 24/7, and most of us, I mean, yeh, everyone. And some part that can’t. I mean, you gotta know how to take it..., and its real hard for you.

[‘Remy’ (P1, SG1-L)]

In addition to concerns about trusting medications, for some people having too many tablets, was “too much.” While pill burden from TB and leprosy treatment has been identified in Chapter 2.2 as a challenge to taking treatment, in this scenario pill burden was related to safety concerns, that is a *fear* of taking too much medicine and the consequence of this, coupled with an associated stress.⁸⁵ A prime example was for Remy, where there was some confusion with a doubling of the monthly DOT leprosy medications rifampicin and clofazimine packed into the DAA with other medications, resulting in an admission into hospital⁸⁶:

⁸⁵ Polypharmacy is identified by WHO as one of the key risk areas for medication safety (World Health Organization, 2017)

⁸⁶ According to the Pharmaceutical Society of Australia (2017, p. 15) in an audit on DAA packing at an aged care facility, the proportion of DAAs with an incident that was considered likely to have major or catastrophic

I don't like them telling me what to do [...] because I had a problem here one time. I had to cut that monthly and that normal one, same time. That's the one what made me sick. I ended up in hospital, overdose. And that's what I told 'em—I can't have both at the same time. Either I have my normal tablet and my monthly on separate occasion, like Monday on a week or month.

[‘Remy’ (P1, SG1-L)]

This event resulted in a reduced confidence and trust in health staff and an increased desire to assert more control over self-management of the medications. Remy explaining “and I told ‘em it’s me, I’m the one who’s gonna feel all these things. It’s up to me, what time I got to take it, and what’s making me sick, you know?”

Stress in relation to concerns over the safety of medications also resulted from changes to medications, particularly when information was not provided by health staff. Familiarity of medicines meant knowing what to expect and changing this contributed to confusion about the medications. As Remy explained:

Remy: Well, that’s like I’d rather have that, what medication I know. The more they change, you know, you gonna get frustrated you don’t know which ones you were taking, which one I’m really on. Like that’s sometime...it’s really thing for me.

Interviewer: Because you have this medicine you know and then it changes?

Remy: Yeh it changes and then you don’t know and “what’s this medicine for, and what,” you know, all that. I mean I know you gotta make changes and all that. Same way you go back to square one. I know they test all these, what medicine you gotta have, but to us, it’s too much for us you know?

[‘Remy’ (P1, SG1-L)]

The impact of medication changes was noted by another participant in Study Group 2, from their experience regarding changes, even changes in generic brands, explaining people “get confused, and sometimes ask questions—but they’re not asking the doctor.” According to this participant, “It’s quite a big thing any change” [P3-FG2, SG2].

The experience of safety was also related to the experience of adverse drug effects from treatment. Common side effects that cause issues with tolerance can be similar between first line TB and leprosy medications. For example, clofazimine (leprosy) can cause a discolouration of the skin, (however this was not an issue raised by any participants), rifampicin (TB and leprosy) can cause body fluids to turn an orange/yellow colour, rifampicin as well as isoniazid (TB, latent TB) can cause hepatotoxicity (liver damage), and

consequences was 4%. This was mainly due to packing errors and packing of medications not suitable for DAAs.

many of the medications used can cause gastro-intestinal intolerance, mainly nausea and vomiting (Australian Medicines Handbook 2020, online)⁸⁷ (see [Appendix J for a list of adverse drug effects](#)). The colouring of urine by rifampicin was one that was particularly noticed, although did not present any issues, as one person explained:

Because when I first took ‘em, you know the colouring of my gumbu [urine], was a different colour, so I was like “somethings happening.” And I went back to the clinic, and they said, “oh no, that’s fine you know it happens at first it will eventually go away”.

[‘Sam’ (P3, SG1-L)].

In further questioning as to whether this information was provided to Sam at the start, the reply was “no, no, no! well they probably did but I’ve forgotten.” For leprosy treatment, a common side effect noticed was nausea and/or vomiting. Nausea was debilitating for some, to the extent of regular vomiting, subsequently putting people off taking treatment. For one person this also impacted the ability to work. As one Health Care Worker recounts, “[this person] said they felt ‘so sick’, and ‘I can’t function’, and they said you know they’re working and sometimes they have to be off work for two days because of the side effect.” [Regional Chronic Disease Co-ordinator, SG3]. The Infectious Diseases physician provided another example of this side effect in another situation:

They had a lot of gastrointestinal upset, and so that may have actually been the moxifloxacin, because they were off the dapsone, because of hypersensitivity. So they were vomiting, again, we were trying to address that, so I could imagine how that would put somebody off if that’s happened for a few weeks.

[Infectious Diseases Physician, SG3]

While common, nausea can range in severity and at times be a sign of more serious drug toxicity (David & Hamilton, 2010). Knowledge of potential side effects and how to counteract them forms a critical part of overall treatment management for TB and leprosy. This reifies the link between knowledge and safety of medications used. Another aspect of this safety is the potential interaction between medications. Rifampicin is particularly noteworthy, given the numerous drug interactions that exist⁸⁸. Some people were concerned

⁸⁷ In their study of tolerance of MDT for leprosy, Deps et al. (2007) found that nearly half of all patients had one side effect to MDT and the majority was to dapsone.

⁸⁸ Rifampicin is a strong Cytochrome P450 enzyme inducer and p-glycoprotein inducer, metabolic pathways utilised by several other drugs. Subsequently there are a significant number of potential drug-drug interactions with rifampicin with the potential of altered therapeutic effect. The number of interactions complicates

about mixing medications, such as newly prescribed antibiotics for an unrelated infection, with their current leprosy medications. Drug interactions and their subsequent management were not investigated exhaustively due to the research design not including access and investigation of medication histories in participants medical files.

5.4.2 Mapping medicines safety

5.4.2.1 Multiple systems, prescribing confusion

In addressing health system factors related to medication safety for TB and leprosy, several themes were identified. The first was the risk of errors related to having multiple electronic health systems between Perth and the Kimberley, and within the Kimberley, which do not always share medication information. It's one thing that one of the Regional Physicians identified as a risk for monitoring of safety:

The diverse health information systems create, it is one of the things that creates a very high level of risk. Risk of defaulting therapy, risk of adverse effects, risk of adverse effects not being picked up. Risk of adverse effects, particularly lepra reactions not being picked up and managed appropriately, is very risky.

[Regional Physician1, SG3]

This became relevant when specialists from Perth prescribed treatment as well as when people moved between health sites within the region in transitions of care (such as admissions to hospital), or for example when needing to access care whilst visiting family in different communities⁸⁹. The visiting Infectious Disease Physician commented on the challenges this created for prescribing when asked about the potential difficulties of separate health records between Perth and the Kimberley, and also inter-regionally:

, I think that probably is problematic. And even just generally problems with documentation so they can't access what we're writing, and we can't access what they're writing. Although I mean generally, I find often people will get on the phone and ring, so that's usually ok,, so I guess yes and no. So as much as possible we try to keep our system updated here. And if there's an email correspondence, that will get uploaded. But things like a prednisolone reducing schedule, I will just put in what I've suggested, but it's often really difficult to find out whether that schedule was adhered to.

[Infectious Diseases Physician, SG3]

prescribing safely and is reflected by the fact that rifampicin is used to test drug interactions in pre-registration drug studies (Australian Medicines Handbook 2020, online).

⁸⁹ At the WA TB centre, an up-to-date medication chart is required to be kept for each person. In the Kimberley, there are different electronic systems between Aboriginal Medical Services, government run remote clinic and community health centre, private GPs, and public hospitals.

Duplicate documentation of medication records across sites from separate health record systems increased the risk of medication error when current medication regimens were changed and not communicated (i.e. altered prednisolone dosing schedules and/or changes to leprosy treatment). This was further complicated from the use of DAAs which require updated medication orders to be sent to the packing pharmacy in order to facilitate any change in the DAA⁹⁰. TB and leprosy medications packed into the DAA, if not sent back to the packing pharmacy, were wasted and ongoing supply complicated from original prescription records being kept in Perth. In this situation, pharmacists performed a central role in medication reconciliation to ensure the correct medication was provided and all DAAs were changed over, acting as a central source of knowing current medications being prescribed.

Confusion over who could prescribe what medication in relation to TB and leprosy, including adjunctive treatment, contributed to duplication of records, as noted by one Regional Physician:

I think there is still a lack of clarity of what is been written in terms of medications from down south to here—both antibiotic and adjunctive treatment—and there is still not a consistently followed system for who prescribes what things... I mean people could be easily supplied drugs from two different sites, which are recorded in two different systems, by health professionals that never know about the other records. So it's very easy to see whether in regard to TB or leprosy treatment, or any other condition, how that could impact on the safety of prescribing medications for patients, and also inappropriate stopping of medication.

[Regional Physician1, SG3]

The inconsistent system for prescribing TB and leprosy treatment also applied to latent TB, where inappropriate starting of medication (isoniazid) by doctors on two separate occasions occurred, outside of standard programmatic management. The first example was from a local GP who prescribed treatment for a person they knew after this person presented with a positive Mantoux test (as part of community screening). This GP was not part of the community with the screening or linked in with the TB taskforce that had been assigned.. The second example was when an emergency doctor prescribed isoniazid to a person with a positive Mantoux from the same community screening, without any plan for monitoring, again not linked in with the assigned taskforce:

⁹⁰ As per professional requirements pharmacists are required to obtain a medicine order from an appropriate prescriber before packing a DAA (Pharmaceutical Society of Australia (PSA), 2017, p. 87)

I remember a girl up the peninsula, maybe two to three years ago now, who got started on isoniazid for latent TB and when she got discharged from Broome hospital ED, there was someone very smart who, well she was in for a completely different reason, and this is the reason why it wasn't very smart, one of the ED doctors was like "uh-huh!, this is someone we've been trying to track down, let's start the isoniazid." And then she disappeared and came back with a roaring hepatitis because she hadn't had her monitoring done.

[Regional Physician2, SG3].

These examples outline the potential safety consequences from not having clarity about prescribing recommendations as part of TB and leprosy programmatic management and how and where regional GPs and physicians not assigned to specialist TB and leprosy services can be involved in making changes and initiating medications.

5.4.2.2 Pragmatics of clinical monitoring requirements

While not common, some adverse drug reactions from TB and leprosy treatment can be severe and even life-threatening. Consequently, all treatment requires clinical monitoring, such as routine blood tests and monitoring for physical signs and symptoms to identify these reactions early enough to prevent any considerable damage. Reviewing the response to treatment is essential after prescribing TB and leprosy medications and is required on a routine basis. The concerns around maintaining routine clinical monitoring for medications within the remote setting of the Kimberley were raised by one Regional Physician, explaining, "what worries me about that is monitoring, [...] you're supposed to be doing regular blood tests to keep an eye on, for example people's liver function, and they're way overdue for those blood tests" [Regional Physician2, SG3]. This physician further described how the primary health care team and GPs at remote area Aboriginal Medical Services played a vital role in assisting this monitoring. This occurred through increased email and phone communication, especially in cases where people may have missed scheduled visiting physician appointments. This demonstrated the need for excellent inter-organisational communication to assist in safety monitoring, often via multi-disciplinary case management meetings. The same physician explained the decision-making process of starting someone on treatment due to this complexity of monitoring requirements:

[When] weighing up the pros and cons of treating now, versus if someone's a bit chaotic and it's worth waiting a few more weeks—I think that applies to Hansen's and latent TB to a certain extent. You need to know that you're going to be able to find that person and follow them up and monitor them properly and make it safe for them to have treatment. It's that balance between, well some things you have to treat—you have to

treat active TB—but some other things it's the balance between of course you should treat this person, but how safe is it to do so?

[Regional Physician 2, SG3]

Inter-organisational planning for care, and even transitions of care when a person goes between hospital and community where health record systems are not shared, meant both persons affected, and Health Care Workers could not always have access to all relevant and up-to-date information. It also again raises issues of privacy which adds another layer onto the complexity of ensuring safety monitoring. However, privacy for persons affected, especially in consideration of a want to keep their diagnosis confidential, was not seen as a barrier in empowering patients to be supported in their safety, as explained by one Regional Physician:

There are ways to empower the patient in what gets shared, but to do so in a way that it doesn't expose them to a risk of adverse effects from drug interactions unnecessarily, and it doesn't expose them to a risk of Addisonian crisis⁹¹ from having prednisolone stopped inadvertently, and I think that surely we have the technology to do that.

[Regional Physician2, SG3]

5.4.2.3 Recognition of harm

I have so far identified that medication safety involves planning, clearly defined roles for responsibilities of prescribing, and effective communication across sites due to the potential for duplicate records. Safety also involves the person affected, their experience of safety and ensuring that allergies and other adverse drug reactions are appropriately documented and managed. An example of appropriate management includes one person who had a severe reaction to dapsone within one month of treatment initiation. Dapsone can cause Dapsone Hypersensitivity Syndrome (hereafter referred to as DHS), described as a “rare, delayed hypersensitivity reaction involving multiple organs” which is potentially fatal (Guragain, Upadhayay, & Bhattarai, 2017) (see [Appendix J](#)). DHS can be quite difficult to recognise due to its similarity in presentation to sepsis. For the local person who experience DHS, there was timely recognition of symptoms, the dapsone ceased, and an effective new treatment regimen was implemented safely after transfer to a Perth hospital. One of the Infectious Diseases Physician had noted that “anecdotally we seem to see higher rates of dapsone sensitivity” (in Aboriginal people) and that “Aboriginal people and Pacific Islanders are thought to have the highest rates of that HLA status [HLA-B*13-01], which is associated

⁹¹ A sudden drop in cortisol levels

with dapsone hypersensitivity”⁹². One Remote Area Nurse who was working in the community in the 1980s recalled a person not being able to take dapsone, which may have been related to hypersensitivity: “I did have one chap, with pure neural leprosy, he had to go onto a combination without dapsone” [RAN5, SG3].

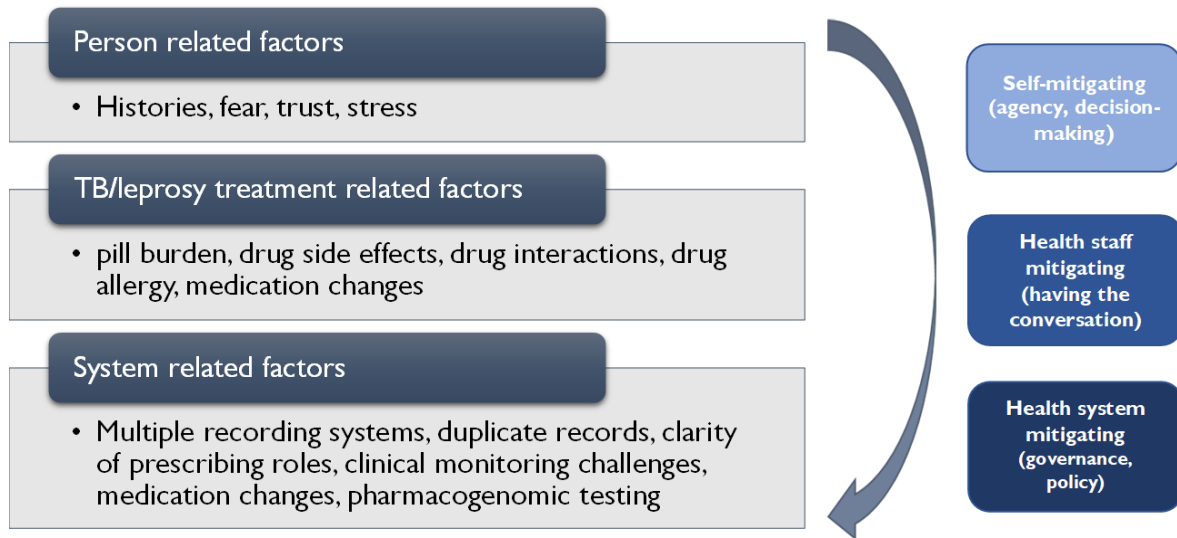
Being able to recognise adverse drug reactions and intervene in a timely manner is important to prevent further harm, and in reflecting on the two cases of isoniazid inappropriately prescribed, discussed above in 5.4.2.1, both resulted in hepatotoxicity. Both people were experiencing symptoms and self-presented. The first person, where an emergency department doctor prescribed the isoniazid, self-presented to their local Aboriginal Medical Service clinic, and the GP recognised the reaction and ceased treatment promptly. The second person, also self-presented with symptoms to the original GP who had prescribed the isoniazid. This GP did not recognise the drug reaction however, and the failure of this recognition was noted by one Health Care Worker: “When that person said, ‘I’m feeling really sick’ said Dr. didn’t think maybe I should do something, just said ‘oh you’ve probably got some helicobacter’ and prescribed some Nexium HP7” [HCW10, SG3].⁹³ The result of missing this key symptom and not monitoring was severe hepatotoxicity, with the person transferred to Perth for medical management. The above examples illustrate the importance of communicating medication safety information to persons affected so they can self-monitor for symptoms—in both situations people had self-presented when feeling sick. As one participant explained “you sort of know—you know when you’re sick, or whatever, to come [to clinic]” [‘Andy,’ P4, SG1-LTBI].

Figure 6 summarises the relevant factors discussed in relation to medication safety and how risk can be mitigated by a) the individual person (by having agency in control over their own medications); b) health staff (by having the conversation about safety), and c) from the health system (such as appropriate sharing of health records).

⁹² As identified in chapter 4.3.2.2, there was never any scientific evidence for an Aboriginal person being more at risk for intolerance of dapsone, however the contribution from the CTPH and observations and stories from Health Care Workers at the time may have contributed to this anecdotal evidence, accompanied by the fact that Aboriginal people were disproportionately affected by leprosy meaning potentially larger numbers for population related effects. See [Appendix H](#). for more information regarding pharmacogenetics.

⁹³ Nexium HP7® is a treatment for *Helicobacter pylori* infection, that causes gastric upset and reflux (Australian Medicines Handbook 2020, online)

Figure 6. Medication safety related factors and mitigators



5.4.3 Summary for medication safety

An underlying narrative of medicines safety exists for people affected by TB and leprosy. This narrative was made visible by the contribution of Aboriginal perspectives and uncovers a cautious approach to taking medications, especially given the challenges specific for TB and leprosy medications such as pill burden, adverse drug reactions and allergies and medication changes. I have described how this approach is intimately linked with a trust of medications related not only to historical experience of forced treatment and experiences of being experimented upon, grounded through personal or familial experience, but also worsened by more current concerns of overdosing and taking too much medicine. Mitigating these challenges and anxieties means regaining control over decisions for persons affected, and addressing broader medication monitoring systems, processes, and knowledge that assist optimal clinical monitoring specific to TB and leprosy medications used.

On a practical level, ensuring that transparency and information is provided in discussing medication safety is significant to assist people not only in their decision-making and recognition of symptoms related to drug adverse effects but also in building trust and ensuring treatment is safe and effective. These provisions I argue provide a platform for which health teams and the overarching system of policy and governance of medication safety for regional health systems and processes can occur. Being cognisant can also allow policy makers and health care providers to work towards solutions for sharing information between sites (whilst maintaining privacy) and improving clarity for prescribers. Overall,

optimising medication safety for TB and leprosy treatment in the Kimberley is challenging and requires excellent inter-organisational and inter-professional communication and competent documentation. To maintain a person-centred focus, proper planning must be done in dialogue with people affected.

5.5 Chapter summary

This chapter presented three sections focussed on building optimal medication management for TB and leprosy—supply and access; medication knowledge; and medication safety. At the foundational level, inequitable access to TB and leprosy treatment reflects a system whereby continuity of treatment is at higher risk of interruption, has an increased risk of error and neglect for those affected. Some of these processes, I have noted, are inherited systems and warrant re-consideration. The operationalisation of services for the specialist area of TB and leprosy within the Kimberley region is dependent upon the capacity of primary health care to provide services that in the urban model are provided by a specialist TB and leprosy centre. Nonetheless, I have outlined that the current arrangements for medication governance function more to control individuals than to provide optimal care. Aboriginal people are restricted in quantities of supply, cultural mobility is not integrated into program design, and a general tendency to not involve persons affected in negotiating *all* aspects of treatment is present.

As well as the need to address the gap in adequate provision of culturally tailored medication information, addressing missing information about medications also means conveying the connection of medication knowledge with the bigger picture of the role and place of treatment. Communicating this connection includes linking this role and place of treatment with the treatment stages, particularly the importance of early treatment intervention by early recognition of the condition. Once treatment has started, ongoing provision of information becomes the responsibility of Health Care Workers providing clear messaging about the importance of treatment, the consequences of taking or not taking treatment, and providing feedback on the treatment process. Additionally, this communication needs to include conversations about medication safety. While the pharmaceutical industry has evolved significantly since antibiotics were discovered for TB and leprosy in the 1940s and 1950s, memories and histories of experiences with these medications remain interwoven into the modern-day fabric of ways of knowing for Aboriginal people in this study. Concerns and fears from people over the safety of treatment are real, current, and not merely distant memories of a past of pharmaceutical

experimentation and forced treatment. The challenges of ensuring that TB and leprosy treatment is provided in safe ways is explicit: TB and leprosy medications need to be monitored and the system needs to be able to support this. Connecting the need for improved medication safety dialogues is the evidence that people themselves are the best ally in identifying emerging signs of adverse drug reactions.

Despite the obstacles and inconsistencies that were found to exist, and the gaps where culturally secure and person-centred care for treatment could be improved, people did receive safe and effective TB and leprosy treatment. The hard work of some individual Health Care Workers in navigating the obstacles that exist for medication management assisted in the completion of treatment for most individual persons affected. This, however, does not mean that the current treatment model is a 'recipe' for success for all people who may in the future become affected by TB or leprosy, nor does it mean the system is tailored to provide optimal care. There is significant room for involving people more in their care than is currently the case that works at the individual, organisational and systems level.

Chapter 6

Approaches and Responses to Taking TB and Leprosy Treatment

6.1 Introduction

One of the most critical parts of any treatment model is the act of people taking treatment as it is intended, in ways that achieve the optimum effectiveness from medications without jeopardising their safety. In the case of leprosy and especially TB, this also involves the arrest of infection transmission and prevention of antibiotic resistance. As I have argued in Chapter 4, an ideology of compliance accompanied the early introduction of antibiotics, an ideology that has evolved with the evolution of person-centred care to consider more negotiated agreements with people who are prescribed treatment. To provide more nuanced detail, within this chapter I propose new additional non-binary descriptors that qualify a person's approach to taking treatment that more closely reflect a person-centred orientation and what was learnt to occur in practice. By using the terms 'approaches' and 'responses' to taking treatment I present the research findings in ways that encompass how persons affected *and* Health Care Workers react and respond to the proposition of treatment regimens. I then discuss in more depth these approaches and responses to taking treatment in relation to adherence monitoring required by Health Care Workers in the context of addressing public health responsibility in situations where a person is unable to or refuses to take treatment, including a detailed look at the use of Directly Observed Therapy (DOT).

The first section of this chapter provides an overview of individual approaches to taking medications and discusses these new descriptors in line with the concept of a person's treatment journey, identifying 'phases' of this journey for both TB and leprosy. Vrijens et al. (2012) describe a "new taxonomy" for adherence that provides uniformity to the international language used in the literature. This language goes beyond mono-phasic considerations of taking treatment, to tri-phasic descriptors of initiation, implementation, and discontinuation, and assists in the translation of adherence to pharmacological action in achieving optimal or sub-optimal therapy⁹⁴. While building on this language, the modelling I present incorporates terminology specific to TB and leprosy treatment discourse and the research findings in relation to patterns of adherence identified.

⁹⁴ The work by Stagg et al. (2020) is one such example that, based on this new taxonomy from Vrijens et al. (2012), links TB therapy adherence with optimal versus sup-optimal dosing.

In the middle section of this chapter, I focus on the ways public health teams, in their responsibility to the wider public, are required to monitor a person's approach to treatment and the response when irregular or nontreatment is perceived or known. Escalation pathways to the use of the Public Health Order as a response to nontreatment, form part of this discussion. In the last section of this chapter, I present the lived experiences of Aboriginal people affected by TB and leprosy, community members, Aboriginal Health Workers, and Aboriginal Health Practitioners regarding the use of DOT. I review the impact that DOT has had as one of the principal tools in responses to adherence. Specifically, I draw attention to the significance of relationships with those Health Care Workers who provided DOT, and the centrality of place, i.e., health clinics or people's homes, for how and where DOT was provided as part of the current treatment model.

6.2 Approaches to taking treatment.

6.2.1 Regularity of treatment

6.2.1.1 Skipping doses: Why does it matter?

Themes of adherence emerged in several conversations with participants across all three study groups. After careful analysis what was identified was a spectrum in the way people approached taking treatment, rather than an adherence/non-adherence binary. For example, interruptions to treatment from missing doses (commonly referred to as 'skipping' by some participants) were common within this spectrum.⁹⁵ This varied from persons affected by TB or leprosy forgetting to take medications or making the decision to not take one or two days of medications on occasion, through to missing longer and more routine periods of time or stopping and starting treatment over a period of months. For active TB and leprosy, there was no evidence of any persons refusing to start medications or of people who stopped and did not eventually re-start. What varied was the duration of treatment secondary to the number of missed doses and having treatment extended or re-started. For latent TB, an unknown proportion of people stopped treatment early.

As discussed in Chapters 1 and 2 the potential consequences of taking treatment irregularly are the extension of treatment duration (by "adding on" weeks missed), sub-optimal effectiveness of treatment, acquired drug resistance, worsening disability, and relapse

⁹⁵ This was also identified by (Urquhart, 2002) in recording electronic adherence, describing a spectrum of six distinct variations in approaches from complete adherence to routine "drug holidays" (>3 days missed), to patients who took few or no doses while maintaining the illusion of complete adherence.

of infection in the years after treatment had been deemed complete⁹⁶. One Remote Area Nurse explained how this extension of treatment duration was communicated, “so we tell them if you miss this week’s, we’re going to have to add another week on to your treatment” [RAN5, SG3]. While it was clear that the *need* to take treatment was articulated by Health Care Workers, effective communication of other consequences of irregular treatment proved more challenging. The topic of acquired drug (or antibiotic) resistance was one of these. Remy revealed no knowledge of the word resistance in relation to antibiotic medication:

Interviewer: Has anyone ever talked about resistance with you? Like, your [leprosy infection] being resistant to the medicine, antibiotics? Does that name, that word, sound [familiar]?

Remy: Nup. Now what you mean by resistant?

[‘Remy’ (P1-SG1-L)]

Fortunately, at the time of finishing the fieldwork for this research in the Kimberley none of the identified eligible participants for both TB and leprosy had known antibiotic resistance reported.⁹⁷ This does not exclude the possibility, or the importance of understanding this potential consequence of this from irregular treatment, as discussed in earlier chapters.

Part of the challenge in communicating the consequences of irregularity in treatment are difficulties in translating pharmacological science into meaningful, mutually understood, non-medical descriptive language, that adequately provides accurate and accessible information to individuals. Instead, simple descriptions of ‘taking’ or ‘not taking’ often prevailed, as exemplified in conversation with Remy about the monthly DOT dose:

Remy: When I’m not around, they ring my phone, and if I’m not here I tell them, I just skip it, you know?

Interviewer: And what’s their response to you skipping it?

Remy: You know [...] doctor told me, you have to take it you know? Well, I know I got to take it!

[‘Remy’ (P1, SG1-L)].

⁹⁶ In terms of the pharmacological science, “serially-omitted” doses of TB and leprosy antibiotic treatment reduces their therapeutic capability to fight against infection. Dependent upon the individual properties of the drug in question, there are “relative degrees of forgiveness” for how many doses can be missed without consequence (Vrijens, Gross, & Urquhart, 2005, p. 227). One of these consequences is the potential for acquired bacterial resistance, forming an important part in justifying adherence interventions such as DOT.

⁹⁷ All microbiological samples for TB and leprosy are sent from the Kimberley region to the PathWest laboratory in the QE11 Medical Centre in Nedlands, Perth, which functions as State Reference facility for Mycobacteria (PathWest, 2020)

In further conversation, when asking if any health staff had explained about what can happen when missing doses, the reply from Remy was ‘no,’ and added:

No-one can tell me, if...I stop taking it, or if I want to take it, you know, if it cause too much pressure or stress on me, then you know, like missing out it won't hurt if I go one day [without it].

[‘Remy’ (P1, SG1-L)]

What was firmly present was the response from the use of the language “you have to take it” being met with resistance (no one can tell me) and the demonstration of being in control (if I *want* to take it), demonstrating a degree of self-determination in the pattern of medication taking. Finding the right way of expressing information that explicitly communicates how optimisation of treatment can be achieved, forms a key part in knowledge exchange and the for Remy again re-iterates the theme of missing information, discussed in Chapter 5. In this case however, it is in relation to consequence of irregularity to better enable informed, and self-determined, decision-making. For effective communication, the emphasis on the taking of everyday treatment would benefit from a shift away of the emphasis on ‘compliance’ and the feeling of being told what to do (hence responses of refusal or resistance) to that of open dialogue and information provision to assist decision-making required for adherence.

Based on these findings, four descriptive categories emerged that assisted the categorisation patterns of adherence in relation to the completion of therapy within the given timeframes for TB and leprosy and the potential consequences. Shifting away from binary descriptors of taking/not taking medications, and away from language such as frequent defaulter, I put forward four patterns of taking treatment that draw on initial discussions of irregularity presented by Fox and colleagues in the late 1950s, as well as more contemporary work by Vrijens et al 2012, in adaption to the patterns of ir/regularity identified that apply to both TB and leprosy; Regular treatment, Irregular treatment–Type 1, Irregular treatment–Type 2, and Nontreatment (See Figure 7). These categories are specific to TB and leprosy timeframes in which to complete treatment, outlined in [Chapter 2.2](#) and I define as follows:

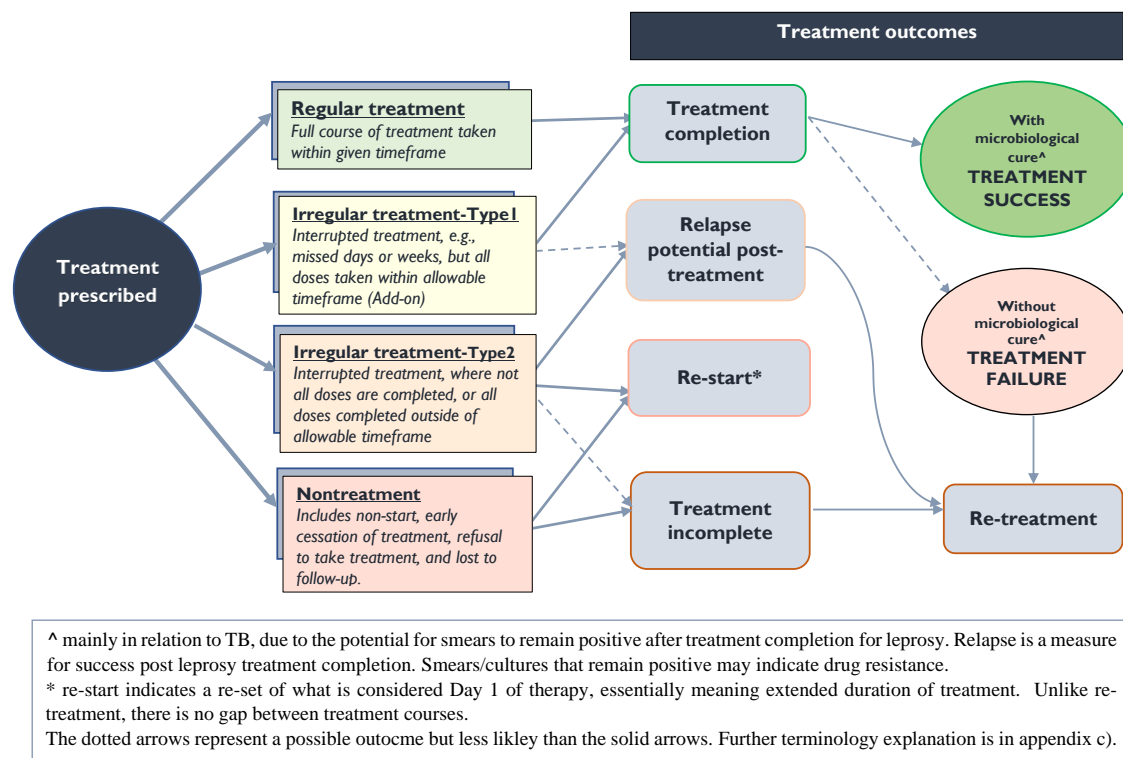
- Regular treatment: the full treatment course completed within the given timeframe with no additional time added on due to missed doses.

- Irregular treatment:⁹⁸ where therapy is interrupted due to non-adherence (as opposed to a result of experiencing adverse drug reaction). Two distinct patterns emerge with this treatment type:
 - Type 1: whereby a person has additional time added on to their treatment course due to missed doses but finishes within the allowable timeframe.
 - Type 2: whereby a person has additional time added onto their treatment course due to missed doses but does not complete therapy within the allowable timeframe, meaning a potential re-setting of the start date for the course of treatment (i.e., a re-start).
- Nontreatment: any situation where a person is not taking treatment after it has been prescribed. This includes not starting treatment, early self-cessation/discontinuation of treatment, lost to follow-up, or refusal of treatment (See [Appendix C](#) for a full explanation of terms used).

I have used the terms irregular treatment and nontreatment instead of adherence in the aim to be inclusive of influencing factors that are not just person-related (i.e., where the person has intentionally decided to not take treatment) but also system-related, (i.e., where a health system failure to support the continuity of treatment is seen). Each category has relatable consequences for treatment outcomes: treatment completion, relapse, re–start or re–treatment, or incomplete treatment, and the subsequent treatment success or failure represented in Figure 7.

⁹⁸ While intermittent therapy is used in some texts to describe missed doses (Stagg et al., 2020), I refrain from using this term so as not to confuse it with prescribed intermittent regimens such as prescribed three time a week dosing regimens that are *not* associated with missed doses.

Figure 7. Treatment regularity and related outcomes



Note. This diagram applies for active TB and leprosy and is adherence related, it does not apply to interruptions due to adverse drug reactions, although some similar principles apply in re-setting the duration of the treatment course..

Redescribing the adherence of treatment into these categories assists with three main aspects; the categories match the findings of the research of where perceived and reported taking of treatment was variable among people in terms of actual doses missed; the categories provide a more descriptive lens into a type of partial adherence, and the in-between of the adherence/non-adherence binary, which further assists the translation of optimal/sub-optimal therapy in relation to consequence; and the description used within the categories removes the position of automatic blame on the person affected, acknowledging shared responsibility and the possibility of system-related factors, i.e. factors that are outside of the control of the person, that may occur. This seeks to re-locate current descriptions within identified policy documents that state adherence is, “a concern for every person diagnosed with leprosy in the Kimberley” (Western Australian Country Health Service, 2018), or the view that, “in nearly all of those, [persons affected by leprosy] there’s been issues with adherence to therapy” [HCW12]. More so, this serves as a template to translate this improved correlation between how treatment is approached with therapeutic outcomes, such as the potential for acquired

drug resistance, ongoing transmission risk, and ultimately for a person's livelihood in achieving cure, preventing infection relapse, and preventing disability (Williams, 2005). In the remaining parts of this thesis, I refer to these patterns of adherence.

6.2.1.2 Establishing routines and adjusting to new treatment.

The adjustment to a person's life after diagnosis in accommodating treatment routines can be significant, even with smaller numbers of tablets. This was the case for Andy, who needed to adjust after starting isoniazid medication for latent TB (three tablets per day, for six months minimum), explaining, "it wasn't something I was used to as a person, taking tablets every-day" ['Andy', (P4, SG1-LTBI)]. Initial adjustment to treatment for both active TB and leprosy was significantly influenced by tablet burden. This was confirmed by several participants in their emphasis on the number of tablets,, "[I] came back and I had to take seven tablets [daily] for the whole year" ['Sam' (P3, SG1-L)], and "that first one [round of treatment] [...] I took nearly 20 tablets" ['Remy', (P1, SG-L)]. The change from not having to take any medication, to this new burden, in some cases impacted on starting treatment as intended:

Participant1: Because we had to get it all, the medication, from Broome. So in that first lot there was like big mob of tablets that they had to take, and then that was their thing, "too much tablet."

Participant3: Put them off.

[FG2, SG2]

Apart from tablet burden, adjustment to taking treatment with such temporal importance was also impacted by forgetting to take medications, i.e., un-intentional.. Remy had established the use of rosters and calendars to assist in remembering, "Yeh, sometimes it's really hard for me, sometimes I miss out, I forget, you know?" While automated reminders set up by health staff were identified to be beneficial, the remote setting, and people's access to mobile phones, both challenged this method of support:

We had one patient who wanted some sort of text reminders or a weekly phone-call from me at one point, for about a month, and then their phone stopped working. Then I'd ring it and the person who answered would say, "nonono, they haven't got this phone anymore."

[RAN1, SG3]

Forgetting to take medications was also attributable to the challenges of adjusting among other social and cultural priorities, as one Remote Area Nurse explained for some people:

It's just that remembering to take the medication every-day, and so many other social issues that interrupt that—whether it's because they've got young kids in the house and they have to put their Webster paks way out of reach, and because they're way out of reach they forget, because they're up on top of the fridge or wherever they are, and because they are so mobile and so busy managing their social issues—housing, food, whatever.

[RAN5, SG3]

The use of DAAs such as Webster Paks is acknowledged as a tool to assist in medication management such as memory assistance. As described in Chapter 5, their use was widespread and often without choice. While sometimes referred to as 'compliance aids', there is limited evidence to support this branding (Elliott, 2014). In a similar note, Revankar (1993) confirms that the wide spread use of the WHO blister pack for leprosy treatment became favourable *not* because of any superiority of evidence of adherence over loose tablets, but rather due to operational aspects of practicality and logistics.

The visiting Infectious Diseases Physician identified the role of the Case Manager as important in this period of initiation and adjustment to treatment, referred to as “case-holding.” This would be for the “first month or couple of months until you feel the patient has established a pattern of compliance” [Infectious Diseases Physician, SG3]. The articulation of case-holding however lent more towards increased surveillance and oversight for assessing what is still referred to as “compliance” in the state guidelines (Government of Western Australia, 2019(b)), rather than the holding of a supportive space for the person affected to establish these new routines. Another Health Care Worker described difficulties in establishing routines as sometimes caused by “chaotic lifestyles” [HCW12, SG3], in a similar line to what RAN5 described above as “social issues that interrupt,” such as “housing, food, [or] whatever.” While I do not intend to dismiss the observational links from some Health Care Workers in establishing routines concerning medication use, I do contend that in their observations there is potential for bias in what constitutes a socio-normative way of thinking about treatment, often constructed within biomedical narratives. For example, influences of cultural and family obligations, such as older women prioritising children or other family member's health, or customs around sorry business prior to funerals for loved ones who have passed, may be misunderstood if operating within a Western-based value system. In addition, social 'issues' or 'barriers' may be resultant of broader social determinants that are structural in nature, such as social inequity and economic hardship, and outside a person's control. These aspects may not be factored in as challenges by non-Aboriginal or economically

privileged Health Care Workers. The consequence of this positioning settles in the perception of a fixed pattern in a person's inability to "comply," versus learning how a person can be supported through this period of "case-holding" in a more person-centred, and culturally safe, manner. As well as the risk of reflecting blame and responsibility back onto the person affected, I contend that this positioning also risks case managers obfuscating any shared responsibility by their reluctance or feeling unable to assist. This in turn can result in misrecognised opportunities to re-think ways of support or problem-solve encountered barriers to treatment.

6.2.1.3 Duration and perseverance

Adjusting to a new routine of taking treatment was an important part of establishing and identifying a persons' approaches to taking treatment. However, it was identified in the research that the persistence through the long duration of treatment was a significant factor in influencing ongoing regularity of taking treatment, regardless of initial approaches. For instance, due to the requirement in WA to complete 24 months of treatment for more severe leprosy, one person affected by leprosy struggled with motivation to persist with treatment after a period of 12 months. For another person (also affected by leprosy), the first month of treatment was taken routinely but due to an adverse reaction (DHS), treatment was changed, and this person fell into a pattern of irregular treatment. Challenges in persevering until the treatment course end was particularly relevant even for isoniazid therapy for latent TB, as explained by the following participants:

Towards the end it was just [...] because I know it was over about three months or something, I had to take it, or so many months. It just seemed to go on forever and I think I just stopped taking it toward the end, because I forgot.

[‘Andy’ (P4-SG1, LTBI)]

There were three or four others that decided part way through [their treatment] that they didn't want to take their medications, not because of severe reactions, just because they decided they didn't want to take their treatment anymore.

[HCW10 -SG3]

Due to the long duration of treatment for both active and latent TB, *and* leprosy, there were increased influences and interruptions from the 'difficulties' of life—unexpected events, changes in relationships with LCMs, family, or personal business such as loss, changes in medications, travel, or re-location. An example of such a change that impacted a younger

female affected by leprosy was the desire to have children when treatment had not been deemed completed. This decision required a review of medications used to ensure that they would be safe in the event of pregnancy. Of note was the challenge associated with the position of difference of preferences between the doctors and this young person. From the perspectives of the HCWs, falling pregnant was discouraged until treatment had been completed, however having children was of significant social and cultural importance and a priority. Despite confirmations from health care staff regarding the safety of treatment in pregnancy, the decision to not take treatment persisted.

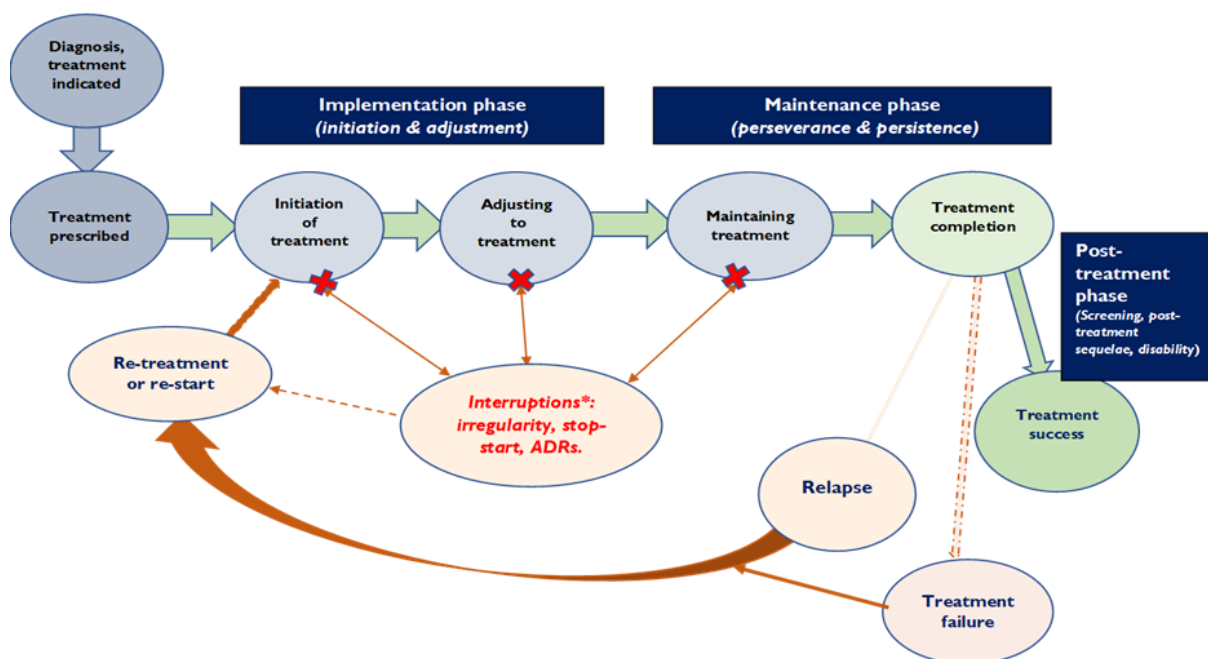
In bringing together these aspects of adjusting to and maintaining treatment, I put forward the second model of what I term an individual person's 'treatment journey' (Figure 6.2.2). This introduces phases of this journey that correspond with the periods of initiation, adjustment, and persistence of taking regular treatment, until completion. This model is specific for the findings of this research that identify the separate challenges of adjusting to and persisting with treatment regularly throughout the treatment course and can be applied to treatment for latent and active TB, and for leprosy. It also incorporates knowledge that identified from this research regarding the challenges of maintaining motivation to persist with treatment, for both persons-affected, and for Health Care Workers in provision of support. Regardless of established patterns of adherence after treatment initiation, irregular treatment or early discontinuation appeared to be more likely to occur in this maintenance phase.⁹⁹ There are no time frames assigned to each phase, due to the variation in treatment completion times for people identified from this research. However, in relation to TB, these phases of 'implementation' and 'maintenance' may correlate with the 'intensive' and 'continuation' phases outlined for active TB treatment. I also include within this model a 'post-treatment phase.' While not always related to taking treatment, this phase has its importance for TB and leprosy treatment due to the monitoring required post-treatment for relapse or reactivation of infection¹⁰⁰ (Government of Western Australia, 2019(a), 2019(b)), post-treatment health complications related to either condition (such as lepra reactions), and

⁹⁹ This waning of regularly taking treatment was demonstrated by Stagg et al. (2020), in their analysis of TB treatment. This phenomenon was represented as "sub-optimal dosing implementation" which increased from month one to month six of the treatment course and worsened in the "continuation" phase of treatment.

¹⁰⁰ For leprosy, follow-up post treatment completion is dependent upon initial treatment. For patients who received WHO MDT, follow-up is recommended annually up to 5 years for more severe cases. For those who did not receive WHO MDT, follow-up can be up to a minimum of 30 years for more severe cases (Government of Western Australia, 2019(b), p. 57). For TB, follow-up is recommended at 2-3 months later and if there has been concerns regarding adherence or a non-standard regimen was used, timeframes determined by the treating physician (Government of Western Australia, 2019(a), p. 33).

disability support. In linking the post-treatment phase with findings from medication knowledge discussed in Chapter 5, this phase serves as an important phase for the provision of feedback in treatment success, especially for latent TB. The following diagram displays the treatment journey, for any person with latent or active infection of TB and active leprosy infection (although consequences such as relapse and the post-treatment phase are not applicable to latent TB treatment).

Figure 8. The treatment journey.



Note. for Figure 8. *The red crosses indicate when a person is interrupted in initiating, adjusting, or maintaining treatment due to decisions to stop medications including adverse drug reactions. Interruptions result in a person starting back at the same point in the timeline, starting back at the same point but with extended duration due to missed time, or needing to re-start from the beginning of the timeline again. Any immunological reactions, such as lepra reaction, and adjunctive therapy indicated, are part of this journey and hence the post-treatment phase still involves monitoring and potential treatment. Treatment duration is a minimum of six months for both TB and leprosy, and could be longer depending on severity, interruptions, and drug resistance

This diagram assists visualising the endurance required for treatment. In considering persistence, attention to the maintenance phase of treatment is also critical in recognising any risk or event of early self-cessation of treatment by the person, putting them at greater risk of experiencing a relapse of infection.

6.2.2 “People don’t want to be sick”: Logic in approaches to taking treatment.

6.2.2.1 Evidence of effectiveness

Findings from this research identified the influence that the perceived effectiveness of treatment has on individual approaches to taking treatment, similar to international studies discussed in the literature review (see Chapter 2.. The first example relates to taking treatment for lepra reaction, where high-dose prednisolone is prescribed over a period of months in a weaning dose regimen adjunctively to antibiotic treatment. For Remy, at one point, there was no demonstrable evidence for the effectiveness from prednisolone, or any other leprosy treatment being taken:

I told this doctor here that’s looking after me, “every medication you been changing, it doesn’t work. It’s not working.” Every time you see them, or they check on me you know, um, if there’s any changes [...] there’s only one change and he’s [the leprosy] still there. It never changes.

[‘Remy,’ (P1, SG1-L)]

The changing of medications in effort to manage the reaction created confusion and fertile ground for mistrust. Trust in the effectiveness of medicines was not always related to the visual observation or the physical response of proof of effectiveness. Trust for one participant equated to having hope of effectiveness, and the attitude to persist through treatment where there was no immediate evidence of benefit:

Interviewer: And at the time did you think “oh maybe the medicine’s not working, or something else is going on”?

Sam: Ah look, I just took the medicine and I hope, I hope this works, you know. I just had to keep taking it and hope it works. Yeh, and in the end if it doesn’t well it doesn’t and if it does well it does. And yeh, a couple of years later I find it did work... because I don’t get any more crampness. I still get a little bit of that numbness, but before my hand, three of these [fingers] would cramp up and go funny, but after a-while, nothing.

[‘Sam,’ (P3-SG1, L)]

Another example specific to lepra reaction is that of a more immediate response to prednisolone demonstrating evidence of effectiveness, but also being perceived that it had worked and was no longer needed. Due to the initial high prednisolone doses used for lepra reaction, a slow weaning of steroids (to avoid any adverse reaction or recurrence of lepra reaction) is required. The visiting Infectious Diseases Physician [SG3] reported from their observations that “adhering to the prednisolone is often hard,” and that people will often “take that initial dose and feel fine, and they’ll stop.”

Persisting through treatment when there was no evidence of physical illness in the first place was also relevant to latent TB, where there were no signs of being unwell. As described in [5.2.2.4](#), several people gave up before the course was due to be finished. What was also identified from the research was the influence of family and oral histories in contributing to this evidence of effectiveness. For example, witnessing other family members and how they approach treatment for the same condition was identified by one Aboriginal Health Worker [P10-FG3] in influencing this observational evidence over time. Another Aboriginal Health Worker explained, similar to what was identified within the theme of pharmaceutical histories discussed in Chapter 5, was a trust or mistrust in evidence related to “fake medicine”. For example, “back in the day” in relation to the injections for leprosy, people remember, “not seeing any evidence of anything working or helping, and causing other things, or things getting worse” [P1, FG-2, SG2]. This again draws in the trust and confidence in the actual effectiveness of medicines used where *no* evidence is obvious of their benefit.

Decision-making related to evidence of effectiveness can be summarised to manifest in five distinct patterns: a) no evidence of treatment working, causing confusion and mistrust in the treatment contributing to irregular treatment; b) no evidence of treatment working but persisting through in hope that it would work; c) evidence of response to treatment leading to a belief that treatment is no longer required hence early discontinuation; d) a lack of evidence for need of treatment in the first place due to not feeling unwell; and e) observational evidence or historical evidence of treatment (in) effectiveness. Evidence of effectiveness is a logic that influences the taking of treatment and has been previously recognised to be a key point of difference between lay and professional people in the evaluation of therapeutic effect and therapeutic goals (Kleinman, 1978, p. 87). Evidence of effectiveness therefore is a primary theme that informs treatment approaches and identifies gaps in communication that can be addressed through recognition of these five patterns.

6.2.2.2 “In denial”

The second influence on logic identified centred on belief /disbelief. This was found to have two significant connected themes of fear and denial, revealed in the following focus group discussion when discussing challenges with taking treatment:

Participant3: Some of them do get scared of taking so much, that’s from my experience.

Participant1: And then don’t want to acknowledge that they got this problem, too,

Participant3: In denial

Participant1: Yeh some fulla are like “yeh I’m alright” like it’s—

Participant3: A lot of our Countrymen are in denial, even now.

Interviewer: So, by not taking the medicine that means that they don’t have a problem kind of thing?

Participant3: Nah, nah, it’s like they’re in denial, medications like for example if for another chronic illness, someone will be taking so much diabetic, plus they might have a heart condition, to them that’s too much. And for some reason they will hand pick out what medication make them feel no good.

Interviewer: And they’ll put it aside?

Participant3: They’ll put it aside. That’s where, when they come in, I think—well we’re all aware of it, like [Participant2] said, non-compliant with their medications. When we sit down with them and the doctor, we liaise and translate for them, because some of them, they won’t take it. And they’ll come, and once they realise, they’ve registered, they think “oh well, I can live without that medication.” I think it’s the fact that some of them are too afraid to be, you know, to know what the diagnosis is.

[FG2, SG2]

Fear in this situation went beyond concerns around medication safety to a deeper fear, or denial, to accept that something was wrong. This, as suggested above, was accompanied by a belief that treatment is not needed. Another participant, Sam also talked about this in our interview:

Because I know there’s a lot of people who refuse to take them [medications], they’re like “I’m not really sick, there’s nothing wrong with me so I’m not going to take it,” you know. And you’d have some people who had that attitude like I had— “I need to take this, I am sick, there’s something really wrong with me and I need to.”

[‘Sam’ (P3, SG1-L)]

Underpinning this denial, not just of disease, but of the logic “I can live without that medication,” or “there’s nothing wrong with me,” is an intentional and rational decision-making process informed by the context of each individual circumstance, cultural values and beliefs about illness and wellbeing. These values and beliefs may override any evidence of a Western biomedical diagnosis that diagnostic tests or biomedical doctor’s advice provided to affirm the need of treatment. To simply pin decisions to not take treatment on cultural “barriers”, or “factors” (as suggested in the state leprosy guidelines, (Government of Western Australia, 2019(b), p. 62)), misses the opportunity to understand other potential confounding factors. As raised in one of the focus groups, a consideration of a deeper underlying state of wellbeing that drives decision-making was important:

Participant3: But did we look beyond them, you know beyond the reason of why they're not taking their medication? Because I know for a fact a lot of them just wanna give up, you know, they don't care.

Participant1: But that's the problem they don't give a damn about themselves fully, [...]

Participant3: Well, that's what I'm trying to say—it affects them, mentally you know, like not this one but mentally.

[FG2, SG2]

The consideration of mental health and wellbeing for a person in relation to approaches to taking treatment is significant, and the impact of TB and leprosy treatment on this wellbeing is discussed further in Chapter 7.

6.2.2.3 Silent disagreement

The third and last influence identified for the logic of taking treatment correlates to the position of intentional decision-making by the person affected, as discussed above, but with more focus on value incongruence. There was recognition from one Remote Area Nurse who has long-term experience in the Kimberley, of the impact of this incongruence:

Since primary health care has come, people can access and they're coming and actually telling you, "My tablets are wrong, I've got too many tablets." That never happened before. So I think that's changed in how people access care, but I still think people are being led, like you need to take this. So they will either take it and not be very happy about it, or they just won't take it at all and then you won't see them again. There doesn't seem to be any in-between.

[RAN2, SG3]

I refer to this as 'silent disagreement.' I use 'silent' in the way that there has been no conversation about the decision, no space made for dialogue to address value incongruence, beliefs, and risk versus benefits, and 'disagreement' as in it is an intentional decision-making process. The consequences of this are not only for individual treatment outcomes, but also impact on future Health Care Worker relationships, especially in the latter example where a person chooses to disengage from or avoid these relationships altogether. In this way, silent disagreement about not taking treatment is an independent decision-making process, rather than one that is shared. It links in with the theme of relationship and lack of effective communication (i.e., being told what to do) and demonstrates a relationality of treatment decision-making. Such relationality was articulated to me by Remy [P1, SG1-L], "Because if they don't listen to me well there's no use taking it." That is, Remy's decision-making was bound up with the need to be heard by the health care team, which was not happening. One of

the Regional Physicians, with long-term experience in the region, provided their perspective in recognition of the importance of this relationality:

I think it's about getting them to trust and make them feel that they're part of the decision-making process as well, that we're not pushing treatment on them [...] and not explaining why they need it, what it's for, what the side effects are, how it might make them feel, what the whole point of [treatment] is.

[Regional Physician2, SG3]

The importance of allowing people to be part of the decision-making process, rather than making decisions for people, was explained by one of the Aboriginal Health workers, "and the fact is that we don't have...we can't really make any decision for them. We can only educate them" [FG2, SG2]. In a similar sentiment, participants in Focus Group 1 also suggested that clinic staff should not be the people making decisions for persons affected, but rather people in the community who are impacted, in relation to a number of community members who had to undergo treatment for latent TB:

Interviewer: Do you think there's a place for that with decision making, how important do you think that decision making is with people?

Participant1: Well, I think it's pretty important. In regards to just starting the program and doing the treatment I think you need to sit down in that group and get ideas of how they, not the clinical staff, but ask the people who take it how they think it might work or how they might have better ideas have than clinic staff.

[FG1, SG2]

Active participation in decision-making and providing information to assist in decision-making even for latent TB treatment, is a key component of person-centred care and cultural safety, especially in this case where the importance of dialogue extends to the community as a whole, not just individuals. Currently there are no decision aids to assist Aboriginal people in understanding the risks versus benefits of latent TB treatment nor is there culturally tailored information available to assist treatment decision-making. Unlike active TB, treatment initiation for latent TB has the benefit of not being dependent on early treatment intervention. Therefore, time can be spent discussing treatment with people and what it means. This is especially relevant from a cultural safety model as well, where historically and even in modernity, Aboriginal people have been excluded from decision-making in their own care.

6.2.3 Summary of approaches to taking treatment.

In this section I reported on research findings of individual approaches to taking treatment that form a significant part of the treatment model of care for Aboriginal persons affected by TB or leprosy. The variability of influence on a person's approach to treatment reflects on the deeper complexity and dynamic that extends beyond current binary description and understanding of taking treatment, to one that incorporates a spectrum of possibilities both within and beyond a person's control. To assist in the description and articulation of this complexity, I have introduced a model for revised terminology of the regularity of treatment. This links directly to an explanation for the associated consequences of treatment decisions related to an individual's approach to treatment and shifts away from standard terminology that has the potential to label people unfairly such as 'non-compliant' or 'defaulter.' I have introduced a second model that outlines a person's treatment journey with identified phases of treatment. This model also incorporates the challenges around motivation during prolonged periods of treatment and considers the post-treatment phase of monitoring as part of this journey.

There is missing information in assisting people with treatment in knowing how to achieve optimal therapy and understanding consequences of skipping doses that presents a gap to be addressed. This is addressed for prescribers in terms of clinical guidance for treatment duration within guidelines (such as percentage complete or allowable timeframe) but is less well addressed for persons affected by TB or leprosy to assist their own individual or shared decision-making. The modelling presented in this section may provide the foundation for addressing the theme from Chapter 5 of communicating the importance and consequences of treatment and providing feedback about the treatment process. This would allow for a shift to a more person-centred, and culturally safe, approach for persons affected by TB or leprosy in dialogues about treatment adherence.

6.3 Monitoring, and responding to, (non) treatment.

6.3.1 Recognising treatment approaches in practice.

6.3.1.1 Monitoring of people and treatment approaches

Maybe if you don't want to take it, well that's you. You just skip a day, but that's you. If it's too much for you then that's you, you know?... They can't force you.

[‘Remy,’ (P1-SG1, L)]

In the protection of public health, and unlike treatment for chronic non-communicable infectious diseases, treatment adherence for active TB and leprosy is required to be monitored to ensure a person becomes and remains ‘non-infectious. Any interruption to this regularity requires a response. As discussed in 6.2., interruptions to treatment from either adverse drug reactions or irregularity in taking treatment can be a set-back in progress due to the addition of extra time added to the treatment course duration. Interruption to treatment from early discontinuation such as a complete refusal of treatment, however, is further complicated by this responsibility to prevent infection transmission to the public.

Monitoring treatment is a task that encroaches to varying degrees on a person’s privacy, livelihood, and trust. It was the responsibility of the LCM to document this monitoring in the form of the weekly compliance reporting and report back to the Regional TB and leprosy coordinator, who would then report back to the WATBCP case manager and provide oversight on what was happening for each person. Types of monitoring identified within this research were observational and relational. The former depended upon counting pills for example by checking returned DAAs, reviewing dispensing histories, or the use of DOT and the associated documentation. The latter was based on discussion and disclosure from the person affected about their actions. Physical monitoring, such as in collecting urine samples or drug serum assays, was not used. One Remote Area Nurse explains about pill counting in practice, “we take back what’s not been taken so we have a record, because we add that on to the length of their treatment” [RAN5, SG3]. Collating dispensing histories was challenging due to the multiple health systems used, as the Infectious Diseases Physician [SG3] explained, “The different information record systems make it very difficult for people to know, to track their adherence with medication. Just on a very practical level [...] it’s harder to see what medications have been dispensed and what has been supplied.” In addition, the use of DOT did not always equate to an actual observation of treatment. One Remote Area Nurse described their experience as a DOT provider where medications handed out to the person to take themselves due to an unwillingness to be observed taking treatment. They found out later that the medications hadn’t been taken, “I just heard recently that they hadn’t taken any of that at all, they were all sitting at home” [RAN3, SG3]. This was confirmed by another Remote Area Nurse, for the same person affected, at a different time, “We had been giving them the medication for a while and they hadn’t been taking it, and we didn’t realise at the time, and yeh I guess now they’re just not willing to take it” [RAN1, SG3].

While monitoring of treatment may provide a sense of confidence in knowing what is occurring, I argue that this was often a false confidence, as accurate information about what was *actually* happening from the combination of monitoring strategies used was difficult to obtain. The example of the recipient of DOT not wanting to be observed also raises two points about the consequences of overt monitoring. The first is that the requirement for monitoring contributed to a disengagement between the RAN and person affected. This highlights tensions between the requirement of monitoring perceived as a paternal measure—especially with no initial agreement by the person to be supervised—and the Health Care Worker not knowing how to, or not wanting to intrude any further into a person’s life to do this monitoring. The second point is that a lack of knowing what was happening through monitoring resulted in a loss of duty to recognise nontreatment, and in turn did not assist the person in optimising outcomes from treatment. This could be seen as a neglect to fulfil the responsibility of monitoring (Bernard. Vrijens et al., 2012, p. 691).¹⁰¹

6.3.1.2 Recognition or judgement? Assumptions about treatment approaches

In the current system, adherence is still considered to be an obvious and binary descriptor, a point which disavows the complexity of approaches to taking treatment. What is often less considered in recognising treatment approaches is the subjective nature of who is in the position of recognising. Pre-formed biases about a person can interfere with monitoring and response through (mis)recognition. I discussed this type of explicit bias in Chapter 4, where decision making from medical doctors such as Dr. Cook in positions of power is inseparable from their own opinions and judgements about Aboriginal peoples. While we may have moved on from this era, the potential for more subtle colonising forces to continue to influence the way Aboriginal people are perceived through implicit or unconscious biases still exist, such as the continuing (ir)responsibility narrative argued in Chapter 4 in relation to treatment adherence and the need for supervision of therapy. One non-Aboriginal Health Care Worker expressed their frustration regarding the response of their colleague’s recognition in this very way, for a person affected by leprosy:

Please don’t make assumptions about this patient that they won’t comply with treatment, that they won’t do this, and they won’t do that. They have, and they will. You’re either just not communicating with them effectively or you’ve made a judgement about this person, and you’ve put them offside, but please don’t pinpoint this on “oh this is just a difficult non-compliant patient.”

¹⁰¹ This latter aspect has been reported by others for TB. Mahmoudi and Iseman (1993) in their study on Multi-Drug Resistant TB identified that the most common error in evaluating care of persons affected was a “failure to identify and address noncompliance”, (p.65).

In this situation, HCW10 had an established professional relationship with the person affected, whereas their colleagues did not. This also demonstrates how uncontested staff attitudes and judgement have the potential to lead unfavourably and unfairly to future recognition. Another point of this potential for future (mis)recognition is through the required documentation of treatment monitoring and response, where (mis)recognition of a person's approaches to treatment becomes cemented through compliance reporting and passed through clinical handovers. In this way, I maintain that a medicalisation of adherence can result in ways that leads to fixed and deterministic integration into a person's medical history rendering a person as either 'compliant' or 'non-compliant' without question, and as a fixed truth.

An example of this future recognition related to clinical decision-making regarding the choice of treatment for severe Type 2 lepra reaction, experienced by one person affected by leprosy. In this scenario, a decision to use prednisolone over thalidomide for the management Erythematous Nodosum Leprosum, or ENL, was made “on the basis of issues with adherence that have been demonstrated with other medications, from that individual person” [HCW4, SG3]¹⁰². Walker (2019, pp. 10,11) maintains that treatment decision making for ENL needs to be individualised, weighing up the risks and benefits of prescribing thalidomide due to its safety risks,¹⁰³ as well as providing information about its management. The justification for the decision to not use thalidomide in this situation without the person affected was not just on pre-determined patterns of taking treatment, but also due to perceived ongoing risks, “a lot of drinking, very out of control household you just wouldn't even let someone store thalidomide in a house like that” [HCW4, SG3]. Apart from judgements on social norms and “chaotic lifestyles” already discussed in 6.2, the exclusion of involving people in their own care is not commensurate with a person-centred or culturally considered approach. Shared treatment decision-making is especially critical for Aboriginal people where TB and leprosy treatment history has been dominated by decisions being made *for* people, not *with* them. In this situation, excluding individuals from their own care does not fit with providing transparency regarding medication safety and “having the

¹⁰² Erythema nodosum leprosum (ENL) is a type 2 severe and painful inflammatory lepra reaction in borderline lepromatous (BL) leprosy and lepromatous leprosy (LL) (Walker et al., 2017).

¹⁰³ The other treatment option, prednisolone, also comes with side effects and safety risks. For both safety on thalidomide and prednisolone, see [Appendix J](#)

conversation” about safety. Each person has a right to be involved in their own care and be offered optimal treatment. If provided with all the information and the risk/benefit of treatment it is possible that this person may have also come to the same conclusion and opted for steroids over thalidomide. Professional opinions on perceptions of nonadherence should not be the basis for future opting out of shared treatment decision making.

6.3.2 Responding to irregular or nontreatment.

6.3.2.1 Responding by increasing surveillance.

The increased programmatic support from the WA TB control program (WATBCP) from 2013 for the Kimberley, which eventually led to the Memorandum of Agreement between the WATBCP and WACHS (2017, April), resulted in an increase in surveillance for Aboriginal people affected by both TB and leprosy in the Kimberley. The requirement of monthly compliance reporting was switched to weekly for the Kimberley (as outlined in Chapter 5), and direct observation of treatment for monthly doses of leprosy treatment was more routinely implemented in combination with weekly compliance checks. Surveillance of treatment for leprosy had not been overseen since active specialist services had wound down in 2002. The weekly compliance reports contrasted with Perth, where only monthly reports were needed, with one Health Care Worker commenting that they thought it was perhaps too much: “Potentially the patient gets a bit overloaded, it’s too much for a lot of the community nurses, but that was what was specified” [HCW4, SG3], and had thought perhaps this decision, “was something that was decided more at an executive level.” Although not mandated for TB, the use of TB-DOT was identified to be used in at least three out of four people affected by TB. For one person this occurred after it was identified this person was not adhering to treatment in when settling in back into community after returning from treatment initiation in a Perth hospital. DOT was soon introduced as a response to this on an intermittent regimen of three times a week, direct observation being provided by a local Aboriginal Health Worker. As well as active TB, the use of DOT for persons affected by latent TB, was also planned to be a part of treatment implementation for the community in the community-wide TB screen for adults and children receiving treatment. Although this had worked well for the children due to the initiatives of one local Aboriginal Health Worker, DOT was never organised for the adults. One participant explained how there was not a lot of understanding “what the DOT treatment was,” and, as a result of this and people “starting to say they didn’t want to have treatment,” it was never organised [P1-FG1, SG2].

The use of routine DOT to improve programmatic oversight and control over treatment adherence for both TB and leprosy was in line with what had previously occurred in the Northern Territory and Northern Queensland, for active and latent TB treatment, as discussed in chapters 2 and 4. It could be interpreted that, despite continuing international debate over best practice, the application of more universal DOT has gained traction within Australia as a solution to gain some degree of control and reliability over ensuring the regularity of treatment for First Nations peoples within TB and leprosy care. Supervision as a solution to oversee treatment adherence was also not limited to anti-infective therapy, spilling over to the use of prednisolone as well. The Infectious Diseases Physician had disclosed some degree of hesitancy in wanting to prescribe prednisolone for lepra reaction, “when it’s not really supervised,” due to people stopping it abruptly rather than weaning the dose when the symptoms of the reaction disappeared: “We’ve had several situations where they’re on steroids, then off, and then come back with more neuritis and then they’re gone” [Infectious Diseases Physician, SG3]. However, this also points to the need to provide more medication information and illustrates the importance of communicating the consequences of not taking treatment. The important take away here is the reliance upon supervision of treatment to gain some more control over the taking of treatment, over and above working to improve understanding of and communication about treatment with individual people, their families or even at a community level. Even if deemed necessary as part of an overall programmatic response, in this case especially in relation to leprosy management, given the lack of programmatic structure that was perceived to be apparent. Punitive and paternal responses to treatment are a step in the opposite direction away from culturally responsive and person-centred care. This type of practice also demonstrates a stagnancy in any evolution of care practice from compliance to adherence and provides messages of mistrust in people.

6.3.2.2 Using incentives.

Incentives were offered to individuals to encourage the improved uptake of treatment in situations of irregularity or nontreatment, mainly evidence from those affected by leprosy. Food was the most common incentive, while in other situations, fuel vouchers were offered. However, they were not found to be sustainable, as one of the Remote Area Nurses explained:

We’ve just found that those interventions will work for a little while, and then one or other in the partnership, whether it’s the nurse or the patient, just seem to just drift away from that. We’ve found that it’s not been sustainable.

[RAN1, SG3]

This once again raises the issues of persistence, motivation, and sustainability. Having the stamina to persist with incentives was difficult for either the person affected or Health Care Worker. The type of incentive and way incentives are offered also matter. In relating the use of incentives to Multi-Drug Resistant TB (MDRTB) for example, the WHO suggests prioritising incentives that “[deliver] enablers to address barriers that would otherwise be insurmountable for patients” (World Health Organization, 2014, p. 178). Providing a sandwich or a choc-milk,¹⁰⁴ while it may assist a person who has barriers for regular food provision, is unlikely to overcome other insurmountable structural issues that contribute to financial stress for a person. This choice of incentives and their appropriateness has not been something that has been evaluated within the Kimberley setting—both for what is appropriate and what is perceived to be of benefit for the person affected, that will provide a notion of reciprocity. One of the Aboriginal Health Workers commented about incentives, suggesting it could be done, but what would be of perceived benefit needs to be voiced by the person affected: “We can’t just say well I’ll get you \$150.00 worth of feed from la butchers’ shop, yeh. It’s gotta come from them mob” [FG-2-SG2]. There is a clear need to review the use of incentives in ways that are sustainable, effective, ethical, and are truly enabling within the specific cultural and individual context.

6.3.2.3 Offering alternate treatment regimens.

Due to the use of standard first line treatment for both TB and leprosy, alternate treatment regimens are usually only implemented when there is intolerance or resistance to first line treatment. However, in the Kimberley for three Aboriginal people affected by leprosy, alternate treatment regimens were offered as a strategy to address irregular adherence. The use of a once a month ‘pulse’ dose of a combination of three antibiotics Rifampicin, Ofloxacin and Minocycline (ROM) given once monthly under direct observation is described in the Western Australian leprosy Guidelines (Government of Western Australia, 2019(b), to be an option for “persistent defaulters with PB [paucibacillary leprosy] or in rare situations with MB [multibacillary] leprosy” (p. 63). All three people offered ROM had multibacillary leprosy. Although there is some early indication that the use of ROM for multibacillary leprosy had similar clinical outcomes to that for MDT (Lockwood & Cunha, 2012), outcomes for longer term success such as relapse and disability prevention are less

¹⁰⁴ Example of food incentives used, as was described to me, and often paid for out of pocket by health care staff.

well studied and is not considered “curative” (Setia, Shinde, Jerajani, & Boivin, 2011). As such, at the time of this review, remained only an accepted option for standard therapy for paucibacillary leprosy as per the WHO guidelines on. The Northern Territory guidelines also do not recommend it for MB leprosy due to the unknown outcomes. As a treatment regimen to address adherence, the stakes for ROM also become higher—missing one dose may mean missing 2 months, unless a person can be followed up with shortly afterwards.

In posing the question of how much does using ROM set back someone in terms of recovery, the response was that “we don’t really know” [Infectious Diseases Physician, SG3]. In asking about the duration of therapy of ROM for one person affected, they further explained:

I don’t know when we’re going to stop the ROM, potentially never. This person is quite happy on the ROM, and [the] thing is when do you stop? I don’t know, I mean we have a timeframe but if someone’s been non-adherent for many years and then we put them on a regimen that we don’t really know how it works, when do you think you can stop?’¹⁰⁵

[Infectious Diseases Physician, SG3]

While ROM may prove to be a valid treatment for MB leprosy, questions remain about its effectiveness, the required duration, and the longer-term implications for relapse and disability prevention. It is in offering such regimens that shared decision making is essential in ensuring that people are informed of the evidence, what the consequences may be, and whether they consent to the use of the regimen, including plans for clinical monitoring. The use of ROM without transparency concerning the lack of supportive clinical evidence relates to the issue of medication experimentation. Due to the potential for an ongoing sensitivity of the experience, feeling, or memory of being experimented upon with pharmaceutical treatment, building trust is critical to overcoming any current or future suspicion. Not ensuring adequate shared decision-making processes at the start risks a breakdown of trust with those affected and can contribute to a lack of shared understanding regarding ongoing monitoring for relapse post-treatment. If, for example, a person affected by MB leprosy who had been prescribed ROM and was considered ‘cured’ suffered a relapse of infection 10 years later, in turn causing an undetected transmission event to a younger person, the consequences become significant not just for the person-affected but also for their family and community.

¹⁰⁵ Towards the end of this project, it was learnt that after two years of ROM therapy, this person had returned negative smears and treatment was stopped, after a total cumulative treatment journey of 10 years from diagnosis.

6.3.2.4 Escalating to the use of the Public Health Order

What do you do? Hold them down and pour it down their throat? (laughs)

[RAN5-SG3]

The above quote from a local Aboriginal Registered Nurse was in response to a question about people refusing treatment. It highlights the issues of instituting authoritative powers in mandatory treatment compliance and restricting a person's liberty for the justification of reducing harm to the public¹⁰⁶, that creates ethical tensions for Health Care Workers required to monitor adherence (Porter & Ogden, 1997, p. 121). It also highlights the reality of the pragmatics of enforcing oral treatment, especially given a history of forced treatment associated with leprosy. In WA, a Public Health Order still exists for enforcing treatment detention for TB and leprosy¹⁰⁷. These days, use of this powerful legal intervention is considered the "last resort" and "all reasonable attempts" should be made to engage the person prior to considering legal action, including exhausting "all socially and culturally appropriate avenues to assist with adherence" (Government of Western Australia, 2019(a), p. 99; 2019(b)). During the course of this research there was no culturally responsible guide identified to ensure "everything," or "all reasonable attempts," were made, nor is there available evidence which thoroughly evaluates and provides consensus on what "all socially and culturally appropriate avenues" entails for Aboriginal people in WA. Inattention to this matter meant that Aboriginal Health staff were often called on to be involved in providing cultural advice, even when they may not have had the 'cultural rights' to speak to or for that person (as explained to me by one of the advisory group members). One Aboriginal Health

¹⁰⁶ Premised on the English philosopher John Stuart Mills 'harm principle', where restrictions on personal liberty are conceivable in order to prevent harm to the broader public (Brink, 2018; Srivastava, 2007). Harm, according to Mills, is an action that is injurious or sets back important interests of particular people, interests in which they have rights (Brink, 2018))

¹⁰⁷ The Public Health Act of 1911, although it had several amendments, was not repealed until 2016, when the new act was published. In this new act, both TB and leprosy have been removed from their special status outlined in the 1911 Act and are now listed under notifiable infectious diseases by the Department of Health and the associated legislation for notifiable infectious diseases. Within this legislation, the detainment of a person affected by TB or leprosy who refuses treatment is still a legal option. According to this act, a public health order can require a person who is in contravention of the legislation to "submit to specified supervision; to specified medical treatment at a specified time and place; to being detained at a specified place for the purpose of undergoing medical treatment; and that force may be used to enforce this order." (Government of Western Australia, 2016, pp. 64,65). This "enforcement" by law allows a police officer to use reasonable force to "apprehend and detain the person" to take to the specified place of detention for medical treatment, including restraint if necessary and the removal of clothes for medical examination.

Worker described their experience in coming into a situation and being asked to provide DOT to a person affected by leprosy who had not been taking their treatment:

Interviewer: How easy is [it] to get in there, half-way through and try and work with somebody who's not taking medicine?

Participant1: It's hard.

Participant5: It is hard because I've tried and tried and I'm not getting anywhere.

[FG2, SG2]

This seeking to rely on Aboriginal Health Workers not only put them in challenging situations but also potentially fails to recognise (or misrecognise) what is a cultural influence on nontreatment, or what is a personal influence such as psychological wellbeing or experience of stigma.

The WA leprosy Guidelines (Government of Western Australia, 2019(b)) specifically highlight the need for a timeline for “tolerance of incomplete adherence and measures to be taken if this threshold is reached.” Most Health Care Workers I spoke with voiced their discomfort in having to go this far with the law. One HCW commenting that, “it would have to be the very last resort,” acknowledging that “most people don't want to infect their family members, and particularly children” [HCW10, SG3]. One of the Regional Physicians expressed concerns about how applying a treatment order would even be carried out, even if the legal authority existed:

I'd have trouble seeing how that was going to manifest. Are we going to detain this person? Take them into custody? For years? Are we going to force them to have oral medication that can't be given IV? The answer to all of those things is no—that would be unreasonable, it would be seen as unreasonable in the context of a stigmatised disease where part of the issue, that is that people have been taken away. I don't personally support that as an option.

[Regional Physician1, SG3]

Despite this I was made aware of one scenario for a person affected by leprosy refusing to take treatment, whom legal advice was sought in regard to the Public Health Order.

According to participants, the treating team had “tried everything.” This included incentives, involving Aboriginal Health Workers, having a family meeting, discussions with this person focussing on “risk to others including grandchildren” (Regional Physician1, SG3). This person was still in disagreement and a stalemate was reached, prompting the seeking of legal advice, to understand “where our responsibility sits with the Public Health Act” [HCW4, SG3]. The legal advice instead lent towards a cultural safety responsibility to the person

affected—the use of a treatment order, or any investigation order, was advised by Health Department lawyers that it “wouldn’t be culturally appropriate”¹⁰⁸ [HCW4, SG3], demonstrating tensions between current public health legislation for nontreatment and the position of Health Care Workers in providing culturally appropriate care. The role of incarceration and imprisonment, public health law and criminalisation and punitive responses have been entrenched into Aboriginal people’s lives since colonisation and especially so in leprosy management (Duncan, 1996; Jebb, 2002; and Rumley & Toussaint, 1990). The risk of re-traumatisation from ongoing punitive responses to taking treatment for infectious disease is real. It is these underlying, and often unknown, histories with police and the law that should inform and re-frame any decision-making with respect to the use of punitive action in the refusal of treatment and subsequent harm which can be enacted. It also raises issues of not addressing the real work of relations that are required to avoid any need for escalation in the first place, as acknowledged by one Regional Physician, “and it might be tempting to look for legal shortcuts, but we don’t have an easy option—we have to do the hard yards over time in helping people understand the disease” [Regional Physician1, SG3].

The importance of this story was not just in the recommendation against pursuing legal action and recognition in the physician’s persistence and commitment. There was also success in re-engagement with this person and their agreement to go back on treatment, after visitation from a new and different Health Care Worker at a later time. This re-engagement was achieved through culturally respectful communication—empathy, explanation of medication side effects, and a negotiation on the place of DOT accompanied with a known Aboriginal Health Care Worker to oversee it. Ironically, after going through the process of escalation, it was revealed by another Health Care Worker, that this new success was “somewhat indicative of what hadn’t happened,” [HCW12, SG3] reinforcing the importance of communication and relationship from the start and throughout a person’s treatment journey. This example also highlights the absence of socio-culturally informed pathways for treatment programs that, if available, may offer a number of steps to take before any escalation in response is considered necessary—pathways that would also reduce such ethical tensions created for Health Care Workers as a result of this legislation.

¹⁰⁸ A copy of the written legal advice provided to assist understanding the context of the advice was unable to be obtained.

6.3.3 Summary for monitoring, and responding to, (non) treatment.

I have illustrated in this section the inherent challenges in the treatment of active TB and leprosy due to the risk of untreated infection being passed on to family and community members. There is an associated complexity that accompanies public health requirements of monitoring and responding to treatment that impacts relations with Aboriginal persons affected, and how critical it is to consider the cultural safety of people within this space to avoid gaps in care or the (further) souring of relations. Navigating this complexity also means considering the most appropriate ways to respond to situations of treatment refusal. Gaps exist within the current treatment model that allow ongoing colonising through recognising and responding to irregular or nontreatment in ways that can still be paternal or punitive via the imposition of western values and assumptions about Aboriginal people. The escalation of response starts at the point of recognition and who is doing the recognising. This point, I insist, is the intervening juncture that ensures cultural safety, especially where implicit bias may exist. At present there is no guidance with an overarching culturally secure framework for responses to irregular or nontreatment to ensure that this colonial logic does not continue to pervade TB and leprosy treatment. In the last example provided in this section, escalation may have been avoided for this person through initial empathetic and supportive responses, which when implemented at a later time resulted in treatment being restarted. This empathetic and supportive response not only fulfilled public health responsibility by assisting re-engagement with treatment but fulfilled the responsibility to support the person through listening to and addressing their concerns.

6.4 Successes and failures of Directly Observed Therapy (DOT): Finding what works.

6.4.1 “It’s intimidating...it could be for anybody”: The lived experience of DOT.

Directly Observed Therapy, commonly referred to as DOT, as discussed throughout this thesis, forms a significant part of the treatment model for TB and leprosy internationally and I have argued that it has also been considered a key adherence intervention for treatment for First Nations peoples in Australia.. As discussed previously This research revealed that DOT was relied upon for adherence assurance for Aboriginal people affected by TB and leprosy in the Kimberley. Routine use of DOT three times a week for active TB treatment, and once a month to observe the monthly dose of rifampicin for active leprosy treatment, was identified. The LCM, as part of the memorandum of agreement between WATBCP and WACHS, was assigned responsibility for the delivery of DOT, “when it is agreed through the multi-agency case conferences of required service partners” (WATBCP and WACHS, 2017,

April, p. 7). However, it appeared there was little deliberation about the need to agree between service partners, as the incorporation of DOT became standard practice. There is no mention of the need for inclusion of the person affected in this decision as part of this memorandum¹⁰⁹.

The WA guidelines outline that the process of DOT should be explained at the start of treatment, the “value of DOT” being reinforced by the “treating physician and case manager” (Government of Western Australia, 2019(a), 2019(b)). How this value of DOT was explained, translated, or interpreted, and perceived by persons affected versus Health Care Workers (as part of operational management) is a key consideration in its benefit for persons affected and whether operated as surveillance or support (as discussed in chapter 2). The use of the binary narrative of taking treatment did not assist any explanation of this value, and for Remy, the receipt of DOT was related to the experience of not feeling trusted:

Well, they think you got to take it, but I know I got to take it, you know. I’m not going to throw it away or just leave it. If I want to do that I can stop it and just leave it out, you know. If they can’t trust me well...

[‘Remy,’ (P1, SG1-L)]

The perceived value of DOT is relative to the benefit it provides to the person affected in treatment completion versus the benefit for programmatic infection control, where values of agency and autonomy were central to Remy and demonstrated being in control. The recognition of mistrust was particularly relevant, as Remy further added, “I dunno, why, I mean how come they don’t trust me?” Remy’s experience also highlights the personal struggles of not being trusted within what is set up to be a dependent relationship with the DOT provider rather than an interdependent one, and the subsequent response of demonstration of agency and taking back control. It also points to the impact on wellbeing and psychological stress from not being trusted.. For Remy, this episode of treatment was for a relapsed infection, after the first treatment round (according to Remy) did not require any DOT. It is understandable then how this would have felt like a punishment. The experience of mistrust felt by Remy also highlights the importance of two-way trust between person-affected and Health Care Worker, where the importance of trust extends to the Health Care

¹⁰⁹ The use of a template for agreement to DOT by the signing of the person affected by TB is outlined in the state TB guidelines (Government of Western Australia, 2019(a)) p57, p58 but not the state WA leprosy guidelines. The use of this agreement did not come up in discussion in any interviews, so it is unclear how often, or if, this was used in practice.

Worker displaying trust *in* the person affected, not just seeking to earn or gain trust *from* the person affected.

One Health Care Worker explained to me that they would explain that DOT was “part of the deal,” of treatment, and that if they didn’t allow them to be observed, “there [would be] side effects” [RAN5, SG3]. Being part of the deal implies a negotiation, with reciprocity. In practice, there was no negotiation. This was also clear in the Memorandum of Agreement between the WA TB control program and the WA Country Health Service, as the person affected was also excluded in the outlining of responsibilities in the coordination of an agreed care plan (WATBCP and WACHS, 2017, April). Negotiation, or shared decision making, does not equate with being told that DOT is part of the deal for TB or leprosy treatment. There are better ways to explain DOT that avoid the use of fear tactics, including how DOT can provide those affected with the opportunity to closely monitor for side effects as part of supportive management, instead of suggestions that without DOT, side effects will occur. The practice of DOT in the Kimberley to be more about direct observation and less about support, potentially underpins the difficulty of explaining or even justifying any value of DOT provision to people from Health Care Workers, some of whom did not agree with the premise themselves:

If someone came to my house and gave me some tablets and said, “take them while I’m here,” I would be livid. If I was only given one week, I would be livid. Any other tablet you get three months’ worth, why not trust people to take tablets, what’s this about?

[RAN3, SG3]

There were several Aboriginal participants including Health Care Workers, who expressed concern in the way DOT was provided, and that it was not something that they would like done to them:

Participant3: You can’t just say “take this, take it in front of me, I’m watching you.”

Participant1: Yeh nah you can’t, well I wouldn’t want you to come in, and “here them tablet, take it right here while I’m here.” I wouldn’t want that.

Participant3: It’s intimidating to them. Its offensive. It could be for anybody in that matter.

[FG-2, SG2]

The overly paternalistic nature of the way DOT for leprosy came across was alluded to by one Aboriginal Remote Area Nurse:

I mean, in one sense well I’m like someone’s got to come and give this tablet once a month and watch them like they’re a kid. That’s on one hand, and on the other hand, this is a pretty serious disease [and] you want them to get well, and you want there to

be, you know you want progress in their getting better. But you do think about, do they do this anywhere else? You know that sort of thought.

[RAN4-SG3]

The reference to wondering if it is happening anywhere else prompts questions regarding differences between treatment for Aboriginal people in the Kimberley and people elsewhere. Drawing on the value of DOT as a benefit over a nuisance is also challenged by how the timing and action of its provision interrupts social and working life, and not assuming all persons affected will be unemployed. To be non-discriminatory, the principles of any value of DOT should be applied to all people affected, regardless of cultural identity or employment status. The value of DOT should be a value accepted by persons affected by TB or leprosy as well as provide value for programmatic management.

6.4.2 DOT in Practice # 1: The person providing DOT matters.

DOT-providers played a critical role in the provision of medications to persons affected by both TB and leprosy. However, there was inconsistency in how DOT providers were selected. In addition, the person affected rarely had a choice in selecting the DOT provider. There were also limitations with trained staff who were available to be DOT providers, if someone different to the assigned LCM was needed to provide DOT. One important aspect of DOT provision was attention to cultural sensitivity in choosing the DOT provider, such as attention to gender. This became a complicating factor in establishing relationships for one man who was affected by leprosy, who had stated to one Health Care Worker interviewed, “why do these women keep chasing me?” in response to the frustration of being tracked down by LCMs to provide DOT. Another Remote Area Nurse relayed their experience with this:

We were to go around and stand and watch this person take their tablets, which he would refuse to do in front of you. He would say, “I’m taking them inside,” so we never knew. I just felt like I was working in a position of lack of respect for him in having to watch him take tablets and giving him that space to say I’m going to take them.

[RAN3-SG3]

At one point this same person had approached a community health Aboriginal Health Worker (AHW) seeking their medication. This AHW, as they were not assigned to being DOT provider, was unable to assist and could only relay the message. It took another two days to locate this person again in the community to provide their medication, at which point this person welcomed the visitation of a male Health Care Worker to provide the medications, engage in discussion and observe the taking of the medications. Another example of

culturally appropriate gender relations being important for beneficial DOT provision was for an Aboriginal man affected by TB. The DOT provider in this instance was a male AHW who had an established relationship with the person affected by TB whom, “trusted this health worker” [HCW10-SG3] and went on to successfully complete treatment.

Aboriginal Health Workers were selected to be the person providing DOT on three other known occasions at various locations across the region, and in many of these situations, worked successfully to support people to treatment completion. Speaking in more depth about DOT provision with Aboriginal Health Workers, they put forward that they were in the best position in the community to help their people given that they already had established relationships. In this way of thinking, DOT provision became more of a sit-down conversation with the person and any family present, providing support not just supervision. Caring for elders and children carried a unique set of responsibilities that was also articulated, for who should be prioritised for DOT: “It’s alright for them old people, maybe old people, and young people, but whereas when they are our [age], they should be responsible for their own, you know?” [P3-FG2, SG2]. In this way the importance of explaining the concept of DOT featured: “it’s just that communication to explain it, why. [...] Tell them and explain everything that could happen if they don’t take it. Try and explain that part, and go from there” [P3-FG1, SG2]. The importance of the involvement of Aboriginal Health Workers in being involved in more appropriate strategies for DOT provision was also discussed by one of the non-Aboriginal Health Care Workers, who had suggested, “when it comes to things like DOT, use your clinic staff to come up with a way that’s going to work better” [HCW10, SG3]. One AHW expressed concern over the limitations of their role with medications, and the need to be professionally supported to supervise medications outside of the clinic, i.e., in the community setting or at a person’s home, stating that they would prefer to hand out medications “where their policies stand strong” inside the clinic [P3-FG2, SG2]. This concern was related to any adverse event from medications that may happen under their watch, such as a drug reaction, that they may be held accountable for in the eyes of the person, family, or their community. Although the observation of someone self-administering medications is not technically medication administration¹¹⁰, the degree of “medication competency”¹¹¹ for the

¹¹⁰ In line with Health professions, such as Registered Nurses, Enrolled Nurses, Aboriginal Health Workers, or Aboriginal Health Practitioners, legislative and organisational policy directives guide medication administration practice, either from a dose administration aid or supplying an already dispensed packet of medication for self-administration.

¹¹¹ Competency relating to experience, training, and skill-base for handling medications.

DOT provider was assessed as part of programmatic operations (Western Australian Country Health Service, 2018), and presents a barrier for AHW–assisted DOT second to medication administration legislative and organisational policies.

One of the key examples where DOT was successfully provided (as in direct observation was completed and assisted the person with treatment completion) was having a supportive relationship with the person who provided DOT. As one Health Care Worker recounted:

It's quite invasive for a patient to have someone chasing them up for tablets all the time and how many did you take, [...] but there have been cases where it worked really well where a relationship has formed, and one person was looked after for the whole duration of their therapy.

[HCW4- SG3]

This relationship was not just about its therapeutic and supportive benefit, but also the continuity. As described to me by another Health Care Worker, “there was a lovely primary health care nurse who was really committed to the therapeutic relationship, and a respectful therapeutic relationship, and that medication started again and she left, and it fell off again.” [HCW12-SG3]. Such relations demonstrate a direct link between successful treatment outcomes and the supportive part of the provision of DOT, via the relationship with the DOT provider. However, inconsistencies were noted in this dependent relationship with DOT providers across the region in the implementation and application of the DOT treatment model. Not all established relationships were therapeutic, continuous, or culturally respectful, especially for reasons that will be discussed further. As well as such relations impacting on the treatment outcomes for people affected, it also impacted on the Health Care Workers being positioned into the role of DOT provider (who was often the same person as the LCM):

But it's quite a struggle because you, they maybe don't want to take it in front of you and that sort of stuff. So perhaps we have given it to them, and they've taken it or taken it later, or not taken it at all, and we've found out later that they haven't been taking it.

[RAN1-SG3]

This Remote Area Nurse also confirmed the challenge in building relationships, stating that “it's very difficult to engage,” and that providing DOT did become, “just handing over medication” with people, “running back into their houses.” This frustration was not just about the inability to do a job effectively, but also in the witnessing of the potential decline of the person affected without being able to help, in discovering that the medications had not been taken regularly.

But if [this person] could just take it for 12 months, they would be fine and then they don't need to take it anymore, and that's a real struggle for us thinking "why don't you just take the medications and it's all done," you know? And you've got other family members that you can see are missing fingers and things, why wouldn't you want to protect yourself from that?

[RAN1, SG3]

As well as DOT in this situation not meeting its intended 'value,' or proving an effective method of monitoring therapy, it created frustrations due to the expectations of the allocated job role:

For me, its professionally totally inadequate. I couldn't get the job done, I wasn't happy with the way the job had to be done, there wasn't a respectful relationship. The only way to build a respectful relationship was compensation on the veranda.

[RAN3, SG3]

By not actually observing treatment, DOT in this respect essentially failed its objective, along with any opportunity to build relationships and provide adequate support. The above examples reveal frustrations from Health Care Worker frustrations who could not provide a culturally safe model of care for the current model of DOT provision especially in coming in during the treatment period and not from the start.. The examples also identify the inconsistency in the current model between one that is stuck in a rigid supervision, 'compliance' mode of operation, versus one that is person-centred model of adherence that supports the patient, prompting (unanswered) questions of why DOT was continued to be pursued as a standard model of treatment for these situations. It could be argued that it is the organisational and overarching structure of service provision of this model of treatment that is at fault. Whilst individual situations have been made to work by different individuals and with the assistance of Aboriginal Health Staff, it is not a model that can be applied to all situations, suggesting the need for its review.

In keeping with the importance of relationship in identifying suitable DOT providers, the use of family members, as per the WA guidelines, were never selected as DOT providers. As discussed in Chapter 2, this is based on experience internationally and does not take into consideration the value of families and extended families for Aboriginal people. There has never been any evidence to suggest that this is or isn't the most appropriate model for DOT in the Kimberley, and warrants inclusion in its review. In discussing the use of DOT with Sam, the suggestion was (without prompting) that a family member providing DOT would be less of an intrusion on privacy:

In my case I wouldn't really want somebody to come check up on me "oh are you taking your tablets." I wouldn't want that, no. If I'm at the hospital and if they're doing that that's fine. But at home, no, you know. It's your own privacy your home you don't want anybody coming and telling you that you have to take your tablets—maybe if it's a family member, yeh! But not someone from the hospital, you know, coming up and telling you all the time.

[‘Sam’ (P6, SG1-L)]

Due to the inherent challenges of providing care within remote areas and the subsequent availability of DOT providers at any given time, the use of family members as accepted by the person affected provides a potential option to support TB and leprosy treatment.

6.4.3 DOT in Practice # 2: The place for providing DOT matters.

Just as important as the person providing DOT, so too was the place for providing DOT, that is clinic-based versus community-based, inclusive of people's home. What this research revealed was that the place for providing DOT, unlike other aspects of care previously discussed, was on most occasions negotiated with the person affected in a shared decision-making process. As a result, the majority of DOT was provided in the community, usually at the person's home, at their request. In some situations, DOT was initially provided at the clinic, and if the person couldn't come in, then the staff would "go and chase them up at home" [RAN2, SG3].

The issue of privacy emerged as a key factor behind decision-making for the place of providing DOT. Maintaining privacy was the underlying reason for refusal of clinic-DOT for one person affected by leprosy, settling on an agreed secluded location within the community (as opposed to the person's work or home). This refusal of clinic-DOT was primarily due to concerns about clinic staff not keeping their diagnosis confidential. Privacy was raised as the motivating factor for choice of location to be home-DOT by other persons affected, including from TB. However, privacy in the home was still considered an issue. When discussing this topic with some Aboriginal Health Workers, they identified the required cultural obligations to that person affected when visiting their home, in the context of their age, family and extended family:

Interviewer: So what about going and visiting someone at home and giving them medicine there?

Participant3: If it's an older person then you have to. Same time you gotta make sure that family is aware of it you know, like the family have got to know why we've gone there. Because I could go into somebody's house and say, "I got some medicine," then sit down and go through it with the family, "so how come he taking it? How come we don't know about it, that he on that medication"?

Participant1: Yeh, everybody's got to be on the same page.

Interviewer: So does that bring up some privacy problems?

Participant1 and 3 in unison: Yeh.

Interviewer: Tell me a bit more about that, like how it works here, culturally [and] familywise.

Participant3: Well, it's only common courtesy that if it's an older person, you got to have a person that, like I said outside of the clinical area, back [at their] home to supervise that family person who's actually taking that medication. And sitting down with that certain person, well you got to let that family know. It's a holistic care thing. And [for] Aboriginal people it might just fall back to cultural situation.

[FG2, SG2]

As well as maintaining privacy within this setting, this also raised other issues of cultural appropriateness of the current model of home-DOT and required cultural protocols. One (non-Aboriginal) Health Care Worker recognised this potential:

And you know because it's not culturally appropriate care either, you know. The cranky nurse turning up at the door and wanting to watch you take your tablets. I don't know how that works really or how culturally sensitive that is.

[HCW12, SG3]

The provision of DOT at home or in other arranged community locations, in addition to not addressing cultural protocols, did not always go to plan. Health Care Workers often turned up unannounced (due to challenges in making appointments or contacting people to see them at home), people could not be located, and in one situation one person refused to come out when the LCM arrived, "sometimes we would get there, and all the kids would be called inside, and no-one would come out. So, it obviously wasn't an appropriate time for them, and you just had to respect that and try again later" [RAN3, SG3]. This not only re-enforces the importance of negotiation within an established relationship about the provision of DOT, but also a required stamina from Health Care Workers to persist with care and not give up on people. As another Remote Area Nurse put it, "you can only do so many drive by's and then you move on to something else" [RAN1, SG3]. The provision of DOT was resource intensive and competed with other work-related priorities. There was not always time for "chasing people up" when they couldn't be found, or continually checking in. On reflecting on the importance of not giving up and continuity of relationships, one Aboriginal Health Worker shared their observations.

Interviewer: Do you think that's what happens, that at the beginning there's all this interest and then do you think people lose motivation?

Participant: They could sometimes. And maybe it's because of the turnover of staff and because [the person-affected] left town and gone out to community, and you just

can't catch up with them. I think those are the main reasons that the gap starts widening between the clinic and the client. And we sort of managed to catch up with them later on, you know, don't leave it too late, you know, just keep going finding out, asking families around town. And even just ringing up the clinic up the road to see if they've seen them or to ask their families, to see if you can track them down.

[AHW1, SG3]

Negotiation of time and place for DOT and respecting privacy formed a central part of providing DOT compatible with Aboriginal ways of being. Surprisingly, the use of technology assisted DOT such as Video Observed Therapy, for example from a smart phone, was not part of treatment negotiations for any individual, despite the potential for technology to assist in overcoming barriers of privacy, geographical distance, and mobility. Finding a private and safe place was the epitome of providing culturally safe care and home was not always the place to do this—the provision of DOT at home intersected with structural and social inequities for Aboriginal people that have led to crowded housing and socio-economic disadvantage. As one Aboriginal Health Worker put it:

I guess it boils down to being in a private safe environment where that person might feel comfortable, you know? They got every countryman, biggest mob of them, two, three family in that house, and then you got no private place for them at all you know?
[P3-FG2, SG2]

As well as the challenges in finding a private and safe place for DOT-provision at home or in the community, this also speaks to broader issues of singling out people within their home space and the potential for shaming—all of which are significant considerations for the place of DOT provision.

6.4.4 Summary for successes and failures of DOT

In Chapter 2, I highlighted the justification for the use of DOT to as both adherence intervention to assist with treatment completion and to prevent drug resistance from sub-optimal therapy related to the self-administration of medications. Current DOT provision in the Kimberley, where numbers of TB and leprosy infections are low and there is no known drug resistance, I have argued is more centred on the guarantee of people taking treatment 'responsibly.', carrying forward the same association of unreliability and (ir) responsibility identified in Chapter 4. The specific need for direct observation of therapy I contend is primarily a fall-back position that aims to maintain control over what is happening with treatment at the level of programmatic requirements for public health, rather than the concern for the provision of support to assist Aboriginal persons affected to optimise treatment. The

current DOT model fails to operationalise consistently in both person-centred and culturally secure ways. There was no evidence found within current national or state treatment guidelines that raised any consideration of the need to consider the benefit of the provision of DOT, over and above the risk of ongoing colonising for First Nations peoples. Nor was there any consideration of its failure as an ‘adherence intervention’ in the implemented objective of improved treatment adherence in situations where people refused to be observed. This section outlines how the current model of DOT, as well as being resource intensive, also risked further division in relationships with Health Care Workers with persons affected, especially regarding issues of two-way trust. This brings up key issues in the current model of DOT for how it is implemented within a remote setting, how DOT providers are chosen, the flexibility of DOT provision, the place of DOT, the doggedness of persisting with DOT when it is not meeting its intention, and the importance of relationships between person-affected and DOT providers.

In observing these aspects of risk and failure within the current model, there were also noted successes in terms of benefits of treatment outcomes and support for persons affected. While there were gaps identified in the capacity of DOT as a model of care that is person centred and culturally secure, (e.g., where incorporating social and cultural values of gender, family, and privacy are concerned), the complete rejection of DOT as a model was not supported. As I have detailed, what became more critical was the way DOT was operationalised and the consistency with this operationalisation. Where there was success in the provision of DOT, this was influenced by shared decision-making practice in negotiating a suitable place for DOT in combination with culturally respectful and established relationships. In this way, I argue that any future use of DOT requires re-thinking the structure of the model as one that considers these factors for those on their treatment journey, and *not* as a tool for control over adherence.

6.5 Chapter summary

Treatment for TB and leprosy is complex and provides several challenges for persons affected. In this chapter I have identified that this was not just about the implementation of and adjustment to new routines of taking a large number of TB and leprosy medications, but also about the need to persist through daily treatment and potential side effects of medications without losing motivation over the course duration of six months to two years. For persons affected by leprosy, it was about experiencing lepra reaction which can be painful and debilitating, contributing to the experience that treatment wasn’t working. This challenge was

overcome by some people through a determination to persist with treatment despite the lack of evidence of treatment effectiveness, and despite having to take adjunctive treatment for these reactions such as corticosteroid medications that came with the additional burden of increased side effects and number of tablets. Health Care Workers also influenced a person's treatment journey not giving up on them and learning to navigate around the vagaries of missed doses and communicating the consequences of this effectively. This chapter discussed how the regularity of taking TB and leprosy medications is significant for everyone involved from persons affected, their families, and community members. Optimising treatment by providing consistency in care and communication to support treatment regularity means a potential cure can be delivered the way it has been scientifically investigated. What was identified to be a barrier to this optimisation was a consistent inclusion of persons affected by TB or leprosy in their own treatment decision making. Additionally, a consistent approach across the region was not evident for working with persons affected to address context-specific and individual approaches to taking medications that influenced optimal treatment, specifically regular adherence. The modelling presented within this chapter visualising treatment outcomes in relation to patterns of adherence and a person's treatment journey in relation to treatment completion, cure of infection and the need for post-treatment monitoring, represent new models that provide clarity for understanding treatment complexity and assist as a tool to communicate the importance and consequence of taking treatment as intended.

This chapter has highlighted the current lack of cultural frameworks for monitoring of treatment and responding to irregular and nontreatment. The use of DOT as a solution to oversee adherence was inconsistently applied and had a variable response in relation to treatment completion. Several issues became apparent for the use of DOT in the remote, cultural, and colonial context. The importance of the person providing DOT and the place for providing DOT were two key areas for these issues and whether DOT helped, or harmed people affected by either latent or active TB, or active leprosy. The current model of DOT is interwoven with an embedded colonial logic and gaps exist in meeting a persons need for privacy, especially in situations of structural and social disadvantage such as overcrowded homes, in the culturally safe provision of DOT. Health Care Workers were also challenged by the current model in being able to provide DOT continuously and in ways that demonstrated benefit. Despite the inconsistencies noted with DOT, it is continued to be pursued and relied upon as an adherence intervention. There is an urgent need to re-construct models of DOT that are safe and provide value in the goal of treatment completion. Part of this is the need to

stratify to context—person and place, active or preventive treatment and decisions regarding tailored versus universal DOT, especially at a community level for prophylactic treatment. Learning from what works and listening to the perspectives of Aboriginal people presented in this research is critical to this re-construction and will be discussed further in Chapter 8.

Chapter 7

Biopsychosocial Considerations for Treatment

7.1 Introduction

In this last chapter of the research findings, I shift the focus to biopsychosocial considerations related to the treatment of TB and leprosy. The connection between physical disease, social factors (i.e., how a person ‘lives’ within society and how people live together in organised ways) and psychological factors (i.e., emotion and behaviour) is significant for any person in their treatment journey. The decision to include an examination of biopsychosocial care in this analysis was to provide a deeper and richer understanding of the impact of treatment on a person’s life, their family, household, and community. To truly draw relevant insights into person centred and culturally safe care, I argue that digging deeper into the areas of stigma, wellbeing, and social relationships are essential. The way that these areas emerged in their influence on treatment became an important part of the research findings.

The lived experience of Aboriginal persons affected by either TB or leprosy in navigating any experience of shame, blame and social exclusion is presented in the first section of this chapter. I build on a definition of stigma by Scambler (2009), who describes stigma as “typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group” (p. 441). A further breakdown by Stangl et al. (2019, p. 3) explicates the experience and manifestation of stigma, into actual (i.e., experienced) versus anticipated (i.e., expected from others on learning about their condition), and can include a “self-stigmatization” that is when a person self-excludes themselves as a result of actual, or anticipated, stigma (Rafferty, 2005, p. 123). While most of the discussion regarding stigma in this section is related to leprosy, it is important to note that persons affected by TB were also impacted, and this is detailed where relevant. In articulating the experience of stigma, it is necessary to consider the way language is used and the limitations of intercultural analysis from the perspective of a Western understanding of stigma. As one of the members of the Aboriginal advisory group cautioned, “Stigma is almost a Western interpretation put onto a culture that has their own way of dealing with it” (Edith Wright, 2020, personal communication). In recognition of this, I use a broad term of stigma, and stigma experience, as per the accepted academic definition above, to allow room for cultural context of what is determined to be a social process and social judgement. I use the

concept of shame as was voiced by participants to direct any emergent thematic of this experience. Other authors, such as Malcolm & Grote, (2007) pointedly note the importance of *not* projecting Western definitions onto cultural shame, arguing that “the concept of shame and its use by Aboriginal English speakers is broader than the one encapsulated in the non-Indigenous use of the word” (p. 169). As such, I identify even more ably how local, social, and cultural contexts determine current social belonging processes related to TB and leprosy treatment.

In acknowledgement of the key role of psychosocial support for a person’s treatment journey, the second section of this chapter shifts the gaze from stigma experience to the impact of relationships defined as social relationships of the person affected, and those with Health Care Workers. Firstly, I detail three principal areas of relationship that related to social and emotional support for persons affected—family, connection to culture and peer support workers. The second part of this section focuses on the adaptation of the case management model specific to the Kimberley region with the use of LCMs. I will discuss how the position of LCMs are a key relationship for supporting persons affected and provide a deeper analysis of the associated challenges and strengths of this model, including the importance of Aboriginal Health Workers and Aboriginal Health Practitioners within this role for TB and leprosy management.

7.2 Stigma experience

7.2.1 Language and constructing stigma.

7.2.1.1 “*That shame thing*”

I have argued in Chapter 4 that the historical social response of fear from settlers towards local Aboriginal people within the Kimberley (such as in Derby town) helped manufacture the stigma experience. In line with this argument when analysing the research findings with one member of the advisory group, they explained, “shame isn’t a cultural thing, it’s introduced. It’s not an Aboriginal thing, it comes with the disease and the way its treated” (Edith Wright, 2020, personal communication). Historically the actions and words from white settlers in authority, such as police round ups and public health segregation of families that occurred over a substantial number of years, contributed to this eventual embodiment of shame associated with leprosy. As one participant explained:

Participant5: And them people were shunned with that sickness. That shame thing coming along. Just been brainwashed at the end, so some wasn't allowed to take their young families [...]. So that was, for that shame thing coming.

Interviewer: So that really comes from the history, the shame?

Participant4: It comes from being isolated from the family.

[FG1, SG2]

The reflection from the participants above in describing leprosy segregation as 'that shame thing coming,' tells of this embodiment, manifesting from the forceful and legislated separation from family. In reflecting on the description of isolation from family, the use of the word shame by Aboriginal participants throughout this research, far outweighed any use of the word stigma in describing social experience of isolation from family, for both TB and leprosy.

7.2.1.2 Hansen's or leprosy?

The change in name in the 1970s from leprosy to Hansen's disease, outlined in [Chapter 2.2.4](#), was a move to address stigma from the synonymous name-association of leprosy with being unclean, and the associated hostility towards people with leprosy. In line with international consensus at the time, the use of the terms Hansen's disease was adopted in the Kimberley by the Derby population health unit, as evidenced from their 1997 inaugural published guidelines (Kimberley Public Health Unit, 1997). There is additional evidence that this term was used by early Aboriginal Health Workers in 1985 (Macale 1985) when detailing job roles that included "Hansen's surveillance" (p. 47). However, during this research, associated stigma with the term leprosy was not raised by any Aboriginal participants interviewed. In fact, most people I spoke with had not heard of the term Hansen's. This caused confusion when only the name Hansen's was used when the initial diagnosis was given:

Remy: They told me that I had this Hansen, but they didn't really tell me what this really was.

Interviewer: So that's all they said, they just said the word Hansen? Did you know what Hansen's was?

Remy: No, I didn't know what Hansen's was. You know, and once [the specialist] told me that down in Perth and I went to that Anita Clayton Centre in Perth [...] that was for patient with leprosy. Because I read it on the front, you see. You know, and I said, "what am I doing here?" you know?

['Remy' (P1, SG1-L)]

Sam (P3, SG1-L) had a similar experience:

Sam: I had never heard of that Hansen's disease until they told me about it, and I'm like "what's that?" and they were like "it's leprosy," and I was "oh ok". Because I always knew it as leprosy.

Interviewer: That's what everyone used to call it?

Sam: Yeh, leprosy. Yeh, and you know, the place out there was called leprosarium, Bungarun you know, leprosarium. And so everybody knew it as leprosy, not Hansen's. You know I, because I [...] even when they told me Hansen's, I was like "what? I never heard of that word, I heard of leprosy."

In these two examples, there was no associated shame expressed with using the term leprosy. More so, referring to it as Hansen, or Hansen's, did not link the condition with the historical knowledge associated with Bungarun and the family history. There is an importance here for the community in recognition of history and that it is the same condition that affected previous (and current) generations. However, the experience of one Regional Physician suggested that this was not universal across all people affected by leprosy:

I've come across a very wide range of willingness to discuss leprosy in Aboriginal people of the Kimberley. Everything from "you should come to my community and give a talk about it, and I will help you and I will stand up and talk about my experience with leprosy," everything from that to it being made very clear that we shouldn't use the word leprosy, probably shouldn't even say the word Bungarun. That any discussion we have has to be off the hospital grounds because they don't want to be seen, don't want to be suspected of having leprosy.

[Regional Physician1, SG3]

While the international community now refers to the use of both terms with efforts to advocate for dignifying terminology (Deps & Cruz, 2020), the path forward for the Kimberley community is not as clear. Connotations associated with a stigmatised use of the term leprosy carries less relevance for shame experienced by Aboriginal people in the Kimberley. The use of the term however does carry important weight for identifying the connection to history-leprosy ('Bungarun' leprosy). This has implications on both spectrums—one, that people who are given a diagnosis of Hansen's may not understand that it is indeed the same thing as 'Bungarun' leprosy—and two, that individuals who want to maintain privacy may be more able to keep their diagnosis private if the broader community does not recognise that Hansen's is the same condition as Bungarun leprosy. As a result, decisions about the most appropriate use of terminology should be taken into context for the individual person, and on a broader community scale warrant more significant discussion with the wider Aboriginal community.

7.2.2 “Being shame”: Stigma, privacy, and disclosure.

7.2.2.1 *Privacy and treatment access*

Yeh could be a thing of [...] being shame, too. I don't know, you know, big shame for [needing to take treatment].

[P1-FG2, SG2]

The above quote was in relation to suggestions of reasons for not coming forward for treatment, by one of the Aboriginal participants in Focus Group 2. Negotiations centred around maintaining privacy was a common theme identified across all three study group participants. For example, one Health Care Worker recounted their experience with a person affected by TB being “worried about their diagnosis getting out and confidentiality being breached” [HCW10, SG3]. As a result, as described by HCW10, they, “weren't that keen on coming into the clinic and wanted as fewer people involved in their care as possible.”

As already described in Chapter 6 regarding DOT, these negotiations about privacy related to the place of DOT provision, impacting on ways of supplying, and accessing treatment. For one person (affected by leprosy) this meant having to re-locate temporarily to another community because of social exclusion (which will be discussed further in 7.2.4), a move which as confirmed by HCW4(SG3), “did affect I suppose the way this person could access their therapy.” It is important to note that in all these situations, the causal link between stigma and any associated interruption to treatment was centred on maintaining privacy. Decisions to stop taking treatment were secondary to either not wanting to be seen accessing or being administered it (i.e., through DOT). Once negotiations were made that met the needs of the person in addressing privacy and a continuity of treatment supply was available, treatment was completed with ongoing support. Therefore, any misrecognition of these privacy needs for a person who is experiencing or anticipating “being shame,” runs the risk of the person being wrongly labelled as non-adherent.

Three main challenges were identified in maintaining a person's privacy within the current health infrastructure of the Kimberley, despite the size of the region. The first was due to the high turnover of staff, and not maintaining a continuity of those staff who knew about the person's diagnosis. Despite trying to “limit the number of people who know about it,” there was acknowledgement from one Regional Physician that the transient workforce made this “very hard,” due to “the number of faces that [people] will engage with over the course of their treatment.” [Regional Physician1, SG3]. The second challenge identified was

the inter-organisational sharing of information (e.g., via clinical handover). In one community, regular meetings were held between the local Aboriginal Medical Service (AMS), and the community health centre attached to the local hospital. One Remote Area Nurse explained their approach in maintaining privacy and their reluctance to ask for advice from the AMS within these meetings, saying that, “it’s not something I would necessarily bring up, because they’re not clients of the AMS” [HCW1, SG3]. This highlights the challenges in respecting the wishes of the person to maintain privacy while conducting usual ‘health care’ business in discussing clients of health services across sites and in transitions of care. The third challenge identified was for Health Care Workers living and working in small communities. The consequences of any breach in privacy not only impacted the person affected, but also the blame on and subsequent trust of local clinic staff, including Aboriginal Health Workers, regardless of if they were responsible. Participants in Focus Group 1 explain how this was specifically related to treatment:

Interviewer: What about things like confidentiality, it must be hard in a small place sometimes, I mean, does that ever come up as an issue?

Participant3: - Mmm not really.

Participant1: Not the screening. I think it’s more after when you’ve been diagnosed.

Participant2: When you’ve been diagnosed and need to take the medication.

Participant1: Some sort of barriers there, that you know [...] (pauses)

Interviewer: You want to keep that information private type of thing?

Participant1: Well, like I say, it’s a small community and everybody wants to know everybody’s business in a way. And the first people who get blamed if information gets out. You might just get one person gossiping in the community, but the first place they pinpoint is the clinic staff.

[FG1, SG2]

This conversation reflects on the difficulties experienced by Health Care Workers within a small community with respect to responsibility and privacy concerns. It also reinforces the importance for health staff that visit the community to uphold patient confidentiality.

7.2.2.2 Disclosure and family

You know, I’m not afraid, or I can share my things. It might [have] happened to other people, but you know, some people hide, and they don’t want to talk about it. But for me I know, I mean I share it with my family. I tell my family what I’ve got.

[‘Remy’ (P1, SG1-L)]

While privacy within the community setting was highly regarded, the findings of this research suggest that persons affected by leprosy were more often willing to disclose their situation within family as Remy described above. This was also the case for Sam:

Interviewer: And you were happy to talk about it with [family]?

Sam: Yes, with my husband, with my children, with my mum, my sisters, you know and whoever else was there. Because someone would be like “oh, you know how come you going to Perth, you know, somethings wrong with you. We know something, what is it now?” So I trained them.

Interviewer: And what was their reaction?

Sam: Well you know, like mum said, “my brothers were all there you know, my niece was there you know, but it’s funny how you’ve got it, and not their children,” you know. Because mum or dad never had it, not my nanna not my papa, none of them.

[Sam (P3, SG1-L)]

This also reinforces the family history link regarding knowledge of the disease, and associated acceptance. Disclosure with family was noted by the Infectious Diseases Physician when visiting people in their homes. From their experience, there was a clear difference in this disclosure among families in comparison with other families they had worked with:

Certainly, when I go there to their house, they will bring all the family out and say, “it’s that thing, you know that thing that I’ve got, that I take the tablets for.” There doesn’t seem to be that sort of shame or wanting to hide it, certainly from the family group... A lot of our southeast Asian patients here, you’ll find they won’t tell anyone. Not even husbands or kids. They are so fearful. But I don’t think Aboriginal people have as much stigma within the family.

[Infectious Diseases Physician, SG3]

The involvement of family raised another salient point for negotiations in accessing treatment and for DOT, especially when being provided at a person’s home, as discussed in Chapter 6. In some situations, extended family visiting or staying at a person’s home, who could be present at any time, were not considered. One Aboriginal Health Worker suggested that getting around privacy challenges of visiting homes and their cultural obligations, often requiring them to talk with families, especially elders, was possible with a prior agreement with the person for an alternate health condition:

Well, you don’t have to tell them that you’re coming to take all this stuff for leprosy all that, you can talk to your family about your diet, or exercising. Or just give them and us just little brief pointers for that family if they ask us. So, we got permission from that client “yeh you can tell my mum if she asks you but talk about, I’m just trying to lose weight,” or “I’m trying to get on this diet, or they make me up an exercise plan,” or something, you know?

[P1-FG2, SG2]

While the findings point towards routine disclosure to the family, it should not be assumed, and it is important to gain prior permission from people before discussing it with family in agreed ways, as suggested by this AHW. Maintaining respect and sensitivity for privacy is a priority for supporting a person to treatment completion. Respecting an individual's privacy should ensure that their wellbeing is considered and that their status within the family and community is not jeopardised. Permission for disclosure to family, moreover, should not be conflated with disclosure in the broader community. Additional barriers, such as restricting supply to weekly instead of monthly (as highlighted in in [Chapter 5](#)), unnecessarily increased the challenges for people around maintaining privacy due to increased treatment access requirements, especially in navigating optics within smaller communities.

7.2.3 Stigma recognition

7.2.3.1 *Being singled out.*

TB is a sort of shame, I suppose, disease. You don't expect anyone or yourself to have TB. You know, TB for me is like having leprosy—you have to isolate yourself from family members and community.

[P1-FG1, SG2]

Although TB wasn't as significant for the history of social isolation as leprosy, it was still considered to be comparable in this impact of separation. In enquiring further about this with Focus Group 1 in relation to shame, they explained:

Participant1: I think it was more of a shock, you know embarrassing, knowing that it was a shame thing that you had TB.

Interviewer: And why do you think it was a shame thing?

Participant1: Because you were the only one who's sort of been diagnosed with it and the others weren't, yet we're all in the same community and we're all together all the time, so you'd expect that there'd be a bigger sort of...(stops).

[FG1, SG2]

In the current setting in the Kimberley, where there are small numbers of infections for both TB and leprosy, the experience of being singled out, for example being the only one in the community affected, can be exacerbated. In shifting to leprosy, Remy reflected on how only they were the one affected, "I mean I was worried [...] not worried, but real upset, why. I was like asking doctor 'why it's me? Why did I end up getting this?'" ['Remy' (P1, SG1-L)]. The experience of being singled out, i.e., experiencing "individual recognition" is significant due to the separation of a person from their extended family and kinship networks, as highlighted by other authors who have discussed shame within the Aboriginal cultural context (Morgan et

al., 1997, p. 598; Vallance & Tchacos, 2001). The link to the history of physical separation in isolation wards or institutions also invoked fear for the need for current segregation for at least one person who was diagnosed, requiring reassurance that treatment nowadays can be safely commenced and completed in the community.

While these experiences relate to a focus on the individual identifying with their status within the family or wider social group, the potential for Health Care Workers to single people out in front of others was noted. The following example was told to me by Charlie, in recapping their story when visiting the local hospital:

We were met at the front door of the hospital by one of the emergency nurses, and she had a mask in her hand, and she said to [this person affected by TB] “you can’t come in here.” Like that. “There’s a lot of vulnerable people in here, you need to have this on, and any time you come to the hospital you need to be wearing this.”

[‘Charlie’ (P6, SG1-LTBI)]

Health Care Workers have the power to recognise and respond to people in ways that do not contribute to the worsening of any anticipated or experienced shame. Unfortunately, the above example of singling out this person, i.e., ‘telling them off’ in front of others in an emergency waiting room, is not one of these ways. This example demonstrates how Health Care Workers can unknowingly misuse their positions of power in harmful ways by singling people out, thereby, perpetuating or causing stigmatisation through routine medical engagement. This scenario, as well as other experiences of avoiding the health clinic, also reinforces the potential for clinical encounters and biomedical sites such as the hospital, the clinic, or the place of providing DOT, to become sites of actual or anticipated stigma. These sites of stigma are set-up by the act of singling people out in front of others or from symbolic markers such as the face mask or the receipt of treatment.

7.2.3.2 Internalised stigma and hurt.

Being the only one within a social network to be affected with disease is also emotionally isolating. Self-stigmatization can occur secondary to this actual or anticipated stigma experience when a person accepts and internalizes any of these experienced social beliefs and feelings associated with their social exclusion/separation (Stangl et al., 2019, p. 2). This can then have an impact on mental health. This was evident for the experience of one person affected by leprosy, who, following their diagnosis of leprosy becoming known within their community, was “shamed out of town for a-while,” [HCW10, SG3] resulting in a loss of social status. Another Health Care Worker noted the difficulty experienced by this person

secondary to this “shunning,” to the point of “expressing suicidal thoughts” [HCW4, SG3]. It was important to learn that despite the challenges of being shamed out of town and the consequences for this person’s wellbeing, there was a notable strength of this person in persisting with treatment until completion, as identified by one Health Care Worker: “The problem wasn’t just the chronic disease, the stigma was from the therapy. Yet [they] persisted with it anyway” [HCW4, SG3], demonstrating resilience despite their experience, and that the actual experience of social isolation and resultant shame was not causative of any irregular or nontreatment.

In understanding loss of status, I was explained the challenges for Aboriginal people socially, by an elder in Focus Group three about how people can get “hurt” as a consequence of being socially isolated:

Participant8: But it’s hard for Aboriginal people, you know, when we sit around and they, if they say, “ah don’t come close to me you might give me that thing.”

Interviewer: Like shame for that?

Participant8: [...] Like it, you know, “don’t come next to me.” If they say, you know—if doctor tell people to say to other people like that, what they got, say it, they’re not really [...] they get hurt you know?”¹¹²

[FG3, SG2]

The expression of isolation as “hurt” was also described by Remy, in talking about historical social isolation, “I mean you know it was really hard then, not really hard, but it was real hurtful for family, like, they didn’t see them you know.” Thus, raising further insight into wellbeing and the potential for re-traumatising people.

7.2.4 Stigma and context

7.2.4.1 Social and cultural diversity

Stigma experience was also found to vary across social and cultural context both within the Kimberley and in understanding stigma manifestation for Aboriginal people in the Kimberley to other cultural groups. The first example of this was for the younger generation in relation to upholding social status. In recapping the story of the young female affected by leprosy or being seen to be taking tablets and being a young person, was not conducive to maintaining social status among peers or in trying for children. In this social setting, being the only one to be affected by disease and seen as affected by disease is a point of difference not desired. It is to be hidden in a way that maintains status and becomes more than simply

¹¹² This example also reinforces the role those medical professionals can have in contributing (or not) to stigma by the way disease is disclosed.

maintaining privacy. Being the only one affected by leprosy within a social group also reveals the varying layers of how stigma can manifest, and where challenges in addressing stigma-related barriers to treatment can become more complicated, particularly for young people. Younger generations had been observed by some participants to have differences in the knowledge of the history of leprosy, as previously discussed in chapter 5.3.2.1. Charlie had also brought up difficulties with younger generations and a disconnect to history, “these young people today I say to them if you want to really improve your life, and have a purpose in life, and know where you want to go, you’ve got to know the past” [‘Charlie’ (P6, SG1-LTBI)]. Engaging younger generations in the connection to history and family, in addition to assisting with treatment importance, may provide a benefit in ways to address any actual or anticipated stigma.

The second example relates to physical signs of taking treatment for leprosy due to one of the side effects of the medication clofazimine, used in standard first-line treatment, to be a darkening of skin-tone. A recognition of this change in skin colour has been identified elsewhere as a signal that a person is being treated for leprosy, regardless of trying to keep the diagnosis private, and a reason to avoid treatment (Lockwood et al., 2019). While this scenario is accepted internationally as a common cause for stigma, it was not identified to be significant for Aboriginal persons affected in the Kimberley¹¹³, as observed by the visiting Infectious Diseases Physician (SG3), “I tend to find that Aboriginal people again, certainly in men not such a big issue. In the women they don’t seem to worry about it.” Variation in relation to TB stigma between cultural groups has also been identified by Chang and Cataldo (2014, p. 171), in their systematic review. This review adds weight to the findings from this research showing that a variation in stigma experiences is not unique to leprosy but also occurs with TB and is entrenched in social and cultural context. This reinforces the importance of incorporating local social and cultural contexts in recognising and understanding stigma (Kleinman & Hall-Clifford, 2009, p. 3; Singer & Clair, 2003).

7.2.4.2 Community and addressing stigma.

While stigma experience can vary across social groups and cross-culturally, there has also been notable variations between communities within the Kimberley region. The two main communities I visited varied in their history, community size, language groups and geographical location. They also varied in the degree of stigma experience of persons

¹¹³ This is not to suggest that narratives within Aboriginal Australia that relate to identity, social status, and skin colour do not exist, but rather that the impact of a drug on imparting this change was not significant.

affected within the communities. The smaller community, and for reasons not explored, appeared to have a higher burden of actual or anticipated stigma experience for individual persons affected by both TB and leprosy, identified directly or indirectly from participant interviews. In the other community, larger in size, expressions of stigma or shame were not as evident. In penetrating these local community contexts, it was a trainee physician who identified the need to understand the impact of structural factors in these contexts:

The question has to be why does that community have a certain level of unemployment, and a certain level of disempowerment, and a certain level of poor housing and certain level of lack of access to water and certain level of x, y, z?

[HCW14, SG3]

In visualising the analysis directly from people's interview using text in the theme 'stigma/shame – place, family,' Figure 9. Shows a word cloud generated that highlights the significance of leprosy diagnosis for the changes a person experiences and the link to their community.

Figure 9. Visual representation of analysis codes 'place,' 'family' from 'stigma/shame'



This understanding for how stigma manifests across context within the region also becomes significant in any attempt to raise community awareness of leprosy or TB in aim to address stigma (Shrivastava, 2014; A. Teo, K.J., et al., 2020). I highlight two lines of risk identified from this research that deserve consideration when attempting to address stigma via community-level awareness. The first risk is in the knowledge that there is the potential for unidentified or ongoing transmission of leprosy infection in the region. As discussed in chapter 5, leprosy was considered a thing of the past by several Aboriginal participants, and new diagnoses were often accompanied by shock, as Remy explained of their family learning about the diagnosis:

I mean, they got a shock. That's why I'm...you know? I mean, they knew about all these things, my mum knew, because her uncle was in that thing, my grandmas' brother you know. They were all in that place now, Bungarun. A lot of family, our family.

[‘Remy’ (P1, SG3-L)]

Knowledge of leprosy continuing to affect Aboriginal people in the region has the potential to invoke fear as both a natural response to contagion and in triggering memory of the history of the disease in the region (Pappas, Kiriaze, Giannakis, & Falagas, 2009, p. 774). When discussed in one Focus Group, the response to learning leprosy was present was, “he’s back” [P9-FG3, SG3]. For Remy, learning about their diagnosis of leprosy triggered new questions of why, “I asked, ‘why, still—why’s that, why is he still here with us?’” Learning of the continuing presence of leprosy also triggered different questions from members of the Aboriginal Advisory Group, such as wanting to know “what we are in for.” While the history was agreed as important, they also insisted it was about what was happening now, posing questions such as “are we still failing the community?” (Advisory group members, 2019, August). The risk in raising community awareness to address any stigma therefore is in not being prepared to answer these questions of why and how, and in failing to appreciate or recognise the potential emotional impact for Aboriginal families and communities.

The second line of risk in raising awareness related to non-Aboriginal community members or visitors. When knowledge of leprosy prevalence within one community became known by some community service providers, Health Care Workers were contacted out of panic, as one Remote Area Nurse explained:

Since I’ve been here, an email came out one day from the police, around leprosy. And there was a new sergeant who had been here, and it was —they sent an email out to people on a certain committee you know, just around “to make you aware there was leprosy in the area and make sure you do good handwashing etc.” It was just bizarre.

[HCW1, SG3]

Another Health Care Worker described their receipt of emails from school managers and other non-health care managers employing staff who worked with children and families in this community. On hearing of cases of leprosy in the community, concerns were raised, as relayed by HCW12, such as asking, “should their workers be able to go to [this community] for example, we’ve heard there’s a leprosy outbreak there and it’s a risk to people” [HCW12, SG3]. The experience of HCW12 in this scenario was that “panic is not in the Aboriginal

community, that's in service providers,"¹¹⁴and specifically, the emphasis on non-health service providers, "when information somehow gets to non-clinical people it can cause panic". The fear of contagion and resultant panic evident in the non-Aboriginal community members had the hallmarks of the beginning processes of stigmatisation. Not just people affected by leprosy but towards the Aboriginal community, who accounted for 90% of the community population in question. It echoes historical sentiment of settler fear identified in Chapter 4 and the rhetoric of being unclean long attached to leprosy within Western culture¹¹⁵ that is still pervasive today. This example also demonstrates the risk of people without knowledge in power positions having the potential to enable or disable this stigma process, as Kleinman and Hall-Clifford (2009) remind us, "we must remember that the stigmatized and those who stigmatize are interconnected through local social networks" (p. 3). Raising community awareness is now part of the new role of Regional Leprosy and TB co-ordinator, appointed within the Kimberley Regional Population Health Unit. In this community awareness, the role was to support primary health care teams who work with communities to help give the community the correct information and to target misinformation circulating among community members. Providing community information may have the impact of addressing stigma but is complicated by the two risk areas I have identified above. These areas need more urgent consideration and attention to Aboriginal cultural leadership in the process of raising community awareness. Doing anything less is potentially short-sighted.

7.2.5. Summary for stigma experience

I have outlined within this section how stigma experience has multiple layers, is complex and exists as a diverse spectrum for people affected within their unique social and cultural location. On one end of this spectrum, a worst-case scenario was an unwillingness to access treatment, a mistrust in clinic staff, affected community relationships, and the impact of internalised shame on mental health. On the other side of this spectrum there was disclosure without shame, finding connection with family and family history, a willingness to talk about it and not hide the diagnosis, and maintenance of hope through a long and challenging treatment regimen. I have also shown the relationship of stigma experience to taking treatment, which presents in the forms of attempts to conceal the condition and maintain privacy linked to accessing or being seen taking treatment. This confirms the

¹¹⁴ Who form the larger proportion of the non-Aboriginal community.

¹¹⁵ As is evidenced in the early stages of the current covid-19 pandemic, this rhetoric continued to be used to compare the way people with covid-19 are being 'treated like a 'leper'' re-circulated through social media.

importance of maintaining confidentiality for persons affected by either TB or leprosy, and not assuming that information is okay to share without explicit consent of the affected person.

I have demonstrated how the maintenance of privacy brings to light challenges within current health service delivery in the Kimberley, due to the turnover of staff and current inter- and intra-organisational clinical handovers. This finding of privacy importance reifies what was also identified within Chapter 2 in the literature review regarding stigma-associated with HIV and HCV. Differences were of note however within the willing disclosure to immediate family, unlike that for HIV, revealed that context for stigma also extends to disease type. Overall, the findings of this research confirm that stigma experience cannot be assumed, and that recognition is key. In providing optimal care, I insist that it is essential for health providers to recognise the diversity of stigma manifestation for people affected by TB or leprosy within their local social and cultural context and avoid universalising assumptions that do not.

7.3 Relationship and wellbeing

7.3.1 Social and emotional support

7.3.1.1 The importance of family

My family went through that, you know, why should I be ‘shamed of it? You know? A lot of people went through that, 50 years ago.

[‘Remy’ (P1, SG1-L)]

The importance of psychosocial wellbeing, mediated through self-support and from relationships with others, is a significant factor in TB and leprosy treatment for active infection. In shifting from the topic of stigma-relation to wellbeing I have focused on the impact of relationships, in what emerged as a central and significant theme with respect to treatment. There is no denying so far within evidence produced within this dissertation that family is important within Aboriginal culture¹¹⁶. A positive social attribute of being connected with family history was identified by Remy, and for some other persons affected by leprosy. This positive attribute worked in two ways. The first was through solidarity, the second, through knowledge. The two themes are interlinked, and I argue assisted not only an understanding of the “why me” question discussed, but also in understanding solidarity, where for Remy, helped overcome any anticipated or experienced shame. This solidarity was also a source of strength, as Remy noted, “I’m not afraid of it, frightened or scared, and I can

¹¹⁶ Family inclusive of complex and dynamic kinship relations that are not adequately represented in non-Aboriginal definitions of family (Lohoar, Butera, & Kennedy, 2014)

share my thing. Cause I know family for us went through this thing.” For Sam, knowing what their family had been through assisted with the acceptance of the diagnosis, “But yeh, after that I got used to it, and accepted it, that I might have Hansen’s disease, because of the history of my family.” These positive social attributes that work against mitigating fear and a sense of shame, point towards the value placed on social relatedness within Aboriginal culture. Another key point that came from the role of family was trust, as explained by the following focus group in relation to supporting treatment:

Interviewer: And you say use family members as well?

Participant4: Generally, this kind will trust us, being...

Participant5: Well, being visitor, you know, some people don’t [trust them]
[FG1, SG2]

The support element for family here is trust in known family members; a trust that is not present or established with ‘visitors’ to the community that may be there to be involved in treatment. A separate focus group also raised this concept of family members being the ones to support people and encourage people through treatment:

Participant7: Yeh, if we find out somebody got him in the family, we got to [...]

Participant9: And be like “take ‘im, take your medicine,” and family will be support [...] you know that person got ‘im, [you need to] speak to the whole family.
[FG3, SG2]

While involving family did mention concerns over privacy, family were recognised by participants in all three study groups as having a priority role in communication and support around treatment. The evidence points to the family model being an essential part of support for a person through their treatment journey to completion and beyond, whether this be in mitigating stigma and fear through solidarity and knowledge of family history, or in providing reassurance through trust relationships. Consequently, treatment becomes more family-centred, especially when more than one family member is affected, or preventative treatment is offered to stop the chain of transmission within the family. This I argue provides cause to challenge the current treatment model in its lack of recognition for the significant role of family for Aboriginal peoples, including the consideration of the provision of DOT, and an opportunity to expand person-centred care to be inclusive of family-centred needs.

7.3.1.2 Traditional medicine for wellbeing

In addition to family, another important and unrecognised element that emerged from the research in terms of wellbeing was the use of or seeking out of traditional medicine,

especially bush medicine.¹¹⁷ The choice to use customary medicine as a way of managing stress and seeking wellbeing was explained to me by Remy, (P1, SG1-L), “And if it’s too much for me going to hospital and all that changes [...] I just go out bush and get that bush medicine.” Within this wellbeing was again a connection to family and generations before, Remy telling me, “My mum used to take it. It’s good for your nerve, and numbness and whatever you got, you know it clean your thing. We’ve got medicine like that.” Using bush medicine assisted Remy in navigating through their illness experience and persisting with the treatment journey. Using bush medicine was in line with cultural values of health and healing, maintaining a cultural and family connection, and mitigating stress. This worldview of health and sickness was explained to me by a local Aboriginal Health Care Worker:

[We] come from a culture where a lot of things are spiritual health. So, there’s like you know spiritual health and you got sick because of you know [...], “juju spiritual,” something other than a physical cause. You know we believe in not just being that physically sick but having that mental, that mental and emotional and spirituality as well, and Western medicine has only been here for 50 years. So it’s that way of thinking as well.

[HCW6, SG3]

As told to me by another participant in the extension to other infectious diseases, often more trust was placed in the effectiveness of bush medicine over antibiotics, “im antibiotics didn’t bin really do anything so I take the bush medicine for this thing here.” [P8-FG3, SG2]. Remy also described occasions where a preference for using bush medicine meant foregoing prescribed treatment for the leprosy, in not wanting to mix the two:

[For me], if I want to take that bush medicine I won’t take my medication on that day, for the whole day. Like for this, when I had all this (points toward legs) there’s a medicine here, a bush medicine that we use, it goes for any sort of thing on your skin, and you have a shower with it.

[‘Remy,’ (P1-SG1-L)]

The skipping of doses by Remy described in Chapter 6.2 was sometimes related to this preference for bush medicine in the seeking of wellbeing, accompanied with safety concerns of mixing the two forms of medicines together. A similar scenario was identified for another person (affected by leprosy) during an admission to the hospital while I was working. This person had asked if it was safe to use the local remedy Gubinge (Kakadu Plum, *Terminalia ferdinandiana*) with their leprosy medication. In this situation rather than stop the leprosy treatment they first asked for advice from a doctor, who promptly advised against it. My

¹¹⁷ Customary use of plants as medicines, passed on through generations.

argument is that some people will continue to seek out bush medicine as an integral part of their social and emotional wellbeing (Oliver, 2013), whether this be due to trust in the knowledge of these medicines, or connection to cultural self-care. While addressing any potential safety concerns with drug-plant interactions is important and should be done within a scientific and evidence-based framework, complete dismissal of or a lack of support for a person's wish to continue customary practices for wellbeing, may translate into decisions to not take TB or leprosy treatment instead.

7.3.1.3 Peer support: Patients as health navigators

The last theme for discussion on wellbeing was the identification of the role for 'peer' support, that is, people affected by leprosy or TB who have completed treatment and are willing to assist others in their treatment journey. Peer support is an emerging area within TB and leprosy care and refers to the utilisation of persons affected by either condition who have been through and completed treatment, to provide support for other people. This has been referred to as "companionship support," "community champions," "expert patient," as well as "peer support," and has been shown to reduce the "psychological burden" associated with long and challenging treatment (World Health Organization, 2014, p. 187). There is currently no model that is in place for this within the Kimberley, however one of the participants who had been through treatment for leprosy had suggested this to me, unprompted, as a way that they would be willing to help support other people going through treatment, especially younger generations:

Well, I suppose you could get people like me who have gone through it sit down and talk with them about it you know, yeh. Tell them about it so they don't feel frightened you know, things like that. I'm usually good with young people talk about this and that.

[‘Sam’ (P3, SG1-L)]

Peer support like that offered by Sam can provide solidarity especially from feeling singled out and socially isolated, especially due to low endemicity. Peer support provides trust and hope from evidence of treatment success. On building on this suggested idea of peer support, I asked one of the focus groups about what their perspective was, and identified empathy as a key factor in peer support:

Interviewer: What about someone who's been through it themselves who's had leprosy who's had treatment, who comes from another place?

Participant2: I reckon, yeh.

Participant1: Yeh because they would know, what they called it, empathy...

Participant3: Speak from experience porbala¹¹⁸.

Interviewer: Like an older woman, like an aunty or something [...] what if they're from a different cultural group, would that be an issue?

Participant3: Nah... if it's [...]

Participant1: It shouldn't be because they'll have the same disease.

Participant3: Yeh, I don't think it'll be, cultural.

[FG2, SG2]

Remy (P1, SG1-L) had also suggested, "I wouldn't mind, to help people. I mean, I will help other people." Remy already routinely checked their children and other children from extended family for any signs of leprosy. Peer support is a participant suggested initiative that matches what is occurring internationally, and I contend can provide a useful tool as part of the treatment model for TB and leprosy in the Kimberley.

7.3.2 The Local Case Management model

7.3.2.1 Providing psychosocial support.

LCMs, as per the Memorandum of Agreement (MOA) between the WATBCP and WACHS are responsible for "delivering services to benefit the patient in accordance with the agreed care plan and in line with the state TB case management standards." (WATBCP and WACHS, 2017, April, p. 7). According to the MOA, the responsibility of the LCM is to assist local primary health care teams with culturally appropriate relationships, "to improve treatment success and with contacts to improve identification, screening and, if required, early treatment intervention." It is not explicit how this responsibility for cultural appropriateness was to be assisted—that is if the position was to be designated to Aboriginal Health Care Workers from the community, or there was consideration that provision of WACHS cultural safety training and orientation to history of leprosy within the Kimberley was enough as a pre-requisite to assist cultivating culturally appropriate relationships adequately and safely. This statement also presumes that the local primary health care team does not already have these relationships in place. In this way, the assignment of the responsibility of the LCM to cultural responsibility, or at least the way it is written, is odd. In practice, there was often no choice in negotiating LCMs by persons affected. As per the MOA, the LCM was identified by the Regional TB and leprosy program coordinator, who assisted in overseeing regional Case Management with the WATBCP Case Manager. My observation was that LCMs were predominantly non-Aboriginal registered nurses working

¹¹⁸ "Poor fellow", i.e., registering empathy for this person and what they are going through.

within community health with varying degrees of experience with TB and leprosy, ranging from zero to many years but rarely from a specialist TB clinical nurse position.

Relationships between Health Care Workers assigned to act as LCMs, as outlined in chapter 6, were significant for a person's treatment journey. This included the provision of psychosocial support. In considering the role for the LCM in the provision of this support, four key themes emerged from the research (see Figure 10). The first aspect is what I have termed 'who's time are we on?' The incongruence in value of time was identified when interviewing Remy. This was not necessarily an intercultural difference in timing, but an incongruence between what timing worked for Remy, and what timing LCMs had in providing care, constrained due to other work priorities. The consequences were on relationship and an increase in stress, as Remy explains:

Remy: That's why I didn't talk to them. There was too much for me, you know, like they got to understand for us what we going through, you know. They not got to rush us [...] you know? They got to be patient.

Interviewer: Do you feel rushed?

Remy: It's too much for me, like, if they're going to do that, then why use to come telling me all this instead of listening to me? I'm the one that in the pressure side, in the stress.

['Remy,' (P1, SG1-L)]

The frustration articulated by Remy links back to previous chapters on issue of communication and the onus on Health Care Workers to provide clear and transparent information regarding treatment. The impetus for this aspect of 'who's time are we on' is the impact on the relationship between LCM and person affected. There were often occasions where an assigned, non-Aboriginal LCM would turn up by themselves to a person's house without an Aboriginal liaison or without prior negotiation of timing. This intrusion was identified by one Remote Area Nurse, who explained, "I think it's about having people barging in on their lives. At our, to meet our need, they don't perceive it as their need." [RAN3-SG3]. Understandably workloads of LCMs complicate timing that can be allocated to provide support and DOT provision. However, in not having patience, or recognising people's needs, there is the risk of fracturing already fragile relationships and interrupting treatment continuity.

The second aspect of psychosocial support I have termed 'recognition of stress or stigma.' I have talked about recognition in Chapter 6 which plays a key part in the relationship between LCM and person affected for oversight of treatment monitoring and response. The recognition of stress and stigma experience, I argue, is also a key part of this

relationship and includes recognition in changes of behaviour or approaches to treatment such as missing doses or harmful use of alcohol or other substances. Viewing these changes in behaviours compassionately as signs of stress instead of labelling them as negative signs indicating ‘non-compliance’ is essential in providing psychosocial support. A positive example I have provided in previous chapters was the negotiation of place for providing DOT with the person affected, in recognition of their want for privacy. The recognition of stigma or stress experience also applies to its nonrecognition. This is particularly relevant for the power position of Health Care Workers who may unknowingly perpetuate stigma or stress, and links back with the importance of communication within the relationship.

But you don’t want people to put up walls and be like “I don’t want to go there,” like “I don’t want to attend that appointment because I feel shame, that person shamed me”. I’ve seen, we’ve had specialists come in here and they’ve been wonderful, really respectful.

[RAN4, SG3]

The third aspect that emerged as a key part of psychosocial support is what I term ‘not giving up.’ I described in Chapter 6 how in the provision of providing treatment as DOT, Health Care Workers would sometimes give up when unable to locate a person. The impact of relationship was identified to be a relevant factor affecting this motivation of the Health Care Worker in relation to persisting with DOT provision, when persons affected purposefully avoided staff visiting households:

Because I remember the staff getting really pissed off because [the staff would] go around there, and they don’t want to take them [medications], or they can’t find them [...]. So there wasn’t that really—well [the staff] started off very passionate about trying to get the tablets to these people to get them to take them, and then in the end it was like, “not my problem, too hard.”

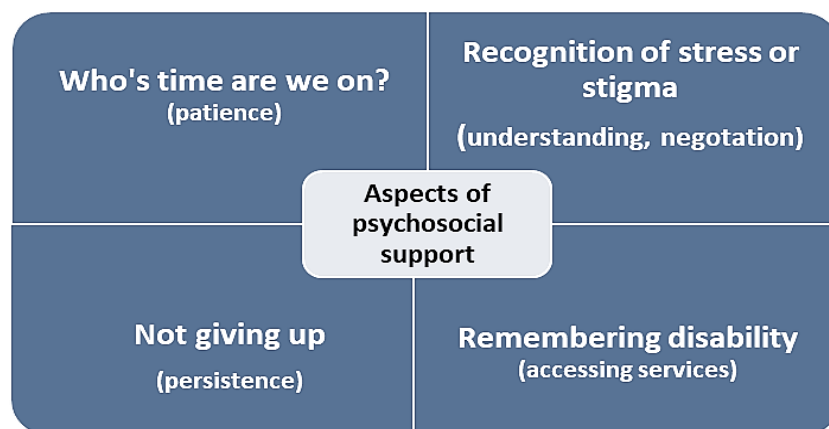
[RAN2-SG3]

One Aboriginal Health Worker describes how perseverance is required, “It’s just perseverance you know with the community health and that client just keeping up that in between, that gap, you know closing that gap in between” [AHW1, SG3]. This ‘gap’ that AHW1 describes is the gap between action (not giving up) and inaction (giving up), in continuing support during challenging times so as not to lose engagement with the person affected.

The fourth aspect for this model of psycho-social support is remembering disability. The relation of early treatment for both disease and lepra reaction in preventing disability has been discussed in Chapters 2 and 6. While disability from leprosy can have physical impacts

(e.g., on the degree of ease with which medication is managed such as when digits are missing), the significant point here is that disability is not reversible and continues to impact livelihoods into the post-treatment phase. Some persons affected at the time of diagnosis already had grade one or two disability, as classified by the WHO (see Brandsma & Van Brakel, 2003). While this research did not purposefully seek to interrogate the disability services support and management for persons affected by either leprosy or TB, no persons with ongoing disability from infection, were identified to be registered for support with the National Disability Insurance Scheme (NDIS). This was learnt during a discussion with one of the Health Care Workers when talking about the barriers for one person in re-integrating back into employment post-treatment. TB is not without its complications. Even after treatment success, residual and chronic respiratory disease can continue from the pulmonary form of TB infection (Byrne et al., 2015; Ralph et al., 2013). Treatment completion from either TB or leprosy does not equate to freedom from the burden of ongoing complications. The post-treatment phase, therefore, becomes an important phase to remember disability. Figure 10 summarises these aspects:

Figure 10. Aspects of psychosocial support



7.3.2.2 Building rapport and establishing relationships.

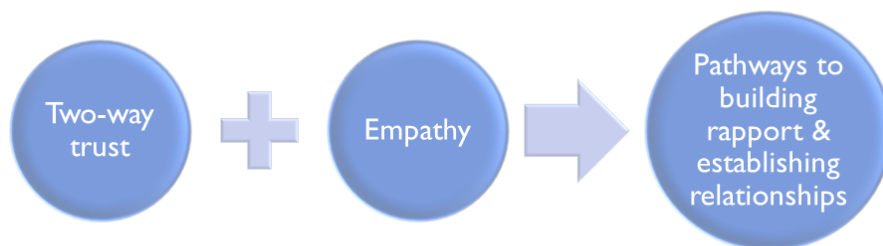
We build on that [relationship]. It's like a rapport, building a rapport, and you know in the future that's just for them to instil a bit of faith in people when they have to be approached.

[AHW1, SG3]

The above Aboriginal Health Worker describes their perspective on working with people affected by leprosy, in the community they live and work. In establishing relationships and earning trust and confidence, building a rapport, or having an established relationship, was

seen as one of the key factors. In further extrapolating this relationship, other participants had recognised that this relationship with case manager was important for treatment, the Regional Physician 2 (SG3), noting it was a “personalised approach that [...] probably works the best” [Regional Physician2, SG3]. In addition, as continued from the conversation with AHW1 (SG3), was, “having that human empathy stuff, be confidential, and making them feel trusted and that they can trust you with all that information”. Two-way trust (as in Health Care Workers must also display trust *for* people, not just earn trust *from* people) and empathy form what I consider the foundation for building rapport and establishing relationship vital for LCMs (see Figure 11) and enable better provision of psycho-social support.

Figure 11. Pathways to building rapport.



Trust is a key theme that has emerged throughout all different sections of this research. This need for trust extended beyond the individual to the community. The example is the TB case that sparked the community wide latent TB screen, where one Health Care Worker, working at the community clinic at the time, had already established relationships with the community. They explained the benefit of this, again in relation to trust, ‘I was glad to be involved because they didn’t want someone from Perth who had no idea about the community and no relationship with the community and the community didn’t know them or trust them’ [HCW10, SG3].

Being able to have the availability of established relationships or maintain a continuity of these relationships was identified to be a challenge and does raise issues for the success of the current LCMS model in aim to integrate public health management into primary health care in the Kimberley region.¹¹⁹ Challenges such as the shortage and high turnover of staff, and current high workloads, coupled with the long duration of treatment,

¹¹⁹ While the structural capacity of primary health care in the region is recognised, and is discussed in Chapter 4, a detailed analysis of this was outside the scope of this thesis.

mean that there were often changes in LCMs during a person's treatment journey. Changes regarding medications and relationships all provide to be stressful. One Health Care Worker recognised the importance of this and was preparing for a known upcoming change to the LCM, stating they were, "going to establish again who would be the next one [LCM] and again I will ask the patient [...], give me time to engage with them" [HCW8, SG3]. This respectful approach recognised the potential stress that this change could have. In considering the current LCM model therefore, I argue that changes in LCM relationships need to be thought of in the same manner as transitions of care. That is with appropriate planning and communication, as a transfer of care *is* occurring with inherent risks impacting on continuity of treatment and ongoing support for an individual person.

7.3.2.3 Aboriginal Health Workers and Aboriginal Health Practitioners as Local Case Managers

One way of ensuring continuity of LCM is with the incorporation of the disciplines of Aboriginal Health Workers (AHWs) and Aboriginal Health Practitioners (AHPs), into the LCM model. AHWs and AHPs were already involved in assisting LCMs and overall treatment program support, via cultural liaison, finding people, assisting with local knowledge, and providing DOT, and in some cases as the principal LCM. Despite this, neither of the current WA guidelines for TB or leprosy, or the regional KAHPF¹²⁰ leprosy protocol recognises their contribution within the LCM model, only referring to the discipline of nursing for case management.¹²¹ With regard to DOT provision, (as a separate role from the LCM), the WA TB Guidelines (Government of Western Australia, 2019(a)) discuss other possible disciplines for administering DOT other than nurses (where agreed to by the person affected) such as pharmacists, clinic staff, although is not explicit about the inclusion of AHWs or AHPs. This lack of clarity in guidelines dismisses this key role that AHWs and AHPs have had in operationalising culturally appropriate ways of supporting treatment within their communities, as identified in DOT provision in Chapter 6. By not clearly promoting the role of AHWs and AHPs, the guidelines also fail to formally acknowledge and legitimise the positioning of AHWs and AHPs as essential for a culturally secure treatment program for TB and leprosy, in reflecting on the MOA between WATBP and WACHS (Bond et al., 2019, p. 7).

¹²⁰ KAHPF is the local Kimberley Aboriginal Health Planning Forum, outlined in earlier chapters.

¹²¹ While some Aboriginal nursing staff had been involved within leprosy care, the proportion of nurses in the Kimberley do not identify as Aboriginal.

The importance of AHWs and AHPs in providing care for persons affected by TB or leprosy, as well as their cultural expertise, was recognised by a number of Health Care Workers. The Regional Chronic Disease Co-ordinator at the public health unit was very firm in their position that, “primary health care is very important, and I will stick on my view that the Aboriginal Health Workers are going to be a big part of the leprosy management.” [Regional Chronic Disease Coordinator, SG3]. Within this statement, however, is the perspective that AHWs are not *already* a big part of management or recognition that they have been since the early 1980s. The diversity among Kimberley communities’ places AHWs and AHPs in optimal positions to know and understand their community and respective cultural protocols, including cultural liaison, bringing strength to the relationship and leadership to the treatment model of care. One Aboriginal Health Worker talked about the way they have empathy for people within their own community:

It’s empowering because yeh that’s something we’re able to do and we do that with respect, and just that empathy. [We] always have empathy when we’re doing our job when you’re dealing with people. Because in our towns, we know everything that’s been going on and how they’ve been coping and all that.

[AHW1, SG3]

As one participant from Focus Group 1 recounts, AHWs and AHPs are often best placed and trusted to provide Directly Observed Therapy (DOT) and a continuity of care in the long-term relationships needed for treatment and post-treatment monitoring:

Participant1: The Aboriginal Health Workers or Practitioners are the ones that are trusted more, because the nurses they come and go, whereas the Health Workers this is their home, they’re not going anywhere. So I reckon if they were to allocate one of the Health Practitioners to do it [DOT], if they want to do it, then it’s a home visit every morning.

Participant5: [...] going drive in there and ask them to take their medicine.

Participant1: [...] then at least you know it’s being monitored.

[FG1, SG2]

Tensions can exist for AHWs and AHPs between mandated job roles in the biomedical health care system, and the need to follow cultural protocols for family and community, unrecognised in this system. An AHW or AHP positioned as an LCM or DOT provider by the regional co-ordinator, without asking the person-affected, may not have the “cultural rights” (Advisory group members, 2019, August). I observed the consequences of this during this research. In aiming to provide a solution to an interruption in local case management for a person affected by leprosy, the regional co-ordinator intervened by asking for assistance

from an AHW at the local Aboriginal Medical Service (AMS) (the person had been a client under the community health service). This person affected was not included in this decision-making. The female AHW selected from the AMS was asked to assist by providing medications but didn't feel comfortable without first involving a family member of this person, so they approached this person's sister. On visiting, this person ended up 'growling' at their sister for getting involved, and consequently requested the AMS not to be involved any more, wanting care to be switched back to community health. A lack of an established and inclusive plan, coupled by a pressure put on AHWs without understanding their local cultural protocols, can jeopardise relations and also place Aboriginal health staff in difficult situations. There is a key role for AHWs and AHPs within both DOT provision and local case management, and it is important to understand from the health workers themselves, the different strengths they bring and the challenges that exist for them in their involvement.

7.3.3 Summary for relationship and wellbeing

In this section I have argued that persons affected exhibited autonomous choices for coping with stress and seeking wellbeing in culturally meaningful ways, such as choosing to use traditional bush medicines. I have shown that family was a key motivator for treatment, demonstrated in family solidarity and a connection with family history. Family was linked with trust, and trust and empathy were identified to be important aspects of providing psychosocial support, not just from family, but also from LCMs. It is presumptive by health providers that the current model of case management utilising LCMS means the designated LCM will provide a continuous and positive therapeutic relationship across social and cultural divides. In practice this is challenging to achieve. Not accounting for changes to these relationships, positive or negative, also does not consider the significance that these transitions can have on interrupting treatment continuity. LCMs were in the majority non-local and/or non-Aboriginal, and I have identified how there was mixed experience in understanding the unique social, spiritual, or cultural psychosocial needs of Kimberley Aboriginal people affected by TB or leprosy. While the model of LCM is a practical improvement on case management provided from Perth due to the ease of existing or building of established relationships and geolocation, there still exists gaps in this model including what I have shown is the need to be more inclusive of the people affected by TB and leprosy in its design. In acknowledgment of these gaps in the current model of care, addressing psychosocial needs extended beyond health care staff for a person affected in finding strength and resilience through to the pivotal role of family and peer support. The move to include

peer workers in this model is an idea from Aboriginal participants and provides one example of this potential for inclusion in the treatment model design.

7.4 Chapter summary

I have demonstrated within this chapter necessary considerations for understanding individual stigma experience and how this is constructed through historical and social contexts of local lives, and the spectrum of experience that exists for Aboriginal individuals. The experience of shame for Aboriginal people, expressed by Aboriginal participants, showed a unique cultural complexity and a diversity across a spectrum. This diversity was demonstrated by individual people's navigation through their treatment journey and associated social worlds, internalisation, and psychosocial support needs. This chapter also demonstrated the importance of key relationships related to treatment and their potential for powerful impact on the wellbeing of people affected by TB or leprosy. This existed on three distinct levels: that with family (and the willingness to disclose diagnosis); that with community and the place within community; and the interaction with health staff and health care services, especially the assigned LCM. I have argued that understanding the role of place and family are key factors in adapting and delivering treatment. Above all, I have argued for acknowledging the resilience and strength among Aboriginal people affected by TB or leprosy in persisting with treatment, overcoming stigmatising experiences, stress, and the challenge of living with chronic infectious disease, along with the changes such diseases bring.

This chapter concludes the findings for examining the current treatment model of care for Aboriginal persons affected by TB and leprosy in the Kimberley region. I have drawn together the treatment model with the biopsychosocial aspects of care. This has brought a richness and depth that better assists an understanding of the dynamic complexity of care and its intersection with culture, place, public health, and social relations, when treating TB and leprosy. Optimising treatment therefore is a culmination of the operational, logistical, and clinical aspects coupled with the deeper evidence identified through Chapters 4—7 of medication safety, treatment supply and access, approaches, and responses to taking treatment, and relationship and wellbeing. To summarise these influences, three overarching organisational themes of decision-making, relationships, and knowledge as primary influences are brought together with the secondary influencing factors for the treatment model, represented in Table 5 on the next page. The implications of these primary factors and

the research findings will be discussed in more depth in Chapter 8, in the goal of answering the thesis research question.

Table 5. Primary and secondary influencing factors on treatment

Influencing factors – secondary							
Influencing factors – primary	Medication knowledge	Medication safety	Attitude & belief	Priorities & wellbeing	Changes	Stigma experience	Supply & access
Decision-making Clinical/Medical Shared Individual (autonomy)	Evidence of effectiveness. Processes (legislative, organisational).	Trust/fear. Treatment intolerance. Too many tablets	Evidence of effectiveness. In denial (I am sick, vs me). Silent disagreement Agency	Motivation, hope vs apathy/not caring. Too much, needing a break. Cultural self-care (e.g., bush medicine). Negotiation of priorities.	Adjustment and livelihood, disability. Choice in LCM. Control over own health. Medication changes.	Negotiation e.g., privacy and treatment. Supply/access. Place-DOT	Mobility. Restrictions. Delayed access & planning
Relationships Health system/organisations Health Care Workers Social/family/community	Communicating importance, consequence, and feedback. Attention to language Mixed messages. Observational-family addressing concerns.	Trust in person administering medication. History forced treatment. Having the conversation, addressing concerns.	Silent disagreement. Control Staff attitudes, bias. Staff motivation Family support.	Family and cultural obligations. Generation and social priorities. Internalised stigma. Psycho-social support. Incentives. Peer-support.	Continuity of care (LCM). Communication about changes. Trust. Support (including reminders). Life and family changes.	Recognition. Perpetuation. Support. Confidentiality, Disclosure (family, others). Social relationships and status, DOT provider	Transitions of care. Stigma experience (privacy). Place.
Knowledge Clinical, Historical Cultural Community	Resources. Missing information. Having the background	Pharmaceutical histories. Personal experience. Observed experience. Multiple systems. Clinical monitoring.	Evidence of effectiveness. Cultural values. Who's the expert. Skipping doses – what does it matter?	Cultural connection. Cultural values on health. Oral histories passed down.	Rationale. Adjustment to new routine. Evidence of effectiveness from changes. Safety.	Solidarity with family history. Community awareness. Processes & place.	Knowing how to access. Organisational planning.

Chapter 8

Identifying and Deconstructing Colonial Logic to Step Toward a Decolonial Praxis

8.1 Introduction

By elaborating on and exposing the colonial wound, narratives of decolonial embodiment urge a departure from the kind of binary thinking that undergirds hierarchical interrelation (such as master/slave, colonizer/colonized, and doctor/patient, among many others) and which produce the attendant monopolization of knowledge and knowledge production. Therefore, understanding the colonial wound as well as its relationship to decolonial thought is essential for the creation of new conceptions of health and healing that take into account devalued perspectives from the underside of modernity.

(Mignolo, 2007, p. 500)

In this chapter I discuss the implications of the research findings in the context of the care-treatment-coloniality/decoloniality intersection, with the intention of addressing the ‘so what?’ of the research question. In doing so, I place emphasis on key research findings that signify ongoing colonising, and present counter-hegemonic strategies to seed new pathways for a decolonial praxis. To start I build on the higher organising themes of the findings presented in Table 5 of Chapter 7 (and re-presented below in Table 6), that is decision-making, relationships and knowledge, and use these as guiding principles for this interrogation.

Table 6. Decision-making-relationships-knowledge guiding principles.

Decision making	Relationships	Knowledge
Clinical/medical ¹²² decision making	Health system/organisations	Clinical (including medicines)
Shared decision making	Health Care Workers	Historical
Individual decision making (autonomy)	Social /family/community	Cultural Community

¹²² I use both medical and clinical decision making to refer to higher-level governance on health decision making and medical care (i.e., medical decision making), and clinical decision making to refer to that that occurs during clinical practice, i.e., “an interaction of application of clinical and biomedical knowledge, problem-solving, weighing of probabilities and various outcomes, and balancing risk-benefit” (Hajjaj et al., 2010)

Each principle, either alone or in combination, have implications for better incorporating care into the treatment model. In answering the research question however, it is not enough to stop at these three guiding principles without further interpretation of what this means for a decolonised practice.

To begin, I present three core areas for discussion. The first is a reflection on the influence of racism in risk determination and the implications of this for clinical decision-making and treatment guidelines. I look at the influence of risk determination in application of chemoprophylaxis, specifically for latent TB, and the implications of this for future TB control, with some reflection on the lessons learned that could also be applied to leprosy. Next I critically reflect on the capacity of person-centred care as a model to be culturally safe without culturally security frameworks in place. This is discussed apropos the influence of neo-liberalism on understandings of responsibility around TB and leprosy treatment; the responses to perceived irresponsibility of people affected by TB and leprosy and subsequent control; and persistent colonial influence at organisational levels on current health care models that assign the location of responsibility. In the third area I focus closely on the nuances of shared treatment decision making and what this means for risk communication, medication safety and power distance within relationships, especially in the context of information exchange and the timing of decisions. To conclude this chapter, I propose a new treatment model of care for Aboriginal persons affected by TB or leprosy and discuss aspects of this model and associated recommendations for practical application.

8.2 Risk determination, clinical decision-making and the influence of racism:

Implications for TB and leprosy treatment process and guidelines.

8.2.1 De-constructing race-based risk

In reflecting on colonial history of public health management of TB and leprosy it is clear that the impact of Western approaches to public health for Aboriginal people have played a major role in the creation, embodiment, and reproduction of racial “discourses of difference” within contemporary clinical practice (Marks, 1997, p. 210). While colonial concepts of biological difference such as inherited ‘racial intolerance’ of leprosy medications or ‘racial lack of resistance’ to TB (see Chapter [4.2](#), [4.3](#)) have long since been disproven as having any scientific basis (Anderson, 2007, p. 144; Chaturvedi, 2001, p. 925) reproduction and normalisation of race-based biological difference and race-based risk factors still occurs (Anderson, 2007, p. 144; Watego, Singh, & Macoun, 2021, p. 4). This continuation of racism is often less overt, disguised through subtle shifts in language that replace race with ethnicity,

‘Indigeneity’ or ‘Aboriginality’ when describing risk associated with populations (Jones, 2000, p. 1212; Kowal & Watt, 2018; Seet & Paradies, 2018).

This becomes relevant to the identified risk of TB for First Nations peoples presented in national and state clinical guidelines. For example, in WA simply “being an Aboriginal Australian” is considered an important risk factor for active TB infection (Government of Western Australia, 2019(a), p. 22). Reflecting on the original TB survey, at the height of the TB epidemic just as treatment was becoming available, incidence rates were lower for Aboriginal people of the North and North West than for non-Aboriginal Australian born residents in Perth. As a result, medical experts at the time dismissed previous concerns of a ‘genetic’ susceptibility of Aboriginal people to TB. It is difficult to understand how the current risk presented in the guidelines all these years later is determined—that is, by geographical location, by proximity to social determinants (as discussed for Indigenous peoples internationally (Basta & de Sousa Viana, 2019)), by other environmental or behavioural factors, by genetic determinism (Gravlee, 2009, p. 49), or by none or a combination of the above. Ironically, this positioning of risk did not assist with the clinical suspicion needed for a timely diagnosis of pulmonary TB for Aboriginal community members presenting to their local clinics. Nor did this positioning of risk aid community members in knowing that because they are Aboriginal, they were considered at increased risk of TB.

In the broader national picture, the 2012 National TB Advisory Committee (NTAC) (2012) guidelines documents First Nations peoples in Australia to be “at higher risk” of susceptibility to TB. By 2019, NTAC had retracted this risk and now *no longer* list First Nations peoples as being more at risk of active TB infection, nor an “at-risk group” more likely to develop active TB infection from latent TB infection¹²³ who would therefore benefit from preventive therapy (Stock & the National Tuberculosis Advisory Committee (NTAC), 2017; The National Tuberculosis Advisory Committee, 2019, pp. 12,13). In fact, Indigeneity is no longer mentioned anywhere in association with risk for progression to active disease by NTAC. In the 2015 Communicable Diseases Network Australia (CNDA) guidelines however, First Nations people in “some parts of Australia” (and later suggest this is localised to Northern Territory or Queensland) are considered to have increased risk of TB infection due to “adverse social and health factors.” They go some way in describing this association due

¹²³ The risk of conversion from latent to active TB is increased with comorbidities of renal disease, diabetes, immunosuppression medications, HIV, in those who are older, children (Stock & the National Tuberculosis Advisory Committee (NTAC), 2017)

to experience of social disadvantage such as overcrowding (that increases likelihood of household transmission), clinical vulnerabilities such as high chronic disease rates that increase the risk of reactivation, or chronic lung disease that can, due to similarities in clinical presentation, confound diagnosis of pulmonary TB infection (Communicable Disease Network Australia, 2015). The variation in risk may be explained by evolving evidence of epigenetics and associated biomarkers with social factors, that is the “embodiment” of social inequities that have biological consequences (Gravlee, 2009; Warin, Kowal, & Meloni, 2020, p. 103). As both authors discuss, this has important bearings for populations experiencing social disadvantage as a result of colonialism and intergenerational trauma (Gravlee, 2009, p. 52; Warin et al., 2020). This line of thinking about risk may provide understanding for how the CNDA guidelines present risk for Aboriginal communities within Australia which either historically have had higher burden of TB or bear the biggest burden of socio-economic disadvantage, however, still presents issues for continuing race-based biological difference.

Caution is required in how risk determination is articulated in guidelines to avoid misrepresentation of actual diversity across First Nations peoples in Australia, as well as to adequately de-link from articulations of racialised risk inherent in colonialism that are “primarily ‘biological’ and ‘natural’, and therefore inherent and unalterable” (Rigney, 2001, p. 4). This is important to re-position Aboriginal people ‘as the problem,’ to, ‘having the problem,’ which alters the direction of resources to address real needs and deter any abrogation of political responsibility. Other authors caution about blaming or fixating on the “social paradigm” (Isaakidis, Smith, Majumdar, Furin, & Reid, 2014) or pointing “a finger at the social determinants” (Orr, 2010, p. 15) whilst ignoring deficit or neglect in health service delivery and equitable access to healthcare. In relation to TB in WA, for example, no lens, to date, has been applied to the national TB campaign—perceived as successful—in failing to adequately achieve the same degree of disease elimination for Aboriginal people as for non-Aboriginal Australian born people in the state, particularly for harder to reach remote areas. Or to current programs that fail to put the effort and resource in to modifying service delivery to ensure treatment programs are culturally meaningful as well as effective.

The mislabelling of race also shows up in perceived social and behavioural traits in the determination of health risk behaviours (such as smoking, alcoholism, and one’s ‘lifestyle’) that influence clinical risk determination and can form part of clinical decision

making (Bond & Singh, 2020, p. 198).¹²⁴ Clinical literature is another area where risk and behaviours associated with First Nations people has been seeded. For TB, this is exemplified in the 1995 article “Aborigines and Tuberculosis: Why They Are at Risk.” Although now 20 years old, given the paucity of literature for TB in First Nations peoples in Australia, such literature holds an important place. Plant, Krause, Condon, and Kerr (1995) conferred that “the existence of concurrent risk factors for TB and HIV, in a population that already has a high rate of infection with TB is cause for grave concern” (p. 487). The concurrent risk factors listed were determined from reported higher rates of others sexually transmitted diseases among Northern Territory Aboriginal peoples (not distinguished by age, gender, place or known sexual or injecting drug use behaviours), as well as chronic disease rates and “alcohol abuse.” This latter risk factor was determined based on evidence outside the Northern Territory, by a report in the Kimberley region that suggested Aboriginal people were “less likely to drink alcohol than non-Aboriginal people,” but those who did drink, did so to more riskier levels (MacRae et al., 2013). How this became extrapolated to a different setting and then applied as a general risk factor of “alcohol abuse” I argue is an example of how risk becomes conflated with Aboriginality at a population level, and how negative stereotypes have perpetuated the linking of Aboriginal people as a population group to anti-social behaviour. The critical issue that presents here is how this subsequently influenced (and still influences) the *intellectual imagination* of clinicians and discernment of behavioural risk determination for TB—eight years after Plant and colleagues released their article a report on TB-HIV comorbidity in the NT identified that there was very little TB-HIV co-infection identified in the NT, despite earlier cause for “grave concern”, (Tropical Health Working Group, 2003, p. 34).

As argued within this thesis, negative perceptions towards Aboriginal people around treatment adherence and social behaviours in the Kimberley persist, particularly in relation to what are deemed ‘chaotic’ lifestyle choices and ‘reliability’. If stereotypical associations of Aboriginal people remain perpetuated through clinical guidelines or clinical literature without counternarratives to these stereotypes, then they continue to hold power within health discourses by implicit association, even for those who “consciously seek to avoid their use” (Hinton, 2017). These stereotypes I argue become part of heuristic thinking, i.e., mental shortcuts or “cognitive efficiency” that act as non-clinical (and subjective) influence on

¹²⁴ Such a risk association with behaviour is prominent in health promotion resources, spurred from the 1986 Ottawa charter and influenced from “La Londe’s Notion of Populations at Risk” report from Canada in 1974 (Frohlich & Potvin, 2008; Tulchinsky, 2018)

clinical decision-making. When under time pressure, this heuristic has been found to be more likely to occur and does so often outside of conscious awareness (Bodenhausen, 1990; Hajjaj et al., 2010; Link & Phelan, 2001, p. 369; Quigley et al., 2021, p. 3; Reyna, 2008). The consequences of such prejudicial heuristics are significant in the capacity to optimise care. The experience of the person affected by leprosy being dismissed on presentation to hospital with unrecognised leprosy neuropathy, instead being told not to sit on their feet, is an example of how this occurs in practice and the delayed treatment intervention that results. It also demonstrates how these negative stereotypes can contribute to the stigmatisation process, via blaming people for their own situation and hence without appropriate care provision (Bond, 2007; Quigley et al., 2021). Stigma experienced from such racial stereotypes can be internalised and coupled with any TB or leprosy stigma, anticipated or experienced, becomes compounded (also referred to as “layered” or “intersectional” stigma) (Jones, 2000; Singer et al., 2017; Treloar et al., 2016, p. 36). This warrants extra attention to wellbeing and the role of stigma as a social determinant of health (Craig et al., 2016) and the consideration of stigma as an environmental risk factor. Working to de-link from and counter these stereotypes through critical reflection in both clinical guidelines and clinical literature that inform risk determination and clinical decision making is an essential step to decolonising care for both TB and leprosy.

8.2.2 Preventive therapy and risk: Individual versus community approaches

The use of preventive therapy (chemoprophylaxis) raises similar concerns for risk determination and clinical decision-making for future application in the goal to elimination of disease and meeting targets of zero disparity for TB (The National Tuberculosis Advisory Committee (NTAC), 2019), and zero disability and disease for leprosy (World Health Organization, 2021b). With respect to TB, the lived experience presented in this thesis of community members involved in the community wide TB screen¹²⁵ provides some important learnings for future decision-making of screening for TB with the intention to treat¹²⁶ latent disease in partnerships with remote Aboriginal communities in a low incidence area. The decision to screen the whole remote community raises questions about how risk was

¹²⁵ In the Northern Territory community wide screening is suggested after 2 or more people become known to have active TB within the same community in a 12-month period, or where a second person is identified through contact tracing from the original person identified with TB disease (Meumann et al., 2021, p. 8).

¹²⁶ Intention to screen is intention to treat with chemoprophylaxis or offer two-year chest x-ray surveillance (Meumann, 2021)

determined and communicated at the community level given a) not all community members met the current risk criteria for risk of active TB or risk of conversion of latent to active TB under the national guidelines (such as household contacts/family, children under five, having diabetes or chronic kidney disease or being immunosuppressed (Stock & the National Tuberculosis Advisory Committee (NTAC), 2017), and b) how extended family and kin networks not resident at the community were included. Screening for TB in a community known to have people also affected by leprosy also raises questions of the reliability of Mantoux testing given reported false positives in the presence of non-TB mycobacteria (Abrahams, 1991, p. 129)¹²⁷. Given the increased resource required for such an intensive screening and the commitment to follow through people for the six-to-nine-month treatment process (if using isoniazid) screening is only one part of the equation. The experience of Aboriginal community members from this research demonstrated it was the treatment and follow-up afterwards that was the challenge. This draws attention to the need for wider discussion at a community level about treatment decision-making, and for follow-up with feedback well after the initial screening campaigns, so people understand future risk of TB for themselves and for the community.

In typical scenarios the benefit of providing treatment is weighed up against any risk of drug toxicity, and, in the situation of incomplete adherence, risk of acquired drug resistance (Fox, Dobler, Marais, & Denholm, 2017, p. 70; Mills, Cohen, & Colijn, 2013).¹²⁸ Decision-making at the community level needs comprehensive consideration of the risks and benefits of blanket screening and treatment relevant to the community, incorporating Aboriginal cultural leadership and knowledge into any TB outbreak response. This will ensure the needs of the community can be adequately met and that caution is taken into avoiding “branding” families within community or the whole community by them being singled out and stigmatised. The other aspect of providing preventive therapy is the decision to use DOT. The use of DOT for LTBI is relevant for aiding regular treatment to assist prevention of acquired drug resistance, but not transmission risk. Given the low incidence of active infection and the tablet burden from preventive therapy is not significant, other methods to encourage people to complete treatment can be employed. This is also where a

¹²⁷ Abrahams writes “It is now accepted that in warm and tropical areas many persons who react to tuberculin tests do so not because of infection by tubercle bacilli but by allied organisms, most probably other mycobacteria” (Abrahams, 1991, p. 129) and has since been confirmed elsewhere (Nayak & Acharjya, 2012, p. 4)

¹²⁸ The use of decision aids that assist with shared treatment decision making has been modelled for latent TB though not adapted for the needs of First Nations communities (Dobler, Martin, & Marks, 2015; Dobler et al., 2017).

decolonial approach is needed in de-linking perceptions of Aboriginal people in community as non-adherent requiring supervision and instead focus on ensuring adequate information exchange and time for deliberation occurs as part of a genuine shared treatment decision-making process.

The experience of chemoprophylaxis management of latent TB also serves as an important lesson for any future implementation of leprosy chemoprophylaxis (i.e., post-exposure prophylaxis or PEP/LPEP). Decisions concerning whether to offer PEP to individuals from close households, or to wider communities as blanket prophylaxis, need to be shared and mutually discussed with individuals, families, or communities. Lockwood and colleagues (quoted in Addis, 2018, p. 97) also raised concerns over the efficacy of PEP in delivering real benefit for communities given that there is no guarantee that taking the currently approved PEP (Single Dose Rifampicin, or SDR) will prevent future infection of leprosy if re-exposed, highlighting the importance of risk communication and dialogue about SDR implementation. Any community chemoprophylaxis would have to be coordinated with active case finding, as the value of community-wide screening is of most benefit where active disease is eliminated at the same time (Fox et al., 2017). Long-term surveillance for the impact of chemoprophylaxis is also needed due to the long incubation and longer-term relapse rates. Finally, decisions to implement PEP need to take into consideration the lessons learned from this research regarding the social experience of people affected by leprosy in regard to their privacy and their anticipation about being singled out/socially excluded if diagnosis becomes known. Therefore, the offering of PEP medications without proper shared decision making and risk communication at individual, family or community levels may exacerbate mistrust with treatment programs where people already hold suspicion of medications and future confidence in these systems.

8.2.3 Integrating cultural knowledge and social history into risk-determination.

How clinical risk is understood, interpreted, or translated for Aboriginal people in remote Kimberley communities or towns for both TB and leprosy treatment warrants attention for current treatment models, especially for chemoprophylaxis and early treatment intervention (where known risk assists clinical suspicion). Cultural and social history have an important role in informing the epidemiological picture and risk of reactivation or recurrence of long-standing latent disease. For leprosy this means considering the widespread incidences across families in the whole region and across generations, and for TB this means inclusion of known past hotspots and how family history is medically and culturally relevant. In

relation specifically to TB, identifying and deconstructing colonial logic is also about abandoning any nationally held perceptions that the Australian TB campaign was a success for *all* Australians, to one that reflects a more truthful reality of the neglect of First Nations peoples through the campaign leading to higher TB rates post campaign. This also links the identity of First Nations people to sharing these effects of colonialism and neglect, but not in linking prevalence to any racially determined risk due to inherited traits of genetics or behaviour.

De-linking from the current narrative that informs criteria for TB reactivation for some areas may also be necessary. Three points are of relevance here. The first is reactivation of latent infection of TB due to waning immunity with age greater than 50 years, or “immune senescence” (Aiello et al., 2019; MacIntyre et al., 2016, p. 4) There are currently different accepted older age criteria (greater than 50 years, as opposed to greater than 65 years) for First Nations people in Australia. How and if this also confers premature ageing in correlation with this age gap has been questioned (Cotter et al., 2012). The relevance for age of potential reactivation or other currently accepted age group cut-offs warrants further consideration. The second is the listed risk factor for active TB in the WA Guidelines as being born prior to 1950 (Government of Western Australia, 2019(a), p. 22), given the possibilities that undiagnosed and/or untreated active TB in Aboriginal people occurred well after treatment became available in 1950, such as the story of the man in his 40s at De Grey station in 1969, (see Chapter 5.3.2.1). The third point is the cultural differences in social networks and families for Western culture that don’t always have relevance for Aboriginal culture that can mean differences in the definitions of close contact and risk of exposure, such as elderly grandparents in looking after children (Lohoar et al., 2014), or for extended family and kin networks.

The use of immunomodulatory therapies such as TNF- α inhibitors may also be a risk factor for reactivating subclinical leprosy (Cogen et al., 2020, p. 1135).¹²⁹ The use of such therapies on the rise calls for a review of how screening of latent disease for Aboriginal people, in consideration of this risk, will be routinely implemented prior to commencing these types of therapies. The inclusion of context for parameters for reactivation of both latent TB and leprosy mean a re-imagining of risk that is grounded in family and the cultural histories and knowledge embedded in Aboriginal communities. Integrating these histories

¹²⁹ TNF-alpha inhibitors (also called TNF-alpha antagonists) are medications that bind to and inhibit the activity of the cytokine TNF alpha, a cytokine involved in inflammatory and immune responses and in the pathogenesis of diseases (Australian Medicines Handbook 2020, online)

and knowledge can potentially address the needs of individuals, families, and community more adequately and determine risk based on a more nuanced place-based, social-cultural-historical context, rather than broad-level associations with Aboriginality. By the incorporation of Indigenous viewpoints and dialogue about what is considered risk, it moves forward in dismantling any “hegemonic colonial construction of Indigenous identities” (Rigney, 2001, p. 3).

8.3 Finding balance in care: Person-centred care, neo-liberalism and locating responsibility.

8.3.1 The self and responsibility

In critically reflecting on person-centred care as a care framework throughout this research, new questions arose about this framework’s capacity as a model of care for persons affected by TB or leprosy to be truly inclusive of culture, disability, and social inequity in addition to that raised in Chapter 1 about the ideology of universal application. Several incongruences were found to exist due to the modern neo-liberal influence on person-centred care and its capacity as a model to embody the principal of care for *all* people (van den Akker., 2019).¹³⁰ The first of these incongruences is the focus on individual autonomy and the value placed upon ‘self-reliant’ individuals as competent or capable individuals (Abrams, 1999; Kendall & Rogers, 2007, pp. 135, 136; van den Akker., 2019). This incongruence has limitations where choice as a ‘health consumer’ is constrained by socioeconomic disadvantage, and therefore can lead to perceptions of ‘incompetent’ individuals through the focus on individual responsibility without pause to consider inequity (Cappelen & Norheim, 2005 p. 478). The question of this capacity of this person-centred care framework is especially relevant to TB and leprosy given the often-associated social inequity and poverty that exists and the subsequent impact on choice and agency (Farmer et al., 2006; Siyoto, 2021) The second incongruence is the limitation in the choice of treatment for TB and leprosy due to fixed recommendations for first- and second-line treatments, but more so the limitation in choice to *not* take treatment altogether. This is due to concerns of infectiousness of TB and leprosy and hence the civic responsibility of an individual to take and complete

¹³⁰ Neo-liberalism arose in the 1970s as part of an economic reform to favour economic growth of governments by dispersal of health care to the private market economy. This resulted in privatisation of healthcare, distribution of responsibility to smaller units and individuals, and influencing health to become for-profit with an emphasis on the consumer and the purchase of health care goods and services, consequently shifting away from the social determinants of health (Baum et al., 2016; Eliason, 2015).

treatment means individual autonomy can be overridden through public health legislation and the argument of the “common good”, creating genuine conflict in practice of person-centred care in treating communicable infectious disease (Horton, 2007, p. 3; Paul, 2009, p. 173; van den Akker, 2019). The third incongruence is in the fiscal sense, that is the option for persons affected by TB or leprosy to receive treatment and services in WA for free through the WA government public health system,¹³¹ as part of the public health goals of TB and leprosy control. This shifts the narrative away from choice and consumerism and reinforces the patient as person, not consumer of services..

The significance of these incongruences is in how this impacts the notions and location of responsibility for the individual. This is exemplified in the state leprosy guidelines where the idea of the neo-liberal self translates to an emphasis on the person affected by leprosy to be self-responsible for their health rather than a “passive recipient” of care (Government of Western Australia, 2019(b), p. 88). Such an emphasis would imply independence and being equipped with the available tools and information to do so, but also carries with it prescribed ideals of what responsibility looks like. A person-centred care-based ideology, along with ideas of the self, is not always commensurate with non-Western cultural values and definitions of the self, and obligations can differ between cultures (Charles et al., 2006; Moreton-Robinson, 2015, p. 12). As such, an additional, fourth incongruence in the neo-liberal model of person-centred care is identified. “Cultural responsibilities” for First Nations peoples means person-centred care may extend to obligations for caring for country and kin (McMillan, Kampers, Traynor, & Dewing, 2010), or balancing “authority with nurturance, relatedness with autonomy” as outlined by Brian McCoy (2008, pp. 18-20) in his work with Kutjungka peoples in Western Australia on the care practice of “Kanyirninpa”, or “holding [...] caring for them.” This is not to suggest that autonomy is not valued within Aboriginal culture, but more so that there are deeper cultural values in relation to responsibilities around health and treatment that may not transport into such neo-liberal paradigms (Brigg & Graham, 2020).

The focus on self-responsibility may reside within biomedical health care through social norms and professional expectations from Health Care Workers about normative health behaviour. Such examples include “social issues” and “chaotic lifestyles” that are perceived

¹³¹ All services associated with notifiable infectious disease management, including treatment for TB and leprosy, are provided free of charge by the WA Department of Health i.e., to protect the public provide access to care and incentivise /remove financial barriers to care (WA Health, 2021, p. 27).

to be causative in interrupting a person's capacity to adhere to treatment. In locating responsibility comes the location of blame. In this sense a person becomes both "victim and vector" of disease, suffering from complications of untreated disease while remaining a risk of transmission to others (Francis et al., 2005). This dichotomy of "victim and vector" is a damaging position also constructed for Aboriginal people through colonial history. This places the responsibility of disease transmission and treatment mismanagement on Aboriginal people, and a person in this situation can be blamed for the ineffectiveness of treatment, justifying punitive or paternal intervention for those deemed to have limited "normative competence" to adhere to treatment (Björnsson & Brülde, 2016; Brink, 2018; Cappelen & Norheim, 2005 p. 477). Refusal of treatment however is a means for some people affected by TB or leprosy in demonstrating agency or taking back control over their own health, recognised as vital for Aboriginal people and considered a social determinant of health (Vickery, Faulkhead, Adams, & Clarke, 2004, pp. 20,30) . In the words of Nakata and colleagues, agency for First Nations people reflects:

[...] a practice of intelligent, self-interested, and pragmatic sense-making based on a distanced observation of the external colonial order being imposed, via the logic and reasoning of traditional modes of analysis, and against the oppressive and often seemingly absurd logic of colonial reasoning applied in local and everyday contexts.
(Nakata et al., 2012, p. 125)

Regaining agency and control therefore is an important method of regaining power and autonomy.

In re-considering individual autonomy however, a relational autonomy may be more apt for TB and leprosy care due to these incongruences of individual autonomy present within public health and for implications from this research for the importance of relationships for treatment outcomes, as well as in considering the meaning of relations for First Nations people's health includes community and Country (Dudgeon et al., 2014, pp. 4,5). Relational autonomy assists in optimising care into treatment models by shifting the location of responsibility to be one that is interrelated rather than placed with the individual and would reconcile with Aboriginal ways of being in ensuring that "autonomous selfhood [...] is grounded in obligation to relations" (Brigg & Graham, 2020, p. 2; Parter et al., 2021). Relational autonomy *balances* relatedness within family and community (and cultural) responsibilities, social positioning, and stigma experience within social contexts and accommodates the fact that the "choices and aspects of self" (such as beliefs, values, self-

ideology) are “shaped and constrained by the social relationship and environments in which we are embedded” (Mackenzie, 2014, p. 43).

8.3.2 Locating responsibility of the Health Care Worker

As relationships with Health Care Workers (HCWs) (in particular with LCMs and DOT-providers) were identified to be significant in relation to treatment, managing expectations of responsibilities within these relationships has implications for the capacity for culturally safe practice. From the perception of Aboriginal people receiving care the onus of communicating information was placed on Health Care Workers (HCWs) rather than the person receiving care being responsible for seeking this information. This expectation was recognised by some HCWs to be their duty to “do the hard yards to make people understand” (see Chapter [6.3.2.4](#)) but was not a uniform practice or understanding across HCWs. Respecting expectations of Aboriginal people is identified within the Cultural Security definition by the Kimberley Aboriginal Health Planning Forum (KAHPF), as well as people’s cultural rights, values, and beliefs (Kimberley Aboriginal Health Planning Forum, 2020). expectations of Aboriginal people can be incongruent with hegemonic neo-liberal ideals of self-reliance and treatment. As (Turner, 2003) points out when considering care in pluralistic settings, it is “unsurprising” that “disputes about morality and the boundaries of acceptable behaviour” occur (p. 114). However, blaming individuals risks absolution of this duty to care from the HCW and their shared responsibility (or even liability) within these relationships, especially in situations where treatment is the intervention to stop infection transmission to others. Such incongruences in expectations also call into question the capacity of the person-centred care model to be one that is also decolonising (and capable of problem-solving the harm from colonisation) *without* also incorporating cultural security measures. It also raises challenges for how a decolonial application of ethical values across cultures would sit within such a framework,¹³² and importantly how these challenges are navigated by Aboriginal health staff.

As a result of mismatched (or uncommunicated) expectations, two outcomes can potentially occur in relation to responsibility. The first is perceived irresponsibility of individuals around treatment that are met with punitive or paternal responses from HCWs,

¹³² In the work on decolonial ethics in human rights and peace education, Zembylas (2020) argues that decolonising ethics is not simply about the recognition of, “the values of intercultural dialogue and cultural differences,” rather that, “decolonial ethics imagines a set of ethical orientations that confront conventional assumptions about culture and history and challenge the normally uninterrogated consequence.” (p. 3).

such as those identified through this research of increased surveillance and the tightening of restrictions on supply duration, to gain more oversight. Paternalising measures can result in DOT being utilised as a method of supervision (as opposed to a model of support), and in decisions being made for people rather than with, a type of paternalism whereby judgement is passed that an individual isn't "competent to make adequate decisions" (Enoch, 2016, p. 22). Such paternalising I argue, sets up dependent, rather than interdependent, relationships prompting a person to become a 'passive recipient' of care, or, on the other hand, 'non-compliant' by refusal. This in turn can cement medicalisation of a person as 'non-compliant', or 'unreliable,' justifying future paternal, or even punitive, intervention. Punishment as a response to nontreatment becomes an allowable (and normative) fallback position in these situations to gain more oversight and control, further normalising diminished autonomy and reinforcing power hierarchies, justified within the framework of Mill's liberalism theory (Brink, 2018, p. 6; Sagbakken et al., 2013). This is especially relevant in relation to decision-making made *for* and not *with* people, for the sake of their best interest in any post-colonial context reinforcing that colonialism is indeed, not 'post', but continuing (Narayan, 1995, pp. 133,134). Such discourse negates the opportunity to work with that person to adequately identify contributing barriers to treatment (such as addressing a person's concerns about the safety of treatment) and provide appropriate incentivising. Punishment, or punitive measures of response, change how people are being cared for, and are unlikely to assist empowerment, risk further damaging relationships, and contribute to cultural harm as a result. In this way, neo-liberalism acts as a guise for ongoing colonising, and reaffirm what Bargh and Otter (2009) argue that the "messy actualities of neoliberalism [...] cannot be extracted from the genealogy of colonisation" (p. 154). Finding ways to negotiate and communicate expectation and responsibility within the HCW-person affected relationship is essential to avoid unnecessary paternal and punitive responses.

Negotiation and communication are also essential to avoid *nothing* being done, the second outcome where *no-one* takes responsibility, allowing for neglect in care altogether. This 'doing nothing', or 'knowing but not acting' related to situations where HCWs gave up on people or, lost motivation due to challenges faced in continuing to support or find people among other competing work priorities. It also related to not knowing how to act or engage in difficult situations or reaching an impasse altogether, consequently widening the gap in the relationship between HCW and person affected. This frustration in disengagement was articulated by one non-Aboriginal Health Care Worker in witnessing someone not taking treatment, exemplifying challenges in reconciling expectations in combination with feeling

powerless to help as is customary for health care professionals. This type of frustration can lead to further neglect or the blaming of individuals for not engaging or co-operating with treatment plans. This type of frustration also led to the seeking of legal advice about the public health order to better understand organisational responsibility where refusal to take treatment persisted. As identified in chapter 6.3.2.4, most HCWs articulated their discomfort and hesitation to act in such a way, demonstrating the inherent complexities and tensions for HCWs in being caught in between their duty to care and their part in higher-level public health legislative requirements for responses to act on non-adherence that they may not always agree with. By having appropriate structures in place for treatment programs assists in removing some of this burden off individual HCWs and may resolve inconsistencies in interpretations at the coalface of care in relation to the location of responsibility.

8.3.3 Responsibility of the state

Archival research provides insight into the basis of the past relationships with the ‘state’ for public health medical decision-making for Aboriginal persons affected by TB or leprosy. While it doesn’t always tell of those favourable relationships among visiting physicians with local community who weren’t in power, it tells us about those physicians such as Dr. Cook who were in power to influence the course of care, highlighting relationships and a history of fractured relationships as key areas of importance for modern healthcare in relation to TB and leprosy. This means additional layers of complexity are present within current health system relationships with Aboriginal people and community due to these past practices and acts of exclusive decision making that have filtered through into health institutions as normalised. A significant part of these relationships are relationships with the state and their responsibility in improving systems to avoid pressure put on HCWs and organisations to be unable to effect better care.¹³³ It is necessary to de-link from the colonial logic that still presents around managing treatment continuity, in order to avoid blame and opportunities to be ‘scolded’ or ‘punished’, instead remembering the beneficiaries of treatment¹³⁴. At a governance level, this applies to the presence and use of the Public

¹³³ In “the tyranny of the neo-liberal public management.” Patrick Sullivan (2018) suggests that the state “at its most abstract is an assemblage of coercive practices tending always to reinforce existing relations of power founded in control of the economy” (p. 201).

¹³⁴ In 1972, in his essay entitled “Aborigines and Australian Society,” (Stanner, 2010) provides reflection on such location of responsibility in discussing matters such as colonial ideals of education, social progress and economic development: “...the presumption that our measures and methods *should* work, and the presumption that there is something almost inexplicable in their failure or comparative failure. Was there also a presumption,

Health Order for treatment detention for both TB and leprosy that still exists. The Public Health Act reinforces the ongoing exercise of state power and with respect to infectious diseases, historically public health powers have been more often used against people with relative powerlessness to object, such as “the homeless, ethnic minority populations and the poor” (Martin, 2006, p. 132). This raises important questions about the actual risk of transmission of disease and how this risk is both decided and communicated based on the “threshold of risk” and Mill’s harm principles (Brink, 2018).¹³⁵ It also raises questions as to why there is still a need to have such powerful legislation as an option for leprosy, given that leprosy transmissibility is low, and it affects a minority of people and predominantly Aboriginal Western Australians, immigrants, and refugees. Given the historical relations between the state and Aboriginal peoples the very inclusion of the option for treatment detention is at ill-ease with any model of culturally secure care.

The implications are for the deep shift in relationship required to arrive at a mutual understanding through dialogue of expectations and responsibilities of each party within a reconfiguration of the political relationship (Bond & Singh, 2020, p. 199; Nakata & Maddison, 2019, p. 408). This applied to TB and leprosy at both individual levels and expectations / information about treatment, and at community levels in supporting systems to ensure safe and effective treatment such as deeper commitments to medication safety and overcoming barriers for people to access timely treatment and diagnosis. At a governance level, the reported widespread occurrence of non-adherence among people affected by TB and leprosy by Health Care Workers (discussed in Chapter 6) points towards a failure of the system to address some fundamental understandings of the importance of treatment at both individual and community levels (Farmer, 1996; World Health Organization, 2010). Health service capacity is an integral part of being able to deliver effective treatment programs. In this way, the ‘recrudescence’ of leprosy in 2010 can also be attributed to a failure in the health system, (rather than a natural cycle of infection) due to the decision to disband specialist leprosy services in the early 2000s and consequently stop active surveillance, despite the predicted need of longevity of services (Mak et al., 2003; McNulty, 1984, October 12). This kind of neglect has also been linked to a type of institutionalised racism, which is, as (Jones, 2000) asserts, “is often evident as inaction in the face of need.” (p. 1212). The

on an unvoiced but deeper level that the Aborigines are a main part of the trouble? In the end it often comes down to dark hints about their mentality, social habits, and oddities.” (p. 248).

¹³⁵ The threshold of risk refers to the threshold that needs to be met in order for harm to others to be considered a risk (Brink, 2018)

lesson learned here in order to not fail the community again is that in the goal of elimination of leprosy specifically, there is an obligation of the state of a long-term commitment and enactment of a long-term strategy with supporting resources. As articulated by regional physician1 [SG3], “If we drop the ball on leprosy again, we’ll look like idiots. As a region/state if we lose the opportunity to control leprosy that would be a mistake,” further adding that *if* such a mistake was to be made again, “I don’t know how we justify that to the next generation.” In improving the political relationship, shared responsibility to enable shared decision making and negotiation of expectations is a step forward. However, caution should be applied to notions of shared decision making that can be misused as a “tacit governmentality strategy” in cycling back to locating responsibility with the individual (Glasdam, Øye, & Thyryssøe, 2015, pp. 1-2). Location of blame with individuals or community can in turn disguise social and political origins of disease or failures to control disease (Lock & Nguyen, 2010, p. 79). A prime example is the Mulan agreement that aimed to reduce trachoma rates in Mulan community, in North West Australia.¹³⁶ This shared responsibility agreement was criticised as the focus of the responsibility fell upon the community to change individual health behaviours (such as increased face washing) while the government failed to address structural reform such as improvement in social housing, shown to contribute to trachoma rates reduction just as equally (I. Anderson, 2006; Collard et al., 2005). Shared responsibility agreements have also been criticised for oversimplifying the complexity of First Nations disadvantage (Boddington, 2016), and serves as a future warning to that aim to eliminate TB and leprosy and address the syndemic of disease with social and structural determinants known to be conducive to TB and leprosy transmission^{137,138} (Cruz, 2018, p. 5; Donaldson & Rutter, 2018; Farmer, 1996). An example of such a syndemic identified during this research was the co–presence of rheumatic heart disease¹³⁹ in two persons affected by leprosy, and the co–presence of both TB and leprosy within one remote

¹³⁶ The Mulan agreement was a shared responsibility agreement (imposed by the federal government) that aimed to improve trachoma in Mulan remote community in Western Australia south of Halls Creek (Collard et al., 2005)

¹³⁷ A syndemic is described as “multiple detrimental interconnections that occur among co-present or clustered diseases and other health related conditions in a population and the social and socioenvironmental factors that prompted and enhance negative effects produced by disease interaction” (Singer et al., 2017, p. ix).

¹³⁸ A fact that First Nations peoples living in remote communities themselves have expressed concern for “sharing sickness” and the hopes for their children and grandchildren (see Lowell et al., 2018).

¹³⁹ Also considered to be a neglected disease relative to its burden worldwide and has been a disease of concern affecting First Nations in Australia, particularly in remote communities (Ghamari et al., 2022; Wyber et al., 2020).

community (Singer & Bulled, 2013). Addressing syndemics, similar to the Mulan agreement, means addressing social and socioenvironmental factors *at the same time as* implementing treatment in the goal of disease elimination, as Mavradis (2008) explains:

According to syndemics theory, if a disease is eradicated without taking measures to correct the social conditions that enabled it to thrive, this disease, or a similar one, will return because the social conditions that create the opportunity for disease to flourish still remain. In other words, the biological and social conditions that act synergistically to create an excess burden of disease must be addressed simultaneously. (p. 43)

How this responsibility is located *and* acted upon by the state and its representative will ultimately determine the allocated resource and political support for structural reform. Such reform surrounds the social and structural determinants of health for TB and leprosy transmission and is acted upon simultaneously with improved treatment programs.

In considering overarching governance of TB and leprosy, the division of centralised and decentralised governance responsibilities also creates tensions for treatment, such as the control of supply from Perth leading to delayed access to treatment and local health staff feeling undermined by specialist staff jeopardising confidence in them from local people affected (see Chapter 5.3 ‘who’s the expert’, and ‘mixed messages’). TB and leprosy treatment requires specialist management and oversight, and the low incidence means that resources to do this in regional and remote compete with other more prominent health issues. However, local health staff and organisations, especially Aboriginal Community Controlled Health Organisations (ACCHOs), are often best placed to know local systems, provide culturally secure care and more likely to have established relationships with those people affected. Determining needs from a distance can jeopardise the adequacy of care provided (Tronto, 1993, p. 109). Getting the balance of responsibilities right within these relationships is critical for the optimisation of care and therefore treatment processes and programs.

Placing care in local hands assists with more culturally secure care by cultural leadership and knowledge. This, however, has potentially unseen implications for a greater amount of responsibility on ACCHOs and their capacity to absorb TB and leprosy services, such as chemoprophylaxis programs and available staff for case management. The integration into primary care also has implications for associated funding allocation from the state (leprosy) or the commonwealth (TB), given the niche area, low incidence, and already challenged capacity with the multiple other priorities that exist. Navigating a way to enable the best care for Aboriginal people affected will require that expectations and responsibilities

within relationships at the individual and the community are adequately addressed in partnerships with community and cultural leaders at the governance level.

8. 4 The essentiality of shared treatment decision–making

8.4.1 Shared treatment decision–making and risk communication.

There are many examples highlighted within this thesis of the exclusion of Aboriginal people in medical and clinical decision-making throughout the history, and in the current day. Shared Treatment Decision Making (STDM) is not only an essential component of person-centred care (Barry & Edgman-Levitan, 2012), but is also essential for Aboriginal people as integral to a culturally secure practice due to the history and ongoing practice of decisions made for people in their best interest.. STDM is described as a three-stage process of “information exchange, deliberation, and deciding on the treatment to implement” (Malloy-Weir et al., 2015). The first step of information-exchange is the key area to address risk communication in providing ‘missing information’, and ‘communicating importance and consequence’ about taking treatment, as key themes that emerged from the research findings. In re-considering these themes with the interrogation of the findings discussed in 8.3 above, I also add to this list the need to communicate *expectations* for treatment. This has implications for information-exchange related not only to initial treatment decision-making for TB or leprosy, but ongoing treatment decision-making through a person’s treatment journey. Risk communication therefore becomes more associated with approaches to taking treatment rather than available treatment options and treatment information related to risk needs to address the more difficult to translate concepts such as the relation of treatment to halt disease transmission, and the risk of acquired drug resistance from sub-therapeutic treatment (the latter exemplified by the conversation with the participant Remy about drug resistance, with the reply being “now what do you mean by resistance?” (see Chapter [6.2.1.1](#)). In considering conceptual communication of risk of the resistance concept, the Yolŋu peoples in the Northern Territory report no direct conceptual translation for antibiotic resistance (Vass, Mitchell, & Dhurrkay, 2011). The authors describe how, after some dialogue, an equivalent term was identified that was “drawn from traditional warfare”:

It refers to knowing how your enemy fights and what his strategies are so that you can predict his actions; you can counter his attack because of your knowledge about him and successfully resist him. These terms (in context) can be applied to bacteria that become familiar with antibiotics and become resistant to them (Vass et al., 2011, p. 36).

Incorporating conceptual communication into information-exchange involves finding shared meaning, or “common ground” across cultural understandings to link in/relate to already

established cultural concepts among traditional culture (inclusive of treatment pluralism) (Gillett, 2016; Malloy-Weir et al., 2015; Wilson, 2008, p. 6).¹⁴⁰ Finding common ground not only enables an “inter-epistemic communication” (Mignolo, 2007, p. 453) that assists informed decision-making, but potentially allows for an ontological shift in the positioning of dominant biomedical conceptual understandings towards strengthening Aboriginal cultural understandings (Mukandi, 2017, p. 75). Another example from the research that would capture this conceptual shared meaning is the association of burns with leprosy (presented in Chapter 5.3.2.1) as linked to initial signs of anaesthetic patches that present early in disease and signal the time for early treatment intervention.

The second phase of STDM, deliberation, would also benefit from embedding shared meaning, particularly in relation to risk and when and why to start treatment (and self-present to the clinic). The key differentiation here is in comparing preventive therapy for latent infection, allowing time for deliberation and decision-making among people involved, to that of active infection, where a time pressure to start treatment as soon as possible exists. On the odd occasion, treatment for active infection has room for deliberation where diagnosis is uncertain or there is less risk to the public, such as non-pulmonary TB, allowing time for discussion with family or other important relations that may impact autonomy. Hence deliberation is also key when respecting cultural differences in the final step of making a decision, such as noted differences in the “*direction* in value-orientation,” that is “individual [decision making] supported by the group” which is more typical for Aboriginal people, as opposed to “individual [decision making] supported by the leader,” which is more typical of Western culture (Eckermann et al., 2006, p. 89). This value orientation deserves more recognition for its impact on STDM and risk communication.

In considering the last stage identified by Malloy-Weir et al as the final process of making a decision about treatment, decisions here provide less room for treatment options and focus more on decisions whether or not to take treatment at all. Due to strong evidence-based recommendations for first- and second-line therapies, TB and leprosy treatment does not offer much in the way of options for initial treatment choices. However, as highlighted in Chapter 5 and 6 there are other ways to apply decisions within the framework of STDM

¹⁴⁰ Traditional Aboriginal medicine and associated concepts of health and healing are often deemed inferior, therapeutically delegitimised, and considered “unscientific” and approached with suspicion (Austin, 2015; Ramugondo, 2018, p. 87; Rigney, 2001, p. 4). A perspective which for Aboriginal people holds no basis as the use of traditional healing and bush medicines continue as part of a pluralistic health system of wellbeing management and connection to culture as evidenced in this research, and also from others alongside, or instead of biomedicine (Oliver, 2013; Saethre, 2007).

around treatment. Such examples include negotiating second line therapies where intolerances of individual medications exist, discussing options for adjunctive treatment, decisions about treatment supply and access arrangements, the use of DAAs, and other tools to assist treatment management (such as medication lists), are all relevant areas for discussion and STDm.

8.4.2 Shared treatment decision-making and considerations for medication safety.

Finding common ground or shared meaning about treatment to facilitate the process of STDm also has implications for talking about medication safety. I discuss two aspects of medications safety from the research findings here in more depth that have relevance to practice and build on the discussion from Chapter 5.4 (medication safety) and Chapter 6.3.2.3 (alternative treatment regimens). The first example of exclusion in decision-making is in the use of adjunctive treatment, in this case in the decision to not use thalidomide alone or in combination with prednisolone for one person with severe Type 2 lepra reaction. The fear about using thalidomide from HCWs can be understood due to its safety risks. Excluding the person affected from these decisions, however, follows the worn path of colonising paternalism in deciding what's best for Aboriginal people (or judging what's best for a person) and not making them an active part of this discussion. 'Having the conversation' identified in Chapter 5.4, means taking time for this STDm process of information-exchange and deliberation, and in situations of adjunctive treatment where there is choice, about deciding on the treatment to implement. This is especially relevant given the memories and experience of medication experimentation without information provision, and the subsequent feeling of being like 'guineapigs', related to people's experience in Bungarun and forced treatment.

The second aspect of medication safety relates to the health system and health organisation responsibility to ensure proper planning and capacity to perform routine clinical monitoring, such as regular blood tests to exclude liver toxicity. The information exchange about medication safety and the recommended steps to ensure medications remain safe and interventions can be made if there are witnessed intolerances or allergies is a necessary part of STDm. This step also allows for deliberation in having the conversation about the required testing and the plan in place for this, throughout a person's treatment journey. Involving people in their plans for clinical monitoring of medication safety is essential and has its challenges within the region. As presented in Chapter 5, the development of severe hepatotoxicity from isoniazid prescribed for latent TB may have been preventable if the

persons affected were provided with initial information about what symptoms to monitor for, and if plans had been made for routine blood tests such as providing the person with pathology forms and instructions on when/where to get the tests done. STDM that incorporates early discussions with the person about clinical monitoring needs also supports clinicians to have more confidence in safely offering early treatment, as long as plans put in place are clearly documented and accessible by other health staff. Determining what is genuinely urgent treatment, such as for active pulmonary TB, versus that which does not have the same urgency, such as preventative treatment, is a critical part of the balance in treatment decision-making that also ensures treatment is safe.

The same principles of STDM related to medication safety can also be applied in the consideration of testing for any genetic susceptibility to adverse drug reactions, such as isoniazid acetylation (Ohno et al., 2000) or dapsone hypersensitivity (DHS) due to HLA*B13 deficiency (Zhang et al., 2013). In identifying anecdotal evidence that was relayed during this research about DHS (Chapter [5.4.2.3](#)), caution needs to be exercised in any perpetuation of anecdotal accounts of “genetic determinism” from generalised pharmacogenomics that link adverse drug reactions to Aboriginality (Emma Kowal & Frederic, 2012). Routine STDM is an important support to overcome any mistrust in the safety of medications and is a necessary step in optimising the use of medicines for treatment of TB and leprosy. Routine STDM also relates to being provided evidence of safety as well as effectiveness, including options for pharmacogenomic testing and the implications of this. Initial and ongoing discussions on these aspects of treatment are important and help to ensure that any gaps in communication between the person affected and health staff do not widen to a point of complete disengagement.

8.4.3 Shifting power within relationships.

Power is not a *substance* that the powerful As possess, but a *relation* between As and Bs
(Selg, 2016, p. 183).

A point of difference in the treatment models for TB and leprosy to non-communicable infectious diseases is the utilisation of LCMs and DOT providers. A deeper consideration of the power locus within these relationships is necessary. The power given to both the case manager based in Perth and the LCM allocated within the Kimberley region is sufficient to be able to escalate concerns about ‘behaviour’ around treatment adherence to

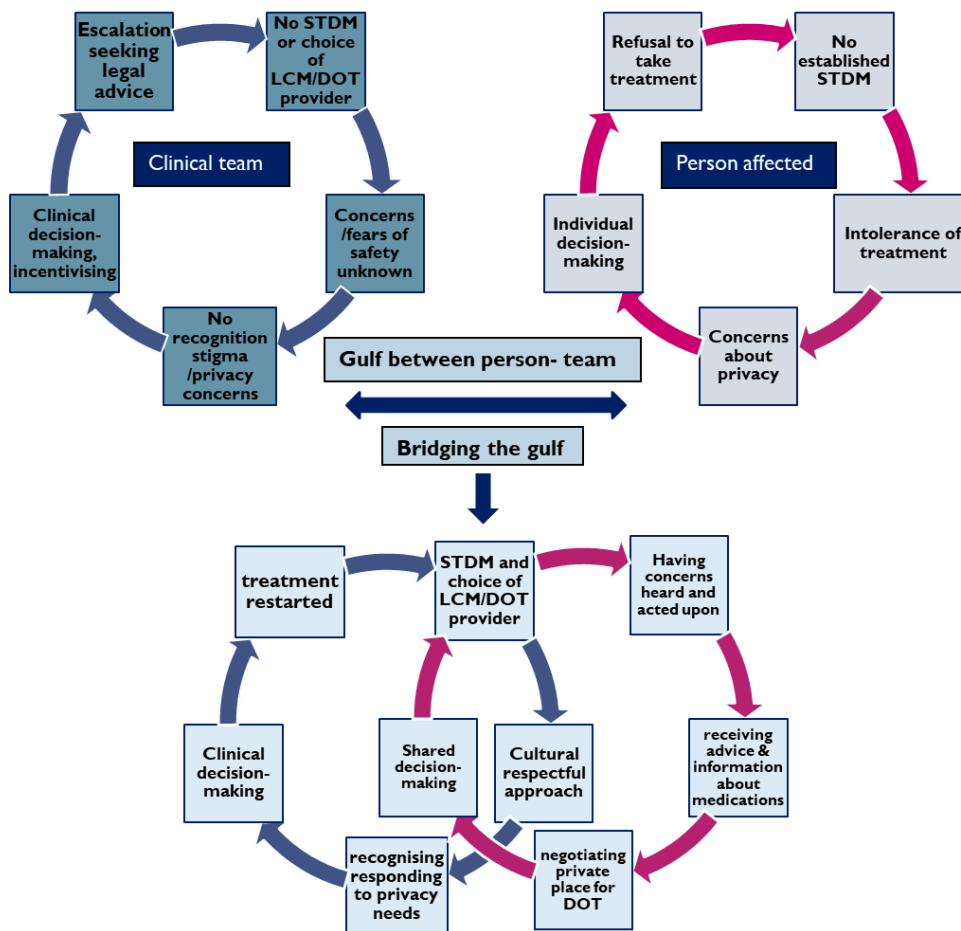
senior staff, and the responsibility to ensure that treatment is uninterrupted as much as possible (Government of Western Australia, 2019(b), p. 98). This power that can exist within newly constructed and potentially dependent relationships and can threaten the autonomy of people affected. In addition, dependent relationships can sustain any power hierarchies. Consequently, the LCM/DOT provider becomes an influential operator in facilitating therapeutic space or perpetuating harm. As most LCMs and/or DOT providers selected are non-Aboriginal, and can even be new to the Kimberley region, the likelihood of an “ontological gulf” in their social positioning to that of persons affected by TB or leprosy is higher (Guthrie & Walter, 2013, p. 241). This is not just due to inhabiting different cultural or social spaces, but also in their proximity to TB and leprosy illness experience. That is, HCWs who do not identify as Aboriginal are statistically less likely to be affected or have family that are affected by either TB or leprosy, creating a distance in the illness experience, and potentially altering the ability to empathise. This distance, both in power and illness, in addition to perspectives about responsibility discussed above, have unknown influences on decisions to escalate when treatment non-adherence is suspected.

Given the criticality of these relationships, shared decision-making for treatment should also be shared decision-making or negotiation about these treatment relationships with LCM and DOT providers. There is often minimal choice for LCMs/DOT providers due to: the remote context; the paucity of specialist experience available from potential LCMs; the variable degree of lived experience within the Kimberley and in working within culturally safe ways; and the duration of the treatment journey meaning that LCMs can go on leave, change sites, or leave the region altogether (prompting a transition of care for the person affected). This is primarily the reason for considering Aboriginal Health Workers (AHWs), or Aboriginal Health Practitioners (AHPs), as valid candidates for LCMs and DOT providers, who, as already evidenced from this research, provide reliable support for people affected. In addition, AHWs and AHPs live and work in the community or wider community and are more proximal to illness experience. Organisational policies need to be supportive of this practice, especially around medication administration for staff not currently recognised under legislative or organisational medication administration policies.

For non-Aboriginal LCMs or DOT providers, bridging the ‘gulf’ within relationships through shared treatment decision making assists a shifting of power through empowerment of people in being involved in their care and having their needs addressed. A fundamental aspect of this is two-way trust, especially in building upon fractured relations from a history of colonisation and colonising that is still present. There is real risk of these relations being

re-fractured in settings or circumstance where trust is broken or never gained. Therefore, the work to value relationships as a priority and establish routine shared treatment decision making, I argue can be considered as an important adherence strategy that should be valued equally, if not more importantly, than the adherence interventions currently in place. They should also be at the front and centre of any decolonised approach to working with any person affected by TB or leprosy. Figure 12 below represents a visual diagram of such an intervention, unrecognised at the time, and initially discussed in Chapter 6.3.2. for a person who refused treatment for leprosy. The first line of the diagram shows the initial situation without shared decision-making and the separation between clinical team and the person affected. The second line shows the outcomes from a renewal of negotiation and shared treatment decision involving place and person for providing DOT as well as addressing medication safety concerns.

Figure 12: Shared treatment decision making and bridging the gulf.



The other important aspect of providing TB and leprosy care as LCM or DOT provider is the provision of care and treatment often at a person's home, rather than the clinic. In this setting there is increased proximity to illness that separates the usual boundaries of care afforded by the design of health sites. It invites HCWs into private spaces of living, forcing persons affected by disease into relation with the health care system in ways that they did not have to engage in previously, extending the gaze of the clinical domain (Foucault, 1989, pp. 108-109). This reinforces the importance of negotiating the place of providing supported treatment, such as DOT, with the person.

Providing treatment at a person's home may permit heightened judgement about social ways of living as well increased attention from family or neighbours. Such clinical encounters increase the potential to be sites of anticipated or actual stigma, as identified within this thesis (see Chapter [7.2.2](#)), making visible a person's attempts to conceal any diagnosis of disease or concealment of unusual treatment (White, 2008). This is not to say that there was not recognition among some non-Aboriginal HCWs of the importance, or the efforts of privacy needs and negotiation required to avoid judgement and achieve therapeutic relationships. However, this was often accompanied by a more reticent feeling of what "should" be done doesn't happen for one reason or another, and often reflected on larger challenges of working within health care within the Kimberley, such as competing priorities.

Proximity to illness can also be viewed from the perspective of relationships with non-health workers. In this way, there are two main roles for non-health workers that were identified as valuable relationships in providing support, given the equitable power hierarchies and established trust. The first dynamic includes family members, once disclosure and involvement have been confirmed with the person affected for both their role as supporting through treatment and their potential for assisting treatment through providing medicines under the DOT program (especially in more isolated communities where resources are constrained). The second dynamic is those with lived experience, that is peer support workers, and therefore are the most proximal to illness experience. Such persons demonstrated a willingness to care to support others affected and in caring for younger generations by checking on others for signs of early disease as well as offering help to speak with others not known to them. This peer support role I put forward as part of a culturally responsive person-centred care model that is discussed further below and forms a part of shared decision making and power shifts within usual choices of support for treatment.

8.5 Toward a decolonial praxis: Implications for a decolonised treatment model of care

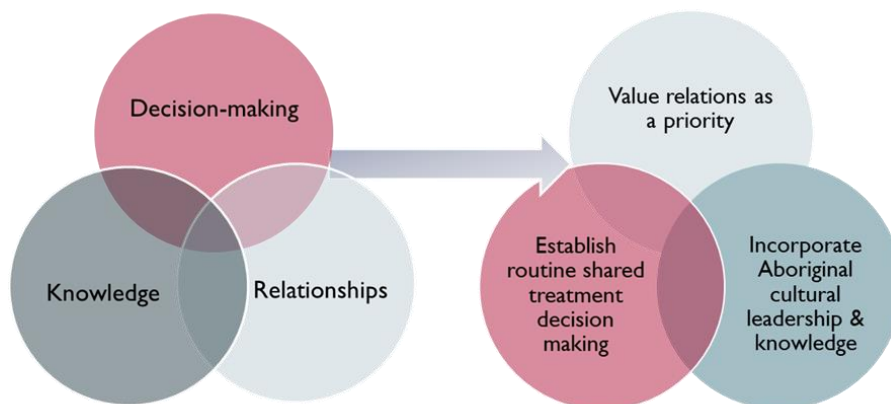
8.5.1 From guiding principles to recommended strategies.

[...] decoloniality refers to efforts at rehumanizing the world, to breaking hierarchies of difference that dehumanize subjects and communities and that destroy nature, and to the production of counter-discourses, counter-knowledges, counter-creative acts, and counter-practices that seek to dismantle coloniality and to open up multiple other forms of being in the world.

(Maldonado-Torres, 2016, p. 7)

The need for a decolonised model that incorporates First Nations worldviews and partners with First Nations peoples has been recognised as an important component of health policy development to address TB infection globally (Basta & de Sousa Viana, 2019; Cormier et al., 2019; Devlin et al., 2019; Møller, 2010; Nogueira et al., 2015). In Australia, the same is true in addressing leprosy infection as well as TB. The identification of colonial logic discussed throughout this thesis and further interrogated in this chapter, assists with its dismantling, and allows space for the seeding of an alternative logic, or new terms of the conversation that have at its core the principal philosophy of care. To do this in a way that provides benefit and a practical place to start, I present here a new treatment model of care. In the path to get to this point from the research findings, I incorporate the interrogation above that review risk, responsibility, communication, power, knowledge, and safety under the guiding principles of decision making, relationships and knowledge to refine recommended strategies into best practice, displayed in Figure 13.

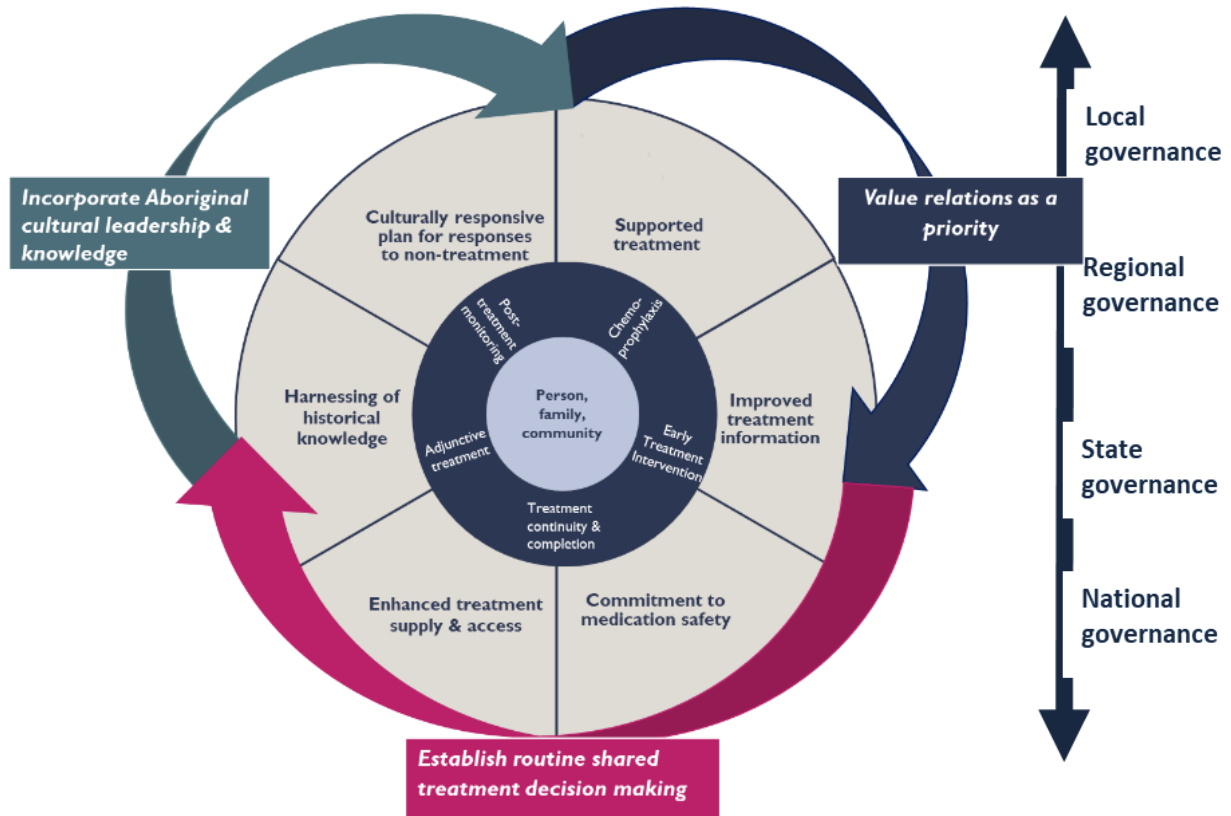
Figure 13. From guiding principles to recommended strategies to better incorporate care



The first of these strategies— ‘value relations as a priority’—not only encompasses the importance of relationships but strives to bring additional focus to placing value on the worth of treatment relationships, cementing, and legitimising them in the strategic place of optimising treatment. Given the history of fractured relations between the settler state and First Nations peoples, the nuance and importance of relationships becomes even more critical in informing the depth and breadth of the relationships associated with treatment extending standard contemporary person-centred care values. This is an essential step to better effect any degree of person-centred care and shared treatment decision making for relationships not just at the individual and family level, but also at community and governance levels. Valuing relations also incorporates the important role of social relations including family in a person’s journey through disease both in the local setting and in the wider society for their experience of solidarity, support, or shame and stigma experience and the benefit that peer support workers can bring as part of this. The second recommended strategy links to valuing relations in ensuring routine shared treatment decision making is established. In addition to treatment information provision, building two-way trust is a priority focus that facilitates this shared process, superseding any deferral to paternal or punitive responses to nontreatment or reaching an impasse. The final recommended strategy is to incorporate Aboriginal cultural leadership and knowledge. In doing so, the strength that Aboriginal people bring to the table can be properly acknowledged and incorporated. Specific areas for incorporating cultural leadership and knowledge are outlined in the goals of care and include informing frameworks for responses to irregular and nontreatment to avoid unnecessary escalation of punitive or paternal responses; in community decision making for chemoprophylaxis and longer-term goals of disease elimination supporting the guidance and training of Aboriginal Health Workers and Aboriginal Health Practitioners; and in providing history education to non-local staff and for community.

In bringing these three recommended strategies together, a new culturally responsive, person-centred treatment model of care for adult persons affected by TB or leprosy (active or latent infection) is represented in Figure 14. As well as responsible to culture, this model also seeks to be responsible to family and community, public health and to individual persons.

Figure 14. A new culturally responsive, person-centred treatment model of care



For practical application of the model five identified components of treatment are incorporated, represented in more detail in table 7. They apply for both TB and leprosy. The separation of aspects of treatment assists with the translation of research findings into practice, such as routine STDM practice and differences for health service delivery related to these components, such as chemoprophylaxis versus early treatment intervention, the latter where treatment initiation may be more pressing to halt infection transmission. In addition, the intention is to draw in the phases of treatment identified in the treatment journey represented in Chapter 6, Figure 8, including the post-treatment phase and the need for managing expectations and concepts of cure from treatment (John & Muliylil, 2001; Venkat, 2018; White, 2009).

Table 7: Integrated treatment components and considerations for operationalisation

Integrated treatment components	Elements for operationalisation
Chemoprophylaxis (latent TB treatment, LPEP)	No risk of transmission of latent infection, treatment is given to prevent future disease
	Key part in strategy of disease elimination as a programmatic response to prevent future disease
Early Treatment Intervention (active infection)	Risk of transmission until after treatment initiated, treatment initiation at hospital or in the community (as per expert guidance).
	Key strategy for improved outcomes for people affected (disability reduction, improved cure, less relapse, reduced transmission period) as well as disease elimination
	Dependent upon optimal combination of early presentation and early detection
Treatment continuity & completion	Important for all treatment with more emphasis on active infection
	Key component of improved outcomes for people affected as well as disease elimination
	Focus on support through treatment journey - implementation and maintenance phases , as well as feedback on progress
Adjunctive treatment	Key component of management of disease complications and prevention of disability
	Key component for wellbeing of person affected
Post-treatment monitoring	Key component for monitoring of relapse of disease (hence risk of transmission)
	Key phase for monitoring for further disease reactions or complications
	Key area for communication to manage expectation about cure after treatment complete

This table is not intended to provide clinical guidance or replace expert input for clinical decision-making associated with TB or leprosy for any component of treatment (especially noting the complexity of some presentations of TB and leprosy and associated factors, as well as the different responses that may be required for latent infection, depending upon the timeframe of exposure to active infection). The table for operationalisation is intended to assist with the concept and integration of the different components of treatment into primary health services in the remote context within the overall treatment model of care presented in Figure 14.

The new model is also completed with six additional goals of care for operationalisation. Primarily, these goals are to support people through treatment, especially for active infection, optimise treatment to be safe and effective, decentralise aspects of treatment supply to improve access, ensure Aboriginal leadership and knowledge is

incorporated, and acknowledge areas of support required from primary health care services in the context of the remote Kimberley region. These goals are outlined in Table 8 and will be discussed individually below in 8.5.2.

Table 8. Goals of care and elements for operationalisation

Goals of care for the treatment model	Elements for operationalisation
Supported treatment	Optional DOT
	Integrated Cultural Case Management – Regional-remote areas (ICCM-R).
	Peer support
Improved treatment information	Aboriginal-led design of treatment resources
	Education modules (medications) for PHC staff
	Clinical pharmacist support
	Tools for effective communication & consistent messaging
Commitment to medication safety	Encouraging transparency about medication safety
	Planning for clinical monitoring
	Streamline & clarify prescribing roles
Enhanced treatment supply & access	Decentralise supply -> Shift dispensing/supply of medications from Perth tertiary hospital to Broome Regional Hospital Pharmacy as central regional base.
	Remove restrictions of 1-2 weekly supply, allowing for routine monthly supply
	Shared Decision Making about the general use of DAAs and WHO packs for leprosy
Harnessing of historical knowledge	Aboriginal-led history education for health staff training and raising community awareness
Culturally responsive plan for responses to nontreatment	Structure & process
	Guidance & action

8.5.2 Describing the goals of care for application of the treatment model.

8.5.2.1 Supported treatment.

Supported treatment relates to people affected by active infections of TB and leprosy and draws from the research findings that identified people benefit from the assistance of communication about the treatment process, encouragement, psychological and social support, assistance in the continuous supply of medications and close monitoring of medication tolerance. This is also in line with evidence internationally presented in chapter 2. Recognition of a person's wellbeing and how they navigate and negotiate for their wellbeing

among other social and cultural obligations is an essential part of providing culturally responsive person-centred care. The concept of labelling this goal of care as ‘supported treatment’ is in the aim of re-positioning the focus on support as the primary element required for the treatment course to assist optimisation for people affected. and includes the model of case management and supportive-directly observed therapy (i.e. not solely supervision of treatment). This impetus for this support is premised on three main principles previously identified and further adapted to results confirmed by this research: a) that treatment is challenging and carries the potential for social stigma; b) that there are public health responsibilities which means that more people have a stake in a person’s individual decision-making; and c) that different levels of support should be stratified to meet a person’s needs such as elderly age, degree of disability, severity of disease, presence of drug resistance and more complicated treatment regimens, co-morbidities, and pre-existing polypharmacy. The concept of supported treatment sets apart treatment for active TB and leprosy from other non-communicable chronic disease and recognises the key role of treatment relationships in optimising treatment.

In considering case management and DOT to be supported treatment, the current treatment models practiced in the Kimberley of LCM and DOT I contend require adaptation and contextualisation and I present these here. Starting with case management, I present an adapted model of ‘Integrative Cultural Case Management for Remote/regional areas’ (ICCM-R). The ICCM-R model embraces the utilisation of LCMs and case management meetings but extends to facilitate improved incorporation of culturally secure and person-centred specific for TB and leprosy. This is through routine and appropriate use of cultural liaison, peer support, and the formal incorporation of Aboriginal Health Workers and Aboriginal Health Practitioners as options for LCMs (with required training). In the spirit of “nothing about me without me,” planning case management means active participation of the person affected and direction from them about willing disclosure and support from family members. The ICCM-R model aims to prioritise continuous care and pragmatics required for the remote region, such as maintaining flexibility with back-up LCMs and the recognition of the person’s wider healthcare and social circle. More detail for ICCM-R is provided in [Appendix K](#), including suggested stratified levels of support for need¹⁴¹.

¹⁴¹ Also of consideration is the inclusion of case management for TB and leprosy as part of the National Aboriginal Community Controlled Health Organisation’s (NACCHOs) core services framework, for 25 years and up (NACCHO., 2021, p. 37).

The second part of supported treatment as a goal of care is in regard to a changing of the terms of DOT, to what I have put forward as ‘Optional DOT’ for active infection only (i.e., not recommended for latent TB/preventive therapy, given there is no risk of transmission of infection and less need for support for adherence, and the need to ensure proper information and safety planning with patients does not require DOT to do this). While it may be considered that DOT is *already* optional, the rationale behind Optional DOT is to cement DOT as optional for people affected and promote empowerment, not optional at the discretion of the treating team without dialogue. While it was clear from this research that there were challenges in providing DOT in person centred and culturally safe ways, there was also evidence that DOT provided support and benefits for treatment continuity and completion. The clear distinction here is the interpretation and application of DOT as a model of supervision/surveillance, versus DOT as a model of support provided at the time of provision of medications, with witness. The research findings did not support completely abandoning DOT but do emphasises the requirement for an amended model of practice for DOT implementation that avoids altogether DOT as a model of supervision/surveillance. It is critical to recognise the differential position for DOT provision for Aboriginal people given the history of fractured relations. If it is continued to be provided as a supervision/surveillance model of “compliance” assurance, rather than a supportive model, DOT provision risks further damaging relationships and exposing people to ongoing colonising and cultural harm. Optional-DOT therefore emphasises the importance of *how* this observation, i.e., witness, is provided, *who* is providing it, and *where* it is provided and is centred on three premises: the objective of providing DOT (i.e., as a support, not as a response to controlling adherence); DOT as a person-centred and self-determining process; and DOT as a culturally suitable and pragmatic process. Further detail on this is outlined in [Appendix K](#).

Some people may require more support and enhanced discussion about DOT as an option, i.e., for those who are young and old, have co-morbidities, pre-existing disabilities, or known or suspected drug resistance (see [Appendix K](#) for specific detail of these premises and suggested stratified levels of support). By shifting the focus of DOT to one of supporting treatment rather than surveillance of adherence, it’s punitive/paternal association dissolves and routine STDM and relationships can be prioritised, including respect for individual privacy. As well as being informed from the research findings, Optional-DOT is in line with recommendations from the WHO regarding the ethical considerations of providing person-centred DOT practice, such as “taking steps to avoid the stigmatization of patients,” “giving

patients choices about who will observe them (and where),” and not “forcing” patients “to do something against their will” (World Health Organization, 2010, p. 16) which are also paramount to avoid aspects of ongoing colonising. There are pragmatic advantages to retaining DOT in the Kimberley region, mainly due to its remoteness, identified staff turnover and limited resource allocation—while DOT can be resource intensive, it is an accepted treatment model, and the amendment to a newly structured Optional DOT model can be readily incorporated into a person’s care where no similar programmatic model of supported treatment may exist in remote areas. The option of family members as a DOT provider in remote areas, with provision of training, is also a valid option. Given the remote location, more routine considerations of technology assisted Optional-DOT should also be considered.

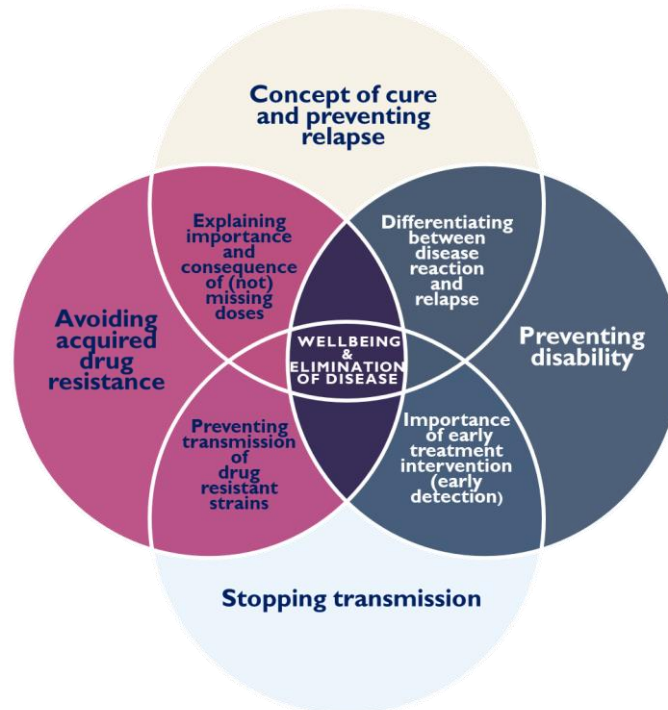
A key part of discussing Optional-DOT is in the explanation of what DOT is and why it is offered as an option for supporting treatment (see [Appendix K](#) for a suggested communication tool). For example, explaining that the chosen DOT-provider will sit down with the person while they take their tablets and have time to check whether everything is going okay, rather than tell people it’s part of the deal and/or hovering over them impatiently and authoritatively. This allows open and transparent agreement that builds trust. Like ICCM-R, Optional-DOT is best offered from the outset, even if not taken up initially can be presented as an option later if needed, such as if a person may be struggling with treatment. Maintaining the current requirement for a contract for DOT between person and organisation may assist with having a documented record for the person-affected so their wishes can be respected by future DOT providers or health staff if this becomes the situation. However, this type of signed agreement needs to be dealt with cautiously, in ensuring that it is not perceived as a contract with any overarching government organisation or that there can be punishment if there are changes to the original agreement. It should represent a record of what was agreed for records sake only. Additionally, the current template for monitoring treatment could build in specific factors related to supportive measures provided, rather than focussing solely on the witness of medications being swallowed and the questioning of medication side effects. Without these guarantees and in incorporating shared decision making into the process of who provides DOT and where it is provided, I have argued that the way DOT is currently operationalised is limited in its usefulness for optimising therapy.

8.5.2.2 Improved treatment information.

Improved treatment information forms the second part of the treatment model recommended actions. There are some key recommendations here for operationalisation that

have been shared with local organisations. There is an identified need for Aboriginal-led and designed resources for both TB and leprosy treatment and disease that incorporate local knowledge as well as relay clinical knowledge in easy-to-understand language, that is not using “high” words. Literacy should also be considered with options for visual tools of information and translated conceptual meaning. As discussed in chapter [5.3](#), incorporating the bigger picture of the role and place of treatment, as well as connecting the components of treatment (e.g., early treatment intervention, chemoprophylaxis) is an important part of this. In addition, developing modules for the treatment of TB and leprosy may also be beneficial for all health staff involved in TB and leprosy care including regionals clinical pharmacists, to further support medication enquiries and reconciliation (see [Appendix L](#) for more detail) Lastly, in aim to work towards shared meanings, a conceptual communication tool to assist both staff and people affected in starting these conceptual discussions to arrive at shared meanings is presented in Figure 15. This incorporates the findings from the research regarding the need to effectively communicate the importance (benefits) of treatment for active infection, the consequences of not taking treatment or not optimising treatment, and discussion about what happens after treatment completion. That is, communicating the *expectations* of treatment. As a starting point, I have presented four main concepts for initial dialogue as points to explore shared meaning in Figure 15. These are concepts of cure and relapse prevention; disability prevention; stopping transmission; and avoiding acquired drug resistance.

Figure 15: Conceptual tool for communicating treatment importance & consequence.



This tool links in supportive information regarding the early detection of disease to enable early treatment start is beneficial and that continuity /regularity of treatment is optimal for wellbeing and elimination of disease for the individual as well as for family and community. Finding shared meaning of early symptom recognition for early treatment is a key message to be communicated from this, and the example of the association with burns for leprosy discussed in [8.4.1](#), may provide such an intercultural communication point. Communication of regularity of treatment means being specific about the allowed forgiveness with missing doses and what limits to missing doses would be recommended, in encouraging people that the more missed does, the more consequences as per the communication tool. A similar tool has been designed for preventive therapy and is in [Appendix L](#).

8.5.2.3 Commitment to medication safety and enhancing treatment supply and access.

Commitment to medication safety and enhancing supply and access form the third and fourth components of the recommended actions. Firstly, in discussing medication safety, at the regional organisational level, issues unique to specialist care of TB and leprosy interact with broader existing issues in the region, such as the capacity of multiple health systems that do not interface to meet the safety needs of a highly mobile community and transitions of care between remote clinics, local hospitals, and tertiary hospitals. To address the potential for erroneous prescribing outside of programmatic management, restrictions on prescribing

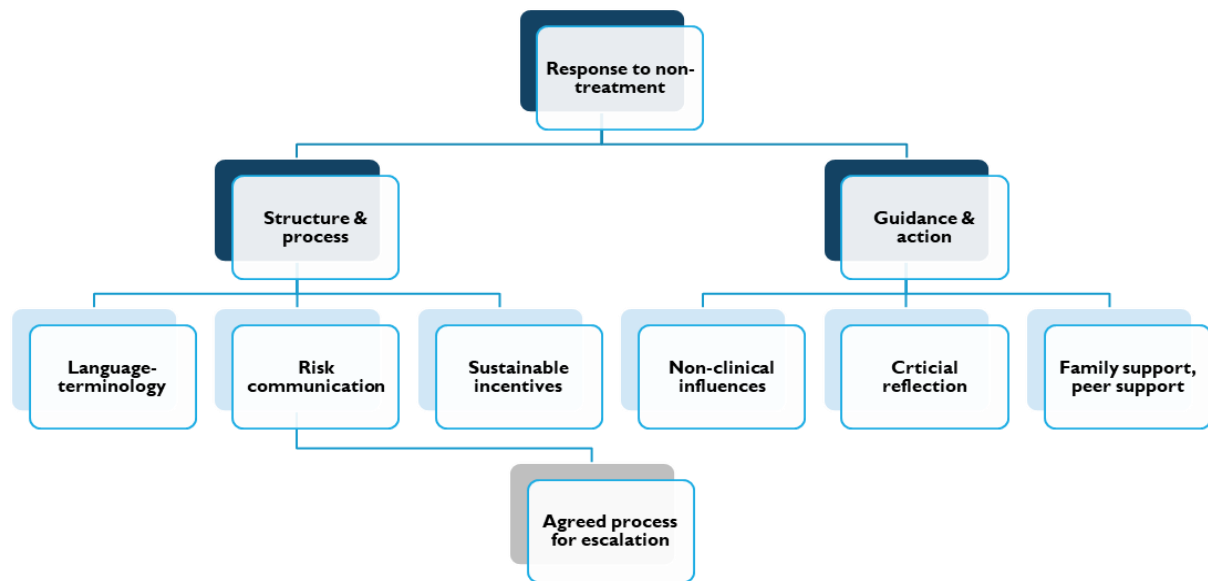
TB and leprosy treatment, which are the antibiotics rifampicin, dapsone, isoniazid, clofazimine, ethambutol and so forth may benefit. This could include the use of a traffic light tool to highlight those antimicrobials recommended to be prescribed with physician or infectious diseases input. This would also assist regional pharmacists in contributing to safety monitoring to not only curb inappropriate prescribing to avoid antibiotic resistance, but also to curb inappropriate prescribing due to safety. In addition, consideration of other formulary amendments to allow regional physicians to prescribe TB and leprosy medications, in consultation with the WATB specialist, could be considered. The other important aspect of committing to medication safety is ensuring that there is a coordinated and documented safety plan for clinical monitoring that has been discussed in a shared decision-making process with the person affected, with current treatment plans. Such a plan may include location for blood tests, and what is needed/how these can be arranged, as well as who will be overseeing the results and keeping the person informed.

Optimising medication management requires a multifaceted approach. As well as committing to medication safety, ensuring adequate supply and access to treatment is vital. Systems and processes that delay access, make access inequitable for people living in remote areas, or restrictions put in place that limit the capacity for ease of continuity of treatment need to be re-addressed as foundational components of the treatment model. As I have argued in Chapter 5.5, “At the foundational level, inequitable access to medications reflects a system in which treatment continuity is at higher risk of interruption, has increased risk of error, and increased risk of neglecting people affected.” Removing restrictions in current supply duration is one such part of this. In addition, recommendations for decentralising supply arrangements by relocating the responsibility of supply to the main regional hospital in the Kimberley in Broome will address the supply delay issues identified. In this way, medications can be kept on site, dispensed, and supplied when required for people in community, as well as if admitted into hospital. This will also have the benefit of dispensing records being able to be accessed and maintained locally at the hospital (and interface with Perth tertiary hospitals). Removing restrictions also removes the number of people involved in a person’s supply and access planning, thus providing people with options in accessing medications locally and supporting patient autonomy in the maintenance of privacy. More detail is presented in [Appendix M](#).

8.5.2.4 Harnessing of historical knowledge and a culturally responsive plan for responses to nontreatment.

In building the recommended strategies of incorporating Aboriginal cultural leadership and knowledge there are two principal elements that complete the integrated care components that specifically relate to this strategy. The first is having a culturally responsive plan for responses to nontreatment, and the second is harnessing historical knowledge. A suggested framework for a culturally responsive plan for responses to nontreatment has been shared with local organisations and is represented in Figure 16, with more detail provided in [Appendix N](#). There are a number of steps that should be taken before getting to any point of escalation and the need for legal intervention. The purpose of this culturally responsible plan is to provide suggestions for these steps informed from the research. The framework is divided into two sections; (a) structure and process; and (b) guidance and action. Under structure and process, the aspects are independent of a person's current or ongoing care and are suggested to be applied across guidelines, policies and processes used such as the use of language and individuals' and community preferred terminology (i.e., of "leprosy" or "Hansen's" or both). This area requires local cultural leadership and knowledge to work out the best communication for shared meaning to enable risk communication and importance as per the communication tool above in Figure 15. For the second section, guidance, and action, while there will be benefits from having pre-discussed strategies, planning is more likely to be dependent on the current situation an individual faces, such as in treatment refusal. This incorporates the identification of non-clinical decision making required, such as for social and cultural matters and advice about family meetings, as well as a critical reflexivity on what has transpired since the beginning of treatment for that person, to identify incidences where the health team may not have provided the most optimal or culturally safe response for that person's care. See [Appendix N](#) for a suggested critical reflection tool. This overall framework requires further consultation and, as for other parts of this treatment model, has been shared with local organisations.

Figure 16. A culturally responsive framework for responses to nontreatment



Current regional health education incorporates and privileges settler accounts of history that perpetuates the exclusion of Aboriginal experience. Putting this into practice, it becomes critical for ongoing TB and leprosy education within health by, or to, non-Aboriginal Health Care Workers who may be required to work in the area to be informed from Aboriginal accounts of history. Harnessing Aboriginal social and cultural historical knowledge means incorporating oral histories from around the region into current understanding of prevalence of disease and importance of treatment. This is especially relevant to leprosy due to the wide social impact over generations of families. This can be addressed by ensuring any history education presented to current or new HCWs to the region about TB or leprosy is coordinated and/or presented by local Aboriginal community members. In addition, any documentation in health education pamphlets or guidelines of history pertaining to either disease, with particular sensitivity to leprosy, should be coordinated with, informed by, or written by local Aboriginal community members. Harnessing historical knowledge can also be addressed through community awareness and mobilising community knowledge, with community engagement or information sessions driven by local Aboriginal people. Engagement at this level can in turn assist in addressing individual and community stigma that may be present, including for non-Aboriginal community members and especially for leprosy, where knowledge of the regional history may be negligible. As identified in Chapter 7, people unaware of this history may respond negatively to news of leprosy infections identified within the community or in the media, contributing to fear and the stigmatisation processes.

Connecting history knowledge to contemporary practice I have argued throughout this thesis is important to assist with prompt treatment intervention from early diagnosis through increased index of suspicion and people self-presenting with symptoms of disease. Long incubation periods mean generations are shifting and new generations may not have been passed on knowledge. Connecting history assists new generations in understanding the background and importance of treatment if newly diagnosed with leprosy or TB infection. In addition, harnessing and incorporating this history into current treatment models of care can assist in learning lessons from the past, so the same mistakes can be avoided into the future.

8.6 Chapter summary

Colonialism is often recycled into care without awareness or consideration. In this chapter I have further interrogated the research findings to highlight how it is not just the weaving of care into the fabric of health services delivery for TB and leprosy that is necessary, but also the careful consideration of the details of how this care is enacted cross-culturally. This demands a shift in terms of attention to pervasive colonial logic, such as race-based risk and problematising populations associated with Aboriginal peoples. While the original ideology of person-centred care in promoting people as equal partners in their care and promoting empowerment, the model as it currently operates is not a solution to prevent ongoing colonising and should not be equated as a ‘fix’ to the harm of ongoing colonising. The National TB Advisory Committee (NTAC) in addressing the goal to zero disparity for TB talks about barriers to care for Aboriginal peoples (The National Tuberculosis Advisory Committee (NTAC), 2019). I conclude that one of the biggest barriers to care is ongoing colonising. Part of this consideration is in how treatment guidelines embody perceived risk and if they are also a site of perpetuation of colonial logic or seek to de-link from this. For example, instead of listing ‘cultural’ as a contributing factor to nonadherence to treatment, treatment guidelines should emphasise ‘failing to provide meaningful information,’ and ‘failing to enact shared treatment decision making.’ Instead of ‘socioeconomic disadvantage’ as a contributing factor to nontreatment, we should be listing ‘failure to adequately address and support social inequity.’ In this way, the responsibility location is re-set and people of cultural diversity and social disadvantage can cease to be blamed or stigmatised (see Government of Western Australia, 2019(b), p. 62). In de-linking from colonial logic, I have demonstrated how a prioritising of relationships is required for optimising care, hence optimising treatment. This includes work to build and prioritise building of trust within relationships, especially in interactions between LCMs, case managers and DOT-providers.

Although person-centred care embodies important aspects that align with culturally secure practice such as shared decision making and empowerment, in practice cultural harm can still occur. Such consequences demonstrate the gap in person centred care frameworks due to what I have argued are the underpinning ideologies of universal, rather than pluriversal, models of care that don't account for or respect diversity in cultural values, and favour the neo-liberal absolute of the responsible consumer. Furthermore, the challenges and tensions that exist between the public health duty to the public good also create tension within person-centred care delivery. A shift in theory requires a shift in policy and practice. The focus on finding a balance of responsibility and communicating expectations within healthcare relationships forms a critical discussion point for considering the lens from which care for Aboriginal persons affected by TB or leprosy is viewed. The consequences are significant. To avoid responses to ways of managing (or not managing) treatment being punitive and paternal, or people affected being neglected, conceptual application of respecting culture, cultural rights, values and customs in the planning and design of TB and leprosy services with Aboriginal peoples in the Kimberley remains an important goal to work towards in re-locating solutions to these tensions within person-centred care. There is a duty of care to find shared meaning about risk and consequences associated with treatment, and establish routine shared treatment decision-making, keeping in mind the person bearing the biggest burden is also the person suffering from disabling infectious disease. There are also larger structural forces at play that intersect with clinical risks imposed on a person for any diagnosis of TB or leprosy. A diagnosis and subsequent requirement for treatment can result in notable changes to a person's livelihood and increased exposures to biomedical care and treatment. It is here that these larger forces, such as the determinants of social inequity, also require addressing concurrently. Hence the treatment model of care necessarily requires a multi-level approach and a multi-level responsibility and necessary engagement and partnership with Aboriginal community leaders.

The presented treatment model of care offers practical application in providing the opportunity to take steps towards such a decolonised pathway to improved care. It embodies evidence from the research and the original research aim in a genuine commitment to optimise treatment and work towards goals of wellbeing and elimination for individual people, families, and community. It is the sustainability of having safe, therapeutic, and caring relations that is pivotal for any culturally responsive person-centred care treatment model for persons affected by TB or leprosy, and the next steps to achieve this beyond this thesis would be having affected people/communities evaluate the model's efficacy.

Chapter 9

Conclusion

9.1 Introduction

The provision of optimal treatment for Aboriginal persons in the Kimberley affected by TB or leprosy, including prophylactic treatment, is influenced by a complex intersection of historical, social, cultural, geographical, and health system factors. The role of colonialism in constructing modern public health care practice and the subsequent embeddedness of these colonial policies and practices, has had a significant influence on how treatment models for TB and leprosy have been decided for Aboriginal people. Within this thesis, I have provided context-specific evidence for the Kimberley region by embracing local perspectives to inform a richer account of these influences on contemporary treatment. This has assisted with new understandings of the challenges that people face and how these challenges can be overcome. Importantly, this research has assisted in a comprehension of the relationship between the operationalisation of treatment models with treatment outcomes that provide benefit for the person affected by disease.

In this final chapter I review the core research findings in relation to the original research aims and questions, and implications of these findings for current and future practice. I discuss the strengths and limitations of the research and the potential benefit for the Aboriginal Kimberley community. Lastly, I propose opportunities for future research that this research has inspired, before concluding the thesis.

9.2 Core research findings and answers to the research question.

9.2.1 The importance of history

This study aimed to understand and improve the current treatment model of care for Aboriginal persons affected by TB or leprosy by the adoption of a decolonial theoretical lens to critically review current treatment models in practice. Adopting this lens meant a switch in constructing the research question from the mindset that the clinical problem is with Aboriginal persons affected by TB or leprosy, but rather considering the problem is in the system that provides care to those people affected. The goal to understand how culturally secure and person-centred care practice can be better incorporated in response to this aligns with the philosophy that improved care equates to more optimal use of medicines for the treatment of TB and leprosy. Given that treatment is a primary intervention for curing disease and stopping its transmission, achieving these goals also assists in strategies to eliminate TB

and leprosy within the community. One of the key aspects of knowledge production from this research was the demonstration of ongoing colonising. This was more easily identified due to the inclusion of a historical review of TB and leprosy treatment in the region which has enabled a comparative timeline to better foreground modern treatment practices. What was found was that the colonial policies of segregation and assimilation largely influenced physical isolation policies even after antibiotic therapy became available, as well as decision-making for Aboriginal people around treatment. This resulted in different social trajectories for each disease in respect of this management. Particularly relevant for leprosy, a key finding was the discriminatory perception of Aboriginal people as irresponsible and not to be trusted to take treatment as they were told. This was managed with responses of punitive or paternal colonial ‘care’ from mandatory supervision of treatment and switching to alternative formulations of medications such as long-acting depot injections, to remove responsibility, in the logic as being ‘for their own good’, continuing even after the close of Bungarun leprosarium. This type of problematising altered the foundations of how treatment for TB and leprosy was managed and subsequently influenced current methods of approaching treatment, specifically responses to perceived non-adherence.

History also informed the identification of deeper narratives of mistrust from Aboriginal participants regarding the safety of medications, including a history of forced treatment and a feeling of being experimented upon, meaning people were, and continue to be, sceptical and discerning over the effectiveness and safety of medicines. A knowledge of social history, especially for leprosy, featured in linking the ongoing presence of infection within family lines hence aiding current diagnosis and reifying contemporary importance of treatment.

9.2.2 Gaps and inconsistencies in care

Challenges exist for current treatment that intersect with this history and the resultant embedded colonial logic of knowledge, power difference and ways of being that has remained. Such colonially influenced treatment practice has coalesced with practical challenges that already exist within the remote and vast healthcare landscape of the Kimberley. This includes challenges for equitable access to consistent and timely supply of treatment for TB and leprosy, made more difficult by restrictions in the duration of supply provided and the multiple steps required before people can access (or are provided) treatment. In addition to being inadequately substantiated for cultural appropriateness for Aboriginal people in the Kimberley, the treatment models of DOT and LCM were also inconsistent in

their application across the region and in their success in providing benefit for treatment outcomes among people affected by active TB and leprosy. These inconsistencies assisted in understanding strengths of where the model was culturally safe and more importantly limitations in its use. People affected by active TB or leprosy did not always understand what DOT was and why it was necessary. For some people affected, the provision of DOT was accompanied with a feeling of not being trusted and signified the importance the history of health care relationships has had for contemporary care for Aboriginal people, and the importance of contemporary treatment relationships between the person providing DOT and person receiving DOT. The place for providing DOT was usually negotiated to be a person's home, however this presented challenges around privacy especially among family and extended family, as well as getting timing right for health visitations and locating people. Aboriginal Health Workers (AHWs) and Aboriginal Health Practitioners (AHPs) were utilised to provide DOT, and this proved beneficial for people affected in assisting culturally safe treatment completion. However, concern was raised over medication administration outside the clinic due to organisational medication policies and practice that were a barrier to DOT administration.

Gaps and absences in care were evident in the wide range of experience among LCMs and DOT providers in specialist knowledge of and experience with working with people affected by TB or leprosy, as well as experience in the region. For Health Care Workers, gaps in knowledge of the epidemiological history and clinical knowledge became relevant for missed opportunities for early treatment intervention. A low index of suspicion of disease led to misdiagnosis for pulmonary TB and missed diagnoses of leprosy by misrecognition of leprosy-associated neuropathy. Conversely, clinicians who had awareness of the regional history and/or family history assisted in providing a timelier intervention. For leprosy, early treatment interventions were also made possible where people knew their family history and self-presented with suspicious symptoms or were able to provide this family history knowledge to clinicians. Safety concerns also came about due to the required clinical monitoring for TB and leprosy medications in the remote area being performed routinely, and the reliance on primary health care to assist. Maintaining accuracy of specialist TB and leprosy current medications was complicated by the multiple recording systems for medications between health sites that don't share information, as well as instances of confusion in prescribing roles such as stopping and starting medications associated with TB or leprosy. These findings highlight the tensions that exist between central and remote control of treatment programs due to varying levels of expertise and dependency on health primary

care, as well as the cultural and geographical setting in which they are applied. They further reveal the need to reconcile these tensions to enable the optimisation of person centred and culturally responsive care and warrant the development of an overarching cultural security framework.

9.2.3 Treatment continuity, completion, and support

The results of this research provide a comprehensive understanding about influences on taking medications regularly both within and external to a person's control. Influences such as missing information, i.e., not enough provision of appropriate medication resources, meaningful communication of treatment importance and consequence, and concerns about medication side effects from observation of others or personal experience were learnt. These concerns contributed to influences on the taking of medications due to mistrust and a lack of confidence in the medications provided, especially where effectiveness was not obvious. Concerns were registered from HCWs about non-adherence for some people affected by leprosy or TB. In practice this was best described as "irregular" adherence. For active TB and leprosy, there was no evidence of any persons refusing to start medications or of people who stopped and did not eventually re-start. What varied was the duration of treatment because of missing doses and having treatment extended. Imparting more information about the forgiveness or consequence of missing doses was an identified area of need.

Attempts to address adherence of TB and leprosy treatment extend back to the time of the discovery of antibiotics and adopted strategies mainly focussed on reducing pill burden, shortening treatment durations, adopting intermittent regimens, and rigid supervision such as the use of DOT. All of these methods were found to be relevant from this research. In addition, this research provided additional strategies to encourage regular adherence in considering a person's treatment journey and the phases of treatment. One of the key findings was the influence that supportive healthcare and social relationships had on treatment regularity through these phases of treatment, especially the motivation to persist. Where people benefited from DOT or LCM, treatment relationships were built on two-way trust and culturally respectful support, including negotiation and effective communication and feedback on the treatment process, even after treatment completion (i.e., the 'post-treatment phase'). This showcases relationships as an important adherence strategy not previously considered and reifies the importance of valuing relationships between Aboriginal people and the health system.

Diagnosis of TB or leprosy contributed to several changes in social and health-care relationships for persons, as well as for medication changes throughout the treatment journey. For some, diagnosis of leprosy brought shock as it was thought to have been eradicated. The social consequences of being or anticipating being singled out and socially isolated, occurred on a spectrum from complete exclusion from community, to finding solidarity with family history. The anticipation or experience of stigma was succinctly related to strong desires to maintain privacy. The causal link between stigma and associated interruption to treatment was centred on maintaining this privacy and had implications for how clinical handovers occurred and how many people become knowledgeable of diagnosis. Sites of stigma occurred at the clinic, places of providing DOT, and local hospitals and on occasion were perpetuated by Health Care Workers by singling out people affected in front of other people. This reified the important role of HCWs in being able to help or harm people affected by TB or leprosy. Family relationships and connection to culture were also significant for the social and emotional aspects of wellbeing for a person going through treatment and the maintenance of Aboriginal ways of being, knowing and doing (Parter et al., 2021).

9.2.4 Answering the research question.

While the main research question focussed on how to better incorporate care for treatment, part of the sub-questions was to understand the gaps, barriers, and limitations to better incorporate care, as well as the practice challenges faced in operating current treatment models. In addition to the key findings presented above, I would add that one of the principal barriers to care that was identified and one that underpins a number of other barriers, is ongoing colonising. This came through predominantly in the hegemonic biomedical model of health care system, and via some health staff attitudes and relationships that Aboriginal people affected by TB or leprosy were exposed to.

In terms of practice challenges, the remote context and capacity of primary health care to safely integrate specialist treatment for TB and leprosy is significant. This is due to the low numbers of people diagnosed with TB and leprosy combined with the complexity of treatment and specialised decision making required for any person affected. Given the competing priorities, maintaining skilled staff and recognition of symptoms means building up capacity in community to understand that these diseases, while rare, can still occur and vigilance is required. In addressing the research question, best practice includes new understandings of models of treatment, i.e. “supported treatment”, rather than any punitive or paternal measure to supervise treatment; prioritising treatment relationships and two-way

trust and responsibilities that come with these; recognition of privacy and the social wellbeing of people affected; and ensuring that there is adequate information available to assist people in being properly informed, by finding shared meanings in the expectations of treatment and addressing medication safety concerns. Another practice challenge in the cross-cultural setting identified is the assertion of what are epistemic and moral norms. This has influence on the approaches and responses to treatment and the structure of treatment models in their lack of incorporation of cultural values and knowledge. Without this integration of cultural security, HCWs sometimes found themselves in challenging and sometimes untenable positions to work effectively and meet their duty of care both to people affected and the wider community. In doing so, this also exposed Aboriginal people to potential harms when conviction of moral normative responsibilities included paternalising or punishing modes of response.

Better incorporating care means valuing relations as a priority, establishing routine shared treatment decision making, and incorporating Aboriginal cultural leadership and knowledge as recommended strategies in the new treatment model presented in Chapter 8.5. Emphasising these layers of best practice is an integral part of this model. So, too, are the treatment components for practice application of chemoprophylaxis, early treatment intervention, treatment continuity and completion, adjunctive treatment, and post-treatment monitoring, in the aim of delineating programmatic management and required treatment for each component. As such this new model addresses pathways for operationalisation of treatment with practical application to the Kimberley context. This model is a deconstructed, critically reflective, evidence informed, and inclusive model that serves as a starting point for decolonised pathways of care for treatment from pre-treatment phases to post-treatment phases. Within this model, recommendations related to cultural security involve the focus on improved recognition and involvement of Aboriginal health staff, and Aboriginal leadership in shared planning for elements of this model and recommends active involvement of people in their own care.

9.3 Contribution of thesis and benefits to the community

This work assists in advocating for a renewed focus on TB and leprosy in the remote Kimberley areas whereby detection of either condition may otherwise go unnoticed, undiagnosed, or deprioritised among more prevalent health issues. Due to the low incidence of endemic infections, a focus on the lived experience of people affected by TB or leprosy is lost within a myriad of other chronic diseases that garner more attention and higher resource

priority, such as diabetes mellitus, cardiovascular disease, chronic kidney disease and rheumatic heart disease. This does not negate the importance of understanding how people are supported in receiving optimal treatment and the associated complexity of care within remote health settings. This project provides the first comprehensive review of TB and leprosy treatment models for Aboriginal peoples in the Kimberley and the first that examines contemporary treatment models for Aboriginal people affected by leprosy in Australia, specifically considering the context of settler-colonialism. It is also the first research identified that purposefully incorporates the lived experience and perspectives of First Nations peoples in Australia regarding the use of DOT for TB or leprosy.

As such this work provides richer and more meaningful insight for treatment that is contextualised to people and place and offers insight on the benefits and harms of DOT. As a research outcome, the learning from this research around DOT provides important recommendations for improving strategies for the best practice for DOT that may provide benefit for other First Nations groups. This thesis also contributes to the academic literature in the provision of evidence of ongoing colonising that impacts on current treatment models and considerations on the dismantling of such colonial logic. More importantly, benefits that this brings are in assisting ways of re-thinking the terms of treatment that assists in re-positioning Aboriginal people affected by either disease to be at the centre of care.

The development of a new treatment model means a starting point for practical action. The model incorporates specific components for Aboriginal-led and partnered design and consultation that will assist in providing Health Care Workers and health organisations guidance for treatment and pathways to optimising treatment adherence. This in turn will provide benefit to individual peoples affected by TB or leprosy in the receipt of improved, culturally safe care and more consistent and successful treatment outcomes, and in turn for the benefit of community in working towards reducing the incidence of disease. In addition, the articulation of categorised components of treatment as per the model may assist primary health care and namely Aboriginal Medical Services (AMSs) in mapping out steps to identify programmatically and clinically what may be required from integrated care for TB and leprosy.

The sharing of research outcomes from this study has commenced with local organisations the Kimberley Aboriginal Medical Services, Kimberley Population Health Unit, and the regional Kimberley Aboriginal Health and Planning Forum (KAHPF) chronic disease subcommittee, with the sub-committee making amendments to the draft regional leprosy protocol. Amendments in the protocol included contribution of new knowledge about

medication safety, recognition of history, new knowledge of shame and solidarity, and recognition of the pivotal role of Aboriginal Health Workers (AHWs) and Aboriginal Health Practitioners (AHPs) in the support of treatment completion for individual persons affected by TB or leprosy. The benefits of this are two-fold; for empowerment and recognition of AHWs and AHPs, and for individual community members affected by TB and leprosy in receiving continuity of care and culturally appropriate care. The provision of formal recognition that includes training also builds capacity for AHWs and AHPs to then provide TB and leprosy specific cultural safety practice awareness to non-local and/or non-Aboriginal Remote Area Nurses who have been identified as possible LCMs. In addition to the regional leprosy protocol, early discussion has taken place about the potential of working towards a new regional KAHPF TB protocol specific for the local context, incorporating the National TB Advisory Committee strategy of eliminating disparity in TB rates for First Nations peoples. These protocols and the work from this thesis also aid in the steps to forming a cultural security framework and the recommendation of a state-based cultural security framework for the Anita Clayton Centre will be recommended in future discussions. The completion of this research project does not mean an end to the commitment to continue working in partnerships with the community to ensure any potential benefit or future research that arises from this project continues with ongoing discussion and consultation.

9.4 Limitations and delimitations

The first limitation for this research is in relation to the research design and the decision to exclude the collection of data from medical, medication and dispensing records from health records of people affected by TB or leprosy. This was an intentional part of the research design to privilege lived experience to inform the analysis rather than question people's truth with electronic health record documentation. However, during the analysis this data may have been helpful in the ability to gain further knowledge or corroborate findings from qualitative interviews. For example, confirmation of documentation of medication safety related events and discrepancies across systems such as documented evidence of duplication or inconsistencies in medication lists, or other safety incidents. Having a timeline of safety events that could be matched with the treatment journey may have provided even more depth for the issues presented around medications safety, especially as most people didn't talk about medications by name or provide detail on timelines.

Archival research also has its limitations, given the choice of what is put into the archive and how much information can be found within a given research timeframe. In

addition, the archive itself represents the colonial method of witness and documentation of the era in examination. The very invisibility of Aboriginal accounts of history in this archive can be seen as a form of “historical erasure,” that is “part of the process of desocialization necessary for the emergence of hegemonic accounts of what happened and why” (Farmer, 2001, pp. 307, 308). In recognition of these limitations, the historical archive serves only as a site for critical analysis of colonial practice, which I have focussed on.

Another limitation of the research was the challenge with recruitment specific for people affected by active TB—it would have been beneficial to have more voice in this area. I acknowledge that there were some barriers with the recruitment processes such as timing delays in identifying eligible participants, health concerns of potential participants and difficulties in locating people. In addition, the use of health care workers known to the potential participant provided both strengths for recruitment and limitations in cases where trust issues existed. The best picture possible has been drawn from those accounts of participants who contributed from their observations and experience. Part of the challenge was the smaller number of eligible participants affected by active TB and extending the initial date back beyond 2012 would have increased this number, and this is a lesson learned. While there is a lot of benefit in including active and latent treatment to get the full picture on TB elimination and the treatment used, it also meant that the focus was spread and in hindsight additional resources and time would have assisted this recruitment strategy. This would have allowed building up more relationships in unknown communities prior to recruitment in addition to time criteria extension.

My positioning as a non-Indigenous researcher may be a limitation for representing the true terms for a decolonised treatment model presented in this thesis. At best, I have been able to work at the cultural interface to critically reflect on Western designed treatment models and the limitations in providing equitable care for First Nations people using these models (Nakata, 2007, p. 215; Nakata et al., 2012). I do not claim any authenticity to decolonised knowledge production within this thesis, rather that knowledge produced here has been used in specific ways to counter current practices that support persistent and pervasive colonising that influence clinical decision making, risk communication, responsibility discourse, punitive and paternal responses to irregular or nontreatment, neglect towards people affected by TB or leprosy or capacity for genuine fostering of health and wellbeing. Through the chosen methodology I have aimed to deconstruct entrenched logic of this system through critical and pragmatic reflection of processes from my personal observation and through the thorough processes adopted in the research design and analysis,

to speak up for improved care within current practice. At worst I have failed to delink or recognise my own embeddedness in this analysis and “problematically” attempted to “reconcile settler guilt and complicity” (Tuck, 2012, p. 1), or in my “preoccupation with interpreting practices,” have introduced my own “principles” of relation to the analysis (Bourdieu, 1977, p. 2) without critical reflection on my own ontological and epistemological position. As such, I have purposefully been transparent about my process and personal-professional positioning.

Finally, it is important to acknowledge the translatability of this research. This work is specific for Aboriginal peoples in the unique setting of the Kimberley, and as such cannot be directly translated to other infectious or non-infectious diseases, other health settings or regions, or groups of peoples. The unique combination of context specific factors, such as the individual disease (i.e., TB or leprosy, including drug resistant strains), place (i.e., geographical location and health service delivery), history (i.e., political, and social), and the population need to be considered prior to any transferability. However, there may be applicability of these findings and the suggested treatment model of care across sites *if* contextualisation is incorporated, and subsequently the model adapted.

9.5 Future research

One aspect evident from this research was the difficulty in learning the real incidence of TB for the Aboriginal community in the Kimberley and if and how the incidence rate has come down since the completion of the TB campaign. Given the recording of old records of suspicious chest x-rays not followed up, and the potential for undiagnosed and untreated active TB in cycling transmission, for example the story of the man working on the cattle station in 1969 (see Chapter 5), there are gaps in this knowledge. Future research into this area would benefit from a more nuanced approach to collecting knowledge of this incidence, for example through story mapping or Indigenist research methods (Rigney, 1999), in combination with a deeper dive into collected epidemiological data since the initial TB survey. This would benefit from including the Pilbara region, given the initial findings of TB in the country between the Kimberley and Pilbara region and as the initial survey covered the North and North West. In embracing a state-based cultural security framework, this may also benefit from including other regions such as the mid-west around Kalgoorlie and Coolgardie due to the historic Coolgardie sanatorium (Proust, 1991c). More importantly an extension beyond regions acknowledges that many family connections networks exist beyond regional or state borders that currently exist. The benefits of such research would be to

establish the impact of the TB campaign for WA Aboriginal people separate to other states; the real impact of TB for Aboriginal people and families and ongoing impact; and assist in establishing risk for where latency-endemicity may be more likely, given the low incidence and large region and lack of clinical suspicion for thinking about TB. This could provide a foundation for local communities and health organisations in assisting strategies for elimination of TB for future generations. Part of this would also be a consideration of paediatric TB and paediatric models of care, such as transmission cycles within families and BCG use, given the current thesis only examined treatment for adults. This would enable more appropriately, Aboriginal-led guidance on what to consider and what is important for children. Mapping TB history in ways that support, and harness collaborative Aboriginal narration would also have the benefit of assisting in an historical database for medical education that considers multiple perspectives.

Another area for future research that this project serves as a platform for is research that conceives possible ways of measuring stigma experienced given its importance as a social determinant of health for individuals and community. Even more broadly, such research could be applied in general to remote health care settings and how stigma experience impacts on access to treatment for other health conditions, whether this be related to ongoing colonising and the reproduction of stereotypes that foster unsafe health spaces, or specific diseases that may compound stigma experience similar to TB and leprosy. In learning from this research, consideration of family and community in perpetuating or minimising shame over a spectrum of experience would be beneficial.

In the duty of providing individual person-centred care for TB and leprosy, several tensions exist for Health Care Workers in their role in providing and managing treatment. Differences in interpretation of, or agreement with, broader public health legislative requirements in place to protect the public can occur, especially in relation to what is considered to be normative moral responsibility. Understanding how these tensions are navigated and influence decisions around treatment for different disciplines of Health Care Workers warrants further focussed research—especially for Aboriginal health staff when working within their own communities. In recognition of the similarities of measures of infectious disease control, any interrogation of coloniality and public health ethics would benefit extending beyond TB and leprosy to include other communicable infectious diseases such as HIV.

Lastly, it is surprising that there is no national strategy within Australia to work towards the goal of eliminating leprosy for First Nations peoples as a neglected tropical

disease. It also raises questions as to why there has not been more investment in First Nations led research, particularly for leprosy, in aim to improve outcomes and disease elimination across the nation. The lack of such a strategy itself is a neglect towards First Nations and reifies the need of working to ensure future generations do not continue to carry this disease legacy. Such research could encompass a review of current treatment options within Australia and the potential of improved pharmaceutical science, and the longitudinal sustainability required for disease elimination. This may serve more as a policy imperative for First Nations led research to better understand how leprosy impacts on people's lives and what place-based solutions for broader goals of disease elimination can inform policy. Given that this research is the first that specifically reviews treatment models on contemporary practices rather than providing an historical review, this research serves as starting evidence for such a national strategy.

9.6 Conclusion

The history of TB and leprosy treatment for Aboriginal people in the North West of Australia is entangled with the nation's darker history of colonialism and discrimination towards First Nations peoples. An examination of current treatment models cannot be separated from the socio-historical significance of these epidemics and how they impacted Aboriginal families and communities. Consideration of these past and present relations is of relevance for optimising treatment models of care to give current persons affected, their family members and communities, and future generations, the best chance of a disease-free future. There is no singular remedy for improving care practice around treatment that has at its essence such complexity. This thesis has demonstrated, rather, that solutions to improving care for the safe and effective treatment of TB and leprosy are multi-layered and contextual, requiring a re-focus of the philosophical gaze towards how care theory and practice around treatment is defined, interpreted, valued, applied, politicised, medicalized, and operationalised. Due recognition of modernity and the influences of neo-liberalism and neo-colonialism is needed as part of any associated problem-solving.

Dialogues regarding treatment adherence must resist maintaining a basis of blame and judgement and instead evolve to incorporate routine shared treatment decision-making and Aboriginal cultural leadership and knowledge at all stages, ensuring needs are being met and confidence in treatment and associated care is instilled. In the goal of improving treatment processes and use, current use of Directly Observed Therapy and case management will benefit from a critical reflexivity of individual biases, socio-cultural values, and privilege (or

lack thereof), incorporating empathy and compassion, and not giving up on the person or people affected, at all health service levels. Health Care Workers involved must endure a specific cultural awareness for the region and particularly for leprosy, given the significance of social history and the Bungarun leprosarium. Oversimplifying the action of taking or not taking treatment fails to appreciate these confounding social and psychological factors from the burden of TB and leprosy treatment and disease, and subsequent influences on a person's treatment decision-making and responsibilities to self or significant others.

In conclusion, I have demonstrated in this thesis that optimising treatment that is culturally responsive and person-centred for Aboriginal persons affected by TB or leprosy in the Kimberley, is *not* just about the clinical, logistical, and economical aspects of treatment. It is also about optimising relationships, establishing routine shared treatment decision-making, and harnessing social and cultural knowledge, inclusive of people and place: culture, community, country, and history.

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Appendix A

Treatment regimens for drug resistant leprosy & drug resistant tuberculosis

Table A1. Drug resistant leprosy

Resistance pattern	Treatment options (total course 24 months)
Resistant to Rifampicin	Treat with at least two of the following second-line drugs <u>daily for 6 months</u> : - clarithromycin - minocycline - a quinolone (ofloxacin, levofloxacin or moxifloxacin) PLUS -Clofazimine FOLLOWED BY daily treatment <u>for an additional 18 months with</u> : -Clofazimine PLUS one second-line drug
Resistant to Rifampicin and Ofloxacin	Treat <u>daily for 6 months</u> : clarithromycin PLUS minocycline PLUS clofazimine FOLLOWED BY daily treatment <u>for an additional 18 months with</u> : -Clarithromycin OR minocycline PLUS clofazimine

This is an adaptation of an original work “(World Health Organization, 2018, pp. xiv, xv). Geneva: World Health Organization (WHO); Licence: [CC BY-NC-SA 3.0 IGO](https://creativecommons.org/licenses/by-nc-sa/3.0/)”. This adaptation was not created by WHO. WHO is not responsible for the content or accuracy of this adaptation. The original edition shall be the binding and authentic edition.

Table A2. Drug resistant tuberculosis

Resistance pattern	Examples of treatment options (duration of course variable, minimum 6 months)
Resistant to isoniazid (monoresistant)	Option to replace isoniazid/rifampicin with a later generation fluoroquinolone 6-9 months: moxifloxacin OR levofloxacin (other options may be considered used such as extending duration of other first line agents with/without fluoroquinolone)
Resistant to Rifampicin (Rifampicin monoresistant)	Preferred – Replace rifampicin with a fluoroquinolone: levofloxacin OR moxifloxacin PLUS extend duration to 12-19 months (Pyrazinamide stopped after 2 months)
Isolated Resistance to other first line agents’ pyrazinamide or ethambutol	Ethambutol resistance – no change needed Pyrazinamide resistance – no replacement used; however, extension of treatment duration will be needed to 9 months (rifampicin, isoniazid extra 3 months)
Resistant to both Rifampicin and Isoniazid	A combination of at least 4-6 effective drugs (and optimally at least 5) required, designed using a hierarchy of recommended medicines, including a minimum number of medicines considered to be effective based on drug-resistance patterns or patient history.

(Multi-Drug-Resistant, MDR-TB)	<p>Combination of drugs is as recommended from WHO groupings (see table 3.1 World Health Organization, 2020, p. 28), duration 18 + months.</p> <p>WHO now recommend an all-oral regimen for 9-12 months in specific circumstances containing seven drugs for 4-6 months followed by 4 months of 5 drugs.</p> <p>NEW shorter 6 month all oral regimens BPaLM*, BPaL (Migliori & Tiberi, 2022)</p>
Resistant to Isoniazid + another 1 st line drug but not rifampicin (polydrug resistance)	<p>Replace isoniazid with a fluoroquinolone: levofloxacin OR moxifloxacin</p> <p>PLUS add a second line agent if >3 first line agents (apart from rifampicin) are resistant.</p>
Unknown but potential for DRTB (<i>contact of DRTB, failed first line Tx, previous Tx for TB, endemic area for DRTB</i>)	<p>Extended empiric regimen until cultures known: 4 standard line drugs PLUS 2 of the following</p> <ul style="list-style-type: none"> -a fluoroquinolone -an injectable agent – amikacin or kanamycin (not streptomycin) -Cycloserine, OR linezolid, OR ethionamide, OR Para-amino-salicylic acid
Extensively drug resistance TB (XDR-TB)	<p>XDR-TB is defined as MDR plus resistance to a fluoroquinolone, and 1 of 3 second-line injectable agents (amikacin, capreomycin, kanamycin).</p> <p>Requires at least 6 likely effective drugs for minimum duration 24 months after culture conversion.</p> <p>Require expert advice.</p>

Adapted from the following sources: (Curry International Tuberculosis Centre, 2019; Migliori & Tiberi, 2022; World Health Organization, 2020)

*BPaLM – bedaquiline, pretomanid, linezolid, moxifloxacin; BPaL – as above without moxifloxacin

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Appendix B

BCG Vaccine

Bacille Calmette-Guérin (BCG) vaccine first became available for TB in WA in 1947, supplied by the Institute of Medicine and Veterinary Science in Victoria. The amount initially produced was insufficient for the whole population, and only health care workers and close contacts were targeted (Fitzgerald, 2006, p. 201). Its use was documented as part of the North and North West TB surveys, discussed in Chapter 4, provided to people who displayed no reaction to the Mantoux test. However, it was not until 1975 it was introduced for all second-year high school students in 1967 and rolled out across the state starting in the northwest in 1975 (Perth Chest Clinic, 1996, p. 17). Interest in the potential cross-protective effects of BCG in leprosy were discussed as early as 1956 at the conference on leprosy management held in Sydney (Public Health Department, 1956). The recommendations made at this conference were that BCG prophylaxis should be used for: a) the children of patients; b) family and other close contacts; c) the “staffs of Leprosaria and others caring for patients”, on the general principles of TB control. While awaiting further international evidence, the use of BCG in this manner was stated by the Conference to enable “the long-term study of its value as a prophylactic agent against leprosy under Australian conditions” (p. 3). This practice had already started whereby all people who received BCG vaccine during the 1950 TB survey had been documented, with the intention of longer-term follow-up to determine the protective effect against leprosy infection (Henzell, 1951). Early trials begun in Papua New Guinea in the late 1960s to establish the effectiveness of BCG for leprosy protection. Published results from these trials identified 48% protection against clinical leprosy, most effective for children under 15 years (Bagshawe et al., 1989).

As the use of BCG vaccine in the Kimberley was already in place as part of the TB prophylaxis campaigns for neonates and children, no additional trial of BCG was required to be implemented for leprosy prevention. In 2009, however, the routine use of BCG vaccination to prevent TB in Aboriginal neonates (most notably against miliary TB and TB meningitis) in high incidence communities (considered in 2006 to include northern parts of Western Australia (National Tuberculosis Advisory Committee, 2006)) was ceased in WA after a change in policy. BCG use continued in the Northern Territory, Queensland, and South Australia only (Khandaker et al., 2017). Reasons for the cessation of the WA TB BCG prophylaxis program in 2009 were cited as follows; a) the vaccine did not offer good population TB control; b) there was a low number of infectious TB in area, hence low exposure; and c) there was a lack of

confidence in how well the program was implemented along with the belief that BCG coverage during the program was poor due to the remoteness. The benefits of continuing the program therefore were not justified over the high cost of the vaccine (Waring, 2009). It is unclear how this shift in policy of routine BCG for TB prevention subsequently affected leprosy control in WA. National recommendations for BCG use now include the recommendation BCG provision to “neonates born to parents with leprosy or a family history of leprosy” and have done so formally since 2012 (National Tuberculosis Advisory Committee, 2013).

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Appendix C

Terminology related to treatment.

Terminology	Explanation
Lost to follow-up (LTFU)	A person who did not start treatment or endured a period of interrupted treatment and disengagement for 2 months or more (TB), 3 months or more (PB leprosy) or after 6 months for MB leprosy.
Cured	A person with pulmonary TB with bacteriologically confirmed TB at the beginning of treatment who was smear-or culture-negative in the last month of treatment and on at least one previous occasion.
Treatment completed	Completion of the full course of prescribed treatment within the given timeframe without evidence of treatment failure. For TB, no record of accompanying evidence of negative smears or cultures may not be done or results not available. (see treatment success).
Treatment failed	For TB, treatment failure is evidence of sputum smear or culture is positive at month 5 or later during treatment. For leprosy, this parameter is harder to define due to the potential for smears to remain positive after treatment has finished (see retreatment).
Treatment incomplete	Where a prescribed course of treatment is not finished due to LTFU, early discontinuation by the person, or relocation without transfer of care (may be referred to as partial treatment).
Treatment success	For TB, the sum of 'cured' and 'treatment completed.' For leprosy, success is reviewed by longer term post-treatment follow-up indicating no signs of relapse.
Relapse	A patient who has completed a full treatment course in the past who returns with signs and symptoms of the disease that are not deemed due to an immune reaction to the disease (e.g., lepra reaction, paradoxical reaction).
Recurrence	Clinical signs of infection after treatment have been completed. Can be due to relapse or a newly acquired infection (re-infection)
Reactivation	New active infection considered to be triggered from an old dormant infection acquired. Active infection is triggered due to immunosuppression or other cause.
Reinfection	Mainly TB - A person who has previously been diagnosed and treated who presents with a new infection (different strain of bacteria).
Re-start	During a prescribed course of treatment where the treatment start date is re-set, due to interruptions in therapy from irregular or non-adherence OR adverse drug reactions. Treatment changes may occur.
Retreatment	Where a patient has previously been diagnosed with TB or leprosy and has already received treatment for the disease in the past. Retreatment relates to a full course of treatment and may be used in relapse, LTFU, incomplete initial treatment, or in re-infection. Treatment may be different from the initial course.

Adapted with modification from the following sources: (Government of Western Australia, 2019(b); World Health Organization, 2013; 2016, pp. 13,14).

Terminology related to adherence.

According to Bernard. Vrijens et al. (2012, pp. 697, 698), quantifying the implementation of medications for adherence requires the following:

- 1) Knowledge of the proportion of drug taken (i.e., full, or partial dose)
- 2) The number of days where the correct number of doses has been taken, i.e., number of days missed.
- 3) The proportion of doses taken on time, in relation to the prescribed dosing frequency e.g., for once daily dosing, variations on 24 hours (i.e., shorter, or longer time periods)
- 4) The number of ‘drug holidays,’ i.e., frequency of clusters of days missed over a period of time.
- 5) The longest interval (gap) between missing doses

“**Management of adherence**” is “the process of monitoring and supporting patients’ adherence to medications by health care systems, providers, patients, and their social networks” (Vrijens et al., 2012, pp.697)

“**Forgiveness**” is the deviation away from the prescribed medication regimen, i.e., missed doses, that does not adversely influence the regimen’s intended effect.

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Appendix D

Aboriginal Advisory Group outline of meetings and advice

The following table highlights some of the key correspondence in meetings, noting that other forms of communication and individual correspondence occurred in between these times.

Date	Stage of research	Comments/discussion
June/Aug 2016	Development of research plan, and initial discussions about research	-Informal conversations about project ideas, feasibility, benefits, involvement.
Oct 2016	Acceptance of the proposal by the university, presentation on research ideas to the group, discussion about research design.	-Discussion about other interested members for advisory group and for connections/networking. -Confirmation of ways to communicate within the group and meeting frequencies, locations, types etc. -Discussion about best ways to work with participants. Ideas from advisory group such as offering to record people's stories and identify if/how they would like this done. -Discussion and reminder about the importance of IGT -suggestions for story-mapping of people's stories -practical considerations for providing food/tea etc during interviews.
April /May 2017	Progress of research design and ethics.	-continued as above, with progress on ethics – who to talk to, how to 'go in safe,' advice on approach within relevant communities, who else I should be talking to, letting know about the research. -guidance of methodology
Sept 2017	Finalisation of research protocol	-continued guidance on local and cultural matters -Feedback on presentation of research protocol
April 2018	Discussion after acceptance by university into candidature	-Discussions regarding respecting confidentiality and not putting pressure on health workers, how to go about this. -Discussions on other areas of appropriate research conduct.
June 2018	Provisions of updates, discussion of recruitment	-Identification of sorry business/difficulty and advice to hold off on visiting certain sites. --reinforcement to be sensitive and be guided. -Discussion/recommendations for conducting workshops in community and talking about the research process and providing food. -reinforcement about recognising needs of community not just nursing staff working at communities who had responded --more suggested contacts and reinforcing connects, ways to go about business to assist with recruitment
Aug 2019	Report back of some early findings of analysis, assistance with analysis for interpretation of culture.	-discussion of interpretation and meanings --Discussion about keeping results relevant for example in relation to what community would want to know, e.g., if/how they are being failed. “we want to know what we are in for; history is important but it's about what's happening now – are we still failing the community now?”

		-insertion of cultural analysis into thematic analysis. -discussion of next steps and finalising data collection.
July 2020.	Presentation of early project results write-up for comment And discussions about dissemination.	-Discussion about the results – additional comments, confirmation or further discussion that was needed. - Translation of research knowledge -> existing structures already represent a challenge for Indigenous representation between WAHCS and ACCHS with respect to a reference group and asked what ‘goals’ for elimination of both TB and Leprosy have been set... step by step dissemination to organisations involved to further discuss aspects. -Plans for dissemination, confirming any changes to organisations etc. Suggestion – cultural awareness training esp for white nurses, including workshops Discussion - Trauma of isolation being re-triggered by COVID
September 2021	Project results dissemination assistance/guidance	-final wrap-up of advice in hurdles with dissemination (covid impacted)
December 2021	Completion of project	Touching base individually and finalise discussions and plans for presentation
May-July 2022	Presentations & acknowledgement	Touching base individually and discussing next steps.

Appendix E

Sample interview questions

Examples of interview questions

Study Group 1

Example of the round 1 open-ended question; More open-ended

- ***'I would really like to hear about your experience, your story, from the time when you were offered treatment^ up until now? What do/did you think about this treatment?'***

^ The word 'care' or 'medicines' will be used as an alternative in place of treatment if the person does not display understanding.

*The specific condition relevant for the individual has been identified in consent forms, and to not impose western terminology of disease names on people's life experiences it will not form part of the question. If this causes misunderstanding, then the preferred term understood by the participant (e.g. 'big sickness'/ 'sickness'), will be used to assist.

Study Group 2

Examples of open-ended trigger questions for focus groups are as follows;

- ***I would really like to hear about your experience caring for or living with someone who has taken or is taking medicines for Tuberculosis or Leprosy.***
- ***As a group, what do you think about the way treatment is offered, supported, and followed up?***
- ***What do people think about Directly Observed Therapy (DOT), where someone observes the person taking the tablets?^***
- ***What would you like to see change if it were to be you or someone you know e.g. an aunty or nephew, who was told they had Tuberculosis or Leprosy and had to take the treatment?***

^A description of what DOT is will be offered to the group in cases where the group required more explanation

Study Group 3

Example of the round 1 open-ended question;

- ***'With respect to Aboriginal peoples in the Kimberley, what is your experience with and what are your views about, the way treatment of active/latent Tuberculosis and Leprosy*is offered and supported?'***

^Prompts regarding 'treatment' will be given if needed, such as positive and negative experiences with initial decision-making, supply, support, the use of DOT, medication management, and follow-up to ensure treatment completion.

*This will depend on the area of their work, the appropriate choice will be selected prior to the interview

Appendix F

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Requestor type

University/Academic

Format

Electronic

Portion

Figure/table

Number of figures/tables

1

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No

Title

PhD thesis: "From Isolation to Inclusion: Embracing local perspectives in examining the treatment model of care for Aboriginal persons affected by tuberculosis or leprosy in the Kimberley region, North Western Australia"

Institution name

University of Notre Dame

Expected presentation date

Nov 2022

Order reference number

080322

Portions

Figure 1 page 6: Map of Western Australia showing the area covered by the sur

Appendix G

TB survey results (1950, 1956)

1950 northwest TB survey results

The first TB survey for the North and North West as discussed in chapter 4 was an aerial survey where a local x-ray unit was used where available and a mobile x-ray unit capable of aerial transport used for the remainder of locations. Of the 3209 people included in the survey, 2677 received initial Mantoux tests and 555 initial chest x-rays without Mantoux (270 of these were from Bungarun due to a concern of false positive Mantoux from the leprosy bacilli). Out of 2677 Mantoux tests conducted, 1191 reacted positively (44.45%) and 1087 negative. Those who had no reaction from the Mantoux test and were under 45yrs were administered the BCG vaccine, and those who had a positive Mantoux reaction were given chest x-rays. Out of the total chest x-rays performed, significant radiological evidence of pulmonary TB was found in fifteen people, and minor evidence of pulmonary TB in twenty-one, bringing the total to thirty-six people out of 3209 (11 in 1000). One person was considered to have miliary disease and 2 probable cases of PTB were identified at Bungarun (King, 1951, October 5).

The working theory of areas with higher incidence was increased exposure to European population – i.e., settlers as the source of infection. This was determined observationally secondary to survey results based on site, degree of contact, and degree of Mantoux conversion. The particular site that was referenced was ‘Pallotine’, the ‘old’ Balgo (Wirramanu community) and determined by separating results based on people arriving from Beagle Bay (70% positive reactors), and people who were originally from that desert country (21% positive reactors) (King et al., 1951, p. 7). Any notion of genetic susceptibility was subsequently dropped in this analysis.

1956 survey

In the winter of 1956, a further survey of Mantoux testing alone was conducted in the same divisions (as the 1950 epidemiological survey), with the addition of the Roebourne and Ashburton areas. “Non-reactors” were vaccinated with BCG, as for the first survey F. G. B. Edwards, Harris, & Slade, 1957). The survey included nine towns, eight missions and eighteen stations and over three months examined a total of 3542 people. Six percent of people failed to report for reading of the reaction. Overall, 998 people had a positive reaction to Mantoux (34.1%). The largest proportion of positive reactors was in the 41 years and over group. The same position of thinking for the “effect of contact with white communities” as observed in the

first survey, was held due to the same pattern repeated in this survey. At Jigalong, Pallotine (now known as Balgo), and Billiluna, among those not previously vaccinated in 1950, 15.5% were found to have “naturally acquired sensitivity”, compared to 34% of the same group for all other centres (Edwards, Harris, & Slade, 1957).

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Appendix H

Pharmacogenomics

Pharmacogenomics, being the study of the effect of human genetic factors on drug metabolism, has identified specific genetic markers responsible for the way a drug is metabolised and broken down that when missing or present are predictable of immunological and other serious drug reactions. There are three known examples of these genetic factors on metabolic drug pathways related to medications used for TB and leprosy, and potentially more. The first is acetylation status. Acetylation is a chemical conversion process and an important route of metabolism for specific drug compounds such as the sulphones (e.g., dapsone, used for leprosy) and hydrazine's (e.g., isoniazid, used for TB) (Silverman & Holladay, 2014). Acetylation status has been shown to be linked to isoniazid hepatotoxicity (that is being a 'slow' acetylator) (Chan et al., 2017). For dapsone being a slow or fast acetylator is not considered to impact on the outcome of toxicity for the oral formulation, whereas Glucose-6-Phosphate-dehydrogenase (G6PD) enzyme deficiency has been linked to an increased risk of haemolysis from dapsone use (Zuidema et al., 1986). HLA (Human Leukocyte Antigen) status is another genetic factor linked to dapsone hypersensitivity syndrome (DHS). The specific HLA allele HLA-B*13:01 presence has found to be a predictor for DHS (Zhang et al., 2013).

There is some evidence that these genetic effects may also be familial, or aggregate in families (Jamrozik, 1986; Kurtz, Beatty, & Franklin Adkinson, 2000). However scientific research, often controversially, tends to correlate genetic biomarkers with ethnic groupings. This has been relevant for Aboriginal people in the Kimberley in both scientific studies and anecdotal accounts. Firstly, a study was conducted to assess acetylation phenotype and genotype for local Aboriginal persons affected by leprosy who attended the Derby public health unit in the early 1990s. The study findings compared Aboriginal people to other ethnic groupings in terms of the distribution of rapid vs slow acetylators, however appeared to do more for postulating genetic heritage than providing any clinical benefit for therapeutics (Ilett et al., 1993). Secondly, from this research it was revealed that there had been anecdotal accounts of a susceptibility in Aboriginal people for DHS. From the small group of people identified within this research, one experienced DHS. However, numbers were too small to assess for HLA status to confirm. Both examples add to the sensitivity and controversy over pharmacogenomics and genetic testing of First Nations people in Australia due to the confusion of racialised science (i.e., inherited genetic traits and 'racial intolerance') with cultural identity.

In 2013 the Australian National University established the world's first genome facility to be governed by First Nations people, to oversee blood samples collected across a number of First Nations communities in the 1960s and 1970s (Kowal, Watt, Weyrich, Kelaher, & Tobler, 2017). The path forward for the role of pharmacogenomic testing to assist in preventing serious adverse drug effects for Aboriginal people is not clear, however more routine testing requires consideration of the highlighted issues from Kowal and colleagues.

Appendix I

Dose Administration Aids

Suitability

The use of a Dose Administration Aid (DAA) is an option to aid medication management and dependent upon the situation and needs of the person, their motivation and willingness, and their physical and cognitive ability (Australian Pharmaceutical Advisory Council (APAC), 2005; Pharmaceutical Society of Australia, 2017, p. 8). Any use of a DAA should involve the patient as an active participant in the decision-making including medications that a patient does not want in the DAA. Decisions should be made in partnership with the patient, pharmacist, and prescriber (Australian Pharmaceutical Advisory Council (APAC), 2005, p. 22 ; Pharmaceutical Society of Australia, 2017, p. 13).

Stability

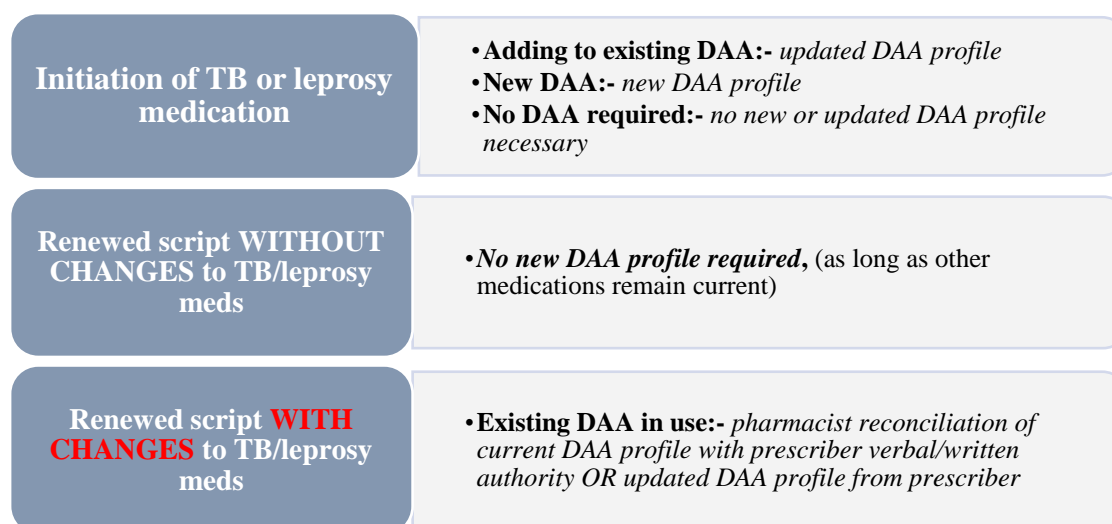
The Pharmaceutical Society of Australia confirms that the removal of medications from their original packing to re-package into DAAs has been considered as “an off-label use,” as re-packaging is not consistent with the manufacturer’s approved product information for drug stability and storage (2017, p. 10). Stability of medications re-packaged into DAAs is currently informed by professional judgement and available stability data (Haywood, 2011). International guidelines recommend a maximum of 8 weeks expiry for a DAA from the time of re-packaging, however in environments of elevated temperature and humidity this maximum time may be reduced. Humidity reduces tablet hardness through moisture absorption leading to early disintegration, and all re-packaged medication increases the chance of microbial contamination (Pharmaceutical Society of Australia, 2017, p. 11 ; Raman, 2017). Current practice in the Kimberley is usually a 3-month expiry for DAAs but may vary dependent upon individual Kimberley community pharmacy policies and procedures for DAA packing. All DAAs must be stored in a cool and dry place as possible and away from light.

Legality

All DAAs require adherence with relevant legislation and professional guidelines. For pharmacists responsible for packing a DAA this means having a ‘DAA profile’ which is a list of current medications (packed and non-packed) approved by the prescriber to ensure accuracy of current medications in the DAA. This is not the same thing as a legal medication prescription—a DAA profile cannot be used to supply medications, but only for accuracy of current medications packed into a DAA. This profile can be generated through electronic health

systems for primary care practice from GPs and sent to the respective pharmacist/pharmacy or be handwritten. Pharmacists also have the option of collating this profile and then getting a prescriber to confirm its currency and sign. Prior to starting a DAA and during any changes, a medication reconciliation should be performed ideally with both the patient and the prescriber. All medications must be dispensed as per standard legislation prior to packing into a DAA and the DAA needs to be labelled clearly according to standard legislation. The incorporation of specialist medications such as for TB and leprosy can become complicated when the primary GP providing the updated medication list does not have a record of specialist medications, or they are not updated on the electronic medication list sent through the specific electronic health systems used in the Kimberley. This means multiple prescribers may be involved and extra caution is required to ensure currency and correctness of medications packed. Changes to medications packed into a DAA have the potential to be problematic in ensuring records are updated and DAA packs are stopped and updated if the change is urgent, without compromising regular dosing. All medication changes follow the same process for the DAA profile and should only be processed after confirmation with the prescribing doctor. The pharmacist therefore has a duty to ensure medication reconciliation and documentation is complete at the start, and during, a person's use of DAAs (Pharmaceutical Society of Australia (PSA), 2017).

Figure 11. Example of the process involving DAA profiles in relation to TB and leprosy medications



Note: This process is for when TB and leprosy medications have been pre-dispensed in Perth and supplied to community pharmacy in Broome. The cty phcy does not have the original prescription, only a labelled supply of medications that have been dispensed to the patient and as such are their property.

Appendix J

Adverse Drug Reactions from leprosy and TB medications.

All medications used in the treatment of TB (both active and latent) and leprosy can cause unwanted drug related effects, also referred to as adverse drug reactions (ADRs), adverse effects or medication side effects. Some of these can be severe and even life-threatening (for example in the case of allergy or other immune type reactions). All TB and leprosy treatment, both preventive therapy and that for active infection, requires clinical monitoring for ADRs through observational and diagnostic intervention (mainly regular blood tests) to assist in preventing medication induced harm. This monitoring is a responsibility of prescribing and part of the role of case managers. For example, any person started on active treatment for tuberculosis will have baseline blood tests, the first test within 2 weeks, and then if tolerating medications every month unless otherwise clinically indicated. Other baseline tests may also be indicated such as colour vision (Ishihara test) and visual acuity prior to starting ethambutol to monitor for changes from the drug due to its potential to cause ocular optic neuritis (inflammation of the optic nerve) (Australian Medicines Handbook 2020, online). There are several ADRs for the range of medications used to treat TB and leprosy. Below I provide some more detail on those used most, followed by a medication summary chart for first- and second-line treatment for leprosy (including lepra reaction) provided to Aboriginal Health Workers as presented at the Aboriginal Health Workers conference.

Specific ADRs for dapsone (treatment of active leprosy)

In addition to its potential to cause haemolysis (rupture or destruction of red blood cells) and methaemoglobinemia (a blood disorder where there is a reduced amount of oxygen to the cells), ‘Dapsone Hypersensitivity Syndrome,’ (‘Dapsone HSS’ or ‘DHS’), a rare but serious adverse reaction that can be potentially fatal, can occur. DHS usually presents with fever, skin eruption and organ involvement within two to six weeks after administration but has been seen delayed until up to six months after the initial administration. It can be misdiagnosed as sepsis due to similarities in initial presentation and requires immediate withdrawal of the drug with clinician guided corticosteroid dosing usually needed (Guragain et al., 2017; Karjigi et al., 2015).

Rifampicin (treatment of active TB, active leprosy)

Rifampicin is also considered to be associated with severe immune-allergic reactions, such as haemolytic anaemia, acute kidney failure and disseminated intravascular coagulation

[abnormal blood clotting throughout the body], more associated with intermittent treatment, or re-starting after an interval of interrupted therapy (Havey, Cserti-Gazdewich, Sholzberg, Keystone, & Gold, 2012; Nishioka et al., 1992; Sadanshiv, George, Mishra, & Kuriakose). Signs and symptoms may not be easily attributed to rifampicin ADRs due to their generalisability such as fever, lowered blood pressure, or abdominal pain and vomiting with hours of ingestion (Havey et al., 2012; Poole, Stradling, & Worlledge, 1971).


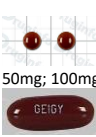

Treatment for lepra reactions

Medications used for lepra reactions can also be problematic, for example, long term use of prednisolone which is commonly used. Adverse effects from prednisolone include elevation in blood glucose levels, immunosuppression, and increased risk of infections (especially at higher doses for prolonged periods), and osteoporosis. People with diabetes need to increase vigilant monitoring of blood glucose and adjustment of diabetic medication as needed. In addition, abrupt stopping of regular prednisolone which can precipitate an adrenal crisis due to its adrenal suppression capabilities, hence high doses are weaned over a period of time to prevent this occurring. This has implications for irregular taking of medications (Australian Medicines Handbook 2020, online; Nicolaidis, Pavlaki, Alexandra, & Chrousos, 2018).

The other medication recommended by the World Health Organisation (officially approved in 2019) and has a long use in managing Type 2 lepra Reaction (Erythema Nodosum Leprosum, 'ENL'), is thalidomide (S. K. Teo et al., 2002). The evidence for the ability of thalidomide to control pain and the severity of ENL has been shown to be more clinically effective than prednisolone (Walker et al., 2017). Thalidomide has earned a marked place in history due to its withdrawal from the drug market in 1961, after the discovery of its teratogenic effect in pregnant women who were advised to take it for morning sickness (S. K. Teo et al., 2002). Its use was re-kindled after discovery of its potential in multiple myeloma (its current approved indication for clinical use) as well as for ENL. Today, the use of thalidomide is heavily regulated due to the previous issues encountered. While its use for ENL is an approved indication, its use for ENL is not subsidised under the PBS, making it a high cost as well as a high-risk drug. Consequently, there are number of strategies put in place by its Australian distributors, to prevent any harm from its use. This involves the treating physician needing to complete a lengthy application and the person receiving treatment required to sign an informed consent and waiver for its use, such as agreeing to the use of contraception (for both men and women).

Table J1. Summary of medications used to treat leprosy and possible adverse effects.

(assembled to provide to Health Workers at the KAMS Aboriginal Health Worker conference September 2019).

Drug (oral)	Class	Dosage (adults) – children [^] by weight or age	Pharmacokinetics & dosing in renal/hepatic impairment	Common adverse effects/relation to food Possible drug interactions	Possible severe drug reactions or allergy	PBS? Supply arrangement
Dapsone (1 st line) 100mg tablets 	Sulphone antibacterial	100mg daily 10-15yrs – 50mg daily <10yrs – specialist advice [^]	<u>Half-life:</u> 10-80 hrs <u>Steady state:</u> 8 days <u>Renal/hepatic dysfunction:</u> Use caution – monitor for toxicity. (Excretion urinary, 20% unchanged).	Nausea/stomach upset TAKE WITH FOOD Rash (must report) <i>Probenecid</i> – increases dapsone levels; <i>Trimethoprim</i> – possible increased levels (watch for dapsone toxicity for both)	Dapsone hypersensitivity syndrome; Caution in sulfonamide allergy; Methaemoglobinaemia, haemolytic anaemia [people with G6PD deficiency more severe]. WATCH FOR <i>Sore throat, fever, swollen glands, pallor, jaundice, purpura, vomiting, severe skin reactions</i>	YES , however supply for leprosy should be free under agreement* SAS in WHO pack. NOT prescribed under PBS/S100.
Clofazimine (1 st line) 50mg; 100mg 	Rimino-phenazine antibacterial (traditionally a dye)	50mg daily, 300mg once a month (3 x 100mg) Dose reduction required for children [^]	<u>Half-life:</u> av 70 days <u>Steady state:</u> up to 30 days <u>Renal:</u> no dose adjustment usually required <u>Hepatic:</u> caution, adjust in severe disease	Pink-brownish discolouration of skin, urine, tears (can take months to reverse); Ichthyosis, dry, itchy, skin; abdominal pain, nausea, diarrhoea, vomiting; eye discolouration, itchy dry eyes. TAKE WITH FOOD. Possible CYP3A4 inhibitor, monitor for other drug toxicity	Enteropathy: Deposits of crystal into GI mucosa and lymph nodes and other organs causing intestinal obstruction (usually doses >200mg daily for >2mths) May prolong QT interval WATCH FOR <i>severe abdominal pain OR other GI symptoms. Impact of skin discolouration on mood/affect/ socialisation</i>	NO – not available in Australia. Imported and supplied under SAS, supply free under Agreement* Agreement*
Rifampicin (1 st line) 300mg capsule 	Rifamycin antibacterial	600mg monthly (2 x 300mg capsules) 10-15yrs 450mg monthly <10yrs spec advice [^]	<u>Half-life:</u> = av 3 hrs <u>Renal:</u> no dose adjustment usually required <u>Hepatic:</u> – use very cautiously, may worsen hepatitis	Body fluids become orange/red (tears, urine, sweat) – reversible; increased LFTs; muscle aches (first few weeks), drowsiness, fatigue BEST half hour BEFORE FOOD (better absorption) Numerous drug interactions – potent CYP3A4 inducer, always check first	Hepatotoxicity; severe allergy (<i>more likely after re-starting form stopping or in intermittent regimes</i>) – respiratory distress with dyspnoea, cough and flu-like symptoms, haemolytic anaemia, acute renal failure, stevens-johnson syndrome all possible as allergy. WATCH FOR <i>jaundice, fever, skin rash, swollen glands, dark urine, breathing difficulty</i>	YES for leprosy (authority required) BUT SAS in WHO pack. Supply is free under Agreement* so not under S100/PBS
Ofloxacin (2 nd /3 rd line)	Quinolone antibacterial (can use <i>moxifloxacin in substitute</i>)	400mg daily OR 400mg monthly as part of triple therapy (ROM) <i>Child- seek advice[^]</i>	<u>Half-life:</u> av 4 hours <u>Renal:</u> reduce frequency and/or dose – seek advice <u>Hepatic:</u> reduce dose in severe disease	Nausea; heartburn; rash; Dizziness/faintness; diarrhoea Food not important. Avoid NSAIDs (may induce convulsions); Increased effect of glimepiride, warfarin; give 2hrs apart from iron, antacids	Arthropathy (degenerative changes in joints); tendon rupture; prolonged QT interval; increase risk of seizures; peripheral neuropathy; angioedema. WATCH FOR: <i>unusual joint or tendon pain or inflammation; numbness or tingling in toes/fingers; skin reactions</i>	NO – not available in Australia. Supply via SAS and free under agreement*
Minocycline (2 nd /3 rd line)	Tetra-cycline antibacterial	100mg daily or monthly (As part of ROM) C/I children <8yr [^]	<u>Half-life:</u> av 13 hrs <u>Renal:</u> avoid in severe impairment – seek advice <u>Hepatic:</u> caution in severe impairment	Nausea, abdominal cramps, vertigo, dizziness, headache. TAKE WITH MILK/FOOD, large glass of water, sit up 30mins. AVOID – antacids, iron/calcium sup's. (sep 2 hrs). Monitor for increased effect of warfarin.	Pigmentation of tissue, skin, teeth (longer term). Autoimmune hepatitis; lupus-like reaction; multi-organ hypersensitivity. WATCH FOR: rash, fever, swollen glands, jaundice, severe headache	NOT for leprosy. Available as non-PBS but supply should be at no cost to patient.
Clarithromycin (2 nd line)	Macrolide antibacterial	500mg daily Child- seek advice [^]	<u>Half-life:</u> 5-7 hrs <u>Renal:</u> Reduce dose CrCl<30 <u>Hepatic:</u> caution in severe impairment	Taste disturbance FOOD NOT IMPORTANT Has many important drug interactions including statins, colchicine – seek advice.	Prolonged QT interval, risk of arrhythmia; Fixed drug eruption; interstitial nephritis; ototoxicity WATCH FOR: tinnitus, rash, fever, mood change,	YES – but supply for leprosy should be free, not under S100/PBS.
Prednisolone (no antibacterial activity)	Corticosteroid. to control leprosy reactions	Up to 50mg daily, weaning regimen over weeks. (25mg, 5mg tabs only) Child – advice [^]	<u>Half-life:</u> 3-4 hrs <u>Renal:</u> no dose adjustment required <u>Hepatic:</u> caution in severe impairment	Nausea, change in mood/energy – adv. effects depend on dose/duration TAKE WITH FOOD, (morning) Caution with drugs that have similar adv. effect profile	Immunosuppression; Increased BSL; Osteoporosis; worsening of heart failure; peptic ulceration; hypokalaemia WATCH FOR: BSL control esp. in diabetics; 'moon face'; oedema; exacerbation of psychiatric disorders	YES – ideally supply should be free under agreement* & not under S100/PBS

*Agreement: All leprosy drugs are provided free of charge via Anita Clayton Centre/RPH. [^]For dosing in children refer to guidelines/specialist advice.

PBS = Pharmaceutical Benefits Scheme SAS = Special Access Scheme for non-TGA approved drugs. LFTs = Liver Function Tests

As with any drug, other adverse reactions are possible – refer/report ANY symptoms/effects noticed by person. In pregnancy and breastfeeding, always seek specialist advice.

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Appendix K

Supported treatment.

Goals of care for the treatment models	Elements for operationalisation
1.Supported treatment	Integrated Cultural Case Management – Regional-remote areas (ICCM-R).
	Optional DOT
	Peer support

Integrated Cultural Case Management for regional-remote communities (ICCM-R)

Cultural Case management in practice should be responsive to identified cultural needs for Aboriginal people as informed by individual people themselves or Aboriginal leadership. In addition, a pragmatic approach in providing care in the remote setting is needed. The intention of the ICCM-R as part of a supported treatment approach builds on the case management model, the use of Local Case Managers and multi-disciplinary case management meetings, but extends care to incorporate these needs, specifically including:

- a) Nomination of suitable family members** by the person affected from the start OR inclusion of a person available for cultural liaison if family are not wanted or not deemed suitable due to availability or willingness.
- b) Formal recognition of Aboriginal Health Workers (AHWs), Aboriginal Health Practitioners (AHPs) and as options for Local Case Managers (and/or DOT providers)**
- c) The person affected as active participant in their care**, relaying discussions from case management meetings and upholding shared decision making, including negotiation about potential Local Case Managers
- d) The option of incorporation (and remuneration) of peer support workers** i.e., those who have been through treatment themselves and are willing to support others through their journey.

For practical application, this model incorporates a stepwise approach, based on a stratified assessment of needs that represents the clinical, psychological, social or treatment complexity for the person affected and corresponding degree of support required. This stratification may assist communication of level of services and visits/appointments recommended, negotiated as part of a shared decision-making process, and allocation of required resources.

Table K1. Suggested stratified levels of support (medication management, psychosocial)

Criteria	Stratified for level		
	Level 1 (low level support)	Level 2 or 3 (moderate & high-level support)	
Living arrangements	Fixed address or resides at least between two known addresses. Yes No →	May have no fixed address, > 2 known addresses OR resides in densely populated household	
Financial barriers	Financial barriers to care? No Yes →	May have financial barriers to care such as loss of employment secondary to condition	
Language	Interpreter required? No Yes →	Requires a formal interpreter or family member	
Social pressures identified* (including stigma)	Social pressures identified No Yes →	Social pressures identified including actual or experienced stigma	
Drug resistance	Drug sensitive Yes No →	If identified drug resistance, level 2 or level 3 support depending on other factors	
Previous treatment	Primary treatment course Yes No →	Known/possible previous treatment	
Complications from treatment (allergy, ADR#, renal or hepatic impairment)	Complications identified No Yes →	Depending upon degree of complication will depend upon level of support	
No. of prescribed medications (prior to TB/leprosy)	<5 Yes No →	Level 2	Level 3
		5-20 Yes No →	>20
Co-morbidities	<3 concurrent medical conditions that do not affect immunity, (e.g. HIV, cancer, or organ transplant). Yes No →	>3 concurrent medical conditions that do not affect immunity, OR <3 medical conditions that include those that affect immunity Yes No →	>5 concurrent chronic diseases including those that affect immunity such as HIV, cancer, OR organ transplant
Age^	>18 years and <55 years Yes No →	>5-18 years and 56 - <80 years Yes No →	Includes children <5 years and adults >80 years
Disability	Pre-existing disability No Yes →	pre-existing disability but does not require carer No Yes →	pre-existing disability and requires part-time or full-time carer
	Level 1: (Low level)	Level 2 (Moderate)	Level 3 (High level)

*such as social pressures non conducive to goals of treatment such as heavy alcohol use/ binge drinking, peer pressure (e.g., younger generations, teens), stigma experience (actual or potential).

^individual assessment is needed for level of support required based on age

#ADR= Adverse Drug Reaction

The above levels are suggestions for the application of the model that would need to be further adapted /tweaked with additional cultural leadership once in practice. Flagging the potential of ‘back-up’ HCWs to step into identified roles of LCM and/or DOT provider is also recommended due to the long treatment time, especially for multibacillary leprosy. Staff may take annual or sick leave, rotate sites of work, or leave the job altogether. Aboriginal Health Workers have been and continue to be a key discipline in the provision of culturally appropriate and person-centred care. Within this formal recognition is the recommendation to improve specific TB and leprosy disease and treatment training and education and a review of policies and procedures that currently restrict medication administration required for this role. Formalising the role of AHWs, AHPs, and AMSOs, addresses two main hurdles with the current reliance on nursing staff to fill the role of LCM and DOT: a) the need to ensure cultural safety training and practice is adequate, and b) the need to ensure available and suitable nursing staff in remote communities. Within this premise flexibility of DOT providers should also be considered when people are unavailable or opportunistic timing is encountered, such as when a person seeks out treatment but cannot find the assigned DOT provider and the given opportunity missed. It is strongly recommended to implement these negotiations from commencement of care, The situation for each person additionally be impacted by:

- a. The degree of remoteness and available services
- b. The willingness of the person for involvement of family members and cultural rights of person/people available to assist
- c. The availability of AHWs, relational appropriateness of AHWs (i.e., not in avoidance relationship).

It is also strongly recommended to use and evaluate technology to assist where possible this model due to the remote setting and vast distances.

OPTIONAL -DOT premises

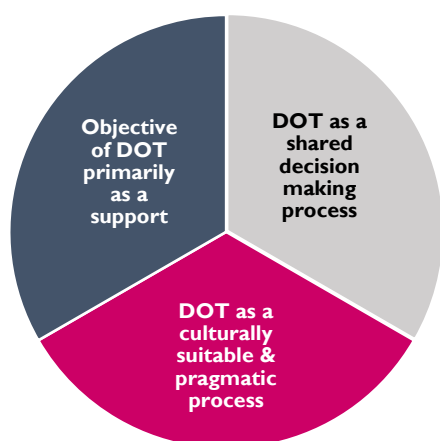
PREMISE 1. *Objective of DOT*

DOT primarily as support, not as a response to controlling adherence.

DOT is offered primarily as a means of support for treatment, not as a punitive/paternal response to perceived or actual irregular or nontreatment. It is recommended that DOT is explained from the initial meeting and offered initially as a means of support and re-offered as an option throughout the treatment journey if the need arises or the person changes their mind.

Support means that DOT is a formal way to ensure a continuity of supply of medication at a negotiated place and time, support with medication side effects and other clinical reactions, and a designated time and opportunity to ask questions about treatment and provide psycho-social support.

Figure K1 Optional DOT premises



PREMISE 2. DOT as a person-centred and self-determining process

DOT as a shared decision-making process

DOT is a shared decision between the health team and the person affected. This includes information-exchange and negotiations of place and person. If DOT has been agreed to initially, but it is not working/starting to jeopardise relations, the benefit

of doggedly pursuing DOT vs the risk of ruining relationships should be taken into consideration and a re-evaluation with the person done. Negotiation should be on mutual terms.

PREMISE 3. DOT as a culturally suitable and pragmatic process.

Increased options for person providing DOT (DOT-provider) and place of DOT

It is recommended to widen the options of DOT providers to formally include:

a) Aboriginal Health Workers, Aboriginal Health Practitioners, and Aboriginal Medication Support Officers. This can then be considered as ‘AHW-DOT, ‘AHP-DOT,’ or AMSO-DOT.’ This is recommended to be accompanied with renegotiated medication policies and practice that allow a process for medication administration outside of the clinic required for DOT. Formal training is also recommended to be accompanied with this role, such as specific training modules for TB, leprosy, and related medications. Widening the options of DOT providers to formally include Aboriginal Health Workers, Aboriginal Health Practitioners, and Aboriginal Medication Support Officers, identified as ‘AHW-DOT, ‘AHP-DOT,’ or AMSO-DOT.,’ would improve not only options but improved culturally appropriate options for people affected and formal recognition of a practice that occurs. By formal recognition, specific training with

modules for TB or leprosy treatment, and assistance can be provided to make sure Aboriginal health staff are also supported in their job roles.

b) Within resource challenged areas, and where the person affected agrees, consider family members as practical options for DOT provision and support. Again, any agreement for this would require training for the family member and provision of supports put in place.

c) Consideration of suitable places for the provision of DOT can extend to other options outside of the clinic and the home, such as local community pharmacies, other community sites appropriate and nominated, or in less formal situations such as meeting at a café, if in line with organisational policies and procedures. This may also reduce the risk to the DOT - provider where a person's home is deemed to provide a degree of risk. Any place should be negotiated to respect a person's privacy.

Figure K2. Suggested communication tool for Optional DOT



Appendix L

Improved treatment information additional detail

Goals of care for the treatment model	Elements for operationalisation
2.Improved treatment information	Aboriginal-led design of treatment resources
	Education modules (medications) for PHC staff
	Clinical pharmacist support
	Tools for effective communication & consistent messaging

Education modules

In line with supporting Health Care Workers to provide services, it is recommended that modules are developed that are specific to TB and leprosy treatment. This would involve the development of specific modules that cover unique aspects of TB and leprosy pharmacotherapy including knowledge of clinical monitoring requirements and recognition of allergy or adverse drug reaction.

Clinical pharmacist support

In addition, re-viewing regional supportive clinical pharmacy services for both persons affected and Health Care Workers, including role for Aboriginal Medication Support Officers, may be of benefit. This could be (with specific training), via regional clinical hospital pharmacists and S100 Quality Use of Medicines pharmacists. Pharmacists can additionally assist in optimisation of medication management and safety such as detection of drug interactions, ADR and allergy documenting and monitoring.

Tools for effective communication & consistent messaging (latent TB)

Based on the following premises:

- 1) Continuity/regularity of treatment is optimal to get the best effect out of the medicine. Finishing the full course is optimal as the studies show that stopping any earlier reduces the benefits of preventing active infection. Stopping and starting treatment also can risk acquired drug resistance.
- 2) Taking the course of treatment as prescribed reduces the risk of the TB bacteria becoming active in the future from older age or from certain prescribed immunosuppressive/immunomodulatory medications by 90% (Government of Western Australia, 2019(a), p. 67).

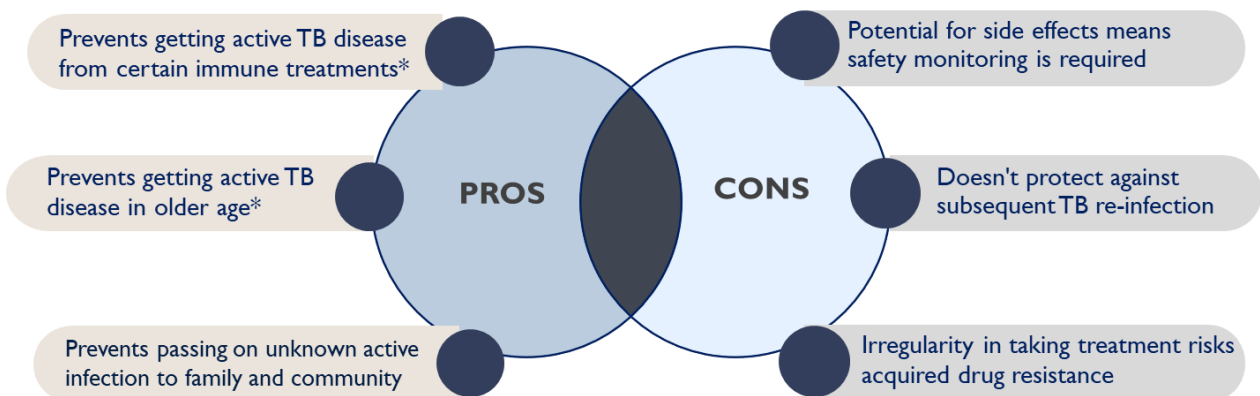
It does not however prevent against new infections from re-exposure to active TB (Dobler et al., 2016, p. 78)

3) By taking preventive therapy there are also benefits for family and community - if the latent bacteria become active then this can be passed on to other people, even if you are not aware you have it.

4) There is a small chance of intolerance to the medication and that this needs monitoring to make sure if it does occur it can be managed properly

Figure L1. Suggested communication tool for Latent TB

The Pros and Cons of latent TB treatment

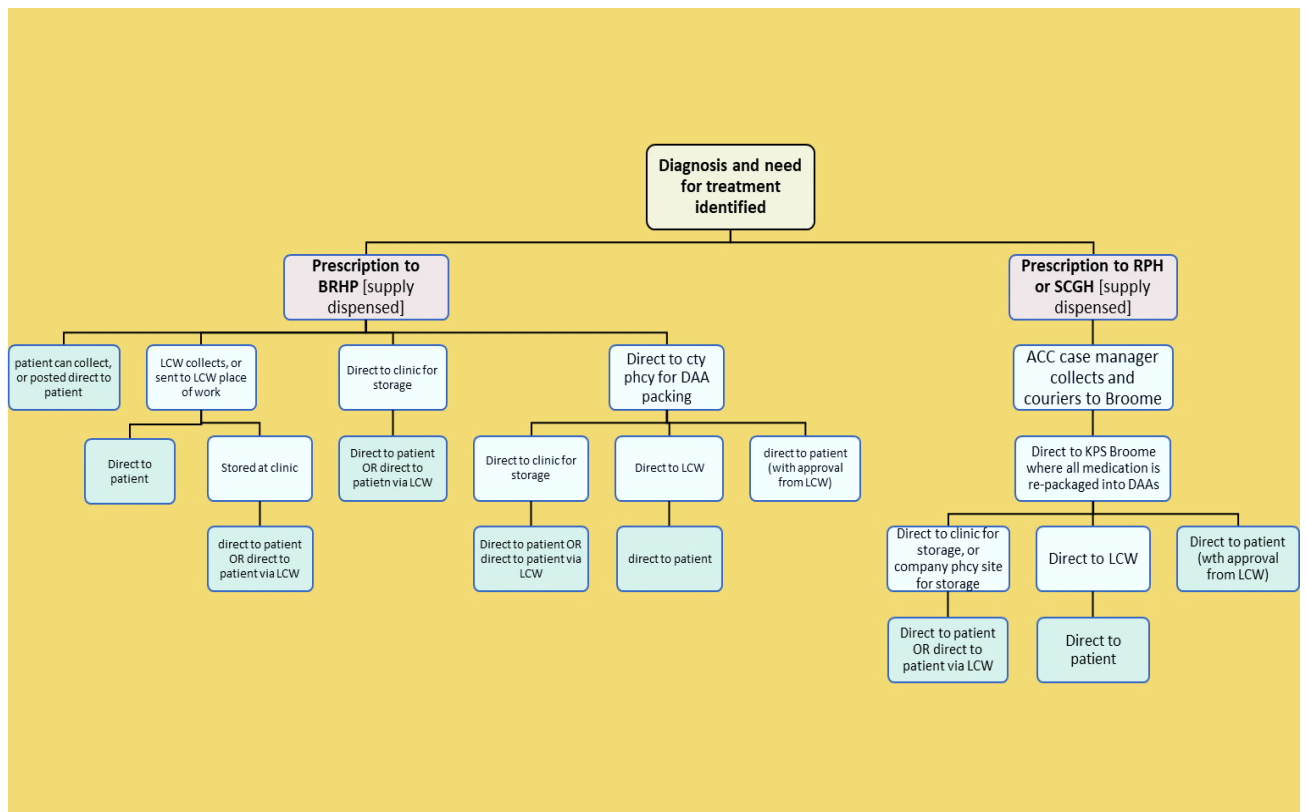


Appendix M

Supply model comparison between central or local-regional sites

Goals of care for the treatment model	Elements for operationalisation
4.Enhanced treatment supply & access	Decentralise supply -> Shift dispensing/supply of medications from Perth tertiary hospital to Broome Regional Hospital Pharmacy as central regional base.
	Remove restrictions of 1-2 weekly supply, allowing for routine monthly supply
	Shared Decision Making about the general use of DAAs and WHO packs for leprosy

Figure M1. Diagram of difference supply route



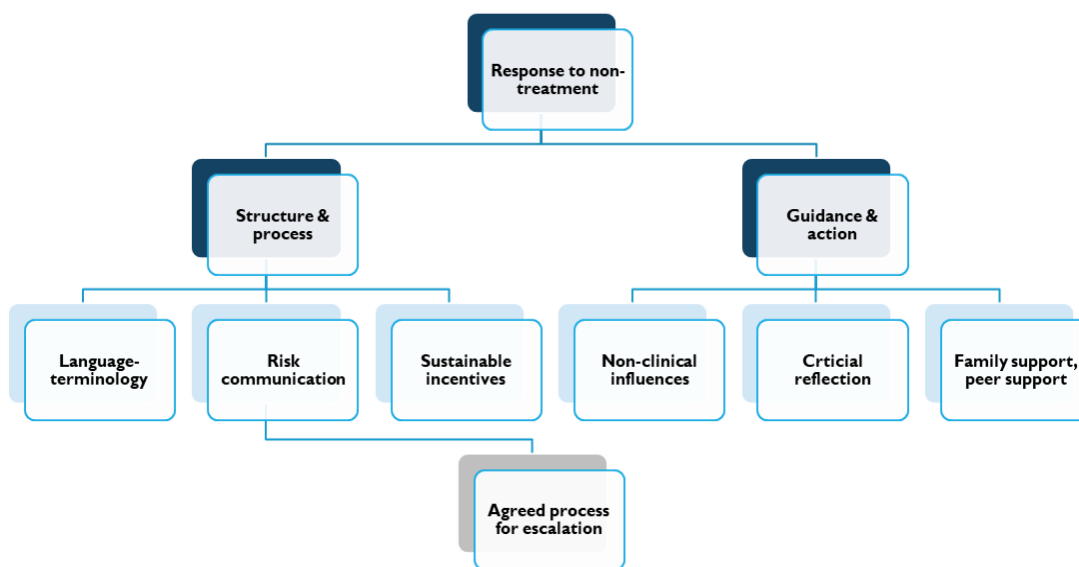
- Light green indicates supply to patient (person affected).
- Cty phcy = contracted community pharmacy to identified clinic. [note that this is in line with current S100 contracts for AMS – see supply diagram].
- Storage of medications, even though they technically belong to the patient, will be in accordance with clinic policies
- DAA packaging requires prescriber authorised DAA profile – usually computer generated e.g., GP software, MMEx etc, even if medications are already “dispensed.” [DAA packaging should be SDM process between prescriber/patient/pharmacist].
- LCW = Local Case Manager (previously called worker)

Appendix N

Culturally responsive framework detail

Goals of care for the treatment model	Elements for operationalisation
6. Culturally responsive plan for responses to nontreatment	Structure & process
	Guidance & action

Figure N1. Culturally responsive plan for responses to nontreatment – detail



Structure & process

The following considerations are suggested for each of the following sub-categories under structure & process:

a) Language-terminology

- Oversight of language used within state guidelines and health education.
- Caution to not use language that singles out Aboriginal people that can perpetuate blame and racialised risk
- Language around descriptors of nontreatment should be in line with WHO recommendations, for example removing the term “defaulters” and replace with “lost to follow-up.” The relevance here is the way blame can be positioned through language.

- Consensus on use of “leprosy” or Hansen’s,” or both, as well as the inclusion of other accepted language such as the “big sick,” “Bungarun,” and so forth. This consensus will assist with, i) knowledge association with language & history, ii) association of shame/stigma with language, iii) privacy & confidentiality especially in documentation of medical histories across health services and clinical handovers.

b) Risk communication

- as discussed in chapter 8

c) Sustainable incentives

- That meet World Health Organisation recommendations: “delivering enablers to address barriers that would otherwise be insurmountable for patients” (World Health Organization, 2014, p. 178).
- Act in genuine reciprocity and to not cause offence or threaten relationships,
- Achieve the desired goal of incentivising treatment and are sustainable with respect to allocated resource.

Guidance & Action

The following considerations are suggested for each of the following sub-categories under structure & process:.

a) Non-clinical influences impacting on treatment,

- as discussed in chapter 8 this relates to recognition of the need for more social assessment or cultural assessment that it outside the scope of standard clinical decision-making.

b) Critical reflection

- Critical reflexive practice by Health Care Workers can assist in reviewing and reflecting on previous (precedented) practice, to shift decision making, relationship and knowledge response to intervention and response processes, prior to escalating responses. The following table provides suggestions of critical reflection through four cornerstones of care for nontreatment (i.e., irregular treatment that is impacting on optimal treatment and durations; refusal of treatment; early cessation; lost to follow-up)

Table N1. Critical reflexive practice

Cornerstone	Reflection
Established detail related to irregular/nontreatment	<ul style="list-style-type: none"> ◊ Have the barriers/factors related to irregular or nontreatment been identified with the person affected, and are they consistent among different Health Care Workers? ◊ What pattern of nonadherence presents? (in reference to figures 7, 8 in chapter 6), i.e., is it irregular type 1 (missing doses here or there), irregular type 2, or refusal of treatment, early cessation, non-start
Review of relationships	<ul style="list-style-type: none"> ◊ Has treatment decision making been shared? ◊ Was the person involved in decision/negotiation for LCM and/or DOT provider? ◊ Has the person got enough support (and by who)? ◊ Has the person willingly disclosed diagnosis to family? And if so, have they selected a family representative/s to assist in support and negotiation? ◊ Has there been nominated cultural liaison if necessary? ◊ Have there been changes in social or healthcare relations that have or are impacting on the person's current priorities & motivation? ◊ Has the person had to relocate houses or community? ◊ Are there mixed messages or tensions between HCWs, or other health staff/organisations that have impacted on relations? ◊ Has the person had their concerns legitimately listened to without dismissal?
Practical arrangements	<ul style="list-style-type: none"> ◊ Has there been difficulty accessing medications? ◊ Has enough information about treatment, including side effects, been provided in meaningful ways? ◊ Has the information provided been checked for understanding, i.e., through teach/talk back? ◊ Has assistance been provided where forgetting to take treatment has been identified as a factor? (e.g., reminders) ◊ Has technology been considered where a valid option? ◊ Has safety monitoring been routine, and documented? ◊ Has disability status been addressed and supported, for example NDIS registration?
Strategies	<ul style="list-style-type: none"> ◊ Has there been any noticeable signs of stigma experience including privacy concerns and mental health impacts? ◊ Has there been any treatment intervention to assist with medication intolerance, such as provision of anti-emetics, supportive advice to pause treatment and monitor, alternative regimens offered? ◊ Is DOT in use, was it optional, and is it providing benefit? ◊ Has intervention involved any punitive/paternal response, such as increased surveillance, increased restrictions or exclusion from treatment decision making?

c) Family support, peer support

- Advice on coordination of family meetings or other appropriate family members, where no initial agreements have been made with the person affected.
- Engaging peer support workers, with remuneration, to provide psychosocial support

Agreed process for escalation.

- Escalation accompanied with a genuine risk assessment – what is the level of risk and to who? And how will this be communicated, and what are the urgency indicators?
- Escalation and the involvement of cultural advice, role of staff
 - a. Appropriate communication with person affected and/or family
 - b. Intended management and duration such as type of treatment (IV/oral) and place of treatment order (i.e., community v hospital), and who is held responsible for overseeing this.
 - c. Agreed intervention after reviewing all other steps above.
 - d. Escalation to senior health management